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Published in:
Disability and Rehabilitation

DOI:
10.3109/09638288.2016.1161841

2017

Document Version:
Peer reviewed version (aka post-print)

Link to publication

Citation for published version (APA):
Lauruschkus, K., Nordmark, E., & Hallström, I. (2017). Parents' experiences of participation in physical activities for children with cerebral palsy – protecting and pushing towards independence. *Disability and Rehabilitation*, *39*(8), 771-778. https://doi.org/10.3109/09638288.2016.1161841

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3

Parents' experiences of participation in physical activities for children with cerebral palsy – protecting and pushing towards independence

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Journal: Disability & Rehabilitation

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Keywords: cerebral palsy, children, parents' experiences, participation, physical activity

Abstract

Purpose: To explore how parents of children with cerebral palsy (CP) experience their child's participation in physical activities and to identify facilitators and barriers for being physically active and reducing sedentary behaviour.

Methods: Twenty-five parents of sixteen children, aged 8-11 years old with CP, with varying gross motor, cognitive and communicative functions and with different cultural backgrounds, participated in focus group or individual interviews. Content analysis was used for analysis.

Results: Five subcategories addressing children's participation in physical activity were found: "Belonging and taking space in the family", "Important persons facilitating and hindering", "Friends important but hard to get", "Good for the body but challenging" and "Availability and opting out possibilities". The subcategories built the main category "Protecting and pushing towards independence", expressing the challenges parents experienced when their child wanted to be physically active.

Conclusions: Parents desire competent persons to be available for support in participation in physical activities. They want support in finding friends for their child to be physically active with. Family culture and attitudes affect their child's motivation for being physically active and should be taken into account when designing interventions for increased participation in physical activities and for reduced sedentary behaviour in children with disabilities.

INTRODUCTION

Children with cerebral palsy (CP) participate in lower levels of habitual physical activity compared to children without CP and are at risk of increased sedentary time [1]. Physical activity in free-living conditions (activities performed in the home or community) is defined as habitual bodily movement produced over one full day [2]. Differences in frequency of physical activity in relation to children without CP increase with the severity of limitations in gross motor and cognitive function [3,4]. CP is the most common physical disability in childhood with an estimated prevalence of 2.0 to 2.5/1000 children, and is often accompanied by conditions such as intellectual, communication, and behavioural impairment, as well as epilepsy and pain [5,6]. An active lifestyle and increased physical fitness are recommended for promoting health for children with CP [7,8,9]. Gross motor function in children with CP is extremely variable and it is likely that their energy expenditure and muscle activity differs in postures such as sitting and standing. Replacing sedentary time with light physical activity might be a beneficial way to reach health-enhancing physical activity goals for children with CP [10].

Physical activity is important for all children and young people for developing healthy musculoskeletal tissues, a healthy cardiovascular system, neuromuscular awareness and for maintaining a healthy body weight [9]. Moreover, participation in physical activity is associated with psychological and social benefits such as relief of anxiety and depression, opportunities for self-expression, and a boost to self-confidence, social interaction, and integration [9]. Even if children in general meet the global recommendations of 60 minutes of moderate to vigorous physical activity per day [9], awareness of physical activity levels for the remaining time increases [10]. Independent effects on health outcomes, physical function and human metabolism are found for sedentary behaviour time [11]. Sedentary behaviour is defined as any waking behaviour characterized by little physical movement and low energy expenditure while in a sitting or reclining posture [12]. Whether this definition suits children with CP is being debated as children with severe CP may be in a sitting posture in their wheelchair when they are physically active. For these children focus should be on energy expenditure rather than on their position [13,10].

When promoting participation of children with disabilities in physical activities, individual activity preferences, availability of equipment and appropriate programs, and the overall health status of the child should be considered [14]. In focus group interviews with parents of ambulatory youth with CP, personal factors such as the physical ability of the child, and environmental factors such as the parents not accepting the extent of the disability or lacking awareness of the benefits of physical activity were found to have an impact on the child's participation in physical activities [15]. Furthermore, the interviews provided insights about physical activity behaviour associated with different stages of change, which might be of interest when supporting the families individually [16]. Environmental and personal factors, the variation in preferences for physical activities, and health benefits were identified as facilitators for being physically active in interviews with parents of youth with CP of varying severity in gross motor function [17]. Family preferences and attitudes towards exercise were described as personal factors for participation in physical activities for children with CP, whereas physical, social and financial support, as well as transportation and access to information were seen as environmental factors of importance for facilitating or hindering physical activity [7]. Attitudes at school and in the community, difficulties accessing personal equipment and both the natural and built environment were perceived as general barriers to participation by the parents of children with CP [18]. A popularised thinking in childhood disability, focusing on every child's individual issues and strengths, is encouraged through the concepts of the ‘F-words’: function, family, fitness, fun, friends and future, which should be the focus in childhood disability according to the authors [19]. The concepts can be seen as a theoretical framework, grounded in the International Classification of Functioning, Disability and Health (ICF) [20], inspiring ‘new’ points of entry to research regarding disabled children.

Parents are important for increasing participation in physical activity and reducing sedentary time for each individual child with CP. There is a need for more knowledge about the ways in which physical activity can be viewed and encouraged among parents and their children with varying degrees of capability and different cultural backgrounds. In addition, the parents’ perception of their child’s participation in physical activities in different settings should be examined: at home, school sports, in leisure time activities and at their habilitation centre. The experiences of children with CP with different limitations in gross motor, cognitive and communicative function and their participation in physical activities have been presented in another study. The children explained in individual and focus group interviews that they wanted to be physically active, they wanted to make choices, have fun and enjoy the sensation of speed [21]. The purpose of this study was to explore how the parents to the interviewed children with CP experience their child’s participation in physical activities. Another purpose was to identify facilitators and barriers to becoming, being and staying physically active and reducing sedentary behaviour, taking different cultural backgrounds into account.

METHOD

Design

The study had an inductive qualitative approach including focus group and individual interviews [22,23].

Procedure

As all children with CP in Sweden are offered support from a local habilitation centre a letter of invitation with information about the study was sent to all legal guardians of children with CP aged 8 to 11 in the Skåne region in southern Sweden (N= 117) during the period from January to June 2012 by an administrative assistant at the Child and Youth Habilitation Services. The age interval 8 to 11 years was chosen as it included school children before puberty. Both children and their legal guardians were invited to participate in interviews and the results of the children's interviews are presented elsewhere [21]. After two weeks, a reminder was sent to all legal guardians who had not answered. Twenty-five legal guardians of 16 children agreed to participate, and the first author contacted them for verbal information and to determine whether they wanted to participate in a focus group or an individual interview. In addition, time and place for the interview according to their wishes, as well as the need of a language interpreter were determined.

Participants

There were 25 participants in the study. Nine married or cohabiting couples, six mothers and one father agreed to participate in the study. Twenty-three of the participants were biological parents, and two were foster home parents; from here on, the term 'parent' will be used for all participants. The parents had different backgrounds regarding to ethnicity, gender, language, socioeconomic status and geographical area. Eleven parents were born abroad (44 %) and eight of them were born outside Europe; five of whom requested a language interpreter for the interviews. In Sweden, the social security system provide for personal assistance to facilitate social participation and equality of living conditions [24,25] and five parents in the present study were employed as personal assistants to their child. The characteristics of the parents and their children are shown in Table 1 and 2.

Data collection

The interviews were carried out from March to June 2012. The participants were offered the choice to participate in a focus group or an individual interview in order to enable the participation for all parents. In connection with the interview, the parents filled in a sociodemographic questionnaire, giving characteristics of themselves and their child with CP (Table 1 and 2). Information about gross motor and cognitive function was provided according to the parents' perceived opinion. Three parents chose to be interviewed individually, and four couples chose to be interviewed at the same time. When being interviewed as couples, both mothers and fathers were asked to answer the questions individually. All individual interviews were conducted by the first author either in the parents' homes or at a habilitation centre and lasted between 40 and 75 minutes. Fourteen parents participated in four focus group interviews; according to the parents' wishes or for practical reasons one focus group consisted of six participants, two of three, and one of two. Three focus group interviews were conducted at a habilitation centre, and one at a hospital. They were all moderated by the first author, three of them with the second author, and one with a doctoral student as an observer and lasted between 90 and 120 minutes.

Both the individual and focus group interviews were semi-structured and started with the parents giving a short presentation of themselves and their child. In order to get a better understanding of what “physically active” meant to each participant and to reach a consensus about it between each parent and the researcher, several minutes were spent discussing their own experiences and habits regarding physical activities. The parents were then asked to narrate their perceived experiences of their child with CP’s physical activity in different environments: at home, during leisure time, at school, and at the habilitation centre. Thereafter, they were asked about perceived facilitators and barriers to their child being physically active. During the interviews, additional questions were asked aiming to encourage further and more reflective narration such as, ‘Can you tell me more about this?’ They were also asked ‘What do you mean?’ or ‘Can you give me an example?’ The procedure was the same in individual and focus group interviews, except that the participants in the focus groups were discussing and reflecting together. All interviews were audio tape-recorded and transcribed verbatim by the first author.

Ethical considerations

The study was approved by the Regional Ethical Review Board at Lund University (Reg. no. 2011/350) and carried out in accordance with the WMA Declaration of Helsinki [26]. The participants were guaranteed confidentiality and the right to discontinue the interview at any time. They all gave written, informed consent and agreed to the interviews being tape-recorded.

Data analysis

Content analysis was used to understand the underlying meaning of the interview texts [27,28]. The transcribed interviews were read several times, with the aim of the study in mind, by all three authors in order to obtain a sense of the content. From all interviews, meaning units relating to the parents' experiences of physical activity were identified. Meaning units are used to describe a constellation of words or sentences relating to the same central meaning [27]. The meaning units were condensed and designated as codes. After determination of similarities and differences among the codes, subcategories were abstracted from all codes sharing a commonality. Agreement about codes and subcategories were achieved after a process of reflection and critical discussion among all authors. Finally, one main category was described as emerging from the subcategories. During the whole process, from planning and conducting the interviews, to all steps of the analysis, all of the authors, who had longstanding experience of working with children with disabilities or chronic diseases, discussed their pre-understanding. This also meant that they reflected about the ways the pre-understanding might affect the analysis, abstraction and interpretation. In addition, the results were discussed in a multidisciplinary research group. To indicate the trustworthiness, quotations were used in the results, where parents participating individually or in couples in the interviews were presented as Parent (1-11), and parents participating in focus groups as Parent FG (1-14).

RESULTS

The interviews revealed the challenges parents faced when their child was being physically active, with the main category formulated as "Protecting and pushing towards independence". Wanting the best for their children was important and natural for the parents, in addition to wishing to protect them from negative experiences. On the other hand, they wanted their children to become as independent as possible and learn to cope with different challenges. Parents tried to monitor and communicate their child's interests to those who were close to the child in order to facilitate and enable them getting support. The subcategories describe aspects of parents' experiences according to their child's participation in physical activities, which affected their approach towards their child's independence: "Belonging and taking space in the family", "Important persons facilitating and hindering", "Friends important but hard to get", "Good for the body but challenging" and "Availability and opting out possibilities".

Belonging and taking space in the family

The child was part of the family, taking time and space with everything that needed to be done. Parents arranged for ordering and adjusting of assistive devices, for home programmes with stretching or exercising, and transporting the child to different activities or medical assessments and treatments; this took a lot of time. The parents experienced a strong coherence within the family even though requirements for attention from their child with CP and their siblings were causing troubles for them as they tried to share their time between their children.

> 'Her sister is playing golf once a week, and when their father can't make it, I have to take her to the golf course as well… then she plays with a golf ball besides her sister and the others… her sister doesn't say anything, but she doesn't like it.' (Parent FG 14 to child with mild physical impairment and severe intellectual disability, born in Sweden)

It was a challenge to find time for their own exercise and, when parents did not prioritise their own physical activities, it was difficult to support their child's participation in physical activities. Not having relatives living close to the family for support hindered the parents from being physically active themselves. In addition, members of the extended family such as grandparents and cousins were important for supporting physical activities. Grandparents had time to come and watch when the child had a performance, whereas cousins were seen as natural playmates similar to siblings.

> 'He has a cousin of the same age who often comes to play with him and his brother.' (Parent 3 to child with mild physical impairment and with mild intellectual disability, born outside Europe)

The parents expressed a desire to protect their child and traditions and values formed individual family cultures: Parents supported their child being independent as it was seen as the best protection for their child. The desire that their child would become more independent included often a distinct pushing towards participation in physical activities. On the other hand, parents born outside Europe were sometimes inhibited by their own experiences and wanted to protect their child from any risks.

> 'I have gone through very tough life experiences. So when one lives in a calm and safe environment, these flash-back visions from the war appear. Therefore I am very scared about him going out, I am afraid that something could happen to him.' (Parent 1 to child with mild physical impairment and with mild intellectual disability, born outside Europe, language interpreter was present)

Such experiences formed a more protective family culture which might decrease any pushing of their child towards participation in physical activities.

Important persons facilitating and hindering

The competence of and engagement among stakeholders dealing with the child were crucial for the child's participation in physical activities. Parents were satisfied and confident when their children had teachers, physiotherapists and coaches who were competent and interested in information about them and who could motivate them to participate in physical activities. Coaches with a disability themselves were found particularly important as role models and motivating the children to try new activities and also to do necessary exercises.

> ‘As soon as you want her to try something new, it is “No!” or “I refuse to do it!” Then you may coax a while, which this guy, the coach, is very good at. So after a while she dares to actually try new things.’ (Parent FG 10 to child with mild physical impairment and without intellectual disability, born in Sweden)

It was a huge relief for the parents when their child was pushed towards participation in physical activities by others. On the other hand, when parents experienced that adults were not competent to work with their child and not interested in gaining knowledge, they believed it inhibited the child’s independence and activity. Assistants at school, who could not do their work properly because of their lack of interest in addition to frequent sick leave, were seen as hindering the child’s participation in school. This forced the parents into a protecting role, including the desire to become more involved in decisions about any assistance that their child received.

> ‘The assistant got all the information and cannot remember … and she is often ill, and then young girls come and can do nothing… so there is no development.’ (Parent FG 3 to child with severe physical impairment and without intellectual disability, born in Sweden)

Friends important but hard to get

Having fun together with others was seen as positive and a strong factor for increased participation in physical activities by the child. Friends were important; doing physical activities together with friends pushed the children towards their physical limits in a motivating way. But parents found it hard for their children to make friends. Parents to children with mild or no cognitive limitations, attending an ordinary school, perceived a greater need of support in making friends compared to parents to children attending special schools. This need increased as the children grew older. In groups at the habilitation centre the children found peers in similar situations, and parents wished more support from the habilitation staff in making friends.

> ‘It’s a pity that when you find children who are like her in a group at the habilitation centre… then the personnel could [help get in touch and] ask, “Is it ok that we give out your phone number?” But they don’t do that.’ (Parent FG 2 to child with mild physical impairment and without intellectual disability, born in Sweden)

When the child’s own friends became more independent, leaving them behind and needing support from an adult, it became more difficult to keep up with friends of the same age. The family and important adults became more essential for the child over time compared to their peers. Parents talked to the peers about their child’s disability with the hope that their child would be included and not bullied. They believed that it could be a combination of being bullied and the behavioural problems of their child if the situation did not improve, which made them want professional help from teachers or a psychologist from the habilitation centre.

> ‘Sometimes I think it still works with friends as it used to do when he was younger. Then suddenly they’ll phone me because he’s hit or pushed other children. I don’t know why he’s like that; I don’t want him hitting someone. Still, I don’t want them to bully him either.’ (Parent 3 to child with mild physical impairment and with mild intellectual disability, born outside Europe)

Parents were also troubled when their child spent most of their leisure time in the company of pets or adults instead of being with other children. On the other hand, pets motivated the child to be physically active when the child for example walked or played with a dog.

Good for the body but challenging

The parents believed that specific exercises, which they equated with physical activity, was good for their child and they were certain that exercises would improve their child's motor ability or prevent the deterioration of function. Exercises were seen as something that had to be done but it was difficult to motivate the child to be more active. It became even more challenging when the child became older and the need to push the child towards independence became more pronounced.

> 'It is much easier when they are younger, then you can trick them into activity a lot more easily.' (Parent FG 7 to child with mild physical impairment and without intellectual disability, born outside Europe)

Parents were worried about the time their child spent in inactivity. They were concerned when their child was sitting playing computer games or doing activities at a table and they had a bad conscience about not always succeeding in supporting the child's exercise. They doubted that their child was supported enough during day time at school.

> 'When she goes to school she becomes very passive and just sits in her wheelchair waiting for someone to help her. At home she always drives the wheelchair herself.' (Parent FG 2) to child with moderate physical impairment and with moderate intellectual disability, born in Europe, language interpreter was present).

Parents were also concerned about the lack of energy, fatigue and pain that affected their child's ability to participate in physical activities, which was an increasing issue the more limited in gross motor function their child was. When the child got tired of walking the same distance as the others, the ability to keep up with the peers was reduced. Walking to a place was just an act of getting around for the peers, while the child with CP did not have any energy left to play when they reached the destination. Parents felt that they had to protect their children and demand a special solution for those situations. On the other hand, parents could push their children to continue with physical activities because of assumed positive effects even if the child was not enjoying it. Although a parent was aware that the sitting position during horse-riding with legs apart was painful for the child, the parent wanted the child to continue with the activity because of perceived effects of improved balance and reduced spasticity.

Availability and opting out possibilities

Parents spontaneously expressed that they were satisfied with the opportunities and support children had for participating in physical activities. During the interviews they came to change their minds as they experienced that they had to fight for information, help and the best treatment for their children. They believed that the children had limited access to physical activities that were both possible and reasonable for them to participate in. Parents were annoyed by the habilitating staff's lack of knowledge about what suited their child the best and what the best possibilities were. More information about opportunities that suited their particular child for participating in physical activities was requested. Furthermore, they asked for support for the child to try an activity in a sports club. Concerning this, parents worried whether limited financial resources in the society implied difficult access to assistive devices or less quality or quantity in the help their child would receive from a school or the habilitation centre. Available resources should be used effectively and in the best way for the child and parents asked for action instead of talking.

> ‘I don’t care so much about meetings; I care about what actually happens. The time we spend on all the meetings… add that time to the help he (the child) gets at school, when there are limited resources. We sit here as six persons at a meeting for one and a half hours, instead of giving him nine hours support and doing the planning by email.” (Parent 11 to child with mild physical impairment and with mild intellectual disability, born in Europe)

Knowledge and information about assistive devices that matched their child’s needs and could increase the availability to participate in physical activities were seen as particularly important for children with more severe limitations.

> ‘It feels as if we parents must keep track of which assistive devices there are. We have to claim her needs for that. There might be very useful assistive devices, but we don’t know about them. And without knowledge you can’t claim anything.’ (Parent FG 14, to child with severe physical impairment and with mild intellectual disability, born in Sweden)

Parents were also concerned about long travel times to get to activities and the need for support in transportation, which complicated their child’s participation in physical activities. Logistics and planning took extra time and affected all members of the family. Parents struggled with protecting their children from getting too tired whilst at the same time pushing them towards participation. Parents often opted out of attractive physical activities because they were offered far away, at inconvenient times or they were too expensive. Regular playtime with peers from the neighbourhood needed support from an adult and could be difficult to achieve.

In families with limited competence in the Swedish language, parents experienced that information and communication about their child's interests and needs was reduced. Language was experienced as a barrier when trying to support the child's participation in physical activities.

DISCUSSION

By exploring parents' experiences, facilitators and barriers for being physically active and reducing sedentary behaviour for their children with various limitations in gross motor, cognitive and communicative function were identified. The results showed that parents' attitudes and cultural background formed each particular family culture, which affected the child's motivation for being physically active. Parents wanted greater access to physical activities that suited their child as well as competent persons who would gently push them towards participation in physical activities. In addition, they asked for support in getting friends for their child to be physically active with.

Qualitative interviews allowed the parents to tell their stories from their own perspectives. The choice of participating in either focus group or individual interviews made it possible even for parents with a full work schedule, who needed a language interpreter or who wanted to be interviewed together with their partner, to participate. Focus groups are used to understand how people think about an issue and to understand differences in perspectives [22]. The response from one parent triggered thoughts in other parents in the groups, and the interaction and discussion were lively. The parents, who participated in individual interviews as couples, also had the possibility to discuss with each other. In the interviews with one parent, the interviewer asked follow-up and in-depth questions when it was important to get more reflective answers.

Ten of the participants were male and eleven were born abroad, which is interesting since these participants are rarely seen in qualitative interviews. However, the Swedish population includes 16 % with a foreign background [29], which enhances the need of including parents born abroad in studies. This is in accordance with another study finding that healthcare staff needs to listen and deal with foreign-born parents' concerns seriously to prevent powerless dependence [30]. In addition, the families in the present study came from both rural and urban areas, lived in various family constellations, and their children had various gross motor, cognitive and communicative functions. The variation among the parents suggests a representativeness of the total population of parents of children with CP aged 8 to 11 years in Skåne. On the other hand, only few of the invited families answered, and it is conceivable that they were those families who were especially interested in physical activity. Some participating families perceived that they were overwhelmed with information which might explain why many families missed the invitation letter for the study or opted out of participating.

Five parents chose to use language interpreters, which might have affected the parents' statements. It could be a challenge for the language interpreters to understand both the parent and the interviewer correctly. The language interpreters were asked to translate verbatim without interpreting the underlying meaning, and the interviewer asked the same questions with different formulations in order to cross-check the answers. On the other hand, opting out of using language interpreters by some parents, might have limited their expression of perceived experiences. This approach is in accordance with the results of another study supporting the use of interpreters in order to facilitate trustful cooperation and persuasive communication, taking risks of loss of information control and information compacting into account [31]. Therefore, during the analyses, all authors reflected on the parents' narrations based on their different perspectives and pre-understanding, and whether they had been present during the interview or not.

The parents in the present study had different cultural backgrounds which were crucial to how they might perceive the needs of their children and in considering how they either pushed more towards participation in physical activities or became more protective. Parents who came from non-European countries worried about possible risks for their child when being physically active. They seemed to be more protective and would rather slow down their child's engagement when they actually wanted to be physically active. A similar point was shown by Rawlins et al. [32] in which parents of obese children who came from diverse ethnic groups participated in a study aiming to identify barriers and facilitators of healthy lifestyles. Their limited knowledge of physical activity guidelines, low priority for physical activity, girls' dislike for physical education, and the cost of physical activities were described as barriers within and between ethnic groups [32]. These findings were only partly consistent with the results of the present study, where the parents were interested in physical activity, which might be due to their voluntary participation in a study about physical activity. However, Callanan & Waxman [33] urge researchers to avoid assumptions of homogeneity within groups, emphasising the risk of labelling. Another study described the predominance of cultural difference theory in science education and its uncritical use without attention to its limitations, such as disregard of possible intra-group differences [34]. A critical approach and sensitivity when describing groups of participants and the identification of individual family cultures seem to be essential for planning interventions aiming to increase participation in physical activities for all children.

The results of the present study showed that limited competence of the Swedish language reduced the access to information and the parents' ability to support their child being physically active, which is in accordance with the findings of another study of children with severe disabilities from multilingual backgrounds [35]. Being aware of language limitations might lead to an increased use of language interpreters when discussing and planning with non-native speaking families.

Despite ethnicity and language, socioeconomic status and geographical area were shown to be facilitators of or barriers to participation in physical activity in the present study. Physical activities that must be paid for or required the purchase of equipment might not fit the family's abilities, or activities which were only offered far away from their living area were sometimes passed over by the parents, implying the need to focus on these factors. That cost and affordability of physical activities, as well as transportation time act as barriers to participation in physical activities, was also described in other studies [5,16,18].

Access to physical activities that suited their particular child facilitated participation in physical activities, but parents perceived the range of suitable physical activities as being narrow. The children's opportunities for natural play and natural physical activity were limited, and parents experienced that they often had to take responsibility for every single part in an activity for the child to succeed. Difficulties in getting access to and information about suitable physical activities for their children are also shown to be problems in other studies [16,18,36,37]. There seems to be a need for future studies exploring natural physical activities for children with disabilities. Parents in the present study worried whether their child was doing enough and the right kind of exercises. Barriers such as fatigue and pain increased with the severity of gross motor function limitations, implying a dilemma for parents who described the continuous need for their children to do exercises. Other studies have also found pain to be a barrier to participation in children with CP, and suggest considering pain in the planning of interventions

[18,37]. As shown by Gibson et al. [39], social beliefs regarding the value of walking and treatment priorities differ between children with CP, aged 9 to 18 years, and their parents. While walking was perceived as exercise by the children, their parents felt the need of trying anything regarding walking exercise as part of being a good parent where they could maintain hope and avoid feelings of guilt and doubt [39]. These findings are in accordance with the findings in the present study, indicating risks for treatment choices by parents without asking the child about his or her opinion, which might lead to negative self-identities for the child. The social values of the children and their parents, as well as individual activity preferences should always be discussed when planning interventions.

As shown in the present study, important persons were strong facilitators for participation in physical activities who could motivate as role models, or by means of their competence, enthusiasm and interest. On the other hand, they could also be barriers because of lack of interest, knowledge or competence. The results also highlighted parents' desire to become more involved in decisions about assistants at school or other help their child received, as access to assistive devices for enhanced participation in physical activities. Moreover, skilled staff were described as a facilitator to physical activity in a systematic review [37]. To our knowledge, the individual access to assistive devices for enhanced participation in physical activities is not described as an important factor elsewhere, but funding and cost of equipment are found to be barriers in other studies [18,36].

The results of the present study showed that the family and other important persons became more essential for the child with CP compared to their peers who were getting more independent over time. For some children this became a facilitator enabling them to develop independence, while others needed more support. A change of factors perceived as facilitators or barriers to participation in physical activity between childhood and adolescence is also described in another study [18], which should be taken into account and discussed when planning physical activities with families.

Having fun together with friends, when being physically active, was perceived as facilitating; however, difficulties in getting friends were a concern for many parents. They expressed the need for support in finding friends, as from the habilitation centre for example, where their child could meet other children in similar situations. Fun and social contacts were identified as facilitators to physical activity in other studies as well [36,37]. In the present study, family cultures were described as being protective and sometimes pushing. The parents had concerns when talking about their child's future and they worried about how to improve their child's function and fitness. Our results support the idea of focusing on every child's individual issues and strengths and are consistent with the concepts of the 'F-words': function, family, fitness, fun, friends and future [20]. These concepts seem to integrate the children's and their families' decision making and quality of life. While parents to children with CP were worrying about whether their child had friends or the right support for participation in physical activities, children with CP said in interviews [15] that they want to enjoy the sensation of speed, have fun together with others and make their own choices about physical activities. Using the 'F-words' might benefit children, their families and personnel when designing fun and personalised interventions for increased motivation when participating in physical activities.

Conclusion

Parents desire competent personnel and persons to be available for support in participation in physical activities for their children. While having friends for their children to be physically active with can be a facilitator, difficulty in getting those friends is a barrier to participation in physical activities; parents want support in getting friends for their children. Parents' attitudes, cultural background and previous life experiences that formed each particular family culture prove to be facilitators or barriers for their child's motivation to be physically active, and should be taken into account when designing interventions for increased participation in physical activities and reduced sedentary behaviour for children with disabilities. In future studies it would be interesting to investigate the siblings' participation in physical activities and the impact that has on the participation in physical activities for children with disabilities.

Declaration of interests' statement

None of the authors reports any conflict of interest.

Acknowledgements

We wish to thank all participating parents who shared their experiences and doctoral student Elisabet Björquist for research discussions. This research was supported by the Research Platform for Disability Studies in Habilitation, Region Skåne, Sweden, and by RBU, the Swedish National Association for Disabled Children and Young People.

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Table 1. Characteristics of the parents

Parents (N=25)	N
Age (years)	
30-35	4
36-40	3
41-45	9
46-50	6
51-64	3
Gender	
Female	15
Male	10
Ethnic origin	
Sweden	14
Europe	3
Outside Europe	8
Language interpretation	5
Marital status	
Married/cohabitant	21
Single parent	4
Children living in the household	
1	3
2	9
3	5
4	5
5	3
Level of education	
Elementary and middle school	6
High school	8
College/University	11
Employment status	
Working full time	12
Working part time	5
Studying	1
Unemployed	7
Working as personal assistant to the child	
Main work	2
Part time	3

Table 2. Characteristics of the children

Children with CP (N=16)	N
Age (years)	
8	7
9	4
10	2
11	3
Gender	
Female	9
Male	7
GMFCS-E&R[a]	
level I	6
level II	5
level III	2
level IV	2
level V	1
Cognitive level[b]	
No mental retardation	9
Mild mental retardation	5
Moderate to profound mental retardation	2
Augmentative and alternative communication	4
Family situation	
Living with biological parents	15
Living in foster home	1
Living with both parents	12
Living with one parent	4

[a] Gross Motor Function Classification System Expanded and Revised [37]

[b] WHO's International Classification of Diseases (ICD): F70 and F71 – F73, ICD-10 codes for mental retardation [38]

Implications for Rehabilitation

- Friends and competent adults facilitate participation in physical activities and reduce sedentary behaviour
- Information on accessible and tailored physical activities is an important facilitator for participation in physical activities
- Service planning and design of interventions may be facilitated by taking the individual family culture into account