Participation in mental health care by ethnic minority users:

Case studies from the Netherlands and Brazil

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Participatie in de geestelijke gezondheidszorg door cliënten uit etnische minderheden.
Case studies uit Nederland en Brazilië.
(met een samenvatting in het Nederlands)

Proefschrift

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List of Abbreviations and Acronyms

CAPS	Centro de Atenção Psicossocial/ Psychosocial Care Service
CIH	Community Involvement in Health
COSAM	Coordenadoria de Saúde Mental/ Brazilian National Mental Health Coordination Agency of the Ministry of Health
CQI	Consumer Quality Index
CSO	Civil Society Organisation
GP	General Practitioner
IDS	Institute of Development Studies
LGBT	Lesbian, Gay, Bisexual and Transgender
MEMs	Migrants and Ethnic Minorities
MNLA	Movimento Nacional da Luta Antimanicomial/ National Anti-asylum Movement
MRS	Movimento da Reforma Sanitária/ National Health Reform Movement
MTSM	Movimento dos Trabalhadores de Saúde Mental/ Mental Health Workers Movement
NGO	Non-governmental Organisation
NPM	New Public Mangement
PACS	Programa de Agentes Comunitários de Saúde/ Community Health Agents Program
PAM	Posto de Atendimento Médico/ Health Care Centre
PAR	Participatory Action Research
PGB	Persoonsgebonden Budget/ Personal Health Care Budget
PHC	Primary Health Care
PSF	Programa de Saúde da Família/ Family Health Program
RIAGG	Out-patient Mental Health Care Service
RRA	Rapid Rural Appraisal
SES	Socio-economic Status
SUS	Sistema Único de Saúde/ Brazilian Public Health System
WGBO	Wet Geneeskundige Behandelingsovereenkomst/ Informed Consent Act
WHO	World Health Organisation
WKCZ	Wet Klachtrecht Cliënten Zorgsector/ Complaint Rights in Health Care Act
WMCZ	Wet Medezeggenschap Cliënten Zorginstellingen/ User Participation in Health and Social Care Services Act
WMO	Wet Maatschappelijke Ondersteuning/ Social Support Act
WVG	Wet Voorzieningen Gezondheidszorg/ Health Care Services Act

Introduction

User participation in mental health care has increased steadily since the 1970s when the first (ex-) psychiatric patients in countries such as the United States and the Netherlands began to join forces to challenge the mechanisms excluding them from society, demand human rights for mental patients and claim a voice in the decisions that affect their lives (Chamberlin, 1978; Haafkens *et al.*, 1986; McLean, 1995). Since then, the involvement of citizens in health care decision-making has been increasingly regarded by both international and national policy bodies as an essential component of good practice in policy-making and service delivery, not least in the field of mental health (Carvalho, 1998; Department of Health, 2000; Ministerie VWS, 2001; WHO, 2002; 2006; CSDH, 2008). This is largely explained by the benefits that user participation is expected to deliver.

Citizen participation in health governance is claimed to improve the quality and responsiveness of health care policy and delivery (WHO, 2006). By acquiring a voice in health decision-making, citizens can make clear their needs and wants, lobby for a fair distribution of the social determinants of health and keep watch over the effective allocation of resources (CSDH, 2008). This can lead to more accessible, acceptable and cost-effective services. In addition, participatory governance fosters a more vigorous notion of the rights and responsibilities that come with citizenship, creating more active and responsive citizens (Barnes *et al.*, 2007; Cornwall, 2008a). User participation is also expected to promote the wellbeing and quality of life of participants by enabling them to gain awareness of the causes of ill-health, acquire resources, confidence and vision, and build capacity to tackle those problems at both personal and collective levels (Dujardin, 1994; Zakus and Lysack, 1998; Frankish *et al.*, 2002; WHO, 2002).

The idea that participation "makes for better citizens, better decisions and better government" (Cornwall and Coelho, 2007: 4) has led to a dramatic increase of (health) participatory spaces across the globe. In some cases, these spaces emerged 'from below', out of grass-roots initiatives for collective action, user-led service provision and mutual aid ('autonomous spaces'). Other spaces were created 'from above', by public agencies aiming to promote an interface for state-citizen dialogue and to bring government closer to the people ('invited spaces') (Brock *et al.*, 2001; Cornwall, 2004b).

These developments are part of a wider trend: the move from 'government' to 'governance', that is from hierarchical forms of 'control' to collaborative forms of 'steering' involving the direct participation of citizens (Kooiman, 2000). This shift toward participatory governance has been motivated by concern with increasing 'democratic deficits' and unresponsive policies and services, as well as by the concerted demands of ever more diverse and complex constituencies for inclusion in decision-making processes (Commonwealth Foundation, 1999; Newman, 2001; Fung and

Wright, 2003). Citizen participation is viewed as having far-reaching potential to deal with these problems by enabling the development of more engaged citizenries and fostering greater public accountability and political renewal (Richardson, 1983; Gaventa, 2004a; Barnes *et al.*, 2007). In a nutshell, participation is seen as capable of getting democracy 'back on its feet'.

Perhaps because of all the promises participation holds out, it has become common to assume that people automatically want to be involved and that achieving inclusive participation is only a matter of "getting the mechanisms and methodologies right" (Cornwall, 2008b: 279). In practice, however, getting people to participate is still a challenge (Simmons and Birchall, 2005) and the power of participation to foster social transformation can be easily undermined by difficulties in achieving representation from all social groups. Groups which have been traditionally at the margins of mainstream society, such as the disabled, elderly, migrants and ethnic minorities, are at particular risk of exclusion from the participatory sphere (Coelho *et al.*, 2005). Failing to involve those whose health needs tend to require most attention jeopardises the potential of participation to foster greater equity in health. Moreover, it may produce or reinforce health inequities as policies and services become increasingly tailored to the needs of more vocal and better-off groups, which do not necessarily reflect the needs of socially excluded groups (WHO, 2006). These risks are even greater in health systems dominated by market principles, in which the demands of 'consumers' are supposed to regulate service provision rather than the decisions of public health planners.

This thesis sets out to investigate the participation of one of the least included groups in health care decision-making: socially disadvantaged ethnic minorities. Studies show that migrant and ethnic minority groups are under-represented in health participatory spaces in several countries around the world including the Netherlands, England, Australia and Brazil (De Savornin Lohman *et al.*, 2000; Sozomenou *et al.*, 2000; Crawford *et al.*, 2003; Coelho *et al.*, 2005). Furthermore, there is also evidence that these groups tend to experience poorer access to adequate health care than majority groups. This is especially evident in the field of mental health (Ferreira, 1996; Rebello, 1997; Knipscheer, 2000; Fernando, 2002; De Freitas, 2005; Ingleby, 2009). It is thus crucial to gain insight into the ways by which these groups can be effectively engaged in participatory processes. Understanding what promotes and discourages participation by minority groups can shed light on the factors limiting the inclusiveness of current participatory spaces and inform strategies to facilitate the emergence of a truly plural citizen voice. This, in turn, will contribute to the development of policies and services more responsive to the needs of all the different constituencies in society.

So far, little empirical research has been done on these questions. This thesis aims to help fill this gap by identifying minority user groups who are engaged in mental health participatory spaces and investigating why and how they get involved, and what they consider to be obstacles to participation. We focus on participation in mental health care because this is a field where 'cultural competence' is a *sine qua non* and which has much to learn from the experience and expertise of the diversity of users it is meant to serve. Furthermore, people affected by psychosocial distress have been historically deprived of agency and voice and continue to endure stigmatisation in virtually all spheres of life (Sayce, 2000; Nelson *et al.*, 2001). This might reduce their willingness to 'come out' and get actively involved. Learning about what encourages their participation can provide valuable lessons to foster the engagement of other marginalised and hard-to-reach groups.

This thesis also aims to evaluate the benefits of participation for involved minority users, and to examine the barriers which undermine the sustainability of participation and impede users from reaching their full participatory potential. Its aims are thus threefold:

1. to investigate minority users' motivations for participation and the ways by which they succeed in entering participatory spaces (*enablers*);
2. to examine the benefits of participation which users experience and how those benefits may contribute to the sustainability of their participation (*benefits*); and
3. to investigate the barriers which discourage or prevent users from pursuing higher levels of participation (*inhibitors*).

To reach these aims, we adopt a qualitative research approach and a case study strategy of enquiry entailing two exemplary situations:

- the case of Cape Verdean migrants' participation in Project Apoio – a community-based advocacy project focused on mental health promotion in Rotterdam, the Netherlands; and
- the case of minority Northeasterners' participation in CAPS Pedro Pellegrino – a community-based mental health care service in Rio de Janeiro, Brazil.

We selected these two user groups because they constitute a positive exception to the general pattern of poor involvement by ethnic minorities in mental health participatory arenas. Reasons for choosing the Netherlands and Brazil as the setting of our case studies are manifold. First, these countries have a long-lasting tradition of user participation in mental health care, starting in the early 1970s and 1980s respectively. Second, in both countries users have the right to participate in health care decision-making; the Dutch and the Brazilian governments have facilitated the creation of 'invited participatory spaces' where users can come together with public officials and service providers to discuss health care policy and service provision. These spaces include client councils and advisory conferences and meetings in the Netherlands, and health councils and health conferences in Brazil. Third, there are vigorous mental health user movements in both the Netherlands and in Brazil, which have been very influential in the democratisation of health care governance in those countries and that continue active until today. Finally, the Netherlands and Brazil take on different approaches to user participation. Brazil adopts an explicitly democratic approach to participation, viewing it as a process entailing the redistribution of power and control over health care decision-making to the citizenry (Cornwall and Shankland, 2008). The Netherlands combines a democratic and consumerist approach to participation, but the latter has been gaining considerable strength in the past decade alongside the increasing marketisation of the Dutch health care system. The consumerist approach views participation as a means of informing the suppliers of health care about consumers' needs and preferences. It emphasises choice, rather than voice. These distinct rationales give rise to different practices of participation in the Netherlands and in Brazil. These countries offer thus a good opportunity to gain an encompassing understanding of the phenomenon of user participation and to reflect on the ways by which the inclusion of minority user groups in health participatory spaces can be further enhanced.

The thesis is organised as follows:

- **Chapter 1,** *The historical background to participation*, provides an account of the meanings of 'madness' and an historical perspective on the position of the mentally ill in Western society. It begins by describing the forces that combined to ensure the segregation of those regarded as 'insane' from the mainstream of modern industrialised society, robbing them of freedom, agency and voice. It then looks into the movements that challenged this system in the 20th century and which fostered the creation of the first spaces for user participation in mental health care decision-making.
- **Chapter 2,** *On the meanings and practice of participation*, considers the broad range of meanings given to 'participation' over the past four decades and the ways by which they influenced its practice. It pays particular attention to the cases of the Netherlands and Brazil, analysing the approaches taken to user participation in these countries (consumerist and/or democratic) and assessing the receptiveness of their health participatory spaces. It concludes that several problems continue to inhibit the full inclusiveness of the Dutch and Brazilian health participatory spheres, to the disadvantage of marginalised groups.
- **Chapter 3,** *Enablers and inhibitors of participation*, reviews the literature dealing with users' motivations to participate and the factors that undermine their participation. It goes on to elaborate the concepts and theoretical framework that will be used in this research to study the enablers and inhibitors of participation by minority users in the Netherlands and in Brazil.

This framework is based on insights afforded by a combination of, on the one hand, new social movement theories and theories of empowerment and citizenship, and on the other, the Mutual Incentives Theory (MIT) and the Participation Chain Model (PCM) developed by Simmons and Birchall (2005). Chapter 3 also defines the participatory initiatives set up by Project Apoio and CAPS Pedro Pellegrino as 'hybrid participatory spaces', i.e. spaces sponsored by public authorities which keep a direct connection to local user movements. In this sense, they are neither 'invited spaces' or 'autonomous spaces' but combine elements of both, lending expression to a growing trend toward the hybridization of participatory spaces (Barnes *et al.*, 2004).

- **Chapter 4**, *Benefits of participation*, reviews the core findings of research concerned with the positive impacts of participation on involved mental health care users and provides the analytical framework that will be employed to assess the benefits of involvement for our user groups. This framework draws largely from the theories mentioned above and the insights offered by Ann Richardson (1983) concerning what she termed 'developmental benefits' of participation, that is the positive effects of participation on people themselves. These include improved self-esteem, increased competencies and self-efficacy, a developed sense of own interest, an increased sense of self-expression and social integration.
- **Chapter 5**, *The fields of research*, looks into recent developments in health care policy and service delivery which stress the importance of making the Dutch and the Brazilian health participatory spheres more receptive to minority users. It also introduces our research groups and describes the ways by which Project Apoio and CAPS Pedro succeeded to get Cape Verdean migrants and minority Northeasterners engaged in their participatory initiatives.
- **Chapter 6**, *Research approach and methods*, describes the qualitative approach and the case study strategy of enquiry adopted to carry out this empirical research, and justifies the selection of cases. It also provides a description of the methods used to collect and analyse empirical materials and the criteria employed to evaluate the quality of the studies. It concludes with a consideration of ethical issues regarding the specific context of this research.
- **Chapter 7**, *Starting participation: enablers*, examines the facilitators of participation among our research groups. It shows that the involvement of Cape Verdean migrants and minority Northeasterners in mental health participatory initiatives is motivated by a broad range of concerns. Some are of a personal nature, including the desire to increase their level of social interaction, find paid work, acquire a meaningful social role, overcome the stigma attached to mental illness and make more use of mental health care. Other motivations for participation have to do with promoting the welfare of

a group which users identify with or whose cause they support. These include the desire to improve the responsiveness of mental health care services and to achieve greater social justice for people affected by mental problems. The individual and collective motivations expressed by users indicate a strong aspiration to promote not just their own inclusion in society but also the exercise of full citizenship by other members of their communities. Chapter 7 also argues that although users' motivations play an important role in their decisions to get engaged, they are not sufficient to guarantee the start and continuation of their participation. In addition to motivations, direct recruitment, capacity-building and empowering participatory spaces are all essential enablers of participation by user groups in a position of disadvantage.

- **Chapter 8**, *Advancing participation: benefits*, looks at the benefits of involvement in mental health participatory spaces experienced by our research groups. It shows that participation can generate a number of substantive benefits for users, including broader social networks, empowerment, an increased sense of citizenship, enhanced health literacy and improved access to mental health care. These benefits have a positive effect on each other and together they strengthen users' willingness to stay engaged, as well as their capacity to take participation a step forward (e.g. by getting involved in health invited spaces). It concludes that the benefits attached to participation play a key role in promoting its sustainability and advancement.

- **Chapter 9**, *Slowing down participation: inhibitors*, examines the barriers to involvement. It shows that despite the success of Project Apoio and CAPS Pedro Pellegrino in engaging Cape Verdean migrants and minority Northeasterners in their participatory initiatives, there are some persistent inhibitors that hold back the full progression of their participation. These inhibitors are largely a matter of unawareness of opportunities for involvement in other participatory spaces, self-exclusion from invited mental health spaces due to fear of stigmatisation, and exclusionary dynamics within participatory initiatives that cause users to drop-out.

- Finally, the **Conclusion** puts together the main findings of this thesis and suggests the need for a proactive approach to participation in mental health care as a means of breaking the vicious circle of under-representation among socially disadvantaged minority groups.

1. The historical background to participation

> [Ivan Dmitritch:] "The doctor has come!" he shouted, and broke into a laugh. "At last! Gentlemen, I congratulate you. The doctor is honouring us with a visit! Cursed reptile!" he shrieked, and stamped in a frenzy such as had never been seen in the ward before. "Kill the reptile! No, killing's too good. Drown him in the midden-pit!"
>
> Andrey Yefimitch, hearing this, looked into the ward from the entry and asked gently: "What for?"
>
> "What for?" shouted Ivan Dmitritch, going up to him with a menacing air and convulsively wrapping himself in his dressing-gown. "What for? Thief!" he said with a look of repulsion, moving his lips as though he would spit at him. "Quack! hangman!"
>
> "Calm yourself," said Andrey Yefimitch, smiling guiltily. "I assure you I have never stolen anything; and as to the rest, most likely you greatly exaggerate. I see you are angry with me. Calm yourself, I beg, if you can, and tell me coolly what are you angry for?"
>
> [Ivan Dmitritch:] "What are you keeping me here for?"
>
> [Andrey Yefimitch:] "Because you are ill."
>
> [Ivan Dmitritch:] "Yes, I am ill. But you know dozens, hundreds of madmen are walking about in freedom because your ignorance is incapable of distinguishing them from the sane. Why am I and these poor wretches to be shut up here like scapegoats for all the rest? You, your assistant, the superintendent, and all your hospital rabble, are immeasurably inferior to every one of us morally; why then are we shut up and you not? Where's the logic of it?"
>
> [Andrey Yefimitch:] "Morality and logic don't come in, it all depends on chance. If anyone is shut up he has to stay, and if anyone is not shut up he can walk about, that's all. There is neither morality nor logic in my being a doctor and your being a mental patient, there is nothing but idle chance." (Chekhov, 1892)

For centuries, people who experience psychosocial distress were deprived of subjectivity, freedom and voice. The quote above, taken from Anton Chekhov's short story *Ward no. 6*, illustrates the first encounter of Andrey Yefimitch and Ivan Dmitritch. Yefimitch is a faint-hearted Russian doctor disenchanted with the futility of life, the griminess and immorality of his hospital and the vulgarity of the intellectuals in his city. After years in the job, he visits the psychiatric ward of his hospital for the first time. There, he meets Dmitritch, one of the inmates. The wit and philosophical incursions of Dmitritch entice the doctor into an interesting conversation, something he had been longing for years. Curious to converse more with his patient the doctor becomes a frequent visitor of the ward. But this attitude is interpreted by the other doctors as an act of rebellion and even a sign of insanity. How else could Yefimitch have a dialogue with a 'madman' if not by having been impregnated with the same illness himself? After all, no sense can ever be found in 'madness'. The story ends with the doctor confined to the very psychiatric ward he used to supervise. One day, after a beating, he is left to die alone, like so many other of his former patients.

Chekhov's short story epitomizes what Michel Foucault (1961) described as the monologue of psychiatry over madness, which commenced in the mid-nineteenth century and extended way into the twentieth century. During that period, the very thought of psychiatric patients' participation in mental health was as incomprehensible as 'madness' itself. An understanding of the emergence of citizen participation in this field calls for a retrospective look into the meanings of 'madness' and the social position of the 'madmen' across time: their confinement, silencing and liberation.

We resort to Foucault's *Histoire de la Folie* (1961) as a support in this exercise. We are aware of the various critiques made to this work and in particular of that by Midelfort (1980) who questioned the factual accuracy of Foucault's account of madness. However, our interest lies more in depicting one of the possible ways by which madness became undeniably segregated and silenced and in highlighting some of the problems which still undermine full participation today, than to claim the existence of a universal and unproblematic history of what came to be referred as 'mental illness'.

In addition, we capitalise on works by Robert Castel (1976), Andrew Scull (1979) and David Ingleby (1983) to discuss the conditions which favoured the emergence of psychiatry as a profession and what enabled it to acquire a function of social control, legitimising the segregation, objectification and constraint of the 'mentally ill'.

Finally, we analyse the actions of some of the social movements which influenced change in the field of mental health by reconceptualising mental illness, challenging the power and authority of psychiatry, devising new forms of care focused on psychosocial rehabilitation, and pressuring for restoring full citizenship to people affected by psychosocial distress. Among those movements are the deinstitutionalisation movement, anti-psychiatry, *Psichiatria Democratica* and the Survivor/User movements. The first two movements found considerable response in the Netherlands, inspiring the dissemination of a psychosocial approach to mental distress and an increase of community-based mental health services. Democratic Psychiatry was one of the major influences in Brazil's psychiatric reform, where Franco Basaglia's message still resonates strongly today. User movements emerged and proliferated in both the Netherlands and Brazil, championing the struggle for users' rights and functioning as true catalysts of users' voices. Their active presence nowadays serves as a reminder that citizen participation in mental health is not a 'conquered terrain' but an evolving phenomenon within which constant scrutiny and reflection are necessary to bring about substantive inclusion of all those whose lives have been affected by psychosocial distress.

In the following sub-sections we show how madness turned into mental illness and how the madmen became excluded from society. We also look into some of the movements which called into question orthodox views and 'treatments' of mental illness, breaking the circuit of control surrounding it and calling for the rights of psychiatric patients.

1.1 Madness, confinement and silence

In *Histoire de la folie* Michel Foucault (1961 [1988]) describes the way in which madness was transformed into mental illness and how this paved the way for the emergence of psychiatry in mid-nineteenth-century France. According to the author, the birth of psychiatry marked the breaking-off of a 'dialogue' with madness. This dialogue, Foucault argues, was still possible until the end of the Renaissance (mid-seventeenth century). How was madness ejected from society? And why was it confined and silenced?

Up to the mid-seventeenth century madness was "a familiar silhouette in the social landscape" (Foucault, 1961 [1988]: 36). The mad were perceived as both 'menace and mockery' and associated with "the dizzying unreason of the world and the feeble ridicule of man" (*ibid.*: 13). Although this led them to be banned from the cities, they were nevertheless allowed to remain in the open. Some were cared by their families. Others strolled through the countryside or floated down the waterways in the 'ship of fools'. This roaming population was constantly encountered by the sane. Renaissance artists and writers, in particular, were fascinated with the secret lessons madness could give them and how much that could enhance their understanding of reason. They thus sought a 'dialogue with madness' exploring its meanings and teachings in their plays, paintings and texts.

This mindset changed dramatically during the 'classical age' (1650-1850). By the end of that era, madness no longer roamed freely but found itself entirely evicted from society and confined in closed institutions. According to Foucault, the founding of the *Hôpital Général* in Paris in 1657 signals the beginning of this 'Great Confinement'. However, as the author indicates, that institution was not created as a response to madness, not even to illness. Originally, it was a semi-judicial institution primarily devised to confine all those whose idleness, unemployment or incapacity to work put at stake the security of the monarchy and its collection of taxes. This would all change with its transformation into an asylum in the nineteenth century.

Unlike Andrew Scull (1979), who examined the rise of the asylum in England[1], Foucault refuses to explain confinement solely in terms of economic rationality, adding

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[1] Scull (1979) explains the changes operated in the 'care' of the insane as a result of changes in the relations of production, i.e. in the economy. The differences between the historical accounts of madness provided by Foucault and Scull do not necessarily derive from inappropriate analysis of facts. Instead, they may be understood on the convergence of two factors. First, the authors have taken two different contexts of analysis: the former centers his account on the French situation, while the latter focuses in England. Developments on those two countries were not synchronous. Second, historical accounts tend to be influenced by the authors' views of society and power and Scull and Foucault differed on these. While Scull

a strong moral component to it. Indeed, according to Foucault, it was the association of the mad with the 'immorality of unreason' which set them apart from the rest of the inmates of the houses of confinement and led to their banishment from society in the nineteenth century.

At the beginning of the eighteenth century 'reason' became the prime element by which humans distinguished themselves from other animals. The classical age took reason to be universal and sacrosanct. By opposition, it linked 'unreason' to sexual deviance, profanation of the sacred and *libertinage*, imprinting it with a strong sense of immorality and perceiving it as a challenge to the existing social order. During this period, the insane were viewed as simply lacking the faculty in which humanity lies – *logos*. It was this idea that catapulted the mad into the opposite domain of reason, rendering them as immoral as unreason itself. This had two highly perverse effects. On the one hand, it de-humanised the mad who, as virtual animals, deserved no kindness; just confinement and brutal treatment. On the other hand, it divested them of any sort of morality, making their presence offensive and an injustice for others. From this moment onwards, the mad became increasingly isolated from the idle poor with whom they had been sharing their cells, having to subsist in the houses of confinement with the criminals.

At this point in time, the *homo medicus* was not yet systematically associated with madness. But in the middle of the eighteenth century a Great Fear of the houses of confinement arose. 'Formulated in medical terms but animated, basically, by a moral myth' a "(…) dread of a mysterious disease that spread, it was said, from the houses of confinement (…)" (Foucault, 1961 [1988]: 202) caused the horror and panic of the population. That disease, people believed, originated from the 'corruption of morals' and the 'decomposition of the flesh' of those confined. It was then, that medical doctors seized the opportunity to establish a bond with madness, not as its healers but as its guardians. Their mission was to protect the public from "the vague danger that exuded from the walls of confinement" (*ibid.*: 205). Madness became perceived as the origin of both moral and physical contagions. The fear which that instilled set in motion an attempt to neutralise the houses of confinement as 'potential causes of a new evil' by isolating them and caging its inmates. Toward the end of the eighteenth century, the houses of confinement had become decrepit, prison-like buildings administered by untouchable superintendents and supervised by cruel staff. The mad, alongside the criminals, were battered, ill-nourished, and chained in its dungeons.

Bicêtre was one such house of confinement. Appalled by the abuses perpetrated against the mad and encouraged by the fervour of the 1789 French Revolution, Philippe Pinel set himself to free its inmates. Politically speaking this was not a difficult task, for the old institutions of confinement symbolised the tyranny of the *ancienne*

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adopted a broadly Marxist approach, Foucault tackled his subject matter in light of the French post-structuralist framework (Ingleby, 1983). In section 1.2 we provide a more detailed description of Scull's thesis on the confinement of the insane.

régime which the new republic desperately wanted to get rid of. In addition, the then recently issued Declaration of the Rights of Man put challenged the justification of the incarceration of the insane on the grounds of penalty since they had not commited any crime. Nevertheless, they were still considered to require some form of care. Pinel's proposal was that of a 'moral treatment', i.e. a comprehensive programme of re-socialisation aimed at re-installing reason. That 'treatment' was to be delivered in newly created establishments where "(…) all the resources of medicine and all the comforts of life compatible with their [mad] state" (*ibid.*: 241) were available – the asylum.

To conventional historians of psychiatry Pinel's 'liberation of the mad' in 1794 represents the overthrow of the old order, the triumph of humanitarianism and the re-admission of the insane to society. But for Foucault, this was the moment at which the banishment of unreason by reason was made complete. For him, the asylum devised by Pinel in France (and Tuke in England) was:

> (…) a system whose essential element was the constitution of a 'self-restraint' in which the patient's freedom, engaged by work and the observation of others [doctors], was ceaselessly threatened by the recognition of guilt. (…) [There,] madness is responsible only for that part of itself which is visible. All the rest is reduced to silence. Madness no longer exists except as *seen* (*ibid.*: 250).

In the asylum, reason performed its ultimate negation of unreason. Subjected to the observation and judgement of doctors, the mad existed only inasmuch as their behaviour approximated the intelligibility and morality of reason: all the rest being denied. Madness was no longer perceived as threat. Instead, it became a 'minority' which "(…) does not have the right to autonomy, and can live only grafted onto the world of reason" (*ibid.*: 252). Pinel freed the mad from the chains which held them in the dungeons. However, according to Foucault, the creation of the asylum allowed a more efficacious form of control to emerge – the guilt ingrained in the mad through 'moral treatment'.

Moral treatment prompted the madmen to take responsibility for everything within them which disturbed morality and society. It instructed them to attribute the responsibility of the punishment received for acting out their madness to no one else but themselves. In the early asylum, fear no longer emanated from the staff's cruelty. It "raged under the seals of conscience" (*ibid.*: 247). The mad had been made prisoners of their own consciousness, something which was consistently enforced through the surveillance of doctors. But as in the houses of confinement, nineteenth-century asylums sought no communication with madness: "the science of mental disease, as it would develop in the asylum, would always be only of the order of observation and classification. It would not be a dialogue" (*ibid.*: 250). That science was psychiatry.

In the next sub-section we describe the rise of the psychiatric profession and how its conceptions of madness and subsequent 'treatment' practices served to enforce and legitimise psychiatric inmates' deprivation of freedom, subjectivity and voice.

1.2 The rise of the psychiatric profession and the making of mental illness

Scholars engaged with providing a critical view of the emergence of psychiatry have pointed out two main periods in its history. The first, termed by Castel (1976) the 'golden age' of psychiatry, is marked by the rise of the asylum as a remedial institution and the capture of that domain by the medical profession. This period corresponds, roughly, to the first half of the nineteenth century. The second period, which Ingleby (1983) dubbed the 'modern age' of psychiatry, follows the former but has no obvious starting date, having been entered at different times in different countries. This phase in the history of the psychiatric profession extended way into the 1970s, up to the moment in which the medical model started to abandon its traditional grounding in the practice of confinement. During psychiatry's modern age, the profession experienced several developments: the consolidation of medical gains; the broadening of the notion of 'mental illness', alongside the acquisition of new functions of control and surveillance of the non-hospitalised population; and the emergence of new therapies and professional alliances, particularly with psychology (Ingleby, 1983). These developments were key for the expansion of the psychiatric establishment and the increase of its authority over the 'mentally ill'. The overwhelming power psychiatry acquired over madness would only start to be questioned, as we shall see later, with the rise of movements such as anti-psychiatry in the 1960s.

In what follows we provide a more detailed account of the 'golden' and 'modern' ages of psychiatry. Many differences characterise the rise and growth of the psychiatric profession across and within countries. However, it is not in the scope of this piece to present a thorough account of all those differences. Instead, we aim to illustrate how the development of that profession went hand in hand with the increasing segregation, objectification and constraint of people interned in psychiatric institutions. For this reason, we focus merely on the cases of England and France, which are used here as examples of the ways by which those processes may have unfolded. We also resort mostly to the works of scholars who share a critical view of this field because they pioneered the discussion we wish to pursue and have, so far, offered one of its finest analyses.

According to Ingleby (1983) the emergence of psychiatry is rooted in two fundamental preconditions: the social practice of incarcerating the insane, and a firm belief in the 'otherness' of the mad. The ways by which these preconditions may have been reached in France were described above based on Foucault's *Historie de la folie*. In the last chapter of that book, Foucault advances the commanding role which the *homo* *medicus* will gain inside the asylum. However, he does not examine how psychiatry got the hold of that institution. That work has been carried out by, among others, Andrew Scull (1979) and Robert Castel (1976). It is mostly based on their contributions that we discuss the 'golden' age of psychiatry.

1.2.1 The 'golden age' of psychiatry

According to Scull (1979), the rise of psychiatry in England was part of a general process of change occurring in the social organisation of deviance. This process was marked by three major developments: the substantial involvement of the state in managing deviance and the implementation of a centralised and highly rationalised social control apparatus; the increasing segregation of deviants from the rest of the population; and the differentiation of various sorts of deviance, each variety being consigned to the ministration of a different group of experts. Initially, medical men were just one among several sorts of experts. By 1850, however, they had not only succeeded to create a new specialism – psychiatry – they also became the most influent group of experts in the care of the insane. How did they get hold of that domain? To answer this question we must first address the process of mass confinement of the mad and their subsequent 'othering' and classification as 'mentally ill'.

As we have seen above, until the end of the eighteenth century the mad were not treated as a separate type of deviants nor were they isolated from the overall class of the morally disreputable. That changed dramatically in the nineteenth century. From that moment onwards, the mad were increasingly "incarcerated in a specialised, bureaucratically organised, state-supported asylum system which isolated them both physically and symbolically from the larger society" (Scull, 1979: 14). Conventional historians tend to explain this transformation in light of a reform in the care of the insane, i.e. the introduction of 'moral treatment'. They claim that the state's acceptance of responsibility for the mad and the creation of public asylums were a result of the growing civilisation of social existence, the rise of humanitarian concern for all citizens, and the advances of science and human understanding. In *Museums of madness*, Scull strongly disputes these claims, arguing that the confinement of the mad did not occur for the higher purpose of their rehabilitation through humane treatment but derived, instead, from the "effects of the advent of a mature capitalist market economy and the associated ever more thorough-going commercialization of existence" (*ibid.*: 30)

Unlike Foucault (1961), who explains the origins of confinement based on both economic rationality and morality, Scull attributes its advent merely to a change in the relations of production, and more specifically to the rise of wage-labour. In the new market-oriented English society which emerged in the late eighteenth century, in-servants stopped being considered part of 'masters' families and were transformed into labourers. This allowed employers to lay them off more easily when there was less work or profits were smaller. At the same time, labourers began to be hired for shorter periods of times and, once paid, employers felt no more responsibility for them. These changes reduced the ability of families dependent on wage earnings to provide for their members in times of economic depression. They also brought about a major shift in the existing social order which ceased to be sustained on the basis of rank and degree and became organised on the basis of class.

These events generated a large number of people dependent on poor relief. However, the Elizabethan system of poor relief which was in place at the time was directly at odds with the market economy: providing the able-bodied with alternative means of survival reduced the number of labourers eager to work, raising the wages. The bourgeoisie was particularly displeased with this, because it threatened the full establishment of the capitalist order which put this class at the top of the social hierarchy. As a result, it began to support an institutional response to the indigent, not in the form of relief but in the form of segregation. Segregating the poor in institutions had several practical advantages over domestic relief: it was efficient; it discouraged able-bodied malingerers; and it improved the quality of labour by instilling work habits in the inmates. Thus, according to Scull, the institutionalisation of deviants in the houses of confinement or workhouses, as he names them, was a practical response to the demands of a rising wage-labour system.

At first, workhouses accumulated both the fit-to-work and the unemployable (usually infirm) indigents. However, the latter, and more specifically the insane, started being perceived as a threat to the maintenance of workhouse discipline, since they could not be persuaded to conform to the regulations. Hospitals adopted a similar stance, refusing to care for the mad who, they argued, menaced the safety of other patients. Yet, to pay for acceptable standards of care for the insane in the community would have required raising their life standards above those of the majority of the population, many of whom lived in extreme poverty. This was likely to lead large groups of people to seek dismissal from work by indulging in behaviour. For Scull, thus, the separation of the mad from other groups of deviants and their incarceration in madhouses (and later on in public asylums) was, to a large extent, a result of an emerging capitalist economic order which, to thrive, depended upon the availability and willingness to work of an almost starving, yet disciplined, population.

At first, the management of the incarceration of the insane was not a state affair. Aware that the construction and operation of institutions for the deviant was a costly endeavour, the English state sought to avoid it by contracting madhouses and the like out to private entrepreneurs. This led to a booming ‘trade of lunacy’ and a significant rise in the number of people confined in those houses. However, in the absence of legal restrictions on the entry into or the subsequent supervision of the ‘mad business’, institutions for the insane became (as in France) large, overcrowded and under-staffed[2].

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[2] Economy of scale was already an applied principle in the eighteenth century, but managerial skills lagged far behind. To reduce the comparatively large investment needed to enter the trade, madhouse owners

There, it was not uncommon for inmates to be chained to their beds over the weekend so that the few attendants employed could have some free time; neither was it unusual for convalescent inmates to be put in charge of other, sometimes moribund, fellow inmates. By the mid-eighteenth century the insalubrity of and the brutality and affliction within madhouses had become so despicable that it was impossible to conceal it.

It was these circumstances which favoured the success of a movement calling the state to take charge of the mad by instituting public asylums in the early nineteenth century. At the head of the public asylums movement were the Reformers. These men were, for the most, influenced by two philosophical systems: Evangelism and Benthamism. The latter was the creed of a class of administrators committed to advocate for a 'science of government' which emphasized institutional mechanisms to uncover as well as to eliminate social evils. Evangelicalism was led by a conservative religious group which sought to induce discipline, regularity and morality to a populace succumbing to disorder and vice, by promoting humanitarianism and paternalism. Unsurprisingly, 'lunacy reform' became of interest to both these groups. They strongly opposed cruel administrators and the maintenance of decrepit madhouses, demanding their replacement by public asylums. Yet, similarly to Foucault (1961), Scull disputes their 'humanitarian' motives to seek reform, arguing that their efforts only subordinated the needs of the insane further to the demands of the economy and that they failed to offer a critical analysis of the abuses of incarceration and of the system of wage-labour that led to it. For Scull (1979), "(…) what divided the reformers from their opponents was not the morality of one group and the immorality of the other, but rather the existence of two mutually incompatible paradigms of the essence of insanity" (*ibid.*: 65).

In the old paradigm, the madman was no more than a beast, for he had lost the essence of his humanity – reason. Fear, force and coercion were thus natural tactics to manage madness. In the early nineteenth century, this traditional perspective began to be replaced by a new cultural meaning of insanity according to which the lunatic was no longer an animal stripped of all remnants of humanity, but a human being lacking in self-control. The new paradigm also asserted that all nature was malleable: the insane could therefore have those qualities restored to them in order to function once again as productive members of society.

According to Scull, the emergence of the latter world-view is directly linked to the social changes occurring at the time. In the previous agriculture-based society, nature rather than man was perceived as the active agent influencing the world: "the world

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hardly ever adapted the dwellings they bought to accommodate the needs of its inmates. In addition, the madhouses which accepted paupers had to compensate by growing in size and providing minimum amenities and staff for the meagre revenues they received. Scull asserts that some of these madhouses grew bigger than any other institutions in England, including factories, hosting at times five hundred inmates. Competition with other institutions led them to charge the very least possible for new inmates as well as to invest close to nothing on the provision of their 'care'.

was not humanely but divinely authored" (*ibid.*: 70). Any attempt to reform men was thus considered a sacrilege. With the arrival of market economy this frame of mind underwent a dramatic change. Economic competition forced men to become ever more conscious of their active role in the success (or failure) of their enterprises; a factor that depended, to a large extent, on the availability of a pool of cheap and disciplined labourers. This made the 'remodelling of the unfit' not only acceptable but desirable. That reformers followed this new paradigm seems only a logic step, for they were deeply driven to implement social transformation. Yet, in Scull's view, reformers did not act from a position of disinterested moral superiority. To reach their goal of creating a countrywide public asylum system, they had to pay attention to the interests of the ruling class. They became, thus, natural allies of the bourgeois entrepreneurs and industrialists whose main aim was to conduct business at the expense of low-cost, obedient workers. It was no coincidence, thus, that work was one of the cornerstones of the moral treatment promoted by reformers.

The asylums which existed in the late eighteenth century were deplorable, pernicious institutions. This was one of the greatest obstacles to the reformers' plan to push for compulsory public asylum provision. To persuade the House of the Lords to issue legislation enforcing the creation of public asylums, they had to create and disseminate a new concept of asylum care. That new concept arose in the form of the 'moral treatment' pioneered by Samuel Tuke in the York Retreat in 1792. This new regime had enormous potential advantages over any existing alternatives at the time.

- First, it allowed the reformers to condemn the traditional methods of physical incarceration, by providing a substitute technique to manage madness based on 'psychological' control. As in the wider capitalist society, external coercion in the form of physical violence was increasingly seen as abhorrent. The internalisation of norms, whose application reformers claimed to master, appeared as a highly suitable alternative method to induce self-restraint. This occurred in the form of a system of rewards and punishments and the relegation of the patient to the role of dependent child within a familial 'total institution', where guilt functioned as the chief agent of coercion.
- Second, the new regime promised 'cure': patients were to be rehabilitated into acting, once again, as "sober, rational citizen[s]" (*ibid.*: 65).
- Third, by emphasizing treatment over punishment the regime made it possible for its real clients – the patient's family, "to ease the guilt which must inevitably be attached to the prospect of confining a loved one in institutions which have never managed to obtain a salubrious reputation" (*ibid.*: 95).

These arguments were supplemented by doctors' concerted actions to produce numerous books and pamphlets about the uncontested advantages of the new regime.

So successful were those actions that in 1845 the implementation of state-run asylums was passed into law. But doctors' commitment to the dissemination of the innovative techniques applied in the new asylums had yet another goal: to "bolster their claims to posses a specific expertise in the treatment of the insane" (*ibid.*: 90). The transformation of madness into a new area of professional expertise served doctors' ultimate purposes of launching a comprehensive asylum system and acquiring a monopoly of it. It was at this point that began to surface the will and necessity for the creation of a new specialism: psychiatry.

According to Scull, the rise of psychiatry is inextricably linked to the rise of the asylum, something he explains on the basis of the concept of 'professionalism' (Freidson, 1970). Professional status involves the effective monopoly over a market for services. It also depends on close supervision of training and qualifications and on the possession of knowledge and skills publicly acknowledged as unique and efficacious. In the beginning of the nineteenth century psychiatry was not yet a profession in these terms but by 1850 it had become one. For Scull, the presence of institutions for the mad was the breeding ground for the emergence of that professionalism:

> On the one hand, (…) the institutions provided the incentive, in the form of a guaranteed market for the experts' services; and on the other, they provided a context within which, isolated from the community at large, the proto-profession could develop empirically based crafted skills in the management of the distracted (*ibid.*: 43).

However, this was by no means an immediate, self-evident process. Initially, there were several competing groups (e.g. ambitious entrepreneurs, strict followers of the Quakers' moral treatment, etc.) seeking to take hold of that market. For professionalism to arise, it was necessary that one group succeeded in driving other competitors out of the running or subordinated them to its authority. This was something unlikely to take place through the mere operations of the market-place. First, there were no clear criteria to evaluate successes in the recovery of the mad. Second, producing 'evidence' of the superiority of one group over the other based on treatment strategies was impracticable. These two aspects undermined any legitimate claims of expertise in the field. In addition, moral treatment reformers posed another barrier to the 'mad-doctors' capture of the 'trade in lunacy'. While the former saw madness as a loss of self-discipline and its remedy as a matter of re-socialisation, most medical men supported a classical idea of insanity and applied harsh treatment methods in line with it. This rendered the mad-doctors vulnerable, for when asked to demonstrate the therapeutic value of their treatments they were unable to do so. In addition, the new paradigm promoted by moral treatment reformers was gathering increasing support, as were the internally induced forms of regaining self-control they promoted as treatment. This made it easy to condemn the physical coercion methods employed by mad-doctors easily as inhumane.

Indeed, the limitations inherent in medical approaches to insanity in the late eighteenth century could have been expected to lead to the extinction of the proto-profession of psychiatry. However, they did not. According to Scull, this was largely due to the ingenuity and political astuteness of medical men. At first, doctors opposed the reformers because the implementation of public asylums would put an end to their business and would imply regular state-led inspection. Since the autonomy of a profession depends, largely, on the right to deny legitimacy to outside criticism of its performance, the prospect of systematic inspection threatened the mad-doctors' ambition of taking full control of the care of the insane. However, when it became clear that moral treatment reformers faired better with the public, doctors changed their tactic radically: they joined them. Any differences that might have been noted between the two parties' approaches were downplayed by doctors by emphasizing the idea of madness as disease. This was not an alien conceptualisation for the reformers who had been employing vocabulary laden with terms from medicine (e.g. 'patient', moral 'treatment', mental 'illness'). Indeed, the failure to develop a technical jargon of their own made reformers vulnerable to medical men's intention to dominate the treatment of insanity. After all, "given the critical role of language in shaping the social construction of reality, to employ terms which imply that something is a medical problem, and yet to deny that doctors are those most competent to deal with it, seems perverse" (*ibid.*: 142).

Doctors' authority over the treatment of 'mental disease' was further reinforced by the fact that Tuke failed to provide a well-articulated theory for moral treatment and, in his modesty, stated that in the absence of a specific treatment for insanity the term 'recovery', rather than 'cure', should be employed to refer to success. Expertise and cure, however, were precisely what doctors claimed to offer. And the claims of being able to influence the outcome of treatment and to master that better than anyone were key elements for the acquisition of a professional status.

To complete their pursuit of professional status, doctors wrote books and articles, organised lectures, and created their own journals and Association. All these initiatives were set to enlarge and disseminate their expertise among their colleagues and, perhaps more importantly, among the public. By 1850, the combination of all these strategies had earned the medical profession powerful support for the contention that insanity was a disease and that doctors were the most qualified professionals to treat it. This, in turn, brought them a position of dominance over the asylum system.

Ingleby (1983) has pointed out that although Scull's account enables us to understand how institutionalisation became a solution for madness and how mad-doctors took over the asylum system, it fails to explain how psychiatry came to acquire a function of social control. This, Ingleby argues, is essential to fully understand how doctors succeeded in persuading public authorities of their suitability for running asylums.

Such explanation has been provided for the case of France by Castel (1976) in *L'ordre psychiatrique*.

According to Castel, the rise of psychiatry in France is directly related to the foundation of a new social order after the overthrow of monarchy by the 1789 revolutionaries. During the *ancien régime*, the confinement of the mad was sanctioned by the king. But with the fall of the authoritarian sovereign and the institution of a new regime based on the principles of citizenship and inalienable rights, incarceration could no longer be justified on the grounds of penalty since the mad were not considered liable for their actions. This brought about an urgent need to devise an alternative system of legitimation for such incarcerations, consistent with the civil liberties just acquired by the people.

The answer to that problem was to 're-brand' confinement as treatment and to place the insane under a relationship of tutelage. Promoting a tutelary system had two obvious advantages. On the one hand, the 'care' of the mad could be presented as a matter of paternalist benevolence. On the other hand, incarceration could be simply justified as a measure applied in the mad's best interest. Yet, in the absence of legitimacy by the legal apparatus to enforce this system, a new class had to come to the fore in making decisions about and taking control of the insane. That new class were the *aliénistes* or the mad-doctors. Together, they formed a profession – psychiatry – which became an apparatus of control, analogous to the 'hard' apparatus of the law but with the 'softness' of an (allegedly) benevolent and expert agent.

How medical men, rather than another group of 'experts', came to take hold of that position is explained by Castel in terms of the adoption of asylum care as the means to deal with the insane[3].

Right after the fall of monarchy, the asylum was not perceived as an acceptable solution for dealing with the insane. For one thing, the existing asylums were associated with the abuses of the previous authoritarian regime. In addition, the public had become sceptical of the therapeutic value of treatments administered there. Nevertheless, the new French administrators were still confronted with a number of 'difficult cases' who threatened the ideal of community life they wished to promote. Some form of confinement was, therefore, considered necessary. But for that to take place through an asylum system, the practices to be operated within it and the image of the asylum itself had to be re-conceptualised. Moreover, it was necessary to identify a group able to exercise authority over the mad. When the judiciary, the family and the local administrators all failed to do that, doctors emerged as a group offering not only expertise on madness but also a new set of devices to deal with it (such as moral treatment). This created the opportunity by which the power of the king to order confinement could be transferred to another 'agent' who, in contrast to the legal apparatus, could claim both legitimacy and know-how on the 'care' of the insane.

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[3] Castel shares this point with Scull. However, unlike Scull, he does not see confinement as a result of the pressures exerted by an emerging system of wage-labour.

According to Castel, the prime function of the *aliénistes* was, from the start, one of social control. The recognition of psychiatry's authority over the mad was, however, not so much substantiated by its ability to cure patients as it was by translating moral problems into technical ones. In a time in which the new social order was trying to promote centralised forms of welfare and the inclusion of its people, repressive measures to deal with social disturbance, particularly that caused by the unaccountable, were difficult to justify. Psychiatry devised both a system of classification of social disturbances and a way of systematising its removal from society within an orderly and accepted framework. This served well the state's need to legitimise the incarceration of the insane. But, perhaps more importantly, it allowed psychiatry to acquire a domain of power of its own. The *aliénistes*, Castel argues, were not merely agents of the state: they had a crucial part in both *policing* and *creating* norms[4].

For Castel, thus, the 'golden age' of psychiatry came into being as a result of three elements: the social practice of incarcerating the insane; the need to create an 'internal order' of restraint, which did not put at stake the values and principles of the new social order but effectively replaced the order of the monarch; and the power acquired by doctors to subordinate patients to their authority. To keep its 'territory', however, psychiatry would eventually need to expand its system of classification and treatment methods beyond the asylum and its population (Ingleby, 1983). We turn to this matter in the next section.

1.2.2 The 'modern age' of psychiatry

The 'modern age' of psychiatry has no formal starting date. According to Ingleby (1983), it is defined by three distinct, yet interrelated, developments. First, medical expertise acquired primacy in dealing with the mad: by the mid-nineteenth century, several countries had issued laws according to which members of the medical profession were entrusted with the management of asylums and the power to decide who was to be incarcerated[5]. This was, to a large extent, substantiated through the framing of a medical model of 'mental illness', which few saw reason to question and many took as the appropriate way to conceptualise all kinds of mental disorder.

Second, psychiatry extended its authority beyond the asylum population. Leaning on its increasingly strong 'scientific' image, psychiatry was able to lay claim to the treatment of new categories of pathology (e.g. 'neurosis'), which were too mild to necessitate hospitalisation but too disturbing to leave untreated. As psychopathology developed and new conditions were devised, so were new specialities. Clinical and educational psychology, psychoanalysis, criminology, and social work were among the specialities coming to light at the beginning of the twentieth century. Yet they were all

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[4] This view is clearly at odds with the notion of the state as the source of all social control. Like the late Foucault, Castel understands power relations as generated within separate and specific 'instances'. For him, psychiatry was one such instance.

[5] In England for example, the 1845 Lunatics Act gave the medical profession statutory support to claim the sole right to treat the mentally ill (Treacher and Baruch, 1980).

based on the medical model and remained for a long time dominated by psychiatry. Family life, school and industry became the new fields of intervention of the 'psy-professions'.

Third, 'human sciences' emerged to legitimise that intervention and increase its efficiency. To achieve that, human sciences modelled themselves on natural sciences, essentially because the latter were acknowledged for their neutrality and trustworthiness: these were two elements which no new discipline could do without if it was seriously seeking to thrive. As time went by, human sciences took over a vast area of social and personal problems by classifying them as illnesses and formulating 'treatments'. Psychiatry, in particular, adopted almost exclusively a 'positivist' paradigm to observe and account for human behaviour and misbehaviour (Ingleby, 1980). This, as we shall explore later, dictated the adoption of a much-criticised stance over mental distress; one which by making biological factors centre stage in explaining mental ill health, compromised the recognition of the role played also by social/environmental factors.

To understand how these developments served to consolidate psychiatry's dominance over mental illness and how the 'mentally ill' were stripped of freedom, autonomy and subjectivity, we must first seek to understand what the 'medical model' implied and how it became instrumental for the function of social control exerted by psychiatry.

The biomedical model has dominated Western formal medical care since the late eighteenth century. According to Atkinson (1988), its main characteristics may be summarised in the following way:

> It is reductionist in form, seeking explanations of dysfunction in invariant biological structures and processes; it privileges such explanations at the expense of social, cultural and biographical explanations. In its clinical mode, this dominant model of medical reasoning implies: that diseases exist as distinct entities; that those entities are revealed through the inspection of 'signs' and 'symptoms'; that the individual patient is a more or less passive site of disease manifestation; that diseases are to be understood as categorical departures or deviations from 'normality' (*ibid.*: 180).

Where biomedical psychiatry is concerned, this translates into the assumption that mental distress is best understood as a medical illness or, in other words, as a disease process which involves an alteration of biological structure and functioning (Johnstone, 2006). Much psychiatric theory and practice taking this standpoint rests firmly upon the positivist paradigm. Positivism aimed to shape human sciences at the image of natural sciences. One of its core assumptions is, therefore, that no features distinguish human beings from nature. This means that observations can be made objectively, using measures that are defined operationally and applied in a precise and replicable way. It also means that theories can take the same causal, deterministic basis as in the natural sciences (Ingleby, 1980). For a biomedical perspective on 'schizophrenia' (to name but one example) to stand objective verification one must produce systematic evidence of the signs which attest a 'departure or deviation from normality' (Atkinson, 1988) due to that particular disease. However, as Johnstone (2006) states, such signs are not available for most psychiatric diagnoses[6] and the measures necessary to classify schizophrenia as a biological disease do not exist (see also Lynch, 2006). Furthermore, the diagnostic criteria listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM) or in the International Classification of Diseases (ICD) are not an inventory of physical states but of experiences, beliefs and behaviour. No absolute and agreed standards of 'normality' can be defined based on the latter, for it is practically impossible to reach agreement on what constitutes 'abnormality'[7]. These flaws challenge not only the reliability and validity of the classification system employed by biomedical psychiatry, but also the entire framing of mental illness as merely a biological disease. So why would psychiatry adopt a model with such shaky epistemological foundations?

To answer these questions we turn again to Ingleby (1980) who asserts that psychiatry's alliance with the natural sciences (and the formulation of a biomedical model) was not only explained by psychiatry's need to conform to the positivist assumptions held by its patron science – medicine – but, more importantly, became a means of acquiring authority. As we showed earlier, psychiatry gained a function of social control in the early nineteenth century which could no longer be easily upheld on the basis of force and coercion half century later. This meant that the basis of its mandate to set deviants apart from society had to be re-defined in terms of illness: psychiatry being the science defining, classifying and treating this illness. In its promise of an objective, value-free human science, positivism lent psychiatry the tools it needed to rise above particular interests and arbitrary prejudices. That mid-nineteenth century psychiatry was actually unable to offer proof of an organic basis for mental illness did not matter too much at the time: the public's indifference, on the one hand, and the 'cult of science', on the other hand, propelled medical doctors to the forefront in the care of the insane (Scull, 1976). The discovery of a treatment for general paresis of the insane (GPI) at the end of that century was construed as undeniable evidence that all mental disorders were illnesses (Treacher and Baruch, 1980). So strong was the need for a 'civilised' approach to the mentally ill (to replace their barbaric treatment in the past), that 'by not inquiring too deeply into what went on behind asylum walls, and by not being too sceptical of the officially constructed reality, people were (are) rewarded

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[6] To establish a diagnosis two main requirements are necessary: first, a cluster of symptoms must be identified; second, because symptoms are subjective complaints presented by people, diagnosis can only be confirmed by a consistent association with signs such as measures of blood sugar, abnormalities that show up on x-rays, etc. Dementia is one of the few exceptions from within a vast range of mental illnesses in which such signs can be found (Johnstone, 2006).

[7] These are just two among various problems associated with positivist psychiatry's take on mental distress. For a more detailed discussion on these issues see Ingleby (1980), Colbert (2001) and Johnstone (2006).

with a comforting reassurance about the essentially benign character of their society and the way it dealt (deals) with its deviants and misfits' (Scull, 1976: 303). This, in turn, conferred on psychiatry the impartial and detached authority it needed to fulfil its social control function.

As Ingleby (1983) shows, this last point is better illustrated if we define the biomedical model in terms of a set of practices and power relations (Foucault, 1973). In these practices, the doctor's authority does not emanate from law or morality, but from his right to choose what shall be in the best interest of the sick person. Being ill evokes a sense of fragility and a need for protection, exemption of responsibility and performance, elucidation and cure. It is within this state of frailty that the patient-doctor relationship (usually) takes its most intense form. As fears of pain and death arise, the patient turns to the doctor for healing and comfort, depositing his/her trust in the latter. The imbalance of power among the two parties is obvious: to the doctor is reserved knowledge about the illness and the authority to act upon it; to the patient is reserved compliance. Indeed, it is not for nothing that the expression 'doctor's orders' usually terminate a patient's attempt to defy a carer's request.

No other instance renders doctors' power more evident as when their authority is exercised in combination with *parens patriae* – the right of the state to make decisions for people deemed unaccountable. With the biomedical model giving rise to the belief that mental illness was a disease in need of treatment, civil commitment (i.e. involuntary hospitalisation) became a common answer by the state to the challenge of people experiencing severe psychosocial distress. In practice, commitment generally only required the signature of one or two doctors; the diagnosis of a particular mental illness and the (currently applied) criterion of 'posing danger to the person herself or to others' were not necessary. As a result, many 'mentally ill' people were placed in psychiatric institutions for long periods of time, sometimes even for the rest of their lives, at the discretion of doctors. The conversion of many of those institutions into 'total institutions' (Goffman, 1961) turned patients' freedom, autonomy and subjectivity into a mirage of their past, and any attempt to recapture them back into a sign of delusion. It would be necessary to wait until the 1960s for anti-psychiatrists to start seeking meaning in mental patients' acts and utterances.

When the patient's experience, beliefs and behaviour are regarded as symptoms of physical illness, they are divested of political and moral significance. According to the biomedical model, symptoms are not intelligible; they are not a consequence of human agency. This invalidates the actions of the 'mentally ill' by making them meaningless. 'Mental patients' are no longer held responsible for their behaviour, simply because they have no control over it. It is at this point that the doctor, who alone has the power to cure, is called to take on the mission of 'controlling the symptoms'. Both Ewins (1974, cited by Treacher and Baruch 1980) and Ingleby (1983) argue that the imposition of the sick role on to the 'mentally ill' is a particularly potent form of social control. By detaching mental illness from any political and moral dimensions it might have, the biomedical model enables its practitioners to regulate morality and deviance without appearing to do anything remotely similar. Granted, once discussion started about the rights of mental patients, the practices of long-term incarceration and involuntary treatment became increasingly more difficult to justify and the power of doctors was reduced, in particular through the application of legislation on informed consent. Yet, for decades, mental patients were forced into often unnecessary institutionalisation, separated from society and deprived of agency in the management of their 'illness'.

The impacts of the incorporation of the 'sick role' (Parsons, 1951) on patients' autonomy and ability to make sense of their illness are well summarised by Treacher and Baruch (1980):

> A sick person's status is conditionally legitimated when he willingly makes himself dependent on other people who are not sick – friends, family members, doctors, etc. – rather than on fellow sufferers. This creates real barriers to group formation among the sick, and little possibility of positive legitimation (*ibid.*: 139).

The more the sick person becomes dependent on others, the less they experience themselves as having an active self. Their point of view is subordinated to that of others. By discarding lay people's competence to reason and make choices about how to deal with their ill-health, medicine renders illness a domain for professionals. Because the biomedical model firmly asserts the biological origins of illness, health problems are construed as residing inside the patients themselves. This distracts attention from the social factors that may have played a role, and implies that the patient's subjectivity can be disregarded. Within this disempowered role the patient tends to offer minimal challenge to medical intervention. This, again, emphasises the authority exerted by the medical profession (Ingleby, 1983).

As noted by Treacher and Baruch (1980), the adoption of the sick role had yet another disconcerting impact: it undermined patients' interaction and association with each other. This is because medical treatment was, for the most, focused on the individual and permeated by unintelligible jargon. In the absence of a 'common language' and a 'common space' to discuss potentially common experiences, patients were left in a position of isolation. This was both more discernible and problematic in regard to mental patients, essentially because they were deemed unaccountable, placed under the tutelage of the psychiatric system, and confined in dehumanising institutions. Within those institutions there was no incentive for the expression of subjective experience or for social intercourse with other inmates: having been reduced to their illness, patients were stripped of their existential being, becoming mere spectators of their externally defined needs and wants and passive recipients of 'treatment'. These constraints on freedom (understood as the possibility to make choices) and autonomy were crucial to the maintenance of a *status quo* which left isolated patients no alternative but to accept the authority of doctors. They also inhibited group formation, for the creation of a group entails, among other things, that its members identify common interests and show willingness to pursue them together. This is unlikely to occur when individuals are allowed no sense of self-determination.

But patients' inability to associate was also transposed to outside the asylum: the strong taboo and stigmatisation associated with mental illness hindered the establishment of contact between and mutual support among people experiencing mental distress, and hampered their recognition in a society which discredited and segregated them. Relegated to a position of exclusion, it would take decades for psychiatric patients to organise and take collective action. Many of the actions by and on behalf of mental patients in the 1970s were aimed at challenging the practices and power of psychiatry and at devising alternative forms of care. Without these actions, participation in mental health would have most likely remained an ideal instead of a reality.

Long before the shifts just described took place, other 'psy-professions' started to emerge alongside medicine. At the beginning of the twentieth century psychology, psychoanalysis, social work, etc. began to put forward proposals for intervention in arenas such as industry, school, and family. This posed an obvious challenge to psychiatry's authority outside the asylum. According to Ingleby (1983), one way by which psychiatry sought to keep its dominance over that territory was by absorbing non-physical approaches to 'mental illness' (e.g. dynamic, behavioural, communal theories and treatments). The treatment of neuroses is perhaps the clearest example of this strategy: when psychoanalysis gained recognition in the treatment of neuroses, many psychiatrists sought training as psychoanalysts[8] and began to employ its techniques.

The attempt to assimilate the new disciplines' knowledge and practice was probably less straightforward in the case of psychology. Psychology placed its first efforts to become a recognised profession in fields where psychiatry had little stake, namely industry and education. Studies on fatigue among workers in munitions factories, and the development of intelligence and personality tests by industrial psychologists in Britain and in the US, raised the army's interest in the application of its techniques. As World War II proceeded, the British army started employing psychologists to evaluate recruits' propensity to 'battle fatigue'. There, they entered a working relationship with psychiatrists. By the end of the war, psychology had gained for itself a much-wanted foothold in mental hospitals (Stone cited by Ingleby, 1983). Clinical psychology and psychiatry have since been engaged in many disputes, shifting between periods of open conflict and reconciliation. As I had the opportunity to

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[8] This is still noticeable in South America where most psychoanalysts are originally psychiatrists.

observe during fieldwork, these tensions are still commonplace, extending beyond hospital settings and to other disciplines[9].

Although classical psychiatry has incorporated some non-physical approaches to mental distress, the biomedical model has remained at the core of its practice. As we noted earlier, this is not explained by the rise of copious evidence establishing the biological nature of 'mental illnesses': although biochemical unbalances in the brain have long been pointed out as the causes of depression or bipolar disorder no measures which can verify that have been developed so far (see Lynch, 2006). Instead, the maintenance of a (predominantly, if not exclusively) positivistic approach to 'mental illness' has served classical psychiatry's need to sustain its link to the chief source of its legitimation and respectability: medicine (Ingleby, 1983). Without that link, psychiatry would be unable to maintain its reputability, as well as the feature which still distinguishes it the most from other 'psy-professions' – the authority to prescribe drugs. Indeed, the discovery of psychotropic drugs in the 1950s, their large-scale prescription and the promise of cure they held, have largely contributed for lay people's acceptance of the biological origins of mental distress, even if alone they are usually not able to heal. Current concerns with the over-consumption of and dependence on drugs such as Valium or Prozac illustrate this point.

The invention of psychotropic drugs is often cited as one of the main reasons for the dismantling of asylums from the 1960s onwards. Because those drugs could be administered anywhere and because it was claimed they would treat 'mental illness', there were few arguments for maintaining institutions whose detrimental effects had been criticised for decades. Yet, the real push factor for deinstitutionalisation policies, Scull (1979) argues, was that capitalist states could no longer meet the costs of keeping such a huge system of confinement. Interestingly, although the massive discharge of psychiatric patients into society enabled psychiatry to extend its field of intervention beyond the asylum (for they still required treatment), it also gave former asylum inmates an opportunity to unite in search of alternative recovery solutions. We must not neglect the fact that many of those people remained hostage to the harmful side-effects caused by drugs, suffered the hardships of stigmatisation and/or were abandoned to a life of begging on the street. However, some ex-psychiatric patients succeed in coming together and generating initiatives and movements which brought significant

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[9] One vivid example of that sort of conflict arose in a multi-disciplinary community-based mental health care service in Rio de Janeiro when a social worker did the 'intake' of a person reporting (what the professional interpreted as) delusions. Both psychiatrists and psychologists argued that the social worker had not been trained to make psychological evaluations and could not produce a diagnosis. Social workers, occupational and musical therapists, on the other hand, countered that the service where they worked was explicitly designed to provide a holistic approach to mental distress and their knowledge and expertise were as relevant to identify and tackle psychosocial problems as those of psychiatrists and psychologists. This is a clear instance of a struggle over the hierarchical system among mental health professionals.

change in the ways people affected by mental distress are perceived and helped to recover. Among those movements was the psychiatric survivor movement in the US. In the next section we provide a general overview of this and other 'movements of change'.

1.3 Movements of change

Social movements have been one of the primary agents formulating critique and effecting social change in modern societies (Wilson, 1973; Habermas, 1991; Melucci, 1996). They have become so prevalent some have argued we live in a 'movement society' (Meyer and Tarrow, 1998). Social movements may be defined as "formally organised group[s] that act consciously and with some continuity to promote or resist change through collective action" (Goldberg, 1991: 2). Put in other words, they are conscious, concerted and sustained efforts by ordinary people to bring about or oppose change regarding an aspect (or more) of the social world in which they are embedded (Goodwin and Jaspers, 2003). Social movements thus entail the presence of a shared ideology, an active membership and leadership. The emergence of an 'us' who feels challenged by a 'them' is critical for social movements to form (Taylor and Whittier, 1992).

Social movements in the mental health field have engendered considerable change. Here we address post Second World War mental health movements. Because we cannot possibly do justice to all such movements, we selected three whose claims and actions resonated in the Netherlands and in Brazil (albeit in different ways), paving the way for the emergence of user participation: deinstitutionalisation, anti-psychiatry and user movements.

Anti-psychiatry and the user movements are examples of 'new social movements' (Crossley, 1998; Barnes, 1999). As with other forms of organised social protest (including peace, environmental, gay and lesbian, and women's movements), their identities, goals, and modes of association differ from those of the 'old' movements. Actors in new social movements are not bond by socioeconomic class, i.e. their class background does not determine their collective identities or the aims of their actions. Instead, they tend to unite in face of shared concerns regarding social arrangements, to focus on grass-roots politics and to create horizontal, democratic associations (Cohen, 1985). New social movements "target the social domain of 'civil society' rather than the economy or state, raising issues concerned with the democratization of structures of everyday life and focusing on forms of communication and collective identity" (*ibid.*: 667)[10].

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[10] A reservation must be made here concerning the fact that contemporary user movements do target both the state and civil society, seeking to influence the way welfare services are provided and to improve the position of people affected by psychosocial distress in society.

Indeed, identity is a central issue within the new movements. According to Melucci (1996), collective identity is "an interactive and shared definition produced by a number of actors (or groups at a more complex level) concerning the *orientations* of their action and the *field* of opportunities and constraints in which such action is to take place" (1996: 70). The 'interactive and shared' elements included in this definition stress the idea that such identities are "constructed and negotiated through a repeated process of 'activation' of social relationships connecting actors" (Melucci, 1985: 793). Thus, the formation of collective identities is a dynamic process which cannot be seen separately from the production of meaning in collective action or from the social relationships that form and develop while carrying out that action. If we take the example of the stream of ex-psychiatric patients in the US who defined their movement as the survivor movement, and themselves as survivors (Chamberlin, 1978), we see clearly how their collective identity was shaped by the 'field of opportunities and constraints', i.e. a psychiatric system in which they were segregated, silenced and abused and their discharge to a stigmatising society; the 'orientations of their action', i.e. the call for the abolishment of psychiatric institutions and its replacement by alternative user-led services; and their 'social relationships', i.e. accepted membership by and liaison with mostly only former psychiatric patients. By using the word 'survival', which implies that they have lived through a life-threatening experience, the members of that movement called attention to their experience of oppression within 'total institutions'.

Another relevant aspect which distinguishes 'new' from 'old' movements is the nature of their goals. While the latter may have fought for a total rupture with the institutions and culture of 'bourgeois' civil society, the former seek to democratise social institutions without renouncing the formal egalitarian principles of civil society or the universalistic principles of the formally democratic state (Cohen, 1985). New social movements fight for symbolic and cultural change, understanding these as important precursors to more general changes in society. They also seek to make power relations visible and to challenge dominant structures. Finally, new social movements believe individual change can emerge from collective action; that one's life can change while struggling for wider social transformations (Melucci, 1985).

The above ideas will be used next to examine the ways by which deinstitutionalisation, anti-psychiatry and user movements contributed to the emergence of a user voice.

1.3.1 Deinstitutionalisation

The first steps toward the deinstitutionalisation of psychiatric patients were taken in the mid-1950s. Although this policy was adopted in much of Europe and the Americas in the decades that followed, the deinstitutionalisation movement began earlier in the US and achieved more far-reaching results. By the 1970s, half a million people had been discharged from US public asylums (Rosenberg and Rosenberg, 2006).

American deinstitutionalisation was the result of several factors. First, the asylum system had reached breaking point: overfull and run-down, it either had to be expensively renovated or replaced. Moreover, it represented an obsolete mode of social control, incompatible with the needs of an advanced capitalist society such as the United States in the second half of the twentieth century (Scull, 1978). Other forms of intervention and control (e.g. psychotherapy and mental hygiene programmes) were already widely disseminated and a critical mass of young psy-professionals was emerging to seek out more prestigious careers in the wider field of mental health, Realising how much of a threat that was to psychiatry's authority over mental illness, psychiatrists themselves were among the first to challenge the need for long-term institutionalisation as soon as the first psychotropic drugs were discovered in the 1950s (Scheper-Hughes and Lovell, 1986). At the same time, the civil rights movement was gathering momentum and exerting increasing pressure for every citizen's rights to be enforced (Everett, 1994). Many commentators believe, however, that the main reason for the change in policy was the need to cut costs (Scheper-Hughes and Lovell, 1986; Rosenberg and Rosenberg, 2006).

However, the sudden release of thousands of psychiatric inmates into the community did not result in society's acceptance of people affected by mental distress. Friends and family of ex-inmates were not as supportive as had been expected and many refused to assist in the care of their relatives. In fact, some of them even became strongly opposed to deinstitutionalisation, creating action groups against its implementation. In the absence of well planned community-based services, former inmates were transferred to federally supported or privately financed community-level institutions, most of which were nursing facilities or private homes. Those establishments, and in particular the for-profit enterprises, were often a more punitive and restrictive milieu than the asylum: as well as the large number of people they accommodated, the focus on making profit and the lack of competent staff, little attention was paid to the needs of a population which had been the target of dehumanising practices for decades (Scheper-Hughes and Lovell, 1986). Furthermore, psychotropic drugs not only did not cure, they indiced major side-effects including facial paralysis and involuntary repetitive movements in different parts of the body (Rogers, Pilgrim and Lacey, 1993). Memory loss, disorganised thought and incontinence were also common among people who endured ECT and insulin-coma therapies. Overall, these conditions made the return to the community an experience of severe hardship and suffering for many ex-psychiatric patients who fell into abandon.

On the other side of the Atlantic a more successful deinstitutionalisation process had been initiated in Trieste, Italy, under the leadership of Franco Basaglia. This was, in fact, a much broader movement which extended beyond decarceration to include a profound questioning of psychiatry and its practices, alternative conceptualisations of mental illness and mental patients, and new forms of treatment and rehabilitation. The movement known as *Psichiatria Democratica* also had a profound influence on Brazil's psychiatric reform (Amarante, 1994). Because Basaglia's critique and practice went much further than merely attacking institutionalisation (though that was one of its most visible achievements), they should be grouped with a more encompassing movement – anti-psychiatry – which we examine in the next section. Before moving on to that, we first draw attention to the manifestations of the deinstitutionalisation movement in the Netherlands.

In contrast with the US and some other European countries, large-scale deinstitutionalisation did not take place in the Netherlands (Oosterhuis, 2005a). This can be explained by two main factors. First, the Netherlands had already quite a broad network of out-patient services dating from as early as the 1920s. Second, mental health care reform was implemented with a greater degree of continuity than in other countries (Gijswijt-Hofstra and Oosterhuis, 2005). As Oosterhuis (2005a: 91) put it, "polarisation and a radical break were averted by gradually integrating new practices in existing institutional frameworks".

Until the 1960's, out-patient mental health care in the Netherlands was largely run by the main religious or ideological 'pillars' of Dutch society. Starting in the mid-nineteenth century, Dutch society adopted a policy of *verzuiling* ('pillarisation'), i.e. a social and political compartmentalisation along denominational (e.g. Protestant, Catholic) and ideological (social democratic, liberal) lines. Within this context, voluntary and religious-inspired initiatives (including Orthodox Calvinist, Roman Catholic, Jewish and Dutch Reformed) had a key role together with public authorities in creating and overseeing mental institutions. Even though the denominational mental health care sector may have been subsidised by the state, it was not until the 1970s that government became more directly involved in the management of the mental health system. This was essentially a result of the *ontzuiling* or 'de-pillarisation' of Dutch society, and of a period of economic prosperity which made possible the expansion of the Dutch welfare state (Gijswijt-Hofstra and Oosterhuis, 2005).

Among the measures adopted by the Dutch government were the regionalisation of mental health care (i.e. a more even distribution of services across the country) and the creation in 1982 of RIAGGs (Regional Institutes of Ambulatory Mental Health Care) – the equivalents of the American Community Mental Health Care Centres (Schnabel, 1998). These measures signalled the government's aim of reinforcing the out-patient sector as a counterpart to institutional psychiatry. As in the US, however, they also reflected the government's need to control the rising costs of in-patient care (Oosterhuis, 2005a). In addition, pressure groups (comprised of both adherents of critical psychiatry and engaged mental care users) became more organised and began to demand the reorganisation of the mental health system. One of their most vigorous actions in the 1980s was the formulation of the 'Moratorium for New Psychiatric Institutions' (1982), which was taken directly to the Dutch Parliament. After much discussion, the Ministry of Health adopted policies in 1984 supporting the substitution of hospital beds by places in sheltered residences, day treatment centres, outpatient clinics, etc. (Haafkens *et al.*, 1986). However, the government did not call a halt to the building of new mental hospitals and there was no significant reduction in the number of people hospitalised; thus, outright deinstitutionalisation as in the US did not take place. Instead, the Netherlands forged its own variant of deinstitutionalisation known as *vermaatschappelijking* or 'socialisation' of mental health care (Gijswijt-Hofstra, 2005; Oosterhuis, 2005a).

Socialisation aimed at reintegrating chronic patients into society by facilitating access to a set of non-institutional service provisions. Policies adopted in the early 1990s established the creation of Multi-Functional Units (MFEs) as a way of furthering socialisation. MFEs offered a broad range of decentralised, small scale forms of mental health care near people's place of residence, or even at home. Psychiatric home care, day activities centres and case-management were devised in order to assist long-term mental care users to remain or become self-sufficient and to live in the community. The merger of psychiatric hospitals with RIAGGs was yet another step taken towards socialisation. This measure aimed at smoothing the transition from institutional to out-patient care and at facilitating integration into society by increasing access to adequate community-based services (Gijswijt-Hofstra, 2005).

Although by the late 1990s 80 per cent of the general psychiatric hospitals had merged with out-patient services (Ravelli and Schrijvers, 1999) and as many as 80 MFEs had been created, de-hospitalisation has been a slow process in the Netherlands: between 1980 and 1996 the proportion of the Dutch population resident in psychiatric hospitals was only reduced by 0,03 percent, changing from 0,15 to 0,12 per cent (Borgesius and Brunenberg, 1999 cited by Gijswijt-Hofstra, 2005). In terms of the institutionalised population, this represents a reduction of 20%. Clearly, we cannot speak of an 'emptying-out' of the institutions in the Netherlands on the scale seen in the USA. However, this small-scale deinstitutionalisation did not give rise to the situations of neglect observed among ex-psychiatric patients in the US. This was due to the existence of a strong welfare state which was prepared to maintain a network of alternative community-based services on a national scale (Oosterhuis, 2005b).

1.3.2 Anti-psychiatry

The term 'anti-psychiatry' was possibly first employed by David Cooper in his book *Psychiatry and anti-psychiatry* (1967) and has since then been used to characterise a kaleidoscopic international movement which had psychiatry as its main target of critique (Gijswijt-Hofstra, 1998). Among its key figures were R.D. Laing, David Cooper, Thomas Szasz, Franco Basaglia and Michel Foucault. Throughout the 1960s and 1970s they argued that psychiatry was an instrument of social control, criticising its purpose, its conception of mental illness, and its treatments. The way they went about this differed widely, however. Indeed, the movement embraced such varied opinions and critical standpoints that some of its main proponents (particularly Laing and Szasz) disowned the label anti-psychiatry altogether (Crossley, 1998; Double, 2006).

Perhaps one of the most noticeable differences among 'anti-psychiatrists' lies in the way they conceived of mental illness. While some envisioned mental illness as a set of reactions to the unbearable stresses of life, others denied its very existence, seeing mental illness as a 'myth'. Laing, Basaglia and Foucault adhered to the first view, Szasz was the main exponent of the second (Szasz, 1972). A further distinction can be made between Laing, on the one hand, and Basaglia and Foucault, on the other. For Laing, interactions within the family underlay the reactions metaphorically labelled 'mental illness'. In contrast, Basaglia and Foucault saw broader societal factors rather than the family as the fundamental determinants (Double, 2006). These visions have inspired different forms of alternative treatment. In England, Laing and colleagues founded therapeutic communities (e.g. Kingsley Hall, 1965-1970). Because mental illness came to be understood as a voyage into the 'inner space' (Laing, 1967), a protective social environment was designed as a 'safe haven' in which people could embark on that journey[11]. Professionals worked and lived in those communities, supporting 'voyagers' as required (Crossley, 1999).

In Italy, proposals for alternative treatment in the early 1970s centred on the re-establishment of links with the community, the development of new personal and social identities, and the regaining of contractual power in society. Treatment, therefore, was envisaged as something to be done outside the institution. Wage labour for ex-psychiatric patients, for example, was seen as a means to counter social exclusion and establish an active presence in the community. Basaglia and colleagues created residences and autonomous housing for former inmates; those who, for one reason or the other, had to remain living in the hospital were given the new legal status of *ospite*, or guest. *Ospites* could go in and out of the hospital as they pleased and some worked in the city. This meant that mental health practitioners had to literally step out of institutions and make their care available in the real world (Scheper-Hughes and Lovell, 1986).

Each of the streams of 'anti-psychiatry' mentioned above influenced developments beyond the countries in which they were devised. In what follows we will focus more closely on the streams which had most impact in the Netherlands and Brazil respectively: British anti-psychiatry and Italian Democratic Psychiatry. We will provide an overview of their central features and analyse the ways in which they influenced mental health care delivery in the Netherlands and in Brazil.

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[11] The 'therapeutic community' concept was introduced into British psychiatry after the Second World War by psychiatrists such as Main (1946) and Maxwell Jones (1953). It was envisaged as a form of in-patient treatment which would counter the process of 'institutionalisation' in patients, by involving them actively in their own recovery. Spandler (2006) regards the therapeutic community as an important contributor to the user movement in the UK. The method was also adopted to a certain extent in the US, particularly in institutions for treating substance abuse.

1.3.2.1 British anti-psychiatry and mental health care reform in the Netherlands

British anti-psychiatry emerged as part of the 'counter-culture' of in the 1960s, which rejected conventional social norms and called for changes in sexual mores, women's rights, race relations, etc. This setting provided fertile ground for critics who set out to expose psychiatry's role as an agent of social control and to liberate psychiatric patients from its sway. Together with Ronald D. Laing, who is usually regarded as the movement's leader, David Cooper, Aaron Esterson, Joseph Berke and others contributed a body of literature and initiatives which sought to challenge the distinction made by psychiatry between madness and sanity and to provide a radically different approach to mental distress. Medical approaches to mental illness and its treatment were anathema to these authors, all of whom had received a traditional medical training in psychiatry. They understood mental illness as a social and political phenomenon, perhaps even as a positive experience of liberation, but not as a disease entity or pathology. The 'madman' was seen as a victim of alienation, whose segregation served the purpose of keeping the social order undisturbed. Anti-psychiatrists criticised not only psychiatry's nosological categories and incarceration practices, but also the notion of adjustment to normality. Taken to be central to 'mental health' by both professionals and lay people, 'adjustment' was problematised by anti-psychiatrists as yet another mechanism for maintaining the existing social order (Crossley, 1998). Accordingly, therapeutic communities such as Kingsley Hall or Villa 21 were created not to deliver cures but to provide places where 'some may encounter selves long forgotten or distorted' (Schatzman, 1972 cited by Double, 2006).

The condemnation of psychiatry's medicalisation of madness was certainly not new. From the nineteenth century onwards various reformers attacked the abuses and neglect of patients in psychiatric hospitals. However, the criticism formulated by anti-psychiatry had some distinctive features. First, it was a protest from within, i.e. it came from psychiatrists themselves. Second, it occurred at a time in which psychiatry had achieved secure hegemony in the 'care of the insane'. Third, the critique posited by anti-psychiatry was more fundamental than earlier ones, extending beyond a critique of the concept of 'mental illness' to the dispute the very concept of normality. Finally, as a result of the new mass media, the rising educational level in the West, and of the favourable counter-culture climate of the 1960s, anti-psychiatric ideas and practices acquired more resonance than ever before. Many young mental health workers, (former) psychiatric patients, academics and artists lent support to the movement, participating in meetings, working in its therapeutic communities, producing academic texts and films inspired by its views, and setting up organisations such as the Mental Patients Union created in 1973 (Crossley, 1998; Blok, 2005).

Despite the fervour with which British anti-psychiatry was received in certain circles, it had all but fizzled out by the early 1970s. When Kingsley Hall closed in 1970 after being repeatedly vandalised by a rather hostile local community, Laing abandoned many of his associations with other organisations and dropped his frail alliances with progressive colleagues in the psychiatric mainstream to move to Ceylon, where he pursued Buddhism. Other therapeutic communities which remained open became much less political. The counter-culture moved on and those who remained engaged in the politics of psychiatry turned to psychoanalysis as a frame of reference and intervention (Crossley, 1998). Later, French post-structuralism became the canon for critical thinkers. For some, anti-psychiatry was a short-lived movement of 'anti-ness' guided by the spirit of delegitimation of established authority so characteristic of the 1960s (Jones, 1998). For others, it was a full-blown movement (albeit short-term) with lasting consequences in the field of psychiatry, particularly where users are concerned. According to Nick Crossley (1998), anti-psychiatry had a fundamental role in setting up the conditions which enabled the creation of the English user movement. By politicising the psychiatric field, anti-psychiatrists broke psychiatry's 'scientific shield' rendering it open to scrutiny by everyone, including those oppressed by it. By questioning and re-defining the meaning of 'mental illness', anti-psychiatry provided users with a different discourse in which they could articulate their experiences and identities. Finally, by advancing alternative care solutions for people affected by mental distress and ruthlessly criticising traditional methods, anti-psychiatry may have encouraged some psychiatrists to think in more humane terms about their patients and to support the emergence of a user voice.

Anti-psychiatry was received with considerable enthusiasm in the Netherlands. Prominent psychiatrists such as Kees Trimbos disseminated its ideas and Jan Foudraine became its Dutch representative, seeing his book *Wie is van hout… een gang door de psychiatrie* (1971)[12] turn into a bestseller. Interest in anti-psychiatry extended up to the government's psychiatric advisors who invited Laing to give a lecture and workshops to mental health care providers in 1965 (Blok, 2005). Indeed, anti-psychiatric ideas met with greater acceptance in the Netherlands than in Britain.

What generated such support for anti-psychiatry in the Dutch soil was the combination of an already blooming desire to reform psychiatric care with the rapid social transformations that gave rise to a thriving Dutch 'counter-culture' (Ingleby, 1998). Immediately after WWII Dutch society could be characterised as conservative and confessional, centred on traditional values such as obedience, hard work and respectable behaviour. However, by the 1970s it had become one of the most liberal and progressive countries in the world. This remarkable transition was strongly associated with the 1960s economic boom and the resulting expansion of the welfare

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[12] Foudraine's book was also published in English under the title *Not made of wood: a psychiatrist discovers his own profession*.

sate. Progressives from the various 'pillars' of society (e.g. Catholic, Protestant, social-democratic) also began to unite, forming new political parties such as the Labour Party (PvdA). One key element common to all of them was the call for the end of hierarchical divisions along class and religious lines, i.e. 'de-pillarisation'. The challenge to traditional authorities was thus not limited to a specific group: the replacement of hierarchical social relationships by relationships based on negotiation extended to many different segments of society. Freedom, autonomy and individual rights became the core principles of Dutch modern society[13].

Like many other citizens, mental health care providers started to search for a new set of values to underpin the rapid transitions occurring in their lives. This was also a time in which traditional psychiatry came under attack. Described as 'immature', biomedical psychiatry was accused of simply disguising and side-stepping mental problems with psychopharmaceutics and pats on the back (see Blok, 2004). It was necessary to find a form of mental care in line with a progressive society. Inspiration came mostly from two sources: anti-psychiatry and humanistic psychotherapies.

From the 1950s onwards group therapy, Gestalt therapy and Rogerian therapy started to be introduced in the Netherlands. Rogerian therapy in particular insisted on a non-directive, client-centred approach very much at odds with the distant and organicist approach favoured by the medical model of traditional psychiatry. Self-esteem, human relations and communication were key aspects in this form of psychotherapy which became widely disseminated in the 1960s. As the impairing side-effects of psychotropic drugs started becoming more visible, more and more professionals began to question not only the value of pills but the whole medical model as such. Meanwhile, many psychiatrists, psychologists and psychiatric nurses received training in psychotherapy and psychoanalysis. Talking therapies gained adherence as the way forward, and a social model of mental illness was seen by many as the alternative to reductionist medical approaches (Ingleby, 1998; Blok, 2005).

It is therefore hardly surprising that anti-psychiatric ideas found ready acceptance in the Netherlands. The writings of Laing, Szasz, Foudraine and others not only offered challenging theories about the social roots of mental illness: they also contained powerful critiques of established religion, capitalism and traditional mores, endorsing individual freedom and self-realisation (Blok, 2005). These theories and values were very much in tune with the agenda of proponents of psychiatric reform. They provided both an alternative vision on mental illness and a framework from which to make sense of the changes in their lives.

Interestingly, as argued by Blok (2005), anti-psychiatry in the Netherlands did not become a call for abolishing the whole mental health system, for most of its adherents worked in that system. Instead, it was absorbed into a movement that promoted psychiatric reform through the improvement of care methods. What this

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[13] This was not a straightforward process in the whole of the Netherlands. In some rural areas traditional values persisted for many years.

meant in practice was the substitution of the medical model by a social model of mental illness, a process which would gain much more expression within the flourishing out-patient care than in psychiatric hospitals. Blok termed the reform ideal of the 1970s as 'emancipatory psychiatry'.

The idea of 'emancipating' the mental patient was strongly inspired by anti-psychiatrists' claims that mental illness could be understood as a breakthrough in people's lives. In the words of Laing, "madness need not be all breakdown. It may also be break-through. It is potential liberation and renewal as well as enslavement and existential death" (1967: 110). This perspective merged well with the Rogerian approach, which emphasised the importance of self-realization for mental health which claimed the functionality of psychotic symptoms as a means of escaping concerted external attempts to undermine a person's autonomy and sense of self. Madness did make sense. But to understand it one had to place it in its social context: there lay its meaning. Side by side with the 'psychotherapeutic optimism' which reigned in the 1970s, these notions resulted in the ideal of liberating patients, which implied the need to expose the social causes of mental distress.

At the same time, attacks on the medical model of mental illness grew stronger. Psychotropic medications gave rise to many noxious side-effects and there was still little knowledge as to how to prescribe them. The under-availability of psychiatric nurses during the 1950s had led patients to be over-medicated in some hospitals. With the rise of the user movement in the early 1970s, many former psychiatric patients came forward to express their discontent with the side-effects of drugs and the lack of professional attention during admission. Nurses found it increasingly difficult to persuade inmates to take their pills. Together with psychologists, they began to look for ways of making their work both more interesting and rewarding. Psychotherapy offered such an alternative. As the proponents of the social model of mental distress began to create therapeutic communities, increasing numbers of professionals sought training in psychotherapy. The large financial investments made in mental health care by the Dutch government in the late 1960s and early 1970s created opportunities for new forms of care and new types of professionals. The way was open for a modern, 'emancipatory psychiatry' (Blok, 2005).

Such treatment started from the premise that serious mental illness could be functional: in the event of an unbearable obstruction to one's freedom, mental problems provided an escape from the agents exerting such intolerable pressure. Mental illness, then, was seen as a means to render one's problems visible; as a call for help and liberation. Influenced by Sartre's existentialism, Laing and colleagues favoured the creation of a psychotherapeutic environment where such freedom could be reinstated. In the Netherlands, this idea was translated into comparable initiatives. Dutch psychotherapeutic communities in the 1970s aimed at restoring clients' self-determination. People affected by mental distress were taken to be stuck in a kind of limbo: while seeking to 'protect' themselves from other people's (usually the family's) efforts to constrain their independence, they found themselves bogged down and unable to carry on with their lives. Talking therapies would make it possible to expose the social roots of such blocks. As well as being stimulated to express their feelings and confront the people who had threatened their autonomy, clients were also encouraged to take responsibility for their actions and their own lives. They were expected to have an active role in bringing about the change necessary to break free and restore their mental health. As Blok (2004) puts it, they had to become 'boss of their own brain'[14] (2004: 15). The main goal of much of the psychotherapy carried out during that period was, therefore, to break down clients' resistance to change while instilling in them (and in their families) a sense of responsibility for making that change happen.

Blok (2005) goes on to argue that paradoxically, the ideal of emancipation which underpinned psychiatric reform in the Netherlands during the 1970s had a strong (albeit implicit) moral agenda attached to it. Even though the liberation of psychiatric clients was a key tenet of most psychotherapy practised during that time, the way by which they were to be emancipated was heavily dictated by professionals' vision of what a free citizen of a modern Western society should look like. This vision allowed little room for variations. Clients were to be guided to change towards mature, independent, open and honest individuals who valued autonomy, human solidarity and personal responsibility. These humanistic values were clearly different from those of moderation, calmness, self-denial and self-control associated with traditional (especially religious) cultures and promoted by nineteenth-century 'moral treatment'. However, they were still values and norms of conduct imposed from above. Once again, it seemed that the 'psy-professions' had succeeded in keeping hold of the function of 'guardians' of the new social order.

This function was harder to legitimate in the 1970s than it had been in previous eras. The anti-authoritarian climate fostered by the counter-culture made it increasingly hard for professionals to adopt a directive attitude in therapy. This often placed them in an impasse, for although therapists believed their clients could heal through change and wanted to guide them through it, they were not keen to be accused of paternalism. The alternative for some was to make the advantages of becoming a 'free citizen' sound as attractive as possible. Others opted for a system of punishment and rewards as a way to 'inspire' change (see Blok, 2004).

Anti-psychiatry was used to further legitimate the ideology of 'psy-professions' in Dutch society. When traditional moral certainties were challenged in the 1970s, 'psy-professionals' offered a new normative framework from which to make sense of and engage in an emerging progressive society. Indeed, mental health professionals were at the forefront of liberalisation, offering alternative views on sexuality, gender relations,

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[14] This phrase ("*baas in eigen brein")* is a play on the well-known feminist slogan *"baas in eigen buik"* (boss of your own belly), which expressed the idea that decisions concerning sexuality and reproduction concerned nobody but the woman herself.

child-rearing, drug use, crime, etc. On all these fronts, the Netherlands acquired a reputation in Europe for progressive social attitudes and government policies. Psychological ideas about these topics were disseminated among the general public, which began to read 'psy books' and to use psychological jargon to express emotions and problems (Ingleby, 1998). Anti-psychiatry thus contributed to the 'psychologisation' of Dutch culture. It also inspired some concrete positive changes where mental health ideology and the care of people affected by psychosocial suffering are concerned.

Perhaps one of the most noticeable aspects of the legacy of anti-psychiatry in the Netherlands is the way in which mental illness came to be conceptualised and dealt with. As the social model of mental illness gained ground over the medical model, mental distress went from being viewed as a disabling condition in need of cure by medical interventions to being understood as a meaningful human reaction to life experiences, and one which could form the starting-point for recovery.

This reconceptualisation of mental illness paced the way for a new kind of relationship between clients and professionals; one in which power relations became less asymmetrical. In line with the anti-authoritarian sphere of the 1970s, hierarchical relationships in the therapy room gave way to relationships based on negotiation. The person in treatment was no longer seen as a dependent and incapable *patient*, but as an autonomous and responsible *client* whose treatment was to be discussed and carried out in the light of their own experiences and understandings of life. Professionals were expected to step down from their position of omniscient experts and to act from the standpoint of a sympathising friend. These shifts served to reduce the distance between professionals and clients (Ingleby, 1998) and opened the way to greater client participation in treatment. We should remember that this shift began much earlier, with the introduction of 'the talking cure' (psychotherapy) as an alternative to medical interventions at the end of the nineteenth century. The active participation of the patient – who had to work hard to get better – is an essential ingredient of these methods. In the 1970's, the transformation of the 'patient' into a 'client' and the adoption of a Rogerian, non-directive stance took this shift even further.

Of course, it would be a mistake to try to generalise about changes in treatment ideology as if all mental problems were the same. Psychotherapy has always been more favoured as an approach to less disabling mental problems than for the 'hard cases' that are labelled as psychotic or psychopathic. The vast expansion of out-patient mental health services during the 1970's and 1980's mainly concerned the former type of problems; most of the latter continued to be treated in psychiatric hospitals, where biological approaches remained relatively popular – though strongly challenged by social, 'emancipatory' models.

Despite this reservation, the change in treatment ideology in the 1970's was a radical one. In the hundred years previous to this period a person diagnosed with a mental illness would most likely have experienced the annihilation of their subjectivity and confinement under the authority of psychiatry. Compared to this, the idea of sitting down and having a conversation with a therapist was revolutionary. After centuries of professionals' monologue over madness, a dialogue was coming into being; user participation in mental health and the return of a 'voice' to patients was a logical outcome of this change.

1.3.2.2 Italian 'Democratic Psychiatry' and mental health care reform in Brazil

Psichiatria Democratica was founded in 1973 by Franco and Franca Basaglia and their colleagues in Bologna as a political movement concerned with the rights of psychiatric patients and struggling against their oppression and exclusion from society. Its actions centred on the public denunciation of symbolic and concrete practices of institutional violence and on the implementation of nation-wide psychiatric reforms (Amarante, 2006). In its founding document the movement made the following pledges:

1. to continue the fight against exclusion by examining both its structural aspects in relations of production, and its ideological aspects in cultural norms and values;
2. to struggle against the asylum as the most obvious and violent paradigm of exclusion;
3. to avoid reproducing institutional mechanisms for exclusion in the community; and
4. to make clear a link between health and the mental health care, especially through the reform of the Italian health care system (Scheper-Hughes and Lovell, 1986).

Deinstitutionalisation was a core feature of the psychiatric reforms proposed by Psichiatria Democratica. However, unlike what had happened in the US in the 1950s, such reforms were meant to go far beyond the mere dismantling of the *manicomio* (asylum) to effect a profound process of democratisation of mental health care and a drastic redefinition of the relationship between madness and society. The public scrutiny of the custodial role of psychiatry, the reconceptualisation of mental illness, the creation of a radical anti-institutional alternative for the care of people affected by mental distress, as well as the sensitisation of local communities to become more receptive and responsive to individuals experiencing psychosocial suffering, were all constitutive elements of the proposed reforms. Ultimately, Democratic Psychiatry aimed to abolish the segregative control of madness (legitimised on the basis of its association with dangerousness), to restore freedom, subjectivity and citizenship to those deemed mentally ill, and to devise a set of services and mechanisms focused on promoting their rehabilitation, emancipation and active participation in society (Nicácio, 2003).

This radical programme of reforms was intended to be implemented in the law no. 180 that came into effect in 1978, which laid out the terms of psychiatric reform in Italy. The central premise of the law was that all psychiatric evaluation and treatment should be voluntary. Its main goal was undoubtedly the demise of the asylum system. Law 180 envisaged the discharge of all psychiatric patients and their reintegration in the community through a network of new out-patient services. It also prohibited new admissions to psychiatric hospitals, providing for the admission of people in acute phases of distress to psychiatric wards in general hospitals. Compulsory hospitalisation was no longer imposed on the grounds of 'dangerousness', nor could it be decided on by doctors alone. Instead, the Mayor – a public official accountable to the citizenry, together with two doctors, was charged with that responsibility. In the new law, 'mental illness' ceased to be defined in terms such as 'irrationality' or 'mental incompetence'. It was also no longer considered a special case of illness, allowing the suspension of patients' civil rights, but rather a condition which, like many others, may cause sufferers to need brief hospitalisation and temporary involuntary commitment (Scheper-Hughes and Lovell, 1986). In a nutshell, Law 180 provided for the demedicalisation, decriminalisation, and destigmatisation of 'mental illness'.

The ideology behind the Italian psychiatric reform of 1978 derived largely from the theoretical and practical advances made by Franco Basaglia and his team in a mental hospital in the town of Gorizia during the 1960s and, later on, in Trieste. Indeed, Basaglia was the chief architect of Law 180. To understand how he came to exert such influence and how the concerted actions of the Democratic Psychiatry movement resulted in the passage of Law 180 we must examine both the Gorizia experiment and the socio-political context of Italy in the 1970s.

In the words of his wife, Franca, when Basaglia left the academy to assume the directorship of the Gorizia psychiatric hospital in 1961 he "had never seen an asylum" and "was upset by that encounter" (Ongaro Basaglia, 1987: xii). The institution he encountered was all too similar to the ones depicted by Foucault and Goffman: a crowd of poor, working-class and immigrant people locked away, put into strait-jackets, tied to their beds, forced to endure ECT and insulin-shock 'therapies', all in the name of 'soothing' the disease and 'quieting' the restless. Basaglia identified strongly with the experience of suffering, coercion and confinement of the Gorizia inmates, for he too had been turned into an object of violence and repression when imprisoned for his involvement with the Italian resistance during German occupation (Amarante, 1994). "It was certainly [this] first emotional reaction from which stemmed his refusal of the reality of the asylum and its logic" (Ongaro Basaglia, 1987: xii). In just one decade this 'negation' would result in the rise of a full-blown movement for the deinstitutionalisation of the mad.

One of the first measures undertaken by Basaglia in Gorizia was to put an end to the most violent institutional practices of physical restraint, isolation and shock treatments. Deeply influenced by the Therapeutic Community model devised by Maxwell Jones in England and French 'institutional psychotherapy'[15], Basaglia went on to pursue the humanisation of the hospital, seeking to restore dignity to its inmates by promoting their gradual recovery of subjectivity, freedom and responsibility. This could not happen, however, if inmates continued to be locked, imprisoned and segregated. And so chains were removed, doors were unlocked and fences were pulled down. However, these measures did not produce the effect of liberation expected by Basaglia and his team. When presented with the opportunity to leave the hospital inmates sat quietly, "passive and imprisoned by an internalized image of the asylum that was part of their new sense of self" (Scheper-Hughes and Lovell, 1986: 164). 'Life' in the institution had depleted patients of their capacity for desire and choice; it had extinguished any remnants of their sense of autonomy and freedom, leaving them in the void of a submissive existence. This disquieting experience led Basaglia to reflect on the role of institutional psychiatry. Influenced by Foucault's *Histoire de la Folie*, he came to understand classical psychiatry as an instrument of power, control and segregation, extracting his own concept of 'institutionalisation' as:

> the complex of 'damages' resulting from a long-term coerced permanence in the psychiatric hospital, when that institution is based on the principles of authoritarianism and coercion. Those principles, from which emerge the rules under which the patient must submit himself unconditionally, lead him to a gradual loss of interest which, through a process of regression and restriction of the Self, induces emotional emptiness in the patient (Basaglia, 1981: 259 cited by Amarante, 1994; our translation).

From the Gorizia experiment emerged the realization that the process of institutionalisation homogenises and objectifies those confined in the institution, robbing them of their personal histories and subjective experiences of suffering (Amarante, 1994); 'mortifying their selves' (Goffman, 1961). Classical psychiatry and its practitioners played a key role in maintaining this state of affairs. By construing the loss of individual identity and the inertia and alienation usually exhibited by mortified patients as symptoms of mental illness, it disguised the oppression operated through institutionalisation as just yet another symptom of illness. To restore a new sense of self to the inmates in Gorizia and to expose and eliminate the negative effects of institutionalisation, Basaglia argued, it was necessary to "bracket mental illness" and to destroy the asylum (Basaglia, 1981 cited by Amarante, 1994).

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[15] 'Institutional psychotherapy' *(Psychothérapie Institutionelle)* is an approach to the institutional treatment of psychosis, based on psychoanalysis and developed in several psychiatric hospitals in France after the Second World War (see e.g. Oury, 1976).

Bracketing mental illness did not mean, as many contended, the denial of its existence. Instead, it entailed leaving the psychiatric diagnosis aside, focusing on listening closely to what patients had to say, and uncovering not only the ‘organic’, but also the institutional and social origins of their illness (Amarante, 1994). Soon, it became clear for professionals in Gorizia that freedom was *conditio sine qua non* for rehabilitation. But how could people stripped of their autonomy seek freedom? How were they to return to the society which had excluded them in the first place? And once ‘free’, how could they avoid being caught up again in the institutions created to segregate them?

The answer devised by Basaglia and his colleagues was to set in motion a multifaceted process of de-institutionalisation which included the following ingredients:

- a radical critique of the psychiatric apparatus as a whole and of the scientificity of psychiatry in particular (both through academic papers and lectures and through daily practice in therapeutic settings);
- the provision of care oriented toward the liberation of psychiatric inmates from the asylum;
- the development of work cooperatives aimed at increasing inmates’ contractual power and at fostering their sustainable reintegration in society, where assistance would continued to be available through new out-patient services; and
- the formation of alliances with community leaders, businessmen and politicians focused on promoting a receptive public attitude toward former psychiatric patients.

As the work in Gorizia progressed, Basaglia and his team came to realise that if inmates were to be emancipated the structure which kept them submissive had to be eliminated. This implied not only the literal destruction of the *manicomio* but also to demolish the ‘internalised’ hospital; to confront patients’ mortified humanity. The latter took place more gradually through two main innovations (Scheper-Hughes and Lovell, 1986).

First, paid work was created in the hospital as a means to encourage inmates to leave the wards and to put an end to the stagnation and emptiness their lives had been forced into. ‘Work therapy’ already existed and its profits were important for sustaining the financial viability of asylums at the time. However, under that scheme, inmates’ work was usually rewarded with no more than tokens such as cigarettes. By introducing fair wages, the Gorizia team succeed in creating a labour framework more in tune with the social reality of labour on the outside, allowing inmates to begin to identify more closely with ordinary working people. If we take into consideration that, as in most European psychiatric hospitals at that time, patients at Gorizia were amongst the poorest and most stigmatised members of society, this initiative had the remarkable effect of increasing their contractual power – an element which is essential to acquire autonomy and respect within society. These earlier forms of paid labour later evolved into work cooperatives, i.e. jointly-owned and democratically-controlled enterprises guided by the principles of self-help, self-responsibility, equity, solidarity and independence. They have been popular in countries such as Brazil until today.

The second innovation to facilitate change was the daily *assemblea*, a gathering of patients and staff set to debate life in the institution and to approach the politics of life outside the asylum (e.g. exclusion, poverty, stigma, unemployment, etc.). Assemblies were not spaces of formal deliberation: topics of discussion emerged from the floor and no distinctions regarding decision-making power were made between doctors, nurses, auxiliary staff, patients and family members. Everyone was welcome to attend, but presence was not mandatory and participants could walk in and out as they pleased. The *assemblea* was a 'mechanism' designed to foster contradiction, participation and co-responsibility in reaching consensus on issues centred on the needs of patients.

Decisions made in the assembly were temporary, remaining in force until someone brought them once again into debate. Authority, power and status were constantly scrutinised within an ever-evolving exercise. For some patients the assemblies provided the first public opportunity to express anger concerning their unmet needs without it being transformed into a symptom of mental illness. As patients and professionals became more aware of the impairments caused by institutionalisation, the inmates' personal histories and identities started to surface and so did new subjectivities.

The first assemblies were dominated by patients' complaints and a joint search for ways to satisfy their needs. In Gorizia, the collectivisation of responsibility became a bastion of anti-institutional practice. Everyone, from professionals to patients, was stimulated to have a say over and collectively take the responsibility for not only the inmates' behaviour, but also decisions about individual discharges, community and work placements, the role of family members in the reintegration of discharged relatives, and on the ongoing process of deinstitutionalisation. As time went by, the *assemblea* changed from a space in which to vent personal grievances into a medium for articulating the collective and the political (Scheper-Hughes and Lovell, 1986). The Gorizian *assemblea* enabled perhaps the earliest, most explicit and encompassing form of user participation to take place in a mental institution.

Aside from the assemblies, there were a whole lot of other meetings at Gorizia in which visitors to the hospital were also invited to participate. Those "meetings became instances of critical consciousness-raising through which 'new subjects' were created and collectively empowered" (Scheper-Hughes and Lovell, 1986: 166). Consciousness-raising soon began to happen outside the asylum, during meetings with family members and other local residents and in political forums. Indeed, if deinstitutionalisation was to succeed, society had to be prepared for receiving and integrating (and not simply tolerating) the people it had been excluding for decades. This meant the deconstruction of the strong negative stereotypes attached to mental illness, something which was both a cultural and a political task. It also implied the creation of provisions able to facilitate former patients' transition into society, such as community-based care, assisted housing, and adequate and fairly paid employment. Without these provisions the wellbeing and the autonomy of former inmates would be at risk. However, that was not enough to guarantee the social integration of people affected by psychosocial distress: as long as the Institution prevailed, the threat of segregation would not cease to exist. In 1968, Basaglia and his team published *The Institution Denied* (1968 [2001]) in which they set the first principles underlining the process of deinstitutionalisation and proposed the abolition of the asylum system. The psychiatric reform this entailed would be pursued by Basaglia and the other members of Psichiatria Democratica in the city of Trieste[16].

A number of contextual and political factors favoured the passage of Law 180 implementing psychiatric reform in Italy (Scheper-Hughes and Lovell, 1986; Nicácio, 2003). First, at the time Basaglia and his colleagues began to question classical psychiatry and to devise an alternative model of care provision, no liberal or humanist social psychiatry existed in the country to challenge the prevailing positivist model of mental illness. Mental health care reforms in France, England and the US had already started and exerted a strong influence on the ideology and practice of the Italian reformers. However, experiments in other countries were critically examined and none were entirely reproduced. Psychiatric reform as proposed by Democratic Psychiatry was of a rather innovative nature when compared to other international experiences.

Second, the existing mental health legislation dating from 1904 was obsolete. It established a direct link between psychiatry and the criminal justice system, assigning functions of social control and custody, rather than of care provision, to psychiatry. The fact that most psychiatric inmates were either poor or foreigners made the role of psychiatry in legitimising the segregation of 'social misfits' all too evident. This policing function was very much at odds with the values and the sort of institutions that a society aspiring to modernisation was seeking to promote.

Third, the socio-political context in Italy in the late 1960s was marked by class struggles, the questioning of the role of the state and that of its institutions, and increased demands for democracy and freedom. This was a climate favourable to change and experimentation, offering an opportunity for broad-based alliances between various social movements including the labour, the feminist, and the student

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[16] Franco Basaglia moved to Trieste in 1971 to become the director of the local psychiatric hospital. For a detailed account of the Trieste experiment see Scheper-Hughes and Lovell (1986).

movements. Of added value to Democratic Psychiatry was the fact that health was a common denominator in the agendas of the labour and the feminist movements. The labour movement was calling for the right to occupational safety and health and for access to health services as means of diminishing dependence on company doctors; the women's movement was claiming control over their reproductive system and opposing the medicalisation of pregnancy and birth. Thus, when Basaglia began questioning the power held by psychiatry to confine the least wanted and most vulnerable segment of society – mental patients – his criticisms resonated strongly with the sympathisers of those movements. Leftist trade unions and political parties offered their support to fight the institutions which abused their citizens. Feminists and students identified with the marginal position of psychiatric patients and participated in protests aimed at promoting their rights. In addition, the novel and revolutionary character of the Gorizia and Trieste experiments attracted many international visitors who worked voluntarily in exchange for knowledge and practical experience, generating a constant flow of ideas and renewed enthusiasm. But it was above all Basaglia's own charisma and remarkable ability to intermingle with high political officials, social movements' supporters, mental health care professionals and members of the underclass alike, which placed him in a privileged position to exert influence. And so, when the Christian-Democrats and the Communist Party united to block the Radical Party's call for a referendum on a proposal for the abolition of asylums which did not envisage the provision of alternative services, they called Basaglia to become the key adviser for a new law aimed at enforcing a well-rounded, comprehensive psychiatric reform: Law 180 (Scheper-Hughes and Lovell, 1986; Nicácio, 2003).

Unlike British anti-psychiatry, Psichiatria Democratica never faded out and continues to this day to struggle for the rights and inclusion of people affected by psychosocial suffering. The strength of the Italian movement derived, to a great extent, from its capacity to mobilise social actors from all walks of life and to sustain alliances with various social movements and political authorities (Donnelly, 1992). Inasmuch as discrepancies exist in the extent to which Law 180 has been implemented across the Italian territory, there is no doubt that Democratic Psychiatry spearheaded one of the most encompassing and progressive health and social reforms of its time, leaving a legacy which extended beyond European borders into other continents.

Brazil is amongst the countries most strongly influenced by the vitality of Democratic Psychiatry and where the principles and practice embodied by the Italian psychiatric reform have been most thoroughly discussed and adapted to the local context. The ideas of movements such as French 'Institutional Psychotherapy', the English Therapeutic Communities and American 'Community Psychiatry' were also applied in Brazil from the 1960s onwards. Over the years, however, they proved insufficient to feed theory and practice concerned with the reintegration of people affected by psychosocial distress in society and with the promotion of their subjectivity and citizenship. Italian Democratic Psychiatry, on the other hand, had taken the discrimination, segregation and exclusion of the 'mad' as problems to eradicate together with the asylum, and its achievements had generated considerable insights and tools for problematising psychiatry's social control function, formulating a critical process of deinstitutionalisation and creating an alternative mental care system aimed at psychosocial rehabilitation and on the promotion of the autonomy, freedom and citizenship of its users (Birman, 1992). These issues became the central goals of the Brazilian psychiatric reform which began to unfold in 1978, headed by the *Movimento dos Trabalhadores de Saúde Mental* (Mental Health Workers Movement, MTSM) (Amarante, 2006).

In 1978, Brazil had been under a repressive military dictatorship (1964-1985) for over fifteen years. An economic crisis had hit the country and inflation was staggering. Cities were growing dramatically on the account of massive internal migration and inequalities were extreme. These adverse political, economic and social circumstances led to the formation of grassroots movements pushing for re-democratisation, particularly in the largest cities. In Rio de Janeiro, workers from a variety of psychiatric institutions also began to mobilise, creating the MTSM. Aggrieved by the rapid deterioration of psychiatric care and by the violence perpetrated against psychiatric inmates, they united to denounce publicly the segregation and inhumane treatment of mental patients in asylums and to protest against poor working conditions and the privatisation of mental care services (Amarante, 2006).

Asylums in Rio de Janeiro and elsewhere mirrored the one encountered by Basaglia in Gorizia. In addition, private asylums were growing steadily in number and size as a result of state policy reducing funds for state-run out-patient mental care and contracting out public psychiatric services to private clinics. Those were for-profit organisations whose revenues grew in proportion to the number of inmates and their length of stay. The end result of that policy was the accumulation of hundreds of patients in dilapidated wards for long periods of time with a minimal level of care. Between 1965 and 1970 the number of mental patients admitted to private clinics went from 14,000 to 30,000, while number of inmates in public hospitals hardly changed (Resende, 1987)[17]. An 'industry of madness' (Cerqueira, 1984), such as the one that arose in eighteenth-century England (Scull, 1979) was flourishing in twentieth-century Brazil, and with it came the intensification of the segregative control of the mentally ill, legitimised by psychiatry and operated through the asylum system.

Even though demands for better labour conditions and more humane psychiatric treatment were key to the formation of the MTSM, it was really the fight against the exclusion of people affected by psychosocial distress and the promotion of their rights that came to inspire the actions undertaken by the movement to reform psychiatry in

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[17] Private psychiatric hospitals sponsored by the state continue to exist until present, alongside public psychiatric hospitals. At the end of the past century, private clinics held 80 per cent of the psychiatric beds available in Brazil, while public hospitals accounted for a mere 20 per cent (Alves, 1999).

the decades that followed. To approach those issues critically and to bring about change it was necessary to expose psychiatry as an instrument of social control and the asylum as a dumping ground for marginalised sufferers. These and other problems were discussed at a congress held in Rio de Janeiro in 1978 to which were invited, among others, Franco Basaglia, Félix Guattari, Robert Castel and Erwin Goffman. During that event a substantial body of knowledge was exchanged and relevant theoretical tools were disseminated, boosting the MTSM's enthusiasm to proceed with the critique of the asylum system in Brazil (Amarante, 2006). In the following year Basaglia returned to the country to participate in various conferences during which he presented Law 180, discussing the psychiatric reform movement in Italy as well as the assumptions and limitations of the new legislation and proposing the eradication of the asylum alongside the creation of care alternatives. During his stay, Basaglia also visited several psychiatric hospitals in the city of Minas Gerais. Appalled by the deplorably inhumane way in which inmates were treated, he denounced the violation of human rights he encountered to the press. Those statements had a tremendous impact in strengthening the mobilisation of professionals concerned with the struggle headed by the MTSM. The lectures and actions of Basaglia also made clear to some members of the movement that humanising and modernising psychiatric care would not suffice to banish the perverse logic and practice used to segregate the mentally ill (Nicácio, 2003).

Nevertheless, the phase of psychiatric reform which followed did not result in direct demands for the 'denial of the institution'. Instead, the MTSM sought to achieve change by allocating some of its leaders to key positions in state agencies. This 'state-centred strategy' was also adopted by the *Movimento pela Reforma Sanitária* (Health Reform Movement, MRS) set up during the 1970s with the aim of guaranteeing all citizens equal rights and access to health care by expanding the public health care system. Similarly to what occurred with psychiatric care, the military regime also contracted out many of the remaining medical services to the private sector. Following demand instead of need, the private sector maintained facilities disproportionally in middle- and upper-class neighbourhoods of urban centres. This concentration generated extreme inequality in the access to health care for the urban poor and rural populations. Furthermore, contracts with the private sector led to much fraud and waste of public resources.

By the late 1970s health care costs had exploded. This put considerable strain on the state which, by then, was undergoing a deep financial crisis. The MRS argued that equality in health could only be achieved through the development of a rights-based, state-funded universal health care system; to regain control of its health care expenditure the state needed to reduce its spending with the private sector and to expand public care. The same demands were made by the MTSM. The confluence of interests between central government, the MRS and the MTSM made it possible for members of these movements to gain high level positions inside state agencies (Weyland, 1995). In 1980, the Ministry of Health and the Ministry of Social Security and Welfare formed a partnership to increase state involvement in the management of public hospitals in Rio de Janeiro. This allowed the entry of leading MTSM figures into public bureaucracies, who then lobbied for the transformation of psychiatric care. During this period, the MTSM strove to limit the number of new beds in psychiatric hospitals, gain control over the admission of new inmates to private psychiatric clinics, expand out-patient care and humanise public asylums (Vasconcelos, 2002a).

The reinstatement of civilian rule in Brazil in 1985 increased the opportunities available to MTSM members to proceed with reform from within the state apparatus. Some even reached the upper echelons of public bureaucracy. However, the clientelistic nature of Brazilian politics was not eliminated with the transition to democracy. State agencies were frequently locked in long-standing bureaucratic rivalries over influence and resources and that delayed the promotion of effective reform measures. By the mid-1980s, the asylum continued to be the main locus of psychiatric care and a powerful mechanism exlcuding the mentally ill from society and an effective mechanism for exclusion. Re-admissions were frequent, and the lack of out-patient services hampered moves toward a community-based care model. These unflattering results led to tensions and conflicts within the MTSM. A strong critique of the bureaucratisation of the movement was launched by one of its factions which argued for the need to adopt a 'society-centred strategy', i.e. to form alliances with other social movements and to engage the population in the planning and implementation of mental health care. That same faction also began to advocate the idea that for as long as the asylum system prevailed, psychiatric reform could not be achieved. These views were strongly influenced by Basaglia's philosophy of deinstitutionalisation. In 1987, after much discussion during the 2nd National Congress of Mental Health Workers, the emergence of the slogan *Por uma sociedade sem manicômios* (For a society without asylums) symbolised MTSM's break with the previous reform ideology and its adoption of a reform initiative centred on the struggle against exclusion and on the promotion of the citizenship of people affected by psychosocial distress. This implied the creation of a new mental care system, accessible and accountable to all citizens, and the gradual dismantlement of the asylum (Vasconcelos, 2002a; Nicácio, 2003). As noted earlier, these became the core goals of Brazilian psychiatric reform as we know it today.

The 1987 Mental Health Workers Congress is regarded as a milestone in the history of psychiatric reform in Brazil, not only because it effected a radical shift in its trajectory but also because that shift was discussed, negotiated and approved by a critical mass of participants – including, for the first time, mental care users and family members, alongside professionals. The emergence of a user voice brought out a profound sense of transformation in the movement. Indeed, the MTSM enjoyed such theoretical and political renewal during that event that it changed its name to *Movimento Nacional da Luta Antimanicomial* (Anti-asylum National Movement, MNLA). The MNLA has since then been the main instigator of psychiatric reform

(Vasconcelos, 1992; Amarante, 2006). In the next section we provide more detailed information about its origins and actions.

The socio-political field in which the MNLA began to push for state-sponsored psychiatric reform was particularly favourable to its aims. This is not to say, however, that no strong opposition existed, for it did and it still does (especially from advocates of classical psychiatry and private clinic owners). However, the state's commitment to developing a universal health care system and the signing of the Declaration of Caracas constituted remarkable opportunities to operate change.

With the transition to democracy and the adoption of the 1988 Constitution, health care became a right of the people and a responsibility of the state. In 1990, the Brazilian government issued the *Lei Orgânica da Saúde* (Basic Health Law) (Brasil, 1990) which sanctioned the reform of the health care sector through the creation of a universal health care system – the *Sistema Único de Saúde* (Unified Health System, SUS) (Carvalho and Santos, 1995). As we explained earlier, the quality and number of public mental health care services had declined significantly since the rise of the dictatorial regime in the 1960s. The effective implementation of the SUS thus entailed an intensive process of needs evaluation, resource allocation and service creation and management. This was to be carried out through the development of mental health programmes by the Secretary of Mental Health of each municipality under the aegis of the National Mental Health Coordination Agency of the Ministry of Health (*Coordenadoria de Saúde Mental*, COSAM). The MNLA concentrated amongst its members much of the know-how and enthusiasm necessary to proceed with the democratisation of mental care. These factors, together with the interest of the Ministry of Health in fostering equality in health, led to the choice of several professionals affiliated with the MNLA for the position of coordinators of municipal mental health programmes. From that position it became more feasible to start operating reform along the lines defined during the 1987 Congress (Vasconcelos, 2002a; Nicácio, 2003; Amarante, 2006).

One of the first initiatives through which the deinstitutionalisation ideology favoured by reformers was put into practice was the creation of a network of alternative mental health care services in the city of Santos, state of São Paulo. In 1989 the press denounced situations involving death, abuse and violation of human rights in a local private psychiatric hospital contracted by the state. After those denunciations were verified by a committee formed by civil society organisations, journalists, MNLA representatives and public administrators, the City Hall decided on the closure of the asylum. Taking hold of the power and greater autonomy conceded by the 1988 Constitution to local governments, the Santos City Hall initiated a process of psychiatric reform without parallel at the time, which entailed not just the replacement of the asylum by a new network of services but also the involvement of the local population (through forums) in discussions concerned with the negative effects of institutionalisation and the definition of strategies for the reintegration of people affected by psychosocial distress in society.

Among the alternative services created in Santos was a community-based service – the *Núcleo de Atenção Psicossocial* (Nucleus of Psychosocial Attention, NAPS) – open 24 hours a day, seven days a week, prepared to cater for most mental care demands under a regime of out-patient care delivery but also capable of accommodating users for short periods of time when the need arose. The NAPS was later turned into a model to be applied all over Brazil. In addition, the new network of services created in Santos included also a Psychosocial Rehabilitation Unit concerned essentially with preparing mental care users to be reintegrated in the labour market, a work cooperative, assisted housing and a cultural centre. All these services were directly inspired by the experiments of Basaglia in Italy (Nicácio, 2003) and were designed to promote psychosocial rehabilitation and social reintegration. In the decades that followed they were adopted by various municipalities across the country.

Aware of the need to make reform initiatives such as the one taking place in Santos more easily transferable and implementable at a national level, Paulo Delgado, a Federal Senate deputy and member of the MNLA, formulated a project-law in 1989 modelled after the Italian Law 180. The project-law proposed the gradual dismantling of asylums, their replacement by community-based services and the regulation of compulsory admissions (Vasconcelos, 1992). While this proposal appeared as a logical development for psychiatric reform advocates, it posed a significant threat to the interests of actors directly involved in the 'trade of madness' and a direct attack on the system through which the authority of classical psychiatrists over mental illness was legitimised. As a result, fierce debates emerged between proponents and opponents of reform. By exerting pressure directly in the Brazilian Senate, opponents succeed in delaying voting on the law several times (Maia and Fernandes, 2002). Ultimately, the Paulo Delgado Law, as it became known, was approved in 2001 (Brasil, 2001).

Although it took until 2001 for the law determining psychiatric reform to be approved, several municipalities and states issued directives for the creation of alternative community-based services and for a gradual reduction of the number of beds in both public and private psychiatric hospitals in the course of the 1990s. The adoption of a deinstitutionalisation perspective at a regional level was facilitated by two main developments. On the one hand, Brazil had just signed the Caracas Declaration (PAHO/WHO, 1990) which sealed a compromise by Latin American countries to develop legislation aimed at guaranteeing the human and civil rights of people affected by psychosocial distress. The COSAM (*Coordenadoria de Saúde Mental)* was determined to enforce it according to the principles of the SUS. Inspired by the successful innovations at Santos, the COSAM designed a new mental health policy which, among other things, provided for rigorous supervision of care quality improvement in the existing psychiatric hospitals and the release of funds for the creation of alternative community-based services[18]. On the other hand, the municipal Secretaries of Mental Health who had been incorporating advocates of psychiatric reform in its workforce were quick in using the new available means to reorganise mental health care. Between 1987 and 1996, the number of beds in psychiatric hospitals across the country decreased by 27% (Vasconcelos, 1996) and about three hundred new out-patient mental health services were created (Schechtman *et al.*, 1996 cited in Vasconcelos, 2002a). Among the latter were the already mentioned NAPS and the *Centros de Atenção Psicossocial* (Centres of Psychosocial Attention, CAPS). CAPS and NAPS have a similar care delivery philosophy but the majority of the existing CAPS are only open 8 hours a day, five days a week. Because CAPS are less costly they compose the bulk of community-based services in Brazil. This has been noted as a problem, for many users could avoid hospitalisation if there were more round-the-clock community services available.

One final aspect to which we wish to draw attention is the centrality of citizen participation in the ongoing process of psychiatric reform. As we mentioned earlier, in 1990 the Brazilian government issued a law setting up a universal health care system – the SUS – based on the principles of universality, equity, decentralisation and social oversight. These principles were formulated, to a large extent, as a response to the demands of the MRS whose members, as we have seen, were appointed in public bureaucracies during the 1980s. The MRS emerged within a context of dictatorship marked by consistent abuses of human and civil rights and by a clientelistic political culture which stimulated the outsourcing of public services and condoned much of the fraud committed by private contractors. Its main struggle has thus been the extension of the right to health care to all Brazilian citizens through the creation of a public health care system responsive to their needs. Aware of the risk of the perpetuation of clientelistic practices and of the threat posed by the adoption of neoliberal policies, when the new democratic state sealed the compromise to create the SUS, the MRS pushed for the concession of the adjacent right of citizen participation in health governance (Cornwall and Shankland, 2008). This right has been acknowledged by the Basic Law of Health (Brasil, 1990) and is enforced under the principle of *controle social*[19] or social oversight of public health and social services.

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[18] Until the early 1990s state funding for mental health care delivery was restricted to psychiatric hospitals and there was hardly any control of the quality of services provided in those institutions (Vasconcelos, 2002a).

[19] The expression *controle social* is not to be confused with the English term 'social control', used to designate the mechanisms which regulate individual and group behaviour, leading to conformity and compliance to the rules of a given society or social group. In Brazil, *controle social* has acquired a particular meaning within the democratization process initiated after the downfall of the dictatorship in 1985. Influenced by a deep distrust of the state, several segments of the population (e.g. social movements and NGOs) have become organised in order to keep watch on state-implemented policies and to monitor state actions. The concept of *controle social*, as currently employed in Brazil thus refers to the organised actions of

Controle social enables citizens to shape health policy, to hold the state accountable in its implementation and to make demands for new health and social care services and for resource redistribution (Correia, 2002). Its operationalization has been achieved through the creation of an innovative institutional framework for citizen engagement. This comprises a set of participatory democratic mechanisms, among which are local and municipal Health Councils (*Conselhos de Saúde*) and periodic Health Conferences (*Conferências de Saúde*) at the local, municipal, state and national levels. Each municipality and each state is required by law to set up *Conselhos de Saúde* composed of both health care users and service providers, with 50% of the seats reserved for each party (Brasil, 2003). Users and providers join together regularly in the *conselhos* to discuss health issues and to propose and adopt policies which are then implemented by the municipal Secretaries of Health. Policies to be implemented at a national level are dealt with during the National Health Conferences, whose delegates are elected after voting at the municipal and state levels. Overall, these councils and conferences have allowed hundreds of thousands of citizens to actively participate in the formation of health policy (Cornwall and Shankland, 2008).

Given the massive process of transformation going on in psychiatric care, the field of mental health has benefited from its own State and National Conferences. Many elements of the mental health policy currently in place have been proposed and adopted during those conferences. Indeed, the 2nd National Mental Health Conference held in Brasilia in 1992 is considered another milestone in the history of psychiatric reform in Brazil for several reasons. First, it gathered about 1000 people, many of whom were mental health care users and family members. For public authorities, this was an important sign of how strong the mobilisation of social actors concerned with mental health care issues had become. Second, the Conference enabled the formalisation of the goal of psychiatric deinstitutionalisation set by the MNLA in 1987, when the vast majority of its participants voted in favour of the eradication of the asylum and the creation of policies and services focused on psychosocial rehabilitation and (re)construction of the citizenship of people affected by psychosocial distress.

As we noted earlier, directives for deinstitutionalisation did not become law until 2001 due to the pressure exerted by private clinic owners in the Brazilian Senate. However, the political vitality of a critical mass of citizens supporting deinstitutionalisation through a participatory mechanism devised by the state served to further legitimise the actions undertaken by the COSAM to supervise and close down asylums that were violating minimum standards of mental care provision, and to continue re-allocating funds for the creation of alternative community-based services (Nicácio, 2003; Vasconcelos, 2002a). Finally, the active participation of people

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civil society to oversee public policies and hold the state accountable to the people (Correia, 2000). To avoid confusion we translate *controle social* as 'social oversight'.

diagnosed with severe mental illness in the Conference, who voiced complaints and articulated proposals for change, provided tangible proof of the emergence of a user voice. It also demonstrated the irrelevance of of orthodox conceptions of severe mental illness which depicted it as a life-long impairment leading inevitably to emotional, social and legal incapacitation.

The success of the 2nd National Mental Health Conference in mobilising so many delegates and reaching accord on pro-psychiatric reform policies was both the result and the expression of the vitality of a civil society concerned with the care and the social position of people affected by psychosocial distress. Indeed, the number of associations of mental health care users and family members grew substantially during the 1990s (Vasconcelos, 2002a). These associations are usually linked to the local branches of the MNLA and are often based within the terrain of mental health care services. Among other things, they advocate for users' rights and interests, provide support to users and to their families, run working cooperatives and organise social and cultural activities. Their members also play a crucial role in the daily monitoring of mental health care delivery, feeding the MNLA with crucial information about what happens on the ground and mobilising the support of other movement members to tackle the problems identified. This is usually done during the monthly meetings of the municipal branch of the movement. The MNLA also organises state and national meetings in which structural problems identified at the local level are discussed and proposals for change are made.

In addition, many local associations of family members and users participate directly in the planning, implementation and evaluation of community-based mental health services. This has become possible through the creation of a participatory mechanism very much alike the one devised by Basaglia and his team in Gorizia, which goes by the same name: *assembleia*. In most services, *assembleias* are weekly meetings in which staff and users come together to discuss the dynamics of care provision and human relations within the service, disseminate information about the process of psychiatric reform, and organise cultural activities. In some of those services, *assembleias* are open once per month to family members and representatives of associations. In this way a constant flow of ideas and criticisms can arise, rendering mental care services open to the scrutiny of the people they are meant to serve and enabling them to be improved according to the needs identified.

Despite the advances made in the field of mental health, psychiatric reform in Brazil is far from completion and is still confronted with much opposition. The country's large size, its complex political structure and the resistance of the people, professions and industries whose interests are threatened by reform, have led to considerable disparities in the extent to which reform measures have been implemented across the nation. In addition, the approval of pro-reform national policies is largely dependent of the sort of political parties in power. Between 1994 and 2002 Brazil was ruled by a conservative government whose neoliberal policies led to massive privatisation of state enterprises, an enormous economic crisis and a significant reduction of state funding of public services. Where psychiatric reform was concerned, the Ministry of Health blocked the approval of several measures to facilitate reform. Among them, was a program – *Programa de Apoio à Desospilatização* (De-hospitalisation Support Program, PAD) – proposed by the COSAM in 1995 which aimed to make the discharge of long-term psychiatric patients from the hospital possible by guaranteeing their right and access to community-based care, as well as to a monthly subsidy in order to facilitate their economic independence (Nicácio, 2003; Vasconcelos, 2002a). This became a serious barrier to the implementation of one of the core goals of psychiatric reform, i.e. deinstitutionalisation.

As we noted earlier, the 'trade of lunacy' has become big business in Brazil not only for private clinic owners but also for the pharmaceutics industry (whose medicines tend to be prescribed in larger doses to inmates of private hospitals). Furthermore, classical psychiatrists have lobbied consistently to keep hold of their authority and power, publishing public manifestos against the reform, seeking political influence in public agencies and establishing partnerships with associations of family members of psychiatric inmates who consider psychiatric reform a threat to the availability of care for their relatives and support actions against it. All these parties together offer considerable resistance to the implementation of reform measures both at a local and at a national level. The most conspicuous example has undoubtedly been the delay in passing the Paulo Delgado Law, which took twelve years to be approved.

Since the election of Lula's leftist government in 2002, psychiatric reform has once again been taking pace. Some measures in line with the PAD have been enforced and other measures seeking to promote the active citizenship of people affected by psychosocial distress are also being implemented. Nevertheless, psychiatric reform is a complex political process which continues to require active participation by civil society in order to succeed. In the next section we discuss the ways in which mental health care users have sought to become part of that civil society by creating their own social movements.

1.3.3 User movements

As we have seen, movements of resistance to the power and controlling function of orthodox psychiatry have sprung up in various parts of the world. In the 1970s such movements gained a different character with the emergence of a new element: the voice of mental health care users[20]. As time went by, (ex-) psychiatric patients became increasingly more organised: small collectives concerned with the struggle against the oppression and exclusion of people affected by psychosocial distress gave way gradually to nationwide social movements. Many of those user movements are still active today

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[20] There is one exception to this generalisation, and a major one at that: Clifford Beers, whose book *A Mind that found itself* (Beers, 1908/1981) gave a harrowing account of his experiences as a psychiatric patient, founded the 'mental hygiene movement' in 1909.

in countries such as Australia, the Netherlands, the UK, the US and Brazil, where their initial struggles to reassert the citizenship of psychiatric patients and to challenge the dominant social practices which perpetuate their objectification, marginalisation and segregation continue to be relevant.

The US consumer/survivor movement is among the first user movements to have emerged in the early 1970s. The following quote from Judi Chamberlin's book *On Our Own* (1978) illustrates the grievances that led to its rise:

> For too long, mental patients have been faceless, voiceless people. We have been thought of, at worst, as subhuman monsters, or, at best, as pathetic cripples, who might be able to hold down menial jobs and eke out meagre existences, given constant professional support. Not only have others thought of us in this stereotypical way, we have believed it of ourselves. It is only in this decade, with the emergence and growth of the mental patients' *liberation movement*, that we ex-patients have begun to shake off this distorted image and to see ourselves for what we are – a diverse group of people, with strengths and weaknesses, abilities and needs, and ideas of our own. Our ideas about our 'care' and 'treatment' at the hands of psychiatry, about the nature of 'mental illness', and about new and better ways to deal with (and truly help) people undergoing emotional crises differ drastically from those of mental health professionals (*ibid.*: xi; our emphasis)

As we noted earlier, by the 1970s thousands of psychiatric patients had been discharged from psychiatric hospitals as a result of the massive process of deinstitutionalisation being operated in the US. Many of those ex-patients shared feelings of disenfranchisement and powerlessness as a result of their perceived abuse in mental institutions and their experience of human rights violations in being institutionalised involuntarily and forced to treatment (McLean, 1995). The user movement constituted an "attempt to give voice to individuals who have been assumed irrational" (Chamberlin, 1990: 323). Deeply influenced by anti-psychiatry, movement leaders such as Chamberlin began to portray madness not as an illness but as an alternative state of being. By re-defining ex-patients as a 'diverse group of people' with 'ideas of [their] own' as she does in the quote above, Chamberlin called for the assertion of users' right to speak on their own behalf and for a change in society so that their difference could be accepted, instead of being used as grounds for involuntary commitment and repressive treatments (Tomes, 2006).

Yet Chamberlin's ultimate goal with *On Our Own* was really to mark a radical opposition to the psychiatric apparatus and to advocate for the creation of a viable alternative to the mental health care system. This intent was uttered particularly through the designation of the movement as a 'liberation movement', but it was also obvious through the clear division made between 'mental patients' and 'mental health professionals', i.e. between a challenged group and a dominant group. The employment of the word 'we' when referring to the challenged group not only stressed the author's identification and affiliation with that group, it also signalled the development of a new collective identity which, in the case of the type of movement supported by Chamberlin, centred on the concept of 'survival' as a constant reminder of the ordeal of ex-patients at the hands of psychiatry. The way forward, survivors argued, was through their own empowerment. This meant setting themselves free from psychiatry by creating a network of self-help and user-led services. The fact that deinstitutionalisation had not been accompanied by the development of sufficient community mental health services provided the field of opportunity for the movement to pursue this goal and to emphasise 'recovery' (i.e. the ability to live fully and independently) as an alternative paradigm to 'cure'.

Chamberlin's book stimulated the creation of many consumer/survivor groups, both in the US and in other countries (Tomes, 2006). As the slashed designation of these groups suggests, the US movement experienced a split into two camps: psychiatric survivors and consumers. The most essential difference between these two streams lies in the way by which they seek to bring about change: while consumers believe the care and the social position of people affected by psychosocial distress can be improved by reforming the mental health care system from within, survivors oppose that idea, insisting that change can only come through liberation from psychiatry and gaining control over their own therapeutic fates. From these contrasting positions, groups within each streams have carried out different sorts of concerted actions[21]. However, as argued by Everett (1994), they do not necessarily constitute two completely separate movements, for both consumers and survivors share core goals such as the promotion of the rights of users, their participation in mental health policy-making and research, and their full citizenship and integration in society.

These demands have been shared by various other user movements, including the Dutch patient/client movement and the Brazilian anti-asylum movement. Similarly to what happened in the US, both these movements have been marked by tensions and conflicts which often led to a change of course. However, such dynamics do not necessarily lead to the collapse of social movement; rather, they are one of their intrinsic characteristics. As explained by Melucci (1996), social movements "are heterogeneous and fragmented phenomena, which internally contain a multitude of differentiated meanings, forms of action, and modes of organization, and which often consume a large part of their energies in the effort to bind such differences together" (1996: 13).

Indeed, the presence of collective actors with different ideas and agendas may contribute to the broadening of the movements' scope of action and achievements.

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[21] While consumers focused more closely on having their experiential knowledge being valued and integrated in the mental health care system (e.g. by acquiring paid positions in mental care services and by informing professionals), survivors invested in creating care alternatives outside the existing psychiatric system (e.g. self-help and mutual aid groups, user-led services, etc.) (Tomes, 2006).

Exchange of experiences, projects and information between Brazilian and Dutch collective actors and their US counterparts have resulted in the promotion of the empowerment philosophy and self-help and mutual aid initiatives since the 1990s in both the Netherlands and in Brazil (see Vasconcelos, 2003; Boevink, 2006; Boevink *et al.*, 2006; Vasconcelos *et al.*, 2008). This, however, has not meant withdrawing from struggles directly concerned with the improvement of local mental health care systems and the participation of users in mental health governance, nor has it weakened the local social movements[22]. In fact, these struggles are often headed by the same people seeking to promote alternative care solutions and philosophies. In the following sections we provide a more detailed account of the Dutch and Brazilian user movements.

1.3.3.1 The Dutch patient/client movement

The Dutch patient/client movement in mental health emerged in the early 1970s out of concern with the high degree of autonomy granted by the state to the medical profession regarding psychiatric treatment and the planning, management and financing of the mental health system (Haafkens *et al.*, 1986). Disquieted by the unbalanced concentration of power in the hands of professionals, groups of mental care users, family members, and critical professionals and academics began to criticise the closed nature of the mental health system and to devise actions aimed at promoting its democratisation. At first, the patient/client movement focused its actions on psychiatric institutions, acquiring a strong position within that sector and becoming among the most radical critics of the biomedical model (Oudenampsen, 1999). As time went by, the movement began to demand a more active role in decision-making and in the implementation of measures to reorganise mental health care.

Today, the patient/client movement is considered an official party in mental health policy making and implementation, and in mental care quality evaluation by the government (Nederland *et al.*, 2003). These functions are exercised by representatives of the various patient/client organisations which compose the movement. In contrast to countries such as Brazil, the Dutch user movement does not exist as an entity in itself but rather as a set of numerous organisations with different backgrounds, goals and fields of intervention. These organisations collaborate whenever necessary in the fields of advocacy, service provision and dissemination of information, their actions being coordinated by umbrella organisations at both regional (Regional Patient/Client Platforms, RP/CPs) and national (Dutch Patient/Client Federation, NP/CF) levels (Oudenampsen and Steketee, 2000).

In what follows, we look more closely into the patient/client movements' history, goals and achievements.

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[22] We should note, however, that a formal split has occurred within the Brazilian user movement in 2003, giving rise to two separate movement streams (Lüchmann and Rodirgues, 2007). This will be discussed in section 1.3.3.2.

History of the movement

Rijkschroeff (1989) distinguishes three phases in the development of the patient/client movement in mental health: 1970-1974, 1974-1980 and 1980-1988. To this can be added, in our opinion, another two phases: 1988-2000 and 2000-present. The beginning of the fourth phase (1988-2000) is marked by the introduction of the principle of *marktwerking* or 'market forces' in the Dutch mental health care system. This principle enabled the patient/client movement to become an official party in mental health policy making and implementation, side by side with the other two 'market agents': the care providers and the payers (i.e. insurance companies). The start of the fifth phase (2000-present) coincides with a reformulation of the roles and responsibilities attributed to the market agents operated by the government at the turn of the millennium.

1rst phase (1970-1974): 'coming-out'

This phase has been termed 'coming-out' (Rijkschroeff, 1989) in allusion to the social visibility acquired by psychiatric patients after they made their experiences with psychiatry public. As in the US, psychiatric patients in the Netherlands broke out of isolation by writing about their lives in mental institutions. Those narratives made public the coercive and repressive 'treatments' patients were subjected to in psychiatric hospitals (e.g. isolation cell, electroconvulsive therapy (ECT), neurosurgery, sterilisation, etc.). The creation of their own journal – *De Gekkenkrant* (The Journal of the Madmen) – served to further publicise those bad practices and to stimulate the creation of a voice opposing the classical psychiatrists who employed them.

The foundation of the *Cliëntenbond* (Clients Union) in 1971 was another important event in the rise of the patient/client movement. In the early 1970s, challenges to the power of the medical profession over the mental health system led to a series of conflicts between mental health care users and their supporters on the one hand and institution directors on the other. The *Cliëntenbond* emerged as a response to those clashes, seeking to promote the rights of users and to democratise mental health care (Oudenampsen and Steketee, 2000).

In the early 1970s, resocialisation had not yet become a goal of mental health policy and community-based services were not widely available. A few experiments concerned with the deinstitutionalisation of people affected by psychosocial problems did exist, however, the most well-known being Dennendal.

Dennendal was a residential ward for men and women with mental disabilities situated in a large mental hospital. Its staff sought to undo the effects of lengthy institutionalisation by allowing patients to live in small-scale residential units, where they could live together with non-patients. In keeping with the anti-authoritarian 'counter-culture' of the time, an informal ethos was encouraged. This progressive initiative caused great commotion in the media. In 1974, on the orders of the hospital board of directors and of the official authorities, the police evacuated the residences taking away all its residents to other premises. The repercussions of this incident were so dramatic that it almost led to the fall of the Dutch government. From that moment onwards, the segregation of people affected by psychosocial problems in psychiatric institutions became a topic of heated public debate, giving increased visibility to the demands of the user movement (Haafkens *et al.*, 1986).

2nd phase (1974-1980): investigation and debate on the rights of users

In 1975, in the wake of the Dennendal incident, the Dutch government appointed a state committee to produce a report on the legal position of people institutionalised in psychiatric hospitals and to make proposals for changes in the mental health legislation, i.e. the Insanity Law[23] of 1884. A novel and relevant aspect of that committee was that it included three representatives of mental health care users. This was one of the first signs of recognition of the user movement by the government.

The report delivered by the state committee confirmed the manifold examples of use of coercive methods and the poor living conditions of psychiatric inmates which had already been described in *De Gekkenkrant* by members of the user movement. Once again public discussion was inflamed and more people agitated for alteration of the Insanity Law (Haafkens *et al.*, 1986). During this period, the actions of the user movement focused on advocating for the rights of users, something which in the 1990s would lead to the formulation of a set of laws protective of those rights and facilitative of user participation in mental care.

3rd phase (1980-1988): participation in the reorganisation of mental health care

From 1980 onwards the user movement began to exert more direct pressure toward the reorganisation of the mental health care system. The creation of the *Stichting Landelijke Patiënten- en Bewonersraden* (National Foundation of Patient Councils, LPR) in 1981 gave further impetus to this drive. The LPR is subsidised by the government and works as an umbrella organisation aimed at coordinating the actions of client councils (*cliëntenraden*) in local mental health care services. Those councils, which started being created in the early 1970s, are composed of groups of users who seek to influence decision-making regarding the planning, delivery and evaluation of mental care from within mental institutions. The official recognition of the LPR granted client councils

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[23] The Insanity Law embodied all the regulations concerning involuntary hospitalisation of people deemed mentally ill, their treatment and the state supervision of the conditions of their hospitalisation. It was issued in 1884 and stayed in effect until 1994, when it was finally revised. Discussions on its reformulation were initiated by the Dutch Parliament in 1971. One of the main problems of the Insanity Law was that it determined involuntary commitment on the grounds of dangerousness, i.e. people diagnosed with a mental illness who were found to pose a danger to others or to themselves could be hospitalized against their will. Another problem of the law was that it largely overlooked the rights of mental health care users (Haafkens *et al.*, 1986). It took twenty-three years of debating before a new bill could be approved.

greater power to have a say in the reorganisation of mental health care, turning them into a pillar of the user movement (Oudenampsen and Steketee, 2000).

The 1981 *Manifesto on Patient's Rights in Mental Health Care* and the 1982 *Moratorium for New Psychiatric Institutions* constituted another two initiatives aimed at persuading the government to bring about change in the mental health system. At the core of the demands voiced in these documents was the dismantling of large psychiatric hospitals and the deinstitutionalisation of their inmates, the creation of community-based mental care services, and the acknowledgement of the right of users to participate in their own treatments. After much debate in the Parliament, the Dutch government approved a mental health policy aimed at reducing the number of beds in psychiatric hospitals and at expanding the network of out-patient mental care services (i.e. the RIAGGs), crisis assistance and protected accommodation. The following excerpt from the address made by the Undersecretary of Health at the time attested the increasing recognition of the user movement as critical agent for change and as a necessary partner in mental health care governance:

> The experience of patients has to be a point of departure for future mental health policy. In recent years there is a growing consensus among the patient movement, mental health professionals, social organisations and policymakers about the idea that an integral framework for decision making, planning and financing is necessary in mental health care (Reyden, 1984 cited by Haafkens *et al.*, 1986).

4th phase (1988-2000): the institutionalisation of user participation

In the late 1980s, the Dutch government launched a set of reforms in the health care sector. Initially, these reforms focused on what was termed 'territorial decentralisation', i.e. the transference of responsibility over the implementation of health care policy from the national government to regional and local authorities. Soon after that, the government announced a new management strategy for health care. Its main goal was to shift the philosophy of care provision from supply- to demand-oriented care (Oudenampsen and Steketee, 2000). The government's principal motivation for effecting these changes was the need to reduce costs. The most salient change in health care management policy consisted, thus, in the introduction of the principle of *marktwerking* or marketisation, according to which it was anticipated that the best 'product' at the lowest price would prevail over the others.

In practice, this meant a transfer of power and responsibility regarding the planning, implementation and quality control of health care from the government to the 'market agents' – the care providers, insurance companies and care users (represented by the user movement). After the implementation of this 'functional decentralisation', the market agents started being considered as 'partners' in health care decision-making and were expected not only to negotiate the best way of delivering care, but also to monitor each other in the exercise of their functions (Oudenampsen, 1999). The user movement was allotted the task of promoting the quality of health care delivery from a user perspective. This function was officially recognised in 1991 when the government first started subsidizing the Regional Patient/Client Platforms and the Patient/Client Federations. From that moment onwards, the user movement began to be formally addressed as the 'third party' in the implementation of health policy and health care quality control (Nederland *et al.*, 2003).

Not all members of the user movement were happy with this institutionalisation of their role as the third party in mental health care governance, and this step led to tensions within the movement. Among the concerns expressed were: 1) the fear that user representatives participating in the 'administrative culture' of institutions (a task which demands tolerance, reasonableness and compromise) would distance themselves from grassroots members; 2) the fear that the movement could lose its power to resist as a result of its tie to the state; and 3) the fear that user representatives would not be able to provide a sufficient counterweight to the interests defended by professionals in health commissions and advice groups, ending up signing for measures unfavourable to the interests of users.

The instability these concerns generated led to the formation of four streams within the movement. The first stream sought to develop new care solutions outside the mental health system. User-led services and self-help groups are some examples of the initiatives undertaken by it. The second stream focused on the user-professional relationship, lobbying for laws which would protect users' rights. The third stream centred its actions on institutional participation. Finally, the fourth stream got involved in stimulating professionals to adopt client-centred treatment approaches by promoting, for example, the training of professionals by users themselves (Oudenampsen and Steketee, 2000). This diversity of positions and fields of action is still present nowadays and is one of the reasons why there are so many patient/client organisations.

In the mid-1990s the government set up a committee entrusted with the goal of framing proposals for cutting costs and downsizing the health care sector. The committee concluded that the shift from supply-oriented to demand-oriented care provision had not been fully realised. Furthermore, it observed that the health care market agents had failed to fulfil their functions: although insurance companies and care providers exerted the authority granted to them, they neglected some of their responsibilities (e.g. transparency and making available a wide range of treatment options). This was caused, in part, by the user movement's inability to function effectively as a counterweight to the interests of the other two more powerful market agents.

As a result of the pressure exerted by the user movement and in the attempt to promote the effective implementation of functional decentralisation, the government approved several laws aimed at strengthening the position and the rights of users (Nederland *et al.*, 2003). Among those laws are the law on involuntary commitment

(*Wet Bijzondere Opnemingen in Psychiatrische Ziekenhuizen*, WBOPZ) which replaced the Insanity Law, limiting the situations in which people can be committed involuntarily to psychiatric hospitals (Ministerie van WVC, 1994); the law on informed consent regarding medical treatment (*Wet Geneeskundige Behandelingsovereenkomst*, WGBO), according to which care users have the right to be informed about their diagnosis, treatment possibilities, prognosis and medical file and to participate in decision-making regarding their treatment (Ministerie van WVC, 1992); and the law on participation in health and social care services (*Wet Medezeggenschap Cliënten Zorginstellingen*, WMCZ) which grants users the right to participate in health care institutions through client councils (Ministerie van WVC, 1996a).

5th phase (2000-present): the deepening of a market-oriented health care approach

At the turn into the twenty-first century the Dutch government effected, once again, a number of changes aimed at transferring more responsibility over the health care sector to the market agents within a logic of regulated competition, i.e. under a set of measures pre-defined by the government. These changes led to the attribution of new roles to the different market agents.

Care users were imputed greater responsibility in evaluating the price and quality of the health care available and in choosing the care services most appropriate to their needs. Although health insurance became compulsory for every citizen in 2006, care users were also given the right to manage their own ‘health care budgets’ (*persoonsgebonden budget*, PGB)[24]. This is expected to grant users greater independence and power to influence the availability of good quality care ‘products’ for fair prices within the market by selecting those products which offer greater value for money and/or by resorting to collective action to influence change.

Care providers were made responsible for offering a set of services diverse enough to accommodate the needs of all users. Transparency and quality became key requirements in health care delivery and new providers were granted more opportunities to make their way in the health market.

Insurance companies were given more power in the steering of health care, becoming able to determine, for example, the capacity, prices, and tariffs operated by care providers. They were also made accountable for providing accessible information to users and grant them the possibility of changing their insurance to another company at least once per year (Nederland *et al.*, 2003).

As when the principle of *marktwerking* was first introduced, the market agents are still expected to supervise each other in the exercise of their functions. This is proving problematic. On the one hand, insurance companies have not been sufficiently

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[24] In that case, users must solicit insurance companies to transfer the budget they are entitled to for the use of health care into their own possession.

transparent and the information they provide is not always complete (NZa, 2007). On the other hand, dissatisfied health care users do not seem to exercise their right to change insurance companies, for fear of having even more problems with a new company (Jong and Groenewegen, 2007). Furthermore, not all social groups are well represented in the user movement. Migrants and ethnic minorities (MEMs), in particular, continue to be under-represented in the patient/client organisations (De Graaf and Eitjes, 2004). These circumstances are likely to hinder the development of health care services able to cater for the needs of the whole Dutch population. They also point to a lack of balance between the different market agents, threatening the interests of care users.

Goals and achievements of the movement

In spite of the challenges just mentioned, the patient/client movement has succeeded in accomplishing several of its goals. As with many other new social movements, the Dutch user movement strives to make power relations visible and to challenge the *status quo* of dominant groups. Its actions during the 1970s and 1980s led to a revocation of the legal mandate of the medical profession to manage the mental health care system and to the official recognition of the movement as a partner in mental health governance. In addition, the movement has also struggled to produce a shift in the political discourse on involuntary commitment from one framing forced psychiatric treatment as a form of *help*, to forced treatment as a *violation of individual rights and freedoms*. The replacement of the biomedical model of mental illness by a social model of psychosocial suffering and the 'socialisation' of treatment through a broad network of community-based services (changes in which the user movement has been deeply involved) have led to a reduction of the situations in which the law on involuntary commitment can be applied[25]. This, in turn, has reduced the instances in which mental health care users may see their rights provisionally withdrawn and their ability to make decisions about their own lives temporarily suspended.

To achieve real change movement members have lobbied for representation in all activities related to the mental health care system. They have sought to establish true partnerships with policy makers and mental health professionals by participating in government committees and task forces, local planning groups, client councils and other groups in which decision-making regarding mental health care takes place (Nederland *et al.*, 2003). They have also succeeded in getting former users employed in

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[25] According to the BOPZ act, a person can only be committed to involuntary treatment in a psychiatric hospital when no other services in the community are able to assist her in a moment of significant distress in which she can pose a risk to herself or to other people. The creation of community-based crisis centres, for example, has been fundamental to diminish the situations in which no alternatives other than forced treatment are available.

mental care services[26] and in delivering training to professionals. In this way they have secured a presence in all aspects of mental care, from policy making to planning, management and delivery of services. Real change will continue to accrue as the perspective of users becomes increasingly ingrained in the services meant to serve them.

Finally, movement members have striven to bring about individual change by engaging in identity-oriented actions. Among these actions are the promotion of *lotgenotencontact* and the creation of user-led projects. *Lotgenotencontact* is the term employed in the Netherlands to refer to initiatives aimed at bringing people affected by psychosocial distress in contact with each other and at promoting the exchange of experiences and practical information, mutual support and the joint search for solutions to deal with social problems. These initiatives are generally promoted by patient/client organisations within self-help groups and talk groups[27].

User-led projects aim to promote social participation and are run by *ervaringsdeskundigen* or 'experts by experience'. They include projects such as shops, restaurants, clubhouses, relief centres (*opvangcentra*) and information centres (Nederland *et al.*, 2003).

Lotgenotencontact and user-led projects have the potential to give people affected by psychosocial problems the opportunity to break out of isolation, to become empowered and to find meaningful ways of participating actively in society. This, in turn, is likely to lead to a renegotiation of their identities from 'dependant patients' toward 'active citizens'.

Indeed, the promotion of the full citizenship of people affected by psychosocial suffering has been one of the major goals of the user movement since the 1990s. Citizenship as advocated by the user movement is not merely understood as entailing certain rights (and concomitant responsibilities), but also as being able to participate in all spheres of society which impact on citizens' lives (e.g. the labour market, recreation, health care, etc.). The user movement has thus been active on two fronts. One concerns the relationship between mental care users and professionals. Here, efforts have been made to discard the notion that 'mental illness' inevitably propels users into a position of dependency and thwarts their ability to have a say in treatment. The passage of the WGBO act constituted a crucial achievement in enforcing the right and practice of individual participation in treatment. The other set of actions is concerned with promoting collective participation in mental health governance. The focus here has been to advocate for the recognition of *ervaringsdeskundigheid* (expertise by experience) as a source of knowledge as valuable and necessary for the governance of the mental health care system as professional knowledge (Oudenamspen, 1999). The

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[26] In 2008, the chairwoman of the board of directors of Altrecht, the regional community-based mental health service of Utrecht, stated the intention of the institution to have between 5% to 10% of its workforce composed by experts by experience in the years to follow (Volkskrant, 22/02/2008).

[27] Other less common forms of *lotgenotencontact* are home visits to people who are ill, recreational activities, and assisted vacationing.

WMCZ act has become fundamental in promoting the expansion of participatory mechanisms within mental care services, i.e. client councils. However, as we discuss in greater detail in the next sub-section, collective participation through client councils is still confronted with several challenges which can undermine the exercise of active citizenship in health care.

1.3.3.2 The Brazilian anti-asylum movement

As we saw earlier, the Brazilian anti-asylum national movement (MNLA) emerged in the late 1980s out of concern with the segregation of people affected by psychosocial distress, mistreatment and violence perpetrated against psychiatric inmates, and the need for a radical psychiatric reform as a means to eradicate those problems. The dismantling of the asylum system and the disavowing of the biomedical model of mental illness have been core goals of the movement since its rise. As time went by, the MNLA paid increased attention to the promotion of the citizenship of people affected by psychosocial problems. This has meant the development of a mental health policy enabling the implementation of a psychosocial approach to mental distress and the creation of alternative community-based mental health care services as well as the issuing of legislation protective of the rights of mental health care users. Nowadays, the MNLA is a key actor in mental health governance, participating actively in monitoring the implementation of the goals of psychiatric reform and placing proposals for its expansion. The MNLA also strives to promote social transformation toward greater acceptance of the subjectivity of people affected by psychosocial distress and their inclusion in society (Vasconcelos, 2002a; Nicácio, 2003).

Unlike in the Netherlands, where the patient/client movement is led mostly by (former) mental care users, the Brazilian anti-asylum movement has been composed from the start of (former) users, family members, mental care professionals, NGOs and civil society organisations. This plurality of voices, alongside the establishment of partnerships with other social movements, is a central feature of the MNLA. Another characteristic which distinguishes the MNLA from the Dutch user movement is its emphasis on remaining independent of the state. Indeed, the MNLA has been keen to avoid institutionalisation out of fear of co-option. It exists, thus, as an independent national forum composed of several nuclei which articulate the actions of movement members at a state level. Representatives of the different nuclei come together during the MNLA National Meetings which take place every two years. These meetings constitute the highest instances of deliberation within the movement. During those events, which usually gather thousands of people, proposals for action are presented, discussed and voted and resolutions for future action are made (Souza, 2003).

Next, we take a closer look at the history of the MNLA, its goals and achievements.

History of the movement

The MNLA was founded in 1987 during the 2nd National Congress of the Mental Health Workers Movement (MTSM) in Bauru, São Paulo. As we noted earlier, that congress was marked by much conflict and debate, which led the MTSM to propose a new ideology to advance psychiatric reform and a different strategy to implement it. Realising that the modernatisation and humanisation of psychiatric care would not suffice to counter the abuses perpetrated against psychiatric inmates and their exclusion from society, the MTSM proposed the eradication of asylums as a key goal of reform. This implied the creation of a network of new mental health care services, accessible and accountable to all citizens and aimed at promoting psychosocial rehabilitation. That was to be carried out through a society-centred strategy, i.e. with the direct involvement of the citizenry in planning, implementing and evaluating mental health policy. These proposals got the support of users and family members, present for the first time at a Congress of the MTSM. From then on, those two segments together with mental health professionals formed a more comprehensive movement – the MNLA (Amarante, 2006).

The field of socio-political opportunities in which the MNLA emerged was rather favourable to its intentions. On the one hand, Brazil was experiencing a transition to democracy which, among other things, brought the promise of a universal health care system to be designed, implemented and monitored according to the principle of social oversight. On the other hand, the violation of human and civic rights was no longer so easily covered up as in the times of dictatorship; reports of abuse and negligence in psychiatric clinics were coming increasingly to the attention of the public. The combination of the government's commitment to create an equalitarian, rights-based health care system with a civil society eager to re-democratise the country afforded the MNLA a substantial pool of opportunities and social capital from which to start operating psychiatric reform.

One of the first initiatives of the MNLA to bring about reform was a proposal to change existing legislation concerning the rights and the care of people affected by mental distress. These aspects were regulated by an act dating back to 1934 which deprived the 'mad' of political, civil and social rights and mandated their compulsory admission should they show 'inconvenient behaviour' (see Maia and Fernandes, 2002). In 1989, Paulo Delgado launched a project-law which, among other things, proposed the restoration of rights to people diagnosed with mental illness, the gradual elimination of asylums and the creation of community-based services. As we mentioned earlier, this decree-project was strongly opposed by private clinic owners and classical psychiatrists. Their political lobby was so strong that they succeeded in getting it rejected by the Senate in 1995. This happened after the Ministry of Health had issued a statement granting it full approval, which illustrates the difficulties faced by democratic majorities in overcoming the interests of powerful minorities in Brazil.

This is, indeed, one of the main reasons why the MNLA continues to stress the need to remain autonomous from the state.

After much struggle, the Paulo Delgado Act was finally approved in 2001 (Brasil, 2001). The price, however, was the inclusion of certain revisions: the directive for the eradication of psychiatric hospitals proposed in the original project-law, for example, is not explicit in the law as it was finally approved. This is a goal the MNLA continues to strive for (MNLA, 2001).

In 1993, the MNLA held its first *Encontro Nacional* (National Meeting). This was an important event in the history of the movement in which were defined the basic principles of its identity:

1. independence from the state,
2. a compromise with the promotion of social transformation,
3. the struggle 'for a society without asylums', and
4. non-affiliation with political parties (MNLA, 1993).

Issues debated during that meeting centred on the segregation of people affected by mental distress and the need to challenge this by reasserting their rights and introducing alternative care provisions in the community. At that point in time, various states in Brazil had issued directives to downsize psychiatric hospitals and create community-based mental health care services (i.e. NAPS and CAPS). However, it soon became evident that discharge into the community did not abolish the social exclusion of former psychiatric inmates: the stigma attached to mental illness was so strong that in 1992 the Ministry of Health felt compelled to launch an awareness-raising campaign under the slogan 'mental illness is no crime'. Since then, promoting the inclusion of people affected by mental distress in society has been a core goal of the MNLA. This goal, movement members argue, cannot be reached unless people with a history of psychosocial problems are able to exercise full citizenship (Maia and Fernandes, 2002).

The MNLA understands full citizenship not merely as the acquisition and exercise of civil, political and social rights, but also as the ability of each and every person to become part of the social fabric and to act in a free and participative way, while preserving their subjectivity (Bezerra Jr., 1992; Vieira, 2001). The promotion of full citizenship has entailed a multiplicity of actions which may be viewed as taking place on three fronts.

- On the one hand, the MNLA has striven to produce a shift in the symbolic representations of 'madness' in society. Initiatives such as public manifestations, television and radio programmes, and cultural events have been instrumental in 'bringing madness into the city' creating channels of communication through which notions such as incapacity and dangerousness, which are usually linked to mental illness, can be debated and discarded.

- On the other hand, the movement has sought to identify the specific ways in which people affected by mental distress are oppressed, discriminated and excluded, and to hold accountable those who violate their rights. The formulation of the *Letter of Rights and Duties of Mental Health Care Users and Family Members* in 1997 was an important step in mobilising actors in the field to take direct action (e.g. public denunciations) in the face of instances of abuse, and to push for the establishment of new rights.
- Finally, the MNLA has participated actively in promoting psychiatric reform on the ground by formulating proposals to improve alternative care services and therapeutic practices, monitoring their implementation and evaluating their outcomes. This has been carried out in line with the psychosocial rehabilitation model which advocates social integration as the best route to recovery. To further its proposals, the movement has engaged actively in the participatory mechanisms devised to enable citizen participation in mental health governance (i.e. health councils and health conferences). It also lobbies political parties and official authorities to keep psychiatric reform on the political agenda and to promote measures necessary to bring it to fruition (e.g. access to sickness benefits, creation of protected housing and assisted work) (Maia and Fernandes, 2002; Vasconcelos, 2002b).

Goals and achievements of the movement

Toward the end of the 1990s the benefits and challenges brought by psychiatric reform, and in particular by deinstitutionalisation, began to take more visible form. On the one hand, thousands of people with a long history of incarceration were finally living in the community and showing signs of remarkable recovery. On the other hand, many others were still waiting for discharge from psychiatric hospitals – not because they needed that type of care but because they had no other place to go. These were mostly people who had lived in the hospitals for several decades. For them to return to the community it was necessary to identify relatives or people willing to assist them with housing, financial support and care. In some cases, family members were nowhere to be found, either because they had died or because they had abandoned their relatives in the hospital under a false name. In other cases, inmates' family members were so poor that they simply could not afford to take care of them[28].

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[28] We should note that in Brazil people unable to work due to illness are entitled to a sickness benefit. However, in the cases of people who were not employed in the formal labour market it is extremely difficult to get access to these benefits. For a more detailed discussion on this issue see Chapter 6.

This problem was used by opponents of psychiatric reform to justify the need for asylums and to argue against dismantling them. The MNLA disputed that, counter-arguing that it is necessary to distinguish between the problems inherent to psychosocial distress and those related to poverty: "the asylum is not a hostel and the poor cannot be punished with permanent internment" (Maia and Fernandes, 2002: 165). One of its first actions in this domain was the proposal of a number of measures aimed at facilitating the transition of long-term unassisted psychiatric inmates to society. Among those measures were the creation of a sheltered home programme able to host people immediately after hospital discharge, the creation of a subsidy to enable them to acquire a home after gathering the necessary conditions to live independently, and the entitlement to free basic medication. These measures were subsequently approved by the Brazilian government. In 2000, directives for the creation of sheltered homes were issued (Vasconcelos, 2002c) and in 2003 the state began to give financial support to long-term psychiatric patients seeking to return to the community (Furtado, 2006).

1.4 Conclusion

To understand the significance of user participation in mental health it has been necessary to trace the origins of psychiatry back to the very beginnings of the profession. Participation implies giving patients agency and voice, and the main criticism aimed at classical psychiatry since its establishment in the nineteenth century has been precisely that it robs the mentally ill of both. Therefore, creating opportunities for participation for mental patients is not just something that can be added on to mental health services as an optional extra or an afterthought. The very nature of mental illness and its treatment is at stake.

To explain this point we have shown how psychiatry arose as a profession and how the asylum system, through which mentally disturbed people were systematically removed from society and stored in huge 'museums of madness', came into being in the nineteenth century and fell into disrepute in the twentieth. Going back even earlier than this, we showed through the accounts of Scull and Foucault how the asylum system itself came into being, and the ways in which it served to maintain social order.

For Scull, this order was essentially economic; the asylum was a response to the problem of what to do with the 'able-bodied unemployed'. To confine the latter in workhouses it was necessary to sift out those whose behaviour was disturbed and disturbing. However, the 'lunatic asylums' or 'madhouses' which had existed on a small scale throughout Europe for centuries had a bad reputation. The invention of 'moral treatment' made it possible to reinvent the asylum as a socially acceptable solution to the problem of what to do with intractable deviance in the form of 'insanity'. Subsequently – and paradoxically, given their own bad reputation in this area and their seeming lack of qualifications to carry out 'moral treatment' – the medical profession was put in charge of the asylums, which grew uncontrollably and became 'black holes' within modern industrial societies from which few who went in ever came out alive.

Foucault's analysis of the rise of psychiatry, though more popular and influential than Scull's, is less closely tied to historical detail; it has been challenged by historians for ignoring the pre-history of asylums and of medical involvement with insanity, and for exaggerating the extent to which madness was a socially accepted phenomenon in the middle ages and Renaissance. Instead of Scull's economic analysis Foucault offers a cultural-historical one, in terms of the affront which the insane provided to the Enlightenment ideal of rationality. Whereas in earlier times a 'dialogue with unreason' was at least thinkable, in the Age of Reason the mad were regarded as devoid of humanity and therefore not worth listening to. Foucault argues that early nineteenth-century psychiatrists such as Pinel did not 'liberate' the insane, but simply replaced one form of oppression (based on physical violence and constraint) by another (based on the negation of their human status). Both were equally effective ways of removing the mentally ill individual from society and denying them citizenship. Positivist psychiatry, based on the premise that mental illness could only be understood as the manifestation of brain pathology, closed off the 'dialogue with unreason' just as effectively as putting the insane behind bars. Pharmacological sedation impaired the individual's agency just as effectively as chains had done, and left scars which were no less serious.

The twentieth century saw challenges to this concept of mental illness and to the system of incarceration which it was linked with. The introduction of alternative treatments, together with social models of 'mental illness' viewing it not as symptoms of a deranged brain but – at least in part – as intelligible reactions to human situations, demonstrated the possibility of other solutions to mental problems and challenged the hegemony of classical asylum psychiatry.

These alternatives came into being slowly at first, but change accelerated dramatically after the Second World War. Institutions were closed, new services were set up based on community care and psychotherapy, and the inhumanity of the traditional asylums was placed under an unforgiving spotlight by the 'anti-psychiatry' movement. In Europe and the US, the 1960s and 1970s witnessed a transformation of mental health services in which classical asylum psychiatry was relegated to a marginal position. At the same time a powerful ideology of 'liberation' and 'empowerment' was applied to the situation of mental patients, who in some quarters came to be regarded as the heroes of the counter-culture. During this period mental patients themselves gained a voice and saw many of their rights restored. Classical psychiatry was revealed as oppressive and dehumanising ('mortifying', in Goffman's words), and the biomedical model found itself on the defensive.

It was against this background that the present-day mental health user movements first came into being in the 1970's and 1980's. They played a central part in mental health service reforms and in the ideological shift within health services generally towards more ‘demand-oriented’ or ‘patient-centred’ approaches which presuppose and led to an increase of user participation in health care policy and provision. A problem that remained, however, was that user participation did not necessarily make health services more inclusive. Socially disadvantaged patients were less able to make use of participatory mechanisms; migrants and ethnic minorities, in particular, seldom played an active role.

In the present thesis, the phenomenon of ‘user participation’ will be examined among two minority groups in very different settings: minority Northeasterners in Rio de Janeiro and Cape Verdeans migrants in Rotterdam. This introductory chapter has described how the user movement arose in Brazil and the Netherlands. Despite very different political and economic situations, common themes can be discerned and indeed, some common sources lay at the root of both developments (though Dutch mental health reformers were more influenced by American and British ‘anti-psychiatry’, while their counterparts drew inspiration from Italian and French models). Both the Dutch and the Brazilian user movements originate from a powerful drive to eliminate repressive and segregating ‘treatments’, promote deinstitutionalisation and devise alternative care solutions within the community. Moreover, they have striven to democratize mental health care governance by bringing a user voice into decision-making over mental health policy and service delivery. The actions of these movements have produced very relevant changes, providing part of the impetus for legislation in both countries which established user participation as a right of all citizens. However, as we will see in the next chapter, neither these movements, nor the participatory mechanisms and spaces now available in the Netherlands and Brazil, have succeeded in becoming completely open to the plurality of social actors they are meant to involve: migrants and ethnic minorities are seriously under-represented. This thesis will investigate the participation of two minority user groups who are a favourable exception to the rule.

2. On the meanings and practice of participation

In this chapter we look into the malleable concept of participation and the ways by which changing notions of participation have influenced the creation and inclusiveness of health participatory spaces in the Netherlands and in Brazil.

Participation, in the political sense, is an age-old notion dating back to the city-states of ancient Greece. More recently, beginning in the 1960s, expressions such as 'popular participation' began to appear in development literature and have since become common currency in various development sectors, including agriculture, water, education and health (Gaventa, 2006a). User participation in mental health emerged in the early 1970s in the form of collective action as disenfranchised mental care users began to mobilise in order to reassert their rights (Chamberlin, 1978; Haafkens *et al.*, 1986). Despite over four decades of debate, 'participation' continues to be a contentious notion (Croft and Beresford, 1996). Much has been written about its meanings (see Brownlea, 1987; Oakley, 1989; Oakley *et al.*, 1991; Kahssay and Oakley, 1999; Rifkin *et al.*, 2000; Cornwall, 2000; 2006) and divergent opinions abound:

- Some view participation as a means to an end, others advocate it as an end in itself (means/end).
- Some present it as a product, others can only conceive of it as a process (product/ process).
- For some participation equals mere consultation, for others it is a matter of asserting power and having a say in the decision-making processes which affect people's lives (consultation/ decision-making)
- More recently, participation has been coupled with the notion of citizenship to illustrate its significance as a right (right) (Cornwall and Gaventa, 2001).

This maze of interpretations has led scholars in the field to conclude that the concept of participation defies any single attempt at definition (Kahssay and Oakley, 1999; Rifkin *et al.*, 2000; Cornwall, 2006; Gaventa, 2006a). This is because participation is a value-laden, context-bound, political concept (Gaventa, 2006a). Its interpretations are thus subjected to the ideological, social and economic positions of the people and agencies initiating and taking part in it. Put in other words, the meaning given to participation will depend much on who participates, what they participate in and on the effects of their engagement on the programmes, services and policies they are seeking to influence (Cornwall, 2008a). This confers on participation a dynamic character which renders impracticable any claim over a universal definition: "Participation has no final meaning. It is not a rock. It is mobile and malleable, an amoeba, a sculptor's clay, a plasticine shaped as it passes from hand to hand" (Chambers, 2005: 104).

One way in which we can seek to grasp the various meanings of participation is by taking a retrospective look and trying to identify variations in the discourse on participation. This exercise has been carried out in the context of development by cultural anthropologist Andrea Cornwall (2000; 2006) and political sociologist John Gaventa (2006a) from the Institute of Development Studies (IDS) in Britain. According to Cornwall, the notions of participation shifted in emphasis between 'beneficiary participation', 'community participation', 'stakeholder participation', 'user/consumer participation', and 'citizen participation'. Each of these prefixes reflects a set of different meanings and practices of participation. However, it should be noted that they are not time-bound, i.e. the emergence of one of those notions does not necessarily imply a discarding of the previous one. In fact, they often co-exist in the same political space and actors' definitions of participation may combine elements of the different notions (Gaventa, 2006a). Nevertheless, they offer a practical tool with which to start distinguishing between the various understandings of participation. In what follows we tap into the insights afforded by development literature and explore the meanings given to participation in the context of (mental) health promotion. Because the notions 'beneficiary' and 'stakeholder' are less current in the field of mental health than in development, our analysis focuses on the more central notions of 'community', 'user/consumer' and 'citizen' participation.

Given the contextualised and dynamic nature of participation an understanding of its meanings would be incomplete without drawing attention to its practice. Taking the cases of user participation in health in Brazil and the Netherlands, we discuss the ways by which shifting notions of participation impact on the creation and inclusiveness of participatory spaces. As we show in section 2.4, 'inclusiveness' can be understood in terms of the degree to which participatory spaces are capable of including the diversity of actors and interests they are meant to involve and represent. Barriers to participation in those spaces can arise at the very point of entry, impeding users from getting involved and undermining their 'formal inclusion' in the participatory sphere. They may also work to impede users from exerting influence over decision-making once they are inside participatory spaces, hampering their 'substantive inclusion' (Pozzoni, 2002).

One final aspect to take into consideration is that the term participation is often used interchangeably with the term involvement. Although some authors have stated a clear preference for 'participation', arguing that it implies greater activity (Meleis, 1992 cited by Sozomenou *et al.*, 2000), others resort to similar arguments to support the use of 'involvement'. For example, the WHO argued that 'community involvement' (as opposed to 'community participation') has the implication of a deeper and more personal attachment of community members to primary health care (Oakley, 1989). In practice, however, there is little agreement in the literature about this distinction. Even the WHO, which for a long period of time used the term involvement exclusively, has recently come to employ the expression ‘community participation’ to discuss local health and sustainable development (see WHO, 2002). Once again, this points to the absence of a universal definition of participation.

2.1 Participation from below

Toward the late 1960s expressions such as ‘popular participation’ and ‘participatory development’ began to emerge in development literature. According to Gaventa (2006a), this was the result of various forces. On the one hand, a strong reaction against what is generally called ‘top-down development’ by both activists and academics unfolded. Critics argued that development programmes had to be based on the needs and knowledge of the people they were meant for. On the other hand, many people campaigning against various forms of oppression (e.g. independence movements in the South, and the women’s, student, and mental health user movements observed more distinctly in the North) came together to demand inclusion and voice.

The notion of communities having a voice in the diagnosis and the tackling of health problems was not a new idea within developing countries. During the 1950s and part of the 1960s, community development initiatives sought to engage local people in management and decision-making. However, this was also a period of considerable technological progress. Many at the time believed that to benefit optimally from this, expertise and technical equipment had to be placed together in large care units. This led to the centralisation of national health care services, which came increasingly under the sole responsibility of health staff. As a result, lay people’s voices were suppressed by a dominant professional discourse and practice emphasising external delivery, physical improvements and the employment of professionals to design and direct health care services and development programmes (Kahssay and Oakley, 1999).

As experiences deriving from this top-down development model began to accrue, so did the realisation that the sort of interventions it fostered failed to tackle a key problem with which poor health is largely associated with: poverty. As a result, a new approach to development began to surface. This approach, which is known by various terms including ‘alternative development’ or ‘participatory development’, rested in two premises. First, it asserted that poverty is structural and has its roots in the political, environmental and socioeconomic conditions which influence people’s livelihoods. Consequently, to tackle poverty, it was necessary to provide the socially-excluded with opportunities, through education and capacity building, to gain the means by which to change these conditions. A second premise was that the existing development programmes and projects had largely bypassed the majority of people they were supposed to benefit. Indeed, top-down development had consistently failed to both capitalise on people’s knowledge and to afford them the chance to develop further the talents, abilities and skills necessary to really bring forth development (Oakley *et al.*, 1991; Rifkin *et al.*, 2000).

Proponents of participatory development were largely influenced by the works of Brazilian educator and critical pedagogue Paulo Freire. As noted by Gaventa (2006a), Freire's *Pedagogy of the Oppressed* (1970a) "articulated the development process not as a 'gift' from the outside, but as a process of transformation gained through critical reflection and action [i.e. *conscientização*] by the people themselves" (2006a: 54). Development, thus, implied both critical awareness of 'oppressive structures' and active participation in decision-making processes concerned with changing those structures. These ideas inspired not only development activists and literacy workers but also academics who started advocating for and creating mechanisms and techniques to foster people's participation in development projects (e.g. participatory action research (PAR), rapid rural appraisal (RRA), etc.). The centrality of people's participation within the new development paradigm also gained emphasis in the health sector. In 1978, the WHO stated 'community participation' to be one of the main principles of its Primary Health Care (PHC) strategy proposed through the Alma-Ata Declaration to achieve *Health for All by the Year 2000* (WHO, 1978). As we will see in the next section, the notion 'community participation' came to combine two disparate views of participation which emerged during the 1980s, i.e. participation as a 'means' and participation as an 'end'.

The demand for popular participation was also sparked by the various social movements emerging in the North in the early 1970s. As we have seen in Chapter 1, this was a decade in which different social groups with a shared sense of disenfranchisement and powerlessness began to organise and to claim rights, recognition and a more equitable distribution of resources (e.g. civil rights, student, women's movements). In the field of mental health, groups of people affected by psychosocial distress and with a long history of oppression and segregation came together to claim a voice, assert their rights, oppose professional control over mental care delivery and generate alternative care solutions (e.g. self-help and mutual-aid groups, user-led services, etc.). Within such movements, participation was often perceived as a process through which those formerly excluded from key decisions affecting their lives asserted their demands for inclusion.

Overall, the notion of participation described in this section is about challenging power. Participation is not understood as mere consultation but rather as the process by which the disadvantaged and marginalised realise power through organised groups and social movements, which have the capacities of critical reflection and action and, in that way, are able to articulate and negotiate demands (Gaventa, 2006a). Self-reliance, capacity building, ownership and empowerment are all key ingredients of the process of transfer of power and control through popular participation (Cornwall, 2000).

2.2 Community participation

In the 1980s, participation acquired a profusion of meanings, some of which were at odds with one another. The dissonant discourses of participation arising during that decade appear to be a result of the presence of two development actors with widely different positions and interests: alternative development advocates and practitioners, and top-down or mainstream development agents (Cornwall, 2000; 2006).

Following up the achievements of the previous decade, alternative development practitioners continued to work through the 1980s giving rise to several innovative and instructive participatory approaches (e.g. PAR). These approaches aimed to foster people's critical analysis and competencies so as to enable them to articulate their own identities and concerns as well as to regain their agency (Fals-Borda and Rahman, 1991). The promotion of people's self-reliance and empowerment through increased control over resources and participation in decision-making processes became core goals within the alternative development paradigm (Cornwall, 2000).

But the 1980s also saw the embracement of neo-liberal economic policies in countries such as the US and the UK where many of the development donors and loaners were based. As neo-liberalism took hold of mainstream development, the notion of participation began to shift. Within the new discourse, people targeted by development programmes were no longer to be seen as passive recipients of assistance. Instead, they were relabelled 'beneficiaries'. In this capacity, they were expected to participate actively in the implementation of development projects designed by others to benefit them, and in bearing its costs (Cornwall, 2006). Arguments used to legitimise this approach included the idea that the participation of communities would make for less-costly, more needs-driven, efficient and sustainable development projects. In the process, ownership would also be built (Gaventa, 2006a). However, mainstream developers laid little or no emphasis on capacity building[29] or empowerment. Their view of participation was one which hardly went further than community involvement in cost-sharing and co-production of services (Paul, 1987). It is hardly surprising then that participation stopped being seen as a challenge to top-down development during this period (Gaventa, 2006a). Depleted of its potential to mobilise power through collective action, "community participation' became a channel through which 'popular participation' began to be actualised in mainstream development initiatives during the late 1970s and early 1980s" (Cornwall, 2000: 23). In other words, participation became an instrument used by top-down developers and policy-makers to reach their goals. A vivid example of this has been documented by Zakus (1998) who studied a case of community participation in health in Oaxaca, Mexico, during the 1980s. At

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[29] Capacity building is an ambiguous concept and it is not within the scope of this chapter to attempt to define it. However, in general terms, it can be said that capacity-building entails building the skills, knowledge, experience, leadership, and managerial capabilities of people to participate in projects, programmes, or governance processes (Cuthill and Fien, 2005).

that point in time, the Mexican Ministry of Health was experiencing considerable national and international pressure to expand health care services. Lacking the necessary resources to increase service provision it turned to its people and ironically found those resources among disadvantaged communities. Although they engaged in the co-production of services, Zakus shows how the Ministry failed to provide them adequate training and supervision. Furthermore, communities were granted no power or decision-making authority over the programmes in which they participated.

In this way, it can be seen that alternative and mainstream development discourses of participation remained distinct until around the mid-1980s, but achieved some convergence in the latter part of the decade. As Cornwall (2000) explains, with the expansion of neo-liberal economic reforms some of the core elements of participatory approaches to development became of great appeal to mainstream developers. This was particularly the case with grassroots 'self-reliance' and 'ownership'. Both these concepts served well the 'do it by yourself' ethos promoted by neo-liberalism. Yet, in the course of their appropriation by the mainstream development perspective, these concepts acquired entirely different meanings. Self-reliance lost its association with people's ability to bring about social change fuelled by common concerns and shared interests and "came to signify the individualism that underlay the marketising regimes of Margaret Thatcher and Ronald Reagan" (Cornwall, 2006: 72). Ownership was divested of "any association with a transfer of power and control (…) [and] became associated with people 'buying in' to development initiatives intended for their benefit through contributions in cash or kind" (Cornwall, 2000: 26).

The convergence of self-reliance and self-provisioning discourses brought together two different perspectives on participation (Cornwall, 2000) which have been described as 'participation as an *end*' and 'participation as a *means*' (Oakley *et al.*, 1991; Nelson and Wright, 1995). The former emphasises participation as a process aimed at empowering communities to take control over their own development and to have a voice in managing the resources and services on which their lives depend. The latter has a clear utilitarian basis, stressing participation as a tool to accomplish the aims of development projects more efficiently, effectively or cheaply by having communities pitching in labour or cash contributions. Toward the late 1980s these contrasting perspectives started being combined to shape new development initiatives. Among the initiatives which merged them was Community Involvement in Health (CIH).

CIH was first articulated by the WHO in 1985 during an inter-regional meeting in Brioni (former Yugoslavia) summoned to discuss community participation in health development (WHO, 1985). As we noted earlier, community participation had been framed as a core principle of WHO's strategy (PHC) to reduce health inequalities in its Alma-Ata Declaration (WHO, 1978). However, as argued by Rifkin (1996), the definition of participation proposed in the declaration[30] was left deliberately vague and

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[30] The definition given in the Alma-Ata Declaration was as follows: "Community participation is the process by which individuals and families assume responsibility for their own health and welfare and those of the community, and develop capacity to contribute to their and the community's development. They

flexible, allowing for the fact that countries were faced with different public health problems and different socio-political contexts. This led to the adoption of various meanings of participation between and within countries, making it difficult to reach agreement on how to promote it in practice (Rifkin, 1986). The Brioni meeting was organised to tackle this problem and promote greater understanding and acceptance of participation in the form of CIH. A few years later, the WHO convened a Study Group to review the concept and practice of participation, which agreed that:

> CIH is essentially a process whereby people, both individually and in groups, exercise their right to play an active and direct role in the development of appropriate health services, in ensuring the conditions for sustained better health and in supporting the empowerment of communities for health development. CIH actively promotes people's involvement and encourages them to take an interest in, to contribute to and to take some responsibility for the provision of services to promote health (WHO, 1991).

While reflecting the neo-liberal spirit of its time (for CIH also entailed that communities should make contributions to ensure service delivery), this definition articulated a concern to prevent participation from becoming a mere instrument at the hands of advocates of the self-provisioning discourse, by emphasizing it as a process strictly linked to empowerment. This was particularly important given the fact that health sector reform in various parts of the world had come to imply an emphasis on cost reduction and privatisation, which usually exacerbate the exclusion of those already struggling to access health care. But empowering people with the skills and confidence to analyse their situation, reach consensus, make decisions and take action through community participation in development was far from a straightforward process. In the 1990s, critics began to warn of the danger of development initiatives such as CIH giving rise (even if unintentionally) to participatory mechanisms (e.g. user committees, development committees) which further intensify the discrimination and exclusion of people already with little agency or voice. As argued by Guijt and Shah (1998), one critical problem was that such initiatives tended to treat 'the community' as a benign and homogenous entity whose members share interests, values and identities and work together for the common good. This view neglected the fact that differences within communities pertaining to gender, ethnicity, religion, economic status, etc., can engender relationships which isolate some individuals, denying them an equal say or even access to participatory development projects. This, in turn, raised concerns of how much decisions reached through community participation were representative of the interests of all community members, how inclusive and empowering participatory community projects really were, and how great was the risk

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come to know their own situation better and are motivated to solve their common problems. This enables them to become agents of their own development instead of passive beneficiaries of development aid…" (WHO, 1978).

for participation in these projects to reinforce exclusion. These issues are still largely unresolved (Cornwall, 2000).

2.3 Consumer participation

The expansion of neo-liberal thinking throughout the 1980s and early 1990s underlay a shift in mainstream development discourse on participation, dislodging participation from the domain of the community and repositioning it in the realm of civil society (Cornwall, 2000). Within this process, 'beneficiaries' and 'communities' were re-defined as 'consumers' of services delivered by civil society organisations (CSOs). In the North, 'consumer participation' in health and social care services also gained ground in the late 1980s with the advent of public sector reforms based on managerial principles. In the remainder of this section we focus first on how these events unfolded in the field of development. We then move on to explore how consumer participation came of age in the North, taking the particular case of the Netherlands.

Consumer participation in development programmes

In the 1980s, the idea began to acquire currency among international donors that smaller-scale organisations operating on a non-profit basis and relatively independent from the state were better suited to operationalise 'community participation' in development. This spurred an exponential growth in CSOs, and in particular in NGOs, through which 'consumer participation' started being fostered (Cornwall, 2000). According to Clayton *et al.* (2000), the burgeoning interest of donors in CSOs was the result of two major global policy changes: the rise of the 'new policy agenda' (Robinson, 1994) on good governance, and the emergence of new public management (NPM) as the dominant paradigm for public sector reform.

The **'new policy agenda'** had its origins in the collapse of communism in the former Soviet Union and in Eastern Europe which brought democracy to the fore as a dominant political ideology. No longer needing to condone corruption and violation of human rights in countries which, during the Cold War, had been strategic allies, Western governments and donors began to explicitly promote political and administrative reform in the South through development co-operation (Robinson, 1994). Political reform aimed to make states more democratically accountable through multiparty elections, respect for human rights and the rule of law. Administrative reform concerned public service reorganisation, decentralisation and anti-corruption measures. At first, proponents of this new agenda sought to stimulate reform by making aid conditional on governments in the South respecting human rights, enforcing multiparty elections and improving performance of their institutions. However, in many cases, donors failed to apply 'political conditionality' in a consistent manner (Stokke, 1995 cited in Clayton *et al.*, 2000). In addition, they came to realise that multiparty elections were no guarantee of change or improvement in governments nor were democratic elected governments necessarily conducive to a more democratic culture. As a result, donors began to support the growth of CSOs, arguing that a strong civil society is likely to place demands for a more accountable and transparent state and to lead to sustainable good governance (Clayton *et al.*, 2000).

While some donors have been keen to fund CSOs concerned with promoting people's empowerment and self-determination through participatory approaches to development, others found in civil society a new way to promote structural adjustments in accordance with a wider neo-liberal agenda which called for a 'hands-off' role for the state and the privatisation of service provision. The latter appeared to be well in tune with NPM thinking (Clayton *et al.*, 2000; Cornwall, 2000).

New Public Management (NPM) has been described as a diffuse ideology (Flynn, 2002a) or a bundle of managerial thoughts (Ferlie *et al.*, 1996) which favours commercial models of organisation and management practice and insists they can and must be applied to public sector services (Rowe and Shepherd, 2002). It has, therefore, also been characterised as 'state managerialism' (Clarke and Newman, 1997).

NPM emerged in the 1980s in countries such as the US and the UK as governments there began to turn to "market disciplines as the solution to the ills of the public sector" (McLaughlin *et al.*, 2002). Although NPM has undergone considerable change and refinement over the years, its main ingredients are relatively straightforward: reduction of public expenditure, reform of state bureaucracies, and an increase in the efficiency of public service provision. The implementation of NPM has been highly context-bound, taking different contours in different countries (Flynn, 2002b). However, marketisation (through privatisation and contracting-out), decentralisation, and output controls of public services under a hands-on and entrepreneurial management (as opposed to public administration) of service delivery have appeared as key strategies promoted by NPM proponents to achieve those goals (Hood, 1991 cited in McLaughlin *et al.*, 2002).

Advocates of marketisation argue that markets allocate resources more efficiently than bureaucratic decisions. They define efficiency in two ways: first, goods and services are produced at the lowest cost since high-cost producers are gradually eliminated by lower-cost producers entering the market; second, only the goods and services in demand by people are produced; producers seeking to respond to individuals' demands are more likely to produce what people want than a bureaucratic mechanism making those decisions for them. For these aspects of efficiency to prevail, several preconditions must be met: consumers must be informed about the products available in the market and of their prices, and must be able to access alternative suppliers; producers must be able to enter any particular market; and existing producers should not have insuperable advantages because of their established operations. This ideal type of free market cannot be fully applied to public services for it implies consumers' free choice, good knowledge of available options and the ability to switch between suppliers. Moreover, in (for example) the health sector, a rationing system must always be enforced and that restricts consumer choice: one may be able to choose a general practitioner (GP), but referrals for secondary care are dependant on GPs' decisions. Nevertheless, an artificial version of the market has been introduced in the public sector, and in particular in health care, through the creation of 'quasi-markets' (Flynn, 2002a). This has entailed, among other things, the contracting-out of previously state-provided services to (sometimes public, sometimes private) organisations with authorities adopting the role of legislators and purchasers of those services (e.g. UK) or, in other cases, handing over the purchaser role to market agents such as insurance companies and keeping the responsibility of issuing legislation in order to assure the quality and access to services (e.g. the Netherlands) (Oudenampsen, 1999; Dawson and Dargie, 2002; Knijn and Selten, 2006). It has also meant the adoption of 'business-like' management practices such as performance monitoring and output control as a means of increasing organisational efficiency and making contractors more accountable for expenditure decisions (Milewa *et al.*, 1998).

Returning to the field of development, Clayton *et al.* (2000) have shown how NPM was increasingly promoted by donors in developing countries in the 1980s as a solution to poor performance in the public sector, and as a means to introduce structural adjustment programmes aimed at fostering economic liberalisation. International donors such as the IMF and the World Bank made future loans to various African countries conditional on NPM reforms which emphasised a reduction of government expenditure and intervention in the economy. This translated into *de facto* privatisation of public service provision and an increase of CSO- and NGO-delivered services. NGOs were argued to be in a better position than governments to deliver cost-effective services as well as to provide welfare to those falling outside the reach of markets (Fowler, 1988 cited in Cornwall, 2000).

Participation as promoted by several NGOs during that period came to be increasingly focused on enabling people to 'own', manage and provide their own services. With the purpose of intensifying such kind of participation, thousands of user committees were created, particularly in Africa (Cornwall, 2000). In practice, however, many of those committees became a means to enforce the parcelling out to communities of recurrent services costs once borne by the state (in the form of user fees, direct cash or kind contributions, etc.) and to have communities take an active role on the co-production of services, rather than providing spaces where users could have a say in determining the kinds of services they needed or wanted. This approach to participation saw it as a functional mechanism to bring about greater cost-efficiency in service delivery by promoting individual contributions. As the 'do it for yourself' ethos gained expression, beneficiaries were recast as consumers: 'users and choosers' of services who, by buying in to those services, were to acquire voice and choice (Cornwall and Gaventa, 2001).

As we noted earlier, the rhetoric of enhanced voice and choice through participation as self-provisioning started being unmasked as scholars looked into who was participating and who was benefiting from such 'participatory initiatives', and learned that power inequalities (associated with gender, economic status, ethnicity, etc.) between 'community' members (now reframed as consumers) often overshadowed the ability of the most disadvantaged to make their demands and have their needs satisfied (Guijt and Shah, 1998). Consumer participation not only seemed to be failing to extend choice to all, it also appeared to be compromising the recognition of the politics involved in participation.

2.3.1 Consumer participation: the case of the Netherlands

Claims for participation based on arguments of efficiency and choice were particularly discernible during the early stages of NPM reforms in countries in the North (Rowe and Shepherd, 2002), and that has also been the case in the Netherlands.

As we showed in Chapter 1, in the late 1980s the Dutch government began implementing a set of reforms aimed at increasing the efficiency of health care delivery and reducing its costs. Those reforms centred on two key shifts: the transformation of the health care system into a quasi-market, and the transition from a supply-oriented to a demand-oriented and demand-driven approach to care delivery. The first shift entailed a transfer of power and responsibility over the planning, provision, evaluation and financing of care from the government to the market agents, i.e. care providers, care sponsors (i.e. insurance companies) and care users. In light of this reform, also known as 'functional decentralisation', health care came to be seen as a commodity whose availability, cost and quality were to be negotiated between the various market agents under a system of 'regulated competition', i.e. under the supervision of the government which retained responsibility for passing legislation aimed at securing the availability of accessible, appropriate and financially sustainable health care (Oudenamspen, 1999).

The second shift (the transition from supply- to demand-oriented care and demand-driven care) meant that no longer were professionals to determine the kind of care users ought to receive but, instead, they were to listen to users' needs and wants and, based on those, search for a matching care approach or treatment and discuss its suitability with the care user. Should a particular form of care requested be unavailable, providers were responsible for either devising it or referring the user to another service. Demand-driven care extended the notion of demand-oriented care from the individual level (i.e. the relationship between care user and professional) to the institutional level (i.e. the relationship between care users and care providers) and to the policy level (i.e. the relationship between care users' representatives and other parties involved on policy-making). Demand-driven care at an institutional level concerned the extent to which care users were able to exert influence on and bring institutions or services to actively pursue a form of organisation, operation and goal setting oriented toward the demand (i.e. toward the satisfaction of users' needs and wants) instead of the supply (e.g. the satisfaction of care sponsors' interests) (Tonkens, 2003). Demand-driven care at a policy level concerned the degree to which care user representatives (i.e. client organisations) were able to bring forth a user perspective when negotiating the course of health care policy with the remaining parties engaged in policy-making, namely care providers, care sponsors and the government (Oudenamspen, 1999).

