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COMMUNITY SUPPORT AND PARTICIPATION AMONG PERSONS WITH DISABILITIES. A STUDY IN THREE EUROPEAN COUNTRIES

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ABSTRACT

Community support and participation among persons with disabilities. A study in three European countries

This article describes a European project which was aimed at improving the situation of persons with psychiatric or learning disabilities with regard to social participation and citizenship. The project took place in three countries (Estonia, Hungary and the Netherlands) and four cities

(Tallinn, Budapest, Amersfoort and Maastricht). The project included research and actions at the policy level, the organizational level and the practice level. At the policy level, the framework of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the European Disability Strategy (European Commission, 2010) were used to look at national and local policies, at the reality of the lives of those with disabilities and at the support that professional services offer with regard to participation and inclusion. The project generated a number of insights, recommendations and methods by which to improve the quality of services and increase the number of opportunities for community engagement. In this article, we present some of the lessons learned from the meta-analysis. Although the circumstances in each country are quite different with regard to policy, culture and service systems, it is remarkable that people with disabilities face many of the same problems.

The study shows that in all three countries, access to services could be improved. Barriers include bureaucratic procedures and a lack of services. The research identified that in every country and city there are considerable barriers regarding equal participation in the field of housing, work and leisure activities. In addition to financial barriers, there are the barriers of stigma and self-stigmatization. Marginalization keeps people in an unequal position and hinders their recovery and participation. In all countries, professionals need to develop a stronger focus on supporting the participation of their clients in public life and in the development of different roles pertaining to citizenship.

Keywords

Community Support, Care, Community work, Participation, Inclusion, Mental Health Services, Social Services, Human Rights

SAMENVATTING

Ondersteuning bij participatie in de samenleving van mensen met beperkingen. Een studie in drie Europese landen

Dit artikel beschrijft een Europees project dat gericht was op sociale participatie en burgerschap van mensen met een psychiatrische of verstandelijke beperking. Het project vond plaats in drie landen (Estland, Hongarije en Nederland) en in vier steden (Tallinn, Budapest, Amersfoort en Maastricht). Het omvatte onderzoek en activiteiten op het niveau van beleid, organisatie en uitvoeringspraktijk. Op beleidsniveau vormden het UN-Verdrag voor Mensen met een Handicap, en de European Disability Strategy het referentiekader om te kijken naar landelijk en

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lokaal beleid, naar de dagelijkse realiteit van mensen met een beperking en naar de steun die professionele organisaties bieden met betrekking tot participatie en inclusie. Het project leverde een aantal inzichten, aanbevelingen en methoden op, die de kwaliteit van de dienstverlening en de mogelijkheden voor participatie in de samenleving kunnen verbeteren. In dit artikel presenteren we een aantal bevindingen. Hoewel de omstandigheden in ieder land verschillend zijn qua beleid, cultuur en voorzieningen, valt op dat mensen met beperkingen gelijksoortige problemen ervaren.

De studie laat zien dat in alle drie de landen de toegang tot hulp- en dienstverlening verbeterd kan worden. Barrières zijn onder andere bureaucratische procedures en een gebrek aan bepaalde diensten. In iedere stad en in ieder land zijn er aanzienlijke belemmeringen als het gaat om participatie op het terrein van huisvesting, werk en vrijetijdsbesteding. Naast financiële problemen is er de barrière van stigma en zelfstigma. Marginalisatie houdt mensen in een ongelijke positie en heeft een negatieve invloed op herstel en participatie. In alle landen zouden professionals een sterkere focus moeten hebben op het ondersteunen van hun cliënten bij participatie in de samenleving en op de ontwikkeling van verschillende rollen behorend bij burgerschap.

Trefwoorden

Maatschappelijke ondersteuning, zorg, participatie, inclusie, ggz, vgz, welzijn, mensenrechten

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BACKGROUND

Demographic, epidemiological, social, and cultural trends in European countries are changing traditional patterns of care. In the decades to come, we will see increasing numbers of care-dependent older people and an increasing incidence of non-communicable disease become the leading cause of chronic illness and disability. The break-up of the traditional large family group

and urbanization will also lead to gaps in care for older or disabled family members. These changes in needs and social structure require a different approach to health and social sector policy and services because a disease-oriented approach alone is no longer appropriate. We need to adopt a comprehensive model of disability, that includes the individual, social, political, cultural, and economic dimensions (Barnes & Mercer, 2010).

People with disabilities encounter many disadvantages. They are poorer than other citizens, fewer of them have jobs, they have a more limited range of opportunities to enjoy goods and services such as education, healthcare, transport, housing, and technology. They face discrimination as well as physical and attitudinal barriers. These disadvantages affect one in six citizens in the EU, or around 80 million people (European Commission, 2010).

By signing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007, the EU and all its member states have committed themselves to creating a barrier-free Europe. Even though the member states bear the main responsibility, EU action is also needed to complement national efforts. The EU treaties empower the EU to take action to combat discrimination against people with disabilities and the Charter of Fundamental Rights (European Council, Council of Europe, & European Commission, 2000) refers to their right to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

Following the signing of the UNCRPD, the EU developed the European Disability Strategy 2010–2020 (EDS) which was adopted in 2010 (European Commission, 2010). The Strategy for the period 2010–2020 is a comprehensive framework that aims for the empowerment of people with disabilities, the removal of everyday barriers in life and ensuring their full rights. Persons with disabilities have the right to participate fully and equally in society and the economy. The denial of equal opportunities is a breach of human rights.

It pursues these objectives through action in eight priority areas:

1. Accessibility: to make goods and services accessible to people with disabilities and promote the market for assistive devices.
2. Participation: to ensure that people with disabilities enjoy all the benefits of EU citizenship; to remove barriers to equal participation in public life and leisure activities; to promote the provision of quality community-based services.
3. Equality: to combat discrimination based on disability and promote equal opportunities.

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4. Employment: to raise significantly the share of persons with disabilities working in the open labour market.
5. Education and training: to promote inclusive education and lifelong learning for students and pupils with disabilities.
6. Social protection: to promote decent living conditions, combat poverty and social exclusion.
7. Health: to promote equal access to health services and related facilities.
8. External action: to promote the rights of people with disabilities in the EU enlargement and international development programmes.

FROM THEORY TO PRACTICE

In view of the development of the EDS, in 2011, a project was initiated by a consortium consisting of four universities in three countries¹, and a number of NGOs² active in the field of social work and mental healthcare. In 2012–2013, pilot projects were organized in the cities of Amersfoort, Budapest, Tallinn and Maastricht. The main question was how the UNCRPD and the EDS is being or could be translated into local policy and professional practice, with the aim of improving the position of those with disabilities in local communities. The project aimed to contribute to the body of knowledge relating to professional intervention with regard to community participation and social inclusion among persons with disabilities.

DESIGN

The target group involved people with psychiatric disabilities who had a desire to live in the community as equal citizens. In Amersfoort, people with learning disabilities and acquired brain damage were also included in the study. The study focused on participation in labour (paid or voluntary) and social networks.

The cities were chosen on the basis of their location and their socio-demographic and institutional characteristics. The variation between the cities includes: being situated in Western Europe, Eastern Europe and Northern Europe; being in different stages of transformation from institutional care to community care; differing in population size (Maastricht: 120,000; Amersfoort: 147,000; Tallinn: 400,000; Budapest: 1,750,000).

In each city, a research group and a project group were created. The research group consisted of researchers and students from the university. The project group consisted of representatives of

the agencies and the university. This group functioned as a Community of Practice and Research, using the model of the Best Practice Unit. This is a model in which research is combined with the innovation of practices (Wilken, Van Slagmaat & Van Gijzel, 2013). The research was aimed at three levels: the policy level, the organizational level and the practice level. From the literature on Community Support Systems (CSS), we know that these three levels are closely connected and that it is necessary to create the right conditions at all three levels (Provan & Brinton Milward, 1995).

As research methods we used document analysis, participatory action research, and narrative research. We gathered data by conducting semi-structured and focus group interviews and by using the PAS questionnaire. This is a standardized instrument including a number of items on participation, autonomy and social support (Wilken & Karbouniaris, 2012). Respondents respond to statements, like "I sometimes lend a hand to someone in my neighbourhood" or "I have people around me who want to assist me if needed" with "yes", "no" or "more or less".

Altogether, data were collected from 92 service users, professionals, relatives and other persons who were identified by the service user as playing supportive roles. Quantitative and qualitative analysis was carried out. The questionnaire and the interviews provided insight into respondent's ideas about participation, the barriers that they encounter and the support that people receive.

During the project, working conferences were organized in the four cities. These conferences were held to exchange and compare data, and reflect on the findings. The conferences were combined with site visits, to reveal daily practices in the cities. In each city good practice was identified and served as a source of inspiration for other cities.

In the following section, we will present some of our findings from the different countries and the comparative analysis that we made. For further details we refer to the research report (Wilken, 2014). We will start with the perspective of the service users. Then we will give a picture of the policies and practices which were developed or studied in the four cities. Finally, we will put the findings in the light of the priority areas of the European Disability Strategy.

THE PERSPECTIVE OF SERVICE USERS

From the interviews and the PAS questionnaire, we can conclude that there are many similarities between service users in the three countries. The majority of the respondents are unemployed, but would like to find a paid job. Nearly half of them participate in the community in the form of

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voluntary activities. Many people want more activities. Eighty percent of them feel connected to the neighbourhood where they live and use facilities in the neighbourhood. When it comes to social relationships, almost everyone has a friend, family-member or neighbour. However, in Budapest, 22% and 11% of the interviewees have “usually no-one” or “no-one at all”, respectively.

When taking a closer look at the reciprocity in giving and receiving support, we discovered that many participants also take care of others, such as parents, a neighbour or a close friend. In Tallinn and Maastricht particularly, a majority of 67% is doing something for relatives or friends. In Amersfoort, few participants provide support to others (18%).

With regard to autonomy, the majority of the population feel fairly independent and self-confident. Still there is a significant difference between the Netherlands and the eastern European countries. In these countries, a quarter of respondents do not feel independent at all, mostly due to poverty. In Hungary, 62% of the respondents indicated that they do not have enough money, in Estonia this is 40% (in the Netherlands this was 19%). This also relates, although not in a statistically significant way, to self-confidence.

Persons with a disability desire to improve their quality of life, and participate more in different roles in the community. They also face quite a number of obstacles to, for instance, having a sufficient income, decent housing and access to the labour market.

PRACTICES

In each city, different actions were developed, attuned to the local situation. We briefly summarize the activities developed in each city as well as the research that accompanied the activities.

Amersfoort

In Amersfoort, a network was developed consisting of nine NGOs in the field of mental healthcare, social services and care for persons with an intellectual disability, an organization for voluntary work, a housing cooperative, user organizations and the municipality³. On the basis of a survey conducted among service users and professionals, three problem areas with regard to participation were identified: housing opportunities, opportunities for voluntary work and opportunities for socializing (Van Rooijen, 2012). Working groups were formed that came up with specific proposals and plans for making improvements. Furthermore, a Community of Practice (CoP) was created

for professionals in the city. This CoP met regularly, working on improving collaboration and developing strategies for using and strengthening social networks for people with disabilities.

Research activities included conducting a survey of the situation of people with a disability and a survey of the policy of local government on participation and support. Additionally the activities of the network and the working groups were monitored. The results of the research formed an input at all the three levels mentioned previously. At the level of practice, professionals from the different agencies working in the city started to get to know each other better, to establish cooperation and to use each other's knowledge and access to resources for the benefit of their clients. At an organizational level, managers and service leaders were able to work on solutions for the issues. One example here is that, together with the housing association and the municipality, improvements have been made in the system of referral for houses in the social sector for people who urgently need a house. At the policy level, cooperation with the municipality was strengthened. This is very important since the new Social Support Act (WMO) will make local governments responsible for support and the employment of persons with a disability from January 2015.

Budapest

In Budapest, the participating partners were ELTE University Faculty of Social Sciences, Soteria Foundation and XII district Félziget-Clubhouse. A CoP was formed in Budapest too. The Hungarian mental health system is still quite influenced by the patterns and attitudes of institutional care. Even though Soteria and the Clubhouse are among the rare examples of a new more progressive form of services, one of the findings in the project was that here too the relationship between professionals and users still tends to be a vertical one. In the project, more equal ways of working together have been developed. A narrative approach was used in the research to identify the story of service users, their wishes and needs, but also the resources that they both use in the service system and the community. Although this method was used for research purposes, this also proved a useful way for professionals to conduct assessments. It produces a clear picture of the life of the person, his or her perspective, strengths, wishes and needs for support, as well as which resources are used and valued by the person.

At the policy level, research has been conducted into the deinstitutionalization process in Hungary. During the next three years, six large long-term care institutions will be closed down and replaced with community based alternatives. The services that were part of the pilot are examples of good

practices that can be part of a “community support system”. Since poverty is a serious problem for many people with a disability, an idea was developed of starting a public laundry service as a social enterprise.

Maastricht

In Maastricht three organizations were involved in the community support project:

- Trajekt, a social work agency providing welfare services;
- Mondriaan, a large mental health agency providing all kinds of mental healthcare, which cooperates closely with the Academic Hospital in Maastricht;
- Gallery Flow, a private initiative which provides opportunities for recovery and entrepreneurship.

During the project, three types of interventions were followed and described, all of which contributed successfully to community participation. The first was an intervention called “Crazy good neighbours”, which aimed at a greater acceptance of persons with a psychiatric disability in the neighbourhoods of the city. This approach was part of a number of activities aimed at building bridges between persons with a psychiatric background and other citizens (in Dutch this is known as “kwartiermaken”).

The second intervention was the FACT model of case management, which is based on the ACT-model developed in the USA but adapted in the Netherlands to create a broader service model. The FACT team which participated in the research operated from a community centre, which enabled the team to make easy connections with the neighbourhood.

The third intervention was an approach which can be typified as “Synergy and Empowerment” initiatives based on eclectic recovery and rehabilitation principles. One example is an Art Gallery where people with a disability can develop and prove themselves as artists. This type of initiatives could be referred to as “small social enterprises” which form a supportive environment in which persons with a disability can explore individual autonomy. This has a consequence for (self-)labelling, for example, choosing the role of “artist” or “entrepreneur” instead of a client role.

The research makes it clear that the three types of interventions are all important elements of a community support system. A FACT team can help a person coping with his mental condition,

but at the same time help him to connect (to stay connected or to reconnect) to natural environments. Initiatives like “Crazy good neighbours” and other forms of bridge-building support destigmatization and social inclusion. Social enterprises can be considered as “social niches”, environments that are safe and provide opportunities for self-direction and personal development.

Tallinn

In Tallinn a close partnership was developed between researchers and students of the Institute of Social Work of Tallinn University and professionals and users of Tallinn Mental Health Centre. By documenting experiences and reflecting on the essential components of community support programmes, a number of factors come to the fore. We will mention just a few examples here.

- To support the clients, it is important to have a clear understanding of their living situation (e.g. housing problems, low income, increased spending on medicines, health problems, tensions in relationships, difficulties in finding suitable work, etc., or a combination of all these problems), to associate the services with the needs of the client and to support opportunities in the community.
- A strengths-based approach is very important in the work with clients with special needs. The approach of the professional should be based on the strengths of clients, but also acknowledge their limitations.
- Both clients and specialists value the work of peer-counsellors; this counselling is considered trustworthy and contributes to the recovery of clients.
- Professionals should also focus on supporting the system around the client. Family members and other people providing support often need attention.

Tallinn University published an extensive report on “Estonian local policy and the local situation of persons with disabilities”, which also provided a number of clear recommendations for improving policies. It is positive that there are five state-funded special care services, but often the necessary special care services are not accessible enough, in other words they are not provided in rural areas, the amount of services is small and different services are not integrated. It is necessary to move towards the more flexible, combined and integrated provision of national and local government services that would allow the use of the resources of both clients and local governments as efficiently as possible. The problems related to the accessibility of special care services were identified as bureaucracy with complex paper-work, long waiting lists (especially

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in case of special care services, including 24-hour special care and housing services), and a lack of clarity among clients and specialists. Besides improving access to the system, there is also a need to improve information exchange and education in the fields of recovery, participation and community support. The services should focus more on personal development and social roles in the community.

The lack of integration between welfare and healthcare services is also problematic. As a result, people with special needs who are using welfare services have difficulty accessing healthcare services, and vice versa. The measures to support family and next-of-kin are more like single positive cases and in reality there is a need for counselling and training for relatives, support groups, family care and monetary benefits. The next-of-kin of clients feel that they need support programmes that would provide persons with mental disorders and their family members with security and clarity about what could happen in the future (e.g. when parents pass away). The lack of knowledge and security that is present today creates tensions and worries. Both specialists and clients feel the need for developing a support system of voluntary support persons, for example so that the service user could go safely with the volunteer to the cinema, to a concert, and so on.

The professionals who were interviewed in the study emphasized the need to develop a range of measures. The risk of poverty should be decreased. Now, people generally have low income jobs, and the unemployment and disability benefits are also low. The labelling or stigmatization of people with mental disorders should be addressed. Their participation, involvement and integration to the community should be better supported.

There is a need for developing support measures for clients with mental disorders who do not acknowledge their problems so that people will not be left out of the healthcare and welfare systems (including social insurance and benefits). Both professionals and clients have high expectations when it comes to cooperation, but in practice these are not realized (including the need to increase the efficiency of case management).

Professionals need training for the development of effective community support programmes in the area of social work and mental health and to support persons and their environment. To develop knowledge, it is firstly necessary to create an executive training system that corresponds to the practical needs of specialists, is available to and of high quality for specialists working with service users with mental disorders and their next-of-kin. The study states that at the moment the

availability of executive training for specialists is limited and uneven and depends on the resources and priorities of the institution. At the same time, the existence of specialists with the necessary knowledge and skills is a precondition for providing high-quality and efficient services.

RESULTS IN THE LIGHT OF THE EDS

As mentioned in the introduction, the European Disability Strategy has eight priority areas for action. To conclude this article, we will put the results in the framework of these areas. We would like to highlight four domains: accessibility, participation, equality and human rights. We chose these domains because it became obvious from the research that a great deal of work remains to be done in these areas.

Accessibility

The study shows that in all three countries, access to services could be improved. It was striking that both in the Netherlands and Estonia, bureaucracy and fragmentation of services formed barriers to access. The project showed that improved collaboration between services, in the form of regional networks of organizations and professionals, leads to better access and the more efficient use of resources. It also helps if the policies of both national and local government provide a clear framework with procedures kept as simple as possible, and with incentives for the integration of services.

In Hungary, availability is more a problem than accessibility. The country is about to start the process of deinstitutionalization, and only a few community-based services are available. This also provides opportunities to create on a network of services from scratch, so that it is well-tuned to the needs of the population and focuses on recovery and inclusion. The services that joined our project can serve as good examples.

Participation

Making a thorough assessment of the local situation with regard to the wishes and needs of people with a disability in terms of participation is a valuable starting point for drawing up a plan of action. In the project, we designed and applied a tool that could be used for this assessment (Wilken, 2012). This tool includes items on policy, demographics, services, and the participation status of persons with a disability.

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We learned that it is important to define the meaning of the notions of participation and community in each country, since these can have quite different meanings. For example, in Estonia and Hungary the heritage of the Soviet regime was that the “community” was narrowed down to a functional, geographical entity, and had little social value at all. In the Soviet era people were not sure who to trust because of the possibility of a neighbour who was a member of the Communist Party or even the secret service. Social control became state control. Since social cohesion could be dangerous, social life was mainly restricted to family life. The challenge for former-Soviet countries is to restore social values and create new vital social networks. Social professionals in these countries can play a valuable role here. However, we learn that most professionals tend to stick to traditional roles, for example maintaining a “clinical view”, thereby remaining part of the old system rather than shifting to a community perspective. In order to make a transformation to a new professional identity, awareness should first be installed concerning the importance and values of community life. Social work education should focus much more on knowledge about social networks and community (re)development. Incidentally, this is also necessary in the Netherlands, where the Social Support Act puts great emphasis on mutual support in the community. Professionals will play more facilitating roles instead of caring roles.

