



# LUND UNIVERSITY

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

Lauruschkus, Katarina; Nordmark, Eva; Hallström, Inger

*Published in:*  
Disability and Rehabilitation

*DOI:*  
[10.3109/09638288.2016.1161841](https://doi.org/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>

*Total number of authors:*  
3

## General rights

Unless other specific re-use rights are stated the following general rights apply:  
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: <https://creativecommons.org/licenses/>

## Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

PO Box 117  
221 00 Lund  
+46 46-222 00 00

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

4

5 Authors: Katarina Lauruschkus\*, Eva Nordmark, Inger Hallström

6 Department of Health Sciences, Faculty of Medicine, Lund University, Sweden

7

8

9 Journal: Disability & Rehabilitation

10

11

12 Corresponding author\* at: Department of Health Sciences, Lund University, Faculty of Medicine,

13 Box 157, SE-221 00 Lund, Phone: +46 7075 19 88, Fax: +46 46 222 18 08. E-mail address:

14 [katarina.lauruschkus@med.lu.se](mailto:katarina.lauruschkus@med.lu.se)

15

16

17

18

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

1 **Abstract**

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

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

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

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

19

20

## 1 INTRODUCTION

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

15 Physical activity is important for all children and young people for developing healthy  
16 musculoskeletal tissues, a healthy cardiovascular system, neuromuscular awareness and for  
17 maintaining a healthy body weight [9]. Moreover, participation in physical activity is associated  
18 with psychological and social benefits such as relief of anxiety and depression, opportunities for  
19 self-expression, and a boost to self-confidence, social interaction, and integration [9]. Even if  
20 children in general meet the global recommendations of 60 minutes of moderate to vigorous  
21 physical activity per day [9], awareness of physical activity levels for the remaining time  
22 increases [10]. Independent effects on health outcomes, physical function and human metabolism  
23 are found for sedentary behaviour time [11]. Sedentary behaviour is defined as any waking

1 behaviour characterized by little physical movement and low energy expenditure while in a  
2 sitting or reclining posture [12]. Whether this definition suits children with CP is being debated  
3 as children with severe CP may be in a sitting posture in their wheelchair when they are  
4 physically active. For these children focus should be on energy expenditure rather than on their  
5 position [13,10].

6 When promoting participation of children with disabilities in physical activities, individual  
7 activity preferences, availability of equipment and appropriate programs, and the overall health  
8 status of the child should be considered [14]. In focus group interviews with parents of  
9 ambulatory youth with CP, personal factors such as the physical ability of the child, and  
10 environmental factors such as the parents not accepting the extent of the disability or lacking  
11 awareness of the benefits of physical activity were found to have an impact on the child's  
12 participation in physical activities [15]. Furthermore, the interviews provided insights about  
13 physical activity behaviour associated with different stages of change, which might be of interest  
14 when supporting the families individually [16]. Environmental and personal factors, the variation  
15 in preferences for physical activities, and health benefits were identified as facilitators for being  
16 physically active in interviews with parents of youth with CP of varying severity in gross motor  
17 function [17]. Family preferences and attitudes towards exercise were described as personal  
18 factors for participation in physical activities for children with CP, whereas physical, social and  
19 financial support, as well as transportation and access to information were seen as environmental  
20 factors of importance for facilitating or hindering physical activity [7]. Attitudes at school and in  
21 the community, difficulties accessing personal equipment and both the natural and built  
22 environment were perceived as general barriers to participation by the parents of children with  
23 CP [18]. A popularised thinking in childhood disability, focusing on every child's individual

1 issues and strengths, is encouraged through the concepts of the ‘F-words’: function, family,  
2 fitness, fun, friends and future, which should be the focus in childhood disability according to the  
3 authors [19]. The concepts can be seen as a theoretical framework, grounded in the International  
4 Classification of Functioning, Disability and Health (ICF) [20], inspiring ‘new’ points of entry to  
5 research regarding disabled children.

6 Parents are important for increasing participation in physical activity and reducing sedentary  
7 time for each individual child with CP. There is a need for more knowledge about the ways in  
8 which physical activity can be viewed and encouraged among parents and their children with  
9 varying degrees of capability and different cultural backgrounds. In addition, the parents’  
10 perception of their child’s participation in physical activities in different settings should be  
11 examined: at home, school sports, in leisure time activities and at their habilitation centre. The  
12 experiences of children with CP with different limitations in gross motor, cognitive and  
13 communicative function and their participation in physical activities have been presented in  
14 another study. The children explained in individual and focus group interviews that they wanted  
15 to be physically active, they wanted to make choices, have fun and enjoy the sensation of speed  
16 [21]. The purpose of this study was to explore how the parents to the interviewed children with  
17 CP experience their child’s participation in physical activities. Another purpose was to identify  
18 facilitators and barriers to becoming, being and staying physically active and reducing sedentary  
19 behaviour, taking different cultural backgrounds into account.

20

## 21 **METHOD**

### 22 **Design**

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

3

#### 4 **Procedure**

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

17

#### 18 **Participants**

19 There were 25 participants in the study. Nine married or cohabiting couples, six mothers and  
20 one father agreed to participate in the study. Twenty-three of the participants were biological  
21 parents, and two were foster home parents; from here on, the term 'parent' will be used for all  
22 participants. The parents had different backgrounds regarding to ethnicity, gender, language,  
23 socioeconomic status and geographical area. Eleven parents were born abroad (44 %) and eight

1 of them were born outside Europe; five of whom requested a language interpreter for the  
2 interviews. In Sweden, the social security system provide for personal assistance to facilitate  
3 social participation and equality of living conditions [24,25] and five parents in the present study  
4 were employed as personal assistants to their child. The characteristics of the parents and their  
5 children are shown in Table 1 and 2.

6

### 7 **Data collection**

8 The interviews were carried out from March to June 2012. The participants were offered the  
9 choice to participate in a focus group or an individual interview in order to enable the  
10 participation for all parents. In connection with the interview, the parents filled in a  
11 sociodemographic questionnaire, giving characteristics of themselves and their child with CP  
12 (Table 1 and 2). Information about gross motor and cognitive function was provided according to  
13 the parents' perceived opinion. Three parents chose to be interviewed individually, and four  
14 couples chose to be interviewed at the same time. When being interviewed as couples, both  
15 mothers and fathers were asked to answer the questions individually. All individual interviews  
16 were conducted by the first author either in the parents' homes or at a habilitation centre and  
17 lasted between 40 and 75 minutes. Fourteen parents participated in four focus group interviews;  
18 according to the parents' wishes or for practical reasons one focus group consisted of six  
19 participants, two of three, and one of two. Three focus group interviews were conducted at a  
20 habilitation centre, and one at a hospital. They were all moderated by the first author, three of  
21 them with the second author, and one with a doctoral student as an observer and lasted between  
22 90 and 120 minutes.



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

14

### 15 **Ethical considerations**

16 The study was approved by the Regional Ethical Review Board at Lund University (Reg. no.  
17 2011/350) and carried out in accordance with the WMA Declaration of Helsinki [26]. The  
18 participants were guaranteed confidentiality and the right to discontinue the interview at any  
19 time. They all gave written, informed consent and agreed to the interviews being tape-recorded.

20

### 21 **Data analysis**

22 Content analysis was used to understand the underlying meaning of the interview texts  
23 [27,28]. The transcribed interviews were read several times, with the aim of the study in mind,

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

16

## 17 **RESULTS**

18 The interviews revealed the challenges parents faced when their child was being physically  
19 active, with the main category formulated as "Protecting and pushing towards independence".  
20 Wanting the best for their children was important and natural for the parents, in addition to  
21 wishing to protect them from negative experiences. On the other hand, they wanted their children  
22 to become as independent as possible and learn to cope with different challenges. Parents tried to  
23 monitor and communicate their child's interests to those who were close to the child in order to

1 facilitate and enable them getting support. The subcategories describe aspects of parents'  
2 experiences according to their child's participation in physical activities, which affected their  
3 approach towards their child's independence: "Belonging and taking space in the family",  
4 "Important persons facilitating and hindering", "Friends important but hard to get", "Good for  
5 the body but challenging" and "Availability and opting out possibilities".

6

### 7 **Belonging and taking space in the family**

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

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

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

1 and watch when the child had a performance, whereas cousins were seen as natural playmates  
2 similar to siblings.

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

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

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

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

19

## 20 **Important persons facilitating and hindering**

21 The competence of and engagement among stakeholders dealing with the child were crucial  
22 for the child's participation in physical activities. Parents were satisfied and confident when their  
23 children had teachers, physiotherapists and coaches who were competent and interested in

1 information about them and who could motivate them to participate in physical activities.  
2 Coaches with a disability themselves were found particularly important as role models and  
3 motivating the children to try new activities and also to do necessary exercises.

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

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

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

19

## 20 **Friends important but hard to get**

21 Having fun together with others was seen as positive and a strong factor for increased  
22 participation in physical activities by the child. Friends were important; doing physical activities  
23 together with friends pushed the children towards their physical limits in a motivating way. But

1 parents found it hard for their children to make friends. Parents to children with mild or no  
2 cognitive limitations, attending an ordinary school, perceived a greater need of support in  
3 making friends compared to parents to children attending special schools. This need increased as  
4 the children grew older. In groups at the habilitation centre the children found peers in similar  
5 situations, and parents wished more support from the habilitation staff in making friends.

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

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

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

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

4

#### 5 **Good for the body but challenging**

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

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

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

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

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

12

### 13 **Availability and opting out possibilities**

14 Parents spontaneously expressed that they were satisfied with the opportunities and support  
15 children had for participating in physical activities. During the interviews they came to change  
16 their minds as they experienced that they had to fight for information, help and the best treatment  
17 for their children. They believed that the children had limited access to physical activities that  
18 were both possible and reasonable for them to participate in. Parents were annoyed by the  
19 habilitating staff's lack of knowledge about what suited their child the best and what the best  
20 possibilities were. More information about opportunities that suited their particular child for  
21 participating in physical activities was requested. Furthermore, they asked for support for the  
22 child to try an activity in a sports club. Concerning this, parents worried whether limited  
23 financial resources in the society implied difficult access to assistive devices or less quality or



1 quantity in the help their child would receive from a school or the habilitation centre. Available  
2 resources should be used effectively and in the best way for the child and parents asked for  
3 action instead of talking.

4 'I don't care so much about meetings; I care about what actually happens. The time we  
5 spend on all the meetings... add that time to the help he (the child) gets at school, when  
6 there are limited resources. We sit here as six persons at a meeting for one and a half  
7 hours, instead of giving him nine hours support and doing the planning by email.' (Parent  
8 11 to child with mild physical impairment and with mild intellectual disability, born in  
9 Europe)

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

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

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

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

5

## 6 **DISCUSSION**

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

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

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

14 Five parents chose to use language interpreters, which might have affected the parents'  
15 statements. It could be a challenge for the language interpreters to understand both the parent and  
16 the interviewer correctly. The language interpreters were asked to translate verbatim without  
17 interpreting the underlying meaning, and the interviewer asked the same questions with different  
18 formulations in order to cross-check the answers. On the other hand, opting out of using  
19 language interpreters by some parents, might have limited their expression of perceived  
20 experiences. This approach is in accordance with the results of another study supporting the use  
21 of interpreters in order to facilitate trustful cooperation and persuasive communication, taking  
22 risks of loss of information control and information compacting into account [31]. Therefore,  
23 during the analyses, all authors reflected on the parents' narrations based on their different

1 perspectives and pre-understanding, and whether they had been present during the interview or  
2 not.