Both demand-oriented and demand-driven care are inextricably linked to participation. Indeed, it is through participation that they are realised. The existence of a 'market' also implies that care seekers participate as 'users and choosers', by buying in to health care through health insurance payments[31] and by selecting the care that is best suited to their needs. The introduction of the market and demand-driven care in the Netherlands has, thus, facilitated the emergence of a new party in health care decision-making: the care user. In what follows we describe briefly the developments underpinning these reforms and the way by which they came to influence the notion of consumer participation.

According to Tonkens (2003), the rise of demand-oriented and demand-driven care is related to a two-fold crisis in the welfare state which unfolded in the 1970s (Clarke and Newman, 1997). Under the classic welfare state, public provision was allocated through two routes: bureaucracy, which adopted a 'one-size-fits-all' approach providing each client with the same treatment and benefits; and professionalism, which afforded professionals the knowledge and discretionary space to do what they believed was best for their clients (Duyvendak *et al.*, 2006). The appeal of bureaucracy lay in its neutrality and predictability. Professionals, in contrast, brought a personal dimension to public provision, choosing from a range of treatment methods and social care provisions the ones they regarded as most appropriate to the needs of their clients. The welfare state's trust in professionals, who became key actors in its rise, was based on a professional ethos of service grounded on values and principles such as helpfulness, selfless dedication to duty and 'doing no harm' (Tonkens, 2003).

In the 1970s, bureaucracy and professionalism came under criticism on several fronts. Under the growing influence of neo-liberal ideology, bureaucracy was accused of being inefficient, costly and incapable of responding adequately to the diverse needs and wants emerging within an increasingly complex modern society. Professionalism got its share of criticism from two sources: the user movement claimed a greater say in care, arguing that no one is in a better position to make decisions over treatment than users themselves; social scientists and philosophers questioned professionals' power and attitudes stressing their tendency to adopt a paternalistic attitude toward their clients, privilege their own interests above the common good and display an elitist behaviour through the use of jargon (Freidson, 1970; Tonkens, 2003; Knijn and Selten, 2006).

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[31] All residents in the Netherlands are obliged to have a health insurance. With the process of marketisation of health care health insurance companies took over the function of the government as the health care purchaser. Nowadays, they are the main sponsors of health care.

Indeed, as noted by Knijn and Selten (2006), the bureaucratic-professional system of the welfare state was contested by both the right and the left.

The combination of the public's plea for greater individual autonomy, choice and voice in care with the government's interest in achieving cost-effectiveness and efficiency in public service delivery led to a restructuring of the welfare state (Knijn and Selten, 2006) in which its central pillars – bureaucracy and professionalism – were to be replaced by the 'market' and the 'active citizen' (Tonkens, 2003).

As we noted earlier, advocates of marketisation such as Philips director Wisse Dekker who chaired the committee whose report to the Dutch government formed the basis of functional decentralisation reform (see Commissie Dekker, 1987), argued that the market was an effective alternative to a failing bureaucratic public administration. To start with, the market delivers what clients request and (in contrast to professionals) is not paternalistic: it responds to existing needs and wants, without being concerned with influencing clients' wishes or decisions. In addition, the market encourages competition and that is likely to promote greater cost-effectiveness and quality in service provision. Finally, the market is quick to reject poor quality products or services, for these will not survive a reduction in demand. The promptness, efficiency and directness of the market were expected to supplant the slowness, inefficiency and aloofness exhibited by public services under bureaucratic rules.

In order to satisfy users' claims for greater influence in care and to enable the market to function properly, it was necessary both to equip users with the competences and tools required to navigate the health care market and to devise policy and participatory instruments through which their perspectives and preferences could be articulated. The active citizen was to exert choice and voice (Tonkens, 2003).

As observed by Tonkens (*op.cit.*), demand-oriented and demand-driven care became the methodological tailpieces through which the active citizen and the market were to be joined together in order to supplant professionalism (in particular paternalism) and bureaucracy: individual demand-oriented actions were to operate against paternalism; institutional demand-driven actions were to work against bureaucracy. Overall, the chief aim of these new approaches to care was to enable users' perspectives, needs and demands to come to the fore and take centre stage in health care policy and delivery. The informed, resourceful, active citizen was envisioned as the ideal actor to bring forth those perspectives. The market, given its promptness and neutrality, was envisioned as the ideal party to facilitate that. Together, market forces and active citizens would contribute to the making of a more efficient, appropriate, cost-effective health care system.

Since the introduction of demand-driven care in the early 1990s, the Dutch government issued several laws with the aim of strengthening the rights, bargaining power and participation of users in care. The WGBO law (1992), for example, grants users the right to have a say in care by regulating informed consent and allowing them to consult their medical files. The BOPZ law (1994) asserts the right to self-determination and rules on involuntary commitment. Finally, the WKCZ law (1995) makes compulsory the existence of a complaint committee in all health and social care institutions, enabling users to seek redress in cases of inappropriate service delivery.

In 1991, the government also started sponsoring client organisations. Its purpose was twofold: on the one hand, it wanted client organisations to act as representatives of care users in policy-making (e.g. in advisory committees) and service quality evaluation; on the other hand, it wanted them to devise and deliver actions aimed at supporting users in acquiring the necessary competences to further effect their participation and to make appropriate choices in the health care market (e.g. individual guidance, information dissemination sessions, *lotgenotencontact* or peer groups, etc.). The right for care users to manage their 'own health care budgets' (i.e. *persoonsgebonden budget,* PGB) has also been instituted with the goal of granting them greater independence and power in choosing to move from one provider to another who offers greater value for money, without fearing reprisal. Another governmental measure set to promote user participation has been the issuing of the WMCZ law (1996) which asserts users' right to participate in health and social care services through client councils (Oudenampsen, 1999; Nederland *et al.,* 2003).

While some of the above mentioned measures are more clearly concerned with facilitating the expansion of users' choice (e.g. PGB), others are focused on increasing users' voice (e.g. WMCZ law). Policy and instruments devised to bring users' perspectives, needs and demands to the fore appear, thus, to stem from two distinct approaches to participation. Beresford and Croft (1993), discussing the British situation, have referred to these approaches as 'consumerist' and 'democratic'. The former is more economic in nature; it sees the user as a consumer and participation as a means to inform the market about consumers' needs and preferences. The democratic approach is explicitly political; it sees users as citizens and participation as a matter of redistribution of power and control as well as a right. Here we focus on the influence of the consumerist approach on user participation in the Netherlands. The democratic approach is addressed in the next sub-section.

The rise of the market, alongside its emphasis on freedom of choice, buying power and competition, has led care users in the Netherlands to be redefined as consumers (Oudenampsen, 1999). However, as some theorists of consumerism have pointed out:

> There is a power imbalance between those who provide goods and services, and those for whom they are provided. The former possess all the advantages of corporate power and organization, resources, and political influence. The latter, in the market-place at least, have the choice of buying or not buying a product or service, and – where competitive markets exist – of choosing according to their own preferences. They carry weight, therefore, only as the sum of their individual choices (Potter, 1998: 250).

Choice has been at the core of Dutch health care policy. The memorandum on patient/consumer policy *Met Zorg Kiezen* (Choosing with Care) (Ministerie VWS, 2001), for example, sets the terms for the creation of measures aimed at strengthening the position of care users and equipping them to make informed choices and influence care quality. The basic assumption is that if users have the power to choose, as well as an appropriate range of options to choose from, service providers will become more responsive to their needs and preferences in order to prevent clients from switching allegiance to the competition. This, in turn, is expected to reduce existing mismatches between supply and demand, and to contribute to greater quality and efficiency in care provision (Potter, 1998; Ministerie VWS, 2001).

The *Met Zorg Kiezen* policy memorandum proposes five measures for increasing users' competencies and their ability to influence care supply:

1. enforcement of laws protective of users' rights (e.g. WGBO, WKCZ, WMCZ);
2. dissemination of up-to-date, accessible and reliable information regarding the quality of the services delivered by care providers and insurance companies;
3. expansion of advice and consultation services (e.g. information desks, care consultants) aimed at helping users make choices at an individual level;
4. expansion of individual and collective buying power by enabling users to manage their own care budgets (e.g. PGB); and
5. expansion of the bargaining power granted to the bodies responsible for representing users' interests (e.g. client councils, client organisations) (Ministerie VWS, 2001; our translation).

Among these measures are two which imply user participation. The second measure provides for the production and dissemination of information on the quality of health care services, in respect of which a distinction is made between information to be made accessible to users and information to be made available to providers (i.e. information on users' preferences). The fifth measure extends the power of user representative bodies to exert influence over health care decision-making. While the latter has a clear 'democratic' ring (since it is about power redistribution), the former evidences a 'consumerist' approach to participation.

According to theorists of consumerism, information is crucial to enable consumers to make the best choices about the services they want to use and to derive the maximum benefit from them (Potter, 1998). This has been one of the arguments put forward by the government for further stimulating the creation of information regarding health care quality and availability and to foster users' access to it. Participation in *lotgenotengroepen* or peer groups is one of the ways by which users are to get hold of that information, something which is expected to happen as experiences with and knowledge about care are exchanged between peers.

The government has not only argued in favour of the production and distribution of information *for* users, but also *about* users: i.e. information concerning users' needs, preferences and perceptions of the quality of the health care services. Such information is regarded as important for the development by care providers and insurance companies of a customer-oriented approach to care, and for more effective matching supply to demand (Ministerie VWS, 2001). This has led the government to support the creation of qualitative and quantitative instruments to elicit users' views on care quality. For example, focus groups are used to elicit users' experiences. The Consumer Quality Index (CQ Index) is one of the most recent quantitative instruments created to measure consumers' experiences and preferences in a systematic and standardized way (Delnoij, 2006). Both these instruments facilitate and depend on 'consumer participation'. However, this kind of participation appears to hardly go beyond mere consultation. This is essentially because it is a rather indirect and individualized form of participation designed to elicit consumer intelligence and foster consumer choice. The theory is that consumers can use the information gathered through the CQ Index, for example, to their own advantage when choosing a care service or an insurance company. Should the majority of care consumers become conscious of the poor quality of a particular care service and decide to switch to another one, through the 'sum of their individual choices' they might influence the management of the first service to reconsider its care policy. But to what extent is the mechanism of 'exit' (Hirschmann, 1970) enabled through consumer participation an effective way to make services more responsive to users' needs and preferences?

Exit can be a strong signal for the management of an organisation that something is off beam. However, it is an indirect and uninformative signal which carries weight only to the extent that care managers find a rise in drop-out rates problematic and decide to investigate what is causing it (e.g. by consulting data obtained with the CQ Index). This is not always what happens. For example, in services with long waiting lists the management may feel relieved by a decrease in the number of clients, discarding altogether the need to enquire why that happened. But even when research is carried out, that is no guarantee that change will be effected. Research results may indicate, for example, that the group of users dropping-out was actually composed by very critical clients. Their departure may be found opportune, instead of problematic (Tonkens, 2003). Of course, there are also cases in which the management makes a concerted effort to tackle the shortfalls which caused users to leave. Yet whether those efforts are made or not, and the extent to which they lead to more responsive services, remains a decision of care providers. Seen from this perspective, we can say that consumer participation enables users to 'vote with their feet'. However, opting-out is by no means a guarantee that services will become more 'fine-tuned' to the needs of all users. Much depends on how care providers interpret and deal with that signal. If we take this into account, it is not difficult to understand why there are many warnings of consumer participation being turned into a mere instrument to inform the providers and increase organisational learning, without devolving decision-making power to users (Beresford, 2002; Rowe and Shepherd, 2002).

This concern with an instrumentalisation of consumer participation is further accentuated by the fact that, to be activated, exit requires the existence of alternative providers (i.e. choice) operating in competitive terms (i.e. delivering better and/or cheaper services) as well as users' access to reliable and up-to-date information on service quality. As we noted earlier, choice is not always readily available in health care. But even when it is, not all users are able to act as critical consumers who engage in care quality monitoring and hop from one service to the other in response to rising and falling performance figures. Access to such kind of information is dependent on a variety of resources and skills (i.e. an Internet connection, digital literacy, ability to read and interpret complicated arrays of data, etc.) which are not within reach of all users. Most likely, the users accessing online health care data banks and making choices based on that information (including exit) will be well-informed, middle-class people. This means that if services opt to change as a result of investigation of exit patterns they might actually be adapting to the demands of that particular group while leaving the needs of less privileged groups unanswered. In other words, effecting change on the basis of exit patterns may actually lead to less inclusive services. One way by which this can be prevented is the effective implementation of other participatory mechanisms through which a wider spectrum of users can voice their needs and demands (e.g. client councils). This is something consumer participation appears insufficiently equipped to do.

Even if consumer participation *per se* is unlikely to enable users to challenge the *status quo* in health care decision-making, this is not to say that such participation is inherently flawed. On the contrary, consumer participation does have its merits: without participatory mechanisms such as peer groups, focus groups and the CQ Index, users would stand even less chance of acquiring the information and competences they need to distinguish between appropriate and inappropriate service delivery and to eventually engage in shaping health care services and policy. Internet sites such as *Kies Beter* (Choose Better) – an initiative of the Ministry of Health, Wellbeing and Sport designed to facilitate information about illnesses, care quality, insurance prices and coverage, client organisations and users' rights – are a valuable resource to enable users to navigate the health care system and assert their rights, and to keep care providers on their toes (after all it is rather bad publicity to be ranked low on user satisfaction surveys). However, consumer participation, very much like consumerism, 'is fine as far as it goes, but it does not go far enough to effect a radical shift in the distribution of power' (Potter, 1998: 257), something which is crucial if users are to exert real influence in health care. In other words, consumer participation affords users the opportunity to make more informed choices but it does not go far enough as to enable them to directly determine priorities, plan new services, and monitor implementation. For that to happen, power must be brought into the equation. As evidenced by the *Met Zorg Kiezen* memorandum, this has been acknowledged by the Dutch government which expressed the intention to support user representative bodies in acquiring greater bargaining power. In the next section we discuss this issue further.

Before proceeding to the next section, it is important to note that there seems to be no talk of consumer participation in Brazil. This is essentially because participation in this country has been promoted from the start as a legitimate right of citizens and a way to hold the state and public services accountable to the people. Indeed, Brazil adopts a clearly democratic approach to user participation, viewing it as a process entailing the devolution of power over health care decision-making to the citizenry (Cornwall and Shankland, 2008).

2.4 Citizen participation

Toward the late 1990s, shifts in development discourse and intervention together with increased efforts to 'deepen democracies' across the globe led to a re-conceptualisation of participation as a right of citizenship and a key element in the decentralisation of governance (Gaventa and Valderrama, 1999; Cornwall, 2000; Gaventa, 2004a). The dissemination of this approach to participation, alongside the creation of new spaces for public engagement in governance in both northern and southern countries, fostered a re-definition of public service users as 'citizens', i.e. 'makers and shapers' of the social provisions and policies which affect their everyday lives (Barnes, 1999; Cornwall and Gaventa, 2001). In what follows, we describe the main developments which fuelled the formulation of participation as a right and a core feature of democratic governance. We also draw attention to different notions of citizenship – a critical component of the type of participation discussed in this section. We then zoom in on citizen participation in health care in Brazil and the Netherlands, taking in particular consideration the inclusiveness of new participatory spaces in those countries.

2.4.1 Participatory governance, citizenship and democratic spaces

At the turn of the millennium, concerns with a crisis in the quality of democracy expressed throughout the 1990s were further strengthened by a range of studies reporting a rising gap between ordinary people and the institutions which influence their lives, particularly those of the state (Clark and Stewart, 1998; Commonwealth Foundation, 1999; Narayan *et al.*, 2000; Skocpol, 2003 cited by Gaventa, 2004a). Those studies presented empirical evidence of 'democratic deficits' in both 'emerging' and 'mature' democracies: citizens in the South showed growing disappointment with their governments on account of corruption, lack of responsiveness to people's needs, and unaccountability. In the North, particularly in the UK and in the US, there were clear signs of increasing public distrust of the state, a decline in traditional forms of political participation, and a take over of political processes by special interests (*ibid.*).

As explained by Gaventa (2006b; 2007), responses to this perceived crisis in democracy have been framed along three competing approaches, which adopt very different views on the ways by which citizens are to influence the decisions that affect their lives.

- One of those approaches is the neo-liberal approach which argues in favour of a 'minimal state', promoting decentralisation, privatisation and contracting out. As we saw in the previous sub-section, this approach tends to view citizens as rational and critical consumers who express preferences through market choices and service quality assessments, but who exercise little influence over decision-making.
- Another influential approach derives from the liberal representative model which emphasises the need to get democratic institutions and procedures 'back on their feet' through the promotion of free, fair and competitive political processes and multiparty elections. Within this view, citizens are given a somewhat passive role: they are expected to participate through voting and they are granted certain rights, but those are mostly individual rights of freedom meant to limit the authority of governments over matters of private property and political association.
- Finally, there is another view – the 'deepening democracy' approach – which rests on the age-old tradition of participatory democracy. This approach goes beyond an understanding of democracy as a mere set of rules, procedures, and institutional design, and a conception of participation as simply a matter of involvement in electoral processes, to embrace a more dynamic notion of democracy. Within this view, democracy is understood as a process through which citizens are enabled to take an increasingly deeper control over collective decision-making. Put in other words, this approach argues that democratic states have a duty to directly involve citizens in the decisions that have a bearing on their lives. As such, it is also concerned with an expansion of rights. Advocates of this view assert that the realisation of full citizenship entails not only the exercise of political and civil rights but also of social rights, and that the latter can be expanded through collective action and participatory processes. They argue, thus, that to deal with the democratic deficit it is necessary to:

> To extend democracy itself – that is, to go beyond traditional understandings of representative democracy, through creating and supporting *more participatory mechanisms of citizen engagement*, which in turn are built upon, and support, more robust views of rights and responsibilities of citizenship (Gaventa, 2006b: 12; our emphasis).

Taking its inspiration from early state formations such as the city-states of ancient Greece and the writings of nineteenth-century political philosophers such as John Stuart Mill, the idea of deepening democracy through citizen engagement in governance beyond the mere use of the ballot box is far from new (Gaventa, 2006b). Since the mid-1990s, however, support for citizen participation in processes of democratic governance has enjoyed a considerable revival. This has been a result of a confluence of the democratization and development agendas and the organised action of social movements seeking inclusion for those hitherto excluded from public decision-making (Barnes and Bowl, 2001; Cornwall and Coelho, 2007). In what follows, we focus on how participatory governance has been promoted from each of these angles. In the sub-sections thereafter we discuss the relationship between participation and citizenship and the emergence of democratic spaces.

A move towards participatory governance

As we noted earlier, advocates of the 'deepening democracy' approach argue that the procedures of representative democracy alone are insufficient to tackle the crisis of legitimacy experienced by many of the world's democracies. They claim the solution to that problem lies in bringing government closer to the people. This can be achieved, for example, through programmes for decentralised governance, i.e. the devolution of "meaningful authority to local units of governance that are accessible and accountable to the local citizenry" (Blair, 2000: 21). This view of democracy has gained considerable support since the mid-1990s. This appears to be the result of two general developments.

- On the one hand, there has been growing agreement that the traditional institutions of representative democracy face increasing difficulties in managing effectively the diverse social, environmental and economic interests of ever more complex and heterogeneous constituencies (Newman, 2001). This has brought about the need to re-design democratic institutions and devise new mechanisms through which more pluralistic forms of knowledge can be brought to the decision-making table and state bureaucrats can be hold to account on a more regular basis (Fung and Wright, 2003).
- On the other hand, there has been growing consensus that market reforms of neo-liberalism have failed to deliver all that had been promised (e.g. social inclusion, community safety, poverty reduction, health equity, etc.) (Jessop, 2000 cited by Newman, 2001) and, in addition, have led to a more fragmented and dispersed pattern of service delivery and regulation (especially through the creation of a divide between the entities which legislate, purchase and provide services) (Rhodes, 1997).

These developments, alongside the challenges of growing social complexity, have made the task of governing more difficult, leading governments in a variety of countries (e.g. the US, the UK, and the Netherlands) to seek for new strategies to 'steer' (rather than control) complex social systems (Kooiman, 2000). Increasingly, such strategies have involved coordination through participatory forms of governance and partnership – in other words, instead of acting alone governments are 'opening up' and seeking to involve citizens in the co-production of policy, services and programmes, particularly at the local level. The underlying principles here are that "no single agency, private or public, has all the knowledge and information required to solve complex problems in a dynamic and diverse society" (Newman, 2001: 15) and that the interests of some (usually those already in a more privileged position) are likely to prevail over the interests of others, unless the latter are also given the opportunity to inform and influence policy and service delivery (Sousa Santos and Avritzer, 2003). This has fostered a call for new forms of engagement between ordinary people and the state which resulted in the creation of various new institutional participatory mechanisms (e.g. public referenda, citizen's juries, neighbourhood councils, etc.) aimed both at ensuring citizen voices in democratic governance and greater state responsiveness and accountability (Gaventa, 2004a).

In the South, too, shifts in development discourse and practice in the late 1990s contributed for greater public involvement in processes of governance (Cornwall, 2000). As we saw in the previous sub-section, throughout the 1980s international donors favoured a hands-off role for the state, claiming that NGOs were better suited to realise community participation in development projects and service delivery. However, evidence of rising democratic deficits in various developing countries increased donors' concern about the relationship between citizens and the states they sought to assist. This led to a call for institutional reform to make government policy and service delivery more responsive to people's needs. Since the late 1990s, donors have increasingly pressured aid-recipient governments to engage citizens in broadly-based consultation processes over key policy directions and in monitoring public service delivery (Holland and Blackburn, 1998). Supra-national agencies such as the World Bank stimulated the development of new consultative mechanisms such as Participatory Poverty Assessments (PPAs) which sought to gather people's views on poverty and feed that information to policy makers as a means to promote better policy choices (Cornwall and Gaventa, 2001). In other parts of the world such as Brazil, local governments promoted the creation of participatory budgeting through which citizens got a direct say over the allocation of resources and in checking the execution of planned budgets (Sousa Santos, 1998). While early versions of PPAs may have been concerned with eliciting information without necessarily devolving decision-making power to the people, participatory budgeting is an institutional mechanism which enables citizens to have direct influence in policy making and bring elected officials to account in its implementation (Cornwall, 2000). As Gaventa and Valderrama (1999) show, the proliferation of initiatives such as participatory budgeting have levered open formerly closed off decision-making processes which in turn have served to broaden the practice of participation in development: once limited to the domain of projects and service delivery, citizen participation in development now extends to the domains of policy formulation and public sector accountability. This 'scaling up' of participation from projects to policies has given rise to new and more direct forms of citizen-state interaction which are being increasingly used by ordinary people to widen further the spaces available for citizen participation in governance (Gaventa, 2004a).

Indeed, top-down government prompting and international donors' pressure have not been the only driving forces in the expansion of participatory governance. Organised action groups have also had a major role in creating opportunities for citizen participation in public policy and service decision-making (Barnes and Bowl, 2001). This has been particularly visible in health care policy and provision, in regard to which Brazil hosts a remarkable example of how community action and social movements can foster democratic innovation.

As we noted in Chapter 1, participation in health governance is a right of all Brazilian citizens enshrined by the 1988 Constitution, which established the formal transition to democracy. Until then, however, not only had people no voice in health care decision-making, the majority (i.e. all but the wealthy) had also limited or no access to health care. Disgruntled with such exclusion and the rising health inequities associated to it, progressive health practitioners, academics, and members of Christian associations (particularly those influenced by the Theology of Liberation) formed a social movement in the 1970s – the Movement for Health Reform (MRS) – which strived to create a public health system based on the principles of universality, equity, decentralisation and social oversight. In the mid-1980s, already during the period of transition from dictatorship, various MRS members got high level positions in public health bureaucracy (Weyland, 1995). Some of them seized this opportunity to 'work from within' to open up to the public decision-making spaces which had previously been the domain of technocrats alone. This was the case of the 8th National Health Conference held in 1986 in which, for the first time, bureaucrats joined up with thousands of health activists to discuss future health policy. So great was the impact of the mobilisation power of MRS supporters that the "Conference declared health to be 'the duty of the state and the right of the citizen', affirmed the principles of universality, equity, decentralization and participation and generated sufficient political momentum to ensure that these principles were written into the new Constitution in 1988" which also determined the creation of the public health system (SUS) (Cornwall and Shankland, 2008: 2175; see alsoCarvalho and Santos, 1995).

Yet, given the history of clientelistic politics in Brazil (Weyland, 1995), to create a public health system with no means to enforce its responsiveness and accountability to the people was to render it an easy target for exploitation by special interests. In another instance of intense collective action (this time, from outside the state apparatus), "hundreds of thousands of interest groups worked throughout the country as the Constitution was being drafted and collected half a million signatures to demand the creation of participatory democratic mechanisms" (Coelho *et al.*, 2005: 174) aimed at ensuring citizen engagement in the formulation, management and monitoring of social policy. When the Constitution was issued participation in policy-making and monitoring was made into a right (Carvalho and Santos, 1995). This legal foundation enabled the development of an innovative and extensive institutional framework for participation throughout the 1990s (including management councils, conferences and public hearings), affording people in Brazil the opportunity to have a voice in the decisions that affect their lives, not least in health governance (Coelho *et al.*, 2005).

Participation and citizenship

As we have just seen, the intersection of growing demands for inclusion by those at the margins, local governments' support and advocacy for decentralised governance, and central governments' search for legitimacy and political renewal has fostered a move toward more participatory forms of governance in various parts of the world. This, in turn, has given rise to 'new democratic spaces' (Cornwall and Coelho, 2004) where public officials and ordinary people meet to dialogue, scrutinise and/or deliberate over policy, budgets, service delivery, etc. (Fung and Wright, 2003). Within these spaces, new forms of engagement between state and citizens are being framed as traditional modes of political representation give way to more direct forms of citizen participation in planning and policy processes (Gaventa, 2004a), and state-led service planning and delivery is opened to consultation with and assessment by service users (Barnes, 1999). No longer seen as mere beneficiaries or consumers of statutory programmes and services who participate by 'using and choosing' services provided by others, citizens are increasingly taking part in processes of governance as 'makers and shapers' of public policy and service provision (Barnes, 1999; Cornwall and Gaventa, 2001). This has brought about an expansion of the notion of participation from what we referred to in the previous sub-sections as 'community participation' and 'consumer participation' to what Gaventa and Valderrama (1999) termed 'citizenship participation', i.e. "the direct ways in which citizen's influence and exercise control in governance" (1999: 5). Seen in these terms, participation entails both the direct intervention of citizens in public affairs and the accountability of the state and its institutions to citizens.

Linking participation to the political sphere, Gaventa (2004a) argues, calls upon a re-conceptualisation of the meanings of participation and citizenship in relationship to democratic governance.

Similarly to 'participation', 'citizenship' is a value-laden, contextualised concept subjected to much discussion (Turner, 1993; Lister, 1997; Gaventa, 2002). Within the academic literature, citizenship has been conceptualised in terms of three distinct perspectives: liberal, communitarian and civic republican (Isin and Wood, 1999; Jones and Gaventa, 2002).

- The **liberal** tradition emphasises the idea that citizenship is a status on the basis of which individual citizens are entitled to universal rights bestowed by the state. Initially confined to the civil and political rights necessary to protect individual freedom, this notion of citizenship has also come to encompass social rights since T.H. Marshall's seminal work *Citizenship and Social Class* (1950). Elemental in liberal thought is a conception of the self-regarding individual who protects and advances his or her interests in a rational way, and a view of the state as the protector of citizens in the exercise of their rights (Oldfield, 1990 cited by Gaventa, 2002). Whether and when citizens exercise their rights is seen as a choice, with no derogating consequences over their citizenship status should they choose not to be active (Isin and Wood, 1999). The right to participate is an important one within this perspective but it is usually circumscribed to political and civil participation (e.g. traditional voting, exercising free speech, forming associations, etc.) (Gaventa, 2002).

- Opposing the notion of the self-interested or sovereign individual, **communitarian** approaches to citizenship assert that individuals are socially situated and embedded, not isolated (Isin and Wood, 1999). Their sense of identity, it is argued, is forged "through dialogical relations between the individual or social group and its communal others" (Taylor, 1992 cited by Smith, 1998: 117). Communitarianism, thus, places strong emphasis on community belonging, defining citizenship in terms of rights arising from membership of a particular community. The role of the state is seen as more active. Instead of taking the neutral position advocated by liberal thinkers, the state intercedes to insure that all individuals are able to exercise their rights (e.g. by providing welfare benefits) and pursue the common good. Egalitarianism, rather than individual freedom, is the main goal (Sandel, 1998; Smith, 1998).

- **Civic republicanism** attempts to reconcile the liberal notion of the self-interested individual with communitarians' emphasis on egalitarianism and community belonging (Isin and Wood, 1999; Jones and Gaventa, 2002). Civic republicans, thus, emphasise what binds citizens together into a political community while, at the same time, highlighting the primacy of individuals' duty to participate in political and civic affairs (Oldfield, 1998). Seen from this perspective, citizenship is "a practice, and not simply a status, so that not to engage is, in important senses, not to be a citizen" (*ibid.*: 79). In other words, "it is enduring political attachment that provides the citizen with her *identity*… Citizens are who they are by virtue of participating in the life of their political community, and by identifying with its characteristics" (Shafir, 1998: 10-11, emphasis in original). Recognising that individuals require support to engage in the practice of citizenship, civic republicans argue that they need to be empowered and afforded the opportunity to participate in

> political debate and decision-making (Oldfield, 1998). Accordingly, many civic republican thinkers favour deliberative forms of democracy, as opposed to liberal representative political systems (Jones and Gaventa, 2002; see also Kymlicka and Norman, 1994).

As Jones and Gaventa (2002) note, several scholars have sought to develop a more comprehensive notion of citizenship by integrating some of the core features of the perspectives outlined above (see Mouffe, 1992; Lister, 1997; Isin and Wood, 1999). Ruth Lister (1997), for example, argues that a more rounded conception of citizenship can be advanced by knitting together two notions of citizenship usually held as opposites, and which mark the divide between liberal and republican thought: 'citizenship-as-status' and 'citizenship-as-practice'. The former is essentially concerned with the rights and duties of the individual citizen; the latter prioritizes the interests of the wider community, emphasising the importance of citizen participation in the political sphere for the common good (Oldfield, 1990 cited by Lister, 1997). As Lister (1997) goes to on to argue, a synthesis of these two perspectives can be achieved through the notion of human agency[32]:

> Citizenship as participation represents an expression of human agency in the political arena, broadly defined; citizenship as rights enables people to act as agents (*ibid.*: 36).

Such a synthetic approach, Lister claims, is necessary to grant the concept of citizenship the fluidity required to accommodate the fact that the content of citizenship rights is not fixed but subjected to political struggles. Seen as an expression of agency, citizenship can contribute to recasting the disadvantaged and the marginalised as political actors who engage in the struggle to gain new rights and to bring substance to existing ones (*ibid.*). However, unlike Oldfield (1998), Lister does not construe political participation as an obligation of citizenship. As she asserts, to assume that all citizens share equally the resources necessary to fulfil such an obligation is to ignore the differences in gender, ethnicity, religion, economic status, state of health, etc. that frame social relations and give rise to heterogeneous (political) communities within which some are much better placed to defend their interests than others. As we noted earlier, participatory initiatives which fail to consider these issues carry the risk of intensifying further the exclusion of people with already little agency and voice (Guijt and Shah, 1998). In a similar vein, to conceive of citizenship as mandatory political participation carries the danger of excluding those who do not participate because they

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[32] Following Gould, Lister defines human agency "as a process of self-development, of concretely becoming the person one chooses to be through carrying out those actions that express one's purposes and needs" (Gould, 1988 cited by Lister, 1997: 36). Seen in these terms, human agency conveys the idea of "individuals as autonomous, purposive actors, [who are] capable of choice" (*ibid.*: 36).

are either unwilling or unable to (Lister, 1997). For this reason, Lister suggests that a distinction is made between being a citizen and acting as one:

> To be a citizen, in the legal and sociological sense, means to enjoy the rights of citizenship necessary for agency and social and political participation. To act as a citizen involves fulfilling the full potential of the status. Those who do not fulfil that potential do not cease to be citizens (*ibid.*: 41).

The conception of citizenship as both status and practice has further implications for the notion of participation. Contesting the idea of participation as obligation, Lister claims participation be recast as an opportunity and a right, for if the conditions necessary for people to act as citizens are created, chances they will do so increase, and with that their capacity to participate is likely to develop. Building on Gould (1988), she suggests "the right of participation in decision-making in social, economic, cultural and political life should be included in the nexus of human rights" (1988: 212). Underpinning this is the idea that social and economic rights help to promote the exercise of political and civil rights. In other words, it is through social and economic rights that an attempt to guarantee people the material conditions and securities they need to participate in political and civil life can be realised. This is particularly relevant where groups disadvantaged in terms of power and resources are concerned, for the economic and social exclusion they may experience tends to undermine their ability to act as agents and to fully exercise their citizenship (Gould, 1988; Plant, 1992; Lister, 1997).

As noted earlier, citizenship rights are not static. Social rights, in particular, tend to vary over time and are usually dependent on the socio-economic and political contexts in which citizens are found. In order to claim, extend or enforce social rights, citizens must be able to participate in the decisions that affect their lives. As Ferguson (1999 cited by Cornwall, 2000) argues, citizens cannot realise their right to health, for example, unless they are able to exercise their democratic right to participation in decision-making processes about heath care provision. Hence, "while social rights can be seen as positive freedoms in terms of enabling citizens to realise their political and civil rights, participation as a right can be seen as a positive freedom which enables them to realise their social rights" (Gaventa, 2002: 5). Seen from this perspective, participation turns into a "prior right, necessary for making other rights real" (Gaventa, 2004a: 29) or, as Gaventa put it elsewhere, participation becomes the 'right to claim rights' (2002: 4).

Democratic spaces

The re-conception of participation as a right of citizenship which extends beyond traditional voting to include citizen engagement in processes of governance has been accompanied by the creation of new participatory arenas which were referred to earlier as 'new democratic spaces' (Cornwall and Coelho, 2007). These spaces take a variety of forms and can involve a multiplicity of actors. Some are “one-off listening exercises or consultative events” (e.g. PPAs, Citizens’ Jury, etc.); others are “more durable, regularized institutions” (e.g. health councils, national advisory bodies, etc.). While some host a plethora of representatives of civil society, the private sector, government, donors and lenders, others are limited to citizens’ and public authorities’ representatives (Cornwall, 2004: 76). Common to these spaces, however, is a “semi-autonomous existence, outside and apart from the institutions of formal politics, bureaucracy and everyday association life” which turns them into a “distinct arena at the interface of state and society”, termed by Cornwall and Coelho the ‘participatory sphere’ (2007: 1-2).

Many of the democratic spaces created to expand participatory governance are backed by legal or constitutional frameworks (see McGee *et al.*, 2003) and supported by elaborate technical innovations (Shankland and Cornwall, 2008). However, albeit crucial, such legal and technical apparatuses are not sufficient to guarantee that participatory sphere institutions will be genuinely inclusive (Barnes, 2007; Cornwall and Coelho, 2007). Democratic spaces hold the potential of transformation; of enabling the development of more engaged citizenries, more efficient policies, and more responsive governments (Mansbridge, 1999; Fung, 2003; Gaventa, 2004). But they are also ‘spaces of power’ whose boundaries and dynamics are framed by those who create and integrate them (Cornwall, 2004). Within these spaces, inequalities in technical knowledge, communication skills, status and power may work to lead some, usually those already experiencing discrimination and exclusion in mainstream society, to silence themselves, or they may be instrumentalised by others, usually the members of well-off and powerful groups, to impede disadvantaged groups from entering participatory spaces or to consistently overshadow the promotion of their interests once they are in (Pozzoni, 2002; Cornwall and Coelho, 2007; Mahmud, 2007; Williams, 2007). These barriers undermine the inclusiveness of health participatory spaces, i.e. they limit the capacity of participatory institutions to reflect the diversity of actors and interests they are meant to involve and represent.

Studies concerned with the inclusiveness of the health participatory sphere usually distinguish between two types of inclusion: ‘formal’ and ‘substantive’ inclusion (Pozonni, 2002). The former refers to “the extent to which citizens are able and willing to enter deliberative arenas” (*ibid.*: 10). Substantive inclusion entails “the extent to which citizens are actually able to exert influence over decision-making processes in which they partake” (*ibid.*: 21). As noted earlier, both Brazil and the Netherlands have established legal frameworks for participation in health care governance. In what follows, we look into the participatory spaces created to enable citizen engagement in health care decision-making in those countries and draw attention to some of the user groups whose inclusion and effective participation in processes of health care governance is still challenged.

2.4.2 Citizen participation and inclusiveness: the case of Brazil

In Brazil, citizen participation in health governance is put into effect through two sorts of participatory spaces: health councils and health conferences. As we saw in section 2.4.1, the creation of these spaces was largely a result of the claims made by Brazil's national health reform movement (MRS) for the right of citizens to participate in the formulation, management and monitoring of health policy and programmes. The 1988 Constitution and the Basic Law of Health (1990a) determined the creation of a public health system (SUS) and formalised citizens' right to engage in its governance through health councils and conferences. Since then, participation has been promoted as a process aimed at devolving power over health care decision-making to the citizenry. This democratic approach to user participation has been enforced not just to give users a voice over policy-making and service provision, but also as a means to stamp out the clientelistic interests and the authoritarian political culture which continue to reign in many public offices across Brazil. Participatory institutions in Brazil are thus looked at as mechanisms devised to hold the state to account in fulfilling its responsibilities (Weyland, 1995; Cornwall and Shankland, 2008).

In what follows we introduce the main health participatory spaces in Brazil and discuss issues pertraining to their inclusiveness.

Brazilian health participatory spaces

Health conferences are periodic events organised at the municipal, state and federal levels, every two to four years. By law (Brasil, 1990b), the conferences must be composed by representatives of government, health service providers, health professionals and health care users, with half of the available seats reserved to the latter. Delegates of each of these segments are entrusted the task of making proposals for health policy, which are carried up from the municipal to the national level after deliberation and voting in conferences at each tier of government (Cortes, 2002; Cornwall and Shankland, 2008).

Health councils are regularised institutions mandated to approve health budgets and plans and monitor their implementation, as well as to hold to account the government in the execution of the resolutions passed in health conferences (Cornwall, 2007). Introduced in the late 1980s, they were rapidly established throughout the country, from local to federal levels. This was essentially possible because the transfer of funds from the Ministry of Health to municipal and state Secretariats of Health was made dependent on the creation of health councils (Cortes, 2002) and of their approval of health budgets and plans on a yearly basis. The fact that health councils have the right to veto such budgets and plans grants them considerable deliberation power (Coelho *et al.*, 2005).

Health councils abide by the same law regulating representation in health conferences: following a 'principle of parity', councils are to be constituted by 50 per cent of user representatives; the other half of the seats is distributed between representatives of health professionals (25%) and of governmental institutions and private service providers contracted to deliver public services (another 25%) (Brasil, 1990b). Aside from this requirement, health councils are free to define their internal regulations and to decide which organisations and associations from within each of the four groups mentioned are entitled to representation (Coelho *et al.*, 2005). This means, for example, that the civil society organisations from which user representatives are drawn vary from one council to the other.

Inclusion in health participatory spaces

Evidence on the formal inclusion of users in health councils appears to be mixed. Some studies indicate that groups which have been historically excluded from the policy making process and experience discrimination by mainstream society as a result of poverty, ethnicity or disability (i.e. poor dwellers, the black and indigenous populations, disabled people) continue to lack voice as well as the resources necessary to get organised and articulate their demands in health councils (Coelho *et al.*, 2005). Analyses of the socioeconomic profiles of councillors representing users show they have little in common with people from disadvantaged groups: the former are generally better paid and educated and share little of the latter's identity and experiences (Labra and Figueiredo, 2002; Gerschman, 2004). Other studies, however, show that participatory institutions do create opportunities for organisations promoting the interests of disadvantaged groups to acquire voice in policy making. Gurza Lavalle *et al.*, (2004), for example, found that rich and poor civil society organisations in São Paulo have similar propensities to participate. As they go on to argue, civil organisations' representation in participatory institutions is not dependent on their budget size or on whether they work with or for the poor but rather on their ties to traditional political actors (i.e. parties, unions, and the state) and on the design of the participatory spaces they seek to become part of. Those organisations which have stronger ties to agents of representative democracy and that seek access to democratic spaces with institutional designs favouring the selection of a diverse set of actors are more likely to gain representation. Furthermore, some health councils have adopted a sort of quota system which reserves seats to organisations representing the interests of traditionally excluded groups (e.g. people with disabilities, AIDS, etc.) (Coelho, 2004). This is likely to enable those groups to improve their access to the councils.

Where substantive inclusion is concerned the situation appears somewhat grimmer. Various studies suggest that once members from traditionally marginalised and under-represented groups make it into the participatory arena, several barriers work to undermine their influence in decision-making processes (Dal Poz and Pinheiro, 1998; Pozzoni, 2002; Coelho *et al.*, 2005). Studying the Municipal Health Council of São Paulo, Pozzoni (2002) found that although disadvantaged citizens are formally included in the council as civil society representatives their voices are seldom heard. This, however, is not explained by their lack of intervention but rather by a set of limitations which more powerful actors (particularly, government representatives) take advantage of to discredit civil actors' arguments as unintelligible and unproductive, or to simply ignore them. Poor communication skills, insufficient technical expertise, and lack of self-confidence all work against citizen representatives' attempts to gain respect, recognition and authority within the deliberative arena. They are also appropriated by better-off and educated government representatives to discard proposals which are not in line with their political agenda: classifying civil actors' contributions as "unstructured, unclear, disruptive and even irrelevant" they often succeed to silence their voices (*ibid.*: 71). This is especially the case when citizen representatives have a low socioeconomic status and show feelings of intimidation and shame in the presence of public administrators or health professionals who they regard as more knowledgeable, articulate and powerful. Such entrenched inequalities of power and knowledge, compromise civil actors' ability to act as a critical and influential party in the definition of health policy, programmes and budgets, undermining their effective inclusion in health governance (Dal Poz and Pinheiro, 1998; Pozzoni, 2002; Coelho *et al.*, 2005).

According to Coelho (2007), the differences found in regard to formal inclusion pointed out above can be explained by three interrelated factors which impact both on the democratic potential and on the inclusiveness of participatory institutions: civil society mobilisation, public authorities' commitment to the participatory project and institutional design. Where a broad spectrum of social movements and civil associations with a vested interest in participation in health policy exist; public officials show allegiance to the project of citizen participation; and institutional designs enable a transparent selection of councillors and address exclusionary practices in policy deliberation, disadvantaged groups are likely to be represented and to participate in policy-making. But where one or more of these conditions are absent, i.e. where social mobilisation is weak, bureaucrats resist power-sharing, or institutions are implemented with little attention to design features that facilitate conflict mediation and secure inclusive forms of representation, open or tacit domination of participatory arenas by powerful groups is prone to arise, rendering less privileged groups voiceless or even determining their exclusion (Coelho, 2007; Cornwall and Coelho, 2007).

Requirements for fully inclusive participation in health governance are not exhausted by measures aimed at guaranteeing the entry of a diversified set of actors in the participatory sphere. To exert political agency people need to recognise themselves as citizens (Cornwall and Coelho, 2007). In other words, to influence decision-making people need to be able to get hold of the resources and securities which enable them to act as agents, i.e. as "autonomous, purposive actors, capable of choice" (Lister, 1997: 36). Popular education, coaching in technical information, and training of competences for effective deliberation are key strategies through which such resource distribution can be effected among less privileged citizens (Mansbridge, 2003a; Cornwall and Coelho, 2007). In addition, it is also necessary to promote the creation of societal spaces outside the participatory sphere in which members of marginalised groups can develop a critical consciousness of dynamics of power and exclusion, identify and forge common interests, and build a politics of engagement (Fraser, 1992;

Mansbridge 2000; Von Lieres and Kahane, 2007). Engagement in such spaces and the acquisition of new skills, information and knowledge can grant citizens previously excluded from decision-making processes the chance to build the confidence, agency and capacity required to exert influence in health governance and to assure their substantive inclusion in participatory institutions.

2.4.3 Citizen participation and inclusiveness: the case of the Netherlands

In the Netherlands, there are many participatory spaces through which users and their representatives can participate in health care decision-making. These include national and regional advisory councils and committees, advisory conferences and meetings with the government, client councils in care institutions and insurant councils in health insurance companies (Nederland *et al.*, 2003). Although the legal framework which formalises their status did not start to develop until the 1980s, some of these institutions emerged in the early 1970s (e.g. client councils in psychiatric hospitals). This is because, similarly to what happened in Brazil, the inclusion of care users in the Dutch health participatory sphere was not only an initiative of the government but resulted also from the pressure exerted by user interest groups (and in particular, the mental health movement) to have a voice in health governance (Rijkschroeff, 1989; Oudenampsen, 1999). In what follows, we introduce the developments that led to the creation of health participatory spaces in the Netherlands.

The Netherlands has a long history of involving different interest groups in socio-economic policy-making (Trappenburg, 2005). This emanates from a centuries-old tradition of consensus democracy which evolved more recently toward a consensus neo-corporatist model of governance[33] (Kickert, 2003). Until the 1970s, however, health care policy-making was dominated by the government and well-organised interest groups including health care providers, insurance companies and professional groups. Health care users had no seat at the decision-making table (Blaauwbroek, 2002). This all changed as the democratization wave which hit France in the late 1960s reached the Netherlands and citizens started demanding a greater say on the issues which affect their lives. The fact that the government was interested in improving the effectiveness of health care and in reducing its costs led it to be particularly supportive of the (mental) health user movement's attempts to democratise health care which, among other things, entailed money-saving initiatives such as the replacement of regular care with self-help and user-led services and the abolishment of certain treatments (e.g. electroshock therapy) (Trappenburg, 2006).

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[33] The model of neo-corporatist democracy present in the Netherlands is characterized by the State's recognition of a restricted number of well-organised groups, which are entitled to deal directly with government over policy in almost every sector (i.e. education, housing, health etc.). Specific legislation determines at what stage of the decision-making process the government has to co-operate with which interest group (Kicker, 2003).

As we saw in Chapter 1, from the mid-nineteenth century onwards Dutch society experienced a strong compartmentalisation along denominational and ideological lines, or 'pillars'. These pillars carried out socio-cultural and political activities within their own confessional and ideological circles, having an influential role in politics and also in the creation and management of health and social services (e.g. psychiatric institutions). When measures and regulations concerning all these sub-groups came under discussion, their representatives met together to deliberate, reaching decisions through pragmatic compromise and consensus (Lijphart, 1969 cited by Kickert, 2003). According to Kickert (2003), pillarisation and the consensus democracy it reinforced worked against the institution of a 'rational central-actor' model of governance, i.e. top-down control and planning by government. When the Dutch pillars began to wane in the 1960s, a strong central state – at that time a novelty in the Netherlands[34] – started to develop, gaining in size and power until the 1970s. Its actions, first directed at the technical planning of infrastructure, soon became more oriented toward the expansion of the welfare state through the rational planning of policy sectors such as education, housing, and health. In just a matter of a few decades, the Netherlands had shifted to a top-down control model of governance which had little in common with its age-old tradition of consensus (*ibid.*).

Infused by the May 1968 spirit and the general opposition to authority which characterised it, Dutch citizens changed their typically docile and law-abiding attitude and started contesting top-down control and the power held by key figures of 'the establishment' (i.e. doctors, teachers, policeman, politicians, etc.). Their main claim centred on the democratisation of decision-making (Kickert, 2003; Trappenburg, 2006). Public policy and provision were no longer to be the exclusive domain of government and well-organised corporations accustomed to reach compromises 'under the table' (Trappenburg, 2006). All interest groups concerned were to participate in decision-making forums, have an equal voice in agenda-setting, and co-produce final resolutions (Kickert, 2003). A direct result of this standpoint was the mobilisation of various pressure groups, which launched concerted actions to attain greater influence. This was particularly visible in regard to mental health care. Mental care users and progressive professionals joined to fight against medical doctor's control over psychiatric treatment and their almost full power over the planning and financing of the mental health system. Their actions (which included the creation of client organisations and of a Journal – the *De Gekkenkrant*) served to develop a voice strong enough to challenge that authority and to grant users a sitting at the table with the direction boards of some Dutch psychiatric hospitals. The first client councils were created in these institutions (Haafkens *et al.*, 1986).

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[34] As Kicker (2003) notes 'the central state had for centuries been virtually non-existent [in the Netherlands], and since its origin in the early nineteenth century had remained relatively small' (*ibid.*: 122).

The replacement of the old pillars and corporations by pressure and interest groups made it seem as if the Netherlands were shifting into a pluralist democracy. As Kickert (2003) explains, this was indeed the case, but only for a short period of time:

> Consociationalism soon recovered. Deliberation, compromise and consensus again became the main characteristics of Dutch political culture. That is not to say that protest, demonstration, participation do not exist any more. Single issue protest and pressure groups and lobbying, the typical traits of pluralist democracy, have penetrated political life and become part of daily life. The consociational model has shifted in the direction of pluralism, but it still prevails (*ibid.*: 123).

In 1974 the government issued a memorandum – the *Structuurnota* – in which care users were recognised, for the first time, as a party to be involved in the democratisation of health care (Oudenampsen, 1999). However, this was also a period in which the Netherlands fell into a serious economic crisis (the 'oil crisis'). When attempts based on government planning failed to revive the economy, a new model of governance inspired by neo-liberalism and 'new public management' ideas came to the fore. Economy, efficiency and effectiveness became its ideals; managers became its shock troops. Many of the policies issued from the early 1980s onwards focused on reducing budget deficits and in downsizing the welfare state. Marketisation, performance audits, output controls and decentralisation of policy and management responsibilities became key strategies to accomplish this (Kickert, 2003).

In 1982 the Dutch government issued a provisional act aimed at reducing costs in health care and at improving its efficiency – the Health Care Services Act (*Wet Voorzieningen Gezondheidzorg,* WVG). The WVG determined the decentralisation of health care planning and implementation to the regional level. It also acknowledged client organisations as a consultative party, determining their involvement in health policy-making (Blaauwbroek, 2002). As a result, client organisations were granted representation in advisory councils to the government such as the National Council for Public Health and the Sickness Fund Council (Oudenampsen, 1999). Given the variety of organisations which existed at the time and the lack of hub organisations able to coordinate and articulate the diversity of interests they sought to promote, the government requested client organisations to regroup in regional platforms (RP/CPs). These platforms were responsible for delegating user representatives to meetings with local governments in which issues such as the implementation of community-based mental health services were being discussed (Schnabel, 1998; Oudenampsen, 1999; Trappenburg, 2006). Although the WVG law was never formalised (Blaauwbroek, 2002), the emphasis it laid on users' participation in policy-making did not fade. In the decades that followed, several measures were undertaken to foster the involvement of users not only in consultative bodies but also in health and social care institutions.

By the late 1980s, as we saw in the previous sub-section, the influence of a more neo-liberal style of governance in health policy had become quite strong. After the report issued by the Dekker Committee in 1987, the government opted for a system of regulated competition: providers, insurers and users were to take the role of 'market agents' and monitor each other in the planning, delivery and financing of good quality health care 'products'. Emphasis on the role of users as consumers was particularly salient at that time and participation was mostly seen in consumerist terms. Although the consumerist approach to participation has never really left the scene (marking its presence once again in the 2001 Choosing with Care memorandum), the 1990s saw the rise of a more democratic stance on user participation.

After the disastrously low turnout at the 1990 local elections, local politicians initiated a 'search for the lost citizen' (Kickert, 2003: 126). Among the actions they devised was the creation of new participatory mechanisms such as citizen polls and citizen panels. The main goal was to bring citizens closer to local government by enabling them to have a more active role in local decision-making (*ibid.*). This move toward participatory governance was also observed in relation to health care. As we saw earlier, in the early 1990s the government passed several laws aimed at strengthening the rights of users and at increasing their participation in treatment decision-making (i.e. the WGBO, BOPZ, WKCZ laws). In 1996, the WMCZ law was issued, determining users' right to participate in health care institutions' policy through client councils. In that same year, the government approved the creation of a Patient Fund to finance client organisations.

The Patient Fund was created to enable client organisations to participate in advisory councils and committees at the local, regional and national level, which required them to have permanent staff and to professionalise (Oudenampsen, 1999). This measure, however, appears to have not been applied simply with the intent of democratising health care governance but also to facilitate the transfer of responsibility for health care monitoring from the government to client organisations. This goal had been advanced as part of the implementation of a system of regulated competition (see the previous sub-section). The Quality Law (Ministerie van VWS, 1996b), also enacted in 1996, reflected the aspiration to carry this goal through, setting the terms according to which it was to be realised. Care providers were requested to devise a quality evaluation system and to deliver annual quality reports; these reports had to be submitted to client organisations and health insurance companies, who would then evaluate the efforts made by providers to improve the quality of the services delivered (Trappenburg, 2006). The Quality Law thus formalised the implementation of regulated competition and recognised client organisations as the so-called 'third party' in health care governance. Together with the other two main interest groups, i.e. health care providers and insurers, user representatives were to have a voice in health care planning and quality control (Oudenampsen, 1999). The Patient Fund was set up to strengthen client organisations' access to the resources necessary to participate in health governance. At the same time, it fostered the institutionalisation of the majority of client organisations which comprise the Dutch health care user movement. It is essentially these organisations which the government expects to see representing citizens in the health policy-making arena.

This ‘high-level’ form of participation was complemented by a more direct and grassroots form of engagement, i.e. participation in client councils (WMCZ law). Through these participatory institutions users themselves can have a say and exert influence over the policy adopted by the health institutions from which they received care. As we mentioned earlier, client councils have existed in the Netherlands since the 1970s but were only regulated in 1996. Turning this type of participation into a right meant not only that all health and social care services had to enable the creation of a client council but also that service directors and managers had to start taking users’ proposals into account. This had the potential to generate a shift in the *status quo* between these two parties. In accordance with the Dutch *overlegcultuur* or ‘discussion culture’, deliberation partners are expected to grant each other the opportunity to present proposals, debate on their pros and cons, and reach a decision based on compromise. This means that users must be heard, even if their perspectives differ substantially from that of service directors and managers. Such an exercise can be very empowering and lead to considerable change in the relationship between users and providers.

In this way, the development of participatory institutions leads inevitably to questions of power redistribution. In these institutions different interest groups come together to discuss and decide over future health policy. Such decisions are usually made on the basis of compromise and consensus. However, to devolve power from the groups which used to have it to the ‘have-nots’ is an inherently difficult process. Recognising the weaker position of user representatives in comparison to care providers, insurers and government officials, the Dutch government issued a memorandum in 2001 – Choose with Care – proposing measures to increase the bargaining power of client organisations (Ministerie van VWS, 2001). In 2007, the Social Support Act (*Wet Maatschappelijke Ondersteuning*, WMO) was passed (Ministerie van VWS, 2007). Among other measures, the WMO law sanctioned the participation of citizens in the planning, implementation and evaluation of social support and welfare policy. Such participation is to take place at the municipal level. In line with previous decentralization directives, municipalities were granted extended powers and can now make their own social support policies based on local needs and demands. However, the exercise of those extended powers was made dependant on two requirements: municipalities must both enable the participation of citizen representatives (e.g. client organizations) in local policy-making and create the mechanisms through which citizens can hold them to account (*ibid.*). In what follows we discuss the extent to which care users in the Netherlands are included in the participatory sphere. Before doing that we describe briefly two participatory institutions which can help us shed light on this issue: advisory conferences and meetings and client councils[35].

Dutch health participatory spaces

Advisory conferences and meetings are temporary consultative events which can be held at the local, regional and national level. They are usually summoned when plans for new policy are in the making. At the national level, for example, before a bill is submitted for voting to the First Chamber for approval, the Ministry sponsoring it is responsible for consulting with experts, other ministries and interest groups. It is at this point that advisory conferences and meetings are held, affording interest groups the opportunity to express their ideas and concerns to public officials. Generally, there is no limit to the number of citizen representative organisations which can seek to exert influence through these participatory forums. However, unlike the conferences in Brazil, the proposals made by citizen representatives are not submitted to voting, and therefore not necessarily binding. They are looked upon as advice deserving due consideration.

Client councils are regularised participatory spaces designed to enable citizens to have a voice in the policy of care institutions. Client councils can advise on various issues such as service reorganisation, human resources policy, yearly budget, culturally-competent practices, food arrangements, complaint procedures, security policy, care quality, etc. They can also make proposals for change (e.g. request the adoption of a broader range of psychotherapeutic treatment methods). Council members meet periodically with the board of directors of their institution, which is expected to adopt the advice given by councillors. When there is reason to believe that advice has been inappropriately evaluated and refused, a national mediation committee can be called to intervene (Blaauwbroek, 2002).

All care institutions in the Netherlands are required by law (Ministerie van VWS, 1996) to facilitate the creation, funding and maintenance of client councils. Since current legislation does not give specific directives on the composition of client councils, each council is free to decide on the number of members it wishes to include and on the ratio between the different groups who are usually represented (i.e. users, former users, family members and/or carers). Many councils are assisted by an *ondersteuner* or facilitator who, among other things, is responsible for assuring the continuation of the council[36] (Van Haaster, 2001). This is especially relevant in

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[35] Citizen participation in policy-making under the WMO Act takes place through advisory boards. Because the WMO is a recent law there is little evaluation of how citizens influence decision-making through such boards. We therefore examine here other kinds of participatory institutions which have been studied in greater detail.

[36] Client council facilitators are usually employed by an entity other than the service where the council operates. Aside from assuring the continuity of the council, they also organise capacity building initiatives, signal clients' needs and wishes and provide support to council members when necessary (van Haaster, 2001).

councils composed by people who experience psychosocial problems and chronic illnesses.

Inclusion in health participatory spaces

Evidence on the formal inclusion of citizens in client councils in the health care sector shows a rather narrow picture where the diversity of represented actors is concerned: client councils are constituted mostly by white people with a low socioeconomic status (De Savornin Lohman *et al.*, 2000; Van Gelder *et al.*, 2000). Although children, youngsters, and people with addictions are poorly engaged in these participatory institutions, migrants and ethnic minorities (MEMs) are without a doubt the most under-represented groups (*ibid.*; Nederland and Steketee, 2004). In a report issued in 2000, De Savornin Lohman and colleagues concluded that "the participation of allochtonous is practically nil"[37] (2000: 65; our translation). This seems to be changing, albeit very slowly. Various barriers continue to hinder MEMs' participation in client councils. Health care institutions claim to have little time and financial resources to reach out, motivate and recruit them for the councils; client organisations have few knowledge and experience with MEMs and many argue their tasks as the 'third party' leave them little time to engage in the promotion of their interests; and MEMs experience language barriers, are not sufficiently acquainted with client organisations, and give priority to family and employment over volunteer work (Nederland and Steketee, 2004).

It is difficult to say which citizens are formally included in other participatory institutions such as advisory conferences and meetings. However, considering participation in those institutions is usually carried out by professionalised members of client organisations (which are generally staffed by Dutch natives) and that the majority of these organisations has little or no experience in advocating for MEMs interests (De Graaf and Eitjes, 2004), it seems reasonable to assume that the situation on this front differs little from the one just described[38], i.e. MEMs are most likely insufficiently represented in advisory meetings with national and local government. This is not to say, however, that users at large lack representation in those spaces. On the contrary, client organisations are highly solicited by public officials to engage in health decision-making processes. Yet such an excess of requests can work against the formal inclusion of client organisations in the participatory arena, especially if they have limited resources and staff. As Van de Bovenkamp *et al.* (2010) show, there is

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[37] The term allochtonous is usually employed in the Netherlands to refer to people who were born in or whose parents came from non-Western countries.

[38] Interestingly, if we were to find a difference it would probably be in the socioeconomic status of professionalised representatives. Unlike the majority of the members of client organisations (i.e. their volunteer members), professionalised representatives are likely to be middle-class, well-educated people. This is probably most salient in the case of client organisations which promote the interests and rights of people affected by psychosocial problems.

indeed overload: many organisations cannot deal with all current demand. A potential solution for this problem would be for client organisations to agree on a common agenda and divide efforts to push it forward across the various institutions of the participatory sphere. Yet, in practice, it is not always easy for client organisations to set their differences apart and collaborate (*ibid.*).

Evidence on the substantive inclusion of citizens in client councils appears to be mixed. While some studies indicate client councils believe they exert effective influence in the policy of their health care institutions (LSR, 2007), other studies show that several barriers undermine their ability to have a real voice in policy-making (Van Gelder *et al.*, 2000; Hoogerwerf *et al.*, 2004; Trappenburg, 2008; Van der Kraan *et al.*, 2008). It is difficult to advance a clear-cut explanation for these differences. However, Van Gelder *et al.* (2000) found that client councils make little use of their authority, avoid giving confrontational advice and hardly ever resort to the mediation committee because they do not want to put their relationship with the board of directors at jeopardy. Indeed, more often than not it is the board of directors which decides the topics on which councils should provide advice (Hoogwerf *et al.*, 2004). The fact that the health care system has been undergoing considerable change in the past decade has made complex issues such as mergers between institutions, service re-allocation, yearly budgets and plans top priorities. In addition, many institutions have realized that client councils can work as a feedback mechanism on users' needs and demands. Councils are thus often asked to conduct satisfaction surveys and to give advice on intricate issues. As a result, many councils get drowned in paperwork, failing to include in the agenda other more mundane subjects such as diet, hygiene and leisure activities which are highly relevant for users whose lifeworld has come to be largely centered on the satisfaction of those needs (Trappenburg, 2008). The inability to discuss subjects that matter increases the danger of client councils becoming detached from grassroots users and the invaluable experiential knowledge they can provide. In addition, the lack of technical expertise over intricate issues experienced by some councils (*ibid.*) jeopardises their potential to work as real democratising mechanisms, while perhaps contributing at the same time to create the false impression that they do.

Where the substantive inclusion of citizen representatives in advisory conferences and meetings is concerned the situation seems to be clearer, albeit not entirely positive. Various studies suggest that opportunities for participation in those participatory institutions abound. However, this does not necessarily mean that client organisations are able to influence decision-making through those forums (Nederland and Duyvendak, 2004; Potting, 2009; Van de Bovenkamp *et al.*, 2010). Studying the drafting and endorsement of the WMO law, Potting (2009) found that although client organisations were widely involved in advisory meetings and round-table discussions with the Ministry of Health, Welfare and Sport, their influence on the first draft of the law was marginal. Collective action and lobbying proved to be more effective strategies to achieve change. Indeed, amendments made to that first draft resulted essentially from intense mobilisation and lobbying outside participatory forums: public actions, protest meetings, press releases, lobbying by parliamentarians, and (perhaps more importantly) a collective manifesto[39] were the key strategies through which the user movement succeeded to have some of its demands included in the law.

In another study about the influence of client organisations over decision-making, Bijlhout (2008) found that some organisations are not willing to adopt confrontational strategies (e.g. leaving the round-table, demonstrating, petitioning, etc.). This is particularly the case with umbrella organisations concerned not to put their reputation as responsible and dependable partners in formal decision-making at risk. The expectation is that staying engaged in advisory meetings with public officials will lead to better results than acting outside the participatory sphere. Confrontational strategies are thus delegated to smaller categorical and general client organisations, which also seek to exert influence from within democratic spaces. However, it is questionable whether those smaller organisations can gather all the resources necessary to wield substantive influence. Participation in policy-making demands a considerable amount of time, perseverance, knowledge, technical expertise, and communication and negotiation skills. This has led many organisations to become increasingly professionalised and to concentrate their efforts on institutionalised participation (Nederland and Duyvendak, 2004; Bijlhout, 2008; Van de Bovenkamp *et al.*, 2008).

Professionalisation programmes are considered crucial if volunteer members of client organisations are to acquire the knowledge and skills necessary to exercise influence in the participatory arena (Van de Bovenkamp *et al.*, 2010). They can also have a highly empowering effect over volunteers. Yet, current demand for user participation in decision-making is so intense that the professionalisation process is increasingly becoming a 'search for the right volunteers', i.e. people who already have many of the necessary capacities to participate (*ibid.*: 81). Recruiting the most capable adds weight to already pressing questions over lack of representativeness: are professionalised volunteers really representative of the ordinary care user? This concern is further intensified by the fact that many client organisations employ professional staff to both safeguard their continuity and advocate for the interests of the constituencies they seek to represent. In a system of governance in which experiential knowledge is the main source of legitimation for the inclusion of client organisations, this is a serious concern. In addition, hiring of professional staff is generally only possible for organisations which receive subsidies from the government (*ibid.*). The more they rely on professional staff, the more likely they are to become dependant on state sponsorship, and to circumscribe their activities to institutionalised participation.

As Van Bovenkamp *et al.* (2010) show, professionalisation may be necessary but it is no guarantee of increased influence. Many barriers continue to hinder the ability of

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[39] The manifesto included 10 requirements which the user movement considered fundamental in order to support the WMO law. The manifesto was signed by 18 organisations. Together they represented almost a third of the Dutch population, i.e. about five million people (Potting, 2009).

client organisations to influence decision-making once they step into participatory institutions. Lack of bargaining power is perhaps the most salient barrier: even if client organisations train their volunteers in the art of deliberation and resort to professional staff to articulate their standpoints, they must still prove themselves worth listening to. Evidence-based knowledge (or rather the knowledge brought in to the discussion table by state and care provider representatives) is still more valued than experiential knowledge. This places user representatives immediately in a position of disadvantage: before acquiring an equal voice in the participatory arena, they must first strive for legitimacy and recognition. This is all the more complicated when in the event of a strong argument user representatives' voice can easily be silenced by more powerful actors with the counter-argument that it is not representative of the common citizen.

For the Dutch neo-corporatist model of governance to work effectively some degree of power symmetry between the engaged actors is required (Van Bovenkamp *et al.*, 2010). In other words, for genuine consensus to be reached an 'ideal speech situation' must be created in which the voices of all those present can be equally raised and heard and rational deliberation can be achieved (Habermas, 1991). However, participatory spaces "are always already permeated with the power effects of difference" (Cornwall, 2004: 83), i.e. engaged actors "are never neutrally positioned players" (*ibid.*: 84). The ways they are constructed by others, and perceive themselves to be constructed, influence perceptions about what they are able to contribute or are entitled to decide (*ibid.*). If the input and knowledge of user representatives in Dutch participatory institutions are perceived to be unrepresentative and of limited value, the risk is high they will be excluded from decision-making.

Such exclusion, however, is unlikely to occur in a blatant way. The Dutch government has openly stated its support for citizen participation in health governance (Ministerie van VWS, 2001) and other 'players' (e.g. care providers and insurers) are unlikely to openly oppose that. Here, another risk emerges: client organisations might be put to instrumental use, i.e. they may be given the opportunity to participate while being clear for other more powerful parties that chances are small they will actually exert influence (Van de Bovenkamp *et al.*, 2010). This form of 'token participation' (Arnstein, 1969) enables powerful parties to claim decisions were made with the support of users, while avoiding challenges to the *status quo*. It also carries the risk of transforming participatory institutions into "pseudo-democratic instruments through which authorities legitimize already-taken policy decisions" (Cornwall, 2004: 80). One way by which client organisations can counter this problem is by seeking to shift power relations from within participatory institutions. This might entail further professionalisation and an increased investment on institutionalised participation. However, if client organisations fail to complement this with other strategies (e.g. lobbying, demonstrating, media, empowerment activities, etc.), they run the risk of losing their countervailing power and autonomy. This concern has been shared by Nederland and Duyvendak (2004) who alert to the need for client organisations to stay close to their grassroots members, invest in their empowerment and keep a perspective of their own, to avoid the far-reaching institutionalization which has led to the assimilation of other social movements (e.g. the Dutch feminist movement). Blaauwbroek (2002) adds that in order for the user movement to perform its role as the 'third party' it must seek greater visibility through public action, increase its financial independence through member contributions, and stimulate more collaboration between its numerous organisations.

Overall, it seems clear that for client organisations to stand a chance of being substantively included in participatory institutions they need to increase their bargaining power through actions both within and outside the participatory sphere. As we noted earlier, in 2001 the Dutch government reasserted its commitment to continue supporting client organisations in acquiring greater bargaining power through the funding of their activities (see memorandum Choose with Care; Ministerie van VWS, 2001). Such funding, however, was to be made conditional on client organisations' ability to give account of their services, products and functions and to represent the plurality of voices of care users in the Netherlands. In the memorandum, a special reference was made to the case of ethnic minority users. This group was particularly under-represented by client organisations and the government explicitly stated the need to improve their position. Regional platforms, the Patient Fund Foundation and the Dutch care research organisation ZorgOnderzoek Nederland (ZonMw) were to combine efforts in bringing the needs and interests of MEMs out into the open (*ibid.*). Yet, these intentions belong to a time in which 'interculturalisation', i.e. the movement aimed at improving the access and quality of care for MEMs, was in its prime[40]. Two years after a right-wing government came into power in 2002, the Ministry of Health dismissed itself from the responsibility of promoting the interculturalistion of care arguing that this was a task to be performed by the market agents ((RVZ, 2004). As we saw earlier, client organisations appear to have made little progress on this front.

Resorting once again to the criteria proposed by Coelho (2007) to explain the inclusiveness of participatory institutions (i.e. civil society mobilisation, authorities' commitment to citizen participation and institutional design), we can conclude that several problems continue to limit the full inclusion of citizens in the Dutch participatory sphere. Where civil mobilisation is concerned, we see that although there are many client organisations determined to participate, they are still not fully representative of the diversity of care users in the Netherlands. Public authorities are favourable to the participatory project but their efforts to promote substantive inclusion have been insufficient. This is especially the case where less vocal groups are concerned. Finally, the institutional design is not ideal: given the power inequalities which appear to permeate some of the Dutch participatory institutions, consensual decision-making may actually be leading to a situation in which the interests of care users are compromised time and again.

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[40] We discuss the interculturalisation movement in greater detail in Chapter 5.

2.5 Conclusion

This chapter looked into the various meanings and practices of participation. Over the past four decades, participation was subject to multiple re-interpretations by different actors whose interests in, approaches to and gains from the practice of participation vary widely. These continuous reconfigurations of concept and praxis render evident the dynamic, highly context-bound and political character of participation. They are also at the root of the various spaces created to enable people to have a voice in the decisions which affect their lives.

Meanings of participation – an overview

'Popular participation' gained prominence during the 1970s. Emerging in a period marked by considerable grassroots mobilisation and struggle for social transformation, participation came to signify a process through which disenfranchised and disadvantaged people asserted demands for inclusion and sought to take the power necessary to change the oppressive structures reinforcing their poverty and marginalisation (Gaventa, 2006a). By the mid-1980s, however, much of the meaning of participation as the transfer of power and control to the have-nots had been lost. 'Community participation' was appropriated by proponents of neo-liberalism who promoted it as a means to reduce project costs and increase efficiency and effectiveness through beneficiaries' contributions to development programmes and public services. Numerous user committees and self-help groups were created to bolster the participation of 'communities' in service delivery. But empowerment and capacity building were neglected; self-reliance and ownership – the core features of previous approaches to participation – made way for individualism and self-provisioning; and popular power over decision-making was removed from the equation (Paul, 1987; Cornwall, 2006). Participation had been, to a large extent, mainstreamed and depoliticised.

With the consumer ethos which came to reign in the 1990s, emphasis on the individual reached its prime: beneficiaries and communities were recast as consumers, i.e. 'users and choosers' (Gaventa and Cornwall, 2001) of services, who were to supply the market with information about their needs and preferences. In return, 'consumer participation' held the promise of greater choice and voice. Focus groups, client panels, and user satisfaction surveys boomed. Consumers were stimulated to 'vote with their feet'. However, their voices waned. The multiple participatory mechanisms devised to elicit consumer intelligence and promote choice were simply not enough to effect the redistribution of power required for people to exert real influence.

Alongside approaches which mainstreamed and individualised participation, there was also a stream of alternative thinkers and practitioners who continued to formulate countervailing discourses and practices of participation (see Fals-Borda and Rahman, 1991). By the late 1990s, notions such as 'empowerment', 'basic rights', 'citizenship' and 'governance' were once again being coupled with participation. 'Citizen participation' epitomised the efforts to restore to participation its political nature and transformative potential. Fuelled by organised groups' concerted demands for inclusion and accountability and the need to counter obvious democratic deficits, governments in both the North and South opened formerly closed-off decision-making processes to the public. This turn to participatory governance fostered the creation of 'new democratic spaces' (Cornwall and Coelho, 2004; 2007). Within these spaces more direct forms of state-citizen interaction emerged and the understanding of citizenship as practice (rather than just an assortment of rights bestowed by the state) was consolidated (Gaventa, 2004a). The recognition of 'citizenship participation' (Gaventa and Valderrama, 1999) as a key element to deepen democracies across the world produced a shift in the role conferred to citizens, who were repositioned as 'makers and shapers' of social policies and provisioning (Barnes, 1999; Cornwall and Gaventa, 2001). As spaces for citizen participation widen, people are increasingly being perceived and perceive themselves as agents (Lister, 1997) who are able to assert their rights and hold to account their governments. Seen from this perspective, participation turns into a basic democratic right through which other rights can be gained and realised and the responsibilities of citizenship exercised (Cornwall, 2000). In other words, participation becomes the 'right to claim rights' (Gaventa, 2002).

The following table offers an overview of shifts in participation in the last four decades.

Table 1 *Shifts in participation*

	Participation from below	Community participation	Consumer participation	Citizen participation
Period	1960s/ 1970s	1980s	late 1980s/ 1990s	late 1990s/ 2000s
Who	Grassroots people	Communities Beneficiaries	Consumers	Citizens
What	Transformation	Opportunities	Means	Rights
In what	Political struggles	Projects	Services	Policies
How	Social arena	User committees Self-help groups	Client panels Satisfaction surveys	Advisory meetings Citizen councils
Type	Collective action	Contributions	Consultation	Decision-making Accountability
Level	Macro	Micro	Meso	Macro

Adapted from Gaventa and Valderrama (1999).

Current arguments for participation

As we have seen, discourses of participation have been influenced by grassroots collective action and shifting models of governance and development which are largely determined by prevailing ideologies about the relationship between citizens and state.

According to Cornwall (2008a), present claims for citizen participation in processes of governance are formulated along three distinct lines of argument:

1. Participation is a basic right

Advocates of participatory democracy argue that democratic states have the duty to engage citizens in collective decision-making. Citizen engagement in governance fosters a more vigorous conception of rights and responsibilities of citizenship; it enables citizens to identify the services they need and want, and to have a voice in making those services better suited to their needs; "participation in governance helps build a polity of and for the people" (*ibid.*: 20). In this view, participation is a basic right, a starting point from which to claim and assert other rights, exert the responsibilities of citizenship and hold the state to account.

2. Participation makes better citizens

Participation in governance can foster social transformation. It can help to reduce feelings of alienation and marginalisation among disadvantaged and excluded citizens by enhancing their access to spaces where decisions which have a bearing on their lives are made. When governments show transparency and accountability to their citizens, make them feel their views matter and engage them on the co-production of policy and services an opportunity rises for the achievement of a sense of belonging and entitlement which is crucial for an active citizenship (*ibid.*). Participation enables citizens to act as agents, i.e. as autonomous and purposive actors; it enables people to have greater control over their lives. By participating in the governance of their own affairs, citizens increase their understanding of the issues which concern them, gain awareness of their interests and how they relate to the interests of others, improve their abilities to deliberate and negotiate, realise the interdependency of individuals in society, and become more tolerant toward others while being better able to assert their values and individuality (Pateman, 1970; Richardson, 1983 Barber, 1984; Mansbridge, 1999). Participation can contribute to create "publics that are responsive and responsible" (Cornwall, 2008a: 21).

3. Participation enhances efficiency

Participation can improve the efficiency of service delivery. Service providers – being that the state, the market or the third sector – can benefit from learning about people's needs and preferences. By knowing what consumers need and want, they can match their supply of services to demand and allocate resources more effectively. Seen from this perspective, participation becomes an extension of market research; a way to elicit consumer intelligence and to enlist citizens as critical consumers who, through the sum of their choices, contribute to make services more responsive.

Another dimension of this argument concerns the direct involvement of the pubic in the provision of services. Having people contribute their time and knowledge to design and provide services can make those services more fine-tuned to users' needs and more affordable. But it can also become a way of "shunting the burden of the management and delivery of services from paid state officials to (…) unpaid volunteers" (*ibid.*: 21).

The arguments just outlined rest on two rather distinct perspectives concerning participation. The first two are clearly influenced by the democratic approach, which views participation as a process entailing the redistribution of power and control over decision-making as well as an end in itself. The third argument has an evident consumerist tone to it, emphasising participation as a means to reach other ends (Beresford and Croft, 1993). As Cornwall (2008a) notes, albeit somewhat dissonant, these arguments are not mutually exclusive. Often, elements of all three of them permeate the definition of participation held by a single actor. It is also not uncommon for these arguments to co-exist in directives formulated according to very different political agendas. Even if those at the left tend to privilege participation as voice, and those at the right emphasise its potential to enhance choice, participation has come to appeal to widely different ideologies (*ibid.*). It is because of this 'trans-ideological character' (Fox, 2007) that participation has been subjected to so many shifts in meaning and practice.

On the practice of participation and inclusion

The participatory sphere is broadening. Over the past two decades many new democratic spaces were created in emerging and mature democracies around the world. These spaces hold the potential for transformation: they can enable more active citizenries, more responsive governments and more effective policies and services (Mansbridge, 1999; Fung, 2003; Gaventa, 2004). However, as examples from citizen participation in practice attest, participatory institutions, and the legal and technical apparatuses designed to implement them, are not sufficient to guarantee the inclusion of all citizens in governance. In Brazil, disenfranchised groups with a tradition of exclusion from governance processes continue to be under-represented in many health councils. This is particularly the case of poor and ethnic minority people (Coelho *et al.*, 2005). In the Netherlands, various groups experience limited formal inclusion in health participatory fora (e.g. children, youngsters, people with addictions, etc.). Migrants and ethnic minorities appear as the least represented group in advisory meetings and client councils (De Savornin Lohman *et al.*, 2000; Nederland and Steketee, 2004).

Where substantive inclusion is concerned, various barriers continue to prevent civil society representatives from exerting effective influence once they make it into the participatory arena. Representatives of marginalised groups in Brazilian participatory institutions often see their voices being discredited, ignored and even silenced by public officials. Marked inequalities in technical expertise, communication skills, self-esteem and power are taken advantaged of by the latter to limit the influence of disadvantaged groups (Pozzoni, 2002; Coelho *et al.*, 2005). In the Netherlands, opportunities and invitations for public participation in health decision-making processes abound. Yet, members of client councils are often too overloaded with paperwork to push forward their own agendas and realise their authority. There is also talk of overload and limited bargaining power among civil society organisations representing care users in advisory meetings (Potting, 2009; Van de Bovenkamp *et al.*, 2010). An emphasis on 'evidence-based' knowledge continues to overshadow the value of experiential knowledge and with it the recognition of a legitimate and influential user voice. Seeking to gain recognition and power, many organisations have opted for professionalising and intensifying their activities in participatory institutions. Professionalisation and institutionalisation can enhance their ability to negotiate with government on more equal grounds. But they can also put at jeopardy the potential of client organisations to work as empowering and democratising mechanisms, by depleting the energy and resources necessary to stay in touch with grassroots users and to frame their own struggles outside the participatory sphere (Nederland and Duyvendak, 2004). In the long run, this can pose a challenge to the representativeness of their views and compromise their countervailing power and autonomy.

To enhance the inclusiveness and transformation potential of participatory institutions a set of requirements needs to be met. Clear and well-rounded design principles are crucial to ensure transparency in selection procedures and equitable citizen representation, to determine what people participate in, and to facilitate conflict mediation. Without a robust institutional design, open or tacit domination of participatory arenas by powerful groups is likely to arise, rendering disadvantaged groups voiceless or even furthering their exclusion.

A strong, inclusive and active civil society is also of vital importance if participation is to extend to powerful and disenfranchised citizens alike, and if the latter are to use democratic spaces to gain recognition and influence. Grassroots mobilisation is imperative to cast light on invisible or forgotten social problems and to equip the people affected by those problems with the tools necessary to solve them. This includes the ability to get organised and receive information about how and where to press demands for change.

Simply entering democratic spaces, however, is not enough. The commitment and responsiveness of public officials to the participatory project is key to ensure their voices are heard (Cornwall and Coelho, 2007). Furthermore, to influence decision-making people need to recognise themselves as agents, i.e. autonomous and purposive actors who are informed, confident and capable of devising alternatives and promoting change (Lister, 1997). This calls upon access to competency-based education and training through which they can gather the knowledge, technical expertise and skills necessary to identify their concerns, articulate their views, and negotiate their demands in the deliberative arena (Mansbridge, 2003a; Cornwall and Coelho, 2007). People with a history of exclusion from governance processes can benefit in addition from the creation of 'spaces of their own' (Fraser, 1992). Situated outside the participatory sphere, these societal spaces offer a middle-ground between a marginalising mainstream society and a distant government from which to start recognising injustice, develop a critical consciousness of power dynamics and exclusion, formulate common interests, devise strategies for action, and build a politics of engagement (Mansbridge, 2000; Von Lieres and Kahane, 2007).

The creation of societal spaces is especially relevant in countries such as the Netherlands. Fostering both a democratic and consumerist approach to participation, with a clear intensification of the latter in the past decade, the Netherlands hosts a plethora of participatory institutions through which the democratisation of health governance can be realised. However, as we have seen, many barriers continue to undermine the formal and substantive inclusion of citizens in the Dutch participatory sphere. Consumer discourse tends to depict the health care consumer as an autonomous, sovereign individual who acts as an economically and socially self-interested agent. Implicit here is the assumption that people are equally well positioned and motivated to participate should they be presented the opportunity to do so. Reality tells otherwise. Some people are much better placed than others to state their needs and assert their rights: unorganised, unresourceful, powerless individuals are unlikely to benefit from genuine inclusive participation. Their absence in the participatory arena is also likely to remain untackled. Both health care services and client organisations claim to have too limited resources to invest in amplifying the diversity of users engaged in their participatory activities. Unless issues of representation and substantive inclusion begin to take centre stage in participation policy and disenfranchised groups find spaces from which to realise their own interests and attain a sense of legitimate voice and action, this situation is likely to go unchallenged.

The challenge of engaging a wide range of people in participatory institutions is not confined to countries where a consumerist approach to participation prevails. In Brazil, where citizen participation emerged with a sound democratic basis, a long tradition of popular education and critical consciousness raising exists, and hindrances to participation are widely debated, much remains to be done to guarantee the full inclusion of citizens from all walks of life. Again, spaces outside the participatory sphere can contribute to enhance people's confidence, capacity and agency to circumvent the barriers which impede them from participating in the governance of their own affairs.

In the following chapter we present the theoretical framework which will be used to assess people's motivations for and experienced barriers to participation.

3. Enablers and inhibitors of participation

In the previous chapter we addressed the ways in which shifting notions of participation have influenced the development of participatory spaces, in particular their inclusiveness. In this chapter, we elaborate the concepts and theoretical framework that will be used to discuss the enablers and inhibitors of participation by mental health care users in the Netherlands and Brazil. We also review the literature concerned with people's motivations to participate and the factors which undermine their participation.

Political encouragement and opportunities for citizen engagement in decision-making over health and social care policy and delivery increased considerably in various democratic countries across the globe since the 1990s (Barnes, 1999; Beresford, 2001; Cornwall and Coelho, 2007; Van de Bovenkamp *et al.*, 2008). This is part of a wider trend: as we saw in Chapter 2, 'democratic deficits', concern with the responsiveness of public services, and demands by ever more complex and heterogeneous citizenries for inclusion and democratization have impelled governments in both the North and South to move toward more participatory forms of governance. Citizen participation is seen as having a far-reaching potential to help deal with these problems and get democracy 'back on its feet'. Participation can empower citizens to become more skilled, confident and active; it can improve the legitimacy of decision-making and increase the efficiency of policy and service delivery; and it can foster public accountability and political renewal (Brownlea, 1987; Zakus and Lysack, 1998; Mansbridge, 1999; Barnes *et al.*, 2007).

Perhaps because of all the promises participation holds, it has become common to assume that people want to be involved and that achieving fully inclusive participation is only a matter of "getting the mechanisms and methodologies right" (Cornwall, 2008b: 279). In practice, however, getting people to participate is still a perennial problem (Simmons and Birchall, 2005) and the power of participation to foster social transformation and more inclusive democracies can be easily undermined by the problem of achieving representation from all social groups. If participation is in principle a 'good thing', why do so few people do it (Clary and Snyder, 2002)? In other words, why is it so difficult to achieve a truly plural citizen voice?

These questions can be addressed with reference to three general problems which hinder the realisation of fully inclusive participatory processes: unawareness, self-exclusion and exclusionary dynamics. The first two have a negative impact on the formal inclusion of citizens, undermining their ability or willingness to enter participatory spaces. The third problem hampers citizens' substantive inclusion by limiting their capacity to exert influence in the participatory arena.

- Unawareness: people are not informed of opportunities to participate and they remain inactive (Lowndes *et al.*, 2001; Clary and Snyder, 2002; Simmons and Birchall, 2005);
- Self-exclusion: people are aware of participation initiatives and choose not to participate (Mansbridge, 2003b; Cornwall, 2008b);
- Exclusionary dynamics: people decide to take part in participatory initiatives but they drop out because they run up against open or tacit adverse attitudes and practices, or because the costs of participation do not outweigh the benefits (Pozonni, 2002).

These barriers pose a serious challenge to the promotion of participatory initiatives which are both representative and transformative. Understanding why people participate and what inhibits their engagement is essential if future efforts to involve citizens in participatory processes are to result in more inclusive and empowering experiences.

Empirical studies of users' motivations for participation in mental health care services and projects in the Netherlands and Brazil, and the barriers they experience, are still scarce. In addition, policy-makers and user movement members in those countries appear to lack the know-how necessary to respond to the problems of unawareness and self-exclusion which seem to be at the basis of poor and ethnic minority groups' under-representation (Nederland and Steketee, 2004; Coelho *et al.*, 2005; Van Vliet *et al.*, 2006). This applies to both 'invited spaces' (i.e. spaces created by state agencies to promote participatory governance) and 'autonomous spaces' (i.e. spaces created 'from below' in which people join together on their own initiative to engage in collective action, provide user-led services, or for mutual aid and solidarity) (Brock *et al.*, 2001; Cornwall, 2004b).

In the Netherlands, several studies show that a number of barriers continue to hinder the access of migrants and ethnic minorities (MEMs) to good quality care (Knipscheer, 2000; Van der Veen *et al.*, 2003; De Freitas, 2005; 2006; Ingleby, 2009). In Brazil social exclusion of the poor is deeply ingrained in society, affecting their access not only to health care but also to housing, social benefits and political participation (Sawaia, 1999; Almeida *et al.*, 2000; Neri and Soares, 2002; Travassos *et al.*, 2006). As health care systems in the North grow in complexity and comprehensive health care delivery in the South continues to be challenged by resource shortages, it is crucial to gain insight into how users can be effectively engaged in participatory processes aimed at increasing the accessibility and effectiveness of health care. Understanding who participates, why, and how, can help to shed light on limitations in the inclusiveness of current participatory initiatives as well as to devise new strategies to broaden their potential for creating more empowered users and more responsive policies and services.

In what follows, we outline the main bodies of theory which have been applied to the study of public participation and justify our choice for combining insights afforded by new social movement theorists and theories of empowerment and citizenship with the Participation Chain Model and the Mutual Incentives Theory (MIT) developed by Simmons and Birchall (2005). We then review the core findings of literature dealing with the enablers and inhibitors of users' participation, focusing mainly on studies concerned with participation in mental health services and projects, but drawing occasionally on research carried out in other fields (e.g. urban planning and community development). In the last part of this chapter, we describe MIT and the Participation Chain Model in greater detail, highlighting their links to concepts afforded by the other theories mentioned above.

3.1 Theorising hybrid participatory spaces

As Marian Barnes and colleagues (2004; 2007) note, the study of public participation has been based on distinct bodies of theory including social movement theories, theories of governance and theories of deliberative democracy. The autonomous action of groups seeking cultural change has typically been theorized using social movement and citizenship theories, while studies of public participation in new democratic spaces created by state agencies usually draw on governance and deliberative democracy theories. In practice, however, as the cases studied by the authors in Britain attest (see Barnes *et al.*, 2007), the distinction between 'autonomous' and 'invited' spaces for participation is blurring. Participatory initiatives are increasingly located on a continuum (Barnes *et al.*, 2004), moving away from the opposing poles of collective action and invited participation toward forms of participation which combine elements of both. It is increasingly common to come across 'autonomous spaces' which have public officials among their instigators and which later on get statutory backing while being able to preserve a fair deal of independence (e.g. client organisations in the Netherlands). The same is true for spaces created 'from above' which were designed by social movement 'activists-turned-officials' and continue to harbour thousands of activists who engage periodically in dialogue and collaboration with public authorities (e.g. health conferences in Brazil).

Our case studies contain two instances demonstrating this trend toward the 'hybridization' of participatory spaces:

- The participation of **Cape Verdean migrants** in mental health advocacy initiatives in Rotterdam has been fostered through the creation of a community-based project (Project Apoio) within a client organisation belonging to the Dutch user movement. The advocacy initiatives developed within Project Apoio focused on the provision of psycho-education and on efforts to improve the access of the Cape Verdean community to mental health care. Those initiatives were developed and implemented with the collaboration of Cape Verdean users. However, establishing partnerships with public officials and care providers to carry out those initiatives was common. Furthermore, having emerged within the user movement (which is officially recognised by the government as a partner in health care policy-making), the project received funding from local government. Although Project Apoio was not a space created from above, it is also not a typical example of collective action. It belongs somewhere in the middle, where the desires of users and public authorities to tackle health inequities meet.

- The participation of descendants of **Northeast internal migrants** in a community-based mental health care service in Rio de Janeiro took place through an assembly in which service users and providers joined together to discuss issues related to service delivery. Modelled after the *assemblea* proposed by the Italian reform movement Democratic Psychiatry, this participatory mechanism was promoted by the Ministry of Health as a space for users to have a voice in mental health care (Brasil, 2004). Some of the providers who took part in the assembly were activists affiliated with the Brazilian anti-asylum movement, as were some of the users. Assembly sessions often included the exchange of information about the movement's actions and direct efforts to mobilise for struggle. The assembly is an example of an 'invited space' where collaboration between users and providers co-exists with expressions of public dissent and efforts to recruit new allies for the fight against social injustice and exclusion.

The initiatives we have studied in both Brazil and the Netherlands are examples of 'hybrid' participatory spaces. The theories used for understanding such activities need to be capable of accounting for *both* the actions of independent groups seeking voice and transformation *and* the involvement of users in spaces created by state agencies to afford them the opportunity to participate in decision-making.

Richard Simmons and Johnston Birchall (2005) developed a 'Mutual Incentives Theory' (MIT) of what motivates service users to participate. MIT explains participation on the basis of individual and collective incentives which interact to influence people's motivations to become engaged. Acknowledging the impact of other more 'structural' factors in making participation more or less likely, the authors also proposed a model – the 'participation chain' – which, in addition to motivations, highlights the importance of cultural and institutional 'dynamics', 'resources' and 'mobilisation' for participation (*ibid.*: 271). To date, this appears to be the only comprehensive theoretical model that attempts to explain why individual service users participate by focusing not just on individual motivations, but also on factors that are usually considered in relation to collective action (e.g. mobilisation and, to a less extent, resources). In our view, combining MIT and the 'participation chain' model offers an appropriate theoretical framework for studying what makes users participate in 'hybrid' participatory spaces. Furthermore, as we show in the last section of this chapter, the 'participation chain' does justice to various insights afforded by new social movement theorists and citizenship and empowerment theory that we consider pertinent for our study. These insights are described in detail in the next section as we go on reviewing the literature concerned with the enablers of participation.

3.2 Enablers of participation

People take part in autonomous and invited participatory spaces for many different reasons.

- They may want to have a voice in decision-making concerning services with which they are dissatisfied (White, 1996) and/or to develop alternative solutions (e.g. self-help and mutual aid groups) to ease the burden of unmet needs and wants (Chamberlin, 1978).
- They may join together because they share experiences of discrimination, exclusion and disadvantage (Barnes, 1999) and want to be active negotiators of ideological and cultural change toward greater acceptance and the exercise of full citizenship (Barnes, 1999; Rutter *et al.*, 2004).
- People may also feel committed to values such as social justice and become involved as an expression of those common values and out of solidarity for others in a position of disadvantage (Barnes *et al.*, 2006). Such commitments tend to strengthen along with the experience of participation (Passy and Giugni, 2000) as people realise they can have a positive impact on the welfare of their communities (Sozomenou *et al.*, 2000).
- Finally, people get involved because participation makes people feel good about themselves, either by enhancing their sense of self-worth and recognition, enabling them to develop more empowered identities, or by simply allowing them to become part of change (Barnes and Wistow, 1994; Barnes and Shardlow, 1997; Higgins, 1999).

As we noted earlier, for all those people who participate many more are unaware of opportunities to participate, deliberately choose not to get involved or opt out soon after they partake in a participatory space. In what follows, we reflect upon the enablers which facilitate people's decision to get involved and to continue their participation over time. More specifically, we look at how empowerment, citizenship, agency, social networks and the building of collective identities impact on participation. The presence of these enablers is likely to facilitate participation and their absence to inhibit it. In what follows, we analyse in more detail the way they influence participation.

Another observation worth making at this point is that both enablers and inhibitors of participation can also be a result of participatory processes. In other words, they can be effects as well as causes. This chapter thus offers a glimpse of some of the potential benefits of participation, such as increased agency, empowerment, and stronger social networks and collective identities.

Participation and empowerment

Empowerment can be defined, in a broad sense, as "a multilevel construct which involves people assuming control and mastery over their lives in the context of their political and social environments" (Wallerstein, 1992: 198). Empowerment has its roots in many different ideological, cultural and theoretical influences and developments which go back as far as the Enlightenment (Vasconcelos, 2003)[41]. However, the term only gained currency in the late 1960s when empowerment started being promoted by the Civil Rights and feminist movements (Swift and Levin, 1987), adult education philosophies (Freire, 1970; 1973) and the self-help and mutual aid movements (Gibson, 1991; Wallerstein, 1992; Rissel, 1994). In the 1980s, empowerment was proclaimed a goal of community psychology, becoming one of its main theoretical pillars (Rappaport, 1981; 1987; Zimmerman and Rappaport, 1988; Chavis and Wandersman, 1990). And in the 1990s, it became a core element of new approaches to psychosocial distress such as the psychosocial rehabilitation and recovery models (Anthony, 1993), as well as a fundamental aim of grassroots movements which had been reacting against social oppression, professionalisation and/or paternalism and were seeking to increase citizens' influence over decisions which affect their lives (e.g. psychiatric survivor and user movements, the women's health movement) (McLean, 1995). More recently, the term empowerment has enjoyed such widespread dissemination that it can be said to have become part of popular culture (Linhorst, 2006).

Empowerment is an ideology, process and outcome (Clark and Krupa, 2002) which is particularly relevant in relation to people who experience psychosocial distress. Historically, these are among the most marginalised and oppressed groups (Lord and Dufort, 1996). Lack of power and control, stigma, unemployment, poverty and poor housing have all contributed to place them at the margins of mainstream society (Nelson *et al.*, 2001), leading many to experience feelings of powerlessness and apathy. Reversing this state of affairs is a central goal for empowerment advocates.

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[41] Among those influences are the liberal thought which developed in the seventeenth century, the cooperative movement, anarchism theories and movements, new social movements, etc. It is not within the scope of this piece to provide a detailed account of these developments. For a thorough analysis of the influences, movements and traditions at the origin of the concept of empowerment see Vasconcelos (2003).

However, empowerment is by no means exclusive to the field of mental health. Disciplines such as sociology, administration, health promotion, development and social work and education have all seen the concept be given multiple (and at times disparate) meanings, from the capacity to build individual and collective power to ability to self-provide services previously delivered by the state (Barnes and Bowl, 2001; Cornwall and Brock, 2005). The concept of empowerment has been applied to groups as diverse as women, the elderly, homeless people, ethnic minorities, gays and lesbians, people with HIV/AIDS and people with disabilities (Gibson, 1991; Gutiérrez, *et al.*, 1998). Unsurprisingly, these are also usually the target groups of studies concerned with socio-economic disadvantage and/or exclusion.

Despite numerous efforts to define and operationalise empowerment (e.g. Zimmerman and Rappaport, 1988; Zimmerman, 1990; Rogers *et al.*, 1997), the term "is used to mean many different things and at times appears to lack any real content" (Barnes and Bowl, 2001: 2). To a large extent, this can be explained by the concept's inherent complexity (Chamberlin, 1997) and political nature (McLean, 1995), its broad-based appeal[42], and the fact that at its core is another equally complex and disputed concept: power (Rowlands, 1995).

Power is a theoretical, political, social and subjective construct which has been extensively debated across the social sciences (see Bachrach and Baratz, 1974; Lukes, 1974; Foucault, 1977; 1980). Foucault (1980), for example, argues that all social relations are imbued with power. In his works, he describes the gradual transition (over centuries) from societies in which power is predominantly visible, physical and repressive (constraining action) to societies in which it is predominantly invisible, normative and productive (enabling action). In doing so, Foucault challenges the relevance of the notion of sovereign power to analysing power from the eighteenth century onwards, i.e. the idea of an autonomous actor who has control over and mobilises a set of power sources to produce particular outcomes. He goes on to argue that all actors are subjected to 'disciplinary power' – a web of power relations and discourses which capture advantaged and disadvantaged groups alike, and structure their possible fields of action (Foucault, 1977; Hardy and Leiba-O'Sullivan, 1998). Seen from this perspective, power is not merely 'situated' in decision-making processes or conflict but is intrinsic to all social relations in everyday life (Lukes, 1974; Foucault, 1980).

Other conceptualisations of power distinguish between 'power-over' and 'power-to' (Hollander and Offermann, 1990; Riger, 1993; Clark and Krupa, 2002). 'Power-over' relates to obedience and dominance and varies in the degree of subtlety. It refers to the control and influence exerted by some people over others which often leads to

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[42] As Rowlands (1995) notes, the concept of empowerment has been eagerly embraced by people and organisations as far apart politically as feminists, Western politicians and the World Bank. This, she argues, has much to do with the profound and often unacknowledged differences in the ways its 'root-concept' – power – is understood (1995: 101-103).

the subjugation and oppression of the latter. This can be overt or tacit dominance wielded with or without resistance (*ibid.*). Subjugation can take different forms, including dependence on, or control by, others. How to liberate individuals not only from the state and its disciplinary institutions but also from 'the oppressive forms of subjectivity' produced by their practices is one of the main questions raised by Foucault (McLean, 1995: 1055).

'Power-to' refers to one's personal ability to do or accomplish something such as taking control over one's feelings, thoughts and behaviour (Clark and Krupa, 2002) or resisting subjugation (Kelly, 1992 cited by Rowlands, 1995). This form of power is generative in nature (Rowlands, 1995). It is associated with a sense of mastery, self-esteem and self-efficacy[43] (Labonté, 1996 cited by Clark and Krupa, 2002), and it entails power sharing. Power-to does not equal a 'zero-sum': "an increase in one person's power does not necessarily diminish that of another" (Rowlands, 1995: 102). This is similar to Foucault's understanding of power not just as a negative but also as a productive force: power is not limited to social relations which work to subjugate people through repression or exclusion but it also "produces things, it induces pleasure, forms knowledge, produces discourse" (Foucault, 1980: 119).

Empowerment, then, refers to power-to, which "is achieved by increasing one's ability to resist and challenge 'power-over' (Kelly, 1992 cited by Rowlands, 1995). These oppositional efforts, McLean (1995) argues, "empower by producing a shift in relations of power productive of less oppressed forms of human subjectivity" (1995: 1055). It is this opposition Foucault (1977; 1980) refers to when he talks of productive or positive power.

Empowerment, however, may also have to entail power-over. In situations in which the oppressor resists change, less powerful groups may need to resort themselves to negative power in order to overthrow the oppressor and persuade him or her to either participate in the creation of a new social order (e.g. to lead an absolute monarch to step down and agree to leave or to become a constitutional monarch; to lead classic psychiatrists to abandon biomedical models of mental illness and to make way for mental health care reform, etc.), or simply stop obstructing its implementation (e.g. when the absolute monarch or classic psychiatrists retire). The next step is to introduce new relations of power which requires power-to, and which is understood here not just as the capacity to resist power-over but also the ability to negotiate.

When efforts aiming at power-to fail to oppose power-over forces a feeling of powerlessness may arise (Clark and Krupa, 2002). Powerlessness has been described in terms of a sense of distrust, alienation from resources for social influence, disenfranchisement and a sense of hopelessness in socio-political struggle (Kieffer,

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[43] Bandura (1977) defines self-efficacy as a persons' belief in his or her capability to organise and execute courses of action required to deal with prospective situations. Self-esteem can be understood as the extent to which a person feels positive about herself (Gergen, 1971). And sense of mastery can be defined as a person's fullest possible participation in shaping the conditions of her life (Rose and Black, 1985).

1984). Long histories of denied power, repression, censorship and exclusion may lead to people absorbing the values and beliefs of those who oppress them to such an extent they perceive themselves unable, or unwilling, to seek respect, inclusion and voice. This 'internalised oppression' intensifies their sense of powerlessness:

> Self-depreciation is another characteristic of the oppressed, which derives from their internalisation of the opinion the oppressors hold of them. So often do they hear that they are good for nothing, know nothing, and are incapable of learning anything – that they are sick, lazy and unproductive – that in the end they become convinced of their own unfitness (Freire, 1970b: 63)

Internalising the self as helpless can lead to a false consciousness, i.e. to one "failing to utilize the power that one has and failing to acquire the power that one can acquire" (Moriss, 1987: 94 cited by Clark and Krupa, 2002). Internalised oppression operates by affecting less powerful individuals or groups' perceptions of themselves and of their ability to participate (Rowlands, 1995) in a way that can lead to self-exclusion. Emerging from a position of powerlessness thus requires the development of empowerment mechanisms through which people can become aware of the dynamics of oppression, access resources, build capacity and confidence, tackle their internalised oppression, and then move on to deal with 'external' forms oppression by realising their right to take action and occupying decision-making spaces (Rowlands, 1995; Zimmerman and Warchausky, 1998). It is here that the concept of empowerment meets with Paulo Freire's notion of 'conscientisation', and the close relationship between these processes and participation is most evident.

Conscientisation refers to the process by which disadvantaged individuals or groups develop a 'critical consciousness' – that is, an understanding of their position in the world and of the sources of their disadvantage – and become subjects in their own lives by taking action to change the unjust structures and mechanisms in society which reinforce their oppression (Freire, 1970). Within this philosophy, taking action is not aimed at acquiring power to dominate others (Rowlands, 1995) (although, as we noted earlier, that may be necessary for a while) but about producing a shift in relations of power which can enable people to take control over their lives and to produce changes in their environment toward more horizontal and inclusive relationships, i.e. to become empowered.

Both personal and collective empowerment require participation in the social and political arenas where the decisions which affect people's lives are made. However, for participation to be meaningful, for people to exert real influence and effect change, they need to see themselves as agents[44] (Lister, 1997). This is something a person disempowered by discriminatory discourses and practices ('internalised oppression') may be less likely to realise. Studies show that people who participate in community

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[44] We discuss the concept of agency in more detail in the next section.

organisations often feel more empowered than those who do not take part, *even before becoming engaged* (Schulz *et al.*, 1995; Smith, 1995). Moreover, involvement in participatory groups[45] has been found to lead to feelings of increased personal competence and a greater sense of control among participants (Kieffer, 1984; Zimmerman and Rappaport, 1988; Barnes, 1999).

Empowerment, however, as Higgins (1999) notes, is not just about one's perception of personal control and power. It also entails a sense of togetherness with others (Rappaport, 1987; Wallerstein, 1992), i.e. a sense of community or belonging (Nelson *et al.*, 1995). This sense of community is found to function both as a precursor to, and a consequence of, participation (Zimmerman and Rappaport, 1988; Chavis and Wandersman, 1990; Smith, 1995; Higgins, 1999). Empowerment and participation can thus be seen "to interact in an upward spiral, with empowerment leading to increased participation and participation contributing to increased empowerment" (Honey, 1999: 265). Nevertheless, this relationship only appears to be valid to the extent that participation really enables power sharing and fosters transformation through substantive inclusion in decision-making (Croft and Beresford, 1996; Guijt and Shah, 1998). When participatory activities are transparent and individuals are informed about the extent to which they can exert influence and given feedback on the outcomes of their actions then, even if their efforts lead only to partial change, participants may still feel they are assuming control and mastery over their lives, and gain increased motivation to continue participating.

Participation, agency and citizenship

As we have seen in Chapter 2, citizenship is a contested concept with various meanings framed on the basis of different political philosophies. Here we draw from a strand of citizenship theory which adopts a notion of citizenship as both status and practice (see Lister, 1997). Seen from this perspective, citizenship is not just about a set of rights and responsibilities bestowed by the state (citizenship-as-status), but also about being able to participate in the social and political arenas (citizenship-as-practice): "citizenship as participation represents an expression of human agency in the political arena, broadly defined; citizenship as rights enables people to act as agents" (Lister, 1997: 36). In other words, these two aspects of citizenship complement and support each other.

The notion of citizenship as status has evolved over time to incorporate civil rights in the eighteenth century, political rights in the nineteenth century and social rights in the twentieth century (Marshall, 1950). Civil rights entail what are usually termed negative freedoms, i.e. freedom of speech, thought and faith, the right to own property, and the right to justice. Political rights include the rights to vote and to participate in

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[45] These groups include government-mandated advisory boards, voluntary organizations, mutual-help groups, and community service activities (Zimmerman and Rappaport, 1988).

the exercise of political power as a political authority. And social rights include the right to health care, education, unemployment and disability benefits and old-age pension (*ibid.*). Some consider social rights as positive freedoms essential for allowing citizens to realise their civil and political rights (Marshall, 1976; Gould, 1988; Plant, 1992; Lister, 1997; Gaventa, 2002). The role of social rights in enabling citizens to become full members of society who are able to participate in community life (Marshall, 1976), i.e. to practice their citizenship, has been the subject of much debate, however, highlighting the fundamental tension between liberal and social-democratic views of citizenship. In what follows, we discuss the extent to which social rights are a condition for participation and at the same time attempt to explain the relationship between participation, agency and citizenship.

Liberal thinkers have traditionally conceived of civil and political rights as the essential rights necessary to achieve citizenship status. They tend to view social rights, on the other hand, as infringing on the freedom of others by placing an obligation on tax payers to bear the costs of the welfare state (Higgins, 1999). In the liberal view, being employed and being self-supporting are seen as preconditions for acceptance as a full member of society (Mead, 1986), although they are not enforced as legal obligations. In other words, meeting the responsibilities of self-provision and self-reliance is viewed as a condition of being regarded as a citizen. In addition, liberals claim that the welfare state and the social entitlements (public education, health care, unemployment insurance, pensions) that it seeks to extend – particularly to the disadvantaged – has generated a culture of dependency and passivity among the poor, without having furthered neither the improvement of their life chances or their active citizenship (Barry, 1990 cited by Kymlicka and Norman, 1994).

In contrast, social democrats argue that guaranteeing welfare benefits is crucial if the underprivileged are to stand a chance of entering the mainstream of society and exercising full citizenship. They claim that the dependence of impoverished segments of the population on welfare is not a result of their lack of initiative or desire to work but rather of reduced opportunities to access proper education, training, and employment (Fullinwider, 1988). This lack of opportunities leads people into a situation of inequity from which requirements such as self-provision and self-reliance (as proposed by the liberal view of citizenship) are difficult to satisfy. In the social-democratic view, social rights are therefore seen as necessary conditions for the realisation of full citizenship. Like liberals, social democrats understand citizenship in terms of rights and responsibilities. However, to impose obligations such as work upon welfare recipients (e.g. people with disabilities, homeless people) is thought to be "futile if genuine opportunities are absent, and unnecessary if those opportunities are present, since the vast majority of people on welfare would prefer not to be" (Kymlicka and Norman, 1994: 358). Proponents of this view argue that people must first be granted the resources necessary to take part in community life and then be called to meet their obligations as citizens. In other words, they claim that the ability to participate must precede responsibilities (*ibid.*).

Advocates of social democracy have acknowledged, however, that welfare institutions can lead to passivity and dependence (Habermas, 1992 cited by Kymlicka and Norman, 1994). However, the solution for stimulating active citizenship among welfare clients is not to diminish welfare rights but to decentralise and democratise the welfare state. This entails devolving meaningful authority to local institutions and creating mechanisms through which the local citizenry can have a voice in decision-making and hold public officers to account (Pierson, 1991). The implicit assumption here is that as people begin to participate and exert influence over the institutions on which their lives depend, they will gain increased insight into existing problems in their communities, acquire new competencies and develop a more empowered identity which can be conducive to a more self-reliant life and greater ability to meet the responsibilities of citizenship (Kymlicka and Norman, 1994; Barnes, 1999).

Indeed, empirical studies show that participation in public service decision-making or collective action can provide a means through which citizenship can be practised even by participants excluded from many of the substantive benefits of citizenship (Dagnino *et al.*, 1998; Barnes, 1999). Discussing the participation of poor segments of Brazilian society in social movements organised around claims for housing, sewage and health, Eva Dagnino (2005) notes how, even in the absence of those rights, movement members perceive themselves as, and strive to be, active citizens:

> … while the large majority of participants of social movements and workers' unions' members did not consider themselves to be *treated* as citizens, they did consider themselves to *be* citizens, primarily because they struggled for their rights (*ibid.*: 156; emphasis in the original). (…) … consciousness, agency and the capacity to struggle are seen by them as evidence of their citizenship, even if other rights are absent (*ibid.*: 155).

These findings stress the importance of recognising participation as a "prior right, necessary to make other rights real" (Gaventa, 2004a: 29) and of acknowledging the key role of agency in fostering active citizenship (Lister, 1997). Social rights may be necessary for the exercise of civil and political rights – but even in situations of deprivation, participation can speed up the transition towards citizenship by enabling citizens to realise rights which are absent and to come together and acquire the capacity to struggle for claiming those rights.

Agency is another contested concept, like citizenship, which is central to these discussions. Agency can be understood as action to intervene in the world and "the capability (…) to 'make a difference' in a pre-existing state of affairs or course of events" (Giddens, 1984: 14). Agency involves power of a generative kind, i.e. 'power-to'. As Lister (1997) argues, citizenship and agency are deeply intertwined: "to act as a citizen requires first a sense of agency, the belief that one *can* act; acting as a citizen, especially collectively, in turn fosters a sense of agency" (1997: 38, emphasis in the original). This close relationship between citizenship and agency, as Kabeer (2005) notes, highlights a conundrum: how are those whose rights have been denied, and whose exclusion is accentuated by their lack of organisational power, to become organised and foster transformation? In other words, how can people who have been disenfranchised from society acquire the confidence and capability necessary to make a difference in that very society toward their own inclusion? Social exclusion can lead people into a state of powerlessness in which they are robbed of the autonomy they require to struggle for inclusion.

As Kabeer suggests (2005), and our own studies attest, the power of socially excluded groups to organise and to become engaged in collective action can arise from alliances with state officials and other citizens committed to social justice who choose to act side by side with those groups (e.g. the Brazilian anti-asylum movement). In other cases, more global forms of solidarity provide the support required by subjugated groups to struggle against their oppressors (e.g. the South African anti-apartheid movement). This brings to light a 'horizontal' view of citizenship, "one which stresses that the relationship *between* citizens is at least as important as the more traditional 'vertical' view of citizenship as the relationship between the state and the individual" (*ibid.*: 23; emphasis in the original). Moreover, it emphasises an understanding of citizenship as 'belonging' (Kaplan, 1993): those citizens who are unable to access all their rights may nevertheless experience a sense of community and connectedness resulting from networks of solidarity through which they can acquire the resources and confidence they need to act as agents.

What this tells us is that although social rights are relevant enablers of participation, they are not a *sine qua non* for participation to be realised. This is by no means to say that people who lack those rights have the same chance of being able to participate as those who posses them, but rather to emphasise that the absence of social rights among certain groups is a reason for doing more, not less, to secure their representation in the participatory sphere. To give but one example, homeless people may be difficult to reach due to a 'nomadic' life and lack of a fixed place for contact. However, this does not mean they are unable to organise (see Anker, 2008) and that their voices should not be sought after and listened to in participatory forums.

As we noted earlier, there is a difference between perceiving oneself as a citizen and being treated as one (Dagnigno, 2005). People unable to exercise all their citizenship rights may feel they are not treated as citizens and yet consider themselves to be citizens. This is especially the case when people believe they have the capability to make a difference, i.e. when they see themselves as agents. Such a sense of agency enables them to act as citizens, whether through political struggle or through participation in governance. Participation, in turn, promotes an increased sense of agency by enabling people to claim and/or extend their rights. Thus, like empowerment, agency can be seen to work both as an antecedent to, and a consequence of, participation: the greater a person's sense of agency the more likely she is to participate; the greater a person's participation the more likely she is to perceive herself as an agent. Participation, agency and citizenship thus are interdependent.

Participation, social networks and collective identity

Another way to understand why people participate is to look at their social networks and the influence of collective identities in prompting and sustaining participation. This line of analysis has been developed by social movement theorists concerned with the study of collective action, but is increasingly coming to be applied to the study of public participation in governance as well (see Barnes *et al.*, 2006; 2007; Abers, 2007).

In 'new social movement theory', a focus on the role of social networks and collective identity on people's motivations to act emerged as a response to the limitations of resource mobilisation and rational choice models in explaining why social actors engage in collective action (Melucci, 1996; Della Porta and Diani, 1999; Polletta and Jasper, 2001; Diani and McAdam, 2003). Resource mobilisation theorists had addressed the processes by which the acquisition of resources and skills facilitate participation (i.e. the 'how' of mobilisation) (e.g. Tilly, 1985; Zald and McCarthy, 1987), but provide few tools to answer questions such as why collective actors come into being when they do (Polletta and Jasper, 2001). Researchers drawing on rational choice theory assume that decisions to participate are based on an individual calculation of costs and benefits: individuals are enticed to participate only when they perceive the benefits of participation to outweigh its costs. Explanations such as a desire to achieve common goals or a commitment to the common good are discarded in favour of claims that people prefer to 'free-ride' on the efforts of others and that they will only act if they can reap private payoffs from participation (Olson, 1965; see also Crossley, 2002; Simmons and Birchall, 2005). This emphasis on personal interest and individual behaviour makes it difficult to explain why some people choose to participate even when costs are high and immediate private payoffs are low (e.g. the anti-apartheid movement).

Alberto Melucci (1996) attempts to resolve this dilemma by relating people's motivations to participate to a cognitive and affective schema which is produced as a result of the interactions between individuals taking place in the context of their social networks. From this perspective, individuals' motivations and decision to participate are not just the product of individual rational thinking but are largely influenced by the relational networks that tie them to other actors:

> Personal friends, relatives, colleagues, and neighbours, may all affect individual decisions to become involved in a movement; so may people who share with prospective participants some kind of collective engagement, such as previous or current participation in other movement activities, political or social organizations, and public bodies (Diani, 2003: 7).

This is not to say, however, that the decision to become involved is not made (in part) on the basis of a 'cost-benefit calculation': individuals do seek to understand if their potential access to benefits through participation measures up to the costs of their efforts. Yet, as Melucci (1996) argues, such 'calculation' does not occur in a vacuum but is always mediated by the individual's social relations. A person can only estimate whether her investment in an action is likely to produce the desired outcome through a system of reference which enables that person to position herself in the world and to give meaning to that action. This is the whole problem with rational choice theory – it is unable to explain how individuals *construct* payoffs and decisions to participate. Melucci conceptualises the system of reference people use to make decisions in terms of identity – a process which involves making sense of oneself and one's relationship to others and which is primarily based on 'affective bonds' and on 'the intuitive capacity of mutual recognition' (1996: 66). In other words, identity is an active process which takes form through social relations and that involves both cognitive and affective elements.

Since identities are created and shaped through social relations, Passy (2003) argues, networks play a central role in building and reinforcing the identity of individuals and in enabling them to gain consciousness of and identify with certain issues and values (e.g. social justice, LGBT rights, animal rights). In a similar vein, Melucci (1996) claims that motivations to participate are also primarily built and strengthened through interaction. As Barnes *et al.* (2006) go on to explain:

> Individuals become motivated to take part in movements with others through a process of deciding that action is worthwhile to achieve change, that it makes sense in terms of their sense of who they are, what they value and how they stand in relation to the world (*ibid.*: 201).

It can be said, thus, that motivations to participate are deeply associated with identity, and that both identity and motivations to participate are strongly influenced by the relational networks that tie individuals together. As Passy (2003) shows, social networks create an initial disposition to participate by providing a context in which individuals can be socialised to specific sets of values. They also play a mediating role by connecting prospective participants to opportunities for action through the distribution of information about ongoing activities, existing organisations and people already engaged. In addition, social networks can facilitate access to resources and the development of competences which help minimise the costs involved in participation (e.g. time, money, risks, stress, etc.) and assist individuals in making the decision to join collective action (*ibid.*). Ultimately, social networks can foster the emergence of a collective identity, i.e. "a process of building an action system" (Melucci, 1996: 67).

For Melucci (1996), collective identity is "an interactive process through which several individuals or groups define the meaning of their action and the field of opportunities and constraints for such an action" (*ibid.*: 67). Or, as Abers (2007) puts it, collective identity is the "recognition by a set of individuals that they belong to a group that is capable of acting collectively" (*ibid.*: 1454). Collective identity entails continuous cognitive and emotional investment. Its construction (and adaptation) is not just the product of the actors directly engaged in change, but requires recognition by other social actors from whom the former are differentiating. Collective identity crystallises in the form of organisations, norms, rules, and leadership relationships as groups become more institutionalised and, according to Melucci, it is a "process that must be constantly activated if action is to be possible" (*op.cit.*, 67).

While some authors see collective identity as a precondition for mobilisation (Melucci, 1996; see also Polletta and Jasper, 2001), others suggest that collective identities develop as people become involved in interest groups, social movements or participatory forums (Hirsch, 1990; Della Porta and Diani, 1999; Barnes *et al.*, 2006). More agreement appears to exist, however, about the role played by collective identity in ensuring the continuity and permanence of social movements and participatory initiatives over time (Melucci, 1996). Collective identity involves a sense of 'we-ness' which establishes a differentiation between collective actors and others in their social environment. Usually, the perceived need for differentiation is premised on problems posed by the environment in which those seeking change live (e.g. inequality, discrimination, exclusion). Collective identity building entails defining aims, making a plan for action, identifying the means necessary to achieve change, and working with the opportunities and around the constraints present in the environment where change is being sought. As actors engage in this process they define a common agenda, build commitment to a group, recognise themselves and are recognised by others. When crises arise, whether of internal or external origin, groups with a strong collective identity are more likely to be able to avoid disintegration by re-orienting and restructuring their actions in a fashion that continues to serve their purposes (*ibid.*) The same applies to groups of citizens involved in participatory forums marked, for example, by profound resistance from public officials.

3.3 Inhibitors of participation

Unawareness of opportunities for engagement is perhaps the most obvious inhibitor of participation. Yet even when people are aware of the opportunities, many choose not to take part, or drop out shortly after becoming involved. As we suggested in the beginning of this chapter, participation can be constrained by three general problems.

- Unawareness explains people's unintentional inaction. People may be inactive simply because they are ignorant of the existence of participatory initiatives.
- Self-exclusion explains people's decision not to participate. People may exclude themselves from participatory projects due to apathy ('too indifferent to participate'), powerlessness ('feeling too incapable to participate'), disbelief

('too many promises, too little results'), apprehension ('too much confrontation, too little perceived support') and fatigue ('too many invitations, too little power sharing').

- Exclusionary dynamics explain people's decision to drop out from participation. People may opt out because they get the impression that they have little influence on decision-making (lack of transparency), because they feel threatened (negative attitudes), or because their efforts are not recognised (lack of feedback).

Unawareness is associated with resource constraints, more particularly with lack of information. Lack of resources can also lead to self-exclusion. Participation requires resources which are not equally accessible to all citizens and that may limit the ability and/or willingness of disadvantaged people to act. Self-exclusion may also result from the perception that the benefits of participation do not outweigh its costs. Participation involves costs which are experienced differently by different groups and that are not always given due consideration by instigators of participatory initiatives. Clark *et al.* (2004), for example, reporting on a case of service user involvement in research in England state the importance of participants acquiring skills to deal with 'work-like' pressures and warn that participation may lead to unmanageable stress and debilitation when participants are not provided with sufficient peer support. Mohanty's (2007) research on grassroots popular involvement in participatory governance projects in rural India shows how poor women were practically absent in those initiatives, not just because it is difficult to take time off from pursuing their livelihoods to participate but – more importantly – because there is an entrenched patriarchy which discredits women's voices and excludes those women who try to challenge the *status quo*. Both these cases highlight different sorts of barriers (insufficient skills, stress, financial costs, discrimination) which can undermine the formal and substantive inclusion of citizens in participatory initiatives.

In addition to the barriers posed by unawareness and self-exclusion, and more specifically by resource constraints and costs of participation, exclusionary dynamics may evolve and crystallise within participatory spaces hampering the ability of some of the participants to influence decision-making. Exclusionary attitudes and practices can take the form of covert attempts to silence less powerful groups by discarding their contributions as unintelligible or simply ignoring them (see Pozzoni, 2002). They can also be more straightforward efforts to delegitimize some voices by questioning the degree to which they are representative of a wider group (see Lindow, 1999). This sort of dynamics is usually centred on power struggles and can lead those least powerful to opt out.

In the remainder of this sub-section we review the literature concerned with the inhibitors of participation and seek to shed light on the ways by which resource constraints, participation costs and exclusionary dynamics affect people's decision to participate and to remain engaged.

Resource constraints

Access to **information** about participatory initiatives is crucial if people are to consider the possibility of getting involved. Social movements, advocacy groups, and state agencies seeking to foster participatory governance all need to make their initiatives known to the public if they are to recruit participants. Yet simply disseminating information about opportunities for participation is not likely to be enough to secure citizen engagement. If we take the case of participation in mental health care, people may be aware of participatory spaces and still feel deterred from participating because they lack access to other fundamental kinds of information including the workings of the mental health care system, mental health care law, the impact of their participation on their welfare arrangements, and the degree to which they can expect to influence decision-making (Honey, 1999; Clark *et al.*, 2004).

Participation is **time**-consuming and not everyone can fit it in alongside their daily responsibilities. Often, participation initiatives take place during the day and last a good few hours. People who work, parents of small children, young people attending school or college may all find it difficult to make time to become actively involved. Participation requires not just the actual time participants spend being consulted or deliberating, but also time to prepare for those tasks. Sozomenou *et al.* (2000), discussing the participation of ethnic minority users in mental health care services in Australia, stress the importance of users being given enough time to prepare for consultation, gain prior knowledge of the subjects to be discussed, talk with others whom they are asked to represent, and share their experiences about the process of engagement with peers. This is even more relevant in cases in which the content of documents or proposals to be discussed is complex and written in a language that is not users' first language.

Participation can be financially expensive and various studies suggest lack of **funding** may undermine user involvement (Pilgrim and Waldron, 1998; Sozomenou *et al.*, 2000; Crawford *et al.*, 2003). The provision of administrative resources (office, computer, Internet connection, etc.) to users is crucial for participation to be effective. Moreover, users should be reimbursed for their out-of-pocket expenses and their expertise and contributions should be recognised. In this respect, a dilemma that is becoming increasingly evident among users involved in mental health services concerns the question of how they can be acknowledged and paid for their contributions without risking their entitlement to welfare benefits. Benefits agencies may argue that if users can participate they are also fit for work. That could result on the cancelation of benefits and subsequent financial insecurity (Clark *et al.*, 2004; Rutter *et al.*, 2004). The fear of losing disability benefits can have a negative impact on users' decisions to get involved.

Participation requires **skills** and **capacities** which are fundamental if citizens are to stand a chance of influencing decision-making. Without these, they may come to find participatory initiatives unappealing or even meaningless. Important here are for example cognitive skills, communication skills (particularly the ability to articulate ideas in group settings), the capacity to listen, to be assertive, to handle criticism, etc. (Honey, 1999; Sozomenou *et al.*, 2000). Analysing the perceptions of public officials concerning the lay members of the public with whom they take part in invited participatory forums in England, Newman *et al.* (2004) found that officials often view the public as passive consumers who require 'skilling up' to participate in an effective manner. This entailed having lay people learn how forums operate, how they should take part in meetings and how they can make minutes on a word processor. As the authors argue, focus on this particular type of skills suggests "an orientation towards enabling the public to operate within the norms set by the bureaucracy, rather than enabling bureaucrats to hear and respect the experience that participants bring to the process of participation" (*ibid.*: 211-212). Building capacity for participation is not a 'one-way street': both lay members of the public and officials, managers, and professionals participating in invited spaces need to be open to acquiring new skills and competencies if experiential and technical expertises are to be exchanged and combined, mutual trust is to be built, and good deliberation is to come to fruition (Beresford and Croft, 1993; Rose *et al.*, 2004).

Participation also requires **confidence**. Lack of confidence can cause people to feel intimidated and insecure in participatory spaces, literally undermining their ability to speak. Reduced self-confidence is often associated with the belief that one does not have the skills or the right to participate (Sozomenou *et al.*, 2000). Confidence-building of users can be facilitated by trainings aimed at increasing their knowledge and skills, and by appropriate feedback and recognition from other actors (e.g. providers, officials) present in participatory spaces (*ibid.*; Simmons and Birchall, 2005).

Costs of participation

Participation **fatigue** is becoming an increasing problem which accounts more and more for people's deliberate self-exclusion from participatory initiatives (Barnes, 1999; Cornwall, 2008b). The increase of opportunities for citizens to engage with the state observed in the past two decades can only be welcomed. However, when participation results in little or no influence over decision-making, or when citizens or civil society organisations are called to represent the public in a scale that is beyond their ability to respond, feelings of scepticism and/or overload may undermine willingness to participate. Van de Bovenkamp *et al.*'s (2010) analysis of client organisations' participation in health policy advisory meetings in the Netherlands provides an example of how organisations overloaded with requests from the government for consultation may start to channel their limited resources into just a small fraction of the activities that first motivated their members to mobilise (e.g. cutting down mutual-aid groups and redirecting resources into the professionalisation of user representatives active in advisory meetings). Seeking to respond constantly to the agendas of officials can sap the energy of user groups and organisations to invest in other, equally important, activities for democratisation and social cohesion (e.g. empowering activities for excluded groups) (Barnes, 1999). This can leave members poorly resourced and motivated to continue participating.

Participation can cost more **money** than people are willing or able to devote to it. Coelho *et al.* (2005) reporting on the participation of lay members of health councils in Brazil note how they have to request permission from employers to attend council meetings[46], sometimes receiving no payment for the hours of work missed. Although the authors conclude that this did not deter lay people's participation in the council – in fact they attended meetings more regularly than other members, i.e. representatives of government and health professionals – it is an example of how architects of participation may fail to realise how they are excluding less privileged groups[47]. In this case, while the participation of government and health professionals' representatives was seen as part of their job responsibilities representing no personal costs, lay councillors had to take time off work to participate and bear themselves the financial penalties for doing so.

As we have seen in the previous sub-section, participation requires skills and capacities which people may need to develop. This entails making **efforts to learn** which for some cost more energy and time than for others. People diagnosed with a mental illness at young age may not have benefited from as much schooling as the majority of the population. People with an experience of institutionalisation may be still suffering from its negative impacts (e.g. dependency, passiveness, low self-esteem). Learning about the (mental) health system and acquiring the capacities and skills necessary for participation can be a long and difficult process for people in those circumstances and it requires support. Even after receiving training, however, entering a participatory arena dominated by inaccessible managerial language and jargon can be daunting and discouraging. Again, it is important to emphasise that public officials, managers and professionals also need to make efforts to learn how to listen, speak, and discuss with lay 'experts by experience' (Sozomenou *et al.*, 2000; Crawford *et al.*, 2003; Rutter *et al.*, 2004).

Participation is not always a smooth process and not everyone is able to deal with **conflict** and criticism (Mansbridge, 2003b; Cornwall, 2008). As Mansbridge (2003b) notes, "what looks like 'apathy' is sometimes a conscious choice not to get involved in a 'disagreeable situation" by people who fear that participation can result in disparagement or hostility from others (*ibid.*: 193; see also Rutter *et al.*, 2004). In addition, as we noted earlier, participation can induce 'work-like' pressures on

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[46] Meetings were scheduled on weekdays at two o'clock in the afternoon.

[47] Here we refer to working people whose income is much too low for them to afford losing a part of it to participation.

participants. Unrealistic demands to deliver, lack of respect for participants' own work tempo, and insufficient support can lead to unmanageable **stress** and the need to withdraw, particularly among people who are also dealing with psychosocial problems (Barnes and Wistow, 1994; Clark *et al.*, 2004; Rutter *et al.*, 2004).

One of the main aims of participation is to include people in the decisions that affect their lives. However, becoming involved can entail **exclusion** from one's community. People living in communities in which mental illness is highly stigmatised face a high risk of exclusion when they engage in participatory initiatives designed for people affected by psychosocial problems (Sozomenou *et al.*, 2000). This is a cost few people may be willing to bear in the absence of alternative support networks.

Exclusionary dynamics

Lack of transparency about the extent to which people can expect to influence decision-making through participation can lead to frustration and the decision to abandon participatory initiatives when expectations are thwarted. Rutter *et al.* (2004), analysing user involvement in the planning and delivery of services in two mental health provider trusts in London, show that disillusionment over lack of power to influence change was the principal reason for users to withdraw from involvement. As the authors go on to conclude, transparency about expectations and the limitations of user participation in services is key if sustainable collaboration between providers and users is to be achieved. However, users are not always informed about what they are getting into on when they are first invited to participate. As Sherri Arnstein's (1969) well-known ladder of participation illustrates, analysing participatory initiatives according to the amount of control transferred from authorities to citizens reveals the existence of widely different forms of participation. These can range from what she terms 'non-participation' i.e. instances of 'involvement' in which no power is transferred to citizens (low rungs of the ladder), to 'tokenism' i.e. informing and consultation activities in which citizens are heard but have no guarantee of influence (middle rungs), to 'citizen control' over decision-making (high rungs). Not specifying the degree to which citizens' views are to be taken into account increases the risk of that participation will be used to legitimise already-taken decisions without any power being devolved to the citizenry. Indeed, the place of participatory initiatives within Arnstein's ladder may be left deliberately unclear, because this enables public officials and service providers "to leave themselves the ammunition to ignore the outcomes of user involvement" (Harrison and Mort, 1998: 67). As Harrison and Mort (1998) remark, "being in favour of better public consultation or more user involvement is rather like being against sin; at a rhetorical level, it is hard to find disagreement" (*ibid.*: 66). However, in practice, as the authors' studies show, there is often disagreement and health authorities do not always feel bound by the decisions made within participatory forums. Transparency regarding both the extent to which citizens can influence decision-making and the degree to which public authorities are to show accountability to citizens is fundamental if consistency between rhetoric and practice is to be effectively assessed and increased.

Several studies show that dissonance exists between professionals' expressed support and actual endorsement of user participation in practice. This is especially evident in regard to the involvement of users in mental health care planning and delivery (Bowl, 1996; Anthony and Crawford, 2000; Campbell, 2001). Staff's **negative attitudes** towards participation have been identified as a major barrier to the promotion and sustainability of user involvement (Barker *et al.*, 1997; Honey, 1999; Peck *et al.*, 2002). Where user participation is met with staff defensiveness or resistance (Barnes and Wistow, 1994; Crawford *et al.*, 2003) users might come to fear reprisal and opt to drop out. Negative attitudes among professionals may originate in paternalism and stereotyped beliefs about users' (lack of) capabilities, concerns about the blurring of professional-client boundaries, unwillingness to listen and accept criticism and reluctance to share power (Barnes and Wistow, 1994; Honey, 1999). Furthermore, as Barnes and Shardlow (1997) note, "giving account and being held to account can be uncomfortable experiences for professionals who see accountability as something to be given to professional peers, rather than to either managers, politicians or the users of their services" (*ibid.*: 297).

Demands for accountability are likely to arise if transferring power to users is specified as an explicit objective of user participation. As we have seen earlier, the kind of power required for users to act as agents, i.e. power-to, is not a zero-sum game. However, for professionals accustomed to have discretionary power over decision-making it may feel that way. As Lindow (1999) argues, one of the strategies employed by professionals to diminish users' influence in decision-making is to invalidate their voices as 'unrepresentative'. Such accusations are often unjustified. However, there is legitimate concern over the extent to which the views expressed by involved users match the views of the 'constituencies' they are expected to represent. This is especially evident in regard to mental health care users. Engaged mental care users are often found to be more articulate and vocal than the majority of 'ordinary' service users who are usually perceived as more diffident, uncertain and passive (Barnes, 1999; Honey, 1999; Sozomenou *et al.*, 2000; Rutter *et al.*, 2004). Concerns that involved users do not resemble the profile of the 'typical' user are shared not just by staff but, at times, by users themselves (Rutter *et al.*, 2004). As Rutter *et al.*'s (2004) study shows, this highlights a dilemma: those users who are vocal and choose to participate stand out as 'atypical' and unrepresentative, while 'ordinary' users may be too unwell or not assertive enough to actually speak out. Representing all users or even a particular sub-group is, as Sozomenou *et al.* (2000) assert, "an impossible task for any one person" (*ibid.*: 73).

Instead of focusing on 'typicality', a more effective solution to assist user representatives to become as representative as possible may be to create ways for them to receive input from other users and report back on subsequent developments. User meetings and forums, surveys and questionnaires, newsletters and informal gettogethers are some of the channels through which a more constant flow of information can be generated (Honey, 1999). This is not to say, however, that the problem of **unrepresentativeness** does not deserve concerted attention. As we showed in the previous chapter, the representation of migrant and ethnic minority (MEM) users in the health participatory sphere continues to be very limited. This is not a problem restricted to countries in which user participation and/or migration are still recent phenomena. Reduced participation by MEMs has been identified in the Netherlands (De Savornin Lohman, 2000; Nederland and Steketee, 2004), England (Crawford *et al.*, 2003) and Australia (Sozomenou *et al.*, 2000). MEMs' under-representation in participatory fora hinders the potential of user involvement to promote the development of more diversity-sensitive care (Crawford *et al.*, 2003). Since one of the purposes of participation in health care is to match services better to users' needs, this may result in people whose needs have not been addressed losing confidence that participation can actually foster change, and subsequently undermine their willingness to get involved causing self-exclusion.

3.4 A framework to assess the enablers and inhibitors of participation

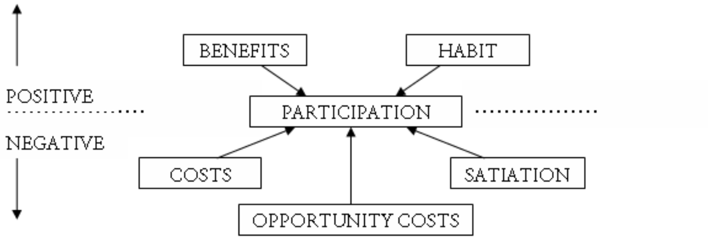
As we have seen in the previous sub-sections, decisions to participate are not simply the result of cost benefit calculations nor are they based on personal motivations alone. Other factors, including opportunities to participate, a sense of agency, and access to resources and to social networks sharing the values of participation, interact with individuals' motivations influencing their decisions to become involved and subsequent considerations of whether or not they want to stay engaged. Seeking to explain how these different factors work together to facilitate or constrain participation, Richard Simmons and Johnston Birchall (2005) developed a theoretical model of what leads service users to participate – the 'participation chain'. The participation chain model integrates what the authors characterise as 'demand-side' and 'supply-side' factors. The latter include personal resources (which enable people to participate), mobilisation factors (by which people are recruited) and dynamics of participation (which work to sustain or frustrate people's desire to continue involved). Demand-side factors include the individualistic and collectivistic incentives which create a demand for activism and motivate people to get involved. Simmons and Birchall consider the impact of this last set of factors in light of their Mutual Incentives Theory (MIT) which postulates that although individual benefits weigh on motivations to participate, collectivistic incentives are the primary mechanism influencing the motivation of service users to get involved (*ibid.*). In what follows, we describe MIT and the participation chain model in greater detail and relate them back to the theoretical insights and to the enablers and inhibitors of participation introduced earlier in this chapter.

Mutual Incentives Theory (MIT)

MIT assumes motivations to participate are influenced by both individualistic and collectivistic incentives (Simmons and Birchall, 2005). Simmons and Birchall developed MIT based on the combination of two general social-psychological theories of motivation – social exchange theory and social cooperation theory, each emphasising one particular type of incentives (individualistic vs. collectivistic). Their approach of the individualistic incentives involved in participation draws from social exchange theory which assumes that people are motivated by rewards and punishments: the more rewarding participation is perceived to be the more likely people are to be motivated to participate. Their collectivistic approach to incentives develops from social cooperation theory and, more particularly, games theory which views human behaviour as inherently collective and assumes participation is influenced by three sorts of factors: sense of community, shared values and shared goals. In the following, we address first the influence of individualistic incentives and then the impact of collectivistic incentives, concluding with the way by which these sets of factors interact to explain motivations for participation.

Individualistic incentives as proposed by MIT consist of positive and negative incentives which are weighed against each other by individuals engaged in the process of choosing whether or not to be involved (see Figure 1).

Figure 1 *Individualistic Incentives*



Source: Simmons and Birchall (2005)

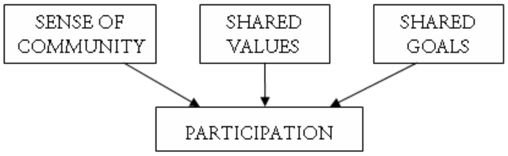
As Figure 1 illustrates participation is influenced by the positive effects of habit and benefits and the negative effects of direct costs, opportunity costs and satiation. Benefits refer to the advantages individuals perceive to result from participation. They can be subdivided in external benefits (e.g. improved social life, solving one's own problems, social recognition, help with one's carrier, etc.) and internal benefits (e.g. chance to have a voice, having a valuable learning experience, sense of achievement, enhanced self-confidence, etc.). Habit refers to those situations in which people are involved because participation has become part of their regular programme of activities. Direct costs are concerned with the losses participants experience as a result of participation (e.g. financial costs, criticism, boredom, efforts to learn, etc.).

Opportunity costs refer to the opportunities participants must renounce to in order to participate (e.g. spending time with family or at work, leisure, etc.). And satiation refers to the reduction of the subjectively perceived value of benefits when they are oversupplied (e.g. getting one's problems solved). According to MIT, when benefits outweigh negative incentives people are more likely to participate. This is especially the case when people perceive internal benefits can be ripped from participation. However, MIT asserts that individual benefits are not sufficient to explain motivations to participate since many people show willingness to get involved even if those benefits would be absent (see Simmons and Birchall, 2005; 2007). This suggests the influence of another set of factors described above as collectivistic incentives.

Collectivistic motivations to participate develop as a result of the presence and/or combination of three types of incentives (see Figure 2):

- shared goals: people express mutual needs that translate into common goals;
- shared values: people feel a duty to participate as an expression of common values;
- sense of community: people identify with and care about other people who either live in the same area or are like them in some respect (Simmons and Birchall, 2005: 266).

Figure 2 *Collectivistic Incentives*



Source: Simmons and Birchall (2005)

MIT asserts that the more each of these incentives are present the more likely people are to engage. It also postulates that collectivistic incentives strengthen progressively as people go on participating: "with participation, people's collectivistic motivations are reinforced and their commitment to the group develops" (*ibid.*: 269). Collectivistic motivations, thus, are at the origin of participation and can become a product from it. In other words, collectivistic incentives are both a cause and an effect of participation.

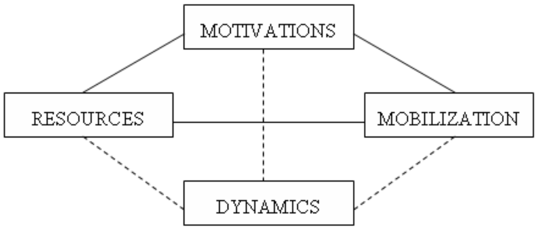
Where the relative effect of individualistic and collectivistic incentives is concerned, MIT asserts that collective motives are more significant to the promotion of participation than individual benefits. Based on an empiric testing of their theory, Simmons and Birchall (2005; 2007) concluded that collectivistic incentives tend to outweigh individualistic ones, that is, as motivators, individual benefits are secondary to collectivistic incentives.

The participation chain model

The participation chain is a non-sequential model which aims to integrate 'demand-side' with 'supply-side' explanations for participation. The 'chain' is a metaphor for the fact that participation is influenced by different factors or 'links' which join up to produce greater willingness and ability among people to take part. The stronger each individual link is the higher the likelihood for participation to develop. Moreover, for participation to strengthen, all the links need to be effectively joined together. Conversely, the weakening of one link might cause the chain to break and the lessening of a connection between two or more links can bring participation to a halt (Simmons and Birchall, 2005; 2007).

The participation chain is composed by four links: motivations, resources, mobilisation and dynamics of participation (see Figure 3).

Figure 3 *The participation chain*



Source: Simmons and Birchall (2005).

Motivations

As we have just seen, according to MIT, individuals' motivations to participate are influenced by individualistic and collectivistic incentives. The perception and/or experience that participation can enable one to have a voice, learn valuable skills, and enhance self-confidence and control are valued motivators. Moreover, having a strong sense of community and sharing values and goals with others belonging to one's group of reference are not only important incentives for participation but can also become part of its outcomes, further reinforcing engagement. In contrast, as explained by empowerment theory, disenfranchisement and lack of control over one's life may produce such feelings of alienation and powerlessness that people become unable to bond to a community and/or to perceive the potential benefits of participation. People who feel they do not belong to a community may not want to spend time in energy in community affairs. People who feel helpless may not be able to anticipate how participation can possibility foster positive change. This kind of feelings obviously works to weaken the motivations link, making participation less probable.

Resources

Resources are another key link of the participation chain. As the literature reviewed earlier shows, resources constraints such as insufficient information and skills and lack of time, funding and/ or confidence work to reduce the chances of people getting involved and undermine the sustainability of participation when people are already engaged. Conversely, when efforts are made to widen people's access to resources opportunities for participation may be evaluated afresh or those already participating may consider moving ahead with their involvement (e.g. from client councils to advisory meetings with public officials). As Simmons and Birchall (2005) show, skills and confidence are particularly important resources. They enhance people's willingness to start participating and foster higher levels of participation. People who have a diverse set of skills tend to feel more confident about their ability to participate. Trainings designed to enhance the competencies necessary to perform the tasks involved in the process of participation will most likely strengthen their confidence. However, being knowledgeable on a certain topic, for example, does not necessarily make people feel they can make a difference. As explained by new citizenship theorists, such a sense of agency may be acquired as participants come to be part of networks of solidarity where they find horizontal support from other fellow citizens and, together, start believing that "Yes, we can!".

Mobilisation

People participate for various reasons. Catalysts of participation include a sense of relative deprivation, dissatisfaction with authorities and a desire for change. People dissatisfied with services which they need in a continuous and prolonged way, for example, are more likely to participate than others who are either satisfied with or do not need those services. Among people showing dissatisfaction, those with greater competence to assess the quality of services and with less access to alternative services (i.e. exit) are also more likely to become mobilised. Yet, it is not enough to be motivated and have the resources required for participation. Providing people with opportunities to exert their voices and asking them to take part are crucial for participation to thrive. As Simmons and Birchall (2005) show, actively recruiting people to engage in activities they perceived as relevant, timely and attractive is much more effective than relying on indirect recruitment (e.g. written notices). Moreover, when asked to participate by people they trust, potential participants also react more positively. This is in line with the insights afforded by new social movement theory on the impact of social networks on participation. As we have seen, social networks provide the basis for the construction of the cognitive and emotional schema people use to make decisions about participation. Social networks enable individuals to gain consciousness over and closer identification with certain issues and values; they connect prospective participants to opportunities for participation; and they facilitate access to resources which lower the costs involved in participation. Moreover, social networks can foster the emergence of a collective identity through which individuals develop a feeling of belonging and the belief that they can act together to bring about a desired change. It is not really surprising, thus, that people invited to participate by a 'recruitment agent' who belongs to their own network usually respond more favourably than people asked to get involved by 'agents' whom they do not know or do not identify with. In this last case, people may think the opportunities for participation on offer do not fit with their aspirations and see little point in participating. Ineffective communication about what those opportunities entail and how appropriate they are can undermine enlistment, weakening the mobilization link and making the participation chain frail.

Dynamics

The dynamics of participation refer to the impact of cultural and institutional factors on the promotion and sustainability of participation. Participants' experiences, motivations and strategy of participation influence group relations which in turn impact on the dynamics of participation. Strategies of participation based on collaboration can foster mutual trust among participants and lead to a positive perception of the structure and success of the participatory group. Positive experiences of participation can lead to the affirmation of participants' key motivations to participate, and foster their commitment to the group and to the participatory project. As commitment to the group builds up collectivistic motivations may be elevated to a primary position in the 'motivation hierarchy': "participants may increasingly align their aims to those of the group (shared goals), or internalize group norms (shared values)" (Simmons and Birchall, 2005). This can strengthen the dynamics link and contribute for the sustainability of participation.

Conversely, problematic group relations, insufficient motivation and negative experiences with participation can determine people's withdrawal from participatory initiatives. These barriers may develop as a result of what we referred to earlier in this chapter as exclusionary dynamics, i.e. open or tacit exclusionary attitudes and practices which undermine inclusive participation. Participatory spaces are often composed by different sorts of participants. In the health care field, these may include public authorities, providers and users. When public authorities or providers are not transparent about their motivations regarding participation and/or the extent to which users can expect to exert influence, frustration may arise among the latter, undermining their commitment to the participatory project. Furthermore, lack of appropriate feedback to participants may disguise providers' resistance to user participation or their unwillingness to embrace accountability. When confronted with unrightfully negative feedback by powerful actors users may feel that if they insist to participate in a substantive way they may come to suffer reprisals. Getting no feedback at all may lead users to feel they are not taken seriously. These feelings can have a negative impact on group relations causing the dynamics link of the participation chain to wane.

The participation chain model illustrates the complexity involved in the participatory project. As it appears, it is just as difficult to initiate participatory initiatives as it is to sustain them. For participation to thrive, the links of the participation chain need to be effectively strengthened and connected to one another. This is an exercise that demands continuous attention and investment.

3.5 Summary

In this chapter we reviewed the literature concerned with the enablers and inhibitors of participation and introduced the theoretical framework which will be used to discuss what facilitates and constraints mental health care users' participation in the Netherlands and Brazil. In our view, the Mutual Incentives Theory and the participation chain model (Simmons and Birchall, 2005) provide a good theoretical support to study user engagement in hybrid participatory spaces and do justice to other relevant insights afforded by new social movement theorists and citizenship and empowerment theory. Pertinent contributes of these theories will be combined with the participation chain model to assist our analysis.

As we have seen, participation can be undermined by many different barriers (e.g. lack of information, time and funding; insufficient skills and confidence; fatigue; fear of reprisal and exclusion; lack of transparency). These inhibitors at are the root of the problems of unawareness, self-exclusion and exclusionary dynamics which work to prevent people from participating. They also act to weaken the links in the chain of participation, undermining the sustainability of participatory initiatives. Counteracting these problems will most likely entail investment in the development of empowerment mechanisms and in the building of supportive networks that can assist people in acquiring the resources and confidence they need to act as agents. Indeed, empowerment, a sense of agency, and social networks have been presented as enablers of participation. However, as we showed, these enablers can rarely be just considered as causes of participation and they often emerge as part of its outcomes. In other words, some of the enablers of participation can also be considered as its benefits. In the next chapter we discuss the benefits of participation in greater detail.

4. Benefits of participation

In this chapter we elaborate the concepts and theoretical framework that will be used to discuss the benefits of participation for users themselves. Insofar as participation is encouraged by the collective and individual benefits individuals expect to get from it, there is an overlap between the enablers of participation addressed in Chapter 3 and the benefits outlined in this chapter. Analytically, however, it makes sense to distinguish between enablers and benefits since the former are determinants of participation and the latter are effects.

As we showed in Chapter 2, arguments for participation centre on the ideas that participation is a right and a practice that can deliver a number of substantive benefits. Citizen participation in governance is believed to "make for better citizens, better decisions and better governments" (Cornwall and Coelho, 2007: 4). Where health is concerned, user participation is expected to have positive impacts at two levels. On the one hand, participation is thought to lead to more responsive policies and more accessible, acceptable and cost-effective services. On the other hand, participation is assumed to promote the health and quality of life of participants by enabling them to gain awareness of health problems, acquire health knowledge, get access to appropriate care and become involved in their own treatments. These gains can also be extended to non-involved members of participants' communities helping to reduce feelings of alienation, particularly among those who have been under-served and disempowered (Beresford and Croft, 1993; Dujardin, 1994; Zakus and Lysack, 1998; Frankish *et al.*, 2002; Coelho, 2007). Summing up, participation is thought to be beneficial for both governance and people. Or as Ann Richardson (1983) argues, participation can generate both instrumental and developmental benefits.

Despite the potential of participation to foster transformation and the existence of many projects across the world that implement this idea, empirical studies of its effects on the quality and accessibility of health care and on people's health and wellbeing are still limited (Zakus and Lysack, 1998; Crawford *et al.*, 2002; Simpson and House, 2002; Rose *et al.*, 2004; Nilsen *et al.*, 2006). Our study aims to fill in part of this lacuna by evaluating the benefits of participation for users themselves. We will do so by looking into how user involvement in mental health services and projects is regarded as impacting on the lives of participants, both at a personal level and in terms of their relationship to the wider society.

Gaining more insight into the benefits of participation can help not only to strengthen the case for increased user participation but also offer valuable hints on how to design more inclusive participatory initiatives. As we have seen in the previous chapter, people's decisions to become involved, and whether or not they stay engaged, are influenced by individualistic and collectivistic incentives, mobilisation strategies, the availability of resources and the very dynamics of participation (Simmons and

Birchall, 2005). Knowing more about what incites people to participate can inform participation advocates about the kind of motivations they need to appeal to, the sort of support they need to provide (e.g. resources and training), and the kind of dynamics they need to promote (e.g. transparency, accountability), when seeking to involve a broad group of people in new participatory initiatives, in a way that is both transformative and sustainable.

In the remainder of this chapter we present the core findings of studies focused on the impacts of participation on involved mental care users. As we will show, some of those studies demonstrate that involvement generates benefits which, in turn, enable users to pursue higher levels of participation. This is the case of benefits such as increased personal empowerment, agency and broader social networks. Subsequently, taking as a starting point the benefits participation is expected to deliver, we discuss its potential to promote participants' health literacy, access to care and social inclusion. In the last section of this chapter, we provide the analytical framework that will be employed to assess the impacts of participation on users. Our framework is largely based on the insights afforded by Ann Richardson (1983) concerning what she termed the 'developmental benefits' of participation and on the works of other political theorists concerned with the effects of political participation such as Carole Pateman (1970) and Benjamin Barber (1984).

Before continuing, it is important to note that participation can also have negative impacts on users. Indeed, participation has costs that not all people are able to bear and that prevent many from participating. Since we discussed those costs (e.g. time, money, criticism, stigmatisation, stress, etc.) in Chapter 3, here we will only focus on the benefits of participation.

4.1 Benefits of participation for involved users

Although there is relatively little empirical evidence of the impacts of participation on involved mental care users, the studies available show that participation in mental health care services, self-help and advocacy groups and/or community-based projects can benefit engaged users by enabling them to:

- have their voices heard and personal competences recognised (Barnes and Wistow, 1994; Barnes, 1999; Honey, 1999)
- socialise: opportunity to contact with new people who may share similar experiences (Barnes and Wistow, 1994)
- acquire information and knowledge about their rights and the workings of the health care system (Honey, 1999)
- develop social and communication skills (Barnes and Shardlow, 1997; Honey, 1999)

- improve their self-esteem and self-confidence (Barnes and Wistow, 1994; Summers and McKeown, 1996; Barnes and Shardlow, 1997; Honey, 1999)
- increase their self-reliance (Smith, 1984)
- regain a sense of control over their lives (Barnes and Wistow, 1994)
- gain employment (Barnes and Shardlow, 1997)
- reassert their identities as citizens and practice their citizenship (Barnes, 1999)
- develop a group identity (Barnes and Wistow, 1994)
- empower themselves (Honey, 1999)

The benefits identified by these studies support our assertion that the enablers of participation discussed in Chapter 3 can work both as antecedents and consequences of participation. This is especially the case with personal empowerment, the formation of collective identities and the ability to practice one's citizenship. Other enablers such as personal agency and broader social networks are not explicitly identified as benefits by the studies reviewed. However, it can be inferred that some of the reported benefits may foster those enabling processes. As users experience having their voices heard and recognised, feel more self-confident and regain a sense of control over their lives, they may come to believe that they can make a difference and behave as agents. In a similar vein, as users develop social and community skills and begin to make contact with new people they may come to experience an expansion of their social skills and networks. Personal empowerment, collective identity, personal agency and social networks thus needed to be viewed as both enablers and benefits of participation.

Since we discussed these enablers/benefits at length in the previous chapter, in this sub-section we confine attention to other potential benefits. As noted earlier, people's participation in health decision-making is expected to lead to improvements in their health and quality of life by fostering access to health knowledge and adequate health care and by reducing feelings of disenfranchisement among under-served, voiceless communities (Beresford and Croft, 1993; Dujardin, 1994; Zakus and Lysack, 1998; Frankish *et al.*, 2002; Coelho, 2007). This is to say that participation can have a positive effect on the promotion of people's health literacy, access to care, and social inclusion. In what follows, we discuss each of these concepts in greater detail.

Health literacy

The term health literacy draws from the concept of literacy (i.e. the ability to read and write) and assumes a broader definition which includes literacy, cognitive and social skills. Health literacy can be described as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker, 2000: ix).

The notion of health literacy was first employed in the 1970s (Ratzan, 2001) and it has since received increasing attention, particularly from the late 1990s onwards (see Ishikawa and Yano, 2008). Underlying the concepts' growing popularity appear to be at least three general developments: demands by care users for the democratization of health care (including the availability of health information, laws on informed consent and participation in health care planning); the ongoing shift from traditional doctor-patient relationships (characterised by information asymmetries favouring the professional end) to more symmetrical relationships (involving shared health care decision-making between service providers and users); and increasing recognition by national and international health agencies of the crucial role played by lack of health literacy in determining health inequities (Nutbeam, 1998; 2008; WHO, 2007).

All these developments highlight the importance of access to and adequate understanding and use of health information. As various studies show, low health literacy is associated with poor health status (Weiss *et al.*, 1992), less use of preventive care (Garbers and Chiasson, 2004), higher rates of emergency care visits and hospitalisation (Baker *et al.*, 2002; 2004), higher medical costs due to use of an inefficient mix of services (Howard *et al.*, 2005) and less involvement in health care decision-making (Mancuso and Rincon, 2006).

Although access to information is crucial to start solving these problems, getting more information *per se* is not enough to improve health literacy. In fact, as Ishikawa and Yano (2008) note, more information can actually have a disempowering effect upon some people. The boom of health information sources (e.g. self-help books, media reports, Internet sites) observed in the past decades, and the ease with which their contents can be disseminated among the general public, can lead people unable to assess the quality of that information to feel confused and powerless. Furthermore, as calls for patients to take greater responsibility over their health intensify and treatment options increase, it is no longer sufficient to get information. Health care seekers need to be able to interpret and use that information appropriately if they are to get the best possible health outcomes. Health literacy thus entails the capacity to assemble, qualify and employ health information to the advantage of the wellbeing of individuals and of communities more generally. This multi-dimensional approach is reflected on the definition of health literacy proposed by the WHO:

> Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. (…) Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions (Nutbeam, 1998: 357).

Seen from this perspective, health literacy involves not only the cognitive capabilities necessary to understand, analyse, and apply health information to decision-making concerning one's health, but also the social competences required to act upon those decisions both in the more personal context of service delivery (e.g. navigation through the health care system, interaction with health care providers and participation in care planning) and at a community level (e.g. promotion of healthy environments and behaviours) (Ishikawa and Yano, 2008; Nutbeam, 2008). Put more simply, health literacy is not just about knowledge but about the ability to make use of it.

These insights reflect elements of a model of literacy composed of three distinct levels:

- Functional/basic literacy: sufficient basic skills in reading and writing to be able to function effectively in everyday situations;
- Communicative/interactive literacy: more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances; and,
- Critical literacy: more advanced cognitive skills which, together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations (Freebody and Luke, 1990 cited by Nutbeam, 2000: 263-264).

When applied to the field of health, progression between these three levels of literacy goes with a greater degree of autonomy and personal empowerment in decision-making, as well as increasing capacity to engage in collective action concerned with health promotion (*ibid.*). Health literacy can be developed through people's own personal experiences with ill-health and health care and through health education. Promoting the highest level of health literacy, i.e. critical literacy, calls upon the development of health education programmes that focus not just on encouraging healthy lifestyles, increasing the ability to negotiate adequate health care, and fostering individual compliance with health treatments but also on developing the skills necessary to examine and act upon the social determinants of ill-health (Nutbeam, 2000; 2008).

Access to care

Equity of access to health care is a central goal of many health care systems and health advocacy groups across the globe. The first studies on access to care date back over half a century with research so far resulting in several hundred publications (Gulzar, 1999; Goddard and Smith, 2001). In general terms, access can be understood as a function of the interaction of at least three sets of factors: entitlement/information (i.e. whether people have the right to health care and the necessary information to use health services); availability (i.e. whether services are on offer and people are able to reach them); and, acceptability/quality (whether the services received meet the needs of care seekers in a way they consider efficient and satisfactory).

Barriers to access have been documented for various social groups in different countries (Goddard and Smith, 2001; Ensor and Cooper, 2004; Ingleby *et al.*, 2005). 'Demand side' barriers may include lack of health knowledge and information about services, health beliefs averse to the use of certain types of care, mistrust of providers, insufficient financial resources and/or social support to deal with costs of service use (e.g. financial costs, stigmatisation), etc. 'Supply side' barriers may include service unavailability, poor quality of care delivered, institutional discrimination, etc.

Despite widespread interest in the topic, there is no generally accepted definition of access (Oliver and Mossialos, 2004). Sometimes, utilisation of health services is used as a proxy for access. Measures of utilisation, however, are problematic, both methodologically and conceptually (Goddard and Smith, 2001; Dixon-Woods *et al.*, 2005). They not only rely on untested normative assumptions about the 'correct' level of utilisation, they are also often based on estimates of 'need' which is a construct difficult to conceptualise and to measure appropriately (Dixon-Woods *et al.*, 2006). To give but one example, the number of contacts with mental health professionals can be employed as a measure of utilisation of formal mental care services by a particular social group. Yet these contact rates might not indicate correctly the amount of care received. People from that group may prefer to resort to less conventional help-seeking pathways that grant them access to alternative care. In that case, the idea that they under-utilise 'needed' services might be incorrect. They may simply be using a type of care (i.e. informal care) that falls outside the scope of standard measurements.

Seeking to deal with the shortcomings of current approaches to access, and in particular those focused on measures of utilisation of services, Dixon-Woods and colleagues (2005) developed a new theoretical conceptualisation of access to health care. At the core of their theoretical account is the construct of 'candidacy'.

> Candidacy describes the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services. Candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, and managed in the context of operating conditions, including the biography of the relationship between patients and staff, the typifications staff use in categorising people and diseases, availability of resources, local pressures, and policy imperatives (*ibid.*: 85).

Seen from this perspective, access to health care is the outcome of the "dynamic interplay between the simultaneous, iterative and mutually reinforcing processes" that influence claims to candidacy, and ultimately combine to determine whether or not people receive appropriate health care (Dixon-Woods *et al.*, 2006: 44). Although very important, candidacy is not the only determinant of access. In order for people to be candidates to health care, health services need to be available and properly resourced and staffed, potential users need to be entitled to utilise them, and the services received have to meet their health care needs in a satisfactory way. Yet even when people are entitled to the use of a comprehensive health care system gaining access to care is still a laborious endeavour which requires users to make considerable efforts. The amount, difficulty and complexity of those efforts may work as barriers to receipt of care. Identifying how, where and when people feel vulnerable in their candidacy (i.e. in their negotiation for medical attention and intervention)is expected to afford a better understanding of access (*ibid.*).

The process of getting access to health care involves different stages of action and negotiation which are influenced by an interplay of several factors. According to Dixon-Woods *et al.* (2005; 2006), these factors include the identification of candidacy, navigation of the health care system, permeability of health services, appearances at services, professional adjudications, and acceptance of or resistance to offers of care. Each stage of the process is subjected to barriers that can block progression. In what follows, we provide a description of the factors which influence access to care based on the explanation provided by Dixon-Woods and colleagues (*op. cit.*).

Identification of candidacy

The first step people need to take in order to use health care is seeking help, i.e. identifying and presenting themselves as having needs to which health care services can respond. In other words, people need to recognise themselves as potential candidates for health care and act on that candidacy so as to commence the process of gaining access to care. Claims for candidacy, and the help-seeking practices they entail, are influenced by a broad range of factors including information, knowledge and beliefs about ill-health and health services, confidence regarding the ability to self-manage health problems (including self-diagnosing, self-medicating and self-treatment), social and professional support regarding decisions to seek help, practical resources, degree of agreement between professional and lay definitions of ill-health, users' perceptions of availability and quality of services, professionals and users' interpersonal and language skills and power relations.

Navigation

Navigation refers to the pathways people take from the moment they ascribe themselves candidacy to the point of gaining entry to health services. Navigating toward the health care system requires the mobilisation of a set of resources and competencies which may not be equally available to the whole population. Awareness about the services on offer and access to the practical resources necessary to reach them (e.g. transportation, time off work, child care) are key at this stage.

Permeability of services

Health care services can be characterised as more or less permeable depending on the amount of effort users need to make in order to use them. Porous services involve few qualifications of candidacy, are easily negotiated and allow people to gain entry in a rapid and almost effortless manner. Emergency care units are an example of this type of services. Its use does not require appointments, (health) literacy or social skills.

Less permeable services, on the other hand, require confirmation of the candidacy of individuals (e.g. referral), are difficult to negotiate, and demand several resources and competencies on the part of users (e.g. a stable address, health literacy, being able to keep appointments). Specialist consultations in hospitals are an example of this type of services.

Appearance at services

Appearance refers to people presenting themselves at services. By making an appearance people assert their claim to candidacy for professional attention and intervention. Claiming candidacy entails efforts on behalf of users which require certain competencies such as the ability to formulate and articulate the problem for which care is being sought, the ability to present need for care in a credible way, and the capacity to be assertive when negotiating the care to be received. The self-confidence necessary for users to speak and act in a clear and assertive way during health care encounters is not only influenced by their cognitive and social skills but also by perceived and real social and cultural differences between themselves and providers. People with a low socio-economic status, for example, may experience intimidation in the presence of health professionals they perceive as more knowledgeable, wealthy and powerful. Providers may also treat them differently on the basis of their own perceptions of the social and cultural differences which distinguish them. Power relations, thus, play an important role at this stage.

Adjudications

Adjudication refers to the judgements made by professionals about individuals' claims of candidacy for service. Professional judgements carry considerable weight in facilitating or inhibiting progression of candidacy. Such adjudications tend to be influenced by the conditions in which professionals work, the amount of care resources available (e.g. staffing, technical resources, staff), and professionals' perceptions of who is likely to benefit the most from interventions. This latter aspect concerns judgements about what is worthwhile for candidates. People who are active in the labour market and who have a healthy lifestyle may be considered more eligible for interventions than people who engage in risky behaviour (e.g. smoking, over-eating), are less economically active or are very old.

Offers and resistance

The last stage of negotiation for access entails the making (or not) of an offer of intervention or service. It is important to note that non-utilisation of services is not always a result of non-offers. Potential users may reject the offers made (e.g. medication, mental health care) and in that way start a re-negotiation for (e.g. second opinion), or terminate the process of, gaining access to care.

Social inclusion

Social inclusion can be broadly defined as feeling part of society, i.e. being allowed and enabled to take part in a range of life domains including social relationships and activities, education, the labour market, consumption, leisure and recreation, and decision-making (Davis and Hill, 2006). Conversely, its antithesis social exclusion can be understood as the inability of individuals to participate effectively in key activities of the society in which they live (Burchardt *et al.*, 2002).

Social exclusion is a relatively recent expression coined by the French Secretary of State for Social Action, René Lenoir, in the 1970s to refer to the poor and other 'social misfits' of French society falling through the net of social protection (Silver, 1994). As recent as the expression may be, it conveys old ideas about the negative effects of poverty and destitution on individuals and society itself. Starting in the 1970s, and gaining impetus from the late 1990s onwards, the reduction of social exclusion has become an explicit part of social policy in various European countries (Burchardt *et al.*, 2002). It has also gained prominence in the field of health promotion, particularly among those concerned with the social determinants of health inequities (Labonte, 2004). At present, the concept 'social exclusion' accommodates different kinds of social disadvantage that go beyond mere economic deprivation (Burchardt *et al.*, 2002; Scharf *et al.*, 2005) to include deprivation in at least one of the following dimensions:

- Material resources: the capacity to purchase goods and to participate in economically or socially productive activities, including education and volunteer work
- Social relations: engagement in meaningful social relationships with others
- Civil activities: involvement in decision-making processes at the local or national level
- Basic services: access to public services, including health and social care
- Neighbourhood affiliations: sense of belonging to and identification with a local community and participation in community life (Scharf *et al.*, 2005: 78).

Each of these dimensions corresponds to an outcome that is relevant in its own right (Bruchardt *et al.* (2002). For maximal social inclusion individuals need to be able to participate in all five dimensions. Non-participation in any one of these dimensions is sufficient for social exclusion. Social exclusion thus can be seen as a matter of degree: the more life domains individuals find themselves unable to participate in, the greater the extent of their exclusion (*ibid.*).

The study of social inclusion/exclusion has particular relevance for people affected by psychosocial problems. People diagnosed with severe mental illness are among the most marginalised groups in society (Sayce and Measey, 1999; Sayce, 2000; Nelson *et al.*, 2001). Low income, unemployment, poverty, poor housing, lack of social networks and loss of social status all work to undermine the inclusion of people affected by mental ill-health, increasing disability further and placing enormous barriers to recovery (Perkins and Repper, 1996; Sayce, 2001). According to Sayce (2001), social exclusion as experienced by mental health care service users needs to be conceptualised "as the interlocking and mutually compounding problems of impairment, discrimination, diminished social role, lack of economic and social participation and disability" (Sayce, 2001: 122). Efforts to promote their social inclusion, thus, inevitably entail access to mental health care. However, this is by no means sufficient. Improved access to work, education, family, friendship and social relationships, religious or cultural groups, meaningful roles and decision-making is required if the negative effects of exclusion are to be tackled and social inclusion is to be achieved (*ibid.*). Such a multi-sectorial approach is, of course, not only relevant for people affected by psychosocial problems but for all socially excluded groups.

4.2 A framework to assess the benefits of participation for users

According to Ann Richardson (1983), participation can deliver two distinct types of benefits: *developmental* benefits related to the individuals who participate and *instrumental* benefits associated with the quality of decisions taken by or for a particular group. In other words, participation is believed to have positive effects both on the wellbeing and behaviour of participants and on the quality of governance processes. Given our focus on the impacts of participation on users themselves, our discussion of the benefits attached to participation will centre exclusively on developmental effects[48].

Richardson (*op.cit.*) argues that participation has the potential to generate at least five developmental benefits for people directly involved in participatory initiatives. These include improved self-esteem, increased competencies and self-efficacy, a developed sense of own interests, an increased sense of self-expression and social integration.

First, participation ensures those involved a sense of dignity and self-esteem. By creating opportunities for lay people to have a say on their own affairs, government,

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[48] The instrumental benefits of participation include organisational efficiency and political legitimacy. For a detailed account of this type of benefits see Richardson (1983: 60-67).

institutions and service providers send out a powerful message that their views matter and that they can make valuable contributions. Participation can indeed be seen as an active expression of a belief in the dignity and worth of individuals. This not only has the potential to make people feel good about themselves, it can also provide them with a sense of freedom. As Carol Pateman (1970) argues "the individual's actual, as well as his sense of, freedom is increased through participation in decision making because it gives him a very real degree of *control* over the course of his life and the structure of his environment" (*ibid.*: 26, emphasis in the original). Participation thus can enable people to experience a heightened sense of self-worth as well as a sense of mastery over their lives. In other words, participation can foster empowerment (Higgins, 1999).

Second, participation has an educative function. Through involvement in participatory initiatives individuals get a chance to acquire new competencies by learning about new issues, finding new strategies to cope with problems and developing negotiation and deliberation skills. This is likely to increase their self-confidence to negotiate solutions to problems in other spheres of life. People with an experience of participation in governance may find themselves more able to take an active role in the unions which represent their interests and the interests of their fellow workers. They may also, for example, come to perceive themselves entitled to and more capable of participating in health promotion programmes or even in their own treatment. Health providers engaged in decision-making processes regarding service planning, delivery and evaluation may also find themselves more sensitive to users' own needs for involvement and more empowered to support the latter in getting a voice. Indeed, participation has the potential to enhance individuals' sense of self-efficacy (i.e. their perceived ability to influence the outcome of decisions), not least in the field of health. Furthermore, substantive participation puts participants right at the core of decisions that have a bearing not just on their lives but on the lives of others. This enables participants to realise the interdependency of individuals in society, to learn about the difficulties involved on the making of public decisions, and to become more accepting of decisions made collectively. The educative role played by participation lies greatly in offering participants a training ground where they can develop the qualities necessary for its practice (Pateman, 1970; Barber, 1984), while at the same time inducing a notion of citizenship as practice, instead of just a set of rights (Lister, 1997).

Third, participation enables people to realise their own interests. By engaging in decisions which impact on their lives individuals are led to learn about themselves and about their real needs so they can form preferences and take stands that not only mirror their values and beliefs but also afford the promotion of their best interests. Warren (1992) takes this a step further claiming that participation has a unique capacity to develop individuals' autonomy, something he considers crucial for self-governance and public governance alike:

> Autonomy describes a capacity of judgment: individuals are autonomous if their preferences, goals, and life plans are not the result of manipulation, brainwashing,

> unthinking obedience, or reflexive acceptance of ascribed roles but, rather, a result of their examining and evaluating wants, needs, desires, values, roles, and commitments. (…) Autonomy is not only desirable for its own sake but essential to the mechanisms of representation and voting that make large-scale democracies possible, since the legitimacy of these mechanisms depends on people's knowing what they want (*ibid.*: 11-12).

The fourth benefit of participation framed by Richardson is concerned with self-expression. Participation provides people an opportunity to express their views on policy issues, which would otherwise remain circumscribed by the indirect way by which preferences are expressed through voting. In addition, participation enables people to raise their wants, needs and desires to the level of consciousness and speech, increasing their sense of identity (Warren, 1992). As Barber (1984) puts it, "participation is a way of defining the self" (*ibid.*: 153). When people perceive themselves as part of a group they identify with, and which can act together to advance their interests, a collective identity may emerge which, in turn, reinforces their participation (Melucci, 1996).

Finally, participation fosters social integration. When citizens are called to engage in the co-production of policy and services an opportunity rises for the achievement of a sense of belonging and identification with a group or community which are crucial for social inclusion. Participation enables people to come together and to become aware of concerns and interests that may or may not be similar to their own. These encounters can lead to the formation of what social network theorist Granovetter (1973) termed weak ties, i.e. social ties between acquaintances that are characterised as distant and marked by infrequent interaction but which work as relevant channels of innovation. Participation also encourages citizens to appreciate each other's point of view and to devise solutions for (common) problems on the basis of negotiation and compromise. This, it is suggested, is likely to lead citizens to ascribe greater legitimacy to the decisions made within participatory institutions and to make them more willing to comply with them (Pateman, 1970), to the greater benefit of communities and society as a whole.

4.3 Summary

In this chapter we reviewed the findings of studies concerned with the benefits of participation for mental health care users. We also introduced the theoretical framework which will guide our discussion of the impacts of participation on users themselves. Our framework is inspired on the model of developmental effects of participation proposed by Ann Richardson (1983) who argues that citizen participation can lead improved self-esteem, increased competencies and self-efficacy, a developed sense of own interests, an increased sense of self-expression and social integration. Based on this model, and on a preliminary analysis of our data, we hypothesise that user participation has the potential to generate a number of substantive benefits including empowerment, broader social networks, increased sense of citizenship and agency, enhanced health literacy, improved access to care, and social inclusion. The extent to which each of these benefits is experienced by the users involved on the participatory projects we investigated will be analysed in Chapter 8.

In the next chapter, we provide an overview of the empirical fields – user participation in a community-based mental health project in Rotterdam and in a mental health care service in Rio de Janeiro – in which our fieldwork took place, giving particular attention to the political, social, economic and geographical specificities of each site.

5. The fields of research

In the following chapters of this thesis we present the empirical research on service user participation in mental health carried out in the Netherlands and in Brazil. Our principal research settings were Project Apoio – a community-based mental health advocacy project in Rotterdam developed to foster the access of Cape Verdean immigrants to mental health care; and CAPS Pedro Pellegrino – a community-based mental health care service in Rio de Janeiro with a high incidence of descendants Northeastern internal migrant users.

We opted for doing research with these two particular groups primarily because they are an example of success amongst the least represented social groups in the Dutch and Brazilian health participatory spheres (i.e. ethnic minorities and/or people with low socio-economic status, SES). Cape Verdeans are one of the few ethnic minorities in the Netherlands engaged in participatory activities concerned with mental health promotion, something which was accomplished through Project Apoio. Northeastern migrants and their descendants tend to be excluded from health governance mostly due the negative effects of low-SES on user participation in Brazil. CAPS Pedro Pellegrino has succeeded, however, to promote their involvement in service planning and evaluation and to foster their engagement in invited and autonomous participatory spaces outside its own domain (e.g. user movement and health conferences).

Despite the exceptional nature of these groups' representation in the health participatory arena, they are still in a position of disadvantage where mental health care use is concerned. Both Cape Verdeans in Rotterdam (De Freitas, 2005; 2006) and Northeastern migrants in Rio de Janeiro appear to experience limited access to mental health care[49]. Such disadvantage (and its underlining causes, i.e. poverty, lack of information, inability to navigate health care system, etc.) may well be inhibiting a broader representation of members of those groups in other participatory spaces (e.g. health and client councils). Focusing on initiatives designed to promote their participation in health has afforded us a privileged standpoint from which to examine why service users seek to get engaged, the barriers they experience in sustaining involvement, and the benefits they rip from participation. Participation in health is ultimately about the promotion of equity and the best possible standard of health for highly diverse populations[50]. Inquiring about the involvement of people who have been traditionally at the margins of mainstream society can offer a more nuanced

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[49] To our knowledge there are no studies reporting on the access of internal migrants to health care in Brazil. Nevertheless, based on secondary sources, it is possible to infer that Northeastern migrants in Rio de Janeiro experience limited access to (mental) health care. We make this argument in section 5.2.

[50] We use the term "diverse" here not just to refer to ethnic and cultural differences but also to differences in age, gender, socio-economic status, religion, sexual orientation, etc.

understanding of the challenges to and successes of participatory health governance, and inform strategies to achieve a truly plural citizen voice.

This chapter introduces our fields of research. We look first into the case of the Netherlands, reviewing recent developments in health care policy and delivery which render evident the need for user participation, and more specifically for the participation of migrants and ethnic minority users. We then describe Project Apoio and the ways by which it succeeded to get Cape Verdean immigrants involved in its participatory initiatives. Following this, we turn to the case of Brazil focusing on the problems that thwart the access of people with a low-SES to health care and how the absence of migrant health policy may be putting low-SES internal migrants in a position of double vulnerability. We conclude by describing CAPS Pedro Pellegrino and the ways by which it fostered the participation of second generation Northeastern migrants in both invited and autonomous health participatory spaces.

5.1 Migrant and ethnic minority user participation in mental health in the Netherlands

Dutch mental health care users began to devise collective actions aimed at democratizing the mental health care system in the early 1970s and have since participated increasingly in the planning, implementation and evaluation of mental health care policy and delivery. As we saw in Chapter 1, their involvement influenced the creation of a number of laws which turned participation into an inalienable right of all users. At present, there is a wealth of invited, autonomous and hybrid participatory spaces, including health conferences and meetings, client councils, client organisations, user-led mental health services, user-led mental health training, self-help groups, health promotion community-based projects, etc. Users have the right to participate in their own care treatment plans and to seek advice and issue complaints in case of inappropriate care delivery. And the user movement has been officially acknowledged by the government as the ‘third party’ in the implementation and evaluation of mental health care, along with the other two ‘market agents’ (i.e. care providers and insurance companies). User participation has without doubt enjoyed considerable progress in the Netherlands[51].

However, the picture is not all rosy. As in other countries, including the UK, the US, and Australia, neither invited spaces nor the user movement have yet succeeded in becoming fully inclusive. Migrants and ethnic minorities (MEMs) are the most visibly under-represented groups in the Dutch health participatory sphere (De Savornin Lohman, 2000; Nederland and Steketee, 2004). To use the words of one of the participants in this study: “the user movement is a white movement” (Expert by

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[51] Even though the expansion of the Dutch health participatory sphere is an undeniable fact there are still some problems regarding the degree to which power over health care decision-making is distributed between the different market agents in health care decision-making (see Chapter 2).

experience 2, NL), and this pretty much sums up the picture everywhere else in the mental health participatory arena.

MEMs make up 20% of the Dutch population (CBS, 2010). Failure to guarantee their representation in health participatory institutions is particularly worrisome in a time in which, as a result of the intensified marketisation of health care, health care users are expected to act as informed consumers, organised lobbyists and involved citizens in the making of health care policy and in the development and evaluation of care programmes capable of responding to the needs and wants of an increasingly diverse population. Moreover, in 2004, in a clear rupture with policy issued just a few years before, the Dutch government stopped considering the promotion of diversity competent health care one of its responsibilities. It is now up to the market agents to decide the extent to which investments in the 'interculturalisation' of health care will be made. Again, this stresses the importance of making the health participatory sphere more receptive to MEM users. Before continuing with this discussion it is relevant to provide a few more insights on the phenomenon of interculturalisation of health care in the Netherlands.

Intermezzo: Interculturalisation of health care

The notion 'interculturalisation' was coined in 1991 to characterise efforts made from the 1970s onwards to provide health and social care services that "are equally accessible and effective for migrants and ethnic minorities as for clients from the cultural majority" (Ingleby, 2006b: 1). The term 'interculturalisation' is a direct translation from the Dutch term *interculturalisatie*. The label never caught on in other countries but in the Netherlands interculturalisation is widely recognised as a movement seeking to improve the access and quality of care for MEMs (Ingleby, 2006a).

Until the mid 1970s, the needs of MEMs for health care, education and other social services were largely ignored (Ingleby, 2006b). MEMs were expected to adapt to the services available to the mainstream (Van Dongen, 2003). This was very much a reflection of the Dutch government political stand on migration at the time. The migrants with the most problems of integration were the 'guest workers'[52], but the assumption was that these people would soon or later return to their home countries. When in the mid 1980s the vulnerable social position of those migrants and their permanent stay in the Netherlands became inescapable the Dutch government changed its approach and began to develop integration policy (Vermeulen and Penninx, 2000). 'Guest workers' were relabelled 'ethnic minorities' (Rath, 2000) and their particular needs started being taken into account. In the health care field, care providers were stimulated to acquire expertise on migrant health and to deliver diversity competent

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[52] During the 1950s and the1960s the Dutch government recruited low-skilled workers from Turkey, Morocco and Southern European countries. These migrants were officially designated *gastarbeiders* or 'guest workers'. Until the 1980s, the government refused to recognise the Netherlands as an immigration country, arguing 'guest workers' were temporary migrants (Vermeulen and Penninx, 2000).

care. ‘Cultural knowledge’ and measures to overcome language barriers were seen as necessary tools to provide adequate care to MEMs and educate migrants about health and the Dutch health system. However, care providers received no specific guidelines on how to bring cultural sensitivity to care provision. The arrival of a large number of asylum seekers from many different countries during the 1990s led to the realisation that it was impossible to have a ‘toolkit of cultural knowledge’ for every single group (Van Dongen, 2003) and that a systematic approach was needed.

In the late 1990s, advocates of interculturalisation published a manifesto pleading for structural policy on the implementation of diversity competent care (see Van Dijk *et al.*, 2000). The manifesto was especially aimed at mental health care; a sector in which MEMs’ limited access to service provision was particularly evident. Among the main claims made was the need for the mental health care system to become more reflexive about its own practices, to reach out more actively to MEM users and to engage MEMs in the development of mental care services (*ibid.*).

In 2000, the Council for Public Health and Health Care (RVZ) released two critical reports (see RVZ, 2000a; 2000b) on the health problems of MEMs and the shortcomings observed among health care services in providing adequate responses to their needs. As a response, the then Minister of Health Els Borst announced the creation of a national Project Group assigned with the task of developing a strategy for the interculturalisation of health care. Subsequently, a four-year Action Plan (2001-2004) for interculturalising of mental health care was launched and an Intercultural Centre of Mental Health Expertise (Mikado) was created (Ingleby, 2006b). These were amongst the most explicit actions ever taken by the Dutch government to promote the development of diversity competent health care. It seemed that, after years of struggle, the interculturalisation movement had finally thrived in its intents.

Returning to the issue of migrant and minority user participation, the early 2000s were without doubt a period of great enthusiasm regarding the development of strategies to tackle ethnic disparities in mental health and promote good health care for all. Much work had still to be done, however, to enable MEM users to have a voice in these affairs. Yet few client organisations and mental health care services (through their client councils) succeeded in embracing the ‘multicultural participatory project’. Basisberaad GGZ Rijnmond was one out of a handful of client organisations accomplishing the implementation of a sustainable participatory project for migrant users – Project Apoio. Project Apoio was specifically designed to reach out and engage Cape Verdean immigrants in mental health promotion. The project ran between 2000 and 2009 when Basisberaad GGZ Rijnmond was extinct.

In 2001, the Dutch government issued the ‘Choose with care’ memorandum (see Ministerie van VWS, 2001) in which it asserted its commitment to support users’ representatives (i.e. client organisations) in improving their bargaining power in health care decision-making. In the memorandum, special reference was made to the case of MEM users’ participation. Acknowledging the problem of their under-representation in participatory institutions, the government assigned the Dutch care research organisation ZonMw and several client organisations the tasks of evaluating MEMs' needs and promoting their interests in the health participatory arena.

Governmental support for migrant user participation and the interculturalisation of health care did not last long, however. Following the assassination of populist politician Pim Fortuyn, a right-wing government was elected in 2002. Discourse on migration shifted considerably. Some politicians claimed migrants had failed to integrate in Dutch society. However, 'integration' no longer meant acceptance of diversity and equity between 'cultures' but a step into 'modernity'. Migrants' culture (especially 'Muslim culture') was portrayed in the media as traditional and backward, in strong contrast with the 'modern' Dutch culture. The often repeated question of whether migrants were willing to integrate actually meant: are they willing to 'modernise'? Since then, MEMs have been overtly expected to adapt to the host society. In the field of health care, this was translated into the need for MEMs to become emancipated care users, i.e. to get familiarised with mainstream services and place care requests in an articulate and assertive way. They are also expected to act as consumers, evaluating and sensibly selecting the care that best suits their needs and, when necessary, create the demand for new types of care through lobbying.

This perspective on migration and migrant health, together with the growing emphasis laid on the application of market principles to health care, led Minister of Health Hans Hoogervorst to revoke the responsibility of national government for facilitating the development of diversity competent health care in 2004 (Ministerie van VWS, 2004). In practice, this meant the extinction of the national Project Group for interculturalisation and the reduction of governmental financial support to a minimal yearly subsidy of €150.000 for the development of intercultural expertise (RVZ, 2004). Since then, the market agents have the freedom to choose whether they want to invest in interculturalisation.

In the years that followed these changes, several regular mental health care institutions continued to develop intercultural policy and service provision (e.g. promoting intercultural training, employing bicultural professionals, making available interpreters and cultural mediators to MEM care users, etc.). Yet another piece of health care reform operated by the government in 2006 – the Health Insurance Act – brought an interesting twist to the Dutch health care field: the creation of categorical health care institutions, i.e. independent services developed for specific target groups.

The Health Insurance Act determines that all residents in the Netherlands have to buy individual health insurance coverage from a private insurer of their own choice[53] and enforces a provider-purchaser split in care provision. This measure has been accompanied not only by an increase in power of health insurance companies which are now the main sponsors of health care, but also by the lifting of a ban imposed

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[53] Until 2006, it was possible for residents in the Netherlands to take public health insurances through the government's 'Sickness Funds'.

earlier by government on the creation of categorical services (Van Mens-Verhulst and Radtke, 2009). These 'policy incentives' have certainly influenced the emergence of categorical mental health services for migrants (e.g. I-psy, NOAGG, etc.) but they are not its sole causes. The idea that in the absence of appropriate regular mental care provision for migrants an alternative must be created ('ideological incentives') and the wish to make health care delivery efficient and cost-effective ('economic incentives') are another two important determinants in the formation and increase of categorical services (May and Ingleby, 2008). Migrant users, on the other hand, can be looked at as providing 'indirect incentives': given their low participation, they are not actively pushing for separate care provision; however, they drop-out from inappropriate regular services, creating demand for new services.

So far, the principal instigators of categorical care appear to be service providers driven by the incentives just described. Health insurance companies may not have been at the origin of categorical services. However, they are a key funder of health care and their role in the development of categorical services is likely to grow in the future. The polyclinic created in 2010 for the Turkish community in Amsterdam – Vatan Kliniek – is an example of how insurance companies are already looking at MEMs as a new 'market niche'. Agis, a big health insurance company popular among migrants in the Netherlands, showed interest in becoming Vatan's sponsor from early on. After members of populist party PVV asked the Minister of Health to take action against the implementation of the polyclinic on the grounds of discriminatory practice, Agis bounced its offer to fund it (Zorgvisie, 01/12/2010). The Minister of Health refused to take any measures against Vatan arguing that the polyclinic is open for everybody, and that there already other hospitals in the Netherlands which also target for specific groups (e.g. the Amstelland Hospital created to serve the needs of the Jewish community) (*ibid*.). According to Vatan's website, negotiations with Agis are still going on (Vatan Kliniek, 2010).

This case highlights the complexity involved in the creation of categorical services. Aside from PVV members, others have expressed concern about this type of services, albeit on entirely different grounds (May and Ingleby, 2008). One of the issues raised is whether the other migrant groups (and, in particular, smaller groups) will benefit from the same amount of attention large minorities are receiving. If the trend to implement separate services continues, regular mental care services may come to see their teams depleted from diversity-competent providers. Moreover, the existence of alternatives may be used as an excuse for regular health care services to stop investing in the interculturalisation of care (*ibid*.). As we saw in Chapter 2, Dutch mental care services have long waiting lists and losing some of the so-called 'difficult' clients to categorical services may come as a blessing. This leads to several questions: How are MEMs to make sure each and every group gets their share of categorical services? Is it sensible and even feasible to think of creating specific services for each group? And if so, when will the 'minorities among minorities' see their health care needs satisfied? How group-specific can the care delivered within categorical institutions actually be (e.g. will a Turkish clinic be able to provide care to Kurd patients)? What say do MEMs have in these developments?

These questions do not have straightforward answers. The proliferation of categorical health services may well be supported in the future by both ideological arguments – 'MEMs need and should have their own services', and market arguments – 'MEMs have specific needs which justify the creation of new 'products'. But it is also possible categorical services will gradually disappear if they do not do a good job. For the time being, one thing seems to be clear: some MEM groups are much better positioned than others where demand for the creation of categorical services is concerned. Size, health-seeking behaviour[54], capability to lobby, the existence of MEM health care professionals in the host country, etc. are all variables that can further the chances of some groups over others. The Turkish community is an example of a minority which, albeit indirectly, is getting a voice (through the Dutch-Turkish medical doctors who set up the Vatan polyclinic). But what about MEM groups who are too small or who lack the capacity to organise in favour of their own interests? Who will speak for them? Will 'ideology' and the 'market' be enough to spiral the development of appropriate responses to their health care needs?

Advocates of health participatory governance will likely answer: "no, they will not". Health care users need to be an important driving-force in the planning, implementation and evaluation of health care policy and delivery as are 'ideology' and the 'market' at present in the Netherlands. Both health authorities and the user movement claim, however, that they lack the know-how and the resources necessary to assist MEMs in entering the Dutch health participatory sphere (Nederland and Steketee, 2004). In the next section, we describe Project Apoio and the ways by which it succeeded to get Cape Verdean mental health care users engaged in its activities.

5.1.1 Project Apoio

Project Apoio was created in 2000 to promote Cape Verdean immigrants' right and access to mental health care (Smulders, 2003). Up until that time, the Cape Verdean community not only had no voice in mental health care: it was also largely unknown to mental care providers. A relatively high rate of psychosocial problems (Huiskamp *et al.*, 2000) and the under-use of mental health services (Dieperink and Wiersdma, 2000) observed among Cape Verdeans revealed, however, a silent suffering, perceptible only to those concerned with groups at the margins of care. The stigma associated with mental illness, lack of information about mental health services, incompatibilities in

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[54] It is interesting to note that one of the arguments made by the Turkish medical doctors to set up the Vatan polyclinic was that many Dutch-Turkish patients (about 30.000 people per year) seek health care in Turkey and return to the host country with more prescriptions and exam results than they would get if they sought care in The Netherlands. This situation, Vatan's spokesman argued, is problematic not only because some Dutch-Turkish patients do not dare to take all the medicines they bring from the home country, but also because they pay their taxes and health insurances in the Netherlands and they should have access to good quality care (Parool, 20/09/2010). This is an example of how transnational health care seeking may get some groups to come under greater attention of categorical services' sponsors than others.

relationships with health professionals, and difficulties in navigating the Dutch health care system all contributed for Cape Verdeans' limited access to mental health care (De Freitas, 2005; 2006). Realising these problems, Basisberaad GGZ Rijnmond, the advocacy and empowerment organisation for mental health care users in Rotterdam, and Avanço Foundation, the umbrella organisation for Cape Verdean associations in the Netherlands, joined efforts to set up Project Apoio.

Apoio was a community-based intervention designed to bridge the gap between Cape Verdeans and mental health care services. Adopting a participatory and diversity sensitive approach, the project began by assigning a social worker of Cape Verdean origin the task of building a close partnership with the Cape Verdean community and pursuing its collaboration in the implementation of the project's main aims. These aims included the dissemination of information about mental health in the community, the provision of individual support to Cape Verdeans suffering from psychosocial distress and advocacy for diversity competent mental health care. In its nine years of activity, Apoio worked together with dozens of participants and assisted hundreds of clients from the Cape Verdean community. In 2003, it was acknowledged by the Intercultural Centre of Mental Health Expertise (MIKADO) as a good practice in the field of mental health and community care. In 2009, the client organisation which hosted Project Apoio – Basiberaad GGZ Rijnmond – declared bankruptcy and Apoio ceased to exist.

Apoio was by and large a product of the socio-cultural context in which it was created – the multicultural city of Rotterdam, where many advocates of interculturalisation are still based. With a population which surpasses 40% of MEMs, Rotterdam is home to the third largest Cape Verdean migrant community in the world. In what follows we provide a brief sketch of Cape Verdean immigrants in Rotterdam and return to the participatory activities promoted by Project Apoio in the section thereafter.

5.1.2 Cape Verdean migrants in Rotterdam

Cape Verdean migration to the Netherlands started in the 1950s (Gemeentearchief Rotterdam, 2002). At present, there are over 20.000 Cape Verdean migrants in the Netherlands, 80% of whom live in the region of Rotterdam (ISEO/COS, 2003; CBS Statline, 2009). Cape Verdeans are a minority group among ethnic minorities in the Netherlands, where the largest migrant groups (i.e. Turks, Moroccans and Surinamese) are well above 300.000 people.

Migration from Cape Verde[55] to the Netherlands can be described along three phases which are directly related to shifts in the immigration policy of the host country and political changes in the homeland. The first phase took place between the 1950s and the independence of Cape Verde in 1975. Among the first migrants were young men trying to escape the hardships caused by severe drought and poverty, or to avoid

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[55] Cape Verde has a population of approximately 500.000 people.

the military service imposed by the Portuguese colonial rule. Attracted by the good labour conditions offered by the Dutch merchant navy they started moving to Rotterdam. The post-war boom of the European shipping industry and the massive growth of the Rotterdam harbour served to consolidate the pace of arrival and by the late 1960s there were already 700 Cape Verdean seamen in the Dutch merchant fleet (Gemeentearchief Rotterdam, 2002).

