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## RESEARCH PAPER

# The lived experience of parents enabling participation of their child with a physical disability at home, at school and in the community

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### Abstract

**Purpose:** The aim of this study was to provide an in-depth exploration and understanding of parents' thoughts, feelings and concerns they experience while reflecting on their actions, challenges and needs in enabling their child's participation at home, at school and in the community. **Method:** A naturalistic inquiry with thirteen Dutch parents using interpretative phenomenological analysis. **Results:** Analysis revealed three super-ordinate themes: "Parents' experiences and concerns about systems, laws and regulations", "Parents' experiences and thoughts about physical and/or social environment" and "Parents' experiences and feelings of finding and/or enabling an activity". Parents' often expressed feelings of disappointment derived from being misunderstood, from dealing with the complexity of systems, from hindrance of participation of their children by the social and the physical environment, and from the lack of leisure activities for their child. It is primarily restrictions in the physical and social environments that urge them to take actions, to experience challenges and think of needs. **Conclusions:** In-depth exploration and understanding of parents' articulated matters must be shared and taken seriously by policymakers and service providers. Parents' knowledge and experiences should be of major relevance to improve paediatric rehabilitation and other services for children with a physical disability.

### Keywords

Activities of daily living, children, parents participation, social participation

### History

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### ► Implications for Rehabilitation

- To achieve tailored pediatric rehabilitation, involvement and needs of parents in enhancing their child's participation ought to be acknowledged.
- Active use of parents' experiences and knowledge regarding the participation of their child on different levels of decision making may improve daily services in pediatric rehabilitation.
- Aiming for optimal participation of a child with a physical disability at home, at school and in the community, the focus of pediatric rehabilitation needs to shift towards enabling, social and physical, environments.

### Introduction

Parents are the one constant in their child's life [1], and for most parents caring for a child is an experience full of triumphs and joy as well as challenges and stress [2]. Similar to parents of non-disabled children, parents of a child with a disability play a crucial role in the development of their child. However, providing care and supporting a child with a disability furnish more intensive

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care that requires a significantly larger amount of time, greater financial stress, more frequent disruption of family routine and reduced social activities outside the family [3–5]. Despite the increased demands of parenting a child with a disability, many families are able to manage life effectively [6].

Participation, defined as being involved in life situations to fulfil social roles [7,8], has a positive impact on children's health and well-being [9,10]. For children, participation domains of involvement in everyday activities, as described in the ICF – Children and Youth (IFC–CY) [8], include “learning and applying knowledge”, “general tasks and demands”, “communication”, “mobility”, “self-care”, “domestic life”, “interpersonal interactions and relationships”, “major life areas”, “community”, “social and civic life”. Research shows that children with a physical disability experience restrictions in participation at school, home and in the community [11,12], feel more socially isolated [13], have fewer friends and decreased opportunities to build relationships compared to children without a physical disability [14].

Varied environmental features, such as accessible or accommodating facilities [15] as well as the support of the social environment, in particular parents, have a major influence on participation of children with a physical disability [16]. Previous studies [4,17–19] have primarily investigated the impact of having a child with a disability on parents' life (e.g. parental mental health or parent personal stress). Moreover, Lalvani and Polvere [20] point out that research concerning children with a physical disability often takes a more medical perspective and tends to look for negative outcomes or patterns of dysfunction and might therefore not sufficiently represent perspectives of families of children with disabilities [20,21]. As parents of children with a physical disability are regarded as vital for their child's participation, understanding the parent's personal experiences and perspectives is fundamental to take further steps in designing better strategies to improve participation.

Efforts towards understanding of parents' actions, challenges and needs while enabling their child's participation have been made. A scoping review of the literature on this topic [22] revealed 14 studies that identified several parents' actions, challenges and needs and underlined how little information is available on what parents actually do every day to enhance their child's participation. A diary study with 47 Dutch parents (Piškur et al., submitted) described parents' efforts to enhance the participation of their child with a physical disability by using, enabling or changing the social and physical environment, or by supporting their child to perform or engage in meaningful activities. A cross-sectional quantitative study among 146 Dutch parents showed that there is a large variety in the number, domains and priority of needs among parents in supporting

participation of their school-aged child with a physical disability; needs are mainly related to environmental aspects at home, school and in the community [23]. These studies, as do others [24–26], illustrate that parents take all kind of actions and experience challenges and needs while enabling participation of their child in all sorts of life situations.

In order to grasp the complexity and get a deeper understanding of parents' daily experiences regarding enhancing their child's participation, exploration of this phenomenon is warranted. As familial matters are embedded in cultural beliefs and values [21], describing, understanding and interpreting the meaning of parents' daily life experiences can only be reached through naturalistic inquiry. The aim of this study is to provide an in-depth exploration and understanding of parents' thoughts, feelings and concerns they experienced while reflecting on their actions, challenges and needs in enabling their child's participation at home, at school and in the community.

## Methods

A naturalistic inquiry with phenomenological design was utilised for this study. More specifically, Interpretative Phenomenological Analysis (IPA) was used [27], considering in-depth exploration of parents' individual experiences as they reflected on their actions, challenges and needs while enabling participation of their child at home, at school and in the community. IPA is theoretically rooted in critical realism [28,29] and the social cognition paradigm [29,30]. Critical realism describes that there are stable features of reality that exist and that differences in the meanings individuals attach to experiences are considered possible. The social cognition paradigm is founded on the premise that human speech and behaviour reflect these differences in meaning either directly or indirectly. Therefore, the key aim of IPA is to explore the (hidden) meaning behind people's subjective experiences.

The method offers insight into a particular perspective on a phenomenon by employing a double hermeneutic, as the researcher attempts to make sense of the ways in which participants make sense of their experiences, while acknowledging the impact of his/her own perspective on the analysis [27]. In other words, the IPA researcher attempts to understand the “insider perspective” to see what it is like from the participants' view and the “perspective alongside the participants”; the researcher puzzles over things participants are saying by “analysing, illuminating and making sense of something” through various actions inherent in the hermeneutic circle [27].

## Sample and sampling procedure

Thirteen participants (Table 1) were interviewed, all mothers, aged between 32 and 43 years. Potential participants had to match

Table 1. Participant information.

Participants	Role	Age	Region	Child	Child's diagnosis	Age	Type of education
1	Mother	45	South	Girl	Cerebral palsy (Hemiparesis)	8	Mainstream
2	Mother	36	South	Girl	Cerebral palsy (Quadriplegia) and intellectual disability	9	Special
3	Mother	41	West	Boy	Cerebral palsy (Hemiparesis)	8.5	Mainstream
4	Mother	46	East	Girl	Cerebral palsy (Hemiparesis)	7	Mainstream
5	Mother	32	South-East	Boy	Cerebral palsy (Diplegia)	5	Mainstream
6	Mother	44	Central	Boy	Cerebral palsy (Quadriplegia) and intellectual disability	11	Special
7	Mother	45	East	Boy	Cerebral palsy (Hemiparesis)	7	Mainstream
8	Mother	43	Central	Girl	Cerebral palsy (Diplegia)	9	Mainstream
9	Mother	39	North-West	Boy	Cerebral palsy (Hemiparesis)	8	Mainstream
10	Mother	35	North	Girl	Cerebral palsy (Quadriplegia) and intellectual disability	7	Special
11	Mother	47	North	Boy	Cerebral palsy (Hemiparesis)	10	Mainstream
12	Mother	45	Central	Girl	Cerebral palsy (Diplegia)	12	Mainstream
13	Mother	38	North	Boy	Cerebral palsy (Quadriplegia) and learning disability	5	Mainstream and special

the following criteria: (a) they were parents of a child (b) who was living at home, (c) aged between 4 and 12 years, (d) with a physical disability that is neurological and non-progressive in nature (e.g. Cerebral palsy, Spina bifida) and (e) they had to be able to communicate in Dutch. There were no exclusion criteria. Recruitment of parents was coordinated through the Dutch Association of People with Disabilities and their Parents (BOSK).

For this study, out of 52 families that took part in a cross-sectional study [31] and had shown their interest to participate in future research studies, 15 were contacted by e-mail. The intention was to cover the different geographical regions in the Netherlands; therefore, three families in five main Dutch regions (North, West, East, Central and South) were approached. Those parents received detailed information about the study with the possibility of contacting the researcher in case of remaining questions. A research assistant contacted the first two parents from each region who expressed interest in participating in this study, via telephone. In addition, three more parents were approached to attain purposed heterogeneity in the children's age and type of education in the sample.

### Data gathering

The medical ethics committee (Atrium Medical Centre, Orbis Medical and Healthcare Centre and Zuyd University of Applied Sciences) approved the study protocol (13-N-51). Following receipt of written and verbal information, participants provided written consent for their involvement in the study; they were able to decide freely to withdraw in any stage of the research process.

An independent experienced moderator (F. A. H.) conducted the interviews in 2013 in the parents' home environment while at the same time the first author (B. P.) took field notes and made observations. In order to respect the privacy and give voice to parents, they were asked how they and their child wish to be named in the findings.

A semi-structured interview guide, developed according to guidelines provided by Smith et al. [27], included a set of guiding questions served to direct the interview. The guiding questions to provide insight into meanings, thoughts, feelings and concerns were, for example: *If you think of a normal day, could you tell me what kind of activities your child is doing? What are you doing yourself when necessary to support the just mentioned activities of your child? Could you tell me about any challenges you might experience while supporting your child at home or at school or in the community? If you think of a possible support, could you tell me something about the kind of support you wish to receive while experiencing those challenges as just described?* The involvement of a client as a co-researcher (B. C.) in designing the interview guide was to ensure the appropriateness of the questions. Producing a guide beforehand forces the researchers to explicitly think about what the interview might cover [27]. A range of benefits has been identified from involving service users in research, like expertise of users improves research process, enable researcher to develop more social understandings and makes research process inclusive [32]. The interview process was still collaborative, emphasising that the participants were the primary experts [33].

First, a pilot (with two parents of a child with a physical disability) was conducted in order to test for flaws, limitations or other weaknesses of the interview design. A pilot test should always be conducted with participants who have similar interests to those who will participate in the implemented study [34]. Based on the reflections obtained during the pilot, the introductory ice-breaking question was changed.

Each participant was interviewed once. The interviews lasted between 89 and 127 minutes; they were recorded and transcribed verbatim.

### Data analysis

Interpretative phenomenological analysis (IPA) recommendations guided data analysis [27]. Each transcript line was annotated with a line number and each participant's transcript was colour-coded to aid the analysis process, allowing for easy reference. An idiographic approach used by the first author (B. P.) followed, focusing on one interview transcript in detail at a time and developing emergent themes before moving on to the next transcript. The idiographic case-study approach is a method suitable for small samples that enables the researcher to write up a single case or an exploration of themes shared between cases [29]. Each interview transcript was analysed individually, read and re-read until the researcher was immersed in, and familiar with, the content of the data. Initial observations were recorded in the margin and a tracking system was used to code relevant quotations. This process was repeated for all participants. Once all transcripts were coded, codes were grouped into "clusters". Each cluster represented a similar topic or theme, hence the name of "sub-ordinate theme" was used to describe each cluster. "Sub-ordinate" themes were then grouped further into similar topics to provide an overarching thematic essence referred to as "super-ordinate theme".

Four interviews were identically analysed by the second author (S. M.). Debriefing sessions took place to discuss the results of the analysis and to reach consensus. Examples of data from the study, as well as suggested themes, were presented and discussed with all authors. Peer debriefing sessions were organised with two co-authors (S. M., B. C.) to discuss the super-ordinate themes, sub-ordinate themes and their sub-categories.

In this study, Lincoln and Guba's [35–38] four criteria (credibility, transferability, dependability and confirmability) for evaluating interpretive research work were applied. The first author took the preliminary results back to one of the participants to receive feedback indicating that experiences in the descriptions given were recognised. The 12 other participants in the study did a member check of the summaries of their interviews and provided written feedback. Confirmability has been applied by reporting findings that are solely the result of the experiences and ideas of the participants. Dependability was assured by reporting, in detail, the processes within this study thus, enabling a future researcher to repeat the work.

### Results

The analysis of the interviews revealed three super-ordinate, and seven sub-ordinate themes with sub-categories portraying parents' experiences described by the meaning of their thoughts, feelings and concerns, illustrated with some examples of actions, challenges or needs. A summary is presented in Table 2.

#### Super-ordinate theme 1: parents' experiences and concerns about systems, laws and regulations

The first super-ordinate theme comprised three sub-ordinate themes: "clashes with the educational system" (Sub-ordinate theme 1.1), "conflicts with administrative procedures and local authorities" (Sub-ordinate theme 1.2) and "struggles with health care professionals" (Sub-ordinate theme 1.3). Within each sub-ordinate theme several sub-categories are present.

##### *Sub-ordinate theme 1.1: clashes with the educational system*

Parents described their experiences as clashes with representatives of the educational system due to (1) differences in perception about the child's abilities, (2) structure, (3) flexibility of the system and (4) lack of professional know-how. In their efforts to

Table 2. Summary of the super-ordinate, sub-ordinate themes and sub-categories.

Super-ordinate theme 1: Parents' experiences and concerns about systems, laws and regulations.	<i>Sub-ordinate theme 1.1</i> Clashes with the educational system.	1. Differences in perception about the child's abilities. 2. Structure 3. Flexibility of the system 4. Lack of professional "know-how".
	<i>Sub-ordinate theme 1.2</i> Conflicts with administrative procedures and local authorities.	1. Complexity 2. Duration 3. Not taking the child's needs into account. 4. Lack of professional "know-how".
	<i>Sub-ordinate theme 1.3</i> Struggles with health care professionals.	1. Not have an understanding what supports their child's social participation. 2. Deficient in providing information. 3. Lack of inter-professional communication.
Super-ordinate theme 2: Parents' experiences and thoughts about physical and/or social environment	<i>Sub-ordinate theme 2.1</i> Problems of the physical environment, available equipment, aids and clothing.	1. Restrictions caused by the physical environmental. 2. Lack of available equipment, aids and clothing.
	<i>Sub-ordinate theme 2.2</i> Paradox in attitudes of other people.	1. Discriminatory and negative attitudes of others.
Super-ordinate theme 3: Parents' experiences and feelings of finding or/and enabling an activity.	<i>Sub-ordinate theme 3.1</i> Efforts to find a suitable leisure activity.	1. Limited choices 2. Lack of adequate information 3. Lack of experiences 4. Lack of professional "know-how"
	<i>Sub-ordinate theme 3.2</i> Strategies to promote independence and participation.	1. Educating a child how to apply new strategies. 2. Providing prompts to support independence and participation.

enable their child's participation, parents reported facing a number of challenges.

All parents explained the intensiveness of the process and their own struggles with making decisions about the right type of education for their child. According to parents, choosing a mainstream school is not an easy decision. Participant 12 gave the following example:

"And then from various people we heard comments like, well, if she can attend a regular school it would be really good because it lays a solid basis for the future. And the special education program (Mytyschool) is, well, it's like a warm cocoon, but afterwards you still have to be able to survive in normal society" (Participant 12).

Parents saw many pitfalls in mainstream education, like peer pressure and the possibility that their child would be bullied. Furthermore, several parents shared that the acceptance of a child with a physical disability in mainstream education is not evident.

Parents mentioned that they went through several complex negotiation processes with school boards to achieve their child's acceptance in mainstream education. Discussions, centred on child abilities, resulted in parents advocating for their child's rights. To convince others, parents sometimes even suggested having their child's IQ tested.

For these parents, requests beyond the usual structure of the system lead to many challenges. Participant 13 spoke very positively about an agreement with the director of a mainstream school and the director of a school for special education about combined education in both schools, considered by all stakeholders to be an optimal solution.

"Because his cognitive skills are just the same as any other child...umm...when he turned four we tried to see if we could set up a combination of both special schooling and normal education, and it worked. Yes, we are just so unbelievably happy with this. But this would seem to be...umm...I would say, something of a unique situation" (Participant 13).

Unfortunately, this part of the conversation ended with less positive news; Participant 13 explained that just a few days before the interview was conducted she heard, according to the law, combined education is not allowed.

Children with a physical disability make use of services, like occupational therapy and physiotherapy. In the eyes of several parents, linking the world of education and these services is hindered by the flexibility of the Dutch system; mainstream education does not allow a child to miss school classes several times a week. Different actions to find solutions were mentioned. One parent explained that they replaced service in a rehabilitation centre with an adequate private service, while another parent chose to include their child in a special education program where all services are available. Several parents expressed a need for flexibility in education, accommodating health care services or a possibility of having a therapist available in mainstream education.

Parents perceived the lack of "know-how" of teachers and teacher assistants in mainstream education as challenging. In their opinion, there is too little anticipation of the needs of their child in the classroom and outside. To illustrate this, Participant 8 said that the teacher lacks the right strategies to support their child, who is excluded and neglected by other children while playing outside during the school-breaks. This family decided to empower their child by doing role-plays at home.

Parents often felt they had a better understanding of the causes of problems than educational staff and consequently were able to propose solutions that worked. Examples parents provided were related to enabling their child during educational activities in the classroom, physical education or activities during a school trip.

"She repeatedly failed the tests. I came to pick her up from school one day and quite by chance she was sitting in the hallway doing a test on the computer. It was then that I saw what was actually happening, because with only one hand, she only has one hand which functions properly, you can't do everything. ...So I wrote another email, like, couldn't it be because of the method used to test her, I think this might be the problem. Well, luckily the next day the teacher teamed her up

with a buddy who was allowed to type for her, she only had to say what needed to be typed and she passed straight away!” (Participant 1).

According to parents, teachers' insufficient understanding of what disability means and lack of experiences with children with physical disabilities leads to incorrect interpretations of problems, as for example one parent said:

“After four years we swapped schools, this was because he got completely stuck . . . umm . . . they underestimated him . . . umm . . . approached him in the wrong manner. For instance, the material offered was very, very visually orientated, even though he suffers from low vision. This was never fully acknowledged by the school. In the end we sort of investigated and made recordings in the classroom. This revealed more than enough!” (Participant 6).

Parents expressed their wish to have more adequately prepared teachers and teachers-assistants during regular classes, during outside play and during school trips. Furthermore, parents talked about having more children with a disability in mainstream education to let other children get used to it and accept differences more easily.

*Sub-ordinate theme 1.2: conflicts with administrative procedures and local authorities*

With the intention of enabling their child's participation, parents experienced conflicts with bureaucratic procedures due to (1) complexity and (2) duration. Parents also struggled with employees of local authorities because of (3) not taking the child's needs into account and (4) lack of professional “know-how”.

Parents expressed their belief that procedures for financial support regarding additional equipment, adaptations or resources are deliberately multifaceted. Parents' right for financial support for reimbursement of an assistant at school, for leisure activities or support at home and a so-called personal budget funded by the Exceptional Medical Expenses Act – AWBZ, is perceived by parents as a battle with bureaucratic procedures. These procedures often take a significant amount of time and the complexity requires good investigation skills.

“Yes, in the beginning I, I was sent back and forth and nobody actually wanted to tell me in detail, how and what to do to get the personal budget. Hmmm, . . . finally it took more than half a year before I . . . could start the application procedure and then still, the whole process was waiting ahead of me, huh, before you get it . . . it's like a complex research project (smile)” (Participant 1).

Another parent said it is strategic to invest in personal connections with staff from the local community to be able to understand how bureaucratic procedures work in order to succeed. Participants stressed the need for changing these procedures. Some parents wonder, in view of the fact that even they do not understand how the system works, how this must feel for parents with a foreign background. The need for a coach or clear signposts was expressed.