The research revealed that in every country and city there are considerable barriers to remove in order to enable equal participation in the fields of housing, work and leisure activities. As far as the provision of community-based services is concerned, we conclude that professionals in all countries should develop a stronger focus on supporting the participation of their clients in public life. The community-based mental health services which participated in the project focused mainly on individual support and hardly used the opportunities available in the community. Our project showed that by focusing on community resources and collaborating with voluntary organizations and social welfare services, participation options can be increased considerably. Professionals should adopt and work on the basis of facilitating inclusion. They assist people who, because of their vulnerability and history, have problems with joining communities. Participation means taking part in activities in different domains of life. Inclusion means that the environment welcomes and enables people who are “different” as full members of the community, respecting and valuing differences.

Equality

Those with a psychiatric history face many forms of stigma and self-stigmatization. They also experience marginalization with regard to participation as equal citizens. In our project we focused

on two specific aspects of equality. The first is the role of human rights (see below) and the second is the attitude and working methods of professionals. In mental healthcare, the focus is shifting more and more towards supporting recovery processes. An important recovery support factor is the personal relationship between the professional and the user, which should be based on equality and partnership (Wilken, 2010). Our interviews with service users confirmed the importance of this. This method of working requires a “new language”, which is based on a humanistic, social and empowerment paradigm, instead of on a medical deficit paradigm.

All kinds of empowerment approaches and “bridge building” strategies can help to promote equality. An example from Maastricht is social entrepreneurship, where people with a disability are creating value by producing art or providing a specific service to the community, such as repairing bikes.

Human rights

In the project, we looked specifically at the UN Convention on the Rights of Persons with Disabilities. This is a legal framework which places the right to opportunities equal to other citizens in different areas of life. We concluded that professionals and users are not familiar with the UN Convention. The first step therefore has to be to spread information about the Convention and raise the awareness about its importance. In Estonia and the Netherlands, information booklets have been published. We have designed and tested prototype guidelines which could be handy for both professionals and users (Knevel, 2013). We have also developed a training module on the UNCRPD. These guidelines will be developed further on the basis of results from pilot schemes. The guidelines include questions in different domains of the convention, such as the accessibility of goods and services, images of disability causing stigmatization, independent living, employment and education. The questions create awareness about individual rights and may lead to action. An example of a question about independent living is: “How have you been promoting the rights of your clients with regard to their housing and living conditions and wishes?” Another question is: “How did you work on informed consent and personal autonomy?”

TO CONCLUDE

There is a huge gap between the ambitions of the UN Convention and the European Disability Strategy on the one hand, and reality on the other. At the policy level, rights and strategies are in the process of being implemented in national and local policy. However, our research shows that

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persons with a disability and the professionals providing services to them are generally unaware of the rights that people have. Furthermore, professionals are not yet focused on community participation and matters of social inclusion. On the other hand, in the cities which took part in this project we found promising examples of how participation and inclusion can be promoted. However, it was remarkable that these practices were not based on or linked to a human rights perspective. As a next step, we would suggest linking the rights perspective with the perspective of participation and community-based services.

NOTES

- 1 Utrecht University and Zuyd University of Applied Sciences in the Netherlands, Elte University in Budapest, Hungary, and Tallinn University in Tallinn, Estonia.
- 2 A non-governmental organization (NGO) is an organization that is neither a part of a government nor a conventional for-profit business. In this article, we refer to NGO's as mental healthcare agencies, welfare services, voluntary organizations and user organizations.
- 3 (In alphabetical order) Alliantie, Amerpoort, Cliëntenbelang, GGZ Centraal, Humanitas DMH, Kwintes, MEE Utrecht Gooi & Vecht, Municipality of Amersfoort, Ravelijn, Reyer ter Burgh, Riagg Amersfoort e.o., Salvation Army, Welzin.

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