The second wave of Cape Verdean migration began after independence. Unable to find a place within the new sovereign regime, a contingent of migrants composed mostly of former military staff, civil servants and school teachers left for the Netherlands. In a time in which Dutch immigration policy was beginning to tighten, many of the newcomers married Dutch citizens acquiring the right to permanent stay in the country (*Ibid.*). This period was also marked by increasing family reunification and by the start of another two migration flows: one composed by Cape Verdeans who had been recruited to work in Portugal in the 1960s (Pires, 2006); and another composed almost exclusively by Cape Verdean women who had been employed in Italy as domestic workers (Andall, 1999).

The first Cape Verdean multi-party elections held in 1991 marked the start of the third phase of migration, which was led primarily by educated young people seeking to further pursue their studies abroad. Cape Verdean women based in Italy and Portugal also continued to arrive. Yet Dutch immigration policy suffered another restrictive turn in the early 1990s: entering the country through family reunification became more difficult and undocumented migrants found it increasingly harder to find employment and to acquire residence permits after a period of illegality. As a result, marriage became one of the main ways of entry into the Netherlands. Similarly to what happened in the US after stringent immigration laws were enforced in the 1920s (Meintel, 1984), many of those unions were 'fixed marriages'. Aware of this unorthodox 'channel of entry' the Dutch government issued a law in 1994 determining income thresholds for sponsors soliciting family reunification and family formation (Holmes-Wijnker *et al.*, 2004).

Restrictions on family formation continued to increase in the 2000s. Between 1993 and 2006, the minimum income required from family formation sponsors almost doubled (Carling, 2008). In 2006, the Civic Integration Abroad Act was introduced stating that all non-EU migrants must have knowledge of the Dutch language and society prior to being admitted into the Netherlands. These measures make migration particularly difficult for people with a low education and scarce financial means, and may help explain the decrease of Cape Verdean migration to the Netherlands observed in the last decade (CBS Statline, 2009).

Cape Verdeans in the Netherlands are usually referred to as *stille migranten* or silent immigrants. This label was coined based on the perception that Cape Verdeans are a group of quiet, hard-working and self-reliant migrants, who fulfil their obligations but are less than assertive when it comes to claiming their rights. The Cape Verdean community has also been generally perceived as somewhat isolated. Its in-group orientation, relative small size and spatial concentration in Rotterdam have given the community little visibility, reaffirming its position as a minority amongst minorities. Nevertheless, whenever Cape Verdeans have become better known, they have usually benefited from a good reputation. In fact, in the early 1990s, immigration authorities described them as well-integrated, asserting that Cape Verdeans were one of the least problematic migrant groups in Rotterdam (Butte, 1991).

The image of silent immigrants attributed to Cape Verdeans has been framed, to a great extent, in relation to first generation immigrants. In recent years, the growth of the second generation and its participation in Dutch society has inspired a more ambiguous portrayal of the community. Young Cape Verdeans raised in the Netherlands do not experience the language barrier their parents did and mingle more with other ethnic groups. They are also credited for further developing and disseminating a genre of music produced by Cape Verdeans living in Rotterdam in the 1980s – *cabo zouk*, making their cultural heritage accessible to other groups. Another interesting aspect of the Cape Verdean youth is their focus in creating an identity of their own. Many youngsters identify themselves as *cabo*. Although this self-attributed designation finds little appreciation among some of the older Cape Verdeans, for the youth it works as a 'bridging' term able to capture both their ethnic roots and the bond they have with the Netherlands. Overall, these are positive developments which attest the community's increasing aperture to, and integration into, Dutch society. However, in the early 2000s, young Cape Verdean men were singled out by Dutch authorities for criminal behaviour (Butte, 2004). This caught both the community and the police off guard. Until then, there was almost no record of Cape Verdeans' involvement with crime and, as a Cape Verdean social worker explained: "the authorities had never come across Cape Verdeans. They didn't know us because we were *stille migranten*. They knew we lived in Rotterdam but we were kind of invisible. They had no problems with us" (De Freitas, 2006: 63). These events may have served to draw attention to the community but in a negative way.

The issue of invisibility brought up in the explanation above has also characterised the Cape Verdean community in the US. Until 1980, Cape Verdeans were not included in the American Population Census, even though they had been in the country for over a century. That lack of recognition can be partly explained by the small size of the Cape Verdean migrant population and its former colonial ties to Portugal. Yet, it was really 'race relations' which had the chief role in determining the identity ascribed to Cape Verdean-Americans. According to Marilyn Halter (1993), racial classification in the US has fallen historically within the oversimplified parameters of 'black' and 'white' and this dichotomy virtually obliterated cultural differences among people of colour. During the initial phase of settlement, Cape Verdeans in the US sought to be recognised as Portuguese-Americans. Yet, mainland Portuguese soon excluded them from their community. Identification with black Americans made little sense to Cape Verdeans who refused to accept a black identity. The outcome of this position and the ensuing lack of identification with one of the two ‘racial poles’ was a never-ending redefinition of their ascribed identity. Over the years, Cape Verdeans were characterised as “neither black nor white, but sometimes white, at other times black, African, Portuguese, brown, even green[56]” (Halter, 1993: 14). These irreconcilable identities placed them in a fragile social position, hampering their recognition as a distinct minority in the US and, subsequently, inhibiting their entitlement to state developed programmes and funds attributable on the basis of race/ethnic background.

In the Netherlands, the identification and recognition of ethnic minorities does not fall within the boundaries of ‘racial identification’. Instead, it is a matter of ethnicity and country of origin. The Dutch usually employ the term allochthonous to refer to migrants and their descendants. In its literal sense, the term means ‘originating from another country’. Yet, within public discourse in the Netherlands, the term allochthonous is usually applied to address only migrants from non-Western countries such as Cape Verde. Non-western migrants are often perceived to share a culture significantly different from (and, sometimes at odds with) that of the autochthonous population.

In spite of the differences in terminology and classification systems, a parallel can be drawn between the social position of Cape Verdeans in the US and that of Cape Verdeans in the Netherlands. As noted earlier, the label silent immigrants was attributed to Cape Verdeans, in part, because they are perceived as diligent and cooperative. Yet that label also derived from an idea of invisibility, capturing the essence of a community which, in its self-reliance, placed little demands on Dutch public authorities. It might have been for those reasons that there was hardly any mention of Cape Verdeans in migrant policy in the Netherlands until the mid-1990s. This absence should not be understood as entirely negative, for implicit in it was the suggestion of Cape Verdeans as a well-integrated group. However, that very same idea might have obscured the necessity to proceed with a thorough evaluation of the community’s needs: up until the early 1990s there were almost no data or studies available on Cape Verdeans but when studies began to emerge the need to improve the community’s position in fields such as education and health was obvious (Huiskamp *et al.*, 2000; Dieperink *et al.*, 2002; ISEO/COS, 2003). In addition, public authorities’ lack of information about Cape Verdeans might have made it more difficult to justify the need for initiatives aimed at promoting community development and emancipation. Similarly to the US, funds in the Netherlands tend to be allocated more promptly to initiatives designed for communities which are acknowledged, organised, and whose needs are properly researched and defined. Problems such as limited access to mental health care and to high education could have been tackled earlier had the community benefited from greater visibility and recognition.

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[56] When unable to classify Cape Verdeans by race some referred to them as ‘the green people’, taking the literal translation of the name of the archipelago (Halter, 1993).

One other aspect which is couched in the label silent immigrants is a certain expectation by society that Cape Verdeans adopt a passive attitude when it comes to claiming rights and advocating for their interests. This characteristic has been contradicted by Cape Verdeans' actions. Over the years, they have become increasingly more committed to improving the living standards of their community. An example of this is the substantial amount of associations and organisations they have initiated in Rotterdam and elsewhere in the Netherlands (Da Graça, 1999). Another example deserving our attention here is their participation in mental health promotion initiatives through Project Apoio. These forms of civic participation are serving to challenge the image of silent migrants ascribed to Cape Verdeans (De Freitas, 2008b).

Even if the socio-economic position of Cape Verdean migrants in the Netherlands has been improving (i.e. rising level of education, income, civic participation), many still have low paid jobs and live in segregated neighbourhoods (Choenni, 2004; Pires, 2006). In addition, one fourth of Cape Verdean households are composed by single parent families which adds pressure to the management of low incomes makes it difficult for parents to devote time to help their children navigate the complex Dutch educational system (ISEO/COS, 2003). Indeed, only 8% of the Cape Verdean students succeed to pursue high education at the university (*ibid.*). Furthermore, although Cape Verdeans' use of mental health care has increased in the last years (Diperink *et al.*, 2007), more efforts are required to extend the access of all those in need to mental health services. Overall, it can be said that Cape Verdeans are increasingly integrated in Dutch society, but where health and education are concerned more investment is necessary to facilitate their full integration.

5.1.3 Participatory initiatives

Apoio promoted the participation of Cape Verdeans in decision-making over its development and implementation since the project's onset. One of its first initiatives consisted of calling the Cape Verdean community to choose the name of the project. This was done through a contest in the Cape Verdean radio in Rotterdam[57]. Upon a brief explanation of the purposes of the project, listeners were invited to respond to a question about mental health which granted them the opportunity to suggest a name. After voting, the winner was rewarded with a coffee machine. This initiative enabled Project Apoio to become known among a community for whom mental illness was a great taboo in a way that was fun, efficient and non-intrusive. The winning name 'apoio' means 'support' in the Portuguese language.

Over the years, Project Apoio developed many different initiatives reaching out to the Cape Verdean community and promoting its interests in the field of mental health. Having only one permanent staff member, the project was highly reliant on the participation of Cape Verdean users and their caretakers to plan, advertise and

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[57] The Cape Verdean radio stations – Cape Verde FM and Rádio Voz de Cabo Verde – are amongst the three most heard ethnic minority radio stations in Rotterdam (COS, 2004)

implement its activities. Among Apoio's most active participatory groups were *Comissão de Apoio* and *Grupo de Conversa*.

Comissão de Apoio was a committee created in 2000 with the goals of disseminating information about Project Apoio and supporting Cape Verdeans affected by psychosocial distress to break out of isolation and find their way into mental health care. The group included twenty 'experts by experience' who started participating by going out into the community and sharing their knowledge about mental health. This happened mostly through visits to people in the comfort and privacy of their homes. Following this outreach intervention, committee members engaged in the organisation of psycho-education activities. One of those activities was a theatre play about the mental health crisis plan acted by group members themselves. Participants considered this a rewarding experience which enabled the community to get information about psychiatric advanced directives.

The Comissão was also involved in the creation of a radio programme to which people could call with questions about mental problems. This afforded many Cape Verdeans the opportunity to clarify their uncertainties anonymously. In addition to this programme, partnerships were established with Cape Verdean associations to further the mental health awareness campaign and assist in the referral of people with psychosocial problems to Project Apoio. Once the disinformation barrier began to lessen, it was time to tackle the stigma attached to mental illness and promote diversity competence in mental health care. This entailed the establishment of bridges for dialogue between Cape Verdeans and health authorities. Public information meetings and debates were organised bringing the community together with health officials, mental health professionals, local politicians and academics. These meetings were held in venues unrelated to mental care on Sunday afternoons. They were also always followed by a cultural activity (e.g. concert, performance, etc.) – an important feature of any public event by and for Cape Verdeans. This culturally sensitive approach enabled community members to join the meetings without being forced to publicly disclose their mental suffering or to miss out on work.

Comissão members participated in the selection of specific themes for the public meetings, made venue and entertainment arrangements, and distributed leaflets in places familiar to Cape Verdeans (e.g. recreational associations, churches, local cafes, etc.). All this work was carried out closely together with the coordinator of Project Apoio. Most Comissão members we interviewed recall these initiatives as a valuable learning experience but also pointed out some problems (e.g. insufficient recognition). In the end of 2003, after a period of justified absence from the project coordinator, the Comissão was dissolved. Attempts were made to re-initiate the group in the years that followed but without success. In our opinion, Comissão had the potential to become a societal space from which Cape Verdean users could acquire the confidence, capacity and agency to build a politics of engagement and get around the barriers which inhibit their participation in the Dutch health participatory sphere. Although Comissão was never pick-up again after its premature ending several of its former members continued to participate actively in Project Apoio and available resources were re-channelled into other participatory groups, including Grupo de Conversa.

Grupo de Conversa was a peer support group[58] created to foster the exchange of emotional, informational and social support between people affected by psychosocial distress. Emphasis was also given to the empowerment of participants, the acquisition of competencies required for the enforcement of one's right to health (e.g. health literacy, knowledge about the health care system, assertiveness, etc.), and overall strategies for recovery. Ultimately, the group aimed at enabling participants to acquire the skills and self-confidence necessary to exercise influence over the decisions which affect their lives.

Grupo de Conversa was set up in the end of 2005 and it was facilitated by two Cape Verdean experts by experience and myself. Weekly afternoon meetings were held on Wednesdays at Basisberaad GGZ Rijnmond, lasting about 2h. The working languages were Cape Verdean Kriol and Portuguese which facilitated the presence not only of Cape Verdeans but also of Portuguese and Brazilian care users. The group had eighteen participants but steady attendance was difficult to encourage. Among the participants were people who had direct experience of low incomes, unemployment, ill-health and disability.

Themes for group meetings were proposed by participants themselves. Selected topics went beyond issues directly related to mental problems to include relationships between parents and children, the workings of the Dutch education system, social rights, health insurance, pensions schemes, housing, HIV/AIDS, menopause, etc. Meetings typically started with a brief educational account and were followed by peer discussions. Not infrequently, conversation elicited the sharing of experiences of discrimination, social exclusion and helplessness. Responses usually focused on the provision of emotional support. Group members appeared to immediately recognise the need to compensate for support deficits in participants' own social networks. They also shared strategies to cope with problems and often made jokes to ease the suffering. Overall, Grupo de Conversa became a space to share laughs and sorrows, get information, find support, build confidence and acquire new competences. All these aspects are crucial for citizen participation. However, compared to Comissão, Grupo de Conversa had less potential to become a space from which to formulate common interests and raise grassroots leaders able to represent the Cape Verdean community in invited participatory spaces, simply because it focused on the promotion of members' personal resources and empowerment.

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[58] In the Netherlands, peer support groups within client organizations are usually referred to as *lotgenotengroepen*.

Both Comissão and Grupo de Conversa were funded with subsidies from public health authorities and local government to which Project Apoio applied for on a yearly basis. Participants in these initiatives received no financial reward for their contributions, essentially because the budget of Apoio was not sufficient for that. They were reimbursed, however, for transportation costs.

5.2 Migrant and ethnic minority user participation in mental health in Brazil

Participation in health governance is a right of all Brazilians enshrined by the 1988 Constitution. This constitutional framework has facilitated the creation of a comprehensive network of participatory mechanisms enabling hundreds of thousands of citizens across the country to have a voice in health care decision-making. Invited participatory spaces include health councils and health conferences which operate at municipal, state and federal levels. In addition, Brazil hosts several meaningful autonomous participatory spaces among which are the Health Reform Movement (MRS) and the Anti-asylum National Movement (MNLA). These social movements were in fact among the main instigators of the inclusion of the principle of social oversight in the Brazilian Constitution which turned user participation into a right. Founded over two decades ago, they continue to keep the public health system under close watch and to struggle for the promotion of the rights of health care users. User participation and collective action focused on mental health care has been so dynamic that the field got a participatory mechanism of its own: mental health conferences.

As in the Netherlands, however, invited participatory spaces in Brazil have not yet become completely permeable to the plurality of actors they are meant to involve. As we saw in Chapter 2, members of socio-economically disadvantaged groups are the least vocal citizens within the Brazilian participatory sphere: even when they succeed to enter participatory institutions, their influence over health care decision-making is often undermined by inequalities in knowledge, resources and power (Pozzoni, 2002; Coelho *et al.*, 2005).

Although little is known about migrant user participation in Brazil we believe internal migrants are under-represented in the health participatory sphere. 40% of all Brazilians have migrated at least once within the country. This means there are about 33,5 million internal migrants in Brazil[59], the majority of whom live in the big metropolises (Fiess and Verner, 2003). A recent study shows that some internal migrant groups are increasingly struggling with economic deprivation and social marginalisation (Brito, 2006). This is especially the case of Northeastern migrants– the largest migrant group in Brazil and the largest minority in the Southeast states of São Paulo and Rio de Janeiro. Since the 1990s, unemployment, poverty and violence have

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[59] Brazil has a population of 170 million people (IBGE, 2000), 0,4% of which are international migrants (UN, 2006).

led thousands of Northeastern migrants to return home (*ibid.*). In the city of Rio de Janeiro, the majority of those who stayed live in impoverished segregated areas (slums) and either have very low-income jobs or are unemployed (Ervatti, 2004). As Brito (2006) notes, migration to big metropolises has become a matter of survival rather than an alternative for social mobility. We can infer thus that, similarly to other underprivileged groups, poor Northeastern migrants in Rio de Janeiro are not sufficiently represented in decision-making processes over health policy and delivery. In the struggle for everyday survival, opportunities to participate in health governance may simply go unnoticed.

In a country where over one third of the population has migrated internally to escape hardship, it is urgent to bring diversity[60] into the health participatory sphere. To begin with, poor Brazilians are entirely dependent on the public health system to satisfy their health care needs. Unlike the well-off who can afford private health care, the poor have no other alternative than waiting in line for public services which are often insufficiently resourced. In addition, in cities such as Rio de Janeiro, the presence of a reminiscent authoritarian political culture continues to threaten the full enforcement of social oversight of health care and corruption often causes major shortages in the financing of health care. This makes it imperative to give a voice to all those whose right to adequate health care may be put at jeopardy as a result of these actions, and in particular to the poor. Migrants with a low-SES may actually be in a position of double vulnerability. As we argue further below, they have difficulties not only gaining entry in health services but also in making sure that the care they receive is appropriate to their needs. This is particularly observable in relation to mental health care. Several studies advance the need for culturally competent mental health services (Rebello, 1997; Ferreira, 1999). However, migrant health policy is not yet in place. Participatory spaces have enormous potential to enable transformation but without the inclusion of migrants in the co-production of policy and service delivery the development of diversity-sensitive care is likely to remain on hold. These problems stress the importance of promoting migrant user participation. Before continuing with this discussion we make some considerations about the access of MEMs to health care.

Intermezzo: Migrants' access to health care

There is little data on the use of health care by migrants in Brazil. One study indicates that recent migrants (i.e. people who are settled in a host municipality for less than nine years) have less chances of using health care services when compared to the rest of the population (Neri and Soares, 2002). The authors suggest no specific explanation for these results. However, it seems fair to argue that the iniquities observed among migrants' health care use are associated with an over-representation of this group

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[60] We use the term 'diversity' here to refer not just to ethnic and cultural differences but also to differences in socio-economic status, age, gender, religion, etc.

among people with a low-SES. As we show next, low-SES has a negative impact on access to health care.

The use of health care in Brazil is strongly determined by income, level of education and geographical location (Travassos *et al.*, 2006). Although all Brazilian citizens are entitled to free health care through the national health system (SUS), those at the bottom of the social ladder are in a position of disadvantage (Neri and Soares, 2002; Noronha and Viegas, 2002). Public health services are under-resourced and have difficulties coping with all the demand: waiting lists are long, facilities are poor and specialised health care cannot always be assured. They are also unequally distributed through the territory. Peripheral neighbourhoods within large cities are often in short supply of health services. Rent fees tend to be lower in those neighbourhoods, contributing for a high population density and an over-representation of poor people. For those with a low income it is particularly difficult to miss a day at work[61] as well as to afford transportation to go to far-away health care centres or hospitals. In addition, low income people tend to have a low level of education which is associated with poor information about the determinants of health, the health services available and the effects of treatment (*ibid.*). These constraints undermine the ability of low-SES groups to identify their candidacy for medical interventions, navigate the health care system effectively and gain entry to health care services.

Private health care has become the main alternative to the shortcomings of public health delivery for many Brazilians. However, the use of private health services is conditioned to the ability to purchase health insurance. Poor people, and even the lower middle-class, are unable to afford that. They are thus completely dependent on the SUS and that reduces their chances of getting prompt health care. As several studies show, individuals with a low-SES have greater need for health care services (due to poorer living conditions), less access to health insurance, and make less use of health care than the rest of the population (Almeida *et al.*, 2000; Neri and Soares, 2002; Travassos *et al.*, 2006). It can be said thus that underprivileged groups have limited access to health care both as a result of the negative effects of socio-economic deprivation and spatial segregation and as a consequence of the shortfalls of the public health care system.

The rather complex and intense migration flows within Brazil make it difficult to characterise the population of internal migrants as a whole. If we look at the case of internal migrants in Rio de Janeiro Metropolitan Region[62] (RJMR) we observe, however, that most of those migrants have a low-SES. According to the 2000 Population Census, 35,3% of the nearly 11 million people living in the RJMR are internal migrants (IBGE, 2000). Among those employed, almost 70% have low qualified and low paid jobs in the service and industrial sectors. Only 11% are high

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[61] Unemployment rates are high and social benefits are low and hard to come around for those under-employed.

[62] The RJMR includes the city of Rio de Janeiro which has a population of nearly 6 million people. 29% of the residents in Rio de Janeiro are internal migrants (IGBE, 2000).

qualified professionals. This suggests that most internal migrants in RJMR have a low education level. In addition, over 17% are jobless. Unemployment rates for the native population are lower (12%) indicating migrants have more difficulties finding work (IGBE, 2000 cited by Ervatti, 2004). As Brito (2006) shows, lack of economic opportunities, together with increasing social conflict ensuing from social and spatial segregation, are leading many migrants to leave the RJMR. These data indicate that the majority of internal migrants in that region are in a position of socio-economic disadvantage which, similarly to other underprivileged groups, diminishes their chances of gaining entry to health care.

According to Ferreira (1999), the violence, discrimination and social exclusion many internal migrants are subjected to in cities such as Rio de Janeiro, together with the lack of social ties and hard living conditions, put those migrants at increased risk for psychosocial suffering. A study of the inmate population of psychiatric hospitals in Rio de Janeiro carried out in 1995 showed that 26,7% of the total of hospitals' inmates were internal migrants, and that approximately half of these were from Northeast Brazil[63] (Silva *et al.*, 1999). To our knowledge, there is no data on the amount of internal migrants who make use of out-patient mental health care. Professionals from the community-based mental health service where I did fieldwork – CAPS Pedro Pellegrino – were aware of only one user who was an internal migrant[64]. CAPS Pedro Pellegrino serves an area of Rio de Janeiro[65] which has a high density of internal migrant residents – Zona Oeste (West Zone) – and whose population has been growing steadily (Becker and Paganoto, 2008). Most newcomers move into squatter settlements which escape the counts of official population registries. As the coordinator of an out-reaching primary health care programme (PACS) told me: "there are new houses every week. We can barely keep our map [of the area] accurate. We are supposed to be serving 6000 people but there are already more than 9000 residents in our catchment area". These figures give just a small idea of how difficult it is for local public health services to keep up with demand. The absence of internal migrants in a service such as CAPS Pedro Pellegrino suggests, on the other hand, that newcomers may not be informed about the existence of this type of services, making their way into mental health care through the more well-known psychiatric hospitals.

Access to care is not only about entitlements and the ability to use services. It entails also the appropriateness of health care responses. Studies on the field of mental

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[63] Among the remaining internal migrants, one third was from Southeastern states and two thirds were from other municipalities within the state of Rio de Janeiro (Silva *et al.*, 1999). The study analyzed the demographic and socio-economic characteristics of 3 223 inmates residing in twenty psychiatric hospitals.

[64] She died the year before I began fieldwork.

[65] The city of Rio de Janeiro is divided in four large areas: Centro (Centre) – the historic and business hub of the city; Zona Norte (North Zone) – one of poorest and most densely populated areas; Zona Sul (South Zone) – the richest and most well known area overseas which includes the district of Copacabana; and Zona Oeste (West Zone) – the area furthest away from the centre of Rio de Janeiro and the region of the city where social differences are starkest and rural areas go side by side with wealthy residential neighborhoods.

health in Rio de Janeiro show that the delivery of mental care may not be adequately adapted to the needs of migrants (Ferreira, 1996, 1999; Rebello, 1997; Oliveira, 2002). It is interesting to note that all these studies focus on the case of *Nordestinos*, i.e. internal migrants from the Northeast of Brazil. As we show in greater detail in section 5.2.2, the *Nordestino* constitutes the representation par excellence of 'the migrant' in the Brazilian collective imaginary (Ferreira, 1999) and, in cities such as Rio de Janeiro, it is the ethnic minority which stands out the most.

In a study of a psychiatric emergency unit in Rio de Janeiro Oliveira (2002) found that a substantial proportion of the users were internal migrants (26%). However, when inquiring about the way diversity was approached in that service the author found that little or no attention was given to migrant users' origin and cultural background. Professionals seemed to understand the importance of developing cultural competence in care stating that Northeastern migrants were likely to have specific needs that required special attention (e.g. problems associated with social isolation and lack of support). However, they did not incorporate users' cultural context and illness explanatory models in their daily therapeutic practice. Ferreira (1996) and Rebello (1997) confirm these findings and add that the 'difference' embodied by internal migrants is sometimes inadequately pathologised by providers who fall short in their ability to comprehend migrants' values, beliefs, habits, language codes, religions, etc. This indicates there may be a mismatch between migrants' mental health care needs and the care currently available to them. Limited access to good quality care is likely to reinforce the position of disadvantage many migrants already find themselves in.

Returning to the issue of migrant and minority user participation, there is no doubt migrants need to be included in the health participatory sphere if their right to adequate care is to be enforced. In our view, lack of diversity competent mental health care does not stem from opposition or disinterest among providers but results, instead, from the absence of policy directives and resources to implement it. The majority of professionals we interviewed realised the importance of bringing cultural competence to mental care delivery and stated willingness to learn. However, migrant health is hardly ever the topic of teaching or debate within university classrooms, training sessions for professionals, health councils or user movement meetings. There are many other pressing needs to consider. As a professional explained: "We have so many problems [in our daily practice]… lack of staff, lack of medication, lack of food… and the [mental health] services are so overloaded, that we struggle everyday to make ends meet" (Psychiatrist 1 BZ). Psychosocial suffering among public mental care users is deeply associated with and exacerbated by the negative effects of poverty, violence and exclusion. Many users are unable to get enough money for food let alone to pay for medication. Professionals are so taken by the efforts required to help users secure their basic needs that they are left with little or no time to invest in diversity-sensitive care. The promotion of cultural competence also appears as a second-class concern for local

NGOs and social movements which are much too busy trying to enforce the rights of the urban poor and monitoring the appropriate distribution of health care resources.

The problems just described are further reinforced by endemic corruption. Two years before I began fieldwork, professionals from several health care services across Rio de Janeiro were without pay for almost eight months. A year later, part of the budget of CAPS Pedro Pellegrino was withheld. The service was unable to get the food and medicines many of its users depended on for six months. In 2008, Gilson Cantarino, a medical doctor and former Secretary of Health of Rio de Janeiro during the government of Rosinha Garotinho (2002-2006), was arrested under allegations of larceny. He was accused of stealing 60 million Reais from the Health State Secretary of Rio de Janeiro (O Globo 15/07/2008).

Brazil has an impressive set of democratic mechanisms which enable citizens to hold public administrators to account. However, political and economic interest groups often try to obstruct their performance. During her mandate, state governor Rosinha Garotinho transferred the public fund legally accorded to health councils into a food programme. According to one of our informants (Coordinator of Health Research Centre, BZ), she stated publicly that people would benefit more from such a programme than from health participatory spaces. A lawsuit was initiated to re-channel the funds back to the health councils. Yet the legal system works slowly and it can take years until a directive like this is reversed. Such acts of authoritarianism are not uncommon in Brazilian politics nor are they exclusive to the upper echelons of government. They spread through the different tiers of governance posing a massive threat to democracy, equity and social justice.

The authoritarian political culture which still reigns in many public offices throughout Brazil is at the origin of the principle of social oversight over health care policy and delivery and is a constant reminder of the pertinence of health participatory spaces. Yet these mechanisms will only work to enforce the democratisation of public care if they succeed to remain independent from established politic groups, engage representatives from all segments of society and guarantee the substantive inclusion of all councillors in decision-making processes (Cornwall and Shankland, 2008). This calls upon a resourced, empowered and diverse civil society from which to withdraw citizens able to promote the interests of the constituencies they represent. Where representatives of low-SES groups are concerned this entails an investment on capacity-building and empowerment. In what follows, we describe CAPS Pedro Pellegrino and how this psychosocial care service has been promoting participatory initiatives which enable users with a low-SES to acquire the competencies and resources required to participate in the health participatory sphere. Many of the users of CAPS Pedro Pellegrino are descendants of Northeastern migrants. In the future, those participatory exercises may enable them to get in the position to place demands not only for strategies able to tackle the problems which undermine the access of poor people to health care but also for the development of health policy sensitive to the needs of migrants and ethnic minority groups.

5.2.1 CAPS Pedro Pellegrino

CAPS Pedro Pellegrino is a community-based psychosocial care service designed to assist people affected by serious psychosocial suffering in their rehabilitation and reintegration in society. The service offers a range of educational, occupational, cognitive and behavioural interventions aimed at long-term recovery and the maximisation of autonomy. Interventions are organised in the form of *oficinas* or therapeutic workshops. They are all led by at least two professionals out of a multidisciplinary team that includes occupational and music therapists, nurses, psychiatrists, psychologists, social workers and nutritionists. Therapeutic contracts are negotiated jointly between users and their professionals of reference and usually entail participation in *oficinas* and individual counselling when necessary. Contracts tend to vary between one to five days of care per week, depending on the gravity of users' problems.

CAPS Pedro Pellegrino was created in 1997 to strengthen the network of public community-based psychosocial services available in Rio de Janeiro. These services were devised to provide an alternative to asylum-like institutions and are one of the most concrete results of the ongoing psychiatric reform. The majority of users of CAPS Pedro Pellegrino have a history of multiple admissions to or long-term institutionalisation in psychiatric hospitals. Many have no income and no social benefits and live in poor neighbourhoods of Zona Oeste, where the service is located. Several of the service's *oficinas* were designed to deal specifically with the negative effects of institutionalisation. This is the case of the Beauty Workshop in which users are assisted in re-acquiring daily habits of hygiene and taking care of their personal image. The Income Generation Workshop, on the other hand, seeks to offer users the opportunity to engage in paid work. People affected by psychosocial distress are highly discriminated in the labour market. The products manufactured in and sold through CAPS (e.g. biscuits, decorative items) are the only source of income for many of its users. At the time of fieldwork, CAPS had almost two hundred users.

CAPS Pedro Pellegrino adopts a participatory approach to care delivery which extends beyond its own 'borders'. In addition to promoting user involvement in treatment plans and service planning and evaluation, CAPS has also invested in the creation of a participatory channel between the service and the community. This has been done in two ways. On the one hand, users' family members and caretakers are stimulated to participate in the service through Grupão – a monthly session in which they can gather with users and professionals to discuss issues related to service provision and care in the community. On the other hand, users are encouraged and supported to get involved in both invited and autonomous participatory spaces (e.g. local health council, mental health conferences and the user movement). Indeed, CAPS is a strong advocate of collective action and participatory initiatives organised to promote the rights of users and the delivery of good quality psychosocial care. We return to this issue in greater detail in section 5.2.3.

The provision of public health care in the city of Rio de Janeiro is organised according to ten geographical areas of intervention (Áreas Programáticas, APs). CAPS Pedro Pellegrino serves the population of AP 5.2 which includes the boroughs of Campo Grande, Guaratiba and Pedra de Guaratiba. Campo Grande is one of the city's boroughs with the highest proportion of people living in poverty (23%)[66] (Szwarcwald *et al.*, 1999). It is also located in the area of Rio de Janeiro most under-supplied with mental health care services – the Zona Oeste. To facilitate the access of its catchment population to psychosocial care CAPS Pedro Pellegrino established partnerships with the primary health care programs in AP 5.2 – the community health workers program (Programa de Agentes Comunitários, PACS) and the family health program (Programa de Saúde da Família, PSF). PACS and PSF employ a range of professionals including several community agents who adopt an outreaching approach to primary care. They walk into *comunidades* (slums) and register the health problems experienced within each household. They also refer people to the appropriate health care services.

The outreaching approach employed by PACS and PSF is particularly relevant in cases of psychosocial distress. Many people are not yet aware of the existence of services such as CAPS Pedro Pellegrino. During fieldwork, I asked the collaboration of community agents from PACS Jardim Maravilha and PSF Barra de Guaratiba to identify Northeastern migrants living in the *comunidades* where they worked and who experienced psychosocial suffering. They got me in touch with five people whose parents had come from the Northeast. They all had a diagnosis of mental illness but none of them was informed about CAPS nor had they used out-patient psychosocial care[67]. This goes to show how difficult it is for people with a low-SES to access good quality mental care.

In what follows, we provide a brief sketch of Northeastern migrants and their descendants in Rio de Janeiro. In the section thereafter we describe the participatory initiatives developed and endorsed by CAPS Pedro Pellegrino.

5.2.2 Northeastern migrants and their descendants in Rio de Janeiro

Migration from the Northeast[68] to other regions in Brazil began to rise in the 1940s. Severe drought, unemployment and economic deprivation pushed 5,5 million Northeasterners to leave their home towns in the 1950s (Martine and Camargo, 1984). The industrialisation of the Southeast region of Brazil, that was gaining pace during that decade, led many *Nordestinos* to migrate to the states of São Paulo and Rio de

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[66] Copacabana is by comparison the borough with the lowest percentage of people living in poverty (2,6%).

[67] They were diagnosed during admission to a psychiatric hospital. They all took medication and used ambulatory psychiatric care, which usually consists of a consultation with a psychiatrist per month or every two months.

[68] The Northeast region of Brazil occupies almost 20% of the national territory and has a population of 53 million people. It includes eleven federal states among which are Maranhão, Piauí, Ceará, Rio Grande do Norte, Paríba, Pernambuco, Alagoas, Sergipe, Bahia, Santa Catarina and Rio Grande do Sul. The inland of Northeast is very arid and living conditions there are bleak. Most Northeastern migrants come from the arid backlands.

Janeiro (Brito and Carvalho, 2004). Lula da Silva, the former president of Brazil, was among them. In 1952, he left the state of Pernambuco with his family to search for a better life in São Paulo. Like many other *Nordestinos*, he travelled in a *pau-de-arara* (open truck) for 13h until the 'promised land' (Brazil, 2007)[69].

The economic recession of the 1960s and the end of drought in the Northeast caused a decline on Northeastern migration flows during that decade. Nevertheless, the modernisation of its agriculture sector operated during the 1970s provoked a massive reduction of jobs and another exodus: more than 4 million people left to the big cities in the Southeast (Patarra, 2005). In the 1980s, Brazil experienced one of its most dramatic economic recessions. Rampant inflation subdued economic growth causing major unemployment, poverty and social conflicts. The situation was especially critical in large urban centres such as Rio de Janeiro and São Paulo which, in addition to staggering poverty, were also confronted with rising violent crime. Low work opportunities and violence have generated a flux of return migration to the Northeast causing those cities to get a negative migration saldo since the 1990s. Nevertheless, between 1995 and 2000, a quarter of a million internal migrants arrived to Rio de Janeiro. 57% of the newcomers were from Northeastern states (Brito, 2006).

Northeastern migrants in Rio de Janeiro tend to be looked at as the poor peasants who travelled for miles to enlarge the city's underclass. As Ferreira (1999) goes on to explain, *Nordestinos* are the archetype of 'the migrant' in the Brazilian collective imaginary and the ultimate embodiment of 'otherness'. Most Brazilians associate internal migration with the need for survival. The North-South exodus, which picked in the 1970s, stayed in the collective memory as a desperate attempt by millions of people to leave behind extreme poverty and pursue a better life in the *sul maravilha* (wonderful south). Indeed, the Southeast region was for many Northeasterners the *El Dorado* the US represented for Mexican migrants.

The inflow of poor rural migrants to Rio de Janeiro has been so intense that it produced dramatic changes in the city's landscape: entire mountains were taken by *favelas* (slums) such as Rocinha[70]. Since then, internal migrants have been deeply associated with *favelados* (slum inhabitants) – a segment of the population who is forced to live side by side with open sewage, drug gangs and murder. *Favelados*, irrespective of who they are, what they do or where they came from, are looked down to and discriminated by the rest of society. They are stereotyped as socially and politically disorganised, lazy, and dangerous (Oliveira, 1996). These traits are also

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[69] Lula da Silva's story of migration was displayed in the website of the Brazilian Presidency during his mandate. A page dedicated to the Presidents' biography presented his life as a story of success in which a poor boy aged seven migrates to the big city and, against all odds, becomes the President of Brazil (Brasil, 2007). To a certain extent, this can be viewed as homage to all rural migrants in Brazil and an inspiration for all those who aspire to climb up the social ladder.

[70] Rocinha is one of Rio de Janeiro 500 slums (Silva, 2000). It is located in the richest area of the city and it has a population of over 200,000 inhabitants, the majority of whom are descendants of Northeast migrants (Ferreira and Magalhães, 2005). About one third of the population of Rio de Janeiro lives in slums (Silva, 2000).

ascribed to *Nordestinos*. Yet their perceived 'differences' makes them vulnerable to further stereotyping as ignorant, backward and needy peasants that are deprived of culture and unable to adapt to urban life.

Nordestinos are not just a symbol for 'the poor migrant' (Ferreira, 1999). For some, they are the 'untouchable other'. In a study about social integration in Rio de Janeiro, Rezende (2001) found that *forró* – a Northeastern music and dance style – had become highly popular among middle-class *Carioca*[71] college students who started going to a social space traditionally visited by low-SES Northeastern migrants – the Feira de São Cristovão. Feira Nordestina, as it is most commonly known, is a huge fair which showcases the culture and traditions from the Northeast. It has hundreds of *barracas* (stalls) selling typical Northeastern food, *cachaça* (sugar cane liquor) and crafts and a large entertainment area where visitors can listen and dance to various traditional music styles. The popularity of *forró* among middle-class Carioca youth emerged as part of an urban movement concerned with rescuing the 'authentic' traditional culture. However, interaction with the people who personified and shaped that culture was not part of the equation. In Feira Nordestina, *Carioca* women refused to dance with *Nordestino* men arguing they drank too much and 'looked a bit dirty'. *Carioca* men did not invite *Nordestino* women to dance claiming their boyfriends could get angry and turn violent. It was clear that the Northeastern culture was appreciated, but from a distance. Young *Cariocas*' invention of a new style for dancing *forró* served to legitimise and widen that distance: *Nordestinos* could not dance like them and therefore it made little sense to invite them. Rezende (2001) explains these attitudes as a result of stigmatisation inspired by social class differences and discrimination based on perceptions of backwardness and 'dirtiness'. Middle-class *Carioca* youth sees poor Northeastern migrants as much too inferior and undesirable to even pull them to dance. From a space with great potential to enable social interaction between *Cariocas* and *Nordestinos* Feira Nordestina becomes, in this way, a place for furthering the exclusion of the latter (*ibid.*).

The descendants of Northeastern migrants are unlikely to experience discrimination on the basis of *nordestinidade*, i.e. the set of characteristics by which Northeasterners are identified (e.g. accent, language expressions, way of walking, etc.) and differentiated from the rest of the host society. Having been born in Rio de Janeiro, they act and talk like *Cariocas* and it may not be easy to tell them apart. However, social mobility in Brazil is very low. Second generation *Nordestinos* in Rio de Janeiro are thus likely to have the same low socio-economic status their parents did. In the highly hierarchised Brazilian society poor people are at the bottom of the social ladder, facing multiple forms of exclusion that include lack of access to formal employment, sanitary housing, good education, health care, entertainment, etc. Where internal migrants are concerned, it may take a few generations before their offspring succeeds to climb the social ladder and leave extreme poverty and exclusion behind.

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[71] Carioca is a term employed to refer to natives of Rio de Janeiro.

5.2.3 Participatory initiatives

CAPS Pedro Pellegrino has fostered the participation of users and carers both within and outside the service since its onset. This has been motivated by four main concerns. First, the coordination of public mental health care in Rio de Janeiro is challenged by problems of bureaucracy, mismanagement and corruption which have a direct negative impact on the performance of local services. A recurrent problem is the holding back of funding which causes CAPS to have periodic shortages of medication and food provisions and impedes it from hiring a sufficient amount of professionals. Mechanisms for social oversight of financial management are in place and public officials can be hold to account. Yet this requires a mass of critical and empowered citizens able to activate those mechanisms toward their advantage. With this goal in mind, CAPS stimulates its users to become aware of their rights and build capacity for collective action. One of the ways it has sought to promote that is by enabling users to get involved in care planning and evaluation, something which is accomplished through a participatory space within the service – the assembly.

The Assembleia was in fact created to respond to two other concerns of CAPS – the need to impede the reproduction of asylum-like practices (e.g. over-medication, authoritarianism, coercion, submission, etc.) and the will to encourage users' ownership over the service. Both these aspirations call for the engagement of users in care provision. On the one hand, by voicing their complaints and proposing alternatives users can help CAPS to keep watch of its practice and to devise forms of care that match the needs of its clients. On the other hand, by taking an active role on care development and evaluation users build a sense of responsibility for and commitment to the service. This, in turn, is likely to impel them to seek accountability when top management fails to allocate the resources necessary for the delivery of good quality care.

Finally, user participation has been promoted as a means to enable the social reintegration of users. Indeed, one of CAPS's concerns has been to prevent what providers usually refer to as 'enCAPSulation', i.e. users' self-enclosure in and dependence on the therapeutic setting. Participatory spaces outside the service are seen as locales of opportunity to build social networks, acquire competences and engage in entirely new activities (e.g. long-course travelling). One space which appears to be particularly conducive to this is the user movement where CAPS users meet with professionals, family members and users from other services in Rio de Janeiro to discuss not just local mental service delivery but also national mental health policy. Not infrequently, those affiliated with the movement travel across the country to promote the rights of all Brazilian citizens to appropriate mental health care. This can be both empowering and fun.

In what follows, we describe in greater detail the participatory initiatives promoted and endorsed by CAPS Pedro Pellegrino, i.e. Assembleia, Grupão and the user movement meetings.

Assembleia is a space for shared decision-making in which users and professionals come together on a weekly basis to discuss the dynamics of human relationships within the service, make decisions about care provision and organise cultural activities. Over the years, assembly members made several contributions to the improvement of the quality of health care delivery. In an under-resourced, under-staffed and overcrowded service such as CAPS Pedro Pellegrino it is not uncommon for problems to arise. One problem that caused considerable disturbance within the service were the negative reactions of some users and carers to professionals' refusal to provide individual counselling without an appointment. This generated so much frustration that it sometimes ended in violent discussions marked by the exchange of offences and threats to providers. The collectivisation of responsibility for these conflicts and the search for joint solutions within assembleia enabled users, carers and professionals to become more aware of the limitations of the service and to build a relationship based on greater transparency, respect and trust.

Another relevant contribution ensuing from participation in assembleia was the proposal of needs-driven therapeutic workshops. One example of this was the Group of Men created out of the need expressed by male users to talk about aspects related to their sexuality exclusively among men. Female users thought this was a good initiative and created their own Group of Women. At the time of fieldwork, users were committed to starting a new income generation workshop to produce and commercialise soap. These initiatives are a case in point of how user involvement can improve the responsiveness of care delivery and enable participants to co-produce services which make sense to them and that they can feel as their own.

Yet the participatory activity users recalled as most successful and rewarding was a demonstration made in front of Rio de Janeiro Town Hall to demand the unblocking of funds for medication and food supplies. This entailed considerable preparation and mobilisation efforts by CAPS users: selecting an organising committee, choosing slogans, making banners, notifying authorities, gathering supporters, making travel arrangements and distributing information to passers-by. All these activities and the action itself gave users a chance to learn new skills and competencies but, perhaps most importantly, it made them feel they could make a difference and contribute for a wider political struggle: the enforcement of rights all Brazilians are bestowed with but which some people (especially the poor) are deprived from on such a structural basis that they do not even recognise them. As a former psychologist of CAPS explained: "unfortunately in our society you need to learn you have rights. You are not born knowing that. It is a hard, daily struggle to get basic things such as the right to eat, the right to have water to wash yourself, [to have] clean water to cook your food. You need to learn you are a citizen with rights and that there are spaces where you can claim and extend those rights" (Psychologist 4 BZ).

The assembly thus was a space which afforded users the opportunity not only to be involved in service planning and evaluation but also to build a critical consciousness and acquire the capacity to take action to change the unjust structures which divest them from their rights and reinforce inequity. In this sense, assembly was both a decision-making space within CAPS and a training ground for participation in the wider health participatory sphere. Indeed, its members were regularly informed about and encouraged to attend the meetings of the user movement (MNLA) and a group of about ten users become habitual participants there. However, during fieldwork, attendance to assembly meetings dropped to less than one third of the usual number of participants. As we will show in Chapter 9, keeping up with participation requires a great deal of investment on the part of users and the instigators of participatory initiatives.

Grupão is a space similar to assembly which takes place once per month and includes carers (in addition to users and providers). Grupão derives essentially from an approach to psychosocial care which values the role of carers in assisting users toward recovery and integration in society and which sees them as key allies in the struggle against the stigmatisation of people diagnosed with mental illness and on the dissemination of information on good practice in mental health care. As a result, CAPS seeks to engage carers in its activities as a means to develop their knowledge about and competences to deal with psychosocial suffering, get their feedback on the quality of care provision, and sensitize them for and acquire their collaboration to tackle the problems impeding the delivery of appropriate care. Judging from its high attendance, Grupão seems to be valued by carers as space for dialogue, learning and cooperation.

The **user movement (MNLA)** is an autonomous participatory space set up to enable mental care users, providers, family members, carers, and any one sensitive to the cause of people affected by psychosocial suffering to come together and devise strategies to promote their rights and access to good quality mental health care (see Chapter 1). Members of the Rio de Janeiro's branch of MNLA meet bimonthly in the Medical Doctors' Union headquarters in the centre of the city (Centro) which is located about 1h away from Campo Grande. Participation in the user movement meetings entails some costs and requires a fair degree of autonomy on behalf of CAPS Pedro Pellegrino users. In addition to expenses with transportation, users need to plan their trips watchfully. Rio de Janeiro is an enormous city and some of its areas are not easy to navigate[72]. Moreover, both Centro and some neighbourhoods of Zona Oeste are quite dangerous and missing the bus at night, for example, may expose users to increased safety risks.

In spite of the costs involved in attending the MNLA meetings (i.e. time, money, safety) several users found participation rewarding enough to leave potential adversities aside. Engagement in the MNLA enables users to come in contact with others sharing similar concerns and goals and to gather support to deal with problems which affect

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[72] This is especially the case with more remote places such as Guaratiba and Pedra de Guaratiba where many users of CAPS Pedro Pellegrino live and which are served by minimal public transportation.

their services of reference ad themselves personally. Furthermore, the user movement functions as a springboard for the involvement of users in invited participatory spaces. The MNLA is represented in the local, state and national mental health conferences. In preparation for those events, proposals for mental health policy and service delivery are widely debated and voted during the MNLA meetings. Conference delegates are also designated through voting. This gives users the opportunity not just to engage in a thorough process of deliberation but to actually become elected MNLA representatives. For many users, this corresponds with their very first chance to travel to another state of Brazil and to speak to an audience of thousands of people. Mental health conferences are events which users tend to await with great enthusiasm both because they are a crucial space to promote their interests and seek the improvement of mental health care and because they are a privileged moment to exchange experiences, build friendships and have fun.

6. Research approach and methods

In this chapter we describe and justify the research approach and the strategy of inquiry adopted on this study. We also provide a description of the methods used to collect and analyse empirical materials and of the techniques employed to evaluate the quality of this research.

We opted for a qualitative research approach in which the interpretation of the meanings given by participants to the phenomenon under study has taken lead. As we have seen in Chapter 2, participation is value-laden, context-bound, political concept whose interpretations are subjected to the ideological, social and economic positions of the people and agencies initiating and taking part in it (Gaventa, 2006a; Cornwall, 2008). As such, the concept of participation defies any single attempt of definition (*ibid.*). To enquire how people affected by psycho-social distress experience and realise participation it is thus crucial to dive in the social, political and cultural context in which participation takes place and to let actors' meanings of participation become centre-stage in that study. For these reasons, we considered that the combination of a case study strategy of inquiry with the employment of grounded theory methodology for data collection and analysis was the best approach to realise our research goals. We began this study by conducting a preliminary review of literature concerned with user participation, collective action, active citizenship and empowerment. However, subsequent theoretical reviews and concept framing have gone hand in hand with data collection and analysis, becoming a part of the data.

In what follows, we elaborate on the approach adopted and its place on the field of health research, justify the cases selected, and provide a detailed account of data collection and analysis. Focusing on people who experience(d) considerable psycho-social suffering asks additional attention from the researcher to remain wary of what is reasonable to inquire and to expect from respondents. It also requires substantial empathy, flexibility and creativeness when approaching participants if one wishes to assure that knowledge and expertise emerge in a manner that is rewarding for both the researcher and the respondents. We conclude this chapter with a consideration of ethical issues.

6.1 The research approach

Scholars concerned with the intricacies of human enquiry have been keen to assert that the choice of research approaches and practices should depend upon the questions asked (Silverman, 2001), and that research "questions depend on their context, what is available in the context, and what the researcher can do in that setting" (Denzin and Lincoln, 1994: 2). As described in the Introduction to this thesis, our study aims to learn about the reasons why ethnic minority users affected by psychosocial distress get involved in participatory spaces, and how they benefit from participation. The main interest of the study lies, therefore, in eliciting participants' perspectives over the process of participation, i.e. how they make sense of it and whether or not they change aspects of their lives as a result of it.

Aside from individual idiosyncrasies, the context in which participation takes place is likely to have a profound impact on how and the extent to which that process occurs but also on how it is experienced by those involved. Understanding of the ways by which participation affects users cannot be reached if dissociated from the actors' social world and the phenomenon's context. It needs to be grounded on everyday world experiences. The researcher must, thus, seek tools which allow direct access to social actors' experiences and facilitate contact with the processes through which meanings of participation "are created, negotiated, sustained and modified within a specific context of human action" (Schwandt, 1994: 120).

Those goals are better reached within an interpretive tradition of human enquiry and through the use of qualitative methods. The interpretive approach foregrounds people' own accounts and interpretations of their social world and seeks to prevent an imposition of the researchers' beliefs and theoretical perspectives on the data, by stressing the gendered and multiculturally situated position of the researcher and the constant need for self-reflection (Denzin and Lincoln, 1994). It also facilitates an inductive and interactive process of enquiry between the researcher and empirical materials (Morse, 1992), where analysis and comprehension of the phenomenon of interest are guided by a set of techniques which provide a direction along which to look but do not prescribe what to see. Finally, the qualitative approach recognises context as a source of data, meaning and understanding, emphasising its value when seeking to interpret and produce an account as complete as possible of human action (Hinds *et al.*, 1992).

Researchers concerned with the field of health care have traditionally adopted a quantitative approach, resorting in large scale to evidence-based studies and randomised control trials. However, the need to resolve problems such as the turmoil and ambiguity created by managed care, the challenge of applying evidence-based medicine to everyday clinical practice, and the accelerated pace of change occurring within health care sectors has led to a growth of interest in and use of qualitative methodologies in that field over the last two decades[73] (Harding and Gantley, 1998; Shortell, 1999).

With public health turning into a major concern in our time, health care systems all over the world are undergoing reform and becoming 'mega-systems' of great complexity. Its study calls for methods able to provide insight on their intricacies (Yin, 1999) and to assess them while being submitted to change (Shortell, 1999). At the same time, the increasing aspiration to diminish health inequalities and to provide

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[73] This is particularly discernible through the amount of books on qualitative health care research published in the last two decades (see Morse, 1992; 1994; Mays and Pope, 2000; Rapport, 2004; Holloway, 2005).

adequate and sustainable health care has fuelled the need to understand how people make sense of their social world, and how it impacts on their health-related behaviour, help-seeking processes, healing, etc. This has highlighted the importance of taking users' needs, beliefs, and wants into account when developing new care philosophies and designing and implementing health care services. The recovery paradigm in mental heath care is a paradigmatic example of this. Its emergence in the early 1990s led to a redefinition of the terms associated with mental illness from purely biomedical labels toward terms based on levels of social functioning, subjective levels of distress, and the meanings people attach to their experiences, attesting the relevance of knowledge by experience. Finally, the rather opposed 'realities' portrayed in regard to the effects of managed care by quantitative studies, which generally show it has no net positive or negative impact on the quality or outcomes of care, and by the media, which reports on its harmful consequences to many patients and their relatives (Shortell, 1999), have pointed out the need for an alternative approach able to evaluate users' needs and systems' performance.

Overall, these developments have led to an increased focus on the understanding or *verstehen* (Weber, 1964) of care users' emic views in the natural settings where health care is delivered and evaluated. This study follows this line of qualitative research and aims to contribute with knowledge about participation from a user perspective.

6.2 Strategy of Enquiry

User participation in health is a complex, dynamic and political phenomenon which is usually conceptualised along a continuum or 'ladder' ranging from the provision of information to citizens, through consultation, co-production, and deliberation, to full citizen control over decision-making on policy and service delivery (Arnstein, 1969; Hickey and Kipping, 1998). The conceptualisation of participation along a continuum is revealing of the significant differences found between and within countries in regards to the practice of participation, the kind of social actors involved, the amount of influence they can expect to wield and the legal and financial frameworks supporting participation. Enquiry into the enablers and inhibitors of user participation needs to be able to accommodate this variability while, at the same time, allow for conceptual clarification and the formulation of substantive theory. In addition, the dynamic nature of participation demands this phenomenon to be studied in a natural setting, using a strategy of enquiry able to grasp its complexity while the phenomenon unfolds over a period of time. The case study research strategy is particularly well suited for 'why' and 'how' questions, when the researcher has few control over the issues and events under study and wishes to focus on contemporary phenomena within some real-life context. Aside from that, the use of multiple sources of evidence enabled by this sort of enquiry also facilitates research where the boundaries between phenomenon and context are unclear, offering the possibility to carefully scrutinise and disentangle them

(Yin, 1994). As explained in Chapter 5, we selected two cases that can provide insight on the reasons why users in a position of vulnerability get involved and on the barriers they face when seeking to further their participation:

- the case of Cape Verdean migrants' participation in a community-based advocacy project focused on mental health promotion in Rotterdam; and,
- the case of minority Northeasterners' participation in a community-based mental health care service in Rio de Janeiro[74].

The choice of these cases lied more on the possibilities they offered to facilitate the understanding of the issues at hand than on the particularity and ordinariness which make the cases themselves of interest.

Robert Stake (1994) defines three types of case studies: *intrinsic*, *instrumental*, and *collective*. Intrinsic case study focuses primarily on the case which, because of its uniqueness, requires study. In instrumental case study a particular case is chosen for examination because it can support the understanding of an issue or the refinement of theory. The case is thus of secondary interest and it is used instrumentally to illustrate an issue. When instrumental study extends to more than one case we are in presence of a collective case study. Our study can thus be termed a collective case study composed of two instrumental cases.

In collective casework, individual cases in the collection may be similar or dissimilar and redundancy and variety each have a voice. The cases are chosen because it is believed that the phenomenon of interest observable in the case represents the phenomenon generally (Stake, 1995). While there are no prescriptions to guide the choice of the best case, most scholars stress the importance of selecting the cases which offer the greatest potential for learning (Stake, 1994; Miles and Huberman, 1994; Yin, 1994; Creswell, 1998). This might mean selecting the case we have more access to, can spend the most time with, and/or share greatest interest in (Stake, 1994). Other authors suggest the selection be guided also in favour of cases that can offer different perspectives on the phenomenon under study (Creswell, 1998).

All these criteria were pertinent for our case selection. They helped to consolidate our awareness about the importance of choosing cases where the approach to and the experience of participation in mental health differed as a result of the political, economic, social, legal and cultural factors that tend to influence the course and the meanings given to that phenomenon. They also served to strengthen the idea that vulnerable groups who, at a given time, begin to participate are prone to offer a more complete perspective on participation as their experiences tend to reflect instances of both success and difficulty in becoming and remaining engaged. Finally, they pointed out the need of opting for cases involving actors, organisations and services I could gain

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[74] It is important to note that in addition to these two groups of participants we also enquired various stakeholders in the field of participation in the Netherlands and in Brazil. See section 2.3.2.

access to. These three insights were crucial for the decision of conducting two instrumental case studies, each in a different country, and with two different groups, where the countries and groups selected should, in their contrasts and similarities regarding participation in mental health, bear witness to the variability intrinsic to that phenomenon.

As described in Chapter 5, the case studies presented in this thesis were carried out in Brazil and in the Netherlands and focused on migrant and ethnic minority groups. In what follows, we discuss the characteristics that made the selected countries and populations appealing for the study of user participation in mental health.

Case Selection

Our selection of case studies has been driven by the aspiration of acquiring an encompassing perspective of the enablers and inhibitors of user participation in mental health care, as well as of its benefits for engaged users. This implied the identification of cases which are similar enough to enable answers to our research questions but also sufficiently different to allow new insights on the phenomena under study. We deliberately opted for selecting one case in the North and one case in the South. As we have seen in Chapter 1, user participation in mental health pioneered in Western countries such as the Netherlands, the US and Italy during the 1970s. Since then, various types of health participatory spaces have been established in those countries. Because of their long-lasting tradition of democracy, there is sometimes a misleading idea that countries in the North have little to learn from countries in the South (Cornwall, 2008a). However, the transition from autocratic rule to democracy operated in several countries in the southern hemisphere over the past three decades (e.g. in Brazil, Argentina, South Africa) has been accompanied by the creation of innovative forms of and new mechanisms for citizen participation, not least in health governance. People's discontent with state capacity to promote social justice and equality is largely at the basis of these developments (Gaventa, 2007). Efforts to deepen democracies in the South and to extend citizens' control over decision-making have led to the emergence of vibrant grassroots movements demanding greater inclusion and voice (Dagnino, 2005) and to the creation of new participatory governance institutions (Avritzer, 2002). As a result, opportunities for citizen engagement have been expanded. These developments have conferred user participation in those countries different features, meanings and outcomes. The study of participation in the South, side by side with a case in the North, can thus offer a more encompassing understanding of the ways by which user involvement can be further enhanced (or hindered).

In addition to differences concerned with the design of participatory spaces, there are also differences in the approaches underlining the promotion of participation. In some countries, participation has a clear democratic ring to it, and involvement is seen as a process entailing the redistribution of power and control over decision-making. In other countries, a consumerist approach prevails and participation is looked at as a means to reach other ends (e.g. eliciting information about consumers' needs and preferences) (Beresford and Croft, 1996). As discussed in Chapter 2, Brazil is an example of a country where participation has been essentially promoted under the democratic model. The Netherlands combines a democratic and consumerist approach to participation but the latter has gain prominence in the past decade. These distinct rationales are likely to imprint participation in those countries with a different 'make up'. Everyday terms employed to address involved users are indicative of these differences: in the Netherlands they are often referred to as 'emancipated clients', while in Brazil there is more talk of 'engaged users' or 'citizens'. Having the opportunity to observe and learn from these two models of participation, and the ways in which ideology influence its practice, has been a key reason for selecting case studies in the Netherlands and Brazil.

As noted earlier, we have also chosen to conduct our study with socially disadvantaged groups. As discussed in Chapter 2 and 3, groups who have been traditionally at the margins of mainstream society are at particular risk of exclusion from the participatory sphere (Coelho *et al.*, 2005). Their experiences with health care use and participation also tend to range more widely between instances of success and difficulty in accessing care and acquiring a voice. Migrants and ethnic minorities (MEMs) are particularly under-represented among the users involved in health participatory spaces. Gaining insight into what promotes and discourages the participation of these groups can provide valuable information on the motivations initiatives should appeal to, and the kind of resources that should be provided, when seeking to mobilise a more diverse group of citizens into participatory spaces. This in turn is expected to enhance a plural citizen voice in health governance and greater equity in health. Inquiring about the participation of groups hitherto excluded from the participatory sphere can advance a more comprehensive analysis of the incentives and disincentives to participation and inform strategies to enhance the involvement of other disengaged groups.

In the following, we provide an overview of the social, economic, cultural and political factors at the basis of our selection of cases. This overview summarises the factors described throughout Chapters 1, 2 and 5 of the thesis.

Case 1: Cape Verdean migrants' participation in mental health in The Netherlands

The study of user participation in the Netherlands can be particularly insightful on the account of several factors.

First, the Netherlands hosts one of the first user movements to have emerged in Europe and accounts for over four decades of user involvement in mental health (Rogers and Pilgrim, 1991; Haafkens *et al.*, 1986). Its long-standing user movement influenced the creation of various autonomous and invited participatory spaces including client organisations, client councils in health care services and advisory conferences and meetings (see Chapter 2), and is acknowledged by government as a partner in policy-making and health care quality control (see Chapter 1).

Second, the Netherlands has passed several laws aimed at strengthening the rights of users and at increasing their participation in treatment (WGBO law, 1992), health care planning and evaluation (WMCZ law, 1996), and social support and welfare policy (WMO law, 2007). Nowadays, user participation in the Netherlands takes place at three levels: the community level (through client organisations that host initiatives such as Project Apoio), the service level (through client councils) and the policy level (through regional and national consultation bodies). On the whole, it is estimated that 2,2 million people are engaged on client organisations concerned with health (Nederland *et al.*, 2003). This provides a rich pool of initiatives and experienced citizens who can be consulted in order to gain a comprehensive understanding of the phenomenon of participation.

Finally, there have been recent changes in Dutch health care policy which stress the importance of active citizen involvement in health governance. As we have seen in Chapter 5, and intensification of the marketisation of health care in the Netherlands and the emphasis put on demand-oriented care delivery has implied a shift on the role attributed to care users. Users are now expected to act as informed consumers, who evaluate and sensibly select the insurance packages and care that best suits their needs; organised lobbyists, who create demand for new types of care when necessary; and, involved citizens who participate in the making of health policy and in the development and evaluation of care programmes. More recently, the government has also dismissed its responsibility for the interculturalisation of health care, transferring it to the hands of the market agents. All these developments call upon the emancipation and proto-profissionalisation of users, i.e. the adoption of fundamental stances and basic concepts used among professional circles in order to articulate requests for appropriate care (De Swaan, 1990). Furthermore, they stress the need for an active user movement capable of advocating for the rights of users and of lobbying for the creation of 'tailor-made care'. As discussed in Chapter 5, however, not all social groups are equally represented by the user movement. MEMs are especially under-represented in client organisations (De Graaf and Eitjes, 2004). They also tend to be insufficiently proto-professionalised, particularly where mental health care is concerned (Kortman, 2003). This may compromise the promotion of their interests and diminish their access to adequate care. A potentially problematic development amidst all this has been the creation of categorical services specifically targeting for MEMs. While these services may come to provide good quality care to some minority groups, other less visible minorities may be left out. In addition, categorical care can lead MEM users to have less contact with mainstream care, increasing segregation (May and Ingleby, 2008). It appears that more than ever before disenfranchised groups need to come forward and voice their needs. Studying the ways by which some of these groups have succeeded to enter the Dutch participatory arena offers a good opportunity to understand the barriers hindering user participation and how they can be overcome.

Given this state of affairs, we opted to focus our Dutch case study on a group of migrants whose participation in mental health is a positive exception in the Dutch health participatory arena: Cape Verdean migrants. Unlike the majority of MEM groups in the Netherlands, Cape Verdeans were engaged in participatory initiatives designed to promote their rights and to advocate for diversity competent mental health care. As noted above, increased emphasis on individuals' responsibility in lobbying for the development of tailor-made care is likely to bring those unable to organise into a position of vulnerability. This was the case of Cape Verdea migrants. Before the creation of Project Apoio in 2000 in Rotterdam their mental health care needs were practically unheard of within the Dutch mental health system. Studies indicated that despite a high rate of psychosocial problems Cape Verdeans made little use of mental health services (Huiskamp *et al.*, 2000; Dieperink and Wiersdma, 2000). Subsequent studies came to explain that on the account of several factors (e.g. stigmatisation, lack of information and trust on providers) which work to limit their access to mental care (De Freitas, 2005; 2006). Project Apoio was created to deal with this problem and to bring a voice to the Cape Verdean community. Over the years, many Cape Verdeans engaged in participatory initiatives concerned with mental health promotion. Project Apoio was also recognised as a good practice in the field of mental health (Smulders, 2003). The fact that Cape Verdean migrants have literally shifted from a position of 'silence' into a position of increased recognition and involvement in the mental health care field can provide an insightful account of how previously excluded groups succeed to get engaged in the participatory arena. Moreover, it can shed light on the benefits of that participation and on how those benefits can be employed to empower other excluded groups to join participatory initiatives.

Case 2: Minority Northeasterners' participation in mental health in Brazil

The study of user participation in Brazil can also be very insightful as a result of the following factors.

First, Brazil is considered one of the world's most important laboratories of democratic innovation[75] (Gaventa, 2007). Citizen participation in health governance is a right enshrined by the 1988 Constitution which established Brazil's formal transition to democracy after twenty-one years of dictatorship. Since then, many invited participatory spaces have been created to facilitate the involvement of citizens in policy-

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[75] Brazil stepped formally into democracy in 1988 issuing a Constitution marked by several political innovations. Amongst those innovations were the decentralization of policy-making and the creation of participatory democratic mechanisms that enable citizens to participate in the formulation, management and monitoring of social policies (Coelho, 2007). The novelty and magnitude (from local to federal level) of these participatory mechanisms, the technology necessary to set them in motion and the problems that thwart their effective performance (e.g. clientelism, fragile associational life, authoritarian political culture, etc.) (Cornwall and Coelho, 2007; Carvalho, 1995), make Brazil an interesting laboratory to study the processes involved in reducing 'democratic deficits' by deepening the participation of citizens in democratic decision-making (Gaventa, 2007).

making (e.g. health councils and health conferences) (see Chapter 2). These spaces are amongst the participatory mechanisms conferring citizens with the greater power of deliberation over decision-making to have been implemented so far.

Second, Brazil hosts two important social movements in the field of health (see Chapter 1). Both the Health Reform Movement (MRS) and the Anti-asylum Movement (MNLA) had a determinant role in having citizen engagement in health policy and service monitoring be made part of the Constitution. They also strived to have the principle of 'social oversight' be put into the Basic Law of Health (Brasil, 1990), which sanctioned the creation of the Brazilian public health care system (SUS). Social oversight enables citizens to take part in the design, management and evaluation of health care, including its funding (Correia, 2000). Over the years, it has facilitated the participation of hundreds of thousands of people in health governance turning Brazil into a fertile ground to study user participation.

It is worth noting that, in contrast to the Dutch user movement, the Brazilian health movements have made it a point to remain autonomous from the state[76]. This stand is explained by the perpetuation of citizen's deep distrust in the state – a problem which developed during the period of military dictatorship and which extended into democracy as governments have consecutively failed to stamp out pervasive clientelism and an authoritarian political culture. This, again, emphasises the importance of social oversight in health care.

Finally, there have been recent changes in Brazilian mental health policy which stress the need for citizen participation, particularly by those citizens belonging to the most impoverished and marginalised segments of society. As we saw in Chapter 1, Brazil is undergoing a process of Psychiatric Reform. The abolishment of asylum-like institutions, the promotion of the full citizenship of people affected by psychosocial distress, and the provision of community-based psychosocial care are among its core goals. Even though reform was initiated in the 1970s, the law determining desinstitutionalisation and the creation of alternative community-based mental health services was only passed in 2001 (Brasil, 2001). The lobby made by owners of private psychiatric clinics succeeded to have its voting delayed several times since the project-law was first presented at the Senate in 1989 (Maia and Fernandes, 2002). Opposition to the implementation of reform by the same actors has been steady since then.

Despite resistance, the Psychiatric Reform has proceeded and enabled the return of thousands of psychiatric inmates to the community. Yet the gradual dismissal of 'total institutions' (Goffman, 1961), and the 'control' and 'exclusion' they represent, has not directly translated into the exercise of full citizenship by people affected by psychosocial problems. Psychiatric reformers understand citizenship not only as the incorporation of civil, political and social rights but also as the ability of each and every person to become part of society and act in a free and participative way while

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[76] Although some of the MNLA members hold positions in the public health sector, the movement has refused time and again to establish a formal link with the state. As noted in Chapter 1, the Dutch user movement is sponsored by the government.

preserving her subjectivity (Bezerra Jr., 1992). The element 'equality', which is usually seen as intrinsic to citizenship (alongside with freedom), is problematised within this conceptualisation since, where mental illness is concerned, it is the acceptance of difference that enables the mentally ill to exercise their citizenship (Bezerra Jr., 1994). This emphasis on *full* citizenship and on mental health care users as rights-holding citizens confers participation in Brazil an outlook different from that encountered in countries in the North. By re-considering and expanding the dimensions inherent to citizenship, the Psychiatric Reform advances a vision of participation in which users can claim their rights and engage on the governance of health services as 'makers and shapers' of decisions, instead of as clients or consumers (Cornwall and Gaventa, 2001). At least in theory, this grants users a more empowered standpoint from which to claim back their rightful position in society. Participation in Brazil has the potential thus to function as a 'spinning motor' in bringing new social actors to the fore of health governance.

In spite of these promises, many citizens continue to be excluded from the health participatory sphere. As discussed in Chapter 5, poor and ethnic minority people face considerable challenges in entering participatory spaces and, once they are in, they often lack the capacity to influence decision-making due to inequalities in resources, knowledge and power (Coelho *et al.*, 2005). Yet these are precisely the groups with most at stake in regard to the SUS: unlike the well-off, they are entirely dependant on the public health care system to satisfy their health care needs.

Psychosocial suffering among public mental care users is deeply associated and exacerbated by the negative effects of poverty, violence and exclusion. Users with a low socio-economic status (SES) depend on mental health services not just for care but also for assuring basic needs such as food, medication and hygiene. However, limited funding, inefficient expenditure control, and endemic corruption, have impeded the creation of sufficient community-based psychosocial care services (i.e. CAPS). Furthermore, actors engaged on clientelism and political authoritarianism work their way to obstruct the effective performance and funding of the participatory democratic mechanisms (e.g. health councils) through which citizens can hold public administrators to account. The authoritarian political culture which reigns in many public offices throughout Brazil is at the origin of the principle of social oversight over health care policy and delivery and is a constant reminder of the pertinence of health participatory spaces. Yet these mechanisms will only work to enforce the democratisation of public care (and the completion of Psychiatric Reform) if they succeed in staying independent from established political groups and in engaging representatives from all segments of society in health policy decision-making and accountability processes (Cornwall and Shankland, 2008).

As noted earlier, bringing representatives of the poor to the fore in the Brazilian participatory sphere is especially critical. Yet there is another social group whose voice is seldom heard and which appears to be in a position of even greater disadvantage: poor migrants and ethnic minorities (MEMs). Poor MEMs endure the negative effects of deprivation affecting low-SES people and are at greater risk of receiving inadequate health care. Unlike the Netherlands, Brazil does not have migrant health policy in place yet. Lack of attention to cultural competence in health care has been found to lead to the inadequate pathologisation of internal migrants' subjective beliefs and habits (Ferreira, 1996). This indicates there may be a mismatch between MEMs' mental health care needs and the care currently available to them. Limited access to good quality mental health care is likely to reinforce the position of disadvantage many migrants already find themselves in. It is imperative thus that low-SES MEMs take part in health participatory spaces and articulate their needs. Studying the ways by which representatives of that group succeed to come into the Brazilian participatory sphere offers a valuable opportunity to learn about how vulnerable groups get empowered to claim the substantive benefits of their full citizenship. It can also advance our understanding of the measures that need to be taken in order to render health participatory spaces more receptive to members of socially excluded groups.

Given this state of affairs, we opted to focus our Brazilian case study on a minority group whose participation in mental health is an example of success among the social groups least represented in the Brazilian participatory sphere: minority Northeasterners. As we saw in Chapter 5, Northeasterners are the largest migrant group in Brazil and the largest ethnic minority in southern megalopolises such as Rio de Janeiro (Brito, 2006). Yet there is only a handful of studies addressing the particular health care needs of this group (e.g. Ferreira, 1996; 1999; Rebello, 1997; Oliveira, 2002), even if Northeastern migrants make up to almost one third of the inmate population of psychiatric hospitals in Rio de Janeiro (Silva *et al.*, 1999)[77]. In addition, when we inquired about the ethnic profile of users in a community-based psychosocial care service – CAPS Pedro Pellegrino – located in an area with a high density of internal migrants, we were able to identify descendants of Northeastern migrants but no first generation Northeasterners were found. As noted above, much remains to be done to bring cultural competence into mental health care delivery in Rio de Janeiro. Furthermore, the high rates of internal migrants in Rio de Janeiro's psychiatric hospitals and their absence in community-based psychosocial care services suggest that Northeastern migrants may be under-using out-patient mental health care, possibly because they are insufficiently informed about these services and lack the resources to use them (e.g. ability to identify candidacy for and gain entry to mental services). CAPS Pedro Pellegrino was created to facilitate the ongoing Psychiatric Reform and to enable the transition of psychiatric inmates into the community. Unlike other services where user participation receives little attention, CAPS Pedro Pellegrino has been particularly keen in adopting a participatory approach to health care delivery and to foster the voice of its users. Although no specific efforts appear to have been done to

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[77] As noted in Chapter 5, we were unable to find data on the amount of internal migrants who make use of community-based mental health care services in Rio de Janeiro.

promote the participation of ethnic minority users in particular, CAPS Pedro Pellegrino has seen representatives of that group get engaged both on its own participatory space – the Assembleia, and on the local branch of the Brazilian user movement. Over the years, minority Northeasterners have participated in many initiatives to promote their rights as citizens and to claim a fair allocation of resources to mental care delivery. In the future, those participatory exercises may enable them to place demands for the development of health policy sensitive to the needs of migrants, an issue which is still overlooked within the Brazilian participatory sphere. Inquiring about their perceptions of and experiences with participation can enhance our understanding of the barriers which limit low-SES ethnic minorities' involvement in Brazilian health participatory spaces. It can also shed light on incentives capable of fostering their participation.

A final consideration here regards the comparison between the two cases selected. As we saw in Chapters 1, 2 and 5, the socio-economic and political context, and the health participatory spheres in the Netherlands and in Brazil are considerably different. However, the user groups researched share a number of characteristics and experiences – ethnic minority status, low-SES, psychosocial suffering, limited access to mental health care, discrimination and social exclusion – which make their cases suited for cross-case analysis employing a case-comparison approach (Yin, 1981) and the analytic technique of explanation-building (Yin, 1994). See section 2.4 for a description of the analysis of the two cases.

6.3 Methods of data collection

Data for the case studies presented in this thesis were collected through various methods, including observation, interviews and a review of secondary sources. In what follows we describe how these methods were employed in each case study.

6.3.1 Observation

"Qualitative case study is characterised by the main researcher spending substantial time, on site, personally in contact with activities and operations of the case, reflecting, [and] revising meanings of what is going on" (Stake, 1994: 242). These activities can be summarised as *observation*, a fundamental method within interpretive traditions of human inquiry (Atkinson and Hammersley, 1994). Observation renders immersion with the social group under study and the interpretation of their subjective experiences and meanings possible (Schutz, 1954 cited by Robson, 1993). In other words, it allows the researcher to get closer to the phenomenon being studied.

Observation for this study took place in the Netherlands (NL) between January 2005 and June 2006 and in Brazil (BZ) between July 2006 and June 2007. It took place in several settings and was focused on various types of activities. The activities observed include:

- health and mental health promotion: observation of health promotion initiatives carried out by out-reaching projects, namely Project Apoio (NL), PSF Barra de Guaratiba and PACS Jardim Maravilha (BZ);
- mental health care provision: observation of group therapy sessions and of the general dynamics of mental health services at RIAGG Rijnmond (NL) and CAPS Pedro Pellegrino (BZ);
- user participation in mental health: observation of user participation in the peer support group (*Grupo de Conversa*) of Project Apoio at Basisberaad GGZ Rijnmond (NL), in the client council of RIAGG Rijnmond (NL), in the user assembly (*Assembleia*) of CAPS Pedro Pellegrino (BZ), in the municipal health council of Rio de Janeiro (BZ), and in the National Anti-asylum Movement (BZ);
- mental health conferences, meetings and information sessions: observation of information sessions organised by Project Apoio (NL), meetings of users, professionals and social scientists concerned with mental health (NL, BZ), the National Mental Health Conference in Belo Horizonte (2006, BZ), and the Jubilee Congress of Interculturalisation of Mental Health Care (2009, NL).

While some methodologists conceive of observation as being possible with minimum or no interference, i.e. non-participant observation, others argue that all observation is in fact *participant* observation because one cannot study the social world without being part of it (Hammersley and Atkinson, 1983). Raymond Gold (1958) proposed a typology of observation which offers a more nuanced alternative by establishing a continuum according to which the researcher may adopt different roles in between those two positions: complete observer, observer as participant, participant as observer, and complete participant.

During the course of this study I introduced myself at all times as a researcher, both when negotiating access to research settings and when doing fieldwork. I almost never adopted the role of complete observer (except when arriving for the first time at a research setting in which I was not yet known to the people) neither the role of complete participant. In most instances, I became acquainted with the different research settings and with participants as 'observer-as-participant'[78]. It was from this position that I began to immerse myself with the social actors from Project Apoio at Basisberaad GGZ Rijnmond in Rotterdam and from CAPS Pedro Pellegrino in Rio de Janeiro, the two settings where observation took place in a more systematic and intense

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[78] One exception were my observations of the RIAGG Rijnmond client council with which I became more acquainted as a hired researcher of a project designed to create a client council in a psychiatric hospital in Suriname. The opportunity to work with some members of RIAGG's client council proved of great value to understand the 'ins and outs' of such a council and to gain a more insider perspective on user participation. In this instance in particular, I began observation as 'participant-as-observer'.

way. However, as time progressed, my position in some of the settings shifted to that of 'participant-as-observer'. This occurred in a subtle manner in both the Netherlands and Brazil. As some of the key stakeholders began to feel more familiar and comfortable with my presence and a relationship of trust was built, they started asking me to get more directly involved with some of the activities and projects they were promoting. This was the case with the *Grupo de Conversa* (Peer Support Group) of Project Apoio which I co-facilitated together with two former Cape Verdean mental health care users, the *Novos Caminhos* (New Pathways) therapy group at RIAGG Rijnmond in Rotterdam to which I contributed as a translator, the *Projeto Sem Crise na Crise* (Project Without Crisis in Crisis) in Rio de Janeiro to which I provided information on user participation in situations of psychotic episodes[79], and the delivery of information sessions in both the Netherlands and Brazil.

The advantages and disadvantages of observation as a method of inquiry in the social sciences are well documented (Robson, 1993; Yin, 1994; Stake, 1995). While observation is time-consuming, and subjected to several biases (e.g. selective attention, selective encoding, selective memory, interpersonal factors; Robson, 1993), it also provides an opportunity, unmatched by any other method, to acquire an 'insider' perspective over the social group under study. This perspective, it has been argued, is essential to produce an authentic portrayal of a case study phenomenon (Yin, 1994). The case studies presented in this thesis benefited from observation in several ways. There were also some shortcomings. In our opinion, former have clearly outweighed the latter. In what follows, we elaborate first on the advantages of observation for this study and then reflect on its drawbacks and the ways by which we sought to minimise its effects.

Overall, observation became a fundamental method to "uncover, make accessible and reveal the meanings (realities) people use to make sense of their daily lives" (Jorgensen, 1989: 15). Its value and appropriateness have been noticeable since the early stages of the study. The observation of activities concerned with health promotion and user participation was critical to begin to understand how participants make sense of these phenomena, how they engage with them and the ways by which they express and interpret their experiences. This has been particularly useful to identify and set aside preconceptions, to formulate hypotheses and to inform the making of interview guides.

The period I spent doing observation as observer-as-participant was also crucial to gain 'real' access to participants. While permission to conduct the case studies was obtained in a swift manner, trust, acceptance and rapport are usually not a given, and this tends to be especially evident when the researcher does not belong to the social group under study. My experience in this respect has been twofold. Whereas in the

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[79] This contribution resulted in a publication focused on transferability of psychiatric advanced directives developed in the Netherlands (namely, the crisis plan and the crisis card) to the Brazilian context (see De Freitas, 2008a). In April 2009 the Brazilian Ministry of Health – National Coordination of Mental Health approved five pilot projects concerned with the implementation of the crisis plan/card.

Netherlands rapport with Cape Verdean participants had to be built step by step, in Brazil it was established in a much more immediate way. Being a middle-class woman from Portugal who had no personal experience with psychosocial distress, I was not an insider in any of the social groups I researched. My background in clinical psychology proved to be an asset as it justified my interest in mental health and it was perceived as a valuable resource by some of the key stakeholders. Nevertheless, whilst in Brazil that served to 'open many doors', particularly with minority Northeastern users who felt flattered by the invitation to take part international study; in the Netherlands, I felt that to reach Cape Verdeans it was necessary to demonstrate genuine interest in their community as well as the ability to keep secrets and to reciprocate good will.

During the first stage of observation in Rotterdam, it was not uncommon for Cape Verdeans to ask why I was interested in them or to timidly interrupt a conversation when I entered the room. With the time, I reasoned this could be explained by the fact that even though I was also a Portuguese speaking *buitenlander* (foreigner) in the Netherlands, we did not share the same cultural background or the same 'language of the heart' (i.e. *Crioulo*)[80], and history between our two countries had proved poignant until just a few decades before[81]. Another aspect which was likely to be delaying 'proximity' is the presence of the habit of gossiping in the Cape Verdean community. This made people wary when talking (especially with someone they did not know) out of fear that their experience with psychosocial distress could be divulged within a community which often stigmatises the 'mentally ill'. Along the way, I learned that to establish rapport it was necessary to spend time on site, putting myself in a position in which I could also be observed and from which I could answer their questions, clarify their doubts and show reliability. As time passed, participants became more open when I was around. The sharing of intimacies and gossip were no longer terminated in my presence and they began to include me in conversations. The issue of gossip deserved quite some of my reflection. What was I to do? Take part on those lively but not always kind and possibly compromising conversations? Avoid them and miss out on potentially relevant information? Or just stay around without actively participating? I chose the latter. This had two interesting effects. At first, it deferred closeness: when not going along with gossiping I noticed inquisitive looks which served as a warning of the risk of falling back into an outsider position. But later it led to a solid relationship of trust with several Cape Verdeans who more directly involved with Project Apoio. This became apparent when some of them started waiting until everyone else left to share their confidences with me. It seemed that, gradually, they

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[80] Although Portuguese is Cape Verde's official language, Cape Verdean *Crioulo* has the status of national language. *Crioulo* is the way of expression Cape Verdeans feel more at ease with and the language most used for storytelling, joking, singing and sharing feelings (Halter, 1993).

[81] Cape Verde was a colony of Portugal between the sixteenth century and 1975, when it acquired independence (Almeida, 1997a). During this period, Cape Verdeans suffered many times the effects of severe droughts. Mainland Portugal was much too often oblivious to that suffering. In 1947, a drought caused a famine which led to death 10 000 people (Pires, 2006). Portugal sent no aid (Meintel, 1984a).

had come to accept me. In due time, the distance between us started shortening and mutual rapport heightened.

Another benefit of doing observation was the opportunity it provided to match 'say's' with 'do's'. This allowed, for instance, a more reliable answer to questions such as: how do participants decide in which health-related initiatives to participate? Why do certain participatory initiatives appear more accessible than others? What undermines participation? In the Netherlands, there were some Cape Verdean volunteers who always participated in the organisation of public events promoted by Project Apoio but hardly ever participated on the events themselves. This was incongruent with the results brought up by interviews in which they said they valued those events. After field observations and some informal interviews, I realised that their absence in public events was not a result of disinterest but, instead, it was explained by the fear of being associated with mental illness and becoming excluded. This was very informative to understand the barriers that inhibit Cape Verdeans' participation in mental health care (see Chapter 8).

Another instance in which observation facilitated an answer to the questions raised above is that of participants' irregular attendance of MNLA's meetings in Rio de Janeiro. For some time, I was puzzled about the reason why the user movement meetings had usually no more than ten participants and, in some occasions, that number doubled or tripled. How were participants to decide which meetings were worth attending and which not? During fieldwork at CAPS Pedro Pellegrino I became aware that apart from personal factors (e.g. participants' availability to attend the meetings) attendance of MNLA meetings was determined by participants presence (or not) on the weekly *Assembleia* meetings at the CAPS and the sort of information divulged in that assembly. When word got round that an important decision or action was about to take place during the next meeting of the user movement, and that at least one of the professionals expressed willingness to attend it, odds were high that participants would join in. But when little attention was given to an upcoming MNLA's meeting no participants were spotted on site. The trip between Campo Grande (where most participants resided) and Centro (where the MNLA meetings were held) was long and not everyone could afford it, both because it was tiring and because it put a financial strain on users' already meagre budgets[82]. When professionals went along they boosted participants' motivation and, at times, sponsored the travel. This increased the accessibility of some meetings over others, serving as yet another important reminder that participation is largely determined by contextual, economic and social factors (see Chapter 7).

Finally, combining observation with participation was also beneficial for this study because it served to elicit particular situations (Robson, 1993) which increased our understanding of specific characteristics and perceptions of the groups under study.

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[82] The trip between Campo Grande and Centro took about 1h30. The price of the return trip was about 8 Reais (about 3 €), a rather high sum for people living on 450 Reais (164€) per month.

This became possible particularly when I adopted the role of participant-as-observer. The following excerpt of my field diary provides a description of one such situation.

> Today, *Grupo de Conversa* was about depression. There was a reasonable number of participants (10). Aside from the Cape Verdean clients that usually attend the sessions, two Portuguese and two Brazilians joined in as well. Their presence was very positive. The Brazilians often took the initiative to talk and share their experiences. This seemed to make other participants feel more comfortable in doing the same. The session was lively and, in spite of various stories of suffering, participants were in a good mood and every now and then someone cracked a joke that made us all laugh.
>
> My feeling that sessions need to be a bit 'spiced up' seems to be right. Instead of starting by giving some information on depression right away, I showed them a [copy of a] painting from Van Gogh – 'Old man in sorrow'[83]. The painting displays a bold man, dressed in blue, sitting in a chair, his hands covering his face, his back curled inwards. I chose it in the hope participants associated it with sadness and grief, like I did. Without revealing the title of the painting I asked what they saw. Reactions soon followed. To my surprise and enthusiasm, the more comments they made the more I realised how possible it was to translate their responses into the professional terminology employed to refer to the 'symptoms' and 'causes' of depression. They did not use the same wording and barely resorted to jargon but their descriptions were accurate and rather complete. They said that the man in the painting was 'sad inside' (*triste por dentro*), that his 'soul was empty' (*alma vazia*), that he lacked 'self-love' (*falta de amor próprio*), that he felt lonely (*só*), oppressed (*oprimido*), frustrated with life (*frustado com a vida*). They supplemented these feelings with explanations about its origins: 'he has been abandoned'; 'he has no family'; 'there is nobody who can understand <u>us</u>'; '<u>we</u> feel unbalanced because <u>we</u> can't find the answer to sort out conflicts'; 'he cannot fulfil the dream of his life'. At some point one of the women said: 'we see in him what we feel'.
>
> Some participants appear to have identified with the man in the painting and this seems to have helped with the sharing of their experiences. A woman told how she spent years thinking life had no meaning and how that almost put her marriage into jeopardy until she got a diagnosis for chronic depression and began treatment. A man told he had to abandon his job as a hairdresser in a previous host country because he was unable to handle customers' racist comments and how that made him fall into a spiral of frustration and sorrow. (…) While these stories were being told there was always someone with a word of comfort for the speaker, sometimes even advice on how to face those problems. This was perhaps one of the most fruitful [*Grupo de Conversa*] sessions I attended to.
>
> After a while, someone asked about treatment. I presented information about different sorts of treatment (e.g. psychotherapy, use of medication, mutual-aid

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[83] For a visual of Van Gogh's 'Old man in sorrow' (1890) see http://www.vggallery.com/painting/p_0702.htm

> groups, etc.) and participants began to discuss the advantages and disadvantages of those they had either tried out or heard about (…). (4 April, 2007)

The data collected during this session has become of good value for this study. First, it offered yet another argument to assert that the use of 'professional jargon' is one of the barriers that prevents Cape Verdeans from participating in mental health care (see Chapter 8). Second, it allowed us to dispute the idea conveyed by some professionals in the Netherlands that non-Western migrants are unable to understand and formulate requests for help to deal with psychosocial problems other than through psychosomatic complaints. Most rightly, some will seek help by presenting psychosomatic complaints, also because that is how they really feel. However, it is crucial to realise and integrate in daily health care practice migrants' (and non-migrants) idiosyncratic ways of experiencing and referring to psychosocial distress, i.e. their idioms of distress (Nichter, 1981). Acting as a participant-as-observer gave me the opportunity to elicit participants' subjective meanings of depression, attesting the relevance of this method to pursue greater understanding not only of the phenomenon of participation but also about participants' systems of reference and idioms of distress.

As mentioned above, observation is subject to several biases and can bring some disadvantages for the study at hand if the researcher fails to remain wary of them. The periods of observation in which these issues have been of greater concern to me were those in which I acted as participant-as-observer. By adopting that role I was likely to influence the situations under observation and, like I just described, this was particularly the case with Project Apoio's *Grupo de Conversa*. In that instance, I was especially concerned participants would become suspicious of my dual role as researcher and co-facilitator of the group and either felt compelled to withhold the sharing of their experiences or dropped-out. To minimise these potential effects, I introduced myself as a researcher with a background in psychology, explained the goals of my study leaving room for questions, and assured them that the confidentiality of their statements would always be respected and any material I was to use from those sessions would be cited without revealing their identities. During the first two sessions most participants were quiet. I could not stop wonder if that was due to my presence or to participants' need to first get acquainted with each other and with the facilitators, or if it was just something else. We had agreed to close our sessions by deciding which topic to discuss in the next one but ideas emerged with difficulty. In the third session, however, there were many questions and suggestions for future topics of discussion. It seemed the 'ice had been broken'. That every now and then someone asked how my study was progressing served as a convenient way to confirm participants' awareness of my dual role as co-facilitator/researcher and as a sign of acceptance.

The role of participant did, at times, take away attention from the role of observer. Some of the activities in which I participated were very lively and dynamic, demanding a lot of attention. I sought to maximise data collection in these situations by supplementing note-taking on the spot with the writing of more detailed notes after the events. Those notes were left open and incremented each time I recalled a relevant conversation or had an insight about the situations described.

Becoming a participant-as-observer did imply an extra time load on the schedule initially planned for this study. However, I perceive this as a relative disadvantage. If on the one hand it delayed somewhat the completion of the study, on the other hand it facilitated access to situations and insights which would have otherwise been inaccessible. In addition, I believe knowledge is only of worth when shared and applied. Participating in the activities promoted by the services and projects I researched gave me the possibility to return the attention and time participants conceded me and to contribute to a field where resources are limited and human suffering is much too prevalent.

6.3.3 Interviews

In-depth, semi-structured interviews were carried out face-to-face with a total of 93 respondents in Brazil (n = 43) and in the Netherlands (n = 50).

We considered in-depth interviews to be an appropriate method for this study (rather than questionnaires) because we aim to understand how people affected by psychosocial distress become engaged in participatory spaces and how they give meaning to their participation experiences. Detailed accounts on these matters rarely emerge spontaneously during interaction and cannot be fully grasped through observation. The in-depth interview is a flexible and adaptable method which enables the researcher to approach participants directly and seek comprehensive answers to the research questions (Robson, 1993).

We opted to conduct semi-structured interviews and to employ mostly open-ended questions because participants tend to have different experiences with and perceptions about participation and to use a variety of expressions to refer to similar phenomena. Semi-structured interviews and open questions are flexible enough to accommodate those differences without loosing focus from the main goals of the research. They encourage cooperation and rapport by allowing interviewees to make sense of the world in their own terms. And they facilitate unexpected answers which can lead to unanticipated relationships and explanations (Cohen and Manion, 1989 cited by Robson, 1993).

Not all respondents were able to articulate their views immediately after a question was made. In some cases, the impairments caused by illness and/or the use of medication made respondents forgetful, distracted or unable to find the words they wished to use. Face-to-face interviews allow the researcher to be more aware of the situations in which a question is not understood and there is a need to repeat or reformulate it. They also enable access to non-verbal cues. Non-verbal cues can foster the understanding of verbal (at times, not completely phrased) responses (Robson, 1993). They can also help to identify instants in which respondents may feel unease, allowing the researcher to discard a question or suggest a pause. This is particularly relevant when interviewing people affected by psychosocial problems as it can reduce the chances of interviews becoming intrusive.

We sampled two clusters of respondents in each of the countries where research was conducted:

- one cluster composed of migrant and ethnic minority mental health care users with who participate in mental health care services or mental health related projects;
- and one cluster composed of different types of stakeholders in the process of participation, including experts by experience, facilitators of client councils, members of user movements, (mental) health and social care providers, care consultants/mediators and researchers.

Although our main goal is to understand how people affected by psychosocial distress give meaning to their experiences of participation, such a study would be incomplete if it failed to include the perceptions of other key actors in the process of participation. Even when they are not directly engaged in health participatory spaces, those actors have often a crucial role in determining the course and sustainability of user participation. For example, there is substantial evidence that user participation in health care services can become tokenistic when implemented within reluctant organisational and professional cultures and allocated insufficient resources (Bowl, 1996; Lindow, 1999; Campbell, 2001; Rutter *et al.*, 2001; Summers, 2003; Rose *et al.*, 2004). Studies also show that participatory fora constituted by public officials, health workers and care users are not free from being exploited in favour of the former's interests (and at times of the second) to the disadvantage of users, when its members have unequal access to knowledge, information and resources (Barnes, 2007; Coelho, 2007; Cornwall, 2007). Enquiry with a broad range of actors is thus essential to understand the cultural, political, economic and organisational factors which compose the 'colour pallet' from which participation's different 'make-ups' emerge.

We resorted to purposive (Kerlinger, 1986) and snowball (Miles and Huberman, 1994) sampling strategies essentially because we aim to enquire about the participation of two user groups over which there is little research done. In addition, it was also necessary to identify individuals who either have a stake in user participation or are actively engaged on it. It was impossible to determine the total amount of people falling into these two categories. A survey study and probability sampling (Babbie, 1995) were therefore unfeasible. Although nonprobability sampling designs are not generalizable, they can provide a comprehensive theoretical understanding of the social processes under study. In addition, they offer the opportunity to access populations who are difficult to reach. These kinds of designs have been found particularly advantageous for studies focusing in sensitive topics and/or vulnerable populations (Lee, 1993), as does our study.

Pilot interviews were conducted in Brazil and in the Netherlands in order to design interview guides able to elicit answers to our research questions and to accommodate the specific terminology employed by the respondents of each cluster. An interesting finding from the pilot interviews was that involved mental health care users in the those two countries refer to themselves in a very different way. Whereas in the Netherlands users tend to employ the terms *cliënt* (client) and *patiënt* (patient), in Brazil they use the terms *usuário* (user), *paciente* (patient) and *militante* (militant). In the Portuguese language *militante* means 'a person who actively defends a cause, a party or a movement' or 'a person who fights for something' (Dicionário da Língua Portuguesa, 2008) and, indeed, that term is mostly employed by users affiliated with the Brazilian user movement. Although there is also a user movement in the Netherlands its members do not define themselves as militants but rather as clients or patients. That realisation alerted us for the possibility that user participation in Brazil and in the Netherlands may be premised on distinct rationales. As we saw in Chapter 2, participation in health governance in Brazil is oriented by a democratic model of engagement, while the Netherlands combines a consumerist and democratic approach to user participation.

All the interviews were carried out by the author of the thesis. The purpose of the study was explained before interviews started and respondents were assured about the confidentiality of their statements. All the names mentioned in this study are pseudonyms. Because the study deals with people who experience(d) psychosocial distress we informed all respondents they could decline to answer any of the questions asked or discontinue the interview at any time they liked without having to give an explanation. Informed consent was obtained from all respondents. All interviews were audio-taped with the permission of respondents and later transcribed by the principal researcher and freelance transcribers[84]. In what follows, we provide more details about the interviews according to the countries where they were conducted.

6.3.2.1 The Netherlands

Interviews in the Netherlands were carried out with two clusters of respondents: Cape Verdean migrants who experience(d) psychosocial problems (hereafter referred to as *The Netherlands client group*) and stakeholders in the process of participation (hereafter referred to as *The Netherlands stakeholder group*). The interviews took place between May 2005 and June 2006. The details pertaining to each cluster are presented below.

The Netherlands client group

This cluster is composed of twenty Cape Verdean migrants who reside in the region of Rotterdam. Respondents were selected through purposive sampling (Kerlinger, 1993)

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[84] None of the interviews with respondents from the clusters composed of individuals who experience(d) psychosocial distress were transcribed by freelance transcribers.

with the cooperation of the coordination of Project Apoio at Basisberaad GGZ Rijnmond.

All respondents were clients of Project Apoio and have experience with psychosocial distress. Invitation to take part in the study was done by a letter accompanied of an information sheet in Portuguese and Dutch explaining the purposes of the study[85]. We asked two volunteers of Project Apoio to review the information sheet in order to minimise misunderstandings and increase its accessibility. Four respondents were handed in the letter personally. The remaining participants received the letter by post.

We interviewed fourteen Cape Verdeans who participated in mental health initiatives promoted by Project Apoio and six Cape Verdeans who did not engage in participatory initiatives but received individual support through the Project. In what follows, we address the former group as 'involved clients' and the latter as 'non involved clients'. We included non involved clients in our sample because their experiences are likely to bring additional insight about the ways by which engaged- and non-engaged clients use mental health care services, enjoy awareness about their rights and realise opportunities for participation.

Involved clients were contacted after identifying two initiatives within Project Apoio created to promote the emancipation of and give a voice to Cape Verdean clients –the *Comissão de Apoio* and the *Grupo de Conversa*. From the fourteen involved clients interviewed, eight took part in Comissão, four participated in the Grupo de Conversa, and two participated in both.

All clients who took part in Comissão were invited by letter to have a meeting with the researcher in which the goals of the study were explained[86]. From a total of twenty members, six attended that meeting[87] in December 2006. During the meeting, a preliminary inquiry about members' experience with Comissão was carried out. Participants considered it a positive initiative and some stated their interest to re-initiate it. Questions about the study were answered and all participants agreed to take part in it.

Attendance to Grupo de Conversa was irregular, ranging between four and eighteen participants. We approached all the four participants who attended the peer group on a regular basis personally and asked them to participate in the study. They all accepted to take part.

Non involved clients were randomly selected from the list of clients of Project Apoio. A total of twelve clients were selected and invited to participate in the study. In

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[85] Apoio clients are used to be informed about and invited to events and new initiatives by letter. We employed the same strategy in the attempt of maximising a positive response to our invitation to take part in the study.

[86] Before setting a date for the meeting the researcher telephoned all members of Comissão to consult about the date and time able to accommodate the highest number of participants.

[87] Four of the twenty members of Comissão were unreachable. From the ten members we succeeded to contact but who could not attend the meeting, four agreed to participate in the study.

the absence of a response, clients were contacted by telephone. From the twelve, only seven were reached. Six agreed to participate in the study.

Interviews with involved and non involved Cape Verdean clients were held at the locations, dates and time suggested by participants: thirteen interviews were conducted in the participants' homes, four in Basisberaad GGZ Rijnmond, two in Casa Tibérias[88], and one in a municipal library. Interviews lasted between 1h and 3h and were carried out in Portuguese (18) and Dutch (2).

In what follows, we present the data regarding the socio-demographic characteristics and the migration background of this cluster's respondents. Data is presented first for the involved clients and then for the non-involved clients.

Table 2 shows the socio-demographic characteristics of the involved Cape Verdean clients and the type of activities in which they participate.

Most respondents in this sub-cluster are women (12) and two are men. The sample closely reflects the gender ratio of clients involved in Project Apoio's participatory activities at Basisberaad GGZ Rijnmond[89]. Women have traditionally adopted the role of caretakers in Cape Verdean families. In addition, illness is experienced in a substantially different way by Cape Verdean women and men. While women tend to seek care when confronted with 'light' symptoms such as headaches or weight variations, men only perceive themselves as ill when they are unable to get out of bed and go to work (França, 1992). According to Project Apoio's coordinator:

> If help is needed women are the first to make an effort to get it. They do this for themselves, for their children, but also for the men in their families. It is very common to have women seeking help for their husbands, partners, brothers, fathers, uncles, and cousins (…) when a man asks for help is in fact because he is in deep need for it (interview excerpt cited in De Freitas, 2006: 79).

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[88] Casa Tibérias is an association for Portuguese-speaking women in Rotterdam which organises social-cultural activities focused on education, emancipation, participation and support in child rearing. Casa Tibérias was originally set up by the Portuguese-speaking parish Our Lady of Peace in 1994 as a relief centre (*opvanghuis*) for Cape Verdean women and their children. In 2005, Casa Tibérias was handed over to the Rotterdam Women Relief Centre (*Vrouwenopvang Rotterdam, VOR*). All the activities promoted by Casa Tibérias are organised by volunteers. Three of the women interviewed were also members of Casa Tibérias.

[89] One exception is the 'Talk Group' for former seamen, composed exclusively of men clients. The group was created when a relatively large group of Cape Verdean men (approximately 40) experiencing psychosocial problems and difficulties to regularise their residence in the Netherlands was identified. Its goals consist of enhancing clients' access to (mental) health care and to promote their participation in mental heath related activities. We did not include members of this group in our sample because at the time we did fieldwork the 'Seamen Talk Group' was just starting and the majority of its participants had not been engaged in other initiatives.

Table 2 *Socio-demographic characteristics of involved Cape Verdean clients (n=14) and type of participatory activity (data colletcted in 2006)*

Name	Age	Gender	Civil Status	Years of Education	Professional Status	Social Benefits	Participatory Activity
Joana	27	F	Single	School: 12 Technical study in education assistant: 1	Unemployed, former school assistant	Unemployment benefit	*Comissão*
Cátia	27	F	Single	School: 12 Technical study in administration: 1	Employed: cooking assistant	None	*Comissão*
Filomena	54	F	Divorced (divorced once before)	School: 4	Sickness leave, former cleaner	Temporary sickness benefit	*Comissão*
Aurora	30	F	Single	School: 11	Unemployed, former cleaner	Unemployment benefit	*Comissão*
José	60	M	Widow (divorced twice before)	School: 6	Pensioner, former seaman	Pension	*Comissão*
Isabel	54	F	Married	School: 5	Permanent sickness leave, former cleaner	Permanent sickness benefit	*Comissão* and *Grupo de Conversa*
Leonor	42	F	Married (divorced once before from current husband)	School: 3	Sickness leave, former factory worker	Temporary sickness benefit	*Comissão* and *Grupo de Conversa*
David	71	M	Married	School: 7 Technical study in merchant navy: 2	Pensioner, former seaman	Pension	*Comissão*
Palmira	64	F	Divorced	Illiterate	Pensioner, former factory worker	Pension	*Comissão*
Márcia	30	F	Single	School: 13 Middle-level applied education in social work: 4	Employed: home caretaker	None	*Comissão*
Sara	51	F	Separated	School: 12	Sickness leave, former bank clerk	Temporary sickness benefit	*Grupo de Conversa*
Simone	39	F	Divorced	School: 13 Higher applied education in business and economics: 4	Sickness leave,former business manager	Temporary sickness benefit	*Grupo de Conversa*
Madalena	49	F	Separated (divorced once before)	School: 4	Sickness leave, former cook	Temporary sickness benefit	*Grupo de Conversa*
Armanda	47	F	Separated (divorced once before from the same person)	School: 3	Unemployed, former waitress	Unemployment benefit	*Grupo de Conversa*

All respondents have relatives in the Netherlands. Four respondents are single, three are married, three are separated, three are divorced, and one is a widow. Two respondents lived alone and the rest shared a home with family members. It is relevant to note that 27% of Cape Verdean families in the Netherlands are single parent families (ISEO/ COS, 2000). Some of our respondents married and separated or divorced several times. Women usually take most household responsibilities, especially child rearing (Meintel, 1984a). In the Netherlands, 50% of Cape Verdean children are raised by single mothers (Naber and Veldman, 1997). Single parents of young children are likely to have households with lower incomes per capita and have less availability to attend participatory activities, events, conferences, etc. Perhaps this helps to explain why only one of the respondents in this sub-cluster is a single parent of children at young age. All the other respondents who are single parents have teenage or adult offspring.

Nine respondents are clients of Project Apoio since 2001. From the remaining respondents, one became a client in 2002, one in 2003, one in 2004 and two in 2005.

Thirteen of the involved Cape Verdean clients are first generation migrants and one is a second generation migrant[90]. Table 3 provides a description of the migration-related characteristics of each respondent.

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[90] We consider first generation migrants those participants who were born outside the Netherlands and perceive themselves as Cape Verdean and second generation migrants the participants who have at least one parent from Cape Verde and were born and raised in the Netherlands. It is important to note that three participants who are described here as first generation migrants were born in Portugal. In that country, they would be considered second generation Cape Verdeans. However, because they are of Cape Verdean descent, have been brought up elsewhere and migrated to the Netherlands, we consider them first generation at the current host country.

Table 3 *Migration-related characteristics of involved Cape Verdean clients (n=14)**

Name	Date of Birth	Place of Birth	Arrival to the Netherlands	Length of Residence in the Netherlands	Previous Countries of Migration
Joana	1978	Lisbon, Portugal	1998	7 years	None
Cátia	1978	Lisbon, Portugal	1998	7 years	None
Filomena	1952	São Tiago, Cape Verde	1989	16 years	Portugal (1974-1989)
Aurora	1976	Amadora, Portugal	1997/2002	2 + 4 = 6 years	The Netherlands (1997-1999) Portugal (1999-2002)
José	1946	Maio, Cape Verde	1974	32 years	None
Isabel	1952	Sal, Cape Verde	1992	14 years	Italy (1970-1974) Portugal (1974-1992)
Leonor	1964	Santo Antão, Cape Verde	1984	22 years	None
David	1935	São Tiago, Cape Verde	1989	17 years	None
Palmira	1942	Santo Antão, Cape Verde	1969	37 years	None
Márcia	1965	Rotterdam, The Netherlands	Not applicable	30 years	None
Sara	1955	São Tiago, Cape Verde	1993	13 years	None
Simone	1966	São Tiago, Cape Verde	1977	29 years	None
Madalena	1957	São Tiago, Cape Verde	1987	20 years	U. S. A. (1980-1983) Cape Verde (1983-1984) Portugal (1984-1987)
Armanda	1959	Fogo, Cape Verde	1977	28 years	Angola (1969-1975) Cape Verde (1975-1977)

* Data collected in 2006.

Most respondents were born in Cape Verde (10), three were born in Portugal and one was born in the Netherlands. Respondents' average length of residence in the Netherlands is 19, 9 years, varying between six and 37 years of permanence in the host country. Ages on arrival to the Netherlands range from 10 to 64 years (mean: 29, 2)[91]. All respondents are legal residents. Seven respondents are naturalised Dutch citizens, three have Portuguese nationality, and four have double nationality, including two with Cape Verdean and Dutch nationality and two with Portuguese and Dutch nationality.

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[91] The mean age on arrival to the Netherlands excludes the participant who was born in that country.

Six respondents are proficient in the Dutch language, five have a fair command of Dutch, and three command the language poorly.

Among the respondents, five migrated to other countries before settling in the Netherlands. This is a relatively common trend among Cape Verdeans. As we saw in Chapter 5, Cape Verde has traditionally been a country of emigration. At present, there are about as many Cape Verdeans living in the archipelago as there are in the world (i.e. approximately 400 000) (Carling, 2001) and many hop from one country to the other until they establish permanent residence[92]. Among the respondents, one migrated to Portugal before settling in the Netherlands, one migrated to Italy and Portugal, one migrated to the US and to Portugal (with a process of return migration to Cape Verde in between), one lived in Angola (also returning to Cape Verde afterwards), and one returned to the country of birth (i.e. Portugal) before migrating for the second time to the Netherlands. The prominence of Portugal as one of the main destinies of our respondents can be explained by the colonial ties which linked Cape Verde to Portugal during a period of their history, the labour recruitment programme initiated by Portugal in the 1960s which led thousands of Cape Verdeans to move to the mainland (Estevão, 2001), and the possibility given to Cape Verdeans to opt for either Portuguese or Cape Verdean nationality after Cape Verde's independence in 1975. At present, Portugal is home to the biggest Cape Verdean immigrant community in Europe hosting over 65 000 Cape Verdeans (SEF, 2006). Several respondents in this study have family, friends and acquaintances in that country.

The US was one of the first destinations of mass Cape Verdean migration. Starting at the end of the nineteenth century (Meintel, 1984b), migration from Cape Verde to the US has led to the formation of the world's largest Cape Verdean migrant community with about 260 000 people. Italy is a relatively more recent (since the 1970s) and less sought out destination, hosting about 10 000 Cape Verdeans (Carling, 2001). The majority of Cape Verdean migrants in that country are women who migrated to take jobs as domestic workers (Andall, 1998).

The following table (Table 4) presents the socio-demographic characteristics of the non-involved Cape Verdean respondents.

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[92] Increasingly restrictive migration laws in Europe (Muss, 2001) and elsewhere have made migration an ever-more difficult process for the majority of Cape Verdeans (Carling, 2001). In most cases, the only ways to switch residence from one European country to the other is by either holding an EU passport or by remaining irregular for a period of time until regularisation becomes possible or until they migrate to another country. The latter situation puts migrants in a particularly hazardous position, sometimes with heavy costs to their psychosocial wellbeing.

Table 4 *Socio-demographic characteristics of non-involved Cape Verdean clients (n=6)*

Name	Age	Gender	Civil Status	Years of Education	Professional Status	Social Benefits
Lucinda	50	F	Divorced	School: 6	Employed: cook	None
Benvinda	30	F	Single	School: 13 Middle-level education in business administration:4	Unemployed, former business assistant	Unemployment benefit
Lurdes	65	F	Cohabitates with partner (divorced once before)	School: 2	Pensioner, former cleaner	Pension
Luís	52	M	Separated (divorced once before)	School: 4	Unemployed, former seaman	Unemployment benefit
Rosa	39	F	Separated (divorced once before)	School: 4	Sickness leave, former factory worker	Temporary sickness benefit
Florência	61	F	Divorced	School: 4	Sickness leave, former cleaner	Temporary sickness benefit

* Data collected in 2006.

This sub-cluster is composed of five women and one man, whose ages range between 30 and 65 years (mean: 49, 5). Their education level varies between primary (4) and high education (1), with a mean at 6, 2 years of schooling. All respondents have worked in the Netherlands. At the time of the interview, one respondent was employed as a cook, one was with pension, two were unemployed and two were on sickness leave. Most respondents had low qualified jobs, except one who was a business assistant. Non working respondents all had social benefits: one was on pension, two had a sickness benefit and two had an unemployment benefit.

One of the respondents had no relatives in the Netherlands and the rest had at least one family member in the host country. Three respondents lived alone and three lived with their families. One respondents was single, one cohabitated with her partner, two were separated, and two are divorced.

One respondent was a client of Project Apoio since 2001, two respondents were clients since 2003 and three since 2004.

Among the non-involved Cape Verdean clients five are first generation migrants and one is a second generation migrant. In Table 5 we present a description of the migration-related characteristics of each respondent.

Table 5 *Migration-related characteristics of non-involved Cape Verdean clients (n=6)**

Name	Date of Birth	Place of Birth	Arrival to the Netherlands	Length of Residence in the Netherlands	Previous Countries of Migration
Lucinda	1955	São Vicente, Cape Verde	1984	22 years	Senegal (1956-1970) Cape Verde (1970-1973) Italy (1973-1984)
Benvinda	1975	Rotterdam, The Netherlands	Not applicable	30 years	None
Lurdes	1940	Santo Antão, Cape Verde	1973	33 years	Portugal (1971-1973)
Luís	1954	São Nicolau, Cape Verde	2004	2 years	Portugal (1983-2002) Cape Verde (2002-2004)
Rosa	1967	Fogo, Cape Verde	1994	12 years	None
Florência	1945	São Vicente, Cape Verde	1978	27 years	Portugal (1960-1975) Cape Verde (1975-1978)

* Data collected in 2006.

Five respondents were born in Cape Verde and one was born in the Netherlands. Their average length of residence in the Netherlands is 19, 2 years, ranging between two and 33 years of permanence in the host country. Ages upon arrival to the Netherlands vary between 27 and 50 years (mean: 34, 4). All respondents have Dutch nationality with the exception of one who has a temporary residence permit.

Two respondents speak the Dutch language fluently, two command it fairly and two have a poor command of the language.

Four respondents migrated to other countries before setting residence in the Netherlands. Among these, three migrated to Portugal (of which two returned to Cape Verde before going to the Netherlands) and one migrated to Senegal and Italy (with a return migration process to Cape Verde in between).

The Netherlands stakeholder group

This cluster comprises thirty respondents selected through purposive and snowball sampling (Lee, 1993; Miles and Huberman, 1994). The first respondents were selected after a period of field investigations in which participatory spaces, organisations and associations linked to mental health and user participation were identified. Some respondents were asked to participate in the study by e-mail and others were approached personally during events and meetings concerned with participation. After the interviews, respondents were asked to refer other people with a stake in participation.

Interviews were conducted in Amsterdam, Rotterdam and Utrecht, capital cities of the centre-west provinces North-Holland, South-Holland and Utrecht, respectively.

Migrant and ethnic minority groups are especially represented in the provinces of North-Holland and South-Holland, and have been growing steadily in the cities where research took place (Martinez *et al.*, 2002). The first client organisations in the Netherlands were also created and have their headquarters in these cities.

Table 6 presents the socio-demographic characteristics of respondents with a stake in participation based in the Netherlands.

Respondents include nine members of client and family organisations (including two care consultants, four researchers, one director, one project coordinator, one family member), three facilitators of client councils, six experts by experience (including three users and three former users of mental health care services), ten (mental) health and social care staff (including one GP, one psychiatric nurse, one psychiatrist, two psychologists, two social workers, one bicultural care consultant, and two intercultural mental health care service managers)[93], one researcher at a health research institution and one director of a health knowledge centre. It is important to note that some respondents accumulate more than one function. This is particularly the case of the experts by experience who work as either health and social care providers or researchers, or are members of client councils[94]. We chose to address them as experts by experience because it was in that quality that they first became stakeholders in the process of participation.

Twenty one of the respondents are affiliated with the Dutch user movement in mental health[95].

Most respondents carried out their professional and participation activities in the city of Rotterdam (16). Ten were based in Utrecht and four in Amsterdam. Sixteen respondents are women and fourteen are men. Respondents have different ethnic origins including Dutch (16), Surinamese (4), Cape Verdean (3), Cape Verdean-Portuguese (2), Indonesian (1), Portuguese (1), Argentinean (1), and Moroccan (1). The Cape Verdean, Cape Verdean-Portuguese, Portuguese and Argentinean respondents are first generation migrants.

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[93] Eight of the ten (mental) health and social care staff respondents worked in services where Cape Verdean immigrants get care.

[94] Their functions are indicated on Table 5.

[95] As we described in Chapter 1, the Dutch user movement exists as a set of organisations, associations and client councils which advocate for the interests of mental health care users. The facilitators of client councils, the members of the client and family organisations and the experts by experience are, therefore, members of the Dutch user movement. There were three respondents who, in spite of not belonging to this type of organisations and councils, also strive to promote users' rights in health and are, thus, affiliated with the user movement.

Table 6 *Socio-demographic characteristics of Netherlands-based stakeholders and affiliation with the user movement (n=30)**

Function	Gender	Ethnic Origin	Affiliation User Movement
Care consultant at client organisation 1	M	Dutch	Yes
Care consultant at client organisation 2	M	Dutch	Yes
Researcher at client organisation 1	F	Dutch	Yes
Researcher at client organisation 2	M	Dutch	Yes
Researcher at client organisation 3	F	Dutch	Yes
Researcher at client organisation 4	M	Dutch	Yes
Director of client organisation	M	Dutch	Yes
Project coordinator at client organisation	F	Cape Verdean/ Portuguese (1rst generation)	Yes
Member of family members organisation	F	Surinamese (1rst generation)	Yes
Client council facilitator 1	M	Dutch	Yes
Client council facilitator 2	F	Dutch	Yes
Client council facilitator 3	M	Dutch	Yes
Expert by experience 1/ researcher at health research institution	F	Dutch	Yes
Expert by experience 2/ researcher at health research institution	M	Dutch	Yes
Expert by experience 3/ member client council	F	Moroccan (2nd generation)	Yes
Expert by experience 4/ member client council	F	Surinamese (2nd generation)	Yes
Expert by experience 5/ member client council	F	Indonesian (2nd generation)	Yes
Expert by experience6/ social pedagogic worker	M	Surinamese (2nd generation)	Yes
Social worker 1	F	Cape Verdean/ Portuguese (1rst generation)	No
Social worker 2	F	Cape Verdean (1rstgeneration)	Yes
Psychologist 1	F	Argentinean (1rst generation)	No
Psychologist 2	F	Portuguese (1rst generation)	Yes
General practitioner	M	Dutch	No
Bicultural care consultant	F	Cape Verdean (1rstgeneration)	No
Psychiatric nurse	M	Cape Verdean (1rstgeneration)	Yes
Psychiatrist	M	Dutch	No
Intercultural service manager 1	M	Surinamese (2nd generation)	Yes
Intercultural service manager 2	M	Dutch	Yes
Researcher at health research institution	F	Dutch	No
Director of health care knowledge centre	F	Surinamese (2nd generation)	Yes

*Data collected in 2005.

Interviews were held at the locations, dates and time suggested by respondents: twenty one were conducted in the respondents' work place, six in the respondents' homes, one in a municipal library, one in a client organisation, and one in a coffee bar. Interviews lasted in average 1,5h and were carried out in English (13), Dutch (11), Portuguese (5) and Spanish (1).

6.3.2.2 Brazil

Interviews in Brazil were carried out with two clusters of respondents: minority Northeasterners who experience(d) psychosocial problems (hereafter referred to as *Brazil user group*) and stakeholders in the process of participation (hereafter referred to as *Brazil stakeholder group*). The interviews were carried out between October 2006 and June 2007. The details pertaining to each cluster are presented below.

Brazil user group

This cluster is composed of seventeen minority Northeasterners who resided in Rio de Janeiro. Respondents were selected through purposive sampling (Kerlinger, 1986) after authorisation from the Research Ethics Committee of Rio de Janeiro's Mental Health Coordination was received and permission and collaboration of the coordinators of CAPS Pedro Pellegrino, PSF Barra de Guaratiba and PACS Jardim Maravilha were achieved to conduct the study.

The respondents are users of CAPS Pedro Pellegrino (12), PACS Jardim Maravilha (4) and PSF Barra de Guaratiba (1) who have experience with psychosocial distress. Invitation to participate in the study was done through professionals of those services. They contacted the respondents and asked them to take part in the research. We provided all respondents with a Term of Consent in Portuguese, in which the purposes of the study and the conditions in which interviews were to be carried out were explained, and then solicited their participation. All respondents were handed in the Terms of Consent personally.

We interviewed twelve minority Northeasterners who took part in participatory initiatives organised within CAPS Pedro Pellegrino. We also interviewed five participants who did not engage in any participatory activities linked to mental health but were covered by the PACS Jardim Maravilha and PSF Barra de Guaratiba programmes and received mental health care at the *Posto de Atendimento Médico* (Health Care Centre, PAM) of Campo Grande[96]. In what follows we refer to the former as 'involved users' and to the latter as 'non involved users'. As explained above, we included non involved users in the sample because their experiences are likely to help us identify and understand differences between the ways these users and involved

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[96] In Rio de Janeiro not all health care centres offer ambulatory mental health care. The health care centre of Campo Grande was one of the few which provided that type of care in the neighbourhood where our respondents resided. Frequency of consultations ranges between once a month and once every two months.

users perceive and use mental health care, realise their rights and encounter possibilities for participation.

Involved users were contacted after identifying two activities within CAPS created to promote users' participation in mental health care – the *Assembleia* and the *Grupão*. From the twelve users involved in Assembleia and in Grupão*,* nine participated also in the user movement – the MLAM.

Because mental health care services usually do not register the place of origin of users' parents, we had to resort to professionals' knowledge of users to identify minority Northeasterners[97] who were involved in the Assembleia and in the Grupão. All users asked to participate in the study accepted the invitation, except one.

Non involved users were contacted with the assistance of the community agents of PACS Jardim Maravilha and PSF Barra de Guaratiba. As we mentioned above, PSF and PACS are programmes designed to facilitate poor people's access to health care. For that reason they are usually located in slum areas. Slums are regularly difficult to access (both because of their geography and because of violence) without the support of 'insiders'. In addition, people who live in those areas usually have very low incomes and are unable to afford amenities such as a telephone. These were the life circumstances of many people who participated in our study. The collaboration of the community agents was fundamental to reach non involved users.

In Jardim Maravilha, the PACS community agents identified six non-involved mental health care users. Although all agreed to participate when they were first contacted we were only able to find and interview four of them.

In Barra de Guaratiba[98] there were few people who experienced psychosocial distress that were not already in our sample of CAPS involved users. The PSF community agents contacted three potential respondents. Only one was able to participate in the study.

Interviews with involved and non involved minority Northeastern users were held at the locations, dates and time suggested by respondents: nine interviews were conducted in CAPS Pedro Pellegrino, four in respondents' homes and front yards, two in PSF Barra de Guaratiba, and two in a public square. Interviews lasted between 1h and 2h and were carried out in Portuguese.

In what follows we present the socio-demographic and the migration-related characteristics of this cluster's respondents. Data is first provided for the involved users and afterwards for the non involved users.

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[97] CAPS had no first generation Northeastern migrants engaged in the *Assembleia* or in the *Grupão* at the time we carried out the interviews. Further on this section we elaborate on the factors that may explain this.

[98] Although the population of Barra de Guaratiba has been increasing it is still a small locality in the West Zone of Rio de Janeiro, somewhat secluded by the nature that surrounds it and by the few means of transportation connecting it to the rest of the city. The community agents estimated the population of Barra de Guaratiba to be about 5000 people. Four respondents in our involved users sub-cluster lived in Barra de Guaratiba.

Table 7 presents the socio-demographic characteristics of the involved minority Northeastern users and the type of activities in which they participate.

This sub-cluster is composed by seven men and five women whose ages vary between 24 and 58 years (mean 37). Their level of education ranges between middle (4) and high-technical education (1) with a mean of 11,3 years of schooling[99]. All respondents were employed at some point in time. When interviews were conducted, three respondents were employed (as an assistant of the CAPS and PAM, a doorman, and a factory worker), seven were unemployed and two were on pension. Jobs held previously by respondents are low qualified and low paid (e.g. bouncer, salesperson, cleaner, etc.) with the exception of two respondents who worked as a primary school teacher and as an accountant. Only three of the nine non working respondents had social benefits: two were pensioners and one had a temporary sickness benefit.

Table 7 *Socio-demographic characteristics of involved minority Northeastern users and type of participatory activity (n = 12)**

Name	Age	Gender	Civil Status	Years of Education	Professional Status	Social Benefits	Participatory Activity
Clara	33	F	Single	School: 12 University study physical education[1]: 2	Unemployed, former primary school teacher	Temporary sickness benefit	*Assembleia, Grupão* and MNLA
Gabriel	35	M	Single	School: 9	Unemployed, former bouncer	None	*Assembleia* and *Grupão*
Benedita	42	F	Single	School: 12 Technical study accountancy: 3	Pensioner, former accountant	Pension	*Assembleia, Grupão* and MNLA
Vinícius	38	M	Single	School: 12	Pensioner, former security guard	Pension	*Assembleia, Grupão* and MNLA
Samuel	58	M	Single	School: 9	Employed: assistant CAPS and PAM	None	*Assembleia* and *Grupão*
Regina	46	F	Widow	School: 12	Unemployed, former secretary	None	*Assembleia* and *Grupão*
Jenifer	24	F	Single	School: 11	Unemployed, former saleswoman	None	*Assembleia, Grupão* and MNLA
Gladys	41	F	Cohabitates with partner	School: 9	Unemployed, former cleaner	None	*Assembleia, Grupão* and MLAM

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[99] The educational system in Brazil is divided in Primary School (4 years), Secondary School (7 years) and Higher Education. School attendance is compulsory for ages 7 to 14. (Education International, 2007d).

Name	**Age**	**Gender**	**Civil Status**	**Years of Education**	**Professional Status**	**Social Benefits**	**Participatory Activity**
Miguel	32	M	Single	School: 12	Employed: doorman	None	*Assembleia, Grupão* and MNLA
Jaderson	33	M	Single	School:12 University study civil engineering[1]: 1	Unemployed, former typist	Free pass	*Assembleia, Grupão* and MNLA
Robson	31	M	Single	School: 11	Unemployed, former salesman	Free pass	*Assembleia, Grupão* and MNLA
Oscar	32	M	Cohabitates with partner	School: 9	Employed: factory worker	None	*Assembleia, Grupão* and MNLA

* Data collected in 2007.

[1] The study was not completed.

In Brazil, a large segment of the population has great difficulties to get social benefits. Unemployment benefits are only awarded to those with *carteira assinada*, i.e. to taxpayers employed within the formal labour market. After the economic recession of the 1990s, Brazil adopted several measures to deregulate its labour market. Deregulation led to an explosion of the informal sector, a reduction of wages and an increase of temporary 'contracts', causing the precarization of labour conditions (Cardoso Jr., 2001). It is estimated that the informal market takes up to 60% of the Brazilian workforce (Cardoso Jr. and Fernandes, 2000). Most of the respondents in this sub-cluster and in the sub-cluster of non-involved users had informal jobs. They were thus unable to get to unemployment benefits when they got ill.

A similar situation takes place in regard to sickness benefits *(auxílio doença)*, i.e. only workers with *carteira assinada* or those workers who make voluntary contributions to Social Security are eligible for these benefits[100]. *Auxílio doença* is granted by the *Instituto Social do Seguro de Saúde* (National Institute of Social Insurance, INSS), under the aegis of the Ministry of Social Welfare (MPS, 2007). Few people with low qualified jobs within the informal market are able to secure enough earnings to grant themselves and their families a fair living standard. This makes it almost impossible to allocate part of their pay-checks to social security, rendering them unprotected in case of illness. The Brazilian law envisions one exception to this. According to the *Lei Orgânica da Assistência Social* (Basic Law of Social Assistance, LOAS) people above 65 years of age and people unable to work as a result of 'disability' and with a family income per capita inferior to one forth of the minimum salary (approximately 450R or 165€) are entitled

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[100] To be entitled to illness benefits workers must have contributed for Social Security for at least 12 months before requesting the benefit (MPS, 2007).

to a social benefit – *Benefício de Prestação Continuada* (Continuous Cash Benefit, BPC) – even in the absence of contributions to Social Security (Brasil, 1993)[101].

The granting of sickness-related benefits, both in the case of *auxílio doença* and of BPC, is dependant on a positive evaluation by the INSS's medical examination services[102]. However, the criteria for entitlement to BCP, for example, are extremely restrictive and few in need succeed to get this type of benefit. This is particularly discernable in the cases of psychosocial problems. For a person to be eligible to BCP on the grounds of mental illness she must have received a diagnosis before the age of 18 years and prove to be unfit to work and to live independently. Although it is true that many people affected by mental illness are able to participate constructively in the labour market (provided there is enough attention and support by employers to deal with potential restrictions they might be subjected to in their ability to work), it is also evident that most face heavy discrimination when seeking a job and are hardly ever selected for it. Under the current law, the BCP is only conceded to people unable to work. However, there are no objective criteria to define 'inability to work'. The decision is thus left entirely to medical examiners. These examiners tend to adopt a biomedical approach which focuses on individual limitations and rarely takes into account the negative impact of structural discrimination on people's inability to *find* work (Diniz *et al.*, 2007). In addition, many people have been diagnosed with mental illness after the age of 18 and have no other option but to live alone. Thus, many of those in need 'slip through the social assistance net' and fall into extreme poverty, a situation which puts their biopsychosocial wellbeing at great jeopardy.

The hardships of getting sickness benefits in cases of mental illness appear to be no different when one is protected by Social Security and solicits *auxílio doença*. One of our participants, who had a diagnosis of schizophrenia, explained the efforts and distress she had to go through to achieve that benefit:

> Clara: I receive the INSS benefit [*auxílio doença*]. (…) I have it for almost two years but I'm sending my CV [to potential employers] because you have to go for [INSS's medical] examinations and the examinations are never satisfactory. You have to shake, you have to go there dirty, drooling, so they believe in your illness. And you must take the paper [diagnosis] from your doctor.
> Researcher: How often do the evaluations take place?
> Clara: It's every six months. I go [there] all ugly, with my clothes stinking, my hair in disarray. And then I shake when I'm there. I pretend I'm shaking. Otherwise, there is no way you can pass the examination.
> Researcher: How did you get to know you have to do that?

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[101] This benefit is conceded by the National Secretary of Social Assistance under the aegis of the Ministry of Social Development. It was created to foster social inclusion and diminish extreme poverty. The value of BCP is equal to one minimum salary.

[102] In order to be evaluated by INSS's medical examination services one must bring a diagnosis from hers/his doctor.

> Clara: Oh, I heard from other people who did the same. They said you must go ugly, shaking, speaking nonsense, speaking with yourself. You must do one thousand things. And I thought: "Oh my God, I don't have the guts. I'm not a clown. I won't manage". But then, when I was there, I started crying. And when I started crying she [medical examiner] said: "Stop crying and stop shaking". And then I started really shaking from nerves and I said: "Oh my Jesus, I'm shaking a lot". That's when she said: "O.K., O.K. you passed. For how many months are you [in treatment] at CAPS Pedro Pellegrino?" I told her I'm there for seven years and she gave me seven months [of illness benefit]. In July the benefit ends so I need to talk to my psychiatrist and go back there.

Clara gets a monthly benefit of approximately 450R (i.e. 165€) which she shares with three other siblings all undergoing treatment at CAPS, unemployed and without any social benefits. Since their parents died, they live in a situation of high deprivation and depend on the aid of a local church and a family member to get enough food supplies to last through the month. It is almost nonsensical to talk of assisting people in reaching psychosocial wellbeing when the social security provisions devised to satisfy users' basic needs are so dramatically difficult to obtain. However, this is the reality of many public mental health care users throughout Brazil. Some are even unable to afford the bus fare to go to the services where they get care. One of our respondents walked 1h every day to go to CAPS. To ease down this problem the Brazilian government created another social benefit which allows poor people with 'disabilities' to travel free-of-charge in public transportation – the *Passe Livre* (Free Pass) (Brasil, 1994)[103]. Yet, the difficulty to prove one's need and entitlement to illness benefits repeats itself with *Passe Livre*. Although several of this sub-cluster's respondents gathered the conditions to be granted a *Passe Livre* only two succeed to get it. They stated that, in spite of feeling privileged when compared to other users, using the *Passe Livre* often put them in a situation in which they are the target of discrimination: public transportation controllers frequently deny them a free ride, alleging their passes are invalid. This makes them feel embarrassed as they have to argue for their rights in front of everyone else in the bus and, because of this, all will know they are mental health care users. What usually follows are disdaining looks and/or cruel comments.

All respondents in this sub-cluster lived with relatives or with their partners. Nine were single, two cohabitated and one was a widow. It is interesting to note that two of the respondents who cohabitate and two of the single respondents have relationships with other CAPS mental health care users. To a certain extent, this shows that mental health care services are also places where people with similar interests meet and relationships evolve.

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[103] According to the law, the *Passe Livre* is awarded to people whose family income per capita is below one minimum salary and who are considered 'disabled'. Public transportation companies which fail to acknowledge the *Passe Livre* are punishable by law with a fine (Brasil, 1994). This, however, does not deter its employees from sometimes denying a free-of-charge trip to *Passe Livre* holders.

Three respondents were mental health care users at CAPS since 1997, one was a user since 1998, once since 1999, one since 2000, three since 2001 and three since 2004.

As we mentioned above, all respondents are ethnic minority Northeasterners. The following table (Table 8) provides a description of the migration-related characteristics of the respondents and their parents. The places of birth presented for the respondents' parents refer to the Brazilian state where they were born. There is one exception of a respondent's parent who was born abroad. In that case, we indicate the country of birth (i.e. Portugal). In what concerns respondents themselves, we present the place of birth and residence according to the localities in the city of Rio de Janeiro where they were born and currently reside. There are also two exceptions of respondents who were not born in the city of Rio de Janeiro but in Nova Iguaçu and Macaé. These cities are both located in the state of Rio de Janeiro (SRJ). Nova Iguaçu is part of Rio de Janeiro Metropolitan Region (RJMR). Macaé is located in the coast, upper north in the state.

Table 8 *Migration-related characteristics of involved minority Northeastern users (n= 12)**

Name	Place of Birth	Place of Residence	Place of Birth of Participants' Parents	Arrival of Participants' Parents to Rio de Janeiro State
Clara	Campo Grande	Campo Grande	Mother: Rio de Janeiro Father: Ceará	Father: early 1970s
Gabriel	Campo Grande	Campo Grande	Mother: Rio de Janeiro Father: Ceará	Father: early 1970s
Benedita	Barra de Guaratiba	Barra de Guaratiba	Mother: Bahia Father: Rio de Janeiro	Mother: early 1960s
Vinícius	Barra de Guaratiba	Barra de Guaratiba	Mother: Rio de Janeiro Father: Bahia	Father: mid 1960s
Samuel	Barra de Guaratiba	Barra de Guaratiba	Mother: Bahia Father: Rio de Janeiro	Mother: mid 1940s
Regina	Macaé (SRJ)	Barra de Guaratiba	Mother: Rio de Janeiro Father: Paraíba	Father: early 1960s
Jenifer	Campo Grande	Campo Grande	Mother: Rio de Janeiro Father: Ceará	Father: early 1970s
Gladys	Barra de Guaratiba	Campo Grande	Mother: Ceará Father: Portugal	Mother: mid 1940s Father: early 1960s
Miguel	Campo Grande	Campo Grande	Mother: Rio de Janeiro Father: Pernambuco	Father: early 1970s
Jaderson	Campo Grande	Campo Grande	Mother: Bahia Father: Rio de Janeiro	Mother: early 1970s
Robson	Jacarepaguá	Campo Grande	Mother: Bahia Father: Bahia	Mother: early 1970s Father: early 1970s
Oscar	Nova Iguaçu (RJMR)	Campo Grande	Mother: Amazonas Father: Bahia	Mother: early 1970s Father: late 1940s

* Data collected in 2007.

Respondents' migrant parents arrived to Rio de Janeiro between the mid 1940s and the early 1970s, coming from the Brazilian Northeastern states of Bahia (7), Ceará (4), Paraíba (1) and Pernambuco (1), from the North state of Amazonas (1), and from Portugal (1). As we saw in Chapter 5, rural-urban migration from the Northeast began to rise in the 1940s and 1950s as a result of severe drought, unemployment and economic deprivation (Martine and Camargo, 1984). The start of the industrialization of Brazil in the 1940/50s, which occurred more intensely in the Southeast region, led many *Nordestinos* to the states of São Paulo and Rio de Janeiro (Brito and Carvalho, 2004).

The economic recession of the 1960s and the end of drought in the Northeast led to a decline of Northeastern migration flows during that decade. However, in the 1970s the Northeast experienced yet another exodus of its people: more than 4 million people left from the countryside to the city (Patarra, 2005). Most of the respondents' parents arrived to Rio de Janeiro during the first half of that decade (8), trying to escape poverty and chasing the dreams of social mobility and modernity. The remaining migrants settled in Rio de Janeiro in the mid 1940s (2) and through the early (3), mid (1), and late (1) 1960s.

The economic and social crises which began to affect Brazil in the 1980s, and extended through 1990s, led to a significant decrease of the populations' ability for insertion in the labour market in the megalopolises of São Paulo and Rio de Janeiro. This caused a reduction of migration to these cities during those decades (Brito, 2006). Perhaps this one of the reasons why we were unable to find first generation migrants at CAPS Pedro Pellegrino. Another factor that might explain this is that the Psychiatric Reform began in the late 1970s (Amarante, 2006) but the services designed to provide community-based psychosocial care (i.e. CAPSs) and to accommodate the people who are being dismissed from psychiatric hospitals were only created in the 1990s (Vasconcelos, 1997). It is possible thus that many of the senior internal migrants who experienced(d) psychosocial problems have not yet been transferred to services such as CAPS Pedro Pellegrino[104] and are still living in psychiatric hospitals. This is a rather probable possibility. During fieldwork, I heard from several psychiatrists that their services hosted long-term inmates who were hospitalized for decades and could have been dismissed already for many years. However, for them to return to the community it is necessary to identify relatives or people willing to assist them with housing, care and the forming of new social relationships and re-integration. Although the Brazilian government began to sponsor a programme in 2003 which gives financial support for long-term psychiatric inmates to return home (*Programa De Volta Para Casa*) (Brasil, 2003b), psychiatrists told how difficult it is to enforce their dismissal on the account of different problems. In some cases, family members are nowhere to be found either

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[104] At the time we conducted the interviews the CAPS Pedro Pellegrino was considerably overcrowded and could only accept new users in situations of severe psychosocial distress. This means that people with milder problems or who do not need continuous attention are not able to receive care at the CAPS.

because they died or because they gave false names when they had their relatives admitted to the hospital. In other cases, inmates' relatives live in extreme poverty and in places of difficult access and affected by great violence (i.e. up the hill in slums). Some psychiatrists felt that dismissing inmates to live in those circumstances would put them at risk of becoming once again 'imprisoned' in inaccessible homes and/or of dying on the account of lost bullets. As a result, many people are still incarcerated in psychiatric hospitals not out of 'need' but because they have no other place to go.

Where more recent internal migrants are concerned, it is possible they have not yet found their way to CAPS and receive treatment mostly in psychiatric hospitals. Some professionals we interviewed stated that after delivering care to migrants in a psychiatric emergency unit it is very difficult to contact them again since most lack a permanent address and, after spending some time in the hospital, they usually loose their jobs. They also said that even if migrant users leave the hospital with a referral for treatment in a CAPS they do not always seek that service because they need to go back to finding jobs.

The following table (Table 9) presents the socio-demographic characteristics of non-involved minority Northeastern users.

Table 9 *Socio-demographic characteristics of non-involved minority Northeastern users (n=6)**

Name	Age	Gender	Civil Status	Years of Education	Professionals Status	Social Benefits
Vitória	44	F	Widow	School: 5	Unemployed, former fish porter	None
Lavínia	32	F	Single	School: 6	Unemployed, former telephonist	None
Paulo	36	M	Single	School: 12	Unemployed, former salesman	None
Gustavo	40	M	Single	School: 10	Employed: fiscal controller	None
Igor	50	M	Cohabitates with partner (divorced once)	School: 12	Employed: cabinet maker	None

* Data collected in 2007.

This sub-cluster is composed by three men and two women, whose ages range between 32 and 50 years of age (mean: 40, 4). Their level of education varies between primary (1) and secondary education (2) with a mean of 9 years of schooling. All respondents have been employed at some point in time. When we conducted the interviews, two were employed (as a fiscal controller and as a cabinet maker) and three were unemployed. Jobs held previously by respondents were low qualified and low paid (telephonist, salesman, and fish collector). None of the non-working respondents had social benefits.

All respondents lived with family members or with their partners. Three respondents were single, one was a widow and one cohabitated with his partner (and had divorced once before).

All respondents received care in PAM Campo Grande except one who got care at PAM Jacarepaguá.

Next, we present a description of the migration-related characteristics of non-involved minority Northeastern users and their parents (Table 10). Resembling the situation described above, two of the respondents' parents were not born in Brazil. In those cases, we refer to their place of birth by naming the countries where they were born. In all other instances we refer to the Brazilian states where respondents' parents were born.

Table 10 *Migration-related characteristics of non-involved minority Northeastern users (n=5)**

Name	Place of Birth	Place of Residence	Place of Birth of Participants' Parents	Arrival of Participants' Parents to Rio de Janeiro State
Vitória	Barra de Guaratiba	Barra de Guaratiba	Mother: Bahia Father: Rio de Janeiro	Mother: late 1950s
Lavínia	Recreio dos Banderantes	Jardim Maravilha	Mother: Rio de Janeiro Father: Ceará	Father: early 1970s
Paulo	Campo Grande	Jardim Maravilha	Mother: Bahia Father: Cape Verde	Mother: late 1960s Father: mid 1960s
Gustavo	São Cristovão	Jardim Maravilha	Mother: Pernambuco Father: Rio de Janeiro	Mother: mid 1960s
Igor	Barra da Tijuca	Jardim Maravilha	Mother: Paraíba Father: Germany	Mother: mid 1950s Father: early 1950s

* Data collected in 2007.

All respondents were born in the West Zone of the city of Rio de Janeiro with the exception of one, who was born in the neighbourhood of São Cristovão, located in the North Zone. When compared to the neighbourhoods where respondents were born, Jardim Maravilha slum is much more deprived in terms of services and infra-structure (e.g. there is no sanitation system) but it is more spacious, cheaper and a rapidly growing area where many people are arriving to settled residence.

Two of the respondents have themselves a history of internal migration. One migrated to the states of São Paulo (in the Southeast Region), Roraima and Tocantins (in the North Region). And one migrated to the states of Pernambuco and Amazonas (in the North Region). In both cases, they migrated in search of better jobs.

Respondents' parents who migrated to Rio de Janeiro arrived between the mid 1950s and the early 1970s from the Brazilian states of Bahia (2), Ceará (1), Pernambuco (1), and Paraíba (1), and from Cape Verde (1) and Germany (1). As we noted above, this was a period of mass rural-urban migration in Brazil. It was also a period in which many European migrants seeking to escape the post-conflict hardships of World War II left to the New World. The case of the Cape Verdean immigrant is curious as migration from Cape Verde to Brazil has never been very expressive (Instituto de Apoio ao Imigrante, 1998 cited by Carling, 2001).

Brazil stakeholder group

This cluster comprises twenty six respondents selected though purposive and snowball sampling. The first respondents were selected after a period of field research in which participatory mechanisms, organisations, associations and institutes linked to mental health and user participation were identified. Some respondents were asked to participate in the study by telephone and others were approached personally during events and meetings concerned with participation. After the interviews, respondents were asked to refer other people with a stake in participation.

Interviews were conducted in several neighbourhoods across the city of Rio de Janeiro including Barra de Guaratiba, Jacarepaguá, Irajá, Olaria, Centro, Flamengo, Botafogo, Urca, Copacabana, and Leblon.

Table 11 presents respondents' socio-demographic characteristics and affiliation with the user movement.

Respondents include four members of user and family associations (two users and two family members), one member of a municipal health council, five experts by experience (four users and one former user of mental health care services), twelve mental health and social care staff (two PSF community agents, three psychiatrists, four psychologists, one occupational therapist, one social worker, and one coordinator of a psychiatric emergency unit), and four members of mental health institutes and research centres (once director, one director of information, one research coordinator and one researcher). It is relevant to point out that some respondents have more than one function. Similarly to the situation encountered in the Netherlands, this is particularly the case with three experts by experience who work as researchers and mental health care workshop coordinators (*oficineiros*) and of one family member who is part of the mental health care staff at a CAPS. We chose to address them as experts by experience and family member because it was in that quality that they first became stakeholders in the process of participation.

Nineteen of the respondents are members of the MNLA, and six are amongst its most active leaderships.

All respondents were based in the city of Rio de Janeiro. Sixteen respondents are women and ten are men. All respondents are Brazilians born in the state of Rio de Janeiro except two who were born in the states of São Paulo and Minas Gerais.

Interviews were carried out in the locations, dates and time suggested by the respondents: ten were conducted in the respondents' place of work, four in the respondents' home, four in the out-patient facilities of psychiatric hospitals, three at the researcher's residence, two in a CAPS, one in the Medical Doctors' Union headquarters, and two in restaurants. Interviews lasted in average 1,5h and were carried out in Portuguese.

Table 11 *Socio-demographic characteristics of Brazil-based stakeholders and affiliation with the user movement (n=26)**

Function	Gender	Affiliation User Movement
Member of user association 1	F	Yes
Member of user association 2	F	Yes
Member of family members association 1	M	Yes
Member of family members association 2/ social worker	F	Yes
Member of municipal health council	M	Yes
Expert by experience 1	M	Yes
Expert by experience 2	F	No
Expert by experience 3/ mental health care workshop coordinator	F	Yes
Expert by experience 4/ researcher at health research centre	M	Yes
Expert by experience 5/ mental health care workshop coordinator	M	Yes
PSF community agent 1	F	No
PSF community agent 2	F	No
Social worker 1	F	No
Psychologist 1	F	Yes
Psychologist 2	F	Yes
Psychologist 3	F	Yes
Psychologist 4	F	Yes
Occupational Therapist	F	No
Psychiatrist 1	M	Yes
Psychiatrist 2	F	Yes
Psychiatrist 3	M	No
Coordinator of psychiatric emergency unit/ social worker	F	No
Director of information at mental health institute	M	Yes
Coordinator of health research centre	M	Yes
Researcher at health research institution	F	Yes
Director of mental health institute	M	Yes

* Data collected in 2006.

6.3.4 Secondary sources

We used several documents to corroborate and supplement evidence from other sources. Among those documents were agendas, announcements and minutes of meetings of the user movement in Rio de Janeiro, written reports of Project Apoio's activities and meetings, studies and evaluations of the 'sites' under study (e.g. Rietra, 1999; De Ruuk, 2002; Maia and Fernandes, 2002; Smulders, 2003) and proceedings of conferences focused on user participation (e.g. Rodrigues and Cunha, 2007).

6.4 Data Analysis

Tesch (1990) proposes a distinction between the different types of analysis within qualitative research according to two main categories: structural analysis and interpretational analysis. Structural analysis is usually employed by researchers focusing on language and communicative processes. The onus of analysis lays on the identification of regularities and language is perceived as social behaviour, instead of as a vehicle to convey information about the social actor's world or feelings and opinions about the social world. Interpretational analysts focus on the comprehension of the meaning of text or action by examining what people say and do. Qualitative data are not perceived as being identical to the experience researchers seek to describe, but they are thought to say something about the way social actors attribute meaning to everyday world experiences when interpreted with reference to the context from which they were drawn.

We opted for interpretational analysis because it is adequate to the purposes of our study, i.e. to understand the meanings given by respondents to participation and to identify the enablers and inhibitors of participation as well as its benefits.

Miles and Huberman (1994) define data analysis as an interactive, cyclical process of data reduction, data display and conclusion drawing and verification. These flows of activity are concurrent, beginning alongside with data collection[105]. Data reduction refers to the process of selecting, focusing, simplifying, abstracting and transforming the data that appear in written-up field notes or transcriptions in such a way that conclusions can be drawn and verified. Data display is the process of assembling and presenting information in an organised, compressed way (e.g. through matrices, maps, charts, etc.) to enable understanding and action. Conclusion drawing consists of giving meaning to things, i.e. noting regularities, patterns, explanations, causal flows, and propositions which are verified or tested for their plausibility, sturdiness and validity.

Another way to define qualitative data analysis is that proposed by Jorgensen (1989) according to whom:

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[105] The authors note that data reduction or 'anticipatory data reduction' occurs even before the data are collected when researchers decide (often without full awareness) which conceptual framework, cases, research questions, and data collection approaches to choose (Miles and Huberman, 1994).

> Analysis is a breaking up, separating, or disassembling of research materials into pieces, parts, elements, or units. With facts broken down into manageable pieces, the researcher sorts and sifts them, searching for types, classes, sequences processes, patterns or wholes. The aim of this process is to assemble or reconstruct the data in a meaningful or comprehensible fashion (*ibid*.: 107).

Together, the two definitions described put forward a notion of data analysis as an iterative process aimed at the construction of meaningful patterns and organisations of facts (i.e. theorizing) based on the segmentation, reduction, display and reassembling of empirical materials about the phenomenon under study. The analysis of empirical materials collected for this study was guided by two principles: the principle of constant comparison (Glaser and Strauss, 1967) and the principle of theoretical sensitivity (Strauss, 1987).

Constant comparison as described by grounded theorists Glaser and Strauss (1967) consists of comparing 'incidents' and the properties of categories identified in the data to develop theoretical generalisations. Its aim lies on describing the variation found within certain phenomenon and, when possible, in indicating in which situations different variations of the phenomenon manifest themselves. The process begins with coding each 'incident' in the data into as many categories of analysis as possible. While coding is occurring the analyst also looks through the rest of the data to compare the current incident with previous incidents, in the same and different categories and, from there, goes on to compare and contrast the properties of the different categories. The constant comparison enables the reduction of categories via amalgamation and delimitation and the identification of core concepts which facilitate the generation of theories and explanations.

Theoretical sensitivity refers to the researcher's ability to develop creative ideas from and give meaning to the data by being sensitive to theoretical issues when scrutinising that data (Strauss, 1987). Taken from this standpoint, analysis requires the ability to interpret research data in light of existing knowledge and theoretical models about social phenomena, i.e. the ability to identify, compare and explain categories which are theoretically charged. This process can be carried out by utilizing a 'coding paradigm' (Strauss and Corbin, 1990), i.e. a system of coding that seeks to identify causal relationships between categories during the process of 'axial coding'.

Scholars concerned with data analysis have also suggested various analytic techniques including open, axial and selective coding (Strauss and Corbin, 1990; 1998), the constant comparison method (Glaser and Strauss, 1967), pattern-matching, explanation-building, time-series analysis (Yin, 1994), analytic induction (Denzin, 1989; Silverman, 2001), deviant-case analysis (Mehan, 1979)[106], etc. In this study we

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[106] According to Silverman (2001) analytic induction involves the combination of two other techniques, namely the constant comparative method (Glaser and Strauss, 1967) and deviant-case analysis (Mehan, 1979). Deviant-case analysis resembles the explanation-building technique (Yin, 1994). Here, we opted for

used open, axial and selective coding, the constant comparison method and the explanation-building technique. These techniques enabled us to adopt both an inductive and a deductive approach in data analysis. Open, axial and selective coding allowed us to disassemble and reassemble our data and to identify and interpret unexpected themes (induction). The constant comparison method enabled us to identify variation in the phenomenon under study and to give form to substantive theory (induction). And the explanation-building technique enabled us to explain the case, i.e. to stipulate a set of causal links about it (deduction). Below we describe in greater detail how these techniques were applied.

Open, axial and selective coding

Coding was employed as a technique to make sense of data by following the grounded theory approach (Glaser and Strauss, 1967). Strauss and Corbin (1990; 1998) distinguish three types of coding: open coding, axial coding and selective coding. Open coding is the analytic process through which "data are broken down into discrete parts, closely examined, and compared for similarities and differences. [Those] events, happenings, objects, and actions/ interactions that are found to be conceptually similar in nature or related in meaning are grouped under more abstract concepts termed 'categories' (1998: 102). Axial coding refers to "a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories. This is done by using a coding paradigm involving the conditions that give rise to the category (phenomenon), the context in which it is embedded, the action/ interactional strategies by which it is handled, managed, carried out, and the consequences of those strategies" (1990: 96-97). Selective coding refers to the "process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development" (1990: 116). Given the principles of constant comparison and theoretical sensitivity which guide this approach to data analysis, open, axial and selective coding do not follow a rigid structure but a cyclical one, in which sampling, data collection and data analysis proceed simultaneously until theoretical saturation[107] and the emergence of substantive theory are reached. In what follows we describe how these coding processes were applied in this study[108].

After the first interviews were conducted and transcribed I used MAXqda2 – a software application for qualitative analysis[109] – to facilitate the commencement of open coding. Open coding entailed reading carefully and dividing data into fragments which, after comparison, were grouped into categories dealing with the same subject

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employing the constant comparative method and the explanation-building technique which, together, enable the application of analytic induction.

[107] Theoretical saturation is the 'point in category development at which no new properties, dimensions or relationships emerge during analysis' (Strauss and Corbin, 1998: 143).

[108] Open, axial and selective coding were applied to both of our case studies.

[109] MAXqda2 was also used during the phases of axial and selective coding.

and labelled with a code. This activity enabled the identification of new lines of enquiry which guided subsequent theoretical sampling[110] (Glaser and Strauss, 1967).

I started writing memos shortly after beginning the open coding. Memos are written records that depict the relationships among codes and concepts. They serve the purposes of keeping the research grounded and maintaining the researcher aware of theoretical contributes by forcing the "analyst to move from working with data to conceptualising" (Strauss and Corbin, 1998: 218). Early memos contained impressions, thoughts and directions for research. As research progressed memos grew in complexity, density, and clarity, assisting the move of analysis beyond description to theory.

The accumulation of codes and memos enabled the detection of relationships between categories. This marked the beginning of axial coding, i.e. the process by which categories are related to subcategories and properties and dimensions of categories are specified (Charmaz, 2006). During axial coding I looked for categories which were likely to take an important role in the definitive findings by working as a handle to more abstract, theoretical ideas. These salient categories or 'sensitizing concepts' were then related to subcategories as a means to identify their properties and to apply the coding paradigm, i.e. to define the phenomenon's context, conditions, interactional strategies and consequences. Tabular summaries of code frequencies were also done with the help of MAXqda2 to achieve an overview of the reassembled data. Altogether, these processes enabled the surfacing of knowledge by allowing the identification of categories and subcategories that were still 'thinly' described. This led to a new period of data collection aimed at gathering information to fill in conceptual gaps. During the following phase of axial coding I continued distinguishing between categories and subcategories and assigning fragments able to 'thicken' salient categories.

The commencement of selective coding was determined by the emergence of a pattern[111], namely that user participation is primarily motivated by users' aspiration to enhance their full inclusion in society, rather than just the desire to increase their access to good quality mental health care. The process of selective coding thus entailed the selection of a core category (i.e. 'social inclusion') which became central to the integration of theory and guided further data collection and analysis (Strauss, 1987). The new data acquired was used to refine and strengthen the connections encountered between the core category and the other categories through a process of constant comparison which led to the formation of the rudiments of theory.

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[110] Theoretical sampling as defined by Glaser and Strauss (1967) "is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analysis his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. This process of data collection is controlled by the emerging theory, whether substantive or formal" (*ibid.*: 45)

[111] A pattern is an orderly sequence consisting of repeated relationships between properties and dimensions of categories (Strauss and Corbin, 1990). Patterns are not 'contained' in categories. They rise above single fragments of text and are difficult to capture in a code. The use of memos was of particular relevance to keep track of potential patterns and explanations.

At that point, existing literature became of extreme relevance to load grounded concepts with theoretical sensitivity, verify whether the conjectures made between the core concept and the other concepts were justified, and to account for negative cases. Readings about social inclusion, citizenship, social networks, empowerment, health literacy, access to care and social justice enabled me to increase the theoretical level of findings and constructs.

When newly gathered data proved to leave the main findings unchanged, not adding any new categories or properties, theoretical saturation was reached and data collection was stopped. Analysis continued until the main questions of the research could be answered and a 'substantive theory' (Glaser and Strauss, 1967) dense with concepts emerged.

Constant comparison

As described above, the constant comparison method aims at describing the variation found within certain phenomenon by comparing incidents and categories during coding and identifying core concepts which will give shape to explanations and theories. In our study, this technique was particularly helpful in identifying the relative weight of collective and individual incentives in explaining users' motivations for participation. As we show in the next chapter (Chapter 7), we found that collective motivations have a stronger role in determining the sustainability of participation, while individual incentives appear to be important in explaining the commencement of participation. This pattern emerged after comparison between the motivations expressed by users with a long-standing practice of participation and the incentives reported by 'beginners'. This was especially observable through the analysis of categories such as 'social justice' and 'finding a meaningful social role'. Social justice is an example of a collective incentive driving participation. Finding a meaningful social role, particularly through integration in the labour market (i.e. getting a job), constitutes an individual motivation for getting engaged. From our analysis, it emerged that participants with a long-term experience of participation attributed greater value to collective incentives such as enhancing 'social justice', while beginners reported individual incentives such as 'finding a job' as the main motivations for their engagement.

Applying the method of constant comparison has enabled us to identify a pattern which can be particularly relevant when seeking to define strategies aimed at getting new mental health care users to join the participatory sphere, i.e. knowing which motivations to appeal when trying to attract new participants.

Explanation-building

Explanation building is an analytic technique proposed by Yin (1994) which consists of a series of iterations aimed at analysing the case study data by building an explanation about the case, i.e. by stipulating a set of causal links about it. Explanation-building includes the following iterations: 1) making a initial theoretical statement or an initial proposition about the phenomenon under study; 2) comparing the findings of an initial case against such a statement or proposition; 3) revising the statement or proposition; 4) comparing other details of the case against the revision; 5) revising again the statement or proposition; 6) comparing the revision to the facts or a second, third, or more cases; 7) repeating this process as many times as needed (1994: 111).

The theoretical statements or propositions Yin refers to should not be considered with the formality of grand theory in social science, but rather as blueprints for the study. They are not prescriptions for what to see, but schemes which offer the researcher a possibility to reflect about relevant existing social theory, keep wary of her own biases from the start of the study, refine explanations while entertaining deviant or rival cases, and ground 'emerging theory' in the data. To a certain extent, the explanation-building technique resembles the constant comparison method, the latter focusing on the relationships between categories and the former focusing on the relationships between patterns. As argued by Silverman (2001), these two techniques complement each other not only as analytic tools but also as indicators to measure the quality of the study through a technique known as analytic induction (see section 2.5).

The following offers an example of the way by which we employed explanation-building in our study:

1. We began by making a theoretical proposition. This proposition was based on a preliminary idea that the user groups we studied in the Netherlands and in Brazil have limited access to mental health care. We thus started with the proposition that at the core of users' motivations for participation is the aspiration of improving the accessibility and quality of mental health care delivery for themselves and other people in their communities.

2. Then we compared this proposition against the case study of Cape Verdeans in the Netherlands. Although 'improving the responsiveness of health care delivery' was an important incentive among Cape Verdean users to engage in Project Apoio, this was far from being their main motivation for participation. Liaising with others, learning about mental health, finding a meaningful social role and enhancing the social position of their community were also important reasons to become involved. It became clear then that improved access to mental care was important, but not sufficient to explain participation.

3. We framed a new proposition: mental health care users' participation is driven by several motivations which include collective incentives (e.g. improving the responsiveness of health care delivery and enhancing the social position of one's community) and individual incentives (e.g. breaking out of isolation, learning about mental health, finding a meaningful social role).

4. After collecting and analysing data from Brazil we framed yet another proposition: mental health care users' participation is driven by a variety of motivations but enhancing social justice and promoting users' full citizenship stand out as the core enablers of their participation.
5. We came thus to the point in which we had two propositions, one for each case study. Employing a case-comparison approach[112] (Yin, 1981) we looked into similarities and variations between the two cases. It emerged that although some of the incentives described above were more salient in one case than on the other, there was a common denominator to the range of motivations expressed by users in the two countries. When put together, those motivations reflect a strong aspiration by users to promote the full inclusion of people affected by psychosocial problems in society. As we argue in Chapter 7, this has led us to identify the promotion of social inclusion as the core goal of participation among our research groups.

6.5 Criteria for evaluating the quality of the research

Triangulation is a technique that can be used to evaluate the quality of research (Denzin, 1978; Patton, 1999). The term triangulation derives from land surveying and navigation where it is used "to describe a technique whereby two known or visible points are used to plot the location of a third point" (Knafl and Breitmayer, 1989: 209). In social science, triangulation was originally conceptualized by Webb *et al.* (1966) as an approach to the development of measures of concepts whereby two or more methods would be employed to develop those measures, resulting in greater confidence of the findings (Bryman, 2004). In qualitative research, its use was first advocated and popularised by Denzin (1978) who outlined four types of triangulation: 1) methods triangulation, which involves the use of two or more methods of data collection such as observation, interviews, secondary sources, etc.; 2) data sources triangulation, involving the use of diverse sources of data, so that one seeks out instances of a phenomenon in several different settings, involving different persons, and at different points in time or space; 3) investigator triangulation, involving team research with multiple researchers in the field; and 4) theory triangulation, which involves the use of multiple perspectives of theories to interpret data.

Triangulation has also been criticised as a technique to measure the quality of research. According to Patton (1999), one common misunderstanding among critics, is that triangulation aims at demonstrating that the use of inquiry approaches or different data sources yield essentially the same results. But, in Patton's view, the point of

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[112] The case-comparison approach consists of producing an explanation for each case singly (within-case analysis) and then comparing cases in such a way that variations between them can be identified. The following step is to produce a final common explanation which accounts for those differences while providing a core characterization of (or argument for) both cases (Yin, 1981).

triangulating is really to test for consistency and the possibility that different sources of data yield somewhat different results may be expected because different types of inquiry are sensitive to different world nuances. Thus, finding inconsistencies is not necessarily a sign of weak credibility of results, but rather an opportunity to seek deeper insight into the relationship between the inquiry approach and the phenomenon under study.

In this study we carried out triangulation of data sources (collected from people with different stakes on participation, in different settings and in different countries), methods (i.e. observation, interviewing, and secondary sources) and theories (i.e. Mutual Incentives Theory, the Participation Chain Model, social movement theory, empowerment theory and citizenship theory)[113].

Triangulation of sources was particularly useful to gain an encompassing understanding of the phenomenon of user participation. By including people with different takes and stakes on participation (i.e. user groups and stakeholder groups, see section 2.3.1) in our respondents sample we were able to inquire about the advantages and disadvantages of user participation from different angles and to use responses coming from different standpoints to test the consistency of our findings. Given the sanctioning of user participation as a right by law in both the Netherlands and Brazil, and its importance in psychosocial approaches to mental health and client-centred therapies, being overtly unsupportive of user participation is usually not well-regarded and few people will openly admit to discourage it. Some of the experts by experience in our stakeholder cluster in Brazil reported, however, that some users experience retaliation from professionals who feel threatened by their participation in the user movement (MNLA). This led us to a more wary inquiry about the negative consequences associated with participation. After asking respondents in the stakeholder group whether participation brought any disadvantages to users, we also asked whether they had witnessed instances of retaliation and why people generally abstain from bringing up that issue. Many respondents said they were never in presence of a situation of retaliation but that it was possible it took place. One respondent answered those questions in the following way:

> People are afraid to take a stand, to talk, and to do. Here [in Rio de Janeiro] you have a hegemony of the traditional psychiatric and psychoanalytic models of therapeutic relationships. They are very strong. So there's a certain resentment of users who question [mental health care and its providers] and who want to talk. To use a concept from psychiatry, there is a double-bind, an ambiguous message [being passed]: 'participate, as long as you don't criticise me [professional]. Talk about everything, as long as you don't talk about me, or as long as you don't talk about this service (Coordinator of health research centre, BZ).

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[113] Investigator triangulation was not possible due to budget limitations.

After hearing this, we inquired respondents in the user cluster about possible experiences of retaliation connected to their participation in the MNLA. All respondents stated that professionals in their mental health service were supportive of their participatory activities. However, some of them reported to know users from other services who complained of retaliation. It seemed that a reluctant professional culture to participation did exist (even though it was not fully widespread) in Rio de Janeiro and that that was a relevant factor to take into consideration when seeking to understand the incentives and disincentives to user participation.

Carrying out research in different settings in two countries has also been valuable to reflect upon the ways by which different models and mandates for user participation impact on user engagement. This has been particularly noticeable where issues of representation are concerned, i.e. how different voices find place within the participatory spaces set up to enable user participation. As described in Chapter 2, user participation in mental health is approached from a democratic or rights-holding perspective in Brazil. In the Netherlands, user participation is approached from both a democratic and consumerist perspective, although the latter has gained prominence in the last decade. These two models make way for different conceptualisations of the role of users as engaged agents. While in the Netherlands they tend to be viewed as *consumers* or *empowered clients*, in Brazil they are treated as *makers* and *shapers* in health governance. As we show in Chapter 8, the consumerist approach is likely to be not only sustaining, but also inadvertently legitimising a situation in which some segments of the population in the Netherlands, such as migrants and ethnic minorities (MEMs), remain under-represented on mental health care participatory spaces. While a rights-holding approach to user participation assumes the participation of all in developing and sustaining an equitable, accessible and good quality health care system, the consumerist approach lays foundation on the assumption that consumers will participate when they are dissatisfied, and/or when they want to lobby for the creation of new health care 'products'. If taken literally, the latter assumption may lead to the idea that if one does not participate that is because he/she finds it unnecessary. This view can easily sustain a situation in which those who experience limited access to care or are unaware of the channels devised to place forth their demands remain unnoticed and under-represented on mental health care participatory spaces. In addition, it might also legitimise the non-allocation of incentives to reach out and promote the participation of poorly represented populations, unless services directors set that as a priority[114]. In contrast, because user participation in Brazil is a core principle of a health care system developed to democratise access to health care and serve the needs of all, there is greater attention to achieve fair representation and more incentives to engage those at the margins of society. This does not mean, however, that clientelistic

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[114] In practice, this seems to be translating in a fair representation of MEMs in some client councils and their absolute absence in others, even when the latter are located in services with high numbers of MEM users.

interests do not operate within participatory spaces to silence the voices of users, but the approach adopted in Brazil appears more concerned with issues of representation than the prevailing consumerist approach in the Netherlands. Thus the possibility to triangulate data from these two countries allowed us to have a more nuanced and informed view over representation.

Triangulation of methods offered an essential approach to match respondents' say's and do's and to test the consistency of data collected through different methods. As described in section 2.3.1, contrasting data collected through interviews with data from observations of public events related with mental health promotion and user participation enabled us to detect some inconsistencies between users' reported appreciation of such events and their decision to not take part in them. This occurred with both Cape Verdeans in the Netherlands and minority Northeasterners in Brazil. Further triangulation of field observations with informal interviews allowed us to disentangle this apparent inconsistency: observations made it clear that some public events are more publicised than others; and, informal interviewing unravelled the existence of impediments to respondents' attendance. This allowed us to understand the incongruence we had identified between what users say and do, and to make a more clear analysis of the barriers which obstruct users' participation in participatory spaces (e.g. fear of stigmatisation, meagre financial resources, etc.) (see Chapter 8).

Triangulation of theories has enabled us to make a deeper analysis of our findings and to decrease alternative explanations for the phenomenon under study. Our theoretical propositions concerning the enablers and inhibitors of participation have been framed (and reframed) in light of the Mutual Incentives Theory and the Participation Chain Model developed by Simmons and Birchall (2005). However, as noted in Chapter 3, the participatory spaces which constitute the main focus of our study combine characteristics of both 'invited' and 'autonomous' spaces. This hybridization of participatory spaces stresses the need for research on incentives and disincentives to user participation to be informed by theoretical insights able to account for both the involvement of users in spaces created by state agencies and the actions of autonomous groups seeking voice and transformation. In order to increase the robustness of our findings, we also resorted to contributes made by social movement theorists and citizenship and empowerment theory. The multiple insights afforded by these theories were scrutinised and employed during analysis, enabling us to move beyond obvious explanations and to rule out competing propositions.

6.6 Ethical concerns

Ethical concerns in social science revolve around several issues including informed consent, confidentiality and anonymity, effects on participants, communities, audiences, organisations, gatekeepers, subsidisers and society at large, and the independence of research. Beneficence is an umbrella ethical principle which refers to the maximisation of good outcomes for science, humanity and individual research participants while avoiding or minimising preventable harm, risk, or wrong doing (Sieber, 1992 cited by Boeije, forthcoming). In what follows we explain how we sought to enforce this principle.

Before commencing the study we contacted the gatekeepers of the services and organisations where we planned to carry out fieldwork. After explaining the purposes of the study and the methods to be employed we asked permission and collaboration to carry out research. An agreement to return the results of the study to the organisations and services was made and permission was granted in all research settings.

As we noted above, this study was conducted with two different groups of participants in both the Netherlands and Brazil: one group composed of various stakeholders in the field of participation (i.e. the stakeholder cluster) and another group composed of migrant and ethnic minority participants who make use of mental health care services (i.e. user cluster). In Brazil, all research to be carried out with people affected by mental problems must be submitted to evaluation by and find approval from local Research Ethics Committees. In the Netherlands, given the goals, participants and methods employed in our study, it was not necessary to get approval from the Ethics Committee to conduct the research. Before initiating fieldwork with the user cluster in Brazil, we submitted our research proposal together with a copy of a Term of Consent for the study to the Research Ethics Committee of the Municipal Secretary of Health in Rio de Janeiro. Approval to conduct the research was obtained.

Informed consent from participants in our study was sought after by: introducing myself at all times as a researcher, explaining the purposes of the study and the methods to be employed in a way that was understandable to all potential participants, making clear that refusal to participate or withdrawal of consent were possible and that no negative consequences for the participant or participants' relatives would derive from that, guaranteeing confidentiality and anonymity, explaining how the data collected would be used (i.e. in articles, a book, or conferences), and by offering participants the possibility for raising questions, making comments or seeking clarifications, both at the beginning and at the end of interviews. In the case of the stakeholder cluster, the issues just described were presented before the interviews and verbal consent was obtained. Participants from the client cluster in the Netherlands were handed in an Information Sheet about the study before soliciting their participation. The content of the Information Sheet was cross-checked for the use of inaccessible language by two lay people and made available in Portuguese and Dutch. Because some participants had a low education level, I always offered to either readout loud the Information Sheet or give them a moment to do it themselves. When it seemed clear that participants understood the purpose and implications of the study I solicited verbal consent which was granted by all respondents. In the case of the user cluster in Brazil, participants were given a Term of Consent in Portuguese containing a description of the issues mentioned above. Its content was also verified by lay people for language accessibility and participants were asked whether they preferred to read it themselves or having me read it out loud. Once participants' questions were answered and they stated to have understood the implications of their participation in the study I asked, in agreement with the guidelines of the Research Ethics Committee of the Municipal Secretary of Health in Rio de Janeiro, for signed consent. All respondents agreed to sign the Term of Consent.

Questions made in the course of the interviews should, in principle, cause no distress to respondents. However, I was aware that asking about experiences with mental health care services could give rise to less positive emotions or memories. For this reason, I was keen to inform respondents they could refuse answering questions they felt uncomfortable with without having to give an explanation. When soliciting permission to record interviews, I also explained that recording could be halted whenever they thought necessary and that interviews could be stopped if they so wished. Finally, I sought to be alert for signs that could indicate respondents' discomfort. When that appeared to be the case I offered to either make another question or to take a pause from the interview.

There was one instance in which a respondent asked for the interview to be discontinued. After 1h20 of interviewing she stated she was tired and had nothing else to say. My interpretation was that, aside from being tired, she also felt uneasy when one of the questions led her to talk about a therapy group with which she was unsatisfied. I respected her request and stopped the interview. There were also some participants who asked that parts of their interview were not published or mentioned in conferences. I made note of those requests during the transcription of interviews and have not used any of those materials.

Like we mentioned before, some of the respondents lived on very meagre financial budgets. To avoid that their participation in this study would pose an additional strain to their budgets, it was always suggested that interviews were carried out in the places and times respondents found more convenient. This implied a great degree of flexibility on behalf of the researcher both in terms of schedule and mobility. In a large and unsafe city such as Rio de Janeiro it also demanded some extra time, energy and audacity. Nevertheless, this seemed the least intrusive way to include participants in our study.

Anonymity appeared to be an issue of concern especially amongst respondents of Cape Verdean origin. While many respondents in Brazil and several respondents from the stakeholder cluster in the Netherlands stated their identities could be revealed after I assured them of the confidentiality of their statements, Cape Verdeans often inquired further on this issue, adverting the importance of keeping their identities concealed. Like we show in Chapter 7, this is likely to be related to the fear of stigmatisation. Mental problems remain a taboo for many people within the Cape Verdean community. Being associated with mental illness can easily lead to discredit and exclusion. As a result, there is often great secrecy regarding mental health care use amongst Cape Verdeans. We have, therefore, been particularly protective of the privacy of both the client cluster in the Netherlands and the user cluster in Brazil. While some of the interviews from the stakeholder cluster were given out to freelance transcribers, the researcher herself transcribed all the interviews from the user and client clusters. In addition, none of the respondents' identities are revealed. Respondents from the stakeholder cluster are referred to according to their function and using the acronyms NL and BZ to differentiate between Netherlands-based and Brazil-based participants, respectively. Respondents from the user and client clusters are referred to through the use of pseudonyms.

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7. Starting participation: enablers

The end purpose of participation in health governance is the promotion of equity in health and social policy and provisioning for all members of society. Participation enables lay people to become 'makers and shapers' (Barnes, 1999) of policies and services more responsive to their needs. Taking part in health decision-making processes is especially important for disadvantaged groups whose needs are often overlooked and/or under-served. However, as we saw in Chapters 2 and 5, they are among the least included groups in the health participatory sphere. One way to begin to understand this problem is to ask members of marginalised groups who succeeded in getting involved in participatory spaces why and how they came to take part in those spaces, and what enables the sustainability of their participation.

This chapter addresses these issues by focusing on the cases of Cape Verdean migrants in Rotterdam and minority Northeasterners in Rio de Janeiro. As described in Chapter 5, both these groups were engaged in mental health participatory initiatives: Cape Verdeans participated through Project Apoio in Grupo de Conversa and Comissão; minority Northeasterners were involved through CAPS Pedro Pellegrino in Assembleia, and on the local branch of the Brazilian user movement[115]. Here we present the results of our cross-case analysis (see Chapter 6)[116]. Taking the cases of both user groups together, we highlight and discuss the similarities and differences between their motivations to participate and the ways by which they got involved. We also draw on data collected with various stakeholders in the Netherlands and Brazil as a means to illustrate the specificities of each research site and the ways by which they may explain variation between cases.

As we will show, both individual and collective motivations underlie the participation of minority Northeasterners and Cape Verdean migrants in mental health participatory initiatives. In addition, mobilisation and access to resources are fundamental to fostering sustainable participation. Finally, both user groups give participation a broad meaning which goes beyond the opportunity to promote better health care policy and service delivery to become a process through which they attempt to assert their rights of citizenship and inclusion in society.

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[115] As noted in Chapter 5, we also interviewed a small group of users who were not involved in participatory initiatives. When referring to them we add the expression 'non-involved user' after their pseudonyms.

[116] As we saw in chapter 6, a case-comparison approach consists of producing an explanation for each case singly (within-case analysis) and then comparing cases in such a way that variations between them can be identified. The following step is to produce a final common explanation which accounts for those differences while providing a core characterization of (or argument for) both cases (Yin, 1981). In this chapter, we present the results of this cross-case analysis.

7.1 Motivations: the quest for social inclusion

The results we are about to describe show that users got involved in mental health participatory spaces for a variety of reasons. Some were of a personal nature such as the desire to break out of isolation, learn how to cope with mental problems and find paid work. Other reasons had more to do with collective concerns. Influenced by values such as equality and social justice, some users identified the drive for their participation as the need to struggle against the discrimination and exclusion of people affected by psychosocial suffering – an experience many of them shared – and to advocate for their rights, not least to adequate mental heath care. It emerged that both individual and collective motivations played a role in decisions to become engaged.

In what follows, we discuss motivations for participation in greater detail and look into the ways by which they form and evolve. As we will see, there is a common denominator in the range of incentives which encouraged users to take part in participatory initiatives. Taken together, these incentives reflect a concerted effort by users to foster not just their own social inclusion but also the exercise of full citizenship by other members of their communities. This concern with the collective is particularly salient among 'old hands', i.e. users with a long-standing practice of participation. Early stage participants, on the other hand, tend to put greater emphasis on the consequences of participation at a personal level. Summing up we can say that the appeal of participatory initiatives depends on perceptions of their ability to generate both collective and individual benefits. However, in some contexts, pursuing certain types of individual gain (e.g. acquiring paid work) may be considered a less legitimate goal of participation. As we will see, this may influence the way by which users describe their motivations for involvement, which shows the need to be alert for social desirability effects when collecting this kind of data.

7.1.1 Individual Motivations

7.1.1.1 Liaising and learning

Liaising and learning were key reasons for users to undertake participatory initiatives. Meeting with others and exchanging experiences, ideas, uncertainties and anxieties were things many users had come to be deprived of from the moment that symptoms of psychosocial problems had started to manifest themselves. In some cases, reduced social interaction resulted from users' need to withdraw from their social circles due to a sense of hopelessness caused by impairment and/or stigma. In other cases, diminished social contact resulted from users being singled out and excluded by others because of their 'madness'. The following quotations illustrate these two types of cause:

> Before, I was very closed off. I was home, took care of the kids, and went to the doctor. Nothing else. And then the children grew up and I was there [home] alone. I didn't know what to do and I had very bad thoughts. I couldn't get myself to go

> out. My head was tired and I forgot a lot. I didn't have the courage to face people. I was very depressed. (Isabel, NL)
>
> I would like us to be looked at with other eyes and not like people with a mental illness who are going to cause harm to society. (…) Society treats us without respect, often because of ignorance. We are also human beings. We are good people and we make our contributions to this country [Brazil]. (…) I used to work but nowadays I'm not as productive as a normal person. The others look at me and say I'm crazy. They put me aside. (Oscar, BR)

Participants described many situations of disrespect, humiliation and rejection endured by themselves or people they knew. Oscar (BR) told how a bus driver once refused his free bus pass shouting for everyone to hear: "this guy thinks he can travel for free just because he is crazy!". Florência (NL) commented on people staring and gossiping about her, making her presence in social gatherings uncomfortable. She was resilient and kept on going, but several other users stopped attending community events in order to avoid having to endure intrigues and belittling remarks. In some cases, experiences of mistreatment were so extreme that users came to fear venturing into the public space itself. A Brazilian social worker described how a young man in his early thirties, receiving care at the out-patient mental health service where she worked, always refused to participate in activities organised outside the service's facilities: "It took me months to convince him to come with us. He didn't want to. He was afraid people would throw stones at him" (Member of family association 2/ social worker, BR). Vulnerability to hostility and aggression led some users to keep off the streets and seek refuge in the safety of their homes.

Feelings of rejection and exclusion are not always the result of active hostile behaviour. Being ignored and neglected can cause as much pain and damage as exposure to offensive language, mockery and violence. As part of his involvement with Project Apoio, David (NL) carried out home visits to ill people from the Cape Verdean community. Reflecting on that experience, he noted how often they apologised for not looking their best, having few refreshments to offer and little to talk about. "You can really see how lonely and sad many people are", he said, indicating the negative effects of social exclusion: low self-esteem, reduced interest in the world and isolation.

The isolation of people affected by psychosocial suffering in their homes can also result from concerns their carers have about their protection and/or the safety of others. This often generates considerable distress among both users and carers, undermining the right to self-determination of the former and imposing demands on the latter which they are often unable to cope with. This was evident in Benvinda's description of her experience in becoming the primary caregiver of her sister after the latter was diagnosed with schizophrenia:

> It's very heavy. You see your whole life falling apart. Its really difficult for me. She is my sister and we are twins. But I think: "I don't know you!" I try to take her out but she doesn't behave appropriately. And if she goes out and doesn't come back on time I get stressed and I start thinking about what she might be doing. You can never leave her on her own and that's very difficult because I also have my own life. (Benvinda, NL non-involved user)

But the sequestering of users by their carers is not just motivated by safety concerns. There is often also a strong element of shame and fear involved:

> It's very important to work with the families. Sometimes a mother comes in and says: "I'm not taking him out because he's going to scream". They're afraid. They are afraid of users making a mess and embarrassing them. So they keep them out of public sight. (…) I tell them [carers] that mad people are just like any other person. They can also go to the theatre, the Carnival, the beach. (…) I organise a lot of outings and I take them with me but it's important they [users] learn to go on their own so they can regain the trust of their families. (Member of family association 2/ social worker, BR)

The idea that people affected by psychosocial distress are too unpredictable, incompetent or unreliable to make their own decisions and live communally with others, and the constant supervision and assistance that ensues, have a negative impact on users' sense of autonomy, self-confidence and self-efficacy, undermining their ability to build and maintain meaningful social relationships and to intervene in the social world. Social disengagement, in turn, leads to a loss of fulfilment and purpose in life causing depression, apathy and social withdrawal. Overall, it can be said that practices of exclusion and self-exclusion are mutually reinforcing.

The deleterious effects of being labelled mentally ill – denigration, loss of status, abuse, shame, rejection, self-exclusion and isolation – serves to reinforce a 'culture of silence' (Parr *et al.*, 2004) and 'hiding' (Barnes and Shardlow, 1997) of psychosocial suffering which is common among, but not confined to, minority Northeasterners and Cape Verdean migrants (see Barnes and Shardlow, 1997; Parr *et al.*, 2004). Rendering mental problems unspoken impedes the dissemination of knowledge about mental illness and perpetuates the myths associated with it. According to participants, it was the idea that 'madness' is dangerous, contagious and irreversible that made people avoid and exclude those deemed to be 'mad'. The fear of being infected by an incurable ailment which would forever disturb the harmony of their lives led many people to seek distance from and/or ostracise people with mental problems. Such practices of intolerance and discrimination led to the (self-) estrangement of many users from their communities, robbing them of the opportunity to participate in key social activities and of the sense of belonging which is fundamental for both personal empowerment and the exercise of active citizenship. Asked about what could enhance the citizenship of people affected by psychosocial distress, the president of a family association in Rio de Janeiro said:

> Society needs to embrace them [users]. The myth that having mad people in the streets is dangerous must end. I usually say that mental illness is like any other pathology. It's like cancer or AIDS. People embrace those pathologies but not mental illness. (Member of family association 2/ social worker, BR)

The powerful metaphor of 'embracing mental illness' refers to the efforts required to change societal attitudes and dispel the fears, ignorance and discrimination that undermine the social inclusion of people with mental problems. But it can also be taken literally to mean the physical contact people need to form and maintain attachments to others and to feel part of social groups. It is not uncommon for 'mad' people to be excluded from simple social conventions such as shaking hands on meeting. During a visit to a psychiatric hospital in Rio de Janeiro, a psychiatrist explained to me how he sometimes greeted patients with a hug because almost nobody else wanted to touch them. This seems to be inspired by a fear of contagion that transforms the 'mad' into 'untouchable others', which the following account illustrates:

> (…) After I finished with my questions [and turned off the recorder] Madalena was keen to continue chatting. She poured us some more tea and talked about her concerns with her youngest son's 'behaviour problems'. (…) Further down the conversation, she began to tell how her mother would sometimes loose control, scream and break things in the house during what I believe to have been psychotic episodes. Usually, these events were followed by her mother's admission to the psychiatric hospital in Praia [Cape Verde] where she stayed for several months each time. Madalena was only eight years old when this first happened. She said: "we were already so poor and then she would break the few things we had or throw them out the window". (…) During her mother's admissions, Madalena was left on her own. She had to take care of her younger sister, clean the house and cook for her father who was out all day working. The neighbours sometimes helped, she said, but mostly people acted as if everything was all right. (…) One day Madalena was called to the psychiatric hospital. Her mother had passed away. With tears in her eyes, she told how she came there to find her mother completely bruised. She couldn't get staff to talk about it much. A nurse simply said her mother had 'lost reason' again and hurt herself. Madalena never found out what really happened but she believes her mother may have been beaten.
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> (…) Amidst all the suffering this incident caused her, Madalena said that what shocked and hurt her most was that nobody wanted to prepare her mother for the burial. She had to clean and dress her all by herself. (…) When I asked why people

> refused to help Madalena said she didn't really understand it then[117] but that looking back it was probably because people were so afraid of madness they wanted no contact with it. "It was as if they were afraid of getting infected", she said. (Excerpts from field diary, 27 March 2006).

After witnessing numerous instances of prejudice, rejection and exclusion occasioned by mental illness, or being cautioned by their families to keep problems a secret, several participants first tried dealing with psychosocial suffering on their own. As problems got worse, they embarked on a process of deepening isolation which disrupted their embeddedness in the community. This undermined their access to the social support, information and resources necessary to seek help and use psychosocial care, contributing to further distress and isolation – a kind of social 'black hole'. For some participants, especially Cape Verdeans[118], participatory initiatives were the very first opportunity they had to share about experiences of psychosocial distress with fellow-sufferers. Participatory spaces were seen by many as 'safe heavens' where they could initiate dialogues, demystify 'madness' and gain the confidence and support required to break the chains of (self-)exclusion.

For other users, participation was a way to meet people whom they either had no chance to come across or were too disempowered to engage with:

> It [participation] helped me learn how to relate with people with different attitudes instead of just sticking to people with a low education like myself. I learned how to liaise with knowledgeable people. (…) Being able to deal with people from all kinds of backgrounds was a very positive experience in my life. (José, NL)

The sense of connectedness to and togetherness with others, which users experienced as they built new relationships and enlarged their social networks, was further enhanced by the opportunity to occupy new social and geographical spaces. Participation enabled users, particularly minority Northeasterners, to exercise their right to free movement and venture out of peripheral territories into the hubs of public life:

> Jenifer: [I participate in the user movement] to get out a bit and go to the city. I like to go there to see people and know what's going on. (…) Many users know almost nothing about what's happening outside.
> Interviewer: Why is that? Why do they know so little about what happens outside?
> Jenifer: Because they live between home and CAPS. They are home and go to CAPS. They never go anywhere [else]. So they end up not knowing much at all. (Jenifer, BR)

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[117] Madalena's mother died when she was 17 years old. Judging from her age, the events she described took place during the mid-1970s in the island of Santiago, Cape Verde.

[118] There were some Cape Verdean participants who started using mental health care only after they got in contact with Project Apoio and were advised to and assisted in finding a mental care provider.

The ‘city’ Jenifer refers to is in fact Centro, one of the four areas which compose the municipality of Rio de Janeiro[119] and its historic, cultural and financial hub. Calling Centro the ‘city’ denotes a feeling of deprivation shared by many people who, like Jenifer, reside in Zona Oeste and do not perceive themselves to benefit fully from the quality-of-life amenities the ‘city’ has to offer. This is largely due to the general scarcity of services and leisure facilities in the area. As a psychologist explained:

> Zona Oeste is a very impoverished territory. It offers very little [to people]. (…) I’ve noticed how some people use health care centres as an extension of their homes. CAPS users do that too.They go there because it’s the only space in which they can socialise. (Psychologist 4, BR)

But as Jenifer noted, limiting oneself to “life between home and CAPS” diminishes users’ access to information and impedes them from taking part in the social world and in processes which have a direct impact on their lives (e.g. psychiatric reform). However, as simple and thrilling a trip to the “outer world” may sound, going to the city centre is in fact a challenging undertaking for many users. As we will see in greater detail in section 7.3, navigating a large and violent city like Rio de Janeiro requires a number of resources (e.g. time, money, autonomy, assertiveness, determination, etc.) which were not within reach for many users. Yet for those able to venture into the ‘city’, participation enabled them to broaden their horizons.

The feeling of living at the margins of the ‘city’ was not observed among Cape Verdean migrants in Rotterdam. Compared to Rio de Janeiro, the city of Rotterdam is safer, smaller, easier to navigate and more widely provided with services and entertainment facilities. However, these migrants did experience alienation from community spaces (e.g. churches, associations, festivities, etc.) which many stopped visiting because of the pain and shame of being ignored or gossiped about. Participation in the activities organised by Project Apoio enabled them to gain access to neutral public spaces (e.g. venues of meetings and information sessions) which were also visited by other members of the Cape Verdean community and were off their own ‘territory’.

We may conclude that, social interaction, learning about psychosocial distress and engaging in new social spaces were key motivations for many Cape Verdeans and minority Northeasterners to start participating.

7.1.1.2 Finding a meaningful social role

However, merely entering new social spaces is not enough to guarantee socio-spatial inclusion. To feel included, people need to engage in valued social relationships. The

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[119] In addition to Centro, Rio de Janeiro is divided in three other areas: Zona Norte (North Zone), Zona Sul (South Zone) and Zona Oeste (West Zone). As seen in Chapter 5, the minority Northeasterner participants interviewed for this study all lived in Zona Oeste.

ability to build and maintain reciprocal interpersonal relationships is largely dependent on people's own social, moral and emotional competencies (Ware *et al.*, 2007) and on how others perceive, evaluate and treat them. The latter, in turn, is influenced by the social roles people occupy (Wolfensberger *et al.*, 1996). According to 'social valorization theory', people who hold socially valued roles are more likely to enjoy the "good things of life" (e.g. respect, acceptance, opportunities for education, work, participation in one's community, etc.) (*ibid.*: 12) and hence to benefit from more positive social interaction. Stigmatised and marginalised people, on the other hand, may find themselves excluded from social spaces time and again if their role and thus their presence and participation within those spaces are not valued by others. Having a meaningful social role therefore is crucial for the construction and maintenance of socially rewarding relationships, and is an important catalyst for inclusion.

Participants considered involvement in economically and/or culturally valued activities as a key strategy for promoting the access of people affected by psychosocial distress to valued roles. As we will see further on, music performances, art exhibitions and volunteer work were all ways by which users sought to change public attitudes and beliefs about the 'mentally ill' and to improve their social image. Employment, however, was viewed as the most efficient means through which a more positive role could be crafted:

> I got my pension for disability but I would like to [work]… Many people think that's crazy. But I think: "I have that money but I don't have work. I don't have a job. I don't go out every morning to work and return in the evening. I'm excluded from society". You know, a person who doesn't work, or who doesn't study, she doesn't have much value for society, especially in a third world country. But what can I do? I have to subject myself to this because they [employers] don't give people with mental problems an opportunity to work. (Expert by experience 3/ mental health workshop coordinator, BR)

Only a small number of the users interviewed in Brazil had access to social benefits, and even less had succeeded in finding a paid job. For the few who worked, being employed enabled them to reach financial security, a sense of accomplishment and self-worth and respect from others, in particular from their families. In the case of Samuel, ability to work was perceived as a passport for life in the community:

> I worked a lot. Before I came to CAPS [Pedro Pellegrino] I was… I don't remember the name, but it [psychiatric hospital] was here in Rio de Janeiro. I worked in the biscuit [income generation] workshop [at the hospital] and then I went to work on the workshop of dolls. Let me try to explain. It's a lot of work to make a doll, you know? So I helped who I could. I put the bottleneck in. I filled it up. And then I made a little doll. So I learned that and I taught the others how to fill up theirs. And then the doctor called me and even took me to the direction. He [doctor] talked

> about me getting access to CAPS. Then I talked to the director and after that I went to a meeting with other doctors… and then the doctor accepted me [in CAPS]. Since then I do all the jobs I can. Or I'm at the phone, or I help the doctors with bringing messages [to the medical centre across the square]. That's my job now. (Samuel, BR)

After years of incarceration in a psychiatric hospital, Samuel believed his working skills had afforded him access to care in the community. That may well have been a decisive factor in considerations about his discharge. Like many other long-term psychiatric inmates, Samuel had no family and his mental health problems did not qualify as serious enough to grant him entitlement to disability benefits. This meant that without a source of income he could not be discharged. In addition to the grant he got for his work in CAPS, he also worked in a cooperative. As noted by the expert by experience cited above, people affected by psychosocial distress suffer considerable discrimination in the labour market. Income generation workshops and cooperatives within hospitals and psychosocial care services are the only chance many users have to work. Creating more opportunities for employment was an important individual incentive driving the participation of Samuel and many other users. Participatory spaces (e.g. Assembleia, the user movement, mental health conferences) were seen as privileged arenas from which to claim the creation of more income generation workshops, cooperatives and retail points of sale (e.g. small shops). In some cases, those spaces became opportunities in themselves for users to display and sell the products of their work:

> I started attending the [user movement] meetings. I travelled a lot. But my militancy was not much focused on speaking. I made bijou jewellery and I took it with me… Back then I didn't have my pension so I seized the [mental health] conferences to participate and to sell my bijous. I set up a little tent, exposed my bijous and sold them. Sometimes I would go to the front [speaker's platform] and say something. I talked to people. That was my form of militancy: working. (Expert by experience 3/ mental health workshop coordinator, BR)

While users in Brazil were uninhibited about describing the personal interests that underlay their motivation to participate, Cape Verdeans in the Netherlands were generally not so forthright about it. Many Cape Verdean users explained their involvement in Project Apoio in terms of their desire to contribute to their community. However, by a small group of those users – especially young people who had experienced mild mental health problems– participation was also seen as a means to advance career opportunities. When asked about what drove them to get involved, however, this consideration emerged as a secondary motive. This was even true when, as in the following case, thwarted expectations about getting a job became a key reason for discontinuing participation:

> Interviewer: What led you to participate [in Project Apoio]?