According to parents, the bureaucratic system does not take the child's needs well enough into account. Participant 3 noted that the allowed frequency of getting, for example, a new foot-splint is fixed no matter how fast a child develops. This participant expressed a need for having flexible rules and regulations that better fit the child's needs.

With astonishment, parents spoke about the amount of time procedures take in the Netherlands from application to receiving a new piece of equipment. For example, it takes roughly a year to get a new wheelchair or half a year to get a three-wheeler. Parents described undertaking several actions, like negotiating with different authorities by phone or face-to-face, to accelerate the procedure. Procedures actually can take so long that, as children grow, the equipment does not fit anymore by the time it arrives.

Parents talked about their conflicts with people working for local authorities and being responsible for decisions about adaptations and aids due to lack of “know-how”. Participant 10 became very emotional about her experience:

“He said to us . . . we can't do much with a house that's hard to manoeuvre in . . . and . . . well . . . I don't know if there is even any point in doing anything at all because . . . umm . . . in a few years your child will only be capable of lying down . . .” (Participant 10).

Parents felt actions to improve these situations were needed. Participant 10 wrote a complaint to the local authorities about the lack of professional attitude of one of their employees. Another participant (3) even suggested that having a non-cooperative attitude might be part of their education and training.

Participants stressed that professionals working at local authorities responsible for the bureaucratic procedures often lack necessary “know-how” and understanding of what a disability is. Participant 11 explained the reason for not getting a disabled parking permit was a note in the child's record saying he is able to walk:

“My son can walk, so of course he won't be getting a disabled parking permit . . . /laughs/ . . . well, so we explained, . . . we really would like to have the disabled parking permit, because he could walk, but for short distances only, and to ensure that he keeps walking, not having to rely on the wheelchair everywhere” (Participant 11).

Parents mentioned initiating different actions to get the support they requested. For example, parents educated the employees of the local authority about the meaning of having a disability for their child's participation or they appeal decisions.

*Sub-ordinate theme 1.3: struggles with health care professionals*

All participating parents had experienced struggles with health care professionals who do (1) not understanding what supports their child's social participation, (2) are deficient in providing information or (3) demonstrate lack of inter-professional communication.

Participant 10 experienced a lack of understanding and insight by health care professionals about her child's functioning in a real context:

“I wish they could see what it's like to drive with my daughter in the car or to play at the playground . . . and then give me an advice” (Participant 10).

Currently, most children receive physiotherapy, speech therapy or occupational therapy in the rehabilitation centre or primary care clinic. The majority of the participants were wondering how practicing in the simulated environment of the institution is beneficial for their child's participation at home or elsewhere. Parents also mentioned that their child does not like practicing without any meaning; in parents' opinion those exercises are difficult to transfer to daily life situations:

“But at home I’m not going to say, like, . . . hmmm . . . from now on you’ve got to train for one hour every day, that doesn’t get you anywhere. She’s not a machine you can program, that’s not how it works, so . . .” (Participant 4).

The above-mentioned struggles generated different types of actions, as described by several parents. Some parents adapted the exercises into a meaningful activity for the child, while others did not exercise at all. In order to support their child in daily life, parents wish therapy would take place at home, at school and in leisure situations.

The quality of information received from health care professionals about supporting their child at home or elsewhere is seen as insufficient; information either was not specific enough to their child’s situation or had little relation to enabling the child’s daily activities. Furthermore, parents missed tips on where to find additional information.

“Yes, from my point of view, for instance, a doctor could easily have referred us to the Dutch Association of People with Disabilities and their Parents (BOSK) and that through BOSK, as I found out later; there is lots of information to be found. Hmm, that there is more of . . . umm . . . yes, a sort of, some sort of a central point you can go to with your questions. That’s what I would like to see” (Participant 5).

As a result of those challenges, parents described various actions undertaken to find information. Most often, information was derived from other parents in similar situations or through the internet. Participant 11 explained that she collected information on the internet before meeting her physiotherapist. She then informed him about a dynamic arm brace resulting in better arm use during several activities, like playing hockey.

Furthermore, participants explained that health care professionals do not sufficiently communicate with each other. Participant 5 gave an example that each time she meets another member of the team she needs to clarify the same things about her child over and over again. Parents expressed a need for improved communication and documentation between professionals.

“Well, you know, in general I’m not really happy with the rehabilitation doctors we have . . . Now, for example, take these splints, well then yeah, if he (the specialist) takes a look he always says, ‘ohh those splints are no good for your son,’ but what about the other rehabilitation doctors, they have never said anything about them” (Participant 11).

The same participant continued saying that their child, while wearing a splint, was not able to engage in several activities, like playing hockey.

Parents expressed, based on those challenges, their wish that therapy would take place in a real context. According to them, this could overcome misunderstandings between professionals and families. Further, they need professionals to keep in mind the participation of their child in daily life whilst engaging in deliberations.

### **Super-ordinate theme 2: parents’ experiences and thoughts about physical and/or social environments**

The second super-ordinate theme comprised two sub-ordinate themes: “Problems of the physical environment, available equipment, aids and clothing” (Sub-ordinate theme 2.1) and “Paradox in attitudes of other people” (Sub-ordinate theme 2.2). Within each sub-ordinate theme several sub-categories were exposed.

#### *Sub-ordinate theme 2.1: problems of the physical environment, available equipment, aids and clothing*

Parents described experiencing (1) restrictions caused by the physical environment, and (2) lack of available equipment, aids and clothing due to differences in parent’s perceptions about their child’s abilities, needs and wishes and what the environment has to offer.

Several parents, some very worried, described a mismatch between what is needed for their child to participate in mainstream education and the actual school environment. Inaccessible entrances, stairs or suitable furniture and shoes were the most often named challenges. For instance, some children with a physical disability are provided with an electric wheelchair to sustain their mobility at home or elsewhere. However, electric wheelchairs can be a major challenge at school due to entrances, space in the classroom and stairs. As such, it creates many dangerous situations for everybody. Participant 12 with the feeling of being powerless in changing the school environment, explained that they – she and her husband – decided to replace an expensive electric wheelchair with an ordinary office chair at school.

Parents also explained that they take actions themselves to overcome these kinds of environmental barriers. For example, parents made an adaptation to the school entrance for wheelchair users, adapted the table height or made an arm support that enabled their child to sit adequately in the classroom. All parents expressed an urgent need to change the school environment into an accessible place for everyone. Similar challenges have been described for public places such as entering a dressing room in a shop or a public toilet with a wheelchair.

Finding adequate equipment and aids like bicycles, beds, shoes or splints is perceived as challenging. Even specialised stores only offer limited choices. For example:

“He attends a regular school, and all of the children have a certain style of bike, because at the moment this is fancy and trendy; my son also wants such a bicycle . . . There was no deal in a special shop; I had to search for it on the internet myself and you know what?; this bicycle also exists as a three-wheeler. Nobody in this special store said so” (Participant 3).

This participant pointed out that the design of equipment and aids should not be stigmatising to a child with a disability.

Several participants illustrated that they were forced to find solutions themselves, like to design an aid for moving-around (Participant 6) or a special bed (Participant 10). Lack of choices was also experienced while looking for appropriate clothes and shoes. Participant 9 gives an example:

“At first he had orthopaedic shoes, but there is absolutely no choice, just one model . . . umm . . . so now I buy two pairs of shoes in two different sizes and occasionally a shoe store will give a 10% discount on the second pair”.

Searching for information on the internet is a common action described by parents seeking equipment and aids. Participant 3 found a store in the US on the internet selling exactly the same arm-splint as offered in the Dutch special store, however, with many more choices of colours and designs. Gathering information from their private social network and collecting ideas from other parents with similar experiences are other often-mentioned actions taken by parents:

“Right, and then you’ve got, we have, you could say, umm, other people’s experiences . . . you can build on these, but if

you don't have that you have no idea that it exists. For instance, we have now ordered one of those toilets with a posterior wash and blow dryer. Well yes, we first saw this at somebody else's place'' (Participant 2).

Several parents expressed the need for tailored, easy accessible quality information and more choices in specialised stores with attention to the child's personal wishes and needs.

#### *Sub-ordinate theme 2.2: paradox in attitudes of other people*

All participants described situations in which they experienced (1) discriminatory and negative attitudes of others that influenced their child's participation in daily life situations. All parents expressed feelings of frustration and pain. Sometimes awkward situations occur as other people judge without understanding, as an example of Participant 8 demonstrates:

''Yes well, take the ''Hema'' [a Dutch retail shop] for instance, they have a wide staircase and normally speaking you would walk up the stairs on the right and down on the right. But her right side is her difficult side so she climbs the stairs on the left. An older person, who also walks with difficulty, could, for instance, come down the stairs on the right. The look that follows clearly says ''move over why don't you'', like, ''why are you going against the flow''. Then I think, well she also has difficulty walking. These are just the really awkward things, the times that you think; if I were an elderly, widowed woman I would also think ''well, come on''. Yes, these are the things you have to face in, yes especially in, the outside world''.

Participant 2 expressed that they often get negative remarks while using a special parking place for people with disabilities; it seems others do not recognise their child as having a disability. Different examples were given regarding professionals having negative attitudes towards their child with a disability. This is illustrated by the following quote:

''They had a letter, one which I was not supposed to receive as it was meant for internal use only, all sorts of things were written in it, umm Jens is umm, it was written, a little bit of a strange lad, that's how it was written in the letter... very painful'' (Participant 3).

Many parents had thoughts and wishes about a less discriminatory and less negative society, and wished for more sensitive professionals.

### **Super-ordinate theme 3: parents' experiences and feelings of finding and/or enabling an activity**

The third super-ordinate theme comprised two sub-ordinate themes: ''Efforts to find a suitable leisure activity'' (Sub-ordinate theme 3.1) and ''Strategies to promote independence and participation'' (Sub-ordinate theme 3.2). Within each sub-ordinate theme several sub-categories were revealed.

#### *Sub-ordinate theme 3.1: efforts to find a suitable leisure activity*

Parents described their efforts to find suitable leisure activities for their child as intensive; a consequence of (1) limited choices, (2) lack of adequate information, (3) lack of experiences and (4) lack of professional ''know-how''.

With a hint of frustration, all participants mentioned a restriction in opportunities to join leisure activities for a child with a physical disability. Participant 7 experienced finding appropriate swimming lessons to be a big challenge; swimming

lessons with specialised trainers are very expensive and mostly scheduled late in the evening.

According to the parents, health care professionals hardly provide information about suitable leisure activities. Moreover, parents stressed that often professionals perceive a leisure activity as an additional therapy instead of something a child wants to do to have fun with other children. As Participant 6 explained:

''Well now, horse riding is actually a suggestion made by the physiotherapist at the time, he said it would be good for him, for his sense of balance as well as a being a form of relaxation,... umm... for his muscles.... And the scouts, they do all sorts of things, everything to do with being a scout... And my son enjoys being outside and partaking in all of sorts of wild and dangerous games etc., yeah, he really enjoys it, and it; it is a part of who he is. And we enjoyed it too, because at the scouts he is part of a group and with his horse riding he is doing something as an individual. We, well, considered this important in respect to his social development''.

Situations as described above stimulated parents taking actions, like asking parents with similar experiences for advice through social media. Furthermore, parents also advocated for their child in sport clubs or looked for a person with experience in working with children with a disability. Participant 7 notes:

''And then we decided to take a further look into judo. I googled a few clubs and turns out that the guy giving the judo lessons is also a movement therapist at our rehabilitation centre, never knew that; yep, you've got to have a bit of luck and know how to meet the right people''.

A lack of experiences and professional ''know-how'' in sport centres is also perceived as a challenge. Parents experienced sport educators' lack of knowledge on how to explain an activity to children and in how to support a child with a physical disability in connecting with other children.

''This has been a pretty traumatic, long journey. All of this didn't fit or it was more like yeah, no, no, we can't do that, this is too difficult for us, huh. Of course, all too often they think like, 'oh, not a person with a disability'''' (Participant 1).

With the intention of including their child in a leisure activity different actions were described; parents joined an activity to support their child, they provided the instructor with additional information or they became an instructor themselves.

#### *Sub-ordinate theme 3.2: strategies to promote independence and participation*

Throughout the interviews parents reflected on the strategies they use to support or improve their child's participation at home or at school. This included (1) educating a child about how to apply new strategies during an activity or (2) providing prompts to support independence and participation.

Participant 2 proudly described that she found pictograms on the internet to enable her child at school; she taught her child to communicate more effectively using pictograms. Participant 2 further described that she taught her child to use pictograms in combination with written language. Another parent (Participant 1) shared her positive experiences with pictograms to enable independence while taking a shower at home; pictograms on the wall in the bathroom showed the sequence of showering.

Pictograms were also used to understand the structure of the day as described by Participant 9:

“Here we have, a shopping list I call it, on the door in the/ coughs/sorry. At a certain point I hung up pictograms for all three of my children (no differentiation there ha-ha) showing the tasks they each had to perform every day. These included putting on their shoes, packing a bag, brushing teeth, combing hair. It’s all on there and it works, otherwise I would be forever on the go”.

In order to increase their child’s participation at home, parents described that using verbal strategies helped their child to become independent, like asking a child before going to take a shower to prepare everything needed. Furthermore, alternative strategies to support communication were mentioned. One parent (Participant 10) used different smells to give prompts for starting a new activity, like lemongrass means that they are going out by car. Participant 9 showed a prototype of their new house made of wood; in this way, they were able to explain what the new house will look like and to enable their child to think with them about how his room should look.

## Discussion

The aim of this study was to provide an in-depth exploration and understanding of parents’ thoughts, feelings and concerns they experienced while reflecting on their actions, challenges and needs in enabling their child’s participation at home, at school and in the community.

The analysis revealed three super-ordinate and seven sub-ordinate themes with sub-categories. Findings mainly illustrated parents’ disappointments related to their interactions on different societal levels while reflecting on their actions, challenges and needs. Their feelings and thoughts of being misunderstood, about dealing with complex systems and about participation of their child being hindered by the social and the physical environment motivated them to take actions, and express needs and wishes. In the eyes of parents, especially situations in which professionals and authorities lack understanding of the life of a child with a disability, lack of understanding of needs of children to participate, and misunderstanding the experience and expertise of the parents, pushes them to take action. Moreover, parents showed their worries and efforts to find appropriate leisure activities and described their strategies to enable independence in activities at home or at school.

The findings of this study seem to be comparable to results from studies in other cultural contexts; barriers in physical and social environments, negative attitudes of other people, fear of bullying and lack of knowledge by professionals are examples of parents’ challenges [25,39–43]. Slade et al. [44] reported that across the United Kingdom, parents of children with a physical disability experience lack of information, lack of knowledge and lack of involvement in decision making when dealing with professionals (treatment, care and support) prompting them to adopt a pro-active approach. Salminen and Karhula [45], in their review study, concluded that environmental interventions may be even more crucial to support participation, than interventions directed to child abilities.

Findings in our previous work ([31], Piškur et al., submitted), other Dutch studies and policy reports support the findings of this study. The Netherlands has laws and regulations to support children with a disability to participate in society. However, Sleeboom et al. [46] conclude that the difficulty to fully understand these laws and regulations often leads to the question of whether or not they optimally support participation of children

with a disability. Parents in this study experienced similar obstacles within the systems, laws and regulations.

At the moment, the Dutch school system is in reform; in August 2014, the new *Law of Inclusive Education and Opportunities* for all children to be included in mainstream education was launched [47]. De Boer [48] demonstrated that Dutch parents of children with a disability feel positively about these changes although they also expressed worries about the attitudes of peers towards their child. Parents in this study were concerned about the lack of knowledge teachers have in mainstream education to support their child’s educational activities. An enquiry by the Dutch national public advocate [49] revealed that teachers lack information about the disabilities of their students and ways to support them.

Furthermore, in the Netherlands, free accessibility to public buildings and places for all citizens was not included in the Equal Opportunities Act. This means that there is no obligation to guarantee access for persons with a disability [50]. De Jong et al. [51] found that only 29% of people with a severe physical disability in the Netherlands can enter shops. In this study, parents expressed that accessibility of schools and public buildings cause participation restrictions. The Netherlands also has no specific regulations for leisure and sports clubs concerning children with a disability [46]. Parents in this study stressed that finding an appropriate leisure activity is a “pretty traumatic, long journey” due to limited choices, lack of adequate information and sport educators’ lack of experience and professional “know-how” concerning their children.

Thirteen parents participated in the current study. This number can be seen as a possible limitation; however, the general aim of the IPA approach is to gather rich information and to explore in-depth individual experiences with a small sample [52]. A second limitation might be the researchers’ prior knowledge having an influence on data analysis. Two authors involved in data analysis have prior experiences and knowledge in this field (as described under “Authors’ information”) and one co-author is a parent of a child with a physical disability. However, all the methodological recommendations have been followed and the data analysis has been done according to the IPA protocol as described by Smith and Osborn [27] to ensure the credibility of the analytic process. Finally, there is a possibility, taking the many negative experiences into account, that the data sampling procedure attracted only the most disillusioned parents. However, triangulation with literature from the Netherlands and other international studies showed that these findings do not stand alone.

The parents in this study seemed to be very aware of the influence of the environment on participation of their child with a physical disability. Social-ecological perspectives [53,54], like Bronfenbrenner’s theory, underlined the importance of interaction among and within systems at different levels and its influence on child development [55,56]. Most studies on environment and child development conducted so far are, however, with respect to family and parenting processes rather than any other environmental components [57]. Investigating parents’ reflection on their actions, challenges and needs in enabling their child’s participation did not aim to evaluate systems and services, but rather to more deeply understand what makes parents take actions in enabling their child’s participation. Among their examples are many negative experiences with environmental support. From a sociological perspective [58], this might point to a conflict between the “life-world” and the “system world”. The life-world is the informal world of the street and the community; the system-world is the world of rules and protocols, often driven by economic interests and power. Shifting processes and decision making from the system world to the life world is a current issue in the implementation of the Dutch Social Support Act with the

municipal authorities having the responsibility to promote participation in society for those who need it [59], including children with a physical disability. Dutch policy puts much emphasis on a civil society, pointing out the importance of local tailor-made solutions, empowerment and involvement of citizens and a facilitating municipality [60]. Parents in this study expressed that their actions are not something additional, but very vital for their child to be able to be part of society. Enhancing participation for children with a physical disability could benefit from acknowledging and learning from these parents' thoughts, feelings and concerns, gathered through their experiences and expertise, and could provide a starting point for finding ways for cooperation on an equal level.

Therefore, future studies ought to focus on ways to involve parents in policymaking, quality improvement of services and learning from their experiences. Furthermore, there is a need for studies focusing on the influence of different environments, other than parents, on enabling children's participation. Finally, it is recommended that similar studies on exploring parents' actions, challenges and needs in other cultural contexts be conducted.

## Conclusions

In-depth exploration and understanding of parents' articulated matters regarding different environmental features and their impact on their child's participation are reported in this study. Parents' thoughts, while reflecting on their actions, challenges and needs to enhance participation for their child with a physical disability, are primarily focused on their interactions on different societal levels. Feelings of disappointment deriving from being misunderstood, from dealing with the complexity of systems, and from hindrance of participation of their children by the social and the physical environment urged them to take actions, and think of their needs and wishes. Their unique perspective on those matters must be shared and taken seriously by policymakers and service providers (e.g. active involvement of parents in designing new policy or in a client advisory board). Parents' knowledge and experiences should be of major relevance to improve paediatric rehabilitation and other services for children with a physical disability.

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