Article

Parents’ experiences of their child with neurodevelopmental disorders participating in a physical activity on prescription (PAP) intervention

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Abstract: Children with disabilities engage less in physical activity and sports during their spare time compared to their peers without disabilities. Modern sports, contextual factors, and parents’ fear of discrimination have been discussed as barriers to participation. The aim of this study is to describe parents’ experiences of their child with neurodevelopmental disorders (NDD) participating in a PAP intervention. The intervention involved a Child and Adolescent Psychiatry outpatient clinic (CAP), the Regional Sport Federation, and local sport clubs in the southwestern region of Sweden. A sample of 13 parents took part in semi-structured interviews, and qualitative content analysis was used for data analysis. The analysis resulted in three main categories, including sub-categories. By being part of a collaboration, the parents experienced two different worlds coming together, the CAP and the sport world, and they were also aware of the collaboration’s organisation and need for resources. In growing with sports, the parents described that treating the children with respect involved learning sports from the child’s condition and creating a social space for them. Regarding individual motivation for participating in sports, the parents expressed that the children felt proud to be part of the PAP intervention and experienced a sense of belonging in the group with the other children. The study highlights perspectives for developing sports for all in local sport clubs and improving sports as part of the CAP care for children with NDD.

Keywords: Child and Adolescent Psychiatry outpatient clinic; collaboration; disability; qualitative method; sports

Introduction

The World Health Organization (WHO, 2011) estimates that 15.6% of the world’s population, corresponding to more than one billion people, are living with some form of long-term illness that is perceived as a disability. Children with disabilities today do not have as great an opportunity for sports and leisure activities as others in society, and children with disabilities engage less in physical activity and sports during their spare time when compared to peers without disabilities (Geidne & Jerlinder, 2016; Willis et al., 2018). Contextual factors (personal and environmental) and parents’ perceived fear have been discussed as barriers to participation. At the same time, it is found that sports, leisure, recreation, and holidays for many children with disabilities have a greater significance in the individual situation compared to others, including in terms of health and well-being (Crawford et al., 2014; Kristén et al., 2015). However, sports participation for this group is
related to several specific challenges and barriers (Coates & Vickerman, 2010; Weiler et al., 2016).

Physical activity contributes to improved health, chronic disease prevention, and increased self-confidence. Moreover, it promotes social interaction among children, including children in need of special support (Arim et al., 2012; King et al., 2003; U.S. Government Accountability Office, 2010). Friendships and relationships have positive effects on children’s development and contribute to improved quality of life (Heiman, 2002). Participating in activities means that young people both feel belonging and learn to socialise with others, and this has an impact on health and well-being throughout life (Coster & Khetani, 2008; King et al., 2003; Law et al., 2006).

For all children and young people, it is recommended that physical activity should be interesting and fun, take place daily and motivate a healthier lifestyle (U.S. Department of Health and Human Services, 2008; Bull et al., 2020; The Swedish Public Health Agency, 2023). Leisure activities in the form of physical activity and physical activity programmes are an arena where children in need of special support do not participate to the same extent as children of a similar age without such needs (Moran & Block, 2010; Rimmer, 2001). This is due to perceived barriers, environmental attitudes, and social aspects as well as difficulties in participating in group sports activities (Riley et al., 2008). Lack of knowledge on the part of sport coaches and the cost of sport activities are also obstacles for children and families (Shields et al., 2011). However, physical activity on prescription (PAP) is a strategy to promote lifestyle changes and increase physical activity (Leijon et al., 2009; Kallings, 2016). PAP has been shown to be an effective intervention among adults and has also been used for children with diagnoses (Lauruschkus et al., 2017). PAP includes tailored prescription counsel by health care professionals and encompasses written suggestion for structured activities such as individual-, group- or community-based activities.