> Cátia: Back then I thought it was a good idea to do volunteer work for people who speak Portuguese and to provide them with information about the world of psychiatry. But then I gave up because being people don't know how to value volunteer work. And in what concerns Cape Verdeans they only complain and they are never satisfied. That's why I gave up. And also because the coordinator of the project… she failed on some things we had arranged. She failed, so I quit.
> Interviewer: So it was a combination of disappointment and people's critical remarks.
> Cátia: Right.
> (…) [Further on the interview]:
> Interviewer: What about the group? Did you get along [with the other participants]? Did you all work well together?
> Cátia: Yes, as it happens we did.
> Interviewer: So what led you to quit was the criticism made by the people for whom you were planning the activities…
> Cátia: It was more (…) [the coordinator]. I (…) [and two other participants] made a lot of projects. Look, I'm going to give you an example. We made a project for an Information Desk that was written by me (…) [and two other participants]. Since Cape Verdeans have a lot of difficulties in acquiring information that Information Desk would be… in principle, we would work there so contact would be easier. We made that project, gave it to (…) [the coordinator] and then she gave it away to someone else. And now there's a Dutch person working in the Information Desk. That happened with that and other projects. (…) All those decisions were taken by her [coordinator] without my consent. She took the projects we made so I quit. At that time I was unemployed and (…) [the coordinator] knew that we were looking for a job. We should have worked on those projects but she gave them to other people. (…) (Cátia, NL)[120]

Cape Verdeans' reservations about reporting individual motives (specifically the desire to find a job) seem to derive from the idea that concerns with the collective are undisputable goals of participation, whilst incentives associated with personal gain are somewhat less legitimate. To begin with, in contrast to Brazil, the Netherlands is a well-developed welfare state and most people in need have access to social benefits. In addition, there are specific projects within client organisations concerned with the integration of people with mental problems in the labour market. This means participatory initiatives can afford to focus on very specific issues and define very concrete objectives, since many tasks are already taken care of by others. Finally, Apoio was a project designed by and for the Cape Verdean community and, although promises of jobs may have been made and taken away, its initiatives did not centre on

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[120] Some elements of this quotation were removed or changed to protect the identity of the participants. I could not verify whether the projects Cátia describes were given away to other people. However, what the quotation is intended to illustrate is Cátia's intention to find a job through her involvement in Project Apoio.

the promotion of employment but on advocacy for the interests and wellbeing of the community as a whole. All these factors appear to have combined to instil the idea that participation should be focused on contributions for the common good rather than on the promotion of self-interest. This accounts for why collective motivations were regarded as more socially desirable. It is possible that because of this, individual incentives may have been under-reported.

Employment was not the only strategy for users to acquire a meaningful social role. Some found an opportunity in volunteer work to enhance their competencies, increase social contact, and even motivate the participation of others.

> Isabel: My psychologist told me I should do volunteer work. That that would be good for me, instead of being at home. (…)
> Interviewer: Why did you continue participating in that way?
> Isabel: Because it's good for me. It encourages me to do things. It gives me pleasure and we learn a lot. We can even learn how to help other people. And we can encourage them to participate, like I often do. (Isabel, NL)

Other users were especially aware of the influence of social environments on their access to valued roles:

> An idea I've been defending at the [user] movement [meetings] is that we need to open ourselves more to society. We have to make more public events, in the public space, to show ourselves, to show our work, to show our bijou jewellery, our craftwork. We need to show that we are capable of producing things. We need to show that side of ours to society. Because we deal with psychiatry and society is afraid. They think we are aggressive. So prejudice is a barrier we have to break. (Vinícius BZ)

What Vinícius draws attention to is that for as long as myths about the dangerousness of people with mental problems persist, gaining competencies and engaging in economically and culturally productive activities will not be enough to improve their image in the eyes of others. For people affected by psychosocial distress to stand a chance of acquiring socially valued roles, those myths need to be unpacked and exposed. This calls for initiatives aimed at debunking and dismantling the social, economic and environmental barriers (e.g. negative stereotyping, prejudice, discrimination, poverty, ostracization, etc.) which obstruct their inclusion in society and prevent them from practising their citizenship. In other words, acquiring a meaningful social role requires not only the development of individual competencies, but also social change to make possible the creation of opportunities to exercise those competencies (Ware *et al.*, 2007). Organising music concerts and art exhibitions were positive and uplifting strategies employed by users to occupy new social spaces and seek to transform the views of others toward greater acceptance and valorisation of their presence and participation as active citizens in society.

7.1.1.3 Overcoming stigma and increasing the use of mental health care

As noted earlier, the stigma attached to mental illness acts as a powerful barrier to seeking mental health care. In our study, this was especially noticeable among Cape Verdean participants. In contrast to minority Northeasterners, not all of these were yet receiving psychosocial care when they started taking part in participatory initiatives.

> It's a pity that anything to do with mental illness continues to be a taboo in our [Cape Verdean] community. Sometimes people know they need help but maybe because they are afraid of being treated like a mad person, or of being *diferenciadas* [set apart], [they don't look for it]. (…) Sometimes, at the information sessions [organised by Project Apoio] I hear people asking: "I would like to know if I can book a consultation for my sister, or for my aunt, or son". I noticed people never ask help for themselves. (Madalena, NL)

Using mental health care, or even admitting the need for it, works as an *atestado de insanidade* (certificate of insanity) in the eyes of others. Many Cape Verdeans make little or no distinction between different types of psychosocial problems (e.g. mild, moderate, and severe): one is either 'mad' or 'sane'; there is little in between. In a similar fashion, consulting with a psychiatrist or a psychologist is generally seen to have no other purpose than dealing with 'madness'. This makes attempts to gain access to mental health care complex, delicate and challenging endeavours since people feel they must keep them out of the public eye in order to avoid being labelled mentally ill. As Madalena notes, such a label leads to 'differentiation', i.e. to being marked as a member of an out-group which, in the case of people with mental illness, equates with increased vulnerability to prejudice, status loss, discrimination and exclusion. Fear of stigmatisation, and the loss of social opportunities this usually entails, prevents potential users from seeking help within the formal mental health system. But it also prevents those around them from offering it:

> There is a woman in our [church] choir who could really use some help. (…) I could try to tell her once: "I'm sorry, I understand you make things really complicated sometimes. Would it not be convenient for you to have a consultation?" But I'm afraid of saying that because she may not be happy to hear it and she could even say: "Who? Me? Going to talk to a psychologist or a psychiatrist! Are you saying I'm mad?" So, instead of making things better I could make them worst. (Madalena, NL)

This goes on to show that people affected by psychosocial suffering may themselves endorse negative stereotypes about mental illness. If they believe mentally ill people to be incompetent, dangerous and/or unreliable, then seeking treatment for themselves can work to confirm those prejudices and to reduce their self-esteem as they may come to ascribe those characteristics to themselves. The potential effects of self-stigma on one's sense of self can be so damaging (e.g. devaluation, diminished self-efficacy) that they lead people to reject (or drop-out from) mental care (Corrigan, 2004) and even to deny the existence of psychosocial problems.

Public and self-stigma are not the only factors determining Cape Verdeans' under-use of mental health care (De Freitas, 2005; 2006). Lack of information about psychosocial care, problems of communication, mistrust of health professionals and difficulties in negotiating care all act to limit the utilization of mental health services (*ibid.*). In addition, Cape Verdeans have a complex 'Christian-spiritual repertoire' (Beijers, 2004a) of health beliefs that sees supernatural phenomena (e.g. spirits, witchcraft, the evil eye), biomedical causes (e.g. hereditary diseases) and socio-economic problems (e.g. debts, poverty) as the origin of psychosocial distress. This makes way for multiple help-seeking strategies, including visits to traditional healers, faith-based communities (e.g. Catholic Church, Pentecostal Church, Christian Rationalism), and transnational health care services (Beijers and De Freitas, 2008). These alternative pathways to health, together with the problems of accessibility, lead Cape Verdeans to inadvertently deflect from the Dutch mental health care system. Stigma, however, has a very powerful role in impeding them from identifying and accepting their candidacy for mental health care. In other words, fear of stigmatisation causes Cape Verdeans to deliberately refuse to seek help within the formal mental health system, emerging as a salient obstacle to their access to good quality psychosocial care.

Unsurprisingly, combating taboos and stigmas concerning mental illness belonged to the core goals of Project Apoio. Its peer support group – Grupo de Conversa – allowed Cape Verdeans to come together and meet others who, like them, experienced psychosocial suffering. It offered a secure, de-stigmatising and empowering space for them to start learning about psychosocial distress, without feeling obliged to disclose their own mental problems. As time went by, some participants began to seize that opportunity to acquire information about mental health care services and gather the resources (e.g. support, confidence, referrals, competencies, etc.) necessary to use them.

> Aurora: Everyone there [meeting of Grupo de Conversa] has their own problems. You learn a lot. You also get a lot of information. The lady who talked about her son's illness [Attention Deficit Hyperactivity Disorder, ADHD]… I know him from the bus and I never imagined he had a problem. I didn't know anything about this illness. But when she explained it in such detail I started thinking that my son has the same problem because everything she told about her son happens to mine.
> Interviewer: So you never heard of ADHD until that meeting?
> Aurora: No. Hearing about her son's symptoms I started analysing and I realised that I've always thought that something was not quite right with my son. (…) I've

> always tried to tolerate the things he does but sometimes it's really unbearable. Since that day I thought: "maybe I should go talk to someone with more studies, who understands this better and who could give me some help". The lady [at the meeting] even gave the name of someone who helped her with her son.
> Interviewer: Was it a psychologist?
> Aurora: She said it's a lady who works in RIAGG [out-patient mental health service]. She gave me her name. I made an appointment but I don't know if the day arrived already because I lost the paper where I wrote it down. I need to call her and apologise if the day is passed and make a new appointment. That's, of course, if she accepts it. Because she might think I wasn't interested. But there's too much happening right now. I really need an agenda. (Aurora, NL)

Participatory spaces enabled several Cape Verdeans to realise their entitlement to and availability of psychosocial care without having to deal with the pressure of being labelled mentally ill. Finding a 'safe route' into mental health care offered a strong incentive to many of them to get involved more actively in Apoio's participatory initiatives.

As we already mentioned, minority Northeasterners were all making use of mental health care services when they first got involved in participatory spaces. Like Cape Verdeans, however, they also experienced stigmatisation. As noted earlier, Brazilian society endorses many stigmatising ideas about mental illness and the internalisation of those ideas induces self-stigma:

> Interviewer: You mentioned taboo. Is there a lot of stigmatisation of mental illness here?
> Psychiatrist 1: Yes, there is. Even by patients themselves. Last week I had a very bad experience. A patient I had been treating for eight years… he was doing very well. He was no longer having psychotic episodes. But he couldn't bear the idea of being a patient. He asked me for a medical report. When I wrote down a diagnosis of schizophrenia he couldn't accept it. (…) Thank God I managed to convince him to not stop treatment. (…) The real problem [here] is being associated with [a mental health] institution. The problem is the burden posed by mental illness. (…) The stigma is a horrible burden. It becomes almost impossible to live when you get such a diagnosis (Psychiatrist 1, BR)

Self-stigmatisation can yield the development of such oppressive forms of subjectivity that users may even feel compelled to abdicate from their rights of citizenship:

> Interviewer: Did participation in the user movement help you personally?
> Vinícius: Yes. I'm going to give you an example. I resisted a lot to get my Passe Livre[121] at first. I thought that was a… it was as if they're putting a sign in my

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[121] Passe Livre or Free Pass enables low SES people with disabilities to travel free-of-charge by bus.

> forehead: “You have a problem”. Because when you show that little card everyone knows that you have a [mental] problem, that you are a special person. I, myself, had a huge prejudice about it. I was ashamed of telling people I got treatment in psychiatry. Nowadays, that’s over. When I started treatment here in CAPS I was ashamed but now I learned to value myself more. I know that I’m capable of doing many things and so are other users. If that [Passe Livre] was a right of mine I should fight for it. (Vinícius, BR)

This account shows how participation can contribute to eliminating long-lasting prejudices and self-discrimination by enabling users to deconstruct negative beliefs and develop a sense of justice and empowerment. As Vinícius notes, rights are something one must fight for. As we will see in the next section, this realisation reinforced his desire and commitment to participate in health decision-making spaces – not just with the intent of promoting his own right to health, but also to enforce the delivery of adequate health care to his fellow citizens.

7.1.2 Collective motivations

7.1.2.1 Improving the responsiveness of mental health care delivery

Coming into autonomous spaces of political struggle for the inclusion of marginalised groups (e.g. user movement) can help members of those groups to gain awareness of the mechanisms determining their (internalised) oppression and exclusion (e.g. public and self-stigma, disenfranchisement, hopelessness). As they go on to realise the sources of their disadvantage, some develop a righteous anger (Corrigan and Watson, 2002) which can rouse them to recast themselves as political actors. As Vinícius (BR) explained, once he realised the harm caused by his own stigma, he rebounded and responded by pursuing a more active role in health governance. He began by taking part in the assembly of his mental health service:

> Vinícius: (…) If you know you have a problem you need to treat yourself. And if you come here [CAPS] you must show interest in recovering and you need to participate in things. Assembleia is there for us to discuss things, and to make our claims. I think everyone should participate. It’s [Assembleia] not only meant for criticism. It’s meant for us to give our opinions about the service. (…)
> Interviewer: And what’s necessary to make CAPS a better service?
> Vinícius: I think there aren’t enough staff. The building is too small. We [users] don’t have a room to seat and talk to each other. We need a bigger building. The user groups [in the workshops] are too big. We need more income generation workshops. (Vinícius, BR)

When I interviewed Vinícius, user participation in Assembleia had already generated change in health care provision. An extra psychiatrist had been hired and the creation of a new income generation workshop was under negotiation. However, as Benedita

(BR) noted, there are aspects of service organisation and management which escape the direct control of local service coordinators (e.g. acquiring well equipped facilities) and fall under the competence of the municipal government. When asked whether there were other channels through which that kind of claim could be made, Vinícius described with a visible feeling of pride and excitement how he occupied one of the spaces reserved for *controle social* (social oversight) – the municipal health council – to express dissatisfaction with service delivery, determine liability and demand change:

> I went to the Municipal Secretary of Health [municipal health council] and I told them all about what's missing. It was funny because they [public health managers] go there [council] and they start describing everything they have done so far. And I started thinking: "We're in another city. We're in another world. I can't see any of that". So I told him: "there aren't enough doctors. We don't have enough space. There's a lot missing in CAPS and you're saying you did this and that. I don't see anything done!" I said that to the Secretary of Health. (Vinícius, BR)

Vinícius' story is a case in point of how critical consciousness can flourish as a result of participation. From acknowledging and discarding self-stigma, to becoming engaged in his own service, and then moving up to the higher tiers of governance to demand accountability from public health managers, Vinícius developed a sense of agency that enabled him to build the confidence and capacity necessary to take action and start changing the internal and structural mechanisms at the root of his disadvantage. Increasing the responsiveness of mental health service delivery became a priority among his participatory contributions. However, that was not a goal he pursued just for himself. By the time he got to voice his complaints at the health council he was already in the last stage of his treatment at CAPS[122]. His advocacy for adequate mental care was largely concerned with promoting the rights and the wellbeing of a group he had come to identify strongly with – the mentally ill. This indicates how individual incentives for participation can evolve into wider concerns with a collective one feels part of.

Invited participatory spaces were not the only means by which users in Rio de Janeiro sought to enforce their right to good quality health care. Collective actions were considered fundamental to exposing local government mismanagement to the wider public and to demand the restoring of rightful provisions. As we saw in Chapter 5, involved minority Northeasterners received care at an under-resourced, overcrowded mental health service which was affected by recurrent and unexplained budget withholdings. This resulted in shortages in food and medication supplies which

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[122] Vinícius started a five day per week treatment programme at CAPS Pedro Pellegrino right after the service was inaugurated in 1997. When I interviewed him in 2007 he was on a one day per week care programme.

undermined the service's capacity to respond to users' needs, causing unnecessary suffering (e.g. users relapsing into psychosis due to lack of medication). In 2006, CAPS users organised a demonstration in front of Rio de Janeiro Town Hall to demand the return of funding. This action was viewed as very successful and recalled with great enthusiasm. The belief in the power of collective action to keep services in check and promote social justice was expressed by the employment of an idiom common among trade unionists: "*a união faz a força*" (union creates strength) (Jaderson, BR).

Like many other users, Benedita (BR) was also keen on improving the quality of mental health care. Adopting a bottom-up approach, she took the opportunity to give a lecture at the public health institute where a great deal of Rio de Janeiro's health legislators, service managers and care providers get their training. Although that involved self-exposure, which for a person recovering from severe depression is a real challenge, she decided to share her experiences with students because she believed in the importance of making future health professionals aware of users' subjectivities and sensitive to their very particular needs. That, she hoped, would contribute for preventing the reproduction of asylum-like practices which homogenise and objectify people affected by psychosocial problems, robbing them of their agency and freedom.

Cape Verdeans, too, came to see participation as a means of enhancing the responsiveness of mental health services. Although they were not represented in invited participatory spaces (e.g. client councils, advisory meetings), they started bringing their *cliëntenperspectief* (user perspective) into Dutch mental health care by organising participatory initiatives themselves (e.g. periodic public information meetings and debates), to which they invited health officials, mental health professionals, local politicians and academics. The potential of those spaces to promote a dialogue with health authorities and raise their awareness of the specific needs of the Cape Verdean community was not immediately realised. As we saw in Chapter 5, Cape Verdeans in the Netherlands are known as 'silent migrants' and that cliché was repeated in the first public meetings. However, as they become more informed and confident they began to advocate for their interests. As explained by the coordinator of Project Apoio, they experienced a process of emancipation:

> Coordinator: They [Cape Verdeans] used to go to the debates to get a lesson. They heard the lesson and they went home without saying anything back. It was a monologue. Nowadays, people want to talk. They want to give their opinion. There's a dialogue. They want to talk even if they do it in the third person. (…) It's like the Dutch say: they are empowered. They're emancipated clients now. They got emancipated in the way they are in life. They no longer go the meetings just to listen. (…)
> Interviewer: What do you think led them to become more participative?
> Coordinator: I think they started getting more information about what [health and social care] institutions are meant to do and then they began to bring institutions back to the community to get a feedback. People started seeing them [institutions'

> representatives] there [meetings] and they thought: "No. I'm going to take this opportunity to ask what they have to offer us". That was very positive for the Cape Verdean community. The activities were very creative. And people came back. They had a lot of questions. They wanted to know more. They wanted to make plans. They wanted to participate more. (…) (Project coordinator at client organisation, NL)

One of the outcomes of these encounters was the creation of a therapeutic group at a mental health service in Rotterdam specifically designed for Cape Verdeans – the group Novos Caminhos (New Pathways). Novos Caminhos was a joint initiative by members of Project Apoio and an ethnic minority psychologist of that service with whom Apoio had previously formed a partnership for the delivery of psychoeducation in its public meetings. The partnership was not based on an institutional protocol but rather on the psychologist's goodwill and personal commitment to community intervention. With the application of principles of managed care (e.g. rationalisation, standardisation, and monitoring of diagnosis and treatment) (Ingleby, 2005) aimed at maximising the efficiency of the Dutch health care system, it has become increasingly difficult for health workers in the Netherlands to step out of their offices and reach out to the community. Daily minimum quotas for consultations and the writing of detailed monitoring reports crowd out their schedules, leaving little room for communal activities. Having mental health professionals take part in participatory initiatives and sensitising them to the specific problems of the Cape Verdean community were seen as valuable strategies to acquire allies to start tailoring care to suit Cape Verdeans' needs. In the case of Novos Caminhos this entailed the delivery of care in languages they were familiar with (i.e. Portuguese and Kriol) and the employment of an approach (group therapy) and terminology (using the term 'stress' instead of 'mental illness') which they perceived to be less intimidating than individual therapy and felt more comfortable with.

7.1.2.2 Pursuing social justice

As we have seen throughout this chapter, user groups in our study endure various forms of discrimination (e.g. in the family and social spheres, the labour market). The negative differential treatment they face, however, is not just associated with negative stereotypes about mental illness. Being members of ethnic minority groups and having a low-SES are characteristics which expose them to additional types of prejudice (racial, class) and place them in more than a disadvantaged group at the same time, rendering them vulnerable to multiple discrimination. The majority of users we interviewed in Brazil were poor and lived in segregated residential areas (i.e. slums) with elevated levels of economic hardship, high rates of violent crime, low quality schools, and few health care services or recreational facilities. Compared to minority Northeasterners, Cape Verdeans were much better off as regards the social determinants of health. By Dutch standards, however, many were in a situation of relative socio-economic deprivation (e.g. inability to purchase goods considered relevant to a fulfilling life such as entertainment), lived in *achterstandswijken* (segregated and socially problematic neighbourhoods with high rates of crime and poor housing), and sent their children to so-called 'black schools' (i.e. schools composed predominantly of migrant and ethnic minority pupils, usually offering a lower level of education when compared to 'white schools'). These circumstances constitute a form of institutional discrimination by which ethnic minority people with a low SES are concentrated in socially and economically poorer geographical areas where they have less access to societal goods and resources. That, in turn, reduces their life opportunities by placing them, and their offspring, on trajectories of low education, low job prospects and low incomes.

Socio-economic disadvantage has been found to have an important contribution to ethnic inequalities in health (Modood *et al.*, 1997; Nazroo, 1998). High rates of underemployment, poor housing and hygiene, exposure to criminal violence and reduced social networks are stressors which can combine to adversely affect health (Pearlin *et al.*, 2005; Oliemeulen and Thung, 2007). Studies in the UK and the Netherlands show that the prevalence of schizophrenia, for example, is higher among certain migrant and ethnic minority groups by comparison to ethnic majorities (Bhugra and Bhui, 2001; Fearon and Morgan, 2006; Veling *et al.*, 2006) and that when those groups have a low-SES and a high rate of perceived discrimination the risk of schizophrenia increases even more (Chakraborty and Mckenzie, 2002; Veling *et al.*, 2007a; 2007b). Social adversity over the life course and multiple discrimination related to ethnicity, low-SES and mental illness thus appear to compound each other's effects in producing health inequalities. If we consider these inequalities in health status to be unnecessary, avoidable, and unfair then we are in the presence of health inequities (Whitehead, 1992).

In the following quotation, Gladys (BR) describes various forms of discrimination and hardship endured by herself and fellow sufferers which are likely to have a negative impact on their health:

> Gladys: I participate [in the user movement] because the people who go mad they are at the mercy of discrimination. They are totally helpless. Nobody cares [about them]. They are looked down on. They are misunderstood in their homes, like I was. It's a total exclusion. (…) Things are very difficult for us. While other people get things easily, we need to carry a huge cross to get just a few things which are our rights.
> Interviewer: What rights do you mean?
> Gladys: (…) Having a place to live. The right to pension. Jobs for those who can work. Many people here at CAPS leave their curriculums [vitae] in many different places but they are never called back [for an interview]. (…) We need jobs, housing, and above all respect. (Gladys, BR)

Gladys speaks of not just restricted life opportunities (e.g. limited access to jobs and income) but also of a lack of rights (e.g. to adequate shelter and social security benefits) that undermine users' capabilities or 'positive freedom' to pursue valued goals in life (Sen, 1993), casting them into a socially unfair position. Indeed, limited freedoms and reduced life opportunities are two conditions which violate the core principles of social justice as defined by Rawls (1971), namely the principles of 'equal basic liberties' and 'fair equality of opportunity'.

Rawls' conception of 'justice as fairness' seeks to reconcile the values of liberty and equality by specifying terms of social cooperation aimed at limiting socio-economic inequalities and meeting the 'needs of equal and free citizens' in a way they consider fair (Daniels *et al.*, 2004: 65). Equal basic liberties include freedom of thought, movement and speech, political liberty (to vote and run for office) and freedom of assembly. These liberties must be protected by institutional safeguards which assure those rights to all citizens alike. Without such guarantee, citizens are unable to develop basic capabilities (*ibid.*) and to assert an active participation in the governance of their own affairs. The principle of equality of opportunity is concerned with people's holdings of 'primary goods' (resources such as liberty, self-respect, income, wealth, etc.) and with their fair distribution. Primary goods are essential to the development of the skills and talents required for people to choose life plans which they have reason to value (Anand, 2004). In other words, they afford people the capability to pursue a meaningful life. Rawls' concept of 'fair equality of opportunity' is also concerned with the promotion of fairness in citizens' access to public offices and positions on the basis of merit. However, opportunities to acquire the skills on the basis of which merit is assed are considered a priority. This principle thus proscribes discriminatory practices and requires measures capable of alleviating the negative effects of socio-economic inequalities on opportunity (Daniels *et al.*, 2004).

In an adaptation of Rawls' social justice theory to health care Daniels (1985) argues that health must be seen as a primary good. Anand (2004) claims that health is an essential good because "it directly affects a person's wellbeing and is a prerequisite to her functioning as an agent", i.e. to do and be what that person finds of value (*ibid.*: 16). Ill-health diminishes the array of life plans people can choose from (Daniels *et al.*, 2004). In this sense, inequalities in health are closely coupled to inequalities in citizens' basic liberties and opportunities (Anand, 2004). Where health inequalities arise from illnesses that could be prevented or treated but are not, due to inadequate social arrangements (e.g. poverty, stigma, limited access to health care) we may speak of a situation of inequity and injustice (Sen, 2004). If we understand 'fair equality of opportunity' in terms of possessing primary goods (which, among others, include health), then reducing health inequities is a requirement for social justice.

Improving the accessibility of health care is certainly one way in which inequities in health can be addressed. Strategies devised to increase the responsiveness of health services have particular relevance in relation to the groups we researched, not least because these groups experience discrimination in that sphere. Beijers (2004b) found evidence of institutional discrimination while investigating Cape Verdeans' use of mental health care in the Netherlands. In Brazil, people affected by psychosocial distress are often excluded from general health care by professionals themselves:

> They are afraid. Professionals are afraid of what users can do. I don't know if you heard about the case of Joana. She went with a professional from CAPS [to a health care centre] and when she arrived the doctor there did not want to consult her. She [doctor] said: "if she causes trouble who is going to take care of my patients?" And she didn't accept her. (Psychologist 4, BR)

As we saw earlier, making health care more accessible and inclusive was a core motivation for participation among participants in our study. However, improving the accessibility of health care is not sufficient in itself to achieve health equity (see Anand *et al.*, 2004). Reducing unjust health inequalities calls for an approach capable of uncovering the social, economic and political institutions and processes which produce them (e.g. poverty, residential segregation, limited access to education, underemployment, etc.) and setting forth intersectoral efforts centred on the making of policy and institutional arrangements for resource allocation that enhance the fair distribution of social determinants of health (Daniels *et al.*, 2004; Sen, 2004). In other words, promoting health equity entails the formulation of policy aimed at "equalising individual life opportunities" which include, but are not limited to, equal access to care (Daniels *et al.*, 2004: 87). Providing members of society with fair equality of opportunity to achieve good health requires thus that, in addition to health care, investments are made to distribute goods such as sanitation, adequate housing, security, education, sufficient income, etc. fairly through all citizens. This is a conviction espoused by advocates of psychiatric reform in Brazil and a goal which users believed could be achieved through participation. In contrast, health participatory spaces in the Netherlands tend to be more focused on the improvement of health care and less so on the allocation of social determinants of health. As we will see in Chapter 9, this narrower focus of the Dutch health participatory sphere may be working as a barrier to the involvement of MEM users who, like Cape Verdeans, may expect participation to deliver greater benefits than just a fairer distribution of health care services.

Many minority Northeasterners participated with the intention of bringing greater social justice to a group suffering significant socio-economic disadvantage and to which they belonged – the 'mentally ill'. They sought to do that in two ways: by claiming the enforcement of their rights and by making proposals for more inclusive policy. The latter was especially influenced by concerns with increasing the opportunities which enable users to pursue a meaningful and valued life. The promotion of work opportunities took the lead at this level. Increasing the access of people affected by psychosocial distress to the labour market entails, among other things, that interpersonal and institutional discriminatory barriers be broken down. This in turn implies profound changes on public beliefs and attitudes towards them. As seen earlier, this was something users sought to foster. Yet acknowledging how slow these processes typically are some advocated for more direct measures, namely affirmative action:

> We need to change the minds of employers out there so they can see us with other eyes, like people who can work. We're very marginalised. They think that if we have a psychotic episode we can't take up responsibility again. But that's not true. I think we need to get into the quota system. (Oscar, BR)

> I participate [in the user movement] because it's a struggle. It's a cause. With that [collective action] we got the Rio Card [Passe Livre]. We can go on the bus for free. With that we can get work, the right to work for those who suffer from psychosocial problems. Because… I never worked in my whole life. I never earned a minimum salary in my whole life. If I were to apply for a job would they give it to me knowing that I do psychiatric treatment? No. Now, if we go after laws… through the user movement… if we get a quota for people who suffer psychosocial distress, things will be different. There is a quota for people with physical disabilities. What about people with psychosocial problems? [Carlos] Minc [Rio de Janeiro state deputy by the Labour Party] wants to do it. (…) Those things are worth fighting for. If it's not for me, it will be for my colleagues. (Member of user association, BR)

One other way by which users in Brazil asserted their commitment toward the promotion of social justice and inclusion was by seeking to give substance to rights which were not always duly enforced. The Passe Livre affair is a case in point here. By law (Brasil, 1994), disabled people whose family income per capita is below one minimum salary[123] are entitled to Passe Livre (Free Pass), which grants the right to travel free-of-charge by bus. Yet for transportation companies Passe Livre means a loss in profit and many of them have lobbied to get the law revoked. It is also not uncommon for bus drivers to refuse pass holders free travel. In addition, authorities' assessment of what qualifies as disability follows rather strict criteria. Sometimes, this results in the denial of Passe livre to people whose life chances are clearly undermined by disability, but whose medical diagnosis is not considered serious enough. This was the case of Gladys who had been in treatment for chronic depression for almost ten years:

> One of the things I fought really hard for myself and others, and they got it and I didn't, was the Passe Livre. I didn't get it. They told me that Passe Livre is not for people with depression, that depression is not an illness. (…) I even went with my

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[123] The minimum salary in Brazil is about 450R (i.e. 165€).

> psychologist to see if she could help… I went to so many places to try to get it. (…) But they always tell me I don't have the right to it. (Gladys, BR)

Passe Livre is a valuable resource for users, especially for those living in poverty. It not only enables them to get to mental health services, it also affords them the opportunity to access societal and participatory spaces where they can liaise with others, acquire information and new competencies and find support to enforce their rights. Like Gladys, many users felt personally victimised when refused Passe Livre. However, when discussing it in the user movement meetings they became aware of the overall circumstances which work to limit its allocation as well as the fact that a great deal of users is affected by this. They also realised they could join efforts to demand greater fairness in its distribution. This process of 'conscientization' (Freire, 1970) resulted in a call for a hearing with the Ouvidor Público (local government ombudsman) where user representatives formalised a complaint regarding unjust rejections of Passe Livre and requested investigation of improper conduct by transportation companies. This was a critical manifestation of active citizenship.

Cape Verdean users were not yet so familiar with the idea of 'citizenship as practice' (Lister, 1997). This does not mean they had less of a commitment to pursue social justice than their user counterparts in Brazil. However, the actions devised on this front were still located at the stage which precedes user participation in invited spaces. In other words, Cape Verdeans' initiatives to promote social justice were not so much focused on lobbying for more equitable policy as on raising critical consciousness about the sources of their disadvantage (i.e. unequal life opportunities, discrimination and unenforced rights) and the mechanisms available to start changing them (i.e. autonomous and invited participatory spaces). With these purposes in mind, they organised a conference for the Cape Verdean community under the slogan "*Rechten krijg je niet. Rechten moet je halen*" (You do not [simply] get rights. You must [actively] get rights). This event aimed to inform Cape Verdeans of their rights and to instil the idea that just having those rights is not enough to tackle the causes of their socio-economic disadvantage and exclusion. To achieve inclusion, they need to become active agents in the decision-making networks which influence the design of policies and institutions that determine their access to life opportunities. This implies an understanding of what opportunities there are and how one can make use of them. These issues were the topic of many sessions of Grupo de Conversa. In addition to disseminating knowledge about the Dutch health care system, that peer group also sought to provide insight into the importance of employment, housing, social benefits and education in furthering members' life chances. Increased awareness of the social determinants of health (and inclusion, more broadly) was expected to assist participants in acquiring the resources necessary to have a voice on how these determinants are distributed. In the meantime, some Cape Verdean users offered support to disadvantaged members of their community in accessing essential goods:

> Interviewer: Why do you participate?
> José: I like to help people. When I see a person weakening, declining… if I can, I give a hand to that person. That's my way of being. I don't do it because I want to show off. That's how I am. I give emotional and financial help. I help that person finding a job. I can even help with doing things in the house. (José, NL)

The solidarity espoused by José was based on a strong sense of belonging to a community and the aspiration to contribute to its welfare. José's sense of connectedness to his compatriots led to, and strengthened, his involvement in Project Apoio. Indeed, from providing assistance to people at a more personal level, he went on to take part in a psycho-education course to learn to deal with people diagnosed with mental illness and, from there, he got involved on the organisation of events such as the conference mentioned above. Engagement in participatory activities brought him an increased sense of membership in the community, i.e. a sense of greater belonging, and provided him with a means to express values of social justice and solidarity. Seen from this perspective, participatory spaces become 'vessels' on which users can embark in the quest for a fairer distribution of opportunities and the enforcement of substantive rights. This is expected to lead not just to better health outcomes but also to a greater experience of inclusion in society.

7.2 Mobilisation: getting in and staying on board the 'participatory vessel'

Motivations for participation are related to what people expect to accomplish with their participation. They are, to a certain extent, expected benefits of participation. However, people are usually not entirely capable of grasping the potential benefits of their involvement when they first begin to participate. Right at the start, participation payoffs may seem too low and too distant, while costs can appear much too high (e.g. getting an 'insanity certificate'). This was the case with several of our respondents who, like José (cited above), started their involvement cautiously and step by step. This suggests that motivations *per se* may not suffice to get people involved. As we show next, mobilisation is essential to get users in and keep them on board the 'participatory vessel'. In other words, mobilisation is fundamental to both the commencement of participation and to assure its sustainability. This is even more so when prospective participants experience feelings of hopelessness and powerlessness. These feelings, however, may start to wane as a collective identity begins to form.

7.2.1 Direct and indirect recruitment

The majority of the involved users we interviewed were recruited into participatory spaces by two key participation instigators. In the Netherlands, the coordinator of Project Apoio had a crucial role in getting Cape Verdeans involved in the client organisation which hosted the project. Minority Northeasterners in Brazil were mobilised to take part in participatory spaces within and outside their service of reference by a former psychologist of CAPS Pedro Pellegrino who was also one of the leaderships of the user movement.

> I asked people directly… people I knew from Casa Tibérias or from the Cape Verdean associations… I asked them whether they wanted to participate in Apoio. And then we created Comissão. It was a good group of people, about thirty of them. There were many young people. They distributed the flyers [announcing public meetings and events]. They made programmes in the radio. They passed information by word of mouth to others. They actually broke the ice. (Project coordinator at client organisation, NL)

> Who are the users taking part in the user movement? How do we get them to know about it and take interest in participation? That depends of us – the professionals. Since I've always invested in that space of militancy, and I will militate for as long as I can, I always brought that enthusiasm with me to CAPS [Pedro Pellegrino] when I worked there. I told them [users] about how important it was to get involved. I told them CAPS is a fragile service and that if we don't keep fighting for it, we may loose it one day. I told them that the [out-patient psychosocial care] policy only became possible in a historical context of anti-asylum struggle and psychiatric reform. I insisted on those things a lot. (…) I, and many other members of the staff, always encouraged them to participate and we succeeded to mobilise them. CAPS Pedro Pellegrino, for example… because I was there and there were several other professionals who believe in the user movement, our CAPS was always the service with the greatest [user] representation [in the movement meetings]. (Psychologist 4, BR)

These quotations illustrate the importance of recruiting people directly, and of knowing how to motivate them, when seeking to promote their participation. They also hint on the importance of continuity in mobilisation efforts. Suck diligence is necessary because most users need time, and the opportunity, to become empowered. Empowerment is essential for users to recognise their ability to participate in the social and political arenas where the decisions that affect their lives are made. It is a vital process for them to seek inclusion and voice without the need for continual external instigation and prompting. As another leadership of the Brazilian user movement noted, professionals are in a privileged position to mediate that process:

> Professionals have the power to keep users going to [the movement] meetings and national gatherings. When they know (…) [Psychologist 4 and Psychiatrist 2] are

> going, they also go. We still don't have the capacity to make all users go by themselves. (Expert by experience 4/ researcher at health research centre, BR)[124]

Personal empowerment can be a slow process, particularly among people who were subjected to years of social isolation and discrimination. Within our research groups, however, there were some users who not only acquired the capacity to participate of their own accord but also became active recruiters themselves. Without exception, these were all users with a long-lasting experience of participation (i.e. five years or more).

> When I see someone who could benefit from the activities of Project Apoio I start making conversation. I tell them about Grupo de Conversa and what we do there. I tell them we go there to listen to what others have to say and see if we hear something that can help us find a solution to our own problems. I tell them they can also share their story and that maybe there's someone who knows about that kind of problem and who can help. I inform them about the Dutch courses, that they can get help to write [official] letters and to deal with the Dutch institutions. (…) But when I notice people thinking I want to intrude in their lives or that I know their secret [i.e. psychosocial distress], I stop. I pretend I forgot I said something about it [joining Apoio's participatory activities]. (…) You need to be really careful with whom you dare having those conversations because people misunderstand your intentions sometimes. (Madalena, NL)

Madalena heard of Project Apoio for the first time in the radio. She contacted the coordinator of the project and offered to help with finding musicians to play during Apoio's inauguration event. However, it was not until the coordinator invited her personally to take part in the project's activities that Madalena decided to actively participate. Like Madelena, many other users only got engaged after a personal invitation was made to them. These findings support the argument that direct recruitment is more effective than indirect mobilisation (e.g. through flyers, posters, radio broadcasts) in getting people involved (Simmons and Birchall, 2005).

Madalena's experience as a recruiter herself also uncovers a feature of user-led mobilisation which is not always given due consideration: directly mobilising people for participation can have costs for recruiters themselves (e.g. being misunderstood or misjudged in their intentions). This seems to be especially noticeable when participation is associated with issues (i.e. 'mental illness') that are deeply stigmatised within potential participants' closest social circles. In these cases, it may be advisable to train user recruiters to deal with the effects of those costs and, at the same time, to invest in indirect recruitment. The former has the benefit of re-assuring users in their participatory efforts while providing them with coping skills to handle problems originating from engagement or in life more broadly. The latter has the advantage of

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[124] Some elements of this quotation were removed to protect the identity of the participants.

reaching out in a non-intrusive way to people who may not yet be fully prepared to discuss psychosocial distress openly with others.

It is worth noting that, unlike Cape Verdeans in the Netherlands, users in Brazil did not attach any personal costs to their own mobilisation initiatives. This is explained by the fact that the people they attempted to recruit were, in their majority, already in contact with mental health care as either users or family members and had less stigmatising attitudes toward mental illness.

> Interviewer: How did you hear about the user movement?
> Jaderson: Oh, it was through Vinícius [CAPS user], a colleague of mine.
> Interviewer: Does he also participate in the movement?
> Jaderson: Yes, he participates. He is a militant.
> Interviewer: And what did he say about it?
> Jaderson: He explained to me the anti-asylum struggle and all those things.
> Interviewer: Did he ask you to join? Did he say something like: "Come! We need more militants"?
> Jaderson: Not quite. It's a matter of quality, isn't it? You can't just take any person there.
> Interviewer: Do you mean he thinks you have what it takes to give a positive contribute?
> Jaderson: Yes. (Jaderson, BR)
>
> I participate because I was elected an adequate person for that kind of struggle [the user movement anti-asylum struggle] here in CAPS. (Gladys, BR)

The strength of direct recruitment comes from making people feel valued and wanted. Being asked time after time to join a collective concerned with improving the social stand of a group one identifies with gives people a feeling of recognition and offers them an opportunity for affiliation and action. These opportunities are especially appealing to people suffering from socio-economic deprivation and social isolation. As evidenced by Jaderson and Gladys' quotations above, invitations to participate work as a 'vote of confidence' on their personal competences and on their capability to make a difference. Direct mobilisation for participation is also an open and deliberate attempt to recruit people into a group. As we saw, our respondents endure discrimination in virtually all domains of life. Participatory groups may well be one of the few social groups they are explicitly and continuously asked to join. As such, they provide an exceptional opportunity for developing meaningful social relationships and a sense of belonging.

7.2.2 Collective identity

As users go on participating they may come to develop a collective identity (Della Porta and Diani, 1999; Barnes *et al.*, 2006). In the case of people affected by psychosocial distress, that identity may form as a result of a common experience of psychosocial suffering and discrimination and the realisation that they can promote the wellbeing and inclusion of all those facing similar problems through participation. This was observed in the Brazilian case but not so much in the Dutch case. Cape Verdean users in the Netherlands had a strong identification with the Cape Verdean community already prior to their engagement in participatory spaces and, unlike minority Northeasterners, almost never referred to themselves as mental health care 'users', or employed its Dutch equivalent term *cliënten*. Their sense of collective was premised on ethnic identity rather than disability and that did not change as a result of participation. Again, this seems to find explanation on the interlocking effects of personal and public stigma associated with mental illness which compound to create a web of barriers to Cape Verdeans' acceptance of psychosocial problems and open recognition of mental health care use.

Ethnicity was not a binding factor among minority Northeastern users. Although most showed pride in their cultural heritage, their *nordestinidade* was very diluted and their ethnic origin only came up when asked directly about it. In contrast, their identity as mental health service users was very salient. Many referred to themselves, and their *companheiros* (fellows), as *usuários* and *portadores de transtorno mental* (which translates literally as 'bearers of mental disorder'). These designations were employed especially by users who, in addition to participating in their service assembly, were also active members of the user movement. Their involvement in that autonomous participatory space enabled them to gain access to new people and information, broadening their social networks as well as their vision of the world and of the factors at the root of their disadvantage. As they went on collaborating on actions aimed at promoting the citizenship and inclusion of people affected by psychosocial distress, they started themselves making proposals for action and gathering the resources necessary to set it in motion. This created a sense of common purpose which bonded participants together, giving rise to a strong emotional attachment between them and to the feeling they belong to a collective whose cause they support and which is there to support them in return.

> Expert by experience: Taking part in the user movement gave me the autonomy to have a voice, to defend my colleagues, to speak like I'm speaking to you, to give my opinions, to feel I should be treated well.
> Interview: Do you think other people also feel that way?
> Expert by experience: Yes, everyone in the user movement has a notion of citizenship. Every *usuário* who participates [in the movement] is aware of the need to fight for his/her rights and for the rights of his/her *companheiros*. (Expert by experience 3/ Mental health workshop coordinator, BR)

> Interviewer: Did the way you look at service provision change after you started participating in the user movement?

> Member of user association: Yes, it did. I become much more critical. Before, I couldn't tolerate it. I thought it [the way psychiatric patients were treated] was very violent but I had to shut my mouth. I didn't have anyone to resort to. Nowadays, that's not the case. You have a choir of hundreds of voices [behind you]. You are united in a chain… in which several voices manifest in unison in favour of your wellbeing, of your life. Taking control of your life is fundamental but that's something you are not always granted. (Member of user association 2, BR)

These quotes illustrate a sense of 'we-ness' (Snow, 2001) which is at the basis of collective identity development and that enhances users' willingness and ability to go on acting in the protection of their own interests and the interests of their group. As noted above, several minority Northeasterners shared a collective identity as *usuários* united in the struggle for adequate care, equal life chances and the exercise of full citizenship. There were others, however, for whom that identity appeared to be still in the making. These were mostly users who were not yet as involved in participatory spaces outside their service of reference. An interesting difference observed between these two groups was that the latter had significantly less insight over the reasons why user participation in their local service assembly began to wane at a certain point in time. The users sharing a collective identity, in contrast, explained the decrease in participation as a consequence of its main instigator leaving the service to work elsewhere and disappointment caused by thwarted expectations (see Chapter 9). They also encouraged the drop-outs to return to the assembly. This incident illustrates the importance of continuous mobilisation for the sustainability of participation as well as the positive role of collective identity in sustaining engagement in both invited and autonomous participatory spaces (Barnes *et al.*, 2006).

7.3 Resources: building capacity to act

Time, money, skills and confidence are fundamental resources for participation. The scarcer those resources are, the more evident their importance becomes.

7.3.1 Time

Time did not emerge as a salient theme in our study. The fact that most users were not employed may explain this: by comparison to people active in the labour market, they had the gift of time which might have led them to understate its importance. Indeed, one user at CAPS Pellegrino explained his inability to attend the Assembeia meetings due to a time conflict with his part-time job. Another instance verifying the significance of time for participation was the challenge faced by Project Apoio's Grupo de Conversa in attracting mothers of young children. Given the project's difficulties in providing childcare, many single-mothers were unable to participate in that peer group[125].

7.3.2 Money

Money was not much of an issue among Cape Verdean users. Most of those in need were entitled to social benefits provided by the state, which freed them from stern concerns with making ends meet. However, as noted earlier, there was a small group of Cape Verdeans who saw in participation an opportunity to advance their careers. For these users, receiving a symbolic reward for their volunteer work at Project Apoio was considered adequate. Yet this expectation was not always met.

> People doing volunteer work [at Project Apoio] are not paid but Basisberaad usually gives a *cadeaubon* [gift voucher]. It's funny to see that all people who worked with Project Apoio… I mean people from outside who sometimes give information sessions, like psychiatrists, psychologists, etc. …they all got a *cadeaubon*. (…) Some people [volunteers] got one but I never did. Things were spoken about: "when you finish this project…". In our first meeting [at Project Apoio] I was told I would get a *cadeaubon* but I didn't get it. (Cátia, NL)

In Brazil, the situation was considerably different. Many minority Northeasterners struggled to have their basic needs met. For some, this was a daily struggle. In spite of a dramatic increase on social provisions in the past decade, the Brazilian welfare system still leaves many of its citizens unprotected. Social rights exist but requirements to obtain social security benefits are so strict that many people in need fall through the public safety net. Participation has financial costs and (seemingly) simple things like buying a bus fare to attend the user movement meetings in Centro is an expense many users were unable to afford. Solidarity was often the answer. Professionals from CAPS Pedro Pellegrino, who also attended the user movement meetings, sometimes paid the fares of users to whom Passe Livre had been refused. Being able to exercise the right to free movement was one of the reasons why fighting for Passe Livre was such a strong motivation for participation and a key issue in the quest for greater social justice.

7.3.3 Confidence

Limited financial resources were not the sole difficulty minority Northeasterners had to overcome to take part in participatory spaces outside their mental health service. As noted earlier, Rio de Janeiro is an enormous city and some of its areas are difficult to navigate due to pervasive violence and poor infrastructure. Centro is one of those areas. At night, streets empty out and danger builds up. Fear of violence and minimal public transportation to some of Campo Grande's neighbourhoods (e.g. Barra de Guaratiba) deterred users from taking part on user movement meetings held at night. Yet several

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[125] In the majority of Cape Verdean single-parent families in the Netherlands, mothers take responsibility for the care of the children.

attended its monthly daytime meetings, which were created specifically to enable the participation of users living faraway. Going to Centro is nevertheless a challenging undertaking which requires a number of resources (e.g. money, assertiveness, determination, etc.) that were not within reach for some users whose autonomy had been reduced as a result of impairment, discrimination and/or long-term institutionalisation. Several of our respondents overcame these limitations by creating a group of 'fellow travellers' who supported each other, minimising the emotional costs (e.g. anxiety of getting lost, stress) of venturing into Centro and boosting participants' self-determination. This evidences the significance of social networks in connecting potential participants to opportunities for engagement (Passy, 2003). It also emphasises the importance of 'confidence' in facilitating participation.

Confidence is strictly linked to agency, i.e. the belief that one can act. Agency, in turn, is closely tied with the notion of 'citizenship as practice' (Lister, 1997). In this sense, confidence emerges as crucial resource for users to come into participatory spaces, develop a voice and effect change:

> Interviewer: Although [like you said] many [Cape Verdean] users have difficulties in engaging more actively, there are some who speak in the 'first person' [at Apoio's events]. What kind of leap did the latter make, which the former have not yet done?
> Project coordinator at client organisation: The leap they made is that of being capable of accepting oneself and having enough confidence to say: "I don't care about what others think. I know who I am". It's about being strong and conquering one's own place in the world. One needs to fight against exclusion but not everyone has enough strength to fight it. (Project coordinator at client organisation, NL)

The 'leap' Project Apoio's coordinator describes is concerned with participants' ability to attain power to control their feelings, thoughts and behaviour and to become subjects in their own lives. In other words, it entails a process of empowerment through which users regain self-esteem and a sense of self-efficacy that are crucial for building the confidence that they can act. This is a big step for people who have been devalued time and again and who may have internalised an unfit and hopeless 'self'. Liaising with others who already 'made the leap' can provide them with the hope and support necessary to believe that they can also become agents in their own lives.

The feeling that one is capable of making a difference is an essential condition for an active exercise of citizenship. In our study, it was clear that those users who were most empowered not only showed greater confidence in their ability to participate but also took part in a broader range of participatory spaces.

7.3.4 Skills

Once users come into the participatory sphere they need to have, and otherwise acquire, skills which enable them to exert influence over decision-making. Participatory spaces are 'spaces of power' (Cornwall, 2004b) where criticism and conflict often arise. Not infrequently, criticism is made not so much in regard to the quality of arguments but rather on the basis of participants' frailties, be that limited knowledge, poor communication skills or low socio-economic status. Cognitive and communication skills, as well as the capacity to listen, to be self-determined and assertive and to handle conflict, are all fundamental for the substantive inclusion of users in participatory spaces.

In general, users had limited skills and competences before commencing participation. As noted earlier, most of our respondents were either in a position of socio-economic deprivation (this was mostly the case with users in Brazil), or had lived part of their lives in that situation (this was mostly the case with Cape Verdeans before migrating to the Netherlands). These circumstances undermined their access to life opportunities (e.g. good education, employment, sufficient income) which can facilitate the acquisition of skills required for participation. As Vinícius (BR) explains, absence of skills is often a major impediment to participation:

> Interviewer: Do you see any difference between the users who participate in Assembleia and the users who don't participate?
> Vinícius: Usually, the users participating in Assembleia are those who have greater lucidity, understand things better and are able to express themselves. Usually, those who don't participate are people with difficulties in communication and understanding things. I don't really like to say this but, generally, I think that's the reality. (Vinícius, BR)

As we saw in the previous sub-section, devising policy aimed at improving users' life opportunities was an important incentive for participation. Involvement in policy-making, however, requires users to be aware of their rights and informed about the mechanisms through which they can take part in decision-making. Furthermore, it requires them to be skilled agents capable of negotiating change. Users with a greater consciousness about how to practice their citizenship were in a far better position to pursue that goal. Yet as less empowered users went on participating, they started acquiring the skills and confidence necessary to adopt an active role in the governance of their affairs: exposure to processes of consultation and deliberation enables users to acquire knowledge about subjects concerning their interests and to develop the skills necessary to pursue them.

Substantive participation, however, may require additional training and support. At the time of fieldwork, some members of the Brazilian user movement were developing a mutual-aid group specifically designed to provide a basis for mutual support and to enhance capacity building. The group was to be coordinated by and composed of mental health care users. Fostering users' abilities to deal with both the gains and costs of participation and enabling them to build capacity to act to the full extent of their aspirations were among its principal goals.

> People [participants I the user movement] are becoming more autonomous. They are starting to speak without fear. They see how other users do it and that helps them overcoming their own fears. This is very important. We are building relationships. People help each other. We even want to create a mutual-aid group. There are many issues which emerge with participation like feeling down because someone criticised you. Politics alone are not enough to deal with that. We need other mechanisms to help our *companheiros* deal with those things. (Expert by experience 4, BR)

7.4 Conclusion

This chapter examined the enablers of participation in mental health participatory spaces among two groups of migrant and ethnic minority users in the Netherlands and in Brazil. Its main purpose was to understand the why and how of involvement as experienced by Cape Verdean migrants in Rotterdam and minority Northeasterners in Rio de Janeiro. As our empirical findings demonstrate, there is a multiplicity of motives driving the participation of these two groups. Some are of a more personal nature while others have to do with collective concerns. **Individual motivations** include aspirations such as increasing social interaction, learning about psychosocial distress, being included in social spaces, finding paid work, getting a meaningful social role, overcoming the stigma attached to mental illness and increasing the use of mental health care. **Collective motivations** include the desire to increase the responsiveness of mental health care delivery and to achieve greater social justice for people affected by mental problems.

The motives for participation expressed by our research groups say a lot about the position of marginalisation they find themselves in. The need for social contact and access to community and public spaces (e.g. festivities, associations and the 'city') reveals the spatial segregation and social isolation many of them are subjected to. The aspiration to acquire socially valued roles, particularly through employment, indicates the economic hardship, financial dependence, disrespect and humiliation they go through on a daily basis as people deemed to be incapable of making a positive contribution to the public good. The desire to overcome taboos and stigmas concerning mental illness reflects the heavy burden of (self-)stigmatisation and the way it generates oppressive forms of subjectivity characterised by a sense of powerlessness and hopelessness, which undermining users' perceived candidacy for and access to mental health care and reinforcing their alienation and distance from mainstream society.

All these forms of discrimination are likely to put our user groups at greater risk for (mental) ill-health, creating a vicious spiral. Moreover, the fact that they belong to poor ethnic minorities living in socially and economically deprived geographical areas reduces their life opportunities and limits their access to the social determinants of health (i.e. safety, good education, sufficient incomes, adequate housing, health care, etc.). This makes them both more vulnerable to illnesses and less liable to obtain treatment for them. As argued by Anand (2004), inequalities in health are closely coupled with inequalities in citizens' basic rights and opportunities. Many of our participants expressed frustration with not being able to exercise their rights of citizenship (e.g. acquiring social security benefits) or to pursue valued goals in life (e.g. participating in economic and socially valued activities). This sense of social unfairness and exclusion made them feel frustrated and angry. Enhancing social justice and promoting the full exercise of citizenship by themselves, as well as by others in a similar position of disadvantage became important motivations for involvement.

Both Cape Verdean and minority Northeastern users showed commitment to the promoting the welfare of the communities they belong to. This concern with the collective was especially salient among users with a long-standing practice of participation (i.e. five years or more). Early stage participants, in contrast, put more emphasis on the individual benefits of participation. This is in line with Mutual Incentives Theory (MIT), which asserts that collective motivations for engagement strengthen as people go on participating (Simmons and Birchall, 2005; see also Passy and Giuni, 2000) and realise that their actions can lead to change and contribute to the wellbeing of their communities (Sozomenou *et al.*, 2000).

This is not to say, however, that individual incentives are secondary to collective incentives in determining participation, as Simmons and Birchall (2005) suggest. In our study, individual incentives emerged as relevant motivations for involvement and the appeal of participatory initiatives depended on their ability to offer both individual and collective benefits. This incongruence with MIT theory appears to be explained by two main factors. First, there is an element of social desirability in collective incentives which may lead people to under-report their individual motivations[126]. As we showed, this was evident among a few Cape Verdean users who seem to have regarded their ambition to find a job as a less legitimate goal of participation and were therefore not very keen to report it. Second, many of the participants in our study were in a position of considerable socio-economic vulnerability and had to struggle to get their basic needs met. Their priorities were thus strongly geared to the satisfaction of personal concerns. This makes the importance for them of individual incentives for participation, such as benefiting from social contact (more evident among Cape Verdeans) and securing enough income to live in community (more evident among minority Northeasterners), very understandable. Better-off and less marginalised groups are less likely to be affected by these concerns and more likely to report collective motivations for involvement.

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[126] Simmons and Birchall (2005: 271) consider the possibility that some people may be "more comfortable, or at ease with themselves, with the discourse of collective incentives" but they discard that explanation arguing that "collectivistic incentives remain the most powerful stated motivations of service user participation".

Taken together, the range of motivations encouraging participation among our user groups reflect a strong aspiration for social inclusion. They evidence a pressing need by users to gain access to and engage in meaningful social relationships, civil activities, education, work, recreation, basic services (including health and social care) and community life. Such aspirations go way beyond the goals and actions typically carried out within (mental) health invited spaces which tend to be narrowed down to issues related to health care governance and provision. This is something that both the Dutch and the Brazilian mental health user movements recognise as insufficient goals for participation among people who have been traditionally devalued and excluded.

As we saw in Chapter 1, these movements strive for the improvement and democratisation of mental health care but they also put considerable emphasis on actions aimed at promoting the rights and integration of mental health care users in society. The success of the participatory initiatives promoted by Project Apoio and CAPS Pedro Pellegrino in enabling the involvement of two of the least represented groups in the Dutch and Brazilian participatory spheres (i.e. poor and ethnic minority mental care users) appears to lie in the adoption of this encompassing approach to participation. As discussed in Chapter 3, both Assembleia at CAPS Pedro Pellegrino and Grupo de Conversa and Comissão at Project Apoio are examples of hybrid participatory spaces, that is, they are spaces sponsored by public authorities which keep a direct connection to the local user movements. As such, they seek to respond to needs and demands coming 'from above' (i.e. state agencies) as well as 'from below' (i.e. grassroots users). In other words, while they realise the importance of promoting the involvement of users in decision-making processes on mental health care policy and delivery, they also recognise that user participation among marginalised groups cannot be limited to that, nor is it likely to be sustained without thorough investment in the active mobilisation and resourcing of these groups. The capacity of Project Apoio and CAPS Pedro Pellegrino to attract so-called 'hard-to-reach' users into their participatory initiatives thus results from concerted efforts on three fronts:

1. recruiting users directly to get involved and repeatedly inviting them to join participatory spaces;
2. embracing and responding to most of the individual and collective motivations they have; and,
3. equipping them with the skills and confidence necessary to exert influence within participatory spaces and to devise actions (e.g. manifestations, public information meetings and debates, cultural activities) aimed at exposing and criticising the social, economic and environmental barriers which impede their social inclusion.

Finally, it is worth noting that even though our research groups live in countries with very different social, political, economic and historical contexts – that is, the

Netherlands in the wealthy North and Brazil in the developing South – their motivations for participation do not differ much because they are in the same position of social disadvantage. In other words, they share similar concerns which can probably be addressed by similar responses. As Cornwall notes (2008a), there is much the North can learn from the South, and vice-versa. On the basis of our study, client organisations in the North could pay attention to the way in which promoters of participation in Brazil foster a sense of citizenship among disadvantaged users to further their engagement in policy decision-making within health invited spaces (e.g. health councils and conferences). Conversely, those in the South could learn from Dutch successes in creating 'safe heavens' allowing stigmatised users to initiate a dialogue about mental illness and start tackling the negative effects of stigma on taking part in community life.

8. Advancing participation: benefits

In this chapter we report on the benefits of participation for users. As we saw in Chapter 4, benefits represent the gains people expect to obtain from participation. As we will argue, benefits enhance people's aspirations and desire to participate by offering a reward for their efforts and the confirmation that they can effect change and transformation, both at a personal level and in the social arena. Furthermore, the benefits attached to participation can offset its costs, thus encouraging people to remain involved. Finally, users' capacity to engage in higher levels of participation can be enhanced by the skills and competencies they acquire through involvement.

It is worth noting already at this point that these effects are only observed when users express collective motivations for participation and the benefits obtained match those collective goals. If users' participation is only driven by individual motivations, then realising those individual goals, or not being able to achieve them, can determine the end of participation. In other words, individual motivations are important to initiate participation but they are not sufficient to sustain engagement. Collective motivations and benefits, in contrast, are crucial to assure the continuation of participation.

As we show next, there are specific benefits attached to participation in mental health participatory spaces. From our data it emerged that involvement in those spaces produced five distinct and yet related benefits for users: 1) broader social networks, 2) empowerment, 3) increased sense of agency and citizenship, 4) enhanced health literacy, and 5) improved access to mental health care. In the remaining of this section, we discuss each of these benefits in greater detail.

8.1 The positive impacts of involvement

8.1.1 Broader social networks

In the present study, participation enabled users to come together with other people and to diversify and broaden their social networks. As noted by Madalena (NL) and Gladys (BR), this was an aspect of participation which they found very beneficial, not least for their recovery:

> Something I really benefited from [by going to user movement meetings] was to make a lot of friends. Some of them have more serious problems than I do but that really helped me feeling better, from depression I mean. It really helped a lot. (Gladys, BR)

> When I started going there [Grupo de Conversa, Project Apoio] I didn't know anyone personally, although I had seen some of them in the street. I feel good going

> there [meetings] because I live alone and that's also a bit worrying. I don't have anyone to confide in. (…) When I go there I feel relieved. There are many people who could use that support. (Madalena, NL)

Users' experiences with participatory initiatives matched their expectations of enhanced social contact: liaising with others was an important individual motivation for several users who lived in isolation on account of illness and stigmatisation (see section 7.1). Broader social ties and greater social embeddedness also facilitated users' access to information about health care, social benefits and alternative treatments and even allowed some of them to find new jobs. The latter, however, happened in only a few instances.

> I got in touch with a lot of new people [through the user movement] and that enabled me to know more about what's being done to help people with mental problems, like what kind of new treatments can help us get better more rapidly; which medications are more efficient; what we are entitled to from social security. There's an infinity of things [to be learned] from that movement. (Gladys, BR)

> Because I participated [in Project Apoio], I think that if I had a problem today… if I was stressed or didn't sleep properly, I know I could ask for a longer appointment [with the general practitioner] to talk about it. I know I can request an interpreter. That type of things… it's good to have learned that. (Aurora, NL)

> Interviewer: Did your participation in the user movement benefit you personally?
> Miguel: Yes. I did a course for carers and I learned a lot from it.
> Interviewer: Where did you take the course?
> Miguel: At FioCruz [Public Health School]. I learned a lot about how to take care of an elderly person with psychiatric problems. I started looking at the world with new eyes. My way of looking at the world changed. (…)
> Interviewer: Are you taking care of someone now?
> Miguel: I used to take care of Maria[127] [user of CAPS Pedro Pellegrino]. I did it for eight months but then her brother came back I don't know where from and he said that wasn't necessary anymore and that he wanted to take care of her. That was a way of having a little job. It was something I never thought of doing.
> Interviewer: Did you like that job?
> Miguel: Oh yes! I liked it. (Miguel, BR)

Although Miguel (BR) did not quit participating when he lost his job – largely because he enjoyed the social relationships he built through participation – other users did withdraw when their expectations were thwarted. This was the case with Cátia (NL), who developed a project to create a mental health information desk for Portuguese-

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[127] This name is a pseudonym.

speaking minorities while she was involved in Project Apoio. When she heard that the possibility of implementing the project no longer existed she terminated her involvement. Her disappointment at not being able to realise a project she had put much effort into, combined with the fact she had no strong collective motives for participation, led to her self-exclusion from Apoio's participatory initiatives. We return to the discussion of the role of individual motivations in sustaining or curtailing participation further ahead in this chapter when referring to the benefit of health literacy.

Our results also show that, as time went by, weak ties (Granovetter, 1973) that were formed through engagement in participatory spaces developed into strong ties of friendship, enabling users to benefit from social support in situations of need. In some cases, those social ties gained special significance: several respondents in our Brazilian user and stakeholder clusters met their partners and spouses through the user movement. As a Brazilian researcher with experience of psychosocial problems explained, the social and personal relationships that arise within this context are both rewarding and challenging:

> My wife has psychiatric problems. Sometimes she's admitted to the hospital and I need to take care of her but I can't always do it because I have to work. I'm going through a lot of pressure in this first semester of my Master studies because of my wife's admissions. (…) Sometimes my marriage gets in crisis. (…) I started family therapy with my wife and we're dealing with it. But there's another thing: my friends demand a lot of my attention. One calls asking me to visit. Júlio[128] [member of user movement] always calls saying he has something urgent to discuss. So, I feel I need to step back a little bit and take more care of myself and of my wife. We're managing. Sometimes I 'fall down'. The good thing is that I made a lot of friends at the Anti-asylum movement [MNLA] and people in the spaces where I participate know I had psychiatric problems. There are people to disturb, but there're also a lot of people to help. (Expert by experience 4/ researcher at health research centre, BR)

Wider social networks not only enabled users to enjoy a sense of belonging, but also furthered their awareness of often overlooked problems (e.g. avoidable and unfair inequalities experienced by mental patients) and the mechanisms available to tackle them (e.g. the Ombudsman, municipal health councils and client councils). Moreover, social networks provided the context for users to gain a greater awareness of their rights and to absorb values (Passy, 2003) such as social justice and equality. As discussed in section 7.1.2, promoting social justice was a core goal of many users and something they learned they could aspire to through activism. Although our analysis here focuses on the effects of participation on users, it is interesting to describe the case of a psychiatrist who became one of the most active leaders of the user movement in Rio de

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[128] This name is also a pseudonym.

Janeiro. Her story of activism dates back to her childhood and extends to her whole family, which continues to struggle for greater justice in Brazilian society. Over the years, she inspired and supported many users in joining the movement and its cause of promoting full citizenship of all people alike.

> I started out in a Catholic movement. (…) That movement was organised like this: it started with primary school children. They had the so-called Benjamin meetings, named after a Biblical family whose youngest son was called Benjamin. I started attending the meetings when I was seven years old. Then, if you went to high school you became JEC – Catholic Student Youth; after, in the university you became JUC – Catholic University Youth. If you're a labourer, you belonged to JOC – Catholic Labourers Youth; and if you're an entrepreneur you belonged to JIC – Catholic Independent Youth. (…) My mother engaged in that movement when she was 15 years of age. Today she's 79 years old and she's still part of it. My town has always been marked by that movement. Then, in 1968, the revolution came and the movement ended. Many Dominicans were arrested and tortured. The movement fought for justice. With the dictatorship, people who belonged to that movement went into another one – the Ação Popular [Popular Action]. [They went] into armed fighting, underground, and many were arrested because, back then, fighting for social justice was associated with Marxism.
>
> (…) So I grew up in a social movement. We were six brothers and sisters. One of my sisters worked 15 years with farmers who were fighting for land. Today, she works with paper collectors and homeless people and she teaches Philosophy and Sociology at the university. I have another sister who is a speech therapist and she's engaged in defending bilingualism as a means of integrating deaf people in society. There's another one who's part of the feminist movement and teaches at the national school of public health. Another brother of mine is an engineer and struggles for fair bus prices through negotiation with entrepreneurs, the local population and the unions. The whole family… my mother belonged to five [social] movements. Now she's 79 years old and she's a bit sad because she has to reduce but they founded a group of Human Rights. (…) I've been in the Mental Health Workers Movement [MTSM] since 1978, 1979. Then the Anti-asylum Movement started and I joined. My main motivation [to join the] social movement was to end dictatorship, to get social justice. By chance, I'm a psychiatrist so I work in the field of mental health. My family has the same values. They engage in different struggles but the basis is the same. (Psychiatrist 2, BR)

As we saw in section 7.2, participation facilitated the development of a collective identity among users in Brazil. Being part of a community committed to the promotion of values and goals they identified with made participants feel they can act to bring about the change necessary to improve their life chances, as well as those of others like them. It also enabled them to find assistance to bear the financial costs of participation, as well as the emotional support required to deal with the stress which sometimes arises from fear of stigmatisation, the need to travel within a violent city, or as a result of conflicts emerging within participatory spaces (see sections 7.1.1 and 7.3). By reducing the costs associated with participation, social networks facilitate participants' decisions to join new participatory initiatives and make them more likely to stay engaged over longer periods of time.

8.1.2 Empowerment

For people with a positive self-image and socially valued roles becoming empowered might mean to acquire some new competencies and finally acquire confidence that they can become masters of their lives by intervening in their social and political worlds to improve their wellbeing and the wellbeing of others. For people who have been historically devalued and excluded and whose voices have been silenced, empowerment starts from a much more disadvantaged position, sometimes entailing the very realisation that one can speak.

> Interviewer: Did you observe changes in users resulting from their participation in the [user] movement?
> Psychologist: Yes. Marco André[129] is one [of them]. He has always participated in the movement meetings but he is big and he was always head down. He spoke very little and looked down. And when he spoke, he spoke so softly you almost couldn't hear him. He also didn't take on any tasks. But as time goes by, we get to know each other and to discover and develop other people's potential. We work a lot toward that within the movement, that is, the idea that everyone is important. We're all different and those differences are important. The movement exists because of that difference. Over the years we discovered that Marco André enjoys doing the minutes of the meeting and that he does them well, whilst everyone else finds it really boring. (…) Nowadays, he's the one doing the minutes. (…) Nowadays, he gives classes. He is invited to give lectures. He looks people in the eyes. When we ask him to talk louder he does it so you can understand him. He writes. He learned that exposing himself could lead others to value him, instead of disrespecting or neglecting him. (Psychologist 4, BR)

One of the benefits of participatory initiatives is that, when well managed, they allow users to grow into new social roles, without expectations of or pressure for abrupt transitions. Few spaces (with the exception perhaps of therapeutic settings) provide the conditions (i.e. opportunity, time and support) to nurture the self into a state of confidence high enough to enable voice. Several of our participants reported the joy of seeing their self-esteem increased through participation and how that fostered their ability to bring their engagement a step further, either by recruiting other participants or by getting involved in a wider range of initiatives.

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[129] This name is a pseudonym.

> I learned that society sometimes despises us but you cannot surrender to that. You have to look ahead and walk with your head up to God, the people and the world. You have to follow through. You have to follow your way with your head up and without creating tumults. (Samuel, BR)

> It [participation] has been very good for me. It encourages me to do more things. It gives me pleasure in doing things. We learn a lot. We can even learn how to help other people and how to encourage other people to participate, like I often do. (Isabel, NL)

> I cooperate whenever I can. I know that participating helps me to progress in my treatment. There are others [users] who can also participate, who can also organise things. I help whenever I can. I give ideas. I take on tasks. I call other people to participate. That's good for me and for others to notice that they can also do it. Many haven't realised that yet. (Benedita, BR)

For many users, higher self-esteem was directly linked to feeling valued and finding a meaningful social role in society – an aspiration many hoped to see realised through participation.

> It [participation] gives me the opportunity to contribute to [the wellbeing of] my community and to do something which is useful for those who don't know much yet about mental illness and about what they can do to get better. (Simone, NL)

> I came to see myself as a more involved person. I find myself more important. I feel more useful. What we do in the [user] movement is not getting things for ourselves but getting things for the whole group, for society, for the excluded in general. For me that's important. (…) It makes me feel more valued. (Vinícius, BR)

Social valorisation enabled users to free themselves from the position of passivity many had found themselves in either due to feelings of subjection caused by illness or (self-) stigmatisation or as a result of ascribed identities which work to reinforce feelings of powerlessness by portraying people as incapable, unproductive and dependent.

> Interviewer: What are the impacts of participation in the user movement on users themselves?
> Coordinator research centre: You create power with participation, which is limited of course. A Senator will also say that he cannot change the country on his own. That doesn't depend only on him. But you see protagonism. You see someone being elected for a certain function. By becoming representatives of users in the municipal, state, and national [health] councils people find an effective channel for participation. A good part of the policies implemented by the Brazilian government are based on proposals born within the [user] movement and taken for discussion in the municipal, state, and national councils, until they become part of legislation.

> That changes people's position. They feel like participatory citizens who have rights and who contribute. (…) Making claims moves users away from the position of patients asking cheaper medicines and subsidies into people who discuss policy, politics, and the position of the madman in society as someone different. So we see a very important change which is the user moving away from the position of object of [therapeutic] intervention to become a social actor who participates in meetings, assemblies, etc. (Coordinator of health research centre, BR)

It is only when users perceive themselves as capable of acting toward social transformation that they come to fully realise the sources of their disadvantage. This is often a long-term process with many 'ups and downs', requiring support to deal with the anger and frustration that can arise as a result of perceiving oneself unjustly excluded or too fragile to immediately take action and challenge the *status quo*. This is where the social networks described in the previous section take on fundamental importance. It is also where the notion at the core of empowerment – power – comes in.

Even if users were not always capable of taking power to effect change, many developed a new understanding of power as something which all citizens can wield, instead of an 'asset' belonging exclusively to traditionally powerful agents. From the moment users accept themselves as people who are rightfully entitled to be included in society, the ideologies and social structures which contribute to their undervaluation, rejection and exclusion lose their legitimacy. This may boost their confidence to question the power of those upholding such social arrangements.

> Interviewer: How do you feel about being a militant of the user movement?
> Oscar: It's very gratifying. I feel good as a person, as a *portador de doença mental* [bearer of mental illness], as a user. It's a really a beneficial thing to know that we have a voice, that we are looked at with other eyes there [user movement], that people there respect you. And it makes a difference when you come home or when you are in your neighbourhood. It changes things… our families and neighbours had no idea of how much strength we have. (Oscar, BR)

Participatory initiatives enabled users to come together with others sharing similar problems and interests. This facilitated two important processes. On the one hand, users realised they were not the only target of neglect and exclusion (e.g. denial of Passe Livre). This allowed for setting aside feelings of personal victimisation and to find support to rebuild their self-image as citizens with rights who are capable of claiming them. On the other hand, users gained increased awareness of the macro factors (e.g. health and social policy, ideology of care delivery, social perceptions and reactions to madness, corporate interests[130]) sustaining their disadvantage. This enabled them to

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[130] Here we refer specifically to the interests of transportation companies which, as we saw in Chapter 7, denied the use of Passe Livre to mental health care users, and to the interests of the pharmaceutical

reorient some of their actions toward key actors (e.g. the local Ombudsman in Rio de Janeiro who could enforce the application of legislation regarding the concession of Passe Livre, or health care providers in Rotterdam who could develop tailor-made mental services; see section 7.1.2). Both these processes were favourable to the development of the critical consciousness which is essential for empowerment and substantive participation.

Working together toward the achievement of common goals also fostered a sense of togetherness (Higgins, 1999), i.e. a sense of being part of a collective which can act to improve users' life chances. As noted earlier, this sentiment was strong enough to forge a collective identity centred on the status of 'user' among minority Northeasterners in Brazil. Cape Verdeans in the Netherlands also expressed a sense of community, but this was focused on their ethnicity rather than their experience as users of mental health services (see Chapter 7). In both cases, however, the sense of togetherness not only gave users a place in the world but also made them more alert to the needs of others and conscious of how they could contribute to help satisfy them.

> I think that here in the Netherlands there're a lot of Cape Verdeans with psychological problems who live on the streets instead of getting care. There're many people who have those problems and nobody knew about it. People used to say: "She is crazy" or "he is insolent". But that's not the case. The person is neither insolent nor crazy. The person has a problem. The person is ill and needs help but doesn't know where to find that help. She doesn't know which door to knock on, where to start. There are many Cape Verdeans here who need help with that. And we need to help [them] instead of saying they are crazy. (José, NL)

As hinted by José, the stigma attached to mental illness was one of many barriers users had to overcome in order to be open about their problems and join participatory initiatives. Once people 'make the leap' into the participatory sphere, the more they participate the greater the chance that they will become more empowered. Indeed, our study confirms the idea that participation and empowerment work in an 'upward spiral' (Honey, 1999) of mutual reinforcement. This is implicit in the remark of a Dutch expert by experience who started participating in the early 1980s in the client council of the psychiatric hospital where she was hospitalised, and has since been active in the promotion of good quality mental health care from a user perspective.

> It [participation in the client council] was very therapeutic. I think I wouldn't have survived if I hadn't done it because then you're just overwhelmed by your own depression or whatever you've got. It was very therapeutic and also empowering. It was not just about relativising your own problems, which is good for everybody, but it is also empowering. On the one hand, I was a patient in a closed [psychiatric]

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companies which support interest groups seeking to terminate psychiatric reform. Both these cases refer to the Brazilian study.

> ward but, on the other hand, I was sitting at the table with the director [of the hospital] and negotiating with him. It was very schizophrenic in a way but very satisfying as well [laughs]. (Expert by experience 1/ researcher at health research institute, NL)

8.1.3 Increased sense of citizenship and agency

The belief that one can make a difference is closely tied with how empowered people are and how much access they have to resources and competencies. As we saw in Chapter 7, many users in our study experienced various forms of deprivation including lack of material, social and mobilisation resources. Their competencies had also been considerably reduced the account of illness and social isolation. Insufficient resources and skills not only limit the array of life plans available to users, they also make it difficult for them to take action to broaden their life opportunities and enforce (or increase) their rights. In other words, it limits their ability to pursue social justice.

Participatory initiatives had a positive impact at this level. By bringing users together with more resourceful citizens (e.g. health professionals and public officials), they allowed the development of relationships of solidarity between those two parties and fostered mutual cooperation in the promotion of the common good.

> Now people listen to them [users]. They can sit next to a doctor or a psychologist. That wasn't the case in the past. Before they couldn't do that. Nobody gave credit to what they said. But now they can work together with doctors and psychologists to make things better. That increases their [users] autonomy. They lose the fear they once had of standing up for what they need. Taking part in the [user] movement enables them to become more open. (Member of family association 2/ social worker, BR)

Participatory spaces also allowed users to acquire more information, develop communicative skills through debate, and find a place to express their opinions and ideas. In the long run, this produced a beneficial effect on their ability to act and to stand up for their rights.

> It [participation in Assembleia] gave me more confidence because I saw I could do something instead of just listening [to others during the meetings]. (…) I used to be very closed because of my problems. I didn't talk much. Now I talk. But before I was quiet. I wasn't sure about what I could and couldn't say and how far I could go. Now I'm looser. I know that I can ask things, that I can talk, and that I can tell them [professionals] that I have this and that right, or that I need help. I didn't know that before. (…) If I changed, others can change as well. Everything helps: the contact with people, the groups, participation in the assembly. (…) It took me ten years to get where I'm today but it's worth it. We change and evolve. (Benedita, BR)

Getting a point across or making a proposal and then see it discussed as an idea for a new project, or as part of new policy, can be extremely gratifying. It can also incite participants to pursue higher levels of engagement. Here, it is worthwhile revisiting the cases of Vinícius (BR) and José (NL) discussed in the previous chapter. After many years of involvement and several positive reactions to their contributions, both these participants seemed to have acquired the confidence that they too could influence decisions. Vinícius (BR) got as far as participating in the municipal health council and demanding accountability from the Secretary of Health for the lack of good quality care facilities. José (NL) broadened his original goal of helping individual members of his community to participate in the planning of events aimed at improving the accessibility of mental health care for Cape Verdeans (see section 7.1.2). Both these instances reflect a broader notion of citizenship as practice (Lister, 1997), which moves beyond the mere holding of rights and responsibilities to include an active role in shaping one's social and political arenas.

> [Through participation in the user movement] they start seeing themselves as citizens. They become interested in broader issues and they start taking more responsibility in making proposals for policy, for example. (...) They feel more valued, more useful. It [participation] gives them a sense of life, a sense of belonging. All this reinforces participation. (Psychiatrist 2, BR)

It is relevant to note that not all interviewed users expressed a sense of increased citizenship and agency. In our study, the idea of being an active citizen was especially present among users who had had the opportunity to acquire competencies, take part in empowering activities, and build up a sense of self-efficacy. These were mostly users with more than five years' experience of participation. Furthermore, shifts toward a position of active citizenship were mostly reported by involved professionals and former users. This shows that not all benefits of participation are self-evident to users and it emphasises the importance of including stakeholders other than users in studies concerned with the impacts of participation.

> You see that at the monthly meetings of the user movement people [users] leave the place of passive patients to become active citizens. They go out front [in the room] and expose the situation of their services. That's a sign of change which repeats itself in their services. So they leave the position of complaining to start fighting for their rights. In the CAPS where my wife gets treatment, there are forty users who are coming out of passiveness to position themselves as people capable of claiming their rights. (Expert by experience 4/ research at health research centre, BR).

A final consideration concerns the fact that, compared with minority Northeasterners, Cape Verdean users were not as familiar with the language of citizenship and hardly ever employed the term 'citizen'. They were at an earlier stage of the process of 'conscientization' (Freire, 1970) required for citizens to adopt an active role in the governance of their affairs. Such a role presupposes knowledge about the ways in which they can occupy decision-making spaces. This became particular evident when we asked them about health invited spaces (e.g. client councils and advisory meetings and conferences): only two users were aware of the existence of such spaces and none of them had taken part in one. Although their knowledge of rights and entitlements relating to health care had increased considerably through their engagement in Project Apoio, it was necessary to continue encouraging a greater sense of agency within the Dutch participatory sphere.

We may conclude that participatory initiatives can work as 'schools of citizenship' (Cornwall, 2007). Yet to maximise their potential to do so, it is necessary to identify the resources and competencies available to users and to devise actions capable of raising awareness not just about rights and responsibilities, but also about the mechanisms through which citizens can practice their citizenship.

8.1.4 Enhanced health literacy

Health literacy is an example of a set of competencies (i.e. literacy, cognitive and social skills) which can both foster participation and be enhanced by it. Our data shows that participation had a positive effect on the first two levels of health literacy: functional health literacy (i.e. the ability to discern between good and bad health information) and interactive health literacy (i.e. the capacity and determination necessary to negotiate the care best suited to one's needs). The effect of involvement on critical health literacy (i.e. the capacity to engage in community actions aimed at promoting health environments and behaviours) appeared to be smaller. Enhanced health literacy increased users' capacity and willingness to continue engaged. However, as we will see later, this was only the case when users had collective incentives among their motivations for participation. Those participants who lacked such motivations, who engaged solely on the basis of individual incentives, opted to interrupt participation either after attaining greater health literacy or as result of not being able to fulfil this expectation. We return to this point again below.

The positive impact of participation on functional health literacy was especially observable in the Netherlands, where Cape Verdean users had very basic knowledge about mental illness when they first got engaged in Project Apoio's initiatives. As we saw in Chapter 2, a strong consumerist approach to user participation has led the Dutch government to make a considerable investment in the production and dissemination of information about the quality of health care services, as well as in the creation of instruments to measure users' needs and preferences (e.g. the Consumer Quality Index). Nowadays, there is a plethora of Internet sites delivering information about illnesses, service providers' performance rates, and insurance prices and coverage. The idea behind this is that by making informed choices and 'voting with their feet' when necessary, users will stimulate the improvement (or even elimination) of poor quality services. Yet this conception of user participation assumes that all users are capable of accessing the information available and of employing it to their best advantage. In practice, however, the ability to interpret complex arrays of health care data is not within the reach of all users. Moreover, not everyone has the resources and competencies necessary to get hold of health information. Several of our Cape Verdean participants were unable to use the Internet and, among those who were, many lacked the cognitive skills to understand and apply the information provided. Digital exclusion was at the basis of their limited knowledge about mental illness – a problem further reinforced by the heavy stigma attached to mental illness, which discouraged the spread of mental health information by word of mouth. For these users, participatory initiatives had a key role in enabling them to obtain, and process, information about mental health care services. Furthermore, by learning about psychosocial problems they were able not only to set aside their own prejudices about mental illness but also started working out ways to make that kind of information more accessible to other potential users.

> Interviewer: If someone came to you and said (s)he was not feeling too well, that (s)he was having difficulties sleeping, feeling sad and didn't feel like speaking to other people or getting up in the morning, what advice would you give that person?
> David: I would try to comfort and cheer the person up. I would advise her to visit a psychologist or a psychiatrist. When you speak of psychiatrists people don't want to hear about it. But if you say psychologist [instead] they accept it more quickly. People think psychiatrists only treat crazy people. If you mention a psychiatrist they think that you're saying they are not normal or that they have a mental disorder. Nobody wants to accept that. (…) I think they both can help but I would advise a psychologist, that is if that person was still mentally balanced. I would also try to cheer her up, to encourage her. That would be a case of depression, right? Yes, I would advice the person to speak to a psychologist. (David, NL)

The ability to distinguish between distinct types of health information and to assert one's needs for care is crucial for the promotion of more symmetrical relationships between users and providers – a goal common to the Dutch and Brazilian user movements which has been increasingly realised in practice. Engaging in shared health care decision-making entails not just the capacity to acquire information but also social skills (e.g. articulation of care requests in a clear way, assertiveness while negotiating the care to be received) which presuppose a certain degree of empowerment on the part of users. As we have seen earlier, participation furthers the empowerment of users as well as their interactive health literacy.

> Interviewer: What benefits did participation bring you personally?
> Robson: I got to know my rights. I know that I have the right to come and go whenever I want. I know I can question things if I think they are wrong. I can also ask the doctor about the medication if I think the medicines aren't good for me. I can talk to them [professionals] about what is best for me. (Robson, BR)

> Interviewer: Does participation have a positive impact on users themselves?
> Expert by experience: Yes, on treating each other with respect. The hierarchy… for example, you are a patient and you go to the psychiatrist: you have the right to look into your medical record. It helps patients talk to their psychologist or psychiatrist as an equal. (Expert by experience 3/ mental health workshop coordinator, BR)

Participation enabled users to become more aware of their rights and to reframe their position as 'patients' into one of 'health care seekers who deserve attention and voice'. Moreover, by promoting contact between users and providers outside the therapeutic setting, participatory initiatives enabled users to perceive themselves as less distant from providers and to acknowledge their humanity in all its strength and fragility. This not only made users more confident when interacting with providers but also eager to become involved in their treatment.

> Interviewer: Did your participation in the user movement help you understand a bit better how CAPS works and what you can expect from it?
> Gladys: Yes. It did. We also start understanding more about the professionals [laughs]. There's one here [CAPS], his name is Frederico[131]. Many people [users] can't stand him because they think he's rude and unfriendly. But I tell them: "people, it's not like that. Frederico is a sweet person. The problem is that you don't know how to get close to him and talk. Go talk to him and then tell me whether he's like what you're saying". And there's also Josué[132]. Everyone if horrified by him. But I tell them: "They [professionals] are really not like that. They're people like we are. They suffer. They cry. They have a busy life. They have a family, children". (…) It's all a matter of how you look at people. (Gladys, BR)

However, there were also users who saw their hopes of acquiring the know-how necessary to participate in the negotiation of mental health care being thwarted. This was the case with Márcia (NL) who joined Project Apoio with the goal of learning how to take a more active role on decisions regarding her father's mental health care treatment. Márcia's father received treatment in a local out-patient mental health care service where he was diagnosed with bipolar disorder. When she started participating, he had contracted a number of debts which were causing the ruin of the family. Márcia spoke about this problem with her father's psychiatrist but received no support in dealing with it. It was only after much searching that she discovered the possibility of becoming legally responsible for her father's finances. That was a piece of information she felt she should have been given at Project Apoio. After a few months, she stopped participating.

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[131] This name is a pseudonym. Although the profession of the person Gladys refers to is mentioned on the original citation we opted for omitting it here in order to preserve the professional's privacy.

[132] This name is also a pseudonym and also refers to a professional of CAPS Pedro Pellegrino.

> When my father got ill I had to arrange everything. I had to take him to RIAGG [mental health service] and to speak with the doctor. People sometimes forget how difficult it is for family members because you simply don't know how to act. (…) I was really not able to handle it very well. I feel people talk a lot about his [father] problems but they don't think about what you [family member] can do. They don't inform you about associations where you can get together with other people to support each other in making the right decisions. It takes really long before you know what's the right way to follow. Recently, the (…) [coordinator of Project Apoio] asked how my father was doing and I said he wasn't well. So she asked: "why?" but I didn't want to speak about it. I did that because when he first got ill I didn't get the help I needed from her. And that's a shame because I got a lot of problems that could have been prevented. (…) I'm not a professional but now I know people [affected by psychosocial problems] can react badly to some things because of the problems they are going through. For example, when they get into debt they often deny it and they don't want to be helped. (…) But there's a way: you can become legally responsible for the financial situation of that person. I didn't know that. (…) If I had been told that earlier, I wouldn't have so many problems now. (Márcia, NL).

Like Márcia (NL), Aurora (NL) also quit with participation. Yet in Aurora's case, she was satisfied with the benefit she had obtained: she learned about mental illness and mental health care as she expected, and she felt more capable of seeking care if necessary. A common denominator in the cases of Márcia and Aurora was that their participation was largely motivated by individual incentives, i.e. the desire to improve their mental health care knowledge and use. Although they both realised they could provide a service to their community by engaging in Project Apoio's initiatives, that motivation was not as salient as it was among some other users, who went on participating even after achieving their personal goals. When Aurora and Márcia felt their aspirations were either fulfilled or stood no chance of being accomplished, they opted out. We may conclude thus that, in the absence of collective motivations, users may terminate their participation once individual incentives such as enhancement of health literacy lose their strength. This adds to the argument that collective incentives play a key role in facilitating decisions to stay engaged (Simmons and Birchall, 2005).

The impact of participation on critical health literacy was not as evident as on the other two types of literacy described above. However, there were some signs that involvement in mental health initiatives was making users more aware of the importance of engaging in actions aimed at promoting healthier behaviours within their communities. Benedita (BR), for example, suggested the need to re-initiate walks around the neighbourhood for CAPS's users. As she noted, non-involved users seemed to be more prone to engage in unhealthy lifestyles and it was necessary to change that:

> The people [users] who don't participate usually have an experience of long-term admission [in psychiatric hospitals]. People who were hospitalised for a long time often have difficulties in relating to others. They also have some vices which get really strong: they beg, smoke a lot and eat too much. Those are characteristics of people who were either hospitalised many times or were hospitalised for a very long time. I don't know why that happens but we observe that. (Benedita, BR)

In the Netherlands, Cape Verdean users organised a theatre play about the crisis plan and the crisis card (i.e. psychiatric advanced directives). The intention behind this action was to inform the community about psychotic episodes and the need to take preventive measures to minimise their negative effects. Overall, users appeared to be acquiring greater consciousness about their capacity to contribute to the wellbeing of their communities.

8.1.5 Improved access to care

The stigma attached to mental illness was one of the most obvious barriers to the use of mental heath and social care amongst our respondents. Fear of stigmatisation impedes the identification of candidacy for mental health services by reinforcing beliefs about mental illnesses (i.e. that they are dangerous and irreversible conditions) which discourage people from accepting and talking openly about it. This, in turn, undermines their chances of getting the support of others to seek help. Hearing other people speak about their mental problems during participatory activities helped users to set aside their fears and perceive themselves as candidates for mental health care. This was not an immediate effect of participation, but something which developed over time.

> Learning that you can get a *tolk* [interpreter], for example, has a really positive effect. It enables people to go to places [services] without needing to call a neighbour to translate. Sometimes people get afraid they [acquaintances] will find out about their problems. If there's a *tolk,* they can just make an appointment. (…) In due time, they [participants at Grupo de Conversa] start looking for help. It doesn't happen right away. But with time… they listen to others. Then comes another person talking about the same problem and then they start looking for help. (Aurora, NL)

Obtaining mental care is also negatively affected by low availability and accessibility of services. Gaining entry into out-patient psychosocial care services (i.e. CAPS) in Brazil is a difficult process. Not infrequently, those services are located in remote areas and often have insufficient capacity to provide a satisfactory response to all care seekers. Moreover, many people are not aware of their existence or what they have to offer.

> There are many people who don't know what a CAPS is. That information doesn't reach out. We have some people from CAPS at the district health council and they

> can provide information there but, generally, it's not really known. Also, some CAPS are difficult to access. They are far away. And many are overloaded and have no vacancies so people are asked to return the next day. That makes them give little credibility to the service because they don't get helped. (Member of family association 2/ social worker, BR)

Finding a way into the Dutch mental health care system can also be a challenging endeavour. Aside from long waiting lists, the use of mental health services requires referral by general practitioners (GPs). As Madalena (NL) explains, such health care requests are not easy to negotiate:

> Madalena: I had never been to the psychologist and to tell you the truth I don't really know what the difference is between a psychologist and a psychiatrist. But then I started getting ill. I went to the Arbeidsdienst [Work Department] doctor and he said: "you have had so many diagnoses and treatments and nothing seems to be coming out of that. I would advise you to go to a psychologist and have a few consultations". So I said: "If you think that's necessary, I'll go". So I went to [the coordinator of Project Apoio] to ask if she knew someone.
> Interviewer: The Arbeidsdienst doctor didn't inform you about how to get in contact with a psychologist?
> Madalena: Yes, he said I should ask my general practitioner for a [referral] letter. I asked my general practitioner for the letter but he said: "oh, that's not necessary". So I told him: "well, if you think that's not necessary that's O.K. but I wasn't the one who decided to ask for this paper [referral]. The Arbeidsdienst doctor told me that it was necessary". But he [GP] said: "no, it will pass". So I went to [the coordinator of Project Apoio] and told her what happened. She said she knows a psychologist who doesn't need the [referral] letter right away and that if the psychologist asks for it directly to the general practitioner, there won't be any excuses. (Madalena, NL)

The events narrated by Madalena underline a story I heard many times from Cape Verdean migrants in the Netherlands: their persistent difficulties in getting referred to specialised care. Yet there were three positive elements in Madalena's story which not all Cape Verdeans are likely to benefit from, especially when they lack access to the support and knowledge resulting from engagement in participatory initiatives. First, Madalena had already been in contact with people using mental health care through Project Apoio and, although she was still unable to discern between the work done by psychologists and psychiatrists, she was more open to try it out. Second, she had been advised to seek psychological care – a type of care many people take a rather long time to realise their need for it. Finally, when refused referral, Madalena succeeded in bypassing the blockades created by the health care system by finding an alternative pathway to mental care through Project Apoio.

The Dutch health care system is one in which the need for users to frame and articulate their problems in a credible and convincing way is most evident. Yet a thorough articulation of health complaints is not always enough. A good dose of assertiveness may also be essential in order to negotiate access to specialist care. For health care seekers lacking the information, confidence, and skills required to claim the type of care they need, there is a considerable risk that they will be trapped in the limbo known as 'watchful waiting'[133]. As we observed elsewhere (De Freitas, 2006), in Dutch medical practice there is a strong emphasis on avoiding unnecessary medicalization of problems and on preventing iatrogenic (medically-caused) illnesses. GPs are expected to work as gatekeepers to the health system (NGH and LHV, 2002). They are expected not to make referrals for specialised care unless there are clear grounds for deciding that is necessary. Although this is a sensible principle, when patients lack the ability to formulate their care requests in an effective way it may lead to unnecessary delays in the provision of adequate care – with potentially serious consequences for the patient. It is therefore not surprising that many Cape Verdean migrants in the Netherlands seek health care in other countries (De Freitas, 2005). Transnational health-care seeking has additional financial and emotional costs. However, for people unacquainted with the intricacies of the Dutch health care system and unable to meet its demands, this is sometimes perceived as the only viable solution. Involvement in Project Apoio had a positive impact in changing this perception, not just by enabling users to become better informed about mental health but also by teaching them how to act when seeking to enforce their right to mental health care.

> The first thing you need to do is to consult with a general practitioner. Then you have to explain your problem and ask to go to the psychologist. You really have to ask for that because sometimes they don't send you to the specialist. I don't know why. Maybe they don't want to spend too much money. So you really need to ask for it [referral]. But, will a person with a mental disorder really ask that? Usually they don't. And if they do then the doctor might say: "but you are asking for it, so you probably don't need it". (David, NL)

David (NL) highlights a paradox illustrated by the case of Madalena cited above: people who suffer from mental problems may not always be able to ask for help, and those who do may not be considered ill enough to get it. The efforts required from users to go through the different 'filters' imposed by health care systems may discourage them from pursuing care further. This seems to be even more the case when care seekers perceive health professionals as figures of authority whose decisions are not open to scrutiny and criticism. Such perceptions tend to be strong among people experiencing feelings of powerlessness. Participation played a key role in the

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[133] 'Watchful waiting' refers to the period following a care request in which users are left under their GP's observation before being considered eligible for medical intervention (NGH and LHV, 2002).

deconstruction of these perceptions, by enabling users to realise their right to engage in decision-making and by equipping them with the competencies and self-confidence necessary to exercise that right in the context of health care delivery.

> When users get more information, when they start talking to Town Hall Mayors or going to [the Senate in] Brasília they start facing authority and their own services in a much more autonomous way. They are less fearful. It's not only them. Professionals and family members also feel the same. If he [user] negotiates a [proposal for] a law, he will also be able to negotiate medication. The user movement enables users to get more aware of their personal interests and to learn how to negotiate for their own interests in a better way. (Psychiatrist 2, BR)

Furthermore, by bringing users and providers together, participatory initiatives foster a reappraisal of commonly held stereotypes and crystallised power relations which work to sustain perceived cultural and social differences between these two groups. This may give rise to more symmetrical doctor-patient relationships as users and providers come to acknowledge that once they take the chance to reduce the physical and emotional distance separating them, they have more in common than they might think.

> Once we went for *feijoada* [traditional dish] in Santa Teresa [neighbourhood in Rio de Janeiro] with a group of professionals and users [from CAPS]. After a while, Mário Cunha[134], who is one of the users, looked to one side and then to the other and said: "Fucking hell, they [professionals] drink like with do, they laugh like we do. This is really great!" He [Mário] saw that the doctors were just like him. I told him: "They are just like you Mário. The difference is that you are their patient". They [users] used to look at professionals as if they were their rescuers but now they can sit together and simply chat. (Member of family association 2/ social worker)

Greater identification and collaboration between users and providers may lead the former to become more responsive to and responsible for their own treatment. Moreover, as users become acquainted with the benefits of active engagement in treatment they may come to develop an interest in becoming providers themselves. This was the case of Simone (NL) who was following a course to become a social pedagogical worker. In the Netherlands, these professionals specialise in facilitating users' access to care by assisting in the planning of their treatment programmes. Assisting others in finding their way into mental health services, either professionally or on a more informal basis, enhances users' belief that they too can contribute to social transformation and increase the responsiveness of mental care provision. As noted by an expert by experience who became a care provider within an Assertive Community Treatment team in the Netherlands, participation enables users to enhance the

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[134] This name is a pseudonym.

accessibility of mental care for themselves and others. This is both rewarding and empowering.

> One of the rewards for people who participate is that they get more access to what they need. And clients [users] who have good access to care are also interesting for other clients. When you get psycho-education you learn how to get what you need (…). I'm starting to do that with clients, [i.e.] to give them psycho-education, to help them understand how they feel and how they can see their illness. I also started paying more attention to psycho-education when I got it from other clients who were more experienced than I was, both because they speak from their own experience and [because] they give you facts. (…). It feels good overall to go to a [user] group and to talk about the people who take care of the problems you wake up with. If there's a good connection between participatory groups and the hospitals or day centres, it feels very good for you as a person to participate, and it will help you regain your trust in yourself to become even better. (…) I used to be in a group which trained professionals to find other ways to care for people rather than putting them in an isolation cell. That group tried to pass those ideas to professionals and when that works you get something back for your own group. (Expert by experience 6/ social pedagogical worker, NL)

The feeling that one is part of a group whose collective actions are capable of fostering change encourage participants to think that they could promote the development of care delivery more in tune with their needs. The benefits realised, such as the creation of a therapeutic group for Cape Verdean migrants at a local mental care service and the restoration of rightful provisions (e.g. food, medications, etc.) to CAPS Pedro Pellegrino (see Chapter 7), had a particular positive effect in advancing users' aspirations to stay engaged and to persevere with action to improve the wellbeing and inclusion of their communities.

> If you want to get something, you have to get organised. One person alone won't get anything done. This is why the Anti-asylum movement is so important. Through the users, family members, doctors… if we get a strong group to claim for our rights, it will be easier for us to stop being excluded. We still have much work to do. The Anti-asylum movement helped me realise we have to fight for what we want. We can't just wait for things to happen. (…) The Passe Livre [free bus pass], deinstitutionalisation, the creation of CAPS and therapeutic residences… those are all things we got through the Anti-asylum movement and we need to make sure they don't take the services away and that they work properly. (Vinícius, BR)

8.2 Conclusion

This chapter suggests that participation delivers a number of benefits which enhance mental health care users' capacity and willingness to go on participating and to take engagement a step forward. Users who have experienced the positive effects attached to participation not only pursue higher levels of involvement, but also recruit and assist others to get involved. This stresses the importance of benefits for advancing participation.

Participation asserts the value of individuals' views and contributions to the public good and renders legitimate the presence of all constituencies in the participatory sphere, including that of "people previously regarded as incompetent to participate within decision-making processes" (Barnes, 1999: 87). This alone has the potential to counter the feelings of powerlessness which usually characterise members of disenfranchised groups, by counteracting the perceptions of unworthiness, incapability and alienation that often prevent them from taking action to effect change. But perhaps more importantly, as our research demonstrates, participation offers stigmatised groups the opportunity to express themselves and to press for a reframing of their ascribed identities from the passive, dependent and unproductive outcasts they are conventionally assumed to be, to active citizens capable of making valuable contributions to society. This is especially meaningful for people who have gone through most of their lives without respect or voice.

Participation also enables people from different walks of life to come together. This allows them to gain awareness both about the interests of and problems experienced by other social groups and about their own needs and wants (Richardson, 1983), and the reasons why they may have been left unattended. Developing such a critical consciousness is the first step on the road to social transformation. Acquiring the support of others who are either in similar circumstances, or who are sensitive to their cause, is crucial to enhance the belief among disadvantaged groups that they, too, can promote change. As our study shows, and other research attests (Barnes *et al.*, 2003), participatory forums offer a space from which users can build relationships of solidarity and create alliances with other, more resourceful, social actors (e.g. mental health professionals and policy-makers). Through these alliances, and the experience of participation, users start acquiring the competencies and resources they need to challenge the *status quo* and to attain a more equal position in society. Moreover, they start developing a sense of autonomy, i.e. the capacity to declare out loud their wants, needs, and preferences (Warren, 1992). This increases their ability not only to partake in decision-making spaces, but also to claim their rights and pursue the substantive benefits of their citizenship (Dagnino *et al.*, 1998). As we observed, however, the potential of participation to enhance full citizenship among members of excluded groups must not be taken for granted. Substantial efforts are required to foster users' awareness of their rights and responsibilities and of the mechanisms through which they can practice their citizenship.

The participatory sphere is also a ground where individuals initially bound by weak social ties (Granovetter, 1973) come to experience the formation of strong ties of friendship. As users join forces to accomplish common goals, they develop a sense of togetherness which is crucial for both empowerment and sustainable participation (Higgins, 1999; Honey, 1999; Simmons and Birchall, 2005). Many users reported the benefits of becoming affiliated to a group which valued their qualities and efforts and encouraged them to acquire new talents and skills. In addition to bolstering participants' self-esteem and self-confidence, participation enabled users to start taking greater control over their social and political lives. These findings are supported by other empirical studies (e.g. Smith, 1984; Barnes and Wistow, 1994; Summers and McKeown, 1996; Barnes and Shardlow, 1997; Honey, 1999) which also point out the positive impact of participation in fostering a sense of 'we-ness' among those involved (Barnes *et al.*, 2006). In our study, this was especially evident among minority Northeastern users whose engagement led to a strong identification with a group they believed capable of acting collectively to promote their interests. This sense of collective identity binds individuals together in the pursuit of a common good, strengthening the social ties between them and facilitating the creation of networks of social support which help to minimise the financial and emotional costs of participation. This, in turn, has a positive effect on overcoming barriers (e.g. lack of information and money, stress) which threaten the sustainability of engagement.

Participation also has a positive impact on users' access to mental health care. This is a benefit of involvement (Barnes and Wistow, 1994) which has been less often explored in the literature. As our data show, participation promotes users' health literacy which is a valuable asset when it comes to realising one's needs and candidacy for care and to navigating the maze of mental health care provisions. Furthermore, involvement in participatory initiatives enables users to develop the competencies and self-assurance necessary to bargain for the care they consider appropriate. This is not an immediate process, however. Such negotiations are mediated by asymmetries in information and power relations which usually favour the professional side. Negotiating care with providers one perceives as figures of authority requires a degree of assertiveness on behalf of users which calls upon a sense of citizenship strong enough to empower them into feeling that their claims for attention and voice are not only legitimate but essential to assure the provision of good quality care. Participation, as we have seen, strengthens users' personal empowerment as well as their commitment toward the exercise of an active citizenship, increasing in that way their ability and willingness to take part in decision-making, not least in the context of health care delivery. This suggests that the benefits of involvement have a cumulative effect, i.e. they have a positive impact on each other and, all together, reinforce participation.

A final issue we wish to address here concerns the role of participation in promoting social integration, as argued by Richardson (1983) (see Chapter 4). Our findings suggest that involvement in health participatory spaces generates a set of benefits which are crucial for and conducive to greater social inclusion. As we have seen, users' engagement in and access to social relations, civil activities and health care services did increase as a result of participation. However, several of them were still struggling against exclusion in other spheres of life. Taking part in economically productive activities, for example, was a particularly difficult goal to satisfy for minority Northeasterners in Rio de Janeiro, on account of discrimination in the labour market. Cape Verdean migrant users in Rotterdam also struggled to find acceptance by their own community (see Chapter 7). This indicates that participation *per se* does not guarantee the full inclusion of mental health care users in society. However, the more users perceive themselves to have the right to be treated as full citizens, the more likely they are to continue pressing for the social changes required to assure their integration. This aspiration is further reinforced by each new 'conquest' users make as a result of their engagement. Seeing change happen not only empowers users to go on participating, it motivates them to mobilise others to get on board. Yet, as discussed in this chapter, that is only observed when users express collective motivations for participation and the benefits obtained match those collective goals. If users' participation is only driven by individual motivations, then realising those individual goals, or not being able to achieve them, can determine the end of participation. This indicates that once users get involved participatory initiatives need to appeal to and work toward the promotion of benefits linked to collective incentives for participation, in order to assure the sustainability of participation.

9. Slowing down participation: inhibitors

In spite of the benefits that can be reaped from it engagement in participatory spaces is not a smooth process and many factors can undermine users' ability and willingness to get involved. As we saw in Chapters 7 and 8, the participation of people affected by psychosocial distress can be hampered by several inhibitors including public and self-stigmatisation of mental illness, limited cognitive and communication skills, digital exclusion, poor knowledge about the determinants of (mental) health and the ins and outs of the mental health care system, limited awareness of rights, lack of confidence and assertiveness, difficulties handling with conflict and criticism, and meagre financial means. The negative effects of these inhibitors can be counteracted, however, by direct and continuous mobilisation and through concerted investment in building users' capacity to act. As evidenced in Chapter 7, users with a long-standing practice of participation were not only better equipped to formulate and voice their concerns, they were also more prepared to deal with the costs of involvement. Since the inhibitors of participation have been introduced and discussed throughout the previous empirical chapters, in this chapter we look into two specific instances in which attempts to promote participation were not sufficient to offset the negative impact of prevalent inhibitors.

As we saw in Chapter 5, our two research groups constitute a favourable exception to the general pattern of poor involvement by low-SES ethnic minorities in mental health participatory initiatives. Nevertheless, there were some obstacles which impeded their participatory potential from being fully realised. When we started research at CAPS Pedro Pellegrino, incentives for minority Northeastern users' participation in their service's assembly appeared to be waning and involvement was declining. Moreover, during our fieldwork in the Netherlands, we were unable to identify any Cape Verdean migrants who had been involved in health client councils. Both these instances attest to the presence of barriers to participation which can overrule the efforts made to foster user engagement. Furthermore, they highlight a marked difference between our research groups: in contrast to minority Northeasterners who succeeded in getting involved in health councils and mental health conferences, Cape Verdean users had not yet gained access to health care invited spaces, i.e. they were unable to secure participation in spaces created by the state to promote dialogue between users and service providers.

As we show next, the slowing down of minority Northeasterners' engagement in the assembly is mainly explained by declining on mobilisation efforts and increasing disbelief among some users that participation could lead to expected change. Cape Verdeans' exclusion from client councils results from a combination of 'demand' and 'supply' factors, including unawareness and fear of stigmatisation and the unappealing nature of participatory activities carried out within client councils. Looking into these two cases can afford insight on the ways by which unawareness of, self-exclusion from and exclusionary dynamics within participatory spaces act to inhibit user participation. Because these cases reflect different sets of barriers to involvement, we take a different approach to that employed in the previous chapters, analysing each case separately instead of discussing them together. We begin with the case of minority Northeasterners in Brazil and then turn to the case of Cape Verdeans in the Netherlands.

9.1 Opting out the assembly: minority Northeasterners in Rio de Janeiro

The assembly at CAPS Pedro Pellegrino is a participatory space where users come together with providers once a week to discuss the dynamics of staff-user interaction, make decisions about care provision and organise cultural activities. As we saw in Chapter 5, problems of bureaucracy, mismanagement and corruption at the top level of administration jeopardize the coordination of public mental health care in Rio de Janeiro and have a direct negative impact on the performance of local services, to which CAPS Pedro Pellegrino is no exception. One of the most critical problems affecting this service was the holding back of funding which caused periodic shortages of medication and food provisions and made the hiring of highly needed staff and the maintenance of facilities very difficult. Although the need to keep resource allocation and service provision under close watch offered a good impetus to user involvement, two weeks after we started fieldwork the assembly seemed to have reached one of its lowest attendance rates counting with the presence of only five users. A week later, attendance increased slightly to 8, but it was still far from what it had been in the previous months and nothing like the total number of users scheduled to receive care on the day the assembly took place (70)[135]. Asking Benedita about what caused such a decline in attendance she replied with visible concern:

> I don't know exactly why but people lost their enthusiasm. Before, there used to be 30 people at the assembly. Then there were only 18 or 20. And now there are less than 10 [attending]. I don't know why that happened but there's a great disinterest in the assembly. The assembly is an important space because it's where patients can express their wills and their ideas about what CAPS should be like and about what's going wrong and what has improved. These things are meant to be talked about in this space [assembly] but the majority [of users] either doesn't understand that or they think it's not worth trying. So they stopped coming. The assembly is really emptying out (…). It is so emptied out that issues don't even arise anymore. The people who come talk about things which are not that important. When there were

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[135] The total number of users receiving care at CAPS Pedro Pellegrino is 300. At the time of fieldwork there were 70 users scheduled to get care at CAPS Pedro Pellegrino on Tuesdays - the day the assembly was held.

> more people, there were more ideas, more heads thinking together, and the issues which needed to be handled were raised. I think we need to encourage people to participate again in the assembly. (Benedita, BR)

As Benedita explains, rising disinterest had a negative snowball effect on participation in the assembly: the less users took part in the assembly, the less appealing it became and the more discouraged users felt to return. It was crucial thus to find out what was causing disinterest in the first place. Echoing some of Benedita's concerns, Robson felt that the assembly was being misappropriated to discuss users' health problems instead of issues related to service delivery.

> Robson: I used to participate in the assembly but now I don't participate anymore because the patients go there to speak about their problems and they should speak about their problems with the doctor. They use the assembly to get problems off their chest and they don't speak of the issues which need more orientation.
> Interviewer: What needs to be changed in CAPS?
> Robson: We need more space. In Inhoaíba [CAPS] they have [enough space] but we don't. Also… the opening time [of CAPS] should change. It opens at 8h30 but people [professionals] only arrive at 9h30. We should begin earlier to get the workshops up and running. (Robson, BR)

As Robson explained later, one of the main causes of disappointment and frustration among users concerned the way by which the income generation workshops offered at CAPS were being managed. Requests to diversify the type of products manufactured in these workshops and to create a small street shop to sell them had been made several times by users at the assembly without success[136]. As we saw in Chapter 7, finding a meaningful social role through employment and securing a source of income were key motivations driving the participation of minority Northeasterners. Discrimination by society at large, and in the labour market more specifically, undermines the chances of people affected by psychosocial distress to get paid work and forces them into a life of financial dependence, and not infrequently of poverty. Income generation workshops at mental health care services are thus the only option available for many users to earn some money. Thwarted expectations regarding the development of successful income generation workshops were giving rise to mounting disbelief about the potential of the assembly to generate answers to users' pressing concerns, leading many to opt out.

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[136] At the time of the fieldwork, users were producing decorative items at CAPS Pedro Pellegrino income generation workshops. Not being basic utilities, those items have less chance of being sold than products used on a daily basis. One of the proposals made by users was the creation of an income generation workshop to produce soap. They expected this product to stand a better chance of being commercialized and they believed sales could be further enhanced by creating a retail sales point either in one of the city's busy squares or near a train station.

> I heard some users saying they are going to abandon the assembly because nothing is being done to improve the income generation workshops and help us make a little money. Just talk, talk, talk… that doesn't solve anything. Everyone can talk but people don't know what to do and that is really discouraging. (…) You get tired of coming here and seeing that things don't change. (…) There should be places for us to sell our products but getting a license from the municipality [to get a street shop] is really difficult. We are only able to sell our products at the fairs during the [mental health] conferences and the [professional] congresses. (Gladys, BR)

Oscar, who was also concerned with the need to create more opportunities for paid work, added that professionals did not provide users with sufficient feedback on the extent to which CAPS could facilitate their access to economically productive activities, or enough guidance about how users could try to do that by their own means. In his view, there was a problem of communication between users and professionals which was having a negative effect on the dynamics of participation in the assembly and causing users to lose confidence in its ability to work as a space for negotiation of appropriate responses to their needs.

> I think that unfortunately users got tired of it [assembly]. They are tired of talking a lot and not sorting out much. The service hasn't improved that much. (…) I know politics don't really help but it's complicated for them [providers] to understand us and for us to understand them. I wish they [providers] were more open and explained what they can do within their field, or until how far they can go to help us sell the things we make. They could say: "look, we can only do this much. After we do this, we can't go any further because we lack this and that. Beyond this point it is up to you [users]. If you really want to change things you need to this and that". I would like them [providers] to explain things better. (Oscar, BR)

Despite feeling that proposals and claims for greater investment in income generation workshops had been ignored, several users stated that their voices were heard. When inquired about what was leading users to discontinue participation in the assembly Jaderson was very straightforward: the main instigator of participatory initiatives at CAPS Pedro Pellegrino – a psychologist who was also a leader of the user movement – had left to work in another institution and other professionals were not very successful in mobilising users to join the assembly.

> Interviewer: Are users heard when they make suggestions for changes here at CAPS?
> Jaderson: Yes, we are.
> Interviewer: Who implements those changes?

> Jaderson: Well, the staff does. The psychologists and the psychiatrists do that. Maria Vitória[137] used to do that.
> Interviewer: Why is the assembly emptying out then?
> Jaderson: Because Maria Vitória left and since then attendance dropped.
> Interviewer: Why?
> Jaderson: Ah, because she was a strong person. She was a leader.
> Interviewer: Is it necessary to have someone leading users into participation?
> Jaderson: Yes, it is. And that position hasn't been taken up. Well, it was [taken up] by different people. The occupational therapist did it and then the other psychologists. But it didn't really work out.

In face of growing disappointment with unanswered claims, the loss of the key instigator of participation at CAPS Pedro Pellegrino became the turning point for a rapid decline of users' engagement in the assembly. As discussed in Chapter 7, the instigator played a crucial role, not just in recruiting users to participate in the planning and evaluation of their own service, but also in encouraging them to venture in the 'outer world' and to become more directly involved in psychiatric reform through the user movement. Her approach fostered users' access to information and in empowered them to act by stressing the importance of their contributions and their ability to make a difference. Such direct mobilisation was required because most users were not yet confident enough and sufficiently well resourced to get on with the participatory project on their own.

In spite of believing strongly in the importance of user participation the instigator also acknowledged that not every single person is cut out for it, nor does each and every citizen need to be engaged in health participatory spaces.

> What matters is that we offer people information about the existing [participatory] spaces and let them try those spaces out and see whether they interest them. I used to think that everyone should take part on the user movement but my work at CAPS [Pedro Pellegrino] showed me that people experience many limitations and that that space is not for everybody nor does it have to be. The same goes for the assembly, although participating in the [movement] or in the health councils is much more difficult because those are spaces of great confrontation and debate. (Psychologist 4, BR)

As noted earlier, in its 'good days' the assembly counted with the presence of less than half of the users expected to receive care at CAPS Pedro Pellegrino. The active involvement of the remaining 56% was undermined by several inhibitors: many users were too withdrawn or suffered from major cognitive and physical impairments as a result of heavy medication and psychosocial distress. Other users were too poor to

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[137] This name is a pseudonym and refers to the psychologist who used to be the main instigator of participation at CAPS Pedro Pellegrino.

afford the bus ticket and go to CAPS, on a day in which there were no workshops during the morning and no lunch, just to attend the assembly and one other workshop in the afternoon[138]. Yet other users were too indifferent to get involved. The cognitive, social and personal limitations holding users back from participation need to be respected, as do people's decisions not to get engaged. However, it is also necessary to invest in decoding the powerful message sent by massive drop-out among users who were once willing to be involved, and to make the necessary efforts to tackle the problems signalled. In the case of the assembly this seemed to include greater investment in direct recruitment, better communication between professionals and users, and a more open negotiation of ways to improve the performance of the income generation workshops.

Importantly, not all users felt impelled to abandon the assembly as a result of failed expectations or disbelief in its power to foster change. Despite being dissatisfied with the current situation, Benedita, Gladys and Vinícius continued to participate and showed much concern with the decline of engagement in a space they considered of great value for users and CAPS itself. Three important elements stood out when looking at the characteristics which distinguished these participants from users who stopped participating. First, they had a longer experience of involvement in the user movement. Second, their participation was driven by both individual and collective motivations: unlike the drop-outs whose engagement was mostly motivated by personal concerns, they expressed commitment to the promotion of social justice for all people affected by psychosocial distress. Third, they had a stronger sense of collective identity as mental health care users.

The three elements described above appear to work as a buffer in situations of disappointment with participation. Long-term engagement in the user movement enabled users to become acquainted with the challenging art of taking part in decision-making processes about highly politicised issues for which there are no simple answers[139]. Moreover, participation in the user movement functioned as a springboard for engagement in health invited spaces, namely in mental health conferences[140].

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[138] On Tuesday mornings CAPS Pedro Pellegrino was closed to users so that professionals could have their team supervision meeting. As noted in Chapter 5, many users receiving treatment at CAPS were very poor. Unlike the other four days of the week, lunch was not served on Tuesdays because the morning was reserved for the staff meeting and there was no service provision. That was a strong disincentive for many of the users who had to make quite a financial effort just to pay for the bus.

[139] Issues recurrently debated in the user movement meetings included questions such as how to improve the social position of people affect by mental illness as well as their entitlement to social benefits; how to prevent the contractualisation of public mental health services to private service providers; whether or not to accept subsidies from pharmaceutics companies to help deal with movement's budget limitations.

[140] As noted in Chapter 5, the user movement is represented in the local, state and national mental health conferences. In preparation for these events, proposals for mental health policy and service delivery are widely debated and official delegates (including users) are chosen through vote to represent the movement in the conferences. Everyone is allowed to attend the conferences, but only official delegates have the right to vote the proposals made during the conference. In addition to sponsoring the travel expenses of official

Participation in the conferences enabled users to gain consciousness about the broad range of actors involved in mental health care governance (i.e. public and private care providers, user and family associations, pharmaceutical companies etc.), the different interests they represent, and the inherent complexity of participatory decision-making. Furthermore, the conferences helped them to understand the intricacies of mental health care organisation and the limitations experienced by local care providers in responding to their claims. This not only enabled users to realise that participation has its ups and downs but also to become more patient in relation to the slow pace of change.

> I believe we are heard but sometimes it [implementing change] doesn't depend only on the will of the coordination of CAPS. It depends of the general coordinators, like the Secretariat of Health or the area coordinators. They are the ones signing the documents, releasing the funds and giving permission to do this or that. There's a lot of bureaucracy. So even if the coordinator [of CAPS] and the professionals have the will to do things they often have to wait to implement those changes. So we can't say they don't listen to us. They do listen. They care. But sometimes solutions take a long time to come around and that causes disappointment among some users because they feel they are not being heard. (Benedita, BR)

The development of a collective identity made users feel part of a group which relied on them to achieve its goals and which supported them in return. This sense of common purpose, reciprocity and belonging empowered users to persevere in their struggle for greater equity and justice. Moreover, being part of a collective with more than twenty years of history – the Anti-asylum Movement (MNLA) – helped users understand that the answer for arising problems was to re-orient the course of action instead of giving up the fight.

> If it [claim] didn't work out you have to think of other ways to make it work. Some people cross their arms but we can't stop fighting. There are many people in much worst circumstances than we are. We have to go on. I learned that it takes time for things to change in politics. You have to debate. You have to fight. You have to be persistent if you want things to work to your advantage. (Vinícius, BR)

For Benedita, Vinícius and Gladys opting out the assembly was not the solution but an indication of problems which required attention and perseverance on the part of users and professionals to sort them out. As noted by Vinícius, effecting change requires

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conference delegates, the user movement also encouraged other users to join the conferences in the quality of observers and gathered the funds necessary to cover for their travel costs. This extended the possibility of participation in the conferences to a larger number of users who were otherwise unable to afford it. Bendita, Vinícus and Gladys were among the users of CAPS Pedro Pellegrino who had taken part in mental health conferences.

diligence, determination and effort and waning participation was a reason to invest more, not less, in bringing users into the assembly. One of the strategies adopted by Benedita, Vinícius and Gladys to get the assembly up and running again was to approach dropped-out users directly and appeal to the value of their contributions as part of a collective concerned with guaranteeing access to good quality mental health care. This example of direct mobilisation proved beneficial. By the end of the fieldwork period, engagement in the assembly was slowly picking up again.

9.2 Ignoring client councils: Cape Verdean migrants in Rotterdam

Client councils are participatory spaces designed to enable users to have a voice in the policies of health and social care organisations. Client councils can advise on various issues related to service provision including human resources policy, yearly budgets, culturally-competent practices, food arrangements, complaint procedures, security policy, care quality, etc. Council members meet periodically with the directors of their care institution, who are expected to adopt the advice given by councillors. Client councils are thus one of the participatory mechanisms through which users in the Netherlands can exert influence over care planning and evaluation in a more direct way. To a certain extent, these invited spaces resemble the user assemblies in mental health care services in Brazil. However, unlike the assemblies[141], client councils have a legal backing (WMCZ law) and are supported by a national mediation committee which can be called to intervene in cases in which the advice provided by councillors is inappropriately evaluated and refused (Blaauwbroek, 2002).

As we saw in Chapter 2, the Dutch participatory sphere has not yet succeeded in becoming fully inclusive regarding the diversity of care users in the Netherlands. Migrants and ethnic minorities (MEMs) are one of the least represented groups in health invited spaces (De Savornin Lohman *et al.*, 2000; Nederland and Steketee, 2004). Failure to promote their inclusion in participatory institutions is particularly worrisome in a time in which, as a result of the intensified marketisation of health care, care users are expected to act as informed consumers, organised lobbyists and involved citizens in the making of health care policy and in the development and evaluation of care programmes capable of responding to their needs. The interculturalisation of Dutch health care is now a responsibility of providers, insurers and users (Ministerie van VWS, 2004), so it is imperative that minority users make their voices heard. As we noted in the introduction, Cape Verdean users do not participate in client councils. In this sub-section we look into the factors determining their exclusion from these spaces in an attempt to shed light on the inhibitors impeding the development of a plural

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[141] Mental health care services' assemblies in Brazil are promoted by the Ministry of Health (Brasil, 2004). However, there is no legislation determining their creation and maintenance by local services (i.e. CAPS). Their implementation is thus left to the responsibility of service coordinators.

citizen voice in Dutch mental health care. As we will show, barriers to participation appear to arise from both the 'demand-' and the 'supply-side' of the participatory sphere. We begin by addressing the inhibitors which impede Cape Verdeans from engaging in client councils and then look into supply-side explanations for non-participation.

The vast majority of Cape Verdean users in our study said that they did not know about the existence of client councils. Unawareness of opportunities for engagement through these participatory mechanisms emerged as the most obvious barrier to Cape Verdeans' involvement in mental health invited spaces. Yet, as we will see below, fear of stigmatisation associated with mental illness also plays a role in Cape Verdeans' self-exclusion from those spaces.

Cape Verdeans' lack of information about client councils appears to stem from two main problems. First, most of our respondents had a low level of digital literacy and had neither the habit nor much ability to search information through the web. As we saw in Chapter 8, the Dutch government has made a considerable investment in the production and dissemination of online information about health care and many client councils have created their own websites where they provide an explanation of their goals and initiatives. Cape Verdeans' inability to use the Internet limits their access to this kind of information. Second, there seemed to be no clear attempts to mobilise Cape Verdean users to participate in client councils, either by Project Apoio or by mental health care services. As we showed in Chapter 7, direct recruitment played a fundamental role in facilitating the participation of Cape Verdeans in Project Apoio's initiatives by helping them to set aside feelings of powerlessness and a certain apprehension in relation to activities in the field of mental health. Being asked to join client councils may have had a positive impact in enabling Cape Verdean users to become acquainted with these spaces, and perhaps even in building confidence that they too could make a meaningful contribution to health care planning and evaluation. However, as we discuss below, without fostering the acceptance of people suffering from psychosocial distress by the Cape Verdean community it is unlikely this would have been enough to guarantee their participation.

Taking part in mental health care participatory spaces entails exposure, i.e. people who are actively engaged in those spaces are more likely to have their health problems disclosed to the public. This is not always a desirable situation where mental illness is concerned. As Finken (1997) observes, the stigma associated with mental illness often emerges as a 'second illness' which carries with it a real threat of social isolation. As we showed in Chapter 7, mental illness is highly stigmatised among the Cape Verdean community in Rotterdam. Admitting that one is a mental health care user puts people at risk of denigration, status loss, discrimination and exclusion. As a result, many Cape Verdeans to not seek psychological help and, when they do, they try to keep it out of the public eye. Indeed, there are few Cape Verdeans who refer to mental health services by their name. Most prefer to say: "I went to that place in Mathenessserlaan[142]". Moreover, the fear of being labelled mentally ill is so prevalent that some users are led to omit and even hide their problems. The case of José (NL) is a paradigm case of this. As we saw in the previous chapters, José was one of the most active volunteers at Project Apoio. However, it took him several years to 'come out' as the father of a young man diagnosed with schizophrenia and to admit he had sought the help of a psychologist to deal with the distress this was causing. For a long time, José said his son had behaviour problems and was put in prison. It was only when the coordinator of Project Apoio ran into him in a psychiatric hospital that José was able to disclose that he was there to visit his son. When the label 'criminal' appears to be less burdensome than the label 'mentally ill' it becomes evident how strong the fear of the negative consequences of stigmatisation really is.

By the time I interviewed José he was comfortable enough to speak about his son and about mental illness with people he trusted. Yet, like many other Cape Verdeans, he was not prepared to discuss those issues openly in his community. Being involved in Project's Apoio participatory initiatives did not require users to disclose their mental problems, nor did it offer evidence to others around them that they may be suffering from psychosocial distress. Project Apoio also provided social support and its public events versed over various subjects that were not always explicitly linked to mental illness. This gave users the feeling that their identities as mental care users were protected. The same cannot be expected from participation in client councils.

> We don't have people from the [Cape Verdean] community participating in client councils. When you speak of *cliëntenparticipatie* [client participation] you are actually saying that you are a 'client' and that you 'participate'. That is the same thing as giving the [Cape Verdean] community a certificate of your insanity. There are very few people who can do that. That's a movement we still need to create. (Project coordinator at client organisation, NL)

Membership in mental health care client councils is usually only available to people who experience(d) psychosocial distress and, in some cases, to their family members. From the moment one joins the council it is no longer possible to deny one's connection to mental illness. As explained by the coordinator of Project Apoio in the citation above, becoming a councillor would function as a 'certificate of insanity' for the whole Cape Verdean community. The threat of exclusion that this entails is a cost few people are inclined to bear. Indeed, of the few Cape Verdeans users who were aware of the possibility to participate in client councils, none showed interest in becoming involved. As observed by Mansbridge (2003b), "what looks like apathy is sometimes a conscious decision not to get involved in a disagreeable situation" by

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[142] Mathenessserlaan is the name of the street where one the main out-patient mental health care services in Rotterdam – RIAGG Rijnmond – is located.

people who fear that participation can result in disparagement and discrimination from others (*ibid.*: 193). Cape Verdeans may prefer to ignore possibilities of engagement in client councils rather than running the risk of being ostracised from their community.

The participation of Cape Verdeans in client councils also appears to be hampered by 'supply-side' inhibitors to engagement. As noted earlier, there were no active attempts by mental health care services in Rotterdam to mobilise Cape Verdean users to participate in their client councils. As evidenced by other studies, health care institutions claim to have too little time and resources to reach out, motivate, and directly recruit migrant and ethnic minority users into their participatory spaces (Nederland and Steketee, 2004). Without more efforts to make their activities known to the wider public it is unlikely that client councils will succeed in having a diverse membership and to representing a plural user voice. Yet the problem does not seem to be just a lack of mobilisation efforts. According to several respondents in our stakeholder cluster, the goals and actions performed by client councils are not appealing enough to attract a heterogeneous set of councillors.

> Intercultural manager: The central client council meets in the same building where I work [mental health care service in Rotterdam]. When I look at them [councillors] coming in I see that there many old people. Most of them are 50, 55 years old, or even older. I think they are still the same people I used to see when I began to work there, and that they're still discussing the same things. They are very willing to participate in all kinds of things but they are also people with a very slow pace. I miss the input of younger clients and I miss a more active way of dealing with client issues. It is now mostly a very slow process of reacting to questions from the central management. The law says that the client council has to be consulted and then they react. But I think it is important to have a more active way of dealing with clients' affairs. It is important they make proposals about things that matter to clients.
> Interviewer: Why don't young people join the council?
> Intercultural manager: I think the client council has a kind of dusty imago. It doesn't appeal to younger people. What I also see is that it's a very white council. Considering that 30% or 40% of our clients are non-natives or have parents born outside the Netherlands, it is a very white, one-sided council. So maybe it's the form, the structure we chose which does not appeal to the young or ethnic patients we have. (Intercultural service manager 2, NL)

The quotation above raises two important issues. One concerns one-sided ethnic composition of client councils[143]. The other is concerned with the type of input expected from client councils in mental health care services and its lack of appeal to the

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[143] Our respondent also talks of the old age of councilors. However, we are not able to say whether this is an aspect which characterises most of the other client councils in the country. For this reason, we do not discuss this issue here.

‘ordinary user’. As observed by our respondent, it is often the management of health care institutions which decides the topics on which councillors should provide advice (see also Hoogwerf *et al.*, 2004). Client councils are increasingly asked to provide feedback on complex issues such as mergers between institutions, service re-allocation, yearly budgets, etc. This is putting considerable pressure on users to professionalise, i.e. users are increasingly required to acquire the knowledge and command the jargon employed by managers in order to discuss issues related to health care. This ‘skilling up’ (Newman *et al.*, 2004) not only demands considerable efforts on the part of users to obtain technical expertise, it also robs them of the time and opportunities necessary to bring their own concerns to the participation table (Trappenburg, 2008). As a result, the scope of the activities developed by client councils is becoming progressively narrower and less interesting for users who, like our Cape Verdean respondents, are still struggling to deal with stigmatisation and gain access to mental health care. Indeed, as we saw in Chapter 7, Cape Verdean users’ motivations for joining participatory spaces (e.g. learning about mental health, finding a meaningful social role, pursuing social justice and inclusion) are very far from the current emphasis given to bureaucratic and technical aspects of health care provision within client councils. Similar mismatches may be undermining the participation of other migrant and ethnic minority groups in those spaces. Moreover, as explained by a facilitator of a mental health client council, the kind of tasks performed by client councils requires a set of resources (e.g. skills to read and interpret documents written in managerial language) which are not easy for Dutch natives to obtain, let alone for migrants.

> Migrant participation won’t thrive on its own. Efforts must be made to create possibilities for migrants to get involved. One of the problems is that the sort of work done by clients [in client councils] is very bureaucratic. They must read a lot of documents and the language used is really complex. Natives have problems doing it… for migrants it is even harder. It is not all that attractive to be in a client council. We need to start discussing more interesting things. We need to find out what migrants want to talk about. (Client council facilitator 1, NL)

What the citation above reveals is that little efforts appear to have been made by client councils to reach out to members of migrant and ethnic communities and to identify their concerns. The more client councils abstain from identifying and dealing with the issues that really matter to users, the less likely they will be to attract members of the social groups they are meant to represent. Furthermore, the more homogeneous client councils become, the further away they will get from fulfilling their ‘third party’ role within the system of checks and balances devised by the Dutch government to keep all the market forces (i.e. care providers, insurers and users) at work in the formulation and implementation of adequate health care policy and delivery. Indeed, the absence of a plural citizen voice within health invited spaces jeopardises the realisation of the principle of demand-driven care and with it the chances that health care services become better tailored to the needs of ever more diverse and complex user groups.

9.3 Conclusion

This chapter analysed the inhibitors undermining the full advancement of participation in mental health care among our research groups. The case of Cape Verdeans migrants in Rotterdam illustrates a situation in which users fail to gain entry into client councils, i.e. in which their formal inclusion in mental health invited spaces is hampered. The case of minority Northeasterners in Brazil provides an example of how limited influence in decision-making concerned with care planning leads users to withdraw from the assembly, undermining their substantive inclusion in the participatory spaces. In both cases, the outcome is non-participation. While the Dutch case evidences a situation in which the commencement of participation is obstructed, the Brazilian case illustrates a situation in which the sustainability of participation is threatened.

These results are explained by the action of different types of inhibitors of user participation. As our data shows, Cape Verdeans' non-participation in client councils is explained by lack of information about and the potential high costs associated with participation in mental health care services, in particular the risk of being identified as mentally ill and, as a result, become excluded from the Cape Verdean community. Lack of recruitment efforts by client councils also fails to create the additional incentives Cape Verdeans may require in order to join.

Minority Northeasterners' withdrawal from the assembly of CAPS Pedro Pellegrino is explained by users' disappointment with not achieving important goals (e.g. developing better income generation workshops), a perceived lack of transparency on the part of professionals regarding the extent to which users can expect to influence decisions related to care planning, and waning mobilisation by participation instigators.

What these cases tell us is that unawareness of, self-exclusion from, and exclusionary dynamics within participatory spaces play a powerful role in slowing down or curtailing participation. This limits the inclusiveness of health participatory spaces. For user participation to thrive, health authorities need to start considering issues related to the representativeness of the health participatory sphere and to develop strategies to enhance its accessibility for under-represented groups. As pointed out by a participant in the Netherlands, it is important to "find out what migrants [or any other under-represented group] want to talk about" (Client council facilitator 1, NL). This means reaching out to voiceless groups, establishing a dialogue about their concerns, and making room within participatory spaces to bring those concerns to the fore. User movements can also have a positive input in increasing the inclusiveness of health participatory spaces. As our study in Brazil demonstrates, long-standing participants in the user movement were not just aware of the barriers causing the drop-out of their fellow users they also showed willingness to promote engagement (e.g. by approaching drop-outs directly and appealing to the importance of their contributions as part of a collective concerned with improving mental care). This kind of insight and dedication needs to be tapped into. In other words, the promotion of a plural citizen voice in mental health care governance requires a combination of efforts 'from above' and 'from below' (Gaventa, 2004a).

For sure not each and every user can be expected to participate. This is not just because it is literally impossible to involve everyone in participatory processes (Cornwall, 2008b), but also because people may experience cognitive, emotional and physical limitations which undermine their ability to get engaged (Barnes and Wistow, 1994). Moreover, the costs of participation can be much higher than the benefits it is expected to deliver and people may abandon participatory spaces, or decide not to become involved, as a result of legitimate concerns with securing their wellbeing (Trappenburg, 2008), as was the case of Cape Verdean migrants in our study. Indeed, we support the view expressed by Lister (1997) that participation needs to be seen as an opportunity and a right but not as an obligation of citizenship, to avoid intensifying the exclusion of people who do not have the necessary resources to participate (Guijt and Shah, 1998). Inaction and self-exclusion, however, must not be caused by lack of opportunities for engagement, insufficient mobilisation or exclusionary dynamics within participatory spaces. For as long as participation is a right – as it is in the field of health care in the Netherlands and in Brazil – governments have the responsibility to provide directives for and enforce the implementation of the participatory spaces necessary for citizens to realise that right. This is to say that where 'supply-side' factors of participation are concerned, all efforts need to be done to render the participatory sphere receptive to representatives of the different constituencies in society.

A key difference between our research groups is that minority Northeasterners in Brazil succeeded in reaching health invited spaces (i.e. mental health conferences and health councils) while Cape Verdean migrants in the Netherlands were not able to engage in comparable participatory spaces (i.e. client councils). A possible explanation for this difference lies in the type of approaches (democratic *vs.* consumerist) to user participation currently in place in those countries. As we saw in Chapter 2, Brazil adopts a democratic approach to participation which sees users as citizens and participation as a matter of devolving decision-making power over governance affairs to the citizenry. Power is at the crux of this approach, which assumes the need to identify the 'haves' and the 'have-nots' and to extend opportunities to the latter to become empowered and take part in decision-making. As a result, several health councils in Brazil have promoted the establishment of a quota system which reserves seats in civil society organisations and social movements representing the interests of traditionally marginalised groups (e.g. people affected by disabilities, AIDS, etc.) (Coelho, 2004). Furthermore, as our study shows, the mental health user movement makes concerted efforts to facilitate the access of disadvantaged users to invited spaces (namely, mental health conferences) not just by gathering funding to sponsor their travel expenses but – perhaps more importantly – by encouraging and mobilising them to get involved. This indicates a concern with fostering the representation of social groups who are likely to experience more difficulties in becoming included in the health participatory sphere on account of inequalities in knowledge, communication skills, status and power.

Such a concern with promoting the participation of less privileged groups in health care governance was also present in the Netherlands during the 1970s and 1980s, and was especially evident in the field of mental health care. At that time, the marginalised social position of people affect by mental illness, and their lack of citizenship, stood high on the agenda of the Dutch user movement and concerted efforts were made to promote their empowerment (in Dutch, *emancipatie*) and to give them voice in mental health policy and service delivery (see Chapter 1). Such emphasis on a democratic approach to user participation has been losing ground to consumerism since the 1990s, when the marketisation of Dutch health care began (see Chapter 2). Consumerist approaches to participation view users as consumers and participation as a means of providing feedback to the market on consumers' preferences and needs (Beresford and Croft, 1993). Within the consumerist discourse, the health care consumer is depicted as an autonomous, sovereign individual who acts as an economically and socially self-interested agent who will complain (or vote with his/her feet) when dissatisfied with the services received. Implicit here is the assumption that people are equally well positioned and resourced to participate if they are presented the opportunity to do so, i.e. if participatory spaces are in place. This might explain the absence of policy directives in the Netherlands aimed at guaranteeing the representativeness of invited spaces such as client councils and at encouraging those spaces to invest in the recruitment of members of under-represented groups. Such an investment appears to be highly needed, however. As the case of Cape Verdean migrants illustrates, not all users are informed about mental health invited spaces nor is everyone capable of coming forward in the defence of their rights and needs when they are not met.

The Dutch user movement could be making the supplementary efforts necessary to facilitate the access of voiceless groups to invited spaces. However, there is little investment by client organisations in the Netherlands to reach out to those groups and to devise initiatives aimed at providing them with the skills and confidence necessary to engage in higher levels of participation. This is most evident in regards to migrant and ethnic minority groups, but people with addictions, the homeless and youngsters are also poorly engaged in participatory spaces (De Savornin Lohman *et al.*, 2000; Nederland and Steketee, 2004). Such lack of investment seems to be explained by two problems. First, many client organisations are overloaded with requests by the government to take part in policy decision-making processes (through advisory conferences and meetings with public officials) and, the efforts made to respond to those requests are draining them from the time and resources necessary to reach out to grassroots users (Van de Bovenkamp *et al.*, 2010). Second, many client organisations are becoming increasingly professionalised as a means to improve their capacity to influence policy-making (Nederland and Duyvendak, 2004) and their attempts to recruit users are turning into a 'search for the right volunteers', that is into a search for people who already have many of the competences necessary to participate (Van de Bovenkamp *et al.*, 2010: 81). Both these problems alert to the risk of client organisations becoming increasingly detached from less empowered and vocal users. Yet these are precisely the users who require most assistance in gaining access to the participatory spaces where decisions with a bearing on their lives are made.

Overall, it appears that neither health invited spaces or the user movement in the Netherlands are making sufficient efforts to reach out to under-represented groups and increase the diversity of user voices in the Dutch participatory sphere. Enhancing the representativeness of Dutch health participatory spaces may require a return to a proactive approach to user participation which acknowledges that marginalised groups need to build confidence, capacity and a sense of entitlement in order to exercise their citizenship and make use of opportunities to participate. Furthermore, it may require the creation of spaces where those groups can feel comfortable enough to share their concerns, develop a critical consciousness of the factors determining their exclusion, formulate common interests and build a politics of engagement (Mansbridge, 2000). As we saw in Chapter 7, the participatory initiatives developed by Project Apoio are an example of such spaces. Yet this was one of a handful of projects promoted by Dutch client organisations to facilitate the participation of one of the least represented groups in the Dutch participatory sphere, i.e. migrant and ethnic minority groups. In the future, more efforts need to be made to create similar spaces that can work as fore-runners for the participation of disadvantaged groups in invited spaces.

A final note concerns the fact that even in countries where a democratic approach to user participation prevails, many barriers work to impede the inclusion of disadvantaged groups in health invited spaces. As we saw in Chapter 2, poor and ethnic minority groups are still under-represented in the Brazilian participatory sphere (Pozzoni, 2002; Coelho *et al.*, 2005). The success of minority Northeasterners in entering mental health invited spaces highlights both the importance of direct recruitment and capacity-building and the need for continuous investment by the government and civil society (e.g. user movements) to overcome the barriers that challenge the inclusiveness of the participatory sphere (i.e. a proactive approach).

Conclusion

This thesis examined participation in mental heath care by users from socially disadvantaged ethnic minority groups. The problem it set out to analyse was the limited inclusion of minority users in health participatory spaces. Reduced participation by ethnic minorities has been identified in the Netherlands (De Savornin Lohman *et al.*, 2000), England (Crawford *et al.*, 2003), Australia (Sozomenou *et al.*, 2000) and Brazil (Coelho *et al.*, 2005). Lack of involvement in health care governance puts minority groups in a position of disadvantage compared with other groups whose voice is more clearly heard. Furthermore, it risks producing or exacerbating health inequities as health care services become increasingly adapted to the needs of the majority, without paying due attention to those of minorities. This can be especially problematic in the field of mental health care, where the success of care practices requires understanding and incorporating the social, cultural and ethnic background of users in treatment.

The potential of user participation to help devise responsive policies and services depends on the capacity of health participatory spaces to faithfully reflect the diversity of (potential) users. So far, few empirical studies have set out to investigate what works in bringing ethnic minorities into the health participatory sphere. The aims of this thesis were to identify minority user groups who are engaged in mental health care and to learn about why and how they get involved, and which factors undermine their participation. To achieve these goals, we investigated two user groups which are an example of success amongst the least represented social groups in the Dutch and Brazilian health participatory spheres: Cape Verdean migrants in Rotterdam and minority Northeasterners living in Rio de Janeiro. Both these groups suffer multiple forms of discrimination on account of low socio-economic status and minority ethnic status, in addition to the prejudices and stigmatisation associated with mental illness. Their participation in health care governance is imperative for developing policies and services more tailored to their needs and to start tackling the factors at the root of their exclusion.

As explained in Chapter 6, there are several reasons why we selected the Netherlands and Brazil as the setting of our case studies.

- First, user participation in health care is treated in these countries as a right.
- Second, both the Dutch and the Brazilian governments have passed legislation promoting the creation of 'invited participatory spaces' (Cornwall, 2004b) that enable public health officials, service providers, insurers[144] and users to

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[144] The participation of representatives of insurance companies is only relevant in the Netherlands, because Brazil has a tax-based public health care system.

come together to discuss health care policy and delivery. These spaces include client councils and advisory conferences and meetings in the Netherlands, and health councils and health conferences in Brazil.

- Third, both the Netherlands and Brazil host mental health user movements that played an important part in the democratisation of health care decision-making and have remained active until today.
- Finally, these countries adopt contrasting approaches to user participation. In Brazil, participation has an explicit political meaning; it is seen as a process involving the redistribution of power and control to the citizenry and as a means to hold the state to account in fulfilling its responsibilities. Users are viewed as 'makers and shapers' (Barnes, 1999) of health policy and service provision, and the stress lies on participatory mechanisms promoting 'voice'. In the Netherlands a combination of democratic and consumerist approaches to user participation is found, but the latter have gained considerable prominence in the past decade. The consumerist approach looks at participation as a means of informing the suppliers of health care about users' needs and preferences. Users are viewed as consumers and the emphasis lies in participatory mechanisms promoting 'choice'.

These different approaches to participation influence the ways by which issues of representation are handled in the health participatory sphere. Although both the Netherlands and Brazil face considerable problems in achieving inclusive health participatory spaces (see Chapter 2), the democratic approach recognises the fact that not everyone is equally well equipped to voice their concerns and that special efforts therefore have to be made to bring those who have been traditionally at the margins of decision-making processes into the participatory sphere. A key conclusion of our research is that **ethnic minority users can be successfully engaged in mental health participatory spaces, but promoting their involvement requires a proactive approach which acknowledges that marginalised groups need to build confidence, capacity and a sense of entitlement in order to exercise their citizenship and make use of opportunities to participate.**

In what follows, we describe the empirical findings that support these arguments. Before doing that it is useful to look briefly into the historical background of user participation in mental health care and recent developments in policy which attest the need for a minority user voice in both the Netherlands and Brazil.

Participation in mental health care

Mental illness is one of the most stigmatised conditions in the Western world (Skinner *et al.*, 1995; Sayce, 2000). Such disorders are also stigmatised in other parts of the world, but according to historians the opprobrium attached to insanity became particularly intense as a result of industrial modernisation and the philosophy of the 'Age of Reason'. From the mid-seventeenth century onwards, the 'mad' became associated with idleness, immorality, violence and dangerousness (Foucault, 1961). Supposedly bereft of the essential human faculty of reason, they were regarded as no better than beasts. An orderly and efficiently organised society required them to be excluded and segregated. In this way arose a 'trade in lunacy', engaged in running madhouses or 'lunatic asylums', and (later on) psychiatric hospitals, in which they could be kept at a safe distance from the rest of society (Scull, 1979). As we saw in Chapter 1, the first psychiatrists were called 'alienists' and treated their patients in complete segregation (Castel, 1976).

In conventional histories of psychiatry, the reformulation of 'madness' in medical terms in the nineteenth century is usually seen as a humanising development, symbolised by Pinel's freeing of the inmates of the Hôpital Bicêtre from their chains. Critical histories, however, regard this step as simply a new and more efficient form of segregation; those whose minds were 'sick' could not be taken seriously or treated as agents, and were just as effectively banished from society as those kept in chains. The system of asylums that sprang up in industrialised countries in the nineteenth century became a sort of gulag in which large numbers of people suffered total social exclusion. In these 'total institutions' patients lost touch with the world and their sense of self and became, as Goffman (1961) put it, 'mortified'.

The American 'mental hygiene movement' was founded in 1909 by Clifford Beers, a 'survivor' of incarceration, to promote alternative approaches to mental illness. However, the asylum system itself was not effectively challenged until half a century later: in the 1960s social movements started to emerge questioning the incarceration and abuse of mental patients in asylums, and calling for a reconceptualisation of mental illness as a reaction to broader societal factors. Among those movements were British anti-psychiatry and Italian Democratic Psychiatry. Anti-psychiatry was enthusiastically received by reformers in the Netherlands and helped to further the development of a psychosocial approach to mental distress and an expansion of community-based mental health services (Ingleby, 1998; Blok, 2005). Democratic Psychiatry was one of the major influences behind the radical process of psychiatric reform in Brazil that aimed at abolition of the asylum system and enabled thousands of psychiatric patients to return to life in the community (Birman, 1992; Amarante, 2006). These developments stimulated the growth of user movements in the Netherlands and Brazil, enabling alliances to be formed between critical professionals and groups of users who were becoming increasingly empowered.

Both the Dutch and the Brazilian user movements are thus rooted in a powerful drive to eliminate oppressive and segregating 'treatments', promote deinstitutionalisation and devise alternative care solutions within the community. They have also striven to democratize mental health care governance by bringing a user voice into decision-making on mental health policy, service planning and care delivery (Haafkens *et al.*, 1986; Nederland *et al.*, 2003; Nicácio, 2003). As we saw in Chapters 1 and 2, their actions have borne much fruit. The Dutch user movement was influential in getting several laws adopted regulating user participation in treatment and health care (the WGBO and WMCZ laws), as well as the creation of many invited participatory spaces including client councils and advisory conferences and meetings. The Brazilian user movement succeeded in turning user participation in health care governance into a constitutional right and in facilitating the creation of municipal, state and national level invited spaces including health councils and mental health conferences.

In spite of these achievements, both the Dutch and the Brazilian movements recognise that the need for user participation is not only justified by its ability to help improve the quality of policy and care provision. The strong stigma attached to mental illness continues to exacerbate the exclusion of people affected by psychosocial distress from society. For these movements, thus, user participation is also viewed as a powerful means to expose and challenge the social structures which impede mental care users from exercising their full citizenship, i.e. from participating in an active and rewarding way in all spheres of life (Oudenampsen, 1999; Maia and Fernandes, 2003).

The need for a minority user voice in mental health care

Although the Dutch and the Brazilian user movements struggle to promote the social inclusion of people affected by psychosocial problems, they are not equally representative of all groups in society. In particular, as we saw in Chapter 5, ethnic minority groups continue to be under-represented. Moreover, minority users have a less effective voice in Dutch and Brazilian invited participatory spaces (De Savornin Lohman *et al.*, 2000; Nederland and Steketee, 2004; Coelho *et al.*, 2005). Recent developments in health care policy in the Netherlands and in Brazil underline the importance of making the health participatory sphere, and the user movements connected to it, more receptive to ethnic minority groups. There is thus an urgent need to strengthen the voice of ethnic minority users in health care.

The Dutch case

As we saw in Chapter 1, the Dutch government has implemented a set of reforms since the 1980s which transformed the Dutch health care system into a quasi-market. At present, the market agents – that is, the care providers, insurers and users – share responsibility for the implementation and evaluation of health care services and are all represented in consultations with government to decide on the course of health care policy. In 2006, the government approved a major piece of legislation – the Health Insurance Act – which made the buying of health insurance compulsory for all residents in the Netherlands and effected a provider-purchaser split, turning the Dutch health care system into an insurance-based and (in principle, though not yet in practice) market-based system.

The increasing marketisation of health care in the Netherlands – in which the 2006 Act was only one of many stages – has had consequences for policies relating to ethnic inequities in health. Whereas the previous administration had introduced in 2000 a national action plan on migrant and minority health, as we saw in Chapter 5, a new Minister of Health announced in 2004 that he saw no role for the government in this area. The problems were left to service providers, users and insurance companies to solve. This statement in itself did not mean that the Minister disregarded the problems, although he made it clear that he did not regard them as very serious and expected that the passage of time would do a lot to resolve them; in the context of the marketisation policy, it was simply an explanation of who was supposed to do what.

However, leaving 'interculturalisation' to the market agents, or the 'field' as it is often referred to, has had important consequences for care delivery. Chapter 5 also describes how the government's commitment to integrated services (which had been maintained, with some exceptions, for 25 years) was allowed to lapse; it now became possible to set up separate services for migrants and ethnic minorities, and many enterprising service providers did just that. At the same time the project of making all health services responsive to diversity began to falter, and 'interculturalisation' came to be regarded as an outdated ideal. This outcome must be regarded as a step backwards for migrant and minority groups. It shows clearly that the participatory mechanisms in place in the Netherlands (based on 'consumerist' rather than 'democratic' principles) are not an adequate means of ensuring good quality care for these groups, who are less well equipped to make use of these mechanisms. This means that concerted efforts must be made to render participatory spaces more receptive to ethnic minority groups and to provide these groups with the resources necessary to participate in decision-making.

The Brazilian case

Brazil has taken the opposite path to that of the Netherlands. Instead of letting the market take over the provision of health care, the Brazilian government created a tax-based national health system. Until the fall of dictatorship in 1985, the military regime contracted out much of its health care services to the private sector, and private psychiatric hospitals became good business. In 1988, the new democratic government issued a new Constitution that declared health a right of the people and a responsibility of the state. As we saw in Chapter 1, this led to the creation of a public health care system with universal coverage and gave impetus to a broad range of health care reforms, including the Psychiatric Reform.

The Psychiatric Reform became mental health policy and a full-blown national process in 2001 when the law providing for deinstitutionalisation and the creation of alternative community-based mental health services was passed. Despite the efforts to increase the accessibility of good quality psychosocial care to all in need, limited funding, inefficient expenditure control and endemic corruption have impeded the creation of adequate community-based psychosocial services (CAPS), leaving many users under-served. Furthermore, there is currently no migrant health policy in place in Brazil even if, in cities like Rio de Janeiro, over one fourth of the inmates of psychiatric hospitals are internal migrants (Silva *et al.*, 1999; Oliveira, 2002). Lack of attention to cultural competence in mental health care has been found to lead to the inappropriate pathologisation of internal migrants' subjective beliefs, habits and behaviour (Ferreira, 1996). This indicates there might be a mismatch between the mental health care needs of minority groups and the care currently available to them. Finally, the 'trade in lunacy' which emerged during the dictatorship is still very strong. Owners of private psychiatric clinics have not yet gone out of business and they pose a concerted threat to the continued implementation of Psychiatric Reform. As recently as 2007, they launched a manifesto calling for its abolition. Seeing that their lobby succeeded in getting the approval of the Psychiatric Reform Law by the Brazilian Senate delayed for over ten years, this is no empty threat.

All these problems stress the need for a plural citizen voice in the Brazilian health participatory sphere which can call attention to the shortcomings of current mental health policy and make proposals for the development of diversity-sensitive health care, and that can work as a counterweight to the actors threatening the implementation of Psychiatric Reform.

Engaging disadvantaged minority groups in mental health participatory spaces

A central question of this thesis is: what facilitates the involvement of disadvantaged minority users? As the empirical findings described in Chapter 7 demonstrate, the involvement of Cape Verdean migrants and minority Northeasterners in mental health participatory initiatives was influenced both by concerns with their own personal wellbeing and concerns with the welfare of the communities they belonged to. However, as we showed, being motivated to participate is not sufficient to get users actively involved. Most only did this after being personally invited by the instigators of the participatory initiatives researched. Moreover, once they got into mental health participatory spaces, it was clearly necessary to assist them in building capacity to act within an environment where they felt encouraged and comfortable to share their concerns and limitations. This suggests that motivations, direct recruitment, capacity-building and empowering participatory spaces are all crucial factors in enabling the participation of users groups in a position of disadvantage. These findings are in line with the Participation Chain Model (Simmons and Birchall, 2005) described in

Chapter 3, which asserts that user participation depends as much on demand-side factors (i.e. users' motivations) as it does on supply-side factors (i.e. mobilization, resources and the dynamics of participatory spaces). In what follows, we show how these factors influenced the involvement of our research groups. We also report on the factors leading to the success of the participatory initiatives we researched: Grupo de Conversa and Comissão at Project Apoio and Assembleia at CAPS Pedro Pellegrino.

Demand-side success factors for participation

The participation of Cape Verdean migrants and minority Northeasterners was driven by a broad range of motives including personal and collective concerns. Following the Mutual Incentives Theory (Simmons and Birchall, 2005) described in Chapter 3, we analysed these concerns in terms of individual and collective motivations which interact to influence people's decisions to participate.

- **Individual motivations** are related to the benefits of participation that individuals expect to obtain for themselves. As our interviews show, participants were concerned with increasing their level of social interaction, being included in social spaces, finding paid work, acquiring a meaningful social role, overcoming the stigma attached to mental illness and increasing the use of mental health care. These motives say a lot about their marginalised status. The need to engage in social contact and to feel accepted in social spaces reveals the rejection and social isolation many of them experienced as a result of discrimination. The desire to acquire valued social roles, particularly through employment, indicates the economic hardship, financial dependence and humiliation many had to deal with on a daily basis through being considered too incompetent to take part in economically productive activities. The aspiration to overcome taboos and stigmas concerning mental illness reflects the negative effects of (self-)stigmatisation: this induces a sense of powerlessness and hopelessness among users and undermines their ability to identify the need for, and gain access, to mental health care. It also reinforces their alienation from mainstream society.
- **Collective motivations** are related to the benefits of participation that individuals expect to obtain for others with whom they identify, or whose cause they support. Participants in our study showed concern with increasing the responsiveness of mental health care services and achieving greater social justice for people affected by mental problems. In addition to the multiple forms of discrimination described above, our respondents belonged to disadvantaged ethnic minority groups living in socially and economically deprived geographical areas with high rates of crime, low quality schools, poor housing and limited recreational facilities. These circumstances limit their life opportunities and their access to the social determinants of health (i.e. safety, good education, sufficient incomes, adequate housing, health care, etc.)

> making them more vulnerable to illnesses and less likely to obtain treatment for them. As argued by Anand (2004), inequalities in health are closely linked with inequalities in citizens' basic rights and opportunities. Many of our participants expressed frustration with not being able to exercise their citizens' rights (e.g. acquiring social security benefits, accessing adequate mental care) or to pursue valued goals in life (e.g. becoming employed and taking part in community activities). This experience of social unfairness and exclusion made them feel angry and motivated to act.

Put together, the individual and collective motivations expressed by our research groups reflect a strong aspiration for social inclusion. They demonstrate an urgent need by users to gain access to and engage in meaningful social relationships, civil activities, work, recreation, basic services (including health and social care) and community life. This is not a surprising finding given the marginalised position they find themselves in. But it is an important indicator for participatory initiatives seeking to involve disadvantaged groups that they might need to invest in activities focused on the promotion of social integration if they are to appeal to those groups. As we show below, this was one of the factors contributing to the success of Project Apoio and CAPS Pedro Pellegrino in getting minority users on board their participatory initiatives.

Supply-side success factors for participation

Active mobilisation was fundamental in facilitating the participation of most Cape Verdean and minority Northeastern participants. When people first consider participating it may be difficult for them to grasp the potential benefits of their involvement. Moreover, the payoffs of participation may seem too low or too distant (e.g. obtaining previously denied social benefits), while the costs can appear much too high (e.g. the fear of being classified as insane). Uncertainties and fears of this sort prevented many of our respondents from taking the first step. Without the efforts of the main participation instigators at Project Apoio and CAPS Pedro Pellegrino to directly approach and recruit users, many of them would have remained inactive. Moreover, once they got engaged, it was necessary to continue mobilising them to join the ongoing participatory initiatives. Perseverance was required until users felt more empowered to participate on their own accord.

The power of direct recruitment lies in making people feel valued and wanted. Being asked time and again to join a collective concerned with improving the social position of a group one identifies with, gives people a feeling of recognition and offers them an opportunity for affiliation and action. These opportunities are especially appealing to disempowered people living at the margins of society. Invitations to participate are experienced as a 'vote of confidence' in their personal competences and their ability to make a difference. This, in turn, generates a feeling that one has what it takes to promote change. Direct mobilisation for participation is also an open and deliberate attempt to recruit people into a group. As we have seen, our respondents suffer discrimination in practically all spheres of life. Participatory groups may well be one of the few social groups they are explicitly and consistently invited to join. In this way, these groups provide an exceptional opportunity for developing new social relationships and a sense of belonging. These factors strengthen participants' resolve to stay engaged.

However, in order to feel they can make meaningful contributions users also need to be resourced. Both Project Apoio and CAPS Pedro Pellegrino invested in providing users with information on their rights, the mental health care system, psycho-social problems, and the instruments available to handle complaints for malpractice. They also promoted information sessions and public debates as a means of fostering users' critical consciousness about the sources of their disadvantage and the mechanisms available to start changing them. Moreover, they created room for users to voice their concerns, discuss their views and plan new actions (e.g. manifestations, mental health awareness-raising activities) without having to fear mockery (more important for minority Northeasterners) or to feel compelled to 'come out' as mental patients (more important for Cape Verdean migrants). Involvement in this broad range of initiatives enabled users to take part in processes of consultation and deliberation which, in turn, increased their knowledge about subjects concerning their interests and enabled them to develop the skills necessary to pursue them. As their skills began to accrue, many users started regaining a sense of self-efficacy and improved self-esteem which were crucial in building their confidence that they can act.

The value of hybrid participatory spaces

As our case studies show, promoting social inclusion emerged as one of the most important motivations driving the participation of Cape Verdean migrants and minority Northeasterners in mental health participatory spaces. These motivations include, but are not limited to, the desire to improve users' access to good quality mental health care. They evidence peoples' need to overcome a wide range of problems (e.g. stigmatisation, devaluation, isolation, socio-economic deprivation, discrimination in the labour market and – indeed – poor access to care) which impede them from fully taking part in social life. These motivations go far beyond the actions usually undertaken within (mental) health invited spaces, most of which are confined to issues of health care governance and provision. As noted earlier (see also Chapter 1), neither the Dutch or the Brazilian user movements consider such actions to be sufficient goals of participation for people with a history of exclusion. These movements have thus oriented themselves toward improving the quality and accessibility of mental health care *and* to promoting the rights and social integration of people affected by psychosocial distress.

The ability of Project Apoio and CAPS Pedro Pellegrino to attract disadvantaged minority users into their participatory initiatives appears to result from an approach to participation which combines those two goals. As we saw in Chapter 3, Assembleia at CAPS Pedro Pellegrino and Comissão and Grupo de Conversa at Project Apoio are hybrid participatory spaces, i.e. they are spaces sponsored by public authorities which keep a direct connection to local user movements. This hybrid nature makes them sensitive to the needs and demands of both government and users. As such, they not only invest in facilitating the engagement of users in mental health care decision-making processes, but in supporting them to deal with the wide-ranging problems underlying their exclusion. Furthermore, they recognise that participation by marginalised groups is unlikely to be sustained without continuous efforts to mobilise and resource them. The success of Project Apoio and CAPS Pedro Pellegrino in enabling the involvement of so-called 'hard-to-reach' groups thus seems to stem from adequate investment in three types of activity:

1. recruiting users directly to get involved and repeatedly asking them to join participatory spaces;
2. taking on and responding to most of the individual and collective concerns they have; and
3. equipping them with the resources and confidence necessary to influence decisions within participatory spaces and to devise actions aimed at exposing and criticising the social, economic and environmental barriers which hinder their social inclusion.

Benefiting from participation and taking it a step forward

Another two key questions of this thesis were: what are the benefits of participation for disadvantaged minority users, and how do these benefits contribute to maintaining their engagement? As evidenced by the data we presented in Chapter 8, participation in mental health participatory spaces can deliver a number of benefits including broader social networks, empowerment, increased sense of agency and citizenship, enhanced health literacy and improved access to mental health care. These benefits have a positive impact on each other and, together, they reinforce participation. Users who have experienced the positive effects attached to participation show greater capacity and willingness to stay involved and are more prepared to pursue higher levels of engagement (e.g. participation in health invited spaces). Furthermore, they are also keen to recruit other users and help them to get involved. This emphasises the importance of benefits not just for sustaining user participation, but also for taking engagement a step forward.

As our case studies show, however, these results are only observed among users who express collective motivations for participation, i.e. who have a commitment to promote the welfare not just of themselves, but also of a group. We elaborate on this point below. First, we describe in greater detail the benefits of participation experienced by Cape Verdean migrants and minority Northeasterners.

Benefits of participation

Participation enabled users to broaden their social networks. By entering the participatory spaces promoted by Project Apoio and CAPS Pedro Pellegrino, users got an opportunity to enhance social contacts and build new relationships. Exposure to a broader range of social actors, in turn, brought users several secondary benefits which combined to enhance their capacity to participate. Wider social networks relieved the isolation of users and provided the context for them to gain a greater awareness of their rights, learn about mental health care and absorb values (Passy, 2003) such as social justice and equality. This, in turn, enabled users to become more aware about the sources of their disadvantage and what they could do to tackle them. Furthermore, social networks helped them find the assistance necessary to meet the financial costs of participation (e.g. travelling costs), as well as the emotional support required to deal with the stress which sometimes arises from fear of stigmatisation (most evident among Cape Verdean users), the need to travel within a violent city (Rio de Janeiro), or from conflicts emerging within participatory spaces. By reducing the costs associated with participation, social networks facilitated participants' decisions to join new participatory initiatives (e.g. public events about mental illness in Rotterdam and the user movement meetings and health invited spaces in Rio de Janeiro) and made them more likely to stay engaged over longer periods of time.

Participation also fostered the empowerment of many users. Participatory initiatives allowed users to take on new social roles (e.g. as organisers of debates and cultural activities or lecturers) which enabled them to escape from the position of passivity they had been in as a result of feelings of powerlessness caused by illness or (self-) stigmatisation. Moreover, those initiatives brought them together with others sharing similar concerns and interests. This enabled users to set aside feelings of personal victimisation as they realised they were not the only target of neglect and exclusion, and to find support to seek responses to their needs and claim the enforcement of their rights. Working together to achieve common goals fostered a sense of togetherness (Higgins, 1999), i.e. a sense of being part of a collective which can act to improve users' life chances. In Brazil, this sentiment was strong enough to generate a collective identity (Melucci, 1996) centred on the status of 'user' among minority Northeasterners. Cape Verdeans in the Netherlands also expressed a sense of community, but that sentiment focused on their ethnicity rather than their experience as users of mental health care. In both cases, however, the sense of togetherness experienced by users not only gave them place in the world, but also made them more alert to the needs of others and conscious of how they could contribute to help satisfy these needs. Many users reported the benefits of becoming affiliated to a group which valued their qualities and efforts and encouraged them to acquire new talents and skills.

This bolstered participants' self-esteem and sense of self-efficacy, enabling them to start taking greater control over their social and political lives (Barnes and Wistow, 1994; Summers and McKeown, 1996; Barnes and Shardlow, 1996; Honey, 1999) and to move forward with participation.

Indeed, some of the most empowered users went on to pursue higher levels of engagement. In the case of minority Northeasterners this meant participating in health invited spaces (i.e. health councils and mental health conferences) to make proposals for policy and to demand accountability for the lack of good quality service facilities. Cape Verdeans did not participate in invited spaces, but they did get involved in the organisation of public events aimed at drawing attention to the specific needs of users in their community and finding ways to improve the accessibility of mental care delivery. Both these instances reflect a broader notion of citizenship as practice (Lister, 1997) on the part of those users, which led them to move beyond the position of simple rights holders into playing an active role in shaping their social and political environments to meet their needs. The users who engaged at this level of participation enjoyed an increased sense of agency and citizenship. Many other users, however, were not yet familiar with the spaces where they can have a say in health care decision-making (i.e. health invited spaces). This was especially evident among Cape Verdean migrants who also showed less familiarity with the language of citizenship. This suggests that although participation can enhance full citizenship among disadvantaged user groups, substantial efforts are required to foster their awareness of the mechanisms and spaces through which they can claim their rights and pursue the substantive benefits of citizenship.

Participation also had a positive impact on users' access to mental health care. By taking part in mental health participatory initiatives, users got a chance to broaden their knowledge about psychosocial distress, find information about mental health services, and improve their social skills (e.g. acquiring the capacity to communicate care requests clearly). These benefits combined to increase users' health literacy, which is a crucial asset when it comes to realising one's needs and candidacy for care and navigating the maze of mental health care provisions. Furthermore, involvement in participatory initiatives enabled users to acquire the competencies and self-confidence necessary to insist on the care they considered appropriate. These assets were applied not just when seeking mental health care for themselves, but also to improve the responsiveness of mental health services. Both Cape Verdean migrants and minority Northeasterners succeeded in promoting the development of mental health services more in tune with their needs. The former inspired the creation of a therapeutic group specifically designed to suit Cape Verdeans' needs at a local mental health service. The latter lobbied for the restoration of proper provisions (food, medications, staff, etc.) to their overcrowded and under-resourced mental health service, organising a demonstration in front of Rio de Janeiro Town Hall. The feeling that they could act as a group capable of fostering change had a particularly positive effect in advancing users' aspirations to go on participating and to persevere with action to improve the wellbeing of their communities.

Finally, it is important to consider the role of participation in promoting the social inclusion of people affected by psychosocial problems. As we saw in Chapter 4, the model of developmental benefits proposed by Ann Richardson (1983) asserts that participation can foster social integration. Our findings support this argument only partially. As we have just seen, involvement in health participatory spaces generated a set of benefits which further social inclusion. As a result of participation, users were able to get engaged in and gain access to social relations, civil activities and health care services. However, there were two other areas of inclusion which remained inaccessible to users: economically productive activities (more evident among minority Northeasterners who endured considerable discrimination in the labour market) and community life (more evident among Cape Verdean migrant users who suffered considerable stigmatisation within their own ethnic community). These findings indicate that participation *per se* is not sufficient to guarantee the full inclusion of mental health care users in society. However, the more users participate the more likely they are to realise their right to be treated as full citizens, and to continue pressing for the social changes required to promote their integration.

Sustaining and advancing participation

As noted above, the benefits of participation can contribute to its sustainability and advancement. Benefits enhance people's motivations to participate by offering a reward for their efforts and the confirmation that they can effect change and social transformation. Furthermore, the benefits reaped from participation can offset its costs, thus encouraging people to remain involved. Finally, users' ability to move forward with participation can be enhanced by the skills, competencies and social support they acquire through involvement.

These effects, however, were observed only among users who have collective motivations for participation. Where users' involvement was driven simply by individual concerns, obtaining an answer for those concerns led users to stop participating after a relatively short period of time. Based in our case studies, we conclude that individual motivations play a role in initiating participation but are insufficient to guarantee its continuation.

The importance of collective motivations for the sustainability of participation (Simmons and Birchall, 2005) is largely explained by the affective social ties that emerge between users (and users and other involved social actors) as they join forces to deal with the concerns and promote the interests of a collective with which they identify (Barnes *et al.*, 2006). These ties enable users to experience acceptance, respect and affection which are crucial to counteract the feelings of powerlessness and hopelessness that often impede marginalised people from taking action. Moreover, they provide users with a sense of affiliation to a group which relies on them to pursue its goals and that supports them in return. This sense of common purpose, reciprocity and belonging reinforces users' commitment to stay engaged and, as we saw in Chapter 9, may even lead users to recruit others to join participatory initiatives concerned with the promotion of their welfare.

The idea that collective motivations are key in assuring the continuation of participation offers participation instigators a valuable hint: they need to invest in fostering a sense of collective identification among participants. This can be achieved by generating opportunities for users to come together, talk about their needs and wants, gain awareness about the problems and interests experienced by others and jointly identify ways by which they can collaborate to solve their problems and pursue their goals.

Overcoming barriers to the participation of disadvantaged ethnic minority groups

The two last questions addressed by this thesis were: what are the inhibitors of participation by disadvantaged minority users, and what can be done to overcome them? As evidenced by the data presented in Chapters 7 and 8, we identified several inhibitors which can undermine users' participation including public and self-stigmatisation of mental illness, limited cognitive and communication skills, digital exclusion, poor knowledge about the determinants of (mental) health and the intricacies of the mental health care system, limited awareness of rights, lack of confidence and assertiveness, difficulties in handling conflict and criticism, and meagre financial means. For the most part, Project Apoio and CAPS Pedro Pellegrino succeeded in assisting Cape Verdean and minority Northeastern users to overcome these barriers and join their participatory initiatives. They did so by creating 'safe spaces' for users to outgrow their anxieties and limitations, and by investing in capacity-building and direct and continuous recruitment. In spite of their efforts, however, some inhibitors persisted, impeding the full progression of participation by our research groups. We discuss their negative effects on involvement below. After that, we look into the ways by which higher levels of engagement can be encouraged among groups in a position of disadvantage.

Limits to formal and substantive inclusion in participatory spaces

As we saw in Chapter 9, several barriers prevented our research groups from becoming fully included in health participatory spaces. Cape Verdeans did not succeed in getting involved in mental health invited spaces (i.e. in client councils). Minority Northeasterners, in contrast, were able to engage in comparable invited spaces (i.e.

health councils and conferences) but several of them dropped out from their participatory initiative of reference: the Assembleia at CAPS Pedro Pellegrino.

- **Cape Verdeans'** exclusion from client councils resulted from both 'demand-' and 'supply-side' factors. The former included users' lack of information about opportunities for participation in mental health care services and the fear of being stigmatised by their community, should they be identified as mentally ill in connection to their involvement in the councils. The latter included lack of recruitment efforts by client councils and the unappealing nature of their participatory activities, which tend to be focused on bureaucratic and technical aspects of health care provision that have little to do with Cape Verdeans' motivations for participation. These 'demand' and 'supply' factors combined to impede Cape Verdean migrants from gaining entry into client councils, undermining their formal inclusion in mental health invited spaces.
- **Minority Northeasterners'** withdrawal from the assembly at CAPS Pedro Pellegrino was determined by 'supply' factors including a decline of mobilisation efforts by participation instigators and lack of transparency on the part of professionals regarding the extent to which users could expect to influence health care decision-making. 'Demand' factors also played a role, including users' mounting disillusionment with not realising important goals (e.g. creating better income generation workshops). On the whole, these factors contributed to increasing disbelief among minority Northeastern users that they could influence decisions and effect change through participation, undermining their sense of substantive inclusion in the assembly and leading them to drop out.

These two cases illustrate the ways by which inhibitors related to unawareness of, self-exclusion from participatory initiatives, as well as exclusionary dynamics within these initiatives, work to limit the inclusiveness of health participatory spaces for minority users. This diminishes the potential of these spaces to foster the development of effective, comprehensive and diversity-sensitive health care policy and service delivery. Since one of the purposes of participation in health care is to make policies and services more responsive to users' needs, this may result in people whose needs have not been addressed losing confidence that participation can actually lead to change, which will undermine their willingness to get involved. This is likely to generate a vicious circle where those whose health needs require most attention are least well-placed to voice their concerns and to demand the formulation of appropriate responses. Unless efforts are made to guarantee the inclusiveness of health participatory spaces for all social groups, participation may come to exacerbate inequalities instead of reducing them.

The need for a proactive approach

This thesis argues that a proactive approach to user participation in mental heath care is required to break the vicious circle of under-representation among socially disadvantaged ethnic minority users. As we have seen, users in this position endure exclusion in virtually all life domains, which renders them much too disempowered and under-resourced to get involved on their own accord. This is not to say, however, that they cannot be successfully engaged. As evidenced by our case studies, disadvantaged minority users can not only take part in mental health participatory spaces, but also develop an effective voice over care delivery if the right efforts are made to stimulate their participation.

In our view, promoting the inclusion of marginalised ethnic groups in mental health care governance requires a joint effort by both government and civil society. Health authorities need to adopt a hands-on approach to issues concerning the representativeness of the health participatory sphere, and to develop strategies to increase its receptiveness for under-represented groups. This might entail creating incentives for members of health invited spaces to go out and bring in representatives of voiceless groups. Issuing directives aimed at promoting a better match between the membership of those spaces and the different constituencies that they are meant to represent can foster more active mobilisation. Stimulating the dissemination of information about opportunities for participation in a more direct and accessible way (extending beyond the simple use of Internet and flyers to include, for example, short programmes on the radio or information sessions at user and minorities associations) can also lower the threshold of participatory spaces at the point of entry. Finally, once users get into those spaces, it is necessary to offer them help to acquire the capacities and skills required to bring their concerns to the fore and to influence decision-making. Building capacity for participation, however, is not a ‘one-way street’: public officials, managers, and professionals participating in invited spaces must also be encouraged to learn how to listen and speak to lay ‘experts by experience’. Setting limits to the use of inaccessible managerial language and jargon, for example, can be a good start.

Civil society organisations and user movements also need to play a more proactive role in facilitating the participation of disadvantaged minority groups. This means reaching out to those groups, asking them to join participatory initiatives, establishing a dialogue about their concerns, and devising actions to tackle them. It might also require the creation of ‘preparatory’ spaces outside the participatory sphere which marginalised users can feel as ‘spaces of their own’ (Fraser, 1992), and where they can meet others sharing similar experiences and problems and join forces to formulate plans for action. Such spaces can work not only to empower users to declare out loud their needs, preferences and wants but also to assist them in building a sense of entitlement to, and the competencies necessary for, pursuing higher levels of participation within invited spaces.

The proactive approach proposed by this thesis is better accommodated by a democratic view of user participation in which the devolution of power to the citizenry takes centre stage, and that recognises the need for supplementary efforts in facilitating the involvement of those who are less well positioned to yield it. In Brazil, where a democratic approach to participation prevails, several invited spaces (e.g. health councils) have enforced a quota system which reserves seats for members of civil society organisations and social movements representing the interests of traditionally excluded groups. Furthermore, the user movement makes concerted efforts to facilitate the inclusion of disadvantaged users in invited spaces, not just by mobilising them and seeking funding to sponsor their trips to state and national level mental health conferences, but also by resourcing them to make meaningful contributions once they are there. These instances indicate a concern from both 'above' and 'below' with fostering the representation of social groups who are more likely to encounter difficulties when trying to gain access to the health participatory sphere as a result of inequalities in knowledge, skills, status and power.

Similar concerns were also present in the Netherlands during the 1970s and 1980s. At that time, promoting the inclusion and full citizenship of people affected by mental illness were key priorities of the Dutch user movement and much effort was made to foster their empowerment and to give them voice in mental health care governance. More recently, however, this democratic approach to user participation has been in decline. Since the start of the marketisation of Dutch health care in the 1990s, consumerism has gained considerable strength and user participation is becoming increasingly promoted from a consumerist standpoint. Consumerist discourse depicts the health care consumer as a sovereign, rational and self-interested individual who is capable of judging the quality of the care received and of complaining (or voting with his/her feet) when dissatisfied. Implicit here is the idea that everyone is equally well equipped to participate and that all that is required for participation to thrive is to make participatory spaces available.

This might explain the lack of directives in the Netherlands aimed at guaranteeing the representativeness of invited spaces such as client councils and at stimulating those spaces to recruit members of under-represented groups. As our case study of Cape Verdean users' participation demonstrates, however, not all user groups are fully informed about and prepared to reach up to invited spaces and come forward in defence of their rights and interests. Without greater investment to make invited spaces more accessible to less privileged groups it is unlikely that they will succeed in having a diverse membership and representing a plural user voice. This jeopardises the realisation of the principle of demand-driven care, and with it the chances that services become better tailored to the needs of an increasingly diverse society. This is a serious failing in the light of the government's own withdrawal from efforts to promote equitable health care.

Similarly to its counterpart in Brazil, the Dutch user movement could be functioning as a springboard for the engagement of voiceless groups in the mental health participatory sphere. However, client organisations in the Netherlands have made few efforts to reach out to those groups and to create initiatives aimed at fostering their participation. This is especially evident where migrant and ethnic minority groups are concerned. Such lack of investment appears to result from two intertwined problems. First, many client organisations are overburdened with requests from government to participate in health care decision-making processes: the effort required to meet those requests diverts energy from reaching out to grassroots users (Van de Bovenkamp *et al.*, 2010). Second, in an attempt to improve their bargaining power and influence over health policy-making, many of those organisations are becoming increasingly professionalised and abandoning attempts to recruit less articulate users (Nederland and Duyvendak, 2004). Both these problems seem to be diminishing the capacity and willingness of client organisations to get in touch with less vocal groups and to empower them to take part in the spaces where the decisions that affect their lives are made.

Enhancing the inclusiveness of the Dutch health participatory sphere will require the adoption of a proactive approach to user participation which recognises that marginalised groups need to be directly asked to join participatory initiatives and that those initiatives must be sensitive to their concerns and make them feel at ease to start discussing the causes of their exclusion and to build capacity to tackle them. These initiatives, in turn, can function as precursors for the involvement of those groups in invited spaces by enabling them to get equipped with the confidence, competencies and sense of entitlement necessary for taking participation a step forward and seeking influence over health care policy and service delivery.

A proactive approach to user participation must also be expanded in countries such as Brazil where, despite the presence of a democratic view of participation, many underprivileged groups are still excluded from the health participatory sphere. Indeed, the success of minority Northeasterners in reaching up to invited spaces attests to both the relevance of direct recruitment and capacity-building and the need for continuous efforts on the part of government and civil society to deal with the barriers that impede socially disadvantaged groups from having a voice.

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Samenvatting

Het onderwerp van dit proefschrift is de participatie in de geestelijke gezondheidszorg (ggz) door cliënten uit kansarme etnische minderheden in Nederland en Brazilië. Ondanks overtuigend bewijs dat deze cliëntgroepen ondervertegenwoordigd zijn in participatieve gremia binnen de gezondheidszorg *(health participatory spaces)*, zijn er nauwelijks empirische studies uitgevoerd om na te gaan hoe de deelname van deze groepen gestimuleerd kan worden. Dit proefschrift tracht deze leemte te vullen door te onderzoeken *hoe* en *waarom* cliënten van minderheidsgroepen succesvol betrokken raken bij participatieve gremia binnen de (geestelijke) gezondheidszorg. Daarnaast wordt een analyse gemaakt van de voordelen van participatie door cliënten uit deze groepen, alsmede de barrières die ertoe leiden dat deze cliënten hun volledige potentieel voor participatie vaak niet bereiken.

Om deze vragen te beantwoorden is gekozen voor een kwalitatieve onderzoeksbenadering en een *case study* strategie waarbij twee situaties worden onderzocht: de cliëntenparticipatie van Kaapverdiaanse migranten in Project Apoio (een *community based* project in Rotterdam dat zich richtte op bevordering van de geestelijke gezondheid); en de deelname van (afstammelingen van) interne migranten uit noordoost Brazilië in CAPS Pedro Pellegrino (een *community based* ggz voorziening in Rio de Janeiro). Deze twee cliëntgroepen zijn geselecteerd omdat zij een positieve uitzondering vormen op het algemene patroon van beperkte betrokkenheid bij participatieve gremia. Bovendien lijden deze groepen onder diverse vormen van discriminatie vanwege hun lage sociaaleconomische status en hun etniciteit, naast vooroordelen en stigmatisering als gevolg van hun psychische aandoeningen. Hun bijdrage aan de besluitvorming binnen de ggz is noodzakelijk voor het ontwikkelen van beleid en voorzieningen die beter afgestemd zijn op hun behoeften. Deze bijdrage biedt ook de mogelijkheid om de problemen aan te pakken, die ten grondslag liggen aan hun uitsluiting. Als we de factoren kunnen achterhalen die hun participatie bevorderen, kan dit ook aanwijzingen geven voor de manier waarop de betrokkenheid van andere gemarginaliseerde en moeilijk bereikbare groepen gestimuleerd kan worden.

Het proefschrift is onderverdeeld in negen hoofdstukken, gevolgd door een Conclusie waarin de belangrijkste bevindingen worden samengevat. Hoofdstuk 1 geeft een overzicht van de veranderende betekenissen van 'krankzinnigheid', samen met een historisch perspectief op de positie van geesteszieken in de westerse samenleving sinds halverwege de zeventiende eeuw. Het hoofdstuk begint met een beschrijving van de ontwikkelingen die ten grondslag liggen aan de systematische segregatie van 'krankzinnigen' in de moderne geïndustrialiseerde samenleving, waardoor ze beroofd werden van hun vrijheid, autonomie en zeggenschap. Vervolgens gaat het hoofdstuk in op de bewegingen die dit systeem in de twintigste eeuw aan de kaak hebben gesteld, die de eerste mogelijkheden voor participatie door cliënten in de besluitvorming over ggz voorzieningen hebben geschapen.

Hoofdstuk 2 beschouwt de brede waaier aan betekenissen die het begrip 'participatie' in de afgelopen vier decennia heeft gekregen, alsmede de manieren waarop deze de praktijk hebben beïnvloed. Speciale aandacht wordt besteed aan de situatie in Nederland en Brazilië, door de interpretatie van cliëntparticipatie (consumentgericht en / of democratisch) en door de inclusiviteit *(inclusiveness)* van de participatieve gremia binnen de gezondheidszorg onder de loep te nemen. Het hoofdstuk sluit af met een analyse van de problemen die de volledige inclusiviteit van de Nederlandse en Braziliaanse participatieve gremia in de weg staat, ten nadeel van gemarginaliseerde groepen.

Hoofdstuk 3 biedt een overzicht van de onderzoeksliteratuur over de motivatie van cliënten om te participeren en de factoren die hun participatie ondermijnen. Hierin wordt het conceptueel en theoretisch kader over stimulerende en remmende factoren in de participatie van minderheidsgroepen in Nederland en in Brazilië uitgewerkt. Dit kader is gebaseerd op inzichten geboden door een combinatie van aan de ene kant, theorieën over nieuwe sociale bewegingen, *empowerment* en burgerschap, en aan de andere kant de *Mutual Incentives Theory* en het *Participation Chain Model* ontwikkeld door Simmons en Birchall (2005). Hoofdstuk 3 laat ook zien hoe de participatieve initiatieven van Project Apoio en CAPS Pedro Pellegrino het concept 'hybride participatieve gremia' illustreren, dat wil zeggen gremia die gesponsord worden door de overheid terwijl ze ook een directe verbinding met de lokale cliëntenbewegingen onderhouden. Deze gremia zijn noch '*invited spaces*', noch '*autonomous spaces*' (Cornwall, 2004b), maar ze bevatten ingrediënten van beide. Ze zijn voorbeelden van een groeiende tendens in de richting van 'hybridisatie' van participatieve gremia (Barnes *et al.*, 2004).

Hoofdstuk 4 geeft een overzicht van de belangrijkste bevindingen van onderzoek naar de positieve effecten van participatie op de betrokken ggz cliënten. Tegelijkertijd verschaft het een analytisch kader om de voordelen van betrokkenheid voor onze cliëntgroepen inzichtelijk te maken. Dit kader komt grotendeels voort uit de hierboven genoemde theorieën samen met de inzichten van Ann Richardson (1983) met betrekking tot wat zij noemde 'ontwikkelingsvoordelen' van participatie, namelijk de positieve effecten ervan op mensen zelf.

Hoofdstuk 5 kijkt naar recente ontwikkelingen in gezondheidszorgbeleid en dienstverlening die het belangrijker hebben gemaakt om de Nederlandse en de Braziliaanse participatieve gremia meer toegankelijk te maken voor cliënten uit minderheidsgroepen. Deze ontwikkelingen betreffen de toenemende marktwerking binnen de Nederlandse gezondheidszorg en de weigering van de overheid sinds 2003 om verantwoordelijkheid te nemen voor het bevorderen van gelijke toegang en kwaliteit in de gezondheidszorg voor migranten en etnische minderheden. In Brazilië gaat het om het verzet tegen de implementatie van hervormingen in de psychiatrie en het ontbreken van beleidsmatige aandacht voor migranten in de zorg. Daarnaast introduceert Hoofdstuk 5 onze onderzoeksgroepen en beschrijft het de manieren waarop Project Apoio en CAPS Pedro erin geslaagd zijn om Kaapverdiaanse migranten en (afstammelingen van) interne migranten uit noord-oost Brazilië bij hun participatieve initiatieven te betrekken.

Hoofdstuk 6 beschrijft de kwalitatieve benadering en case study strategie van het empirisch onderzoek en verantwoordt de keuze van de casussen. Het hoofdstuk beschrijft tevens de gehanteerde methoden van dataverzameling, te weten interviews, participerende observatie en analyse van secundaire bronnen. Daarna komt een beschrijving van de gehanteerde analysemethoden (open, axiale en selectieve codering, de constante vergelijking methode en de uitleg-opbouwtechniek) en de gebruikte criteria (triangulatie) waaraan de kwaliteit van de studies wordt getoetst. Het hoofdstuk sluit af met een analyse van de ethische kwesties die in de specifieke context van dit onderzoek ontstaan.

Hoofdstuk 7 gaat in op de randvoorwaarden *(enablers)* voor de participatie van onze onderzoeksgroepen. Het laat zien dat deze participatie door een breed scala aan factoren wordt aangestuurd. Sommige factoren zijn van persoonlijke aard, zoals de wens om het niveau van sociale interactie te verhogen, het vinden van betaald werk, het verwerven van een betekenisvolle sociale rol, het overwinnen van de stigma verbonden aan psychische aandoeningen en het meer gebruik maken van geestelijke gezondheidszorg. Andere motivaties voor participatie hebben te maken met het bevorderen van het welzijn van groepen waarmee de deelnemers zich identificeren of wiens belangen zij willen behartigen. Het betreft met name de wens om de responsiviteit van de geestelijke gezondheidszorg te verbeteren en om meer sociale rechtvaardigheid te bereiken voor mensen die getroffen zijn door psychische problemen. De individuele en collectieve motivaties van de cliënten wijzen op een sterk streven om niet alleen voor hun eigen integratie in de samenleving te ijveren, maar ook voor de uitoefening van volwaardig burgerschap door andere leden van hun gemeenschap. Hoofdstuk 7 voert ook aan dat, hoewel motivaties van cliënten een belangrijke rol spelen in hun beslissingen om te participeren, deze niet voldoende zijn om het aanzetten en voortzetten van participatie te garanderen. Naast de motivatie van de betrokkenen zijn actieve werving, capaciteitsopbouw en *empowering* binnen participatieve gremia alle essentiële randvoorwaarden van de deelname van kansarme cliëntengroepen. Het succes van Project Apoio en CAPS Pedro Pellegrino in het faciliteren van de participatie is grotendeels gelegen in het feit dat zij in staat zijn om aan de randvoorwaarden van participatie te voldoen.

Hoofdstuk 8 kijkt naar de voordelen die onze onderzoeksgroepen ervaren door hun betrokkenheid bij participatieve gremia binnen de ggz. Het toont aan dat participatie kan leiden tot een aantal substantiële voordelen voor cliënten, waaronder bredere sociale netwerken, *empowerment,* een toegenomen gevoel van burgerschap, betere kennis over gezondheid en betere toegang tot geestelijke gezondheidszorg. Deze voordelen hebben een positief effect op elkaar en samen versterken ze de bereidheid van cliënten om geëngageerd te blijven. Daarnaast versterken ze het vermogen van cliënten om participatie een stap verder te brengen, bijvoorbeeld door betrokken te raken in genodigde participatieve gremia *(health invited spaces).* Deze effecten worden echter alleen waargenomen bij cliënten die collectieve motivaties voor participatie hebben, dat wil zeggen die gemotiveerd zijn om niet alleen hun eigen persoonlijke welzijn te bevorderen, maar ook het welzijn van de gemeenschappen waartoe ze behoren of waarmee ze zich identificeren. Het belang van collectieve motivaties voor de duurzaamheid en de vooruitgang van de participatie wordt grotendeels verklaard door de affectieve sociale banden die ontstaan tussen cliënten wanneer zij hun krachten bundelen in de strijd voor collectieve belangen. Deze banden kunnen cliënten acceptatie, respect en genegenheid geven, die cruciaal zijn om gevoelens van machteloosheid en hopeloosheid bij gemarginaliseerde mensen tegen te gaan. Bovendien bieden ze mensen steun bij het bereiken van hun doelen. Dit gevoel van een gezamenlijk doel, wederkerigheid en verbondenheid, versterkt de motivatie van cliënten om te blijven participeren en om hogere niveaus van betrokkenheid na te streven.

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Tot slot vat de conclusie de belangrijkste bevindingen van dit proefschrift samen. Gesteld wordt dat kansarme minderheidsgroepen succesvol kunnen deelnemen aan participatieve gremia binnen de ggz. Toch vereist het stimuleren van de betrokkenheid van deze groepen een proactieve aanpak die erkent dat gemarginaliseerde groepen zelfvertrouwen, vaardigheden en een besef van hun eigen rechten moeten ontwikkelen om hun burgerschap uit te oefenen en gebruik te maken van de mogelijkheden voor participatie. Het implementeren van een dergelijke benadering van cliëntparticipatie vergt een gezamenlijke inspanning van zowel de gezondheidsautoriteiten als ook het maatschappelijk middenveld. Maatschappelijke organisaties kunnen een positieve bijdrage leveren door de ontwikkeling van 'voorbereidende' gremia te stimuleren waar gemarginaliseerde cliënten bijeen kunnen komen om hun zorgen te delen. In deze gremia kunnen deze cliënten een kritisch bewustzijn ontwikkelen omtrent de factoren die ten grondslag liggen aan hun uitsluiting. Daarnaast kunnen cliënten uitgerust worden met de nodige middelen om hun sociale integratie te bevorderen en hogere niveaus van participatie na te streven, met name in genodigde participatieve gremia. Ook de gezondheidsautoriteiten kunnen een meer proactieve rol spelen, bijvoorbeeld door activiteiten te stimuleren die gericht zijn op het verbeteren van de aansluiting tussen de leden van genodigde participatieve gremia en de verschillende instanties die deze gremia vertegenwoordigen. Dergelijke strategieën hebben het potentieel om de inclusiviteit van participatieve gremia binnen de gezondheidszorg te versterken en ervoor te zorgen dat kansarme groepen meer zeggenschap krijgen.

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Curriculum Vitae

Cláudia de Freitas was born in 1978 in Porto, Portugal. After completing her secondary education in the neighbouring city Gaia in 1996, she moved to Coimbra to study Psychology. In 1999 she went to the Netherlands as an exchange student and spent an academic year at Utrecht University under the Socrates-Erasmus programme. She graduated in Clinical Psychology from the University of Coimbra in 2001. After her graduation she returned to the Netherlands and worked as a research assistant at Utrecht University on a project about health and social care provisions for asylum seekers and refugees. This project sparked her interest in migrant health and in 2002 she enrolled in a Master of Arts in Migration and Ethnic Studies at the University of Amsterdam, from which she graduated cum laude in 2004. In that same year, she was granted a fellowship by the Portuguese Foundation for Science and Technology to do her PhD at the Department of Interdisciplinary Social Science and the European Research Centre on Migration and Ethnic Relations at Utrecht University. In the meantime, she collaborated in research projects in the Netherlands, Suriname, Brazil and Portugal and in 2006-2007 she was a visiting scholar at the School of Social Work of the Federal University of Rio de Janeiro, Brazil. She is the author of *Seeking the good doctor – ´when health knows no borders´. Cape Verdeans´ perceptions of health care providers in the Netherlands* (ACIME, 2006) and of several articles and book chapters. In 2011 she was awarded a conditional Postdoctoral fellowship by the Portuguese Foundation for Science and Technology and she looks forward to continue doing research on user participation at the Lisbon University Institute (ISCTE–IUL), Portugal.