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

22 The results of the present study showed that limited competence of the Swedish language  
23 reduced the access to information and the parents' ability to support their child being physically

1 active, which is in accordance with the findings of another study of children with severe  
2 disabilities from multilingual backgrounds [35]. Being aware of language limitations might lead  
3 to an increased use of language interpreters when discussing and planning with non-native  
4 speaking families.

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

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

1 [18,37]. As shown by Gibson et al. [39], social beliefs regarding the value of walking and  
2 treatment priorities differ between children with CP, aged 9 to 18 years, and their parents. While  
3 walking was perceived as exercise by the children, their parents felt the need of trying anything  
4 regarding walking exercise as part of being a good parent where they could maintain hope and  
5 avoid feelings of guilt and doubt [39]. These findings are in accordance with the findings in the  
6 present study, indicating risks for treatment choices by parents without asking the child about his  
7 or her opinion, which might lead to negative self-identities for the child. The social values of the  
8 children and their parents, as well as individual activity preferences should always be discussed  
9 when planning interventions.

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

20 The results of the present study showed that the family and other important persons became  
21 more essential for the child with CP compared to their peers who were getting more independent  
22 over time. For some children this became a facilitator enabling them to develop independence,  
23 while others needed more support. A change of factors perceived as facilitators or barriers to

1 participation in physical activity between childhood and adolescence is also described in another  
2 study [18], which should be taken into account and discussed when planning physical activities  
3 with families.

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

20

## 21 **Conclusion**

22 Parents desire competent personnel and persons to be available for support in participation in  
23 physical activities for their children. While having friends for their children to be physically

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

9

#### 10 **Declaration of interests' statement**

11 None of the authors reports any conflict of interest.

12

#### 13 **Acknowledgements**

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

18

#### 19 **References**

20

- 21 1. Carlon S, Taylor N, Dodd K, Shields N. Differences in habitual physical activity levels of  
22 young people with cerebral palsy and their typically developing peers: a systematic  
23 review. *Disability and Rehabilitation* 2013, 35(8):647-55.
- 24 2. Bania T, Dodd KJ, Taylor N. Habitual physical activity can be increased in people with  
25 cerebral palsy: a systematic review. *Clinical Rehabilitation* 2011, 25:303–315.
- 26 3. Dalvand H, Dehghan L, Reza Hadian M, Feizy A, Hosseini SA. Relationship between  
27 Gross Motor and Intellectual Function in Children with Cerebral Palsy: A Cross-  
28 Sectional Study. *Archives of Physical Medicine and Rehabilitation* 2012, 93:480-4.



1 4. Lauruschkus K, Westbom L, Hallström I, Wagner P, Nordmark E. Physical activity in a  
2 total population of children and adolescents with cerebral palsy. *Research in*  
3 *Developmental Disabilities* 2013, 34:157–167.

4 5. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson  
5 B. A report: The definition and classification of cerebral palsy April 2006.  
6 *Developmental Medicine and Child Neurology* 2007, 49:8-14.

7 6. Novak I, Hines M, Goldsmith S, Barclay R. Clinical prognostic messages from a  
8 systematic review on cerebral palsy. *Pediatrics* 2012, 130(5):1-28.

9 7. Claassen AA, Gorter JW, Stewart D, Verschuren O, Galuppi BE, Shimmell LJ.  
10 Becoming and staying physically active in adolescents with cerebral palsy: protocol of a  
11 qualitative study of facilitators and barriers to physical activity. *BMC Pediatrics* 2011,  
12 11:1.

13 8. Fowler EG, Kolobe THA, Damiano DL, Thorpe DE, Morgan DW, Brunstrom JE, Coster  
14 WJ, Henderson RC, Pitetti KH, Rimmer JH, Rose J, Stevenson RD. Promotion of  
15 physical fitness and prevention of secondary conditions for children with cerebral palsy:  
16 Section on Pediatrics Research Summit Proceedings. *Physical Therapy* 2007,  
17 87(11):1495-1510.

18 9. World Health Organization, ed. Disability and health. Fact Sheet N° 352; 2010. Available  
19 from: <http://www.who.int/mediacentre/factsheets/fs352/en/index.html> (accessed  
20 13/07/14).