Theoretical framework

This research used the environmentally-relative model. Instead of only considering disability as an individual phenomenon or as a problem created by society, interaction within the individual and the surrounding society is emphasised (Tøssebro, 2004; Lindqvist, 2020). It is possible to distinguish three different theoretical models in disability research: 1) the medical model, 2) the social model, and 3) the environmentally-relative model. The environmentally-relative model was formulated as a reaction to both the medical and social models, and it emphasises the interplay between the conditions of the individual and surrounding society (Tøssebro, 2004; Lindqvist, 2020). Even though a lack of societal support and treatment can help reinforce a disability, the body can be perceived as problematic even outside a social context (Danemark, 2005; Lindqvist & Sauer, 2007). The basic idea is that there is a gap between the individual's ability to function and the design of the environment and that this is what constitutes disability (Lindqvist, 2020). Disability is a relative term, and who is considered disabled is largely determined by how the environment is designed and works. This means, for example, if the sports movement is designed according to children’s and young people's abilities and needs, no one would need to be labelled as disabled. The worse the society responds to the needs of weaker groups in society, the more people fail to cope with the demands of the environment, and more people become disabled as a result (Kristén, 2010; Tideman, 2013). The environmentally-relative model attaches greater importance to individual disabilities and realises that physical and institutional barriers contribute to disabilities in different contexts. If such obstacles are removed, disabilities in society will decrease (Lindqvist, 2020). The social model is based on the fact that society is the "problem". The
focus should then be on removing social barriers such as prejudice, discrimination, inaccessible public buildings, and segregated education (Goodley, 2011). The environmentally-relative definition of disability that exists in the Nordic countries defines a disability in the meeting between an individual with a disability and an inaccessible society (Goodley, 2011; Tøssebro, 2004). Tøssebro (2004) described the environmentally-relative model as the weaker version and the social model as the stronger one when focusing on the surrounding environment. However, both models shift from problematising the individual to problematising the environment.

Parents’ perspectives

Examples of parents’ perspectives on barriers to sport participation were the energy that parents need to have to deal with the demands of daily life and safety issues (McCann et al., 2012; Nichols et al., 2019). There were also barriers related to children’s poorer social skills and the risk of bullying (Ayvazoglu et al., 2015). To facilitate the success of physical activity for children with disabilities, the use of different creative teaching strategies can be crucial. To learn physical skills, it is important that adapted equipment be used in order to acquire skills, competences, and self-confidence. Moreover, it is important that parents see the benefits of effective pedagogy (Hurley & Burt, 2015). In one study (Obrusnikova & Miccinello, 2012), parents of children with autism spectrum disorders showed positive beliefs about participation in physical activity after school. General barriers, such as motor, social, attention, and behavioural deficits, as well as a lack of resources or physical activity programmes, are some other factors that parents often have to deal with (Nichols et al., 2019). Jeong and colleagues (2015) found that parents who had strong behavioural and normative beliefs had greater intentions to support their children with disabilities in participating in physical activity programmes. Education for parents and other people important to the parents, for example, PE teachers, special education teachers, and professionals in disability organisations, is beneficial to promoting the benefits of physical activity participation among children with disabilities. Nichols and colleagues (2019) found that parents played a significant role in the physical activity level of their young adults on the autism spectrum. It turned out that programmes and the availability of programmes played an important role in the physical activities, and the lack of available programmes prevented other young adults on the autism spectrum from engaging in physical activities. The special situation of children with disabilities has attracted attention in recent years. There is an ongoing debate in society about the opportunities for children with disabilities to engage in stimulating and meaningful fitness training as well as the importance of satisfying physical, mental, and social needs through play, movement, and sport (Carbone et al., 2021; Shields et al.,2011; Shields & Synnot, 2016). At the same time, proportionately few children with disabilities practice any sports or other physical activities. Obstacles such as attitudes, accessibility, and a lack of suitably educated coaches are given as reasons for the low level of participation (Kristén et al., 2020).

Parental engagement for their children with disabilities has been identified both as a barrier and as a facilitator of their child’s participation in physical activity, and the family’s interests and priorities influence participations (Willis et al., 2019). It is important to understand parents’ perspectives and their reasoning around their child participating in an intervention to increase physical activity in relation to previous experiences and their own preferences.

The aim of this study is thus to describe parents’ experiences of their child with neurodevelopmental disorders (NDD) participating in a PAP intervention. The research questions were as follows:

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1. How do parents experience the collaboration between the Sports Federation, Child and Adolescent Psychiatry and local sports associations in the southwest of Sweden?
2. How do parents describe and reason about the intervention?
3. How do parents perceive that their children describe sports activities and social integration with other participating children?

Materials and Methods

Physical activity on prescription (PAP) intervention

An intervention with PAP was implemented at a Child and Adolescent Psychiatry outpatient clinic (CAP) in a region in southwestern Sweden (Lydell et al., 2022). The outpatient clinic is one of four in the region and is situated in the major capital of the region (with about 70,000 habitants). Children with neurodevelopmental disorders and their parents who were visiting the outpatient clinic for a regular check-up were offered PAP. The PAP intervention included physical activity in one of the local sports associations with a total cost of 10 euro. The parents and the children could choose between different sports, the frequency per week, and the intensity. In the PAP intervention, a Care Sport Connector (CSC) was involved from the Regional Sport Federation. The Regional Sport Federation works to support the sports movement in the region by giving support to all sport clubs in the region. Local sport clubs received a request from the CSC to participate in the PAP intervention and received financial support from the Regional Sport Federation. The CAP professionals wrote the prescription and sent it to the CSC, who in turn contacted the local sport clubs and helped the child to get started with physical activity. Coaches from the local sport clubs led the activity and offered an adaption within the regular activities for children with neurodevelopmental disorders.

Design and methodological approach

A qualitative descriptive design with qualitative content analysis was chosen in order to explore the experiences of parents who have children with neurodevelopmental disorders participating in PAP (Hsieh & Shannon, 2005)

Data collection

The participants in this study were selected through purposive selection. The inclusion criteria were being a parent of a child with neurodevelopmental disorders who participated in PAP. All parents who wanted to participate in the study (n = 20) received oral and written information regarding the study and were invited by the care sports connector from the Halland Sport Federation. A total of 13 parents agreed to participate in the study, all of whom were women (Table 1).

The data from the individual interviews were collected during January and June 2019 by two of the authors (LK and ML), both of whom are familiar with qualitative methods. The parents of the children with neurodevelopmental disorders were informed about this study with written information from the research group sent out from the CSC. They also received oral information from the research group when they met for the interview. Signed, informed consent was obtained from each participant prior to the interview.
Table 1. Gender of informants and gender and age of the children.

<table>
<thead>
<tr>
<th>Informant</th>
<th>Gender of parent</th>
<th>Gender of children</th>
<th>Age of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Woman</td>
<td>Boy</td>
<td>8</td>
</tr>
<tr>
<td>2</td>
<td>Woman</td>
<td>Boy</td>
<td>12</td>
</tr>
<tr>
<td>3</td>
<td>Woman</td>
<td>Boy</td>
<td>14</td>
</tr>
<tr>
<td>4</td>
<td>Woman</td>
<td>Girl</td>
<td>12</td>
</tr>
<tr>
<td>5</td>
<td>Woman</td>
<td>Boys</td>
<td>10, 11</td>
</tr>
<tr>
<td>6</td>
<td>Woman</td>
<td>Boy</td>
<td>9</td>
</tr>
<tr>
<td>7</td>
<td>Woman</td>
<td>Boy</td>
<td>10</td>
</tr>
<tr>
<td>8</td>
<td>Woman</td>
<td>Girl</td>
<td>10</td>
</tr>
<tr>
<td>9</td>
<td>Woman</td>
<td>Boy, Girl</td>
<td>10, 13</td>
</tr>
<tr>
<td>10</td>
<td>Woman</td>
<td>Girl</td>
<td>12</td>
</tr>
<tr>
<td>11</td>
<td>Woman</td>
<td>Boy</td>
<td>10</td>
</tr>
<tr>
<td>12</td>
<td>Woman</td>
<td>Boys</td>
<td>8, 13</td>
</tr>
<tr>
<td>13</td>
<td>Woman</td>
<td>Boy</td>
<td>13</td>
</tr>
</tbody>
</table>

The interview was conducted at the participants’ home, at the university, or at the CSC’s office and lasted between 30 to 45 minutes. An interview guide was used to facilