



# Struggling to Enable Physical Activity for Children with Disabilities: A Narrative Model of Parental Roles

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RESEARCH



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## ABSTRACT

This article presents a narrative model based on in-depth interviews with parents of children 6–12 years old with a variety of disabilities. It is a grounded theory study aiming to explore the parents' experiences of enabling health-promoting physical activity (PA) for their children. The core of the generated theory *struggling between roles to facilitate PA* describes how the parents, in different contexts and over time, are forced to take on roles as experts, coaches, minesweepers, and activists to facilitate adapted PA for their children. How tiresome this struggle became depended on contextual factors, the extent of effort put into the separate roles, and the interaction between them. The study revealed a complex picture unique for each family but at the same time suitable despite the character of the child's disability. This study adds knowledge to better support parents enabling PA on equal terms for all children.

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## INTRODUCTION

Physical inactivity is the fourth leading risk factor for global mortality as it increases the risk of many adverse health outcomes (Kohl 3rd et al. 2012; Lee et al. 2012). Previous research indicates that reduced levels of sedentary behavior in combination with regular physical activity (PA) contribute to reduced risk of disease and increased quality of life (Anderssen et al. 2007; Ekelund et al. 2016). There is no doubt that PA leads to positive health benefits for children with disabilities (CWD) (Johnson 2009; Sorensen & Zarrett 2014). The World Health Organization (WHO) guidelines on health promoting PA recommend at least 60 minutes per day of PA and a limitation of sedentary time for CWD (WHO 2020). Research from both Sweden and elsewhere indicates lower levels of PA, more sedentary leisure time, and a greater degree of poor health among CWD in comparison to their peers (Lauruschkus et al. 2013; Lobenius-Palmér et al. 2018; Oppewal et al. 2013; Rimmer, Schiller & Chen 2012; Wallen et al. 2009).

Research on factors affecting PA levels for CWD have provided a relatively consistent picture of determinants. Therefore, further research has to focus on mechanisms to enable effective interventions for health promotion targeting CWD (Ginis et al. 2016). Research describes both internal and external obstacles, which limit the individual's possibility of health-promoting PA. Often the disability itself, or medication linked to it, leads to inactivity, with reduced muscle function and fitness as a result. But the difficulties also lead to a negative spiral where PA is deselected and further reduces physical capacity (Rimmer, Schiller & Chen 2012). The obstacles may look different, but self-esteem and the willingness to participate often gets affected by competitive and performance-based activities, which leads to failures for CWD who cannot participate on equal terms (Rimmer & Marques 2012). On the other hand, opportunities to meet friends and an environment that strengthens the child's self-efficacy in accordance with PA is an important facilitator (Ginis et al. 2016; Willis et al. 2017). To overcome these obstacles, support from the family, involvement of peers, accessibility, and knowledge to adapt the exercises are described as important facilitators (Bloemen et al. 2015; Ginis et al. 2016; King et al. 2003; Shields, Synnot & Barr 2012).

A particularly important key to PA is parental support, because parents are the gatekeepers of PA for children (Shields, Synnot & Barr 2012; Siebert, Hamm & Yun 2017). They have unique knowledge about their children's abilities and needs and are essential for enabling development. Seen from a bioecological perspective, it's important to understand the interacting effects that the support system has on the family's intentions. Such a perspective conceptualizes a child's possibilities to participate in health-promoting PA (Bronfenbrenner 2006; Rosa & Tudge 2013). The will of the parents, and how they experience their competence, is crucial to engage their CWD in leisure time activities. Their capability to make PA for their children a habit has also been shown to be of great importance (Bassett-Gunter et al. 2020; Columna et al. 2020; Siebert, Hamm & Yun 2017). Research has shown that society's support systems, both to meet the parents' needs and for inclusion possibilities for the child, are crucial to enable PA in leisure time for CWD (Rimmer & Marques 2012; Rimmer & Rowland 2008). However, how parents experience their possibilities to promote PA among CWD, in interaction with society's support, is not much studied (Columna et al. 2020; Shirazipour & Latimer-Cheung 2017). Such knowledge may assist in developing and optimizing supportive systems that facilitate health-promoting PA for this risk group. Consequently, the aim of the study was to generate a narrative model of parenting related to possibilities for PA among CWD.

## METHOD

To be able to explore the parents' experiences in their social context in depth and to generate a narrative model of parenting and PA for CWD, Constructivist Grounded Theory (CGT) was applied. CGT is a theory-generating method that does not intend to confirm or reject an existing theory but rather to generate new explanations for phenomena and events (Charmaz 2014). It offers a structured systematic research tool theoretically rooted in symbolic interactionism, which means that actions are constructed in social interaction, depending on the context you live in (Charmaz 2014; Higginbottom & Lauridsen 2014; Rieger 2018). Therefore, CGT was considered suitable as it fits the socioecological view of disability research and offers tools to handle the interaction between the researcher and the informant to keep the emerging theory

grounded in the data (Tate & Pledger 2003). The study was performed in accordance with the Declaration of Helsinki, and written informed consent was obtained from all participants. Well-prepared, open-ended questions used with humbleness and sensitivity to what the parents were willing to share were used to reduce the risk of hurting the individual. A plan for support for the participants if needed was developed prior to the start. The Regional Ethical Review Board in Uppsala, Sweden, approved the study protocol (Dnr 2016/508).

## PARTICIPANTS AND INTERVIEW PROCEDURE

Invitations for participation were spread widely with handouts and posters at habilitation centers in a county council in the middle of Sweden to get a broad selection with a wide range of variation in participants (Charmaz 2014). Eligible for inclusion were parents of children aged 6–12 years with a disability. Disability was defined as a congenital or early acquired, chronic mental and/or physical impairment, qualifying for support from a Child and Youth Habilitation center. The parents were required to be able to conduct the interview in Swedish.

In-depth interviews were conducted (J.D.) parallel with ongoing analysis. All interviews (40–110 minutes) were recorded and transcribed verbatim (J.D.). An interview guide with broad themes based on the WHO model of International Classification of Functioning, Disability and Health (ICF) was used to assist the interviewer in keeping the conversations to topics relevant for the aim of the study from a socio-ecological perspective (Tate & Pledger 2003; WHO 2001). It consisted of a few open-ended questions and prompts that guided the informants to share their experiences of the possibilities for their CWD to participate in PA, for example: How would you describe the PA-level for your child? How do you experience that your child’s disability affects the possibilities for an active day? What has worked for you to enable PA? We asked the parent to describe what hinders participation as well as what facilitates PA for their child. In order to strengthen the comparative analysis, the interview guide also included questions on background, such as socio-economic factors, the nature of the child’s disability, and degree of functional impairment. As part of theoretical sampling according to CGT, the interview guide was adjusted after each interview and its analysis based on the conclusions drawn in the memo writing (Charmaz 2014).

The number of participants was determined by saturation of the theory, which was examined following every interview (Charmaz 2014). The children included had varying disabilities, levels of functional impairment, and access to leisure time activities depending on whether they lived in a city or in a rural area (Table 1). To find richer variations of disabilities and experiences to explore and saturate the dimensions and properties of the emerging categories, the number of participants was finally expanded to 11 families (Table 2).

AGE (YEARS)	N
6	1
7	2
8	1
9	3
11	3
12	1
<b>Gender</b>	
Female	5
Male	6
<b>Type and grade of disability</b>	
Congenital or acquired brain damage with little or no impact on intelligence (mild 1, moderate 2, and severe 2)	5
Congenital or acquired brain damage with intellectual disability (mild 1, moderate 2, and severe 3)	6

**Table 1** Characteristics of the children.

Mother	9
Father	1
Foster mother	1
<b>Ethical origin</b>	
Sweden	11
<b>Family situation</b>	
Cohabiting	5
Single parent	6
<b>Living area</b>	
Countryside	3
Smaller society	4
City	4
<b>Level of education</b>	
High school graduate	4
College or higher	7

**Table 2** Characteristics of the informants.

## DATA ANALYSIS

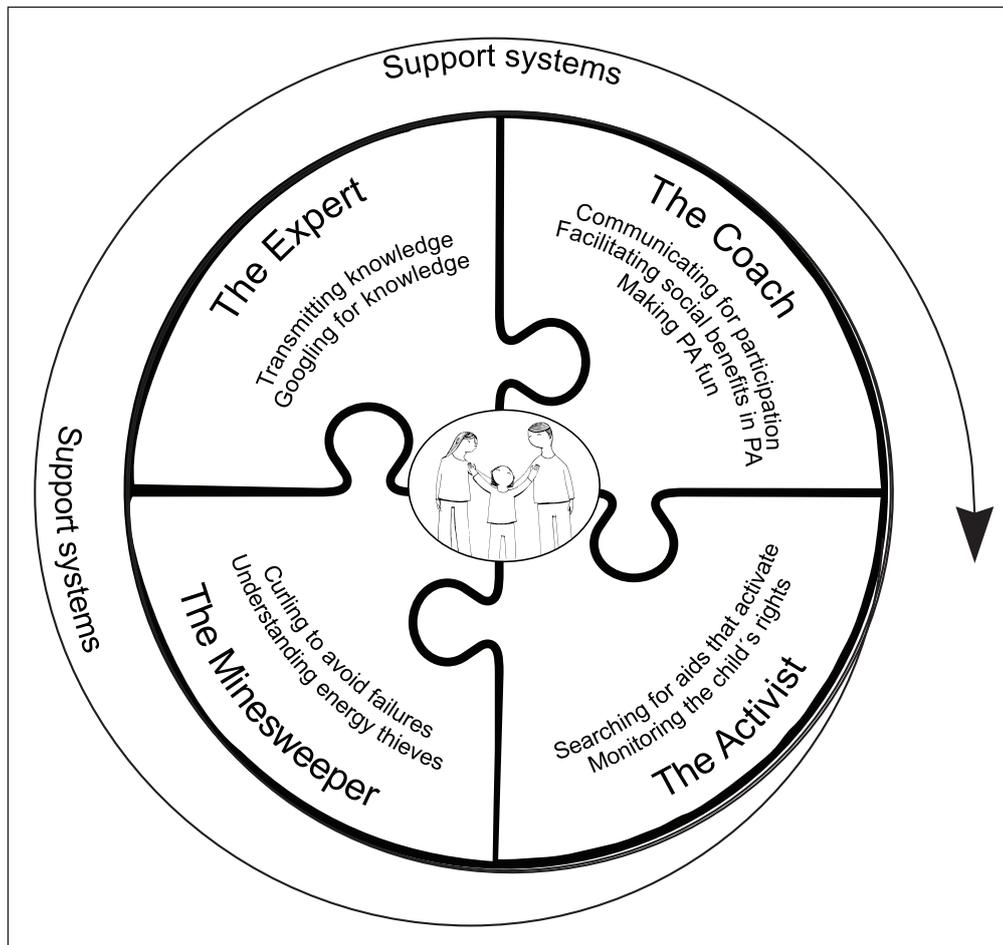
The analysis was conducted in the following two steps. First, there was line-by-line coding of words and sentences according to the meaning of the material. Second, focused coding was applied using constant comparisons between codes based on the interpretation of the importance of the initial codes to categorize them into preliminary categories. The work with codes and concepts was done manually using Post-it Notes and mind-maps to find patterns in the narratives. Clusters of substantive codes describing a phenomenon were explored through extensive memo writing. New questions to understand the phenomenon at focus were used in the next interview, such as questions about the parents' knowledge or about avoiding failures. Focused coding was more selective to advance the theoretical direction of the emerging categories, and it was a process to increase the abstraction of the analyses to emerging concepts in the material. For example, early in the material we noticed that parents described different ways of guiding their children to activity and adjusted the questions to explore this phenomenon in more depth. This was finally conceptualized as the coaching category. To ensure that the emerging theory was grounded in the data, constant comparisons with earlier coded material as well as the original transcripts were conducted and documented in the memo writing (Charmaz 2014). The emerging categories and the conceptualizing into a final model was validated in a more deductive phase, where thoughts about the concepts were used in the interviews to test for recognition. Finally, re-analysis of data was conducted from a new perspective to make sure that the generated model was grounded in the original data. Each step of the analysis was made by J.D. and H.W. separately and discussed continuously in the research group.

## RESULTS

The generated narrative model (Figure 1) illustrates the parents' struggle to facilitate PA for their children by shifting between four different roles: the Expert, the Coach, the Minesweeper, and the Activist. The core of the generated theory, *Struggling between Roles to Facilitate PA*, describes how the parents, in different contexts and over time, are forced to take on different roles to facilitate adapted PA for their children. The overall burden due to this struggle depended on contextual factors in the support systems, such as access to knowledge, society's ability to include CWD in PA, and access to support and aids that enable stimulating PA.

### THE EXPERT

The role as expert dealt with different aspects of knowledge, labeled *Googling for knowledge* and *transmitting knowledge*. This summarized parents' ways of gathering relevant information



**Figure 1** A narrative model illustrating how parents of disabled children struggle between roles to facilitate physical activity.

and transforming it into PA, and the efforts to activate and enlighten the child's network. The narratives illustrated the parents' commitment and power in the search for the competence they needed to be able to give their child the best possible conditions for PA. However, the role as expert was also described as demanding. Parents had different experiences of how quickly they developed this skill, depending on the support they received.

### Googling for knowledge

Many parents expressed frustration due to lack of knowledge and the effort needed to acquire it. The internet was described as one of the most frequently used sources for information seeking:

Ha, ha. I Google! I can sit up in the evenings and Google different things and see how it should be done. And then there are actually the Facebook groups on children with disabilities. They're pretty good. (Parent 3)

The parents described advantages with the internet, as it was accessible around-the-clock from home, which enabled information-seeking in an already tight schedule. Many of the parents described having different networks where they could post questions. It connected them with other families in the same position. However, the availability of information on the internet also contributed to stress, perceived as a pressure to continue the information-seeking. The internet offered a substitute when the support systems failed.

Yeah, networks in general with parents who are like a few steps ahead. They're really good. Especially if they change staff a lot at the habilitation unit because then a lot falls through the cracks about what our child needs because they don't know N. very well. (Parent 11)

### Transmitting knowledge

The parents also described the role as expert as having to inform the network helping their child. Better cooperation within the child's network decreased this strain on the parents. The

quotation below describes how vulnerable it may be to maintain knowledge about PA in a system with a constant shifting of personal assistants:

Because sometimes they do change all of the assistants at the same time and then you wish they had a review of exercises with a physiotherapist so that everyone is updated. Because, sure we parents can do it, but the kids are getting bigger and what was important a year ago might not be important now. The position of their hips might be different, for instance. It might be stiffer here or longer there. Everything is constantly changing so it's not easy to keep up. (Parent 5)

To be an expert, see the child's needs, and help in activities was not easy. To hand over that responsibility to another person outside the family was often described as difficult. Some of the parents described meeting resistance in their role as experts and knowledge-carriers. When it came to leisure time PA, the leaders often lacked the experience needed to interpret the information given. They also described resistance in meeting with PA teachers in school. They described that the information was given higher importance if provided by a professional instead:

Because if I say it as a parent, I can be considered overbearing. But if it comes from somebody who works with this professionally, it becomes a truth in a way. It's not just somebody making a lot of comments. (Parent 3)

## THE COACH

The narratives also revealed a role as coach. It was described as positive guiding towards goals for physical achievements, built on the joy of movement. It is illustrated by the subcategories *making PA fun*, *facilitating social benefits in PA*, and *communicating for participation*, all together strengthening the child's empowerment. The coaching depended on the child's age, impairment, and needs. The findings, as well as the following quotation, show that it is a task that requires knowledge and experience to master:

You have to have the courage to drop the parental role a bit, and sort of push them. Because that's how they grow. Overcoming an obstacle. But that's what you're a little cautious about as a parent. You want to just sort of... 'give them a hug.' (Parent 1).

### Making PA fun

The interviews revealed that coaching one's child and stimulating motivation was partly about making PA fun or making it a part of daily activities. Below is a parent's description of how creativity in daily activities was crucial to promote the joy of movement:

Like this Easter when we were in an Easter parade at school and N. had his/her walker. N. ran around there and really showed off. The walker is so central and has become an important tool to stimulate physical activity. (Parent 1)

The role as coach was described as getting more complicated over time as the child develops and changes habits. Both school and leisure time often involved more sedentary activities as the children grow up. To enable motivation-based training it had to be woven into a socially accepted activity:

It was kind of easier to weave the hand exercises in regular play. Sure, it goes well to some extent with the tablet too, but there are just a few kinds of movements. It used to be more diverse before. You could get everything in by dressing a doll, for example. (Parent 5)

### Facilitating social benefits in PA

The coaching role was also about facilitating social benefits and friendship associated with PA. Activities with peers contributed to making new friends by sharing a mutual interest. However, many of the narratives described failures in participation. A different behavior could be hard for other children to accept, and sometimes it led to conflicts. The parents struggled to create the conditions needed to facilitate a feeling of belonging and not always needing to be different.

The lack of role models or friends with similar disabilities was described as a problem. One parent described using clips from YouTube showing Paralympics horseback riding as inspiration. Another way was to travel to enable participation in adapted PA. This parent described her child's experience of belonging as a chance for self-confidence to grow:

So we were at the rehab center for two weeks. It was like a wake-up call for N. It stuck for several months. He/she could be good there. He/she felt that it was fun to exercise, I think. (Parent 3)

### Communicating for participation

Communication was described as a prerequisite to enable participation in decisions regarding PA and goals to reach. Often this required a person familiar to the child. Knowledge about communication was also about explaining the activity so the child understood and was able to participate:

They put cones out and said 'now you're going to make a goal here.' But N. didn't understand. He/she went and shot at the big goal. So there are communication mistakes, you could say. (Parent 2)

A child with cognitive difficulties might need adapted instructions, as generalization could be a difficulty. The narratives repeatedly expressed examples of misunderstandings and disappointments that led to exclusion and a child opting out of PA.

## THE MINESWEEPER

The narratives were filled with examples of the parents' constant prevention of failures related to PA situations for their children, labeled in the model as being a minesweeper. This involved two duties: *understanding energy thieves* during the day and *curling to avoid failures* emotionally and physically. The parents had to ensure that activities were adapted to avoid constant failures that could lead to decreased motivation and damaging self-confidence.

### Understanding energy thieves

The interviews revealed negative aspects triggered by PA. The situations were often messy, noisy, and built by pronounced and unspoken rules. These took a lot of energy to handle, no matter what type of disability the child had, and were described by the parents as energy thieves leading to fatigue. Some of the children with a physical disability used energy just to sit up straight and keep their balance. Others described games and activities as situations where the child was in constant fear of falling. That resulted in lack of energy to concentrate on their lessons or to interact with their friends. For some children, according to the parents, participation in activities not adapted after their child's needs could lead to exhaustion, pain or fatigue affecting the child's everyday routines for days to come, or even fever and illness. The sports lesson in school was often described as an energy thief:

Tuesday is a tough day at school because they have two math lessons with one PE lesson in between. For other kids, this might be good, but for my child, it's a nightmare. After all, PE is more stress than math precisely because N. must be prepared to manage their balance the whole time. (Parent 3)

Like a minesweeper, the parents needed to be proactive in trying to help the child recognize and eliminate the energy thieves. Often the negative consequences of PA weren't revealed until later, which made it more difficult for the teacher or leader to understand the need for adaption asked for by the parents. As so often described in the narratives, this task was a puzzle that had to be explored by someone who knew the child and their abilities and needs very well to understand the connection between the activities during the day and the reaction. One parent metaphorically expressed how it could be when there is a lack of activity balance finally leading to breakdown:

N. sort of doesn't really have brakes so he/she doesn't wind down in time so he/she gets going and then it can take several days before he/she has settled down. Because he/she is like a car with a broken gearbox. Or he/she is a car with a manual gearbox while the surroundings have a kind of automatic transmission where it's enough to push the

gas and brake and the car automatically handles the tachometer. He/she runs and runs like nothing else. He/she runs at 50 km/h in first gear because he/she can't really control the energy output so he/she runs on and we need to be there. (Parent 8).