21 10. Verschuren O, Darrach J, Novak I, Ketelaar M, Wiart L. Health-enhancing physical  
22 activity in children with cerebral palsy: more of the same is not enough. *Physical Therapy*  
23 2014, 94(2):297-305.

24 11. Hamilton M, Healy G, Dunstan D, Zderic T, Owen N. Too little exercise and too much  
25 sitting: inactivity physiology and the need for new recommendations on sedentary  
26 behaviour. *Current Cardiovascular Risk Reports* 2008, 2(4):292-298.

27 12. Trembley M. Letter to the editor: standardized use of the terms sedentary and sedentary  
28 behaviours. *Applied Physiology 2012, Nutrition, and Metabolism*, 37:540-542.

29 13. Innes J, Darrach J. Sedentary behaviour: implications for children with cerebral palsy.  
30 *Pediatric Physical Therapy* 2013, 25:402-408.

31 14. Murphy N, Carbone P. Promoting the participation of children with disabilities in sports,  
32 recreation, and physical activities. *Pediatrics* 2008, 121:1057-1061.

33 15. Verschuren O, Wiart L, Hermans D, Ketelaar M. Identification of facilitators and barriers  
34 to physical activity in children and adolescents with cerebral palsy. *The Journal of*  
35 *Pediatrics* 2012, 191(3):488-494.

36 16. Verschuren O, Wiart L, Ketelaar M. Stages of change in physical activity behaviour in  
37 children and adolescents with cerebral palsy. *Disability & Rehabilitation* 2013,  
38 35(19):1630-1635.

39 17. Shimmell L, Gorter J, Jackson D, Wright M, Galuppi B. “It’s the participation that  
40 motivates him”: Physical activity experiences of youth with cerebral palsy and their  
41 parents. *Physical & Occupational Therapy in Pediatrics* 2013, 33(4):405-420.

42 18. Vogts N, Mackey AH, Ameratunga S, Stott, NS. Parent-perceived barriers to  
43 participation in children and adolescents with cerebral palsy. *Journal of Paediatrics and*  
44 *Child Health* 2010, 46: 680–685.

- 1 19. Rosenbaum P, Gorter JW. The “F-words” in childhood disability: I swear this is how we  
2 should think! *Child: Care, Health and Development* 2011, 38(4):457-463.
- 3 20. World Health Organization, ed. *International Classification of Functioning, Disability*  
4 *and Health (ICF)*. Geneva, Switzerland; 2001. Available from:  
5 <http://www.who.int/classifications/icf/en/> (accessed 23/07/14).
- 6 21. Lauruschkus K, Nordmark E, Hallström I. ”It’s fun, but...” Children with cerebral palsy  
7 and their experiences of participation in physical activities. *Disability & Rehabilitation*  
8 2015, 37(4):283-9.
- 9 22. Krueger RA, Casey MA. *Focus Groups: a practical guide for applied research*. SAGE  
10 Publications 2009, 4<sup>th</sup> Ed., Inc.
- 11 23. Kvale S, Brinkmann S. *Interviews: Learning the craft of qualitative research*  
12 *interviewing*. Thousand Oaks, Calif.: Sage Publications 2009, Inc.
- 13 24. SFS 2010:387. Lagen om stöd och service till vissa funktionshindrade (LSS) [Act on  
14 support and service to certain disabled individuals]. Stockholm: Socialdepartementet  
15 [Ministry of Health and Social Affairs].
- 16 25. SFS 2010:110. Socialförsäkringsbalk [Social insurance code]. Stockholm:  
17 Socialdepartementet [Ministry of Health and Social Affairs].
- 18 26. WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving  
19 Human Subjects. 2008. Available from:  
20 <http://www.wma.net/en/30publications/10policies/b3/index.htm> (accessed 19/06/14).
- 21 27. Downe-Wamboldt B. Content analysis: method, applications, and issues. *Health Care for*  
22 *Women International* 1992; 13:313-321.
- 23 28. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts,  
24 procedures and measures to achieve trustworthiness. *Nurse Education Today* 2004,  
25 24:105-112.
- 26 29. Migrationsinfo. Available from: <http://www.migrationsinfo.se/migration/sverige>  
27 (accessed 09/08/14).
- 28 30. Pergert P, Ekblad S, Björk O, Enskär K, Andrews T. Protecting Family Interests: An  
29 Interview Study with Foreign-Born Parents Struggling On in Childhood Cancer Care.  
30 *International Journal of Pediatrics* 2012, Article ID 681301, 7 pages.  
31 doi:10.1155/2012/681301.
- 32 31. Pergert P, Ekblad S, Enskär K, Björk O. Obstacles to transcultural caring  
33 relationships: experiences of health care staff in pediatric oncology. *Journal of*  
34 *Pediatric Oncology Nursing* 2007, 24(6):314–328.
- 35 32. Rawlins E, Baker G, Maynard M, Harding S. Perceptions of healthy eating and physical  
36 activity in an ethnically diverse sample of young children and their parents: the DEAL  
37 prevention of obesity study. *Journal of Human Nutrition and Dietetics* 2013, 26:132–144.  
38 doi:10.1111/j.1365-277X.2012.01280.x
- 39 33. Callanan M, Waxman S. Commentary on special section: deficit or difference?  
40 Interpreting diverse developmental paths. *Developmental Psychology* 2013, 49(1):80-83.  
41 doi:10.1037/a0029741.
- 42 34. Carlone H, Johnson A. Unpacking ‘culture’ in cultural studies of science education:  
43 cultural difference versus cultural production. *Ethnography and Education* 2012,  
44 7(2):151-173. doi:10.1080/17457823.2012.693691.

- 1 35. Pickl G. Communication intervention in children with severe disabilities and multilingual  
2 backgrounds: perceptions of pedagogues and parents. *Augmentative and Alternative*  
3 *Communication* 2011, 27(4):229-244. doi:10.3109/07434618.2011.630021.
- 4 36. Buffart L, Westendorp T, van den Berg-Emonds R, Stam H, Roebroek M. Perceived  
5 barriers to and facilitators of physical activity in young adults with childhood-onset  
6 physical disabilities. *Journal of Rehabilitation Medicine* 2009, 41:881-885.  
7 doi:10.2340/16501977-0420.
- 8 37. Shields N, Synnot A, Barr M. Perceived barriers and facilitators to physical activity for  
9 children with disability. *British Journal of Sports Medicine* 2012, 46:989-997.  
10 doi:10.1136/bjsports-2012-090236.
- 11 38. Ramstad K, Jahnsen R, Skeldal O, Diseth T. Parent-reported participation in children  
12 with cerebral palsy: the contribution of recurrent musculoskeletal pain and child mental  
13 health problems. *Developmental Medicine and Child Neurology* 2012, 54:829-835.
- 14 39. Gibson B, Teachman G, Wright V, Fehlings D, Young N, McKeever, P. Children's and  
15 parents' beliefs regarding the value of walking: Rehabilitation implications for children  
16 with cerebral palsy. *Child: Care, Health and Development* 2011, 38(1):61-69.
- 17 40. Palisano R, Rosenbaum P, Bartlett D, Livingston M. Content validity of the expanded  
18 and revised Gross Motor Function Classification System. *Developmental Medicine and*  
19 *Child Neurology* 2008, 50(10):744-750.
- 20 41. World Health Organization (Ed.) (2010): *International Classification of Diseases (ICD)*.  
21 Available from: <http://www.who.int/classifications/icd/en/> (accessed 10/10/12).  
22

1 **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

2

1  
2  
3  
4  
5  
6  
7  
8

**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 <sup>a</sup>	
level I	6
level II	5
level III	2
level IV	2
level V	1
Cognitive level <sup>b</sup>	
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

<sup>a</sup>Gross Motor Function Classification System Expanded and Revised [37]

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

## 1 **Implications for Rehabilitation**

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