### Curling to avoid failures

An important task described by the parents was clearing away emotional mines to spare the child from at least some of the psychological failures and disappointments related to PA. Otherwise, their child might lack motivation and refuse to participate. The following citation describes the curling role:

N. has gone to swim school for four semesters I think because they don't let him/her move on. And the kids are supposed to get a badge at the end and he/she never gets that darned badge. But he/she does get a different badge. A club badge and N. buys it because he/she gets a medal. But I wonder how long I can keep it up. We are covering it up a little that it's a gold penguin badge he/she should have actually received. (Parent 8)

Almost all the parent's described earlier experiences of failure when trying to participate in sports activities with other children. It could be that the activity was physically too demanding or the rules were too difficult to understand. Some parents said participation was okay as the child was younger, but as competition and winning became more important for the teammates, it got harder. To spare their child from stepping on these painful mines of disappointment again, they described trying to withhold activities from them. The analysis indicated that taking the role as a minesweeper and at the same time pushing the child to physical achievements by helping them with exercise was demanding and contributed to the parent's stress.

## THE ACTIVIST

The role as activist was built upon the subcategories *searching for aids that activate* and *monitoring the child's rights*. The narratives revealed that the parents were aware of, and willing to take a great deal of the responsibility for, helping their child have a physically active day. However, when the support systems did not live up to expectations, the family described how troublesome it was having to take on the role and to demand what they needed. This was a role they would rather have been without and was described as crucial in draining parents' energy:

So that N. will be able to be active, he/she has to get what he/she is entitled to, in terms of assistance. For a parent, you don't have the strength to run everything on your own around the clock. Or well, you can handle it for a few years until your body tells you to stop. (Parent 5)

### Searching for aids that activate

Knowledge about, and access to, appropriate aids was a prerequisite for PA for many of the children with physical disabilities. However, the community did not provide several kinds of necessary aids, and this was described as frustrating. Many of the parents described taking the role of activist to fight for the aids they needed. This mother described the connection between getting the right aid and finding motivation for PA:

We were the first ones to get it because N. does have a mum who is a handful (heh, heh). Before, we couldn't get anything to work, but now he/she wants to go! There are other aids that he/she detests like the plague. It's important to find aids that work and make activity possible. Or that it can build on interest sometimes. Everything can't be about compulsion. (Parent 5)

The interviews also contained stories about children who refused aids to avoid being different and seen as disabled. Sometimes aids were described as a solution to keep being active, but sometimes the aid was too big, became an obstacle for PA, and created distance from their friends. To try to get aids they believed would be a key to motivation-based PA for their child, the parents took on the role of activist:

Imagine if you could get the aids and the help you needed. Because there's nothing called getting help with leisure aids for example. Of course, one thing leads to

another, because the more physically active and the more right exercise and the more right things he/she does, the less he/she costs in operations, Botox, and all of these things. Sometimes, it feels like, well Botox is easier to give than to provide another condition to reduce this or... The different things are related, but it's not so simple in reality. (Parent 11)

### Monitoring the child's rights

All parents included in the study described having to monitor their child's rights to make sure they got the interventions needed to enable PA. Some parents used the concept of being a demanding parent. They felt that they were nagging and that they had to do so to get what they needed from the child's support systems. The narratives revealed that parents were knowledgeable on their children's rights. They used facts when fighting for interventions they were entitled to but still did not get.

However, in leisure time activities, parents did not feel they could demand adaptation for inclusion. This was because activities mostly were built on volunteer work, without the support of community resources. Some of the parents described this as an obstacle, but some had taken the role as a plow to make way for changes in the support systems. One mother described the experience of constantly being like a legal activist:

It's taken sooo much energy... That's what I also said about staying one step ahead all the time. And finding out what you have and what you can get. And it has really been a lot I think. N. would never have had this training if we hadn't kept pushing for it. We've been in countless meetings with politicians. (Parent 11)

## DISCUSSION

The narrative model of parents struggling for PA by managing four different roles offers an explanation to better understand the family's efforts to enable participation in PA for their CWD (Figure 1). The analysis revealed a picture, applicable to parents despite the differences of the disabilities of their children, which is of importance for the usefulness of the model. As a complement to earlier research on barriers and facilitators of PA for CWD (Ginis et al. 2016), the present study has generated a model grounded in parents' narratives.

The core of the generated theory, *Struggling between Roles to Facilitate PA*, is built on the parents' narratives in their intentions to enable engagement in PA for their CWD. Seen from a bioecological perspective, a child's development depends on the ability of the surroundings to create an advantageous environment that meets the child's needs (Bronfenbrenner 2006; Rosa & Tudge 2013). The present model contributes important information on how parents compensate for shortcomings in support to enable adapted environments to include their CWD. The way the parents felt insufficient for this task will be discussed in the light of existing research.

The parents' struggle to facilitate PA involves a process of constantly having to fulfil these four roles and the constant change between them, on top of all other duties that comes with the role as parent for a CWD (Goodwin & Ebert 2018; Pelentsov, Fielder & Esterman 2016; Schleien et al. 2014; Woodgate et al. 2015). The feeling of struggle was strengthened by the fact that these parents, unlike others, described their engagement as increasing despite their children growing older. Shortcomings in the support systems forced the parents to engage in several different microsystems surrounding their child to spare them from failures. The generated model provides knowledge about the parents' decisions on involving their children in sports activities, and how they act to spare them from disappointments. It thereby contributes to the existing knowledge gap on parental stress handling risks following PA-participation for their CWD (Columna et al. 2020; Shirazipour & Latimer-Cheung 2017) by illustrating the process of parents constantly shifting between being an expert, a coach, a minesweeper, and an activist.

### INTERPRETATION OF THE FOUR ROLES

The present study views parents in the role of expert as knowledgeable. However, the results also indicate that parents carry a heavy responsibility on their own and that they experience lack of support. Their awareness of their unique competence and responsibility to facilitate PA

for their CWD is in line with previous findings (Shields, Synnot & Barr 2012; Siebert, Hamm & Yun 2017). In contrast, however, the present results illustrate risks associated with the role as expert. This study demonstrates a partly new understanding, showing that the availability of information on the internet, and the expertise needed to evaluate it, strongly contributed to the parents' stress. The demand on parents to keep updated isn't limited to the area of PA. It applies to many areas due to their CWD, which is described as time-consuming (Pelentsov, Fielder & Esterman 2016; Woodgate et al. 2015). The parents' narratives underscore the lack of support in gaining knowledge (Columna et al. 2020; Keim-Malpass, Letzkus, and Kennedy 2015; Bassett-Gunter et al. 2017), but the present model also contributes to understanding the parents' stress related to their role as coach and the struggle of having to transform knowledge into adapted PA. Perhaps social inclusion for parents might be even better to strengthen their empowerment (Willis et al. 2019). The present results suggest that information supporting all aspects of the expert role, adapted in accordance with parents' skills, could be a key to making the parents feel confident in their roles as experts and coaches.

The coaching role was described as requiring more than just encouraging their children to do the right exercises. Constantly seeking fun leisure activities that enabled participation in PA was a concern for all participating parents. The importance of finding activities that are fun is well documented in previous research (Columna et al. 2020). But to our knowledge, the importance of communication skills for inclusion in PA is rarely described. The narratives in this present study revealed a fear that misunderstandings could lead to disappointments. The child's ability to understand the situation and interact with their peers was as vital as their physical ability. The analyses revealed complications when having to put effort into every choice of activity to make it fun and inclusive for their CWD. These results are understandable in light of research showing that, to fully participate and feel empowered to continue, social inclusion of the child is crucial (Columna et al. 2020; Knibbe et al. 2017). Studies have shown that CWD participate to a lower extent in recreational activities they prefer (Woodmansee et al. 2016). They don't necessarily have fewer activities, but they participate with a lower intensity (Ullenhag et al. 2014). To support the parents' facilitation of PA in their role as coaches, developing support systems that enable inclusion and promote a family-centered perspective is important. Inclusion sometimes contributes to the parents' need to act as minesweepers, as they anticipate the risk of damaging their child's self-esteem. Earlier research has shown good results with leisure activity interventions containing education for parents, as well as support towards the network to facilitate continuing participation in PA (Willis et al. 2018). Such interventions may provide support to the parents in their roles as coaches and experts, as well as knowledge carriers.

Parents in the present study found it completely their own responsibility to anticipate pitfalls and act as minesweepers for PA. The roles as coach and minesweeper are well in accordance with the concept of *protecting and pushing towards independence* described by Lauruschkus, Nordmark, and Hallström (2017). To be able to curl away physical and emotional mines, the parents described having to know the child well. Balancing this task is described in previous research as complex and dynamic. The complexity of this role made it hard to hand over to someone outside the family. This led to stress for the parents, not only because it's time consuming but also due to the fact that their presence at leisure time activities contributed to the child's feeling of being different, compared to others participating on their own. The feeling of failure when participating on unequal terms with non-disabled peers could negatively affect the self-esteem of the CWD (Lauruschkus, Nordmark, and Hallström 2015; Shields & Synnot 2016). The parents' fear of exposing their children to disappointments made them engage to an extent that led to fatigue.

Moreover, the present study illustrates that when support systems do not meet the parents' needs, they take on a role as activist to fight for their children's right to PA. Other researchers have made the same description of parents fighting to get appropriate help and aids for their children (Piskur et al. 2016; Schleien et al. 2014; Woodgate et al. 2015). The role as activist was described in this present study as an energy thief for the parents due to the lack of support systems. With regard to the intention in the Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006), support systems need to be developed to create a non-discriminating society that enables inclusion in sports and recreational activities, which reduces the need for individual adaptations and help from parents.

The present study highlights how better support from public health interventions might reduce the burden faced by parents of CWD. This is also in line with the call to action for increased PA in this risk group, demonstrated by Rimmer and colleagues (Rimmer & Marques 2012; Rimmer & Rowland 2008). The generated narrative model of parents struggling between different roles to facilitate PA in their child's life contributes explanations that highlight some of the gaps to actually managing PA on equal terms for all children.

## STRENGTH AND LIMITATIONS

We believe that the narrative model has been constructed in a socially interactive process between the interviewer and the informants, as suggested by Charmaz (2014). The use of CGT in this study has contributed a framework that ensures its credibility. Simultaneous data collection and analysis enabled the theoretical direction of the emerging analysis to be grounded in the parents' narratives. The reflexivity, with its memo writing and author discussions, along with constant comparison of the tentative categories back to the codes and data, has been an important tool to handle the interviewer's pre-knowledge and make sure the conclusions drawn in the analysis are grounded in the data (Charmaz 2014).

The fact that the families had a wide variety of experiences and different access to adapted PA strengthens the usefulness of the generated narrative model. However, almost all the informants were mothers of Swedish descent. Therefore, research in other contexts is needed, involving parents with different ethnic backgrounds and sex, to confirm the model's transferability. Despite the relatively small number of participants, the rich material from the in-depth interviews is thought to be enough to ensure theoretical saturation with robust categories. That assumption is strengthened by the consistency of findings in research targeting participation in PA for CWD. This is what Charmaz (2014) refers to as resonance. This means that the narrative model contributes deeper insights and explanations about a reality familiar to the participants (Charmaz 2014). The present study is also original, as it has contributed a new model to the relatively small body of research targeting parents' efforts to enable PA for CWD. More knowledge about the health literacy of the parent, and the support system surrounding the child, is needed to complement the narrative model and expand its usefulness.

## CONCLUSIONS

Health on equal conditions and the right to leisure time PA made by choice are human rights according to the CRPD (UN 2006). The narrative model developed in this study describes a picture of how parents struggle to facilitate PA that is unique for each family and, at the same time, suitable despite the character of the child's disability. It reveals shortcomings in the community's support systems that are undermining CWDs right to PA and put additional burden on parents. With support from this generated model, the parents' effort when acting as experts, coaches, minesweepers, and activists could be more adequately addressed in further research to form public health interventions that enable PA for all children.

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## COMPETING INTERESTS

The authors have no competing interests to declare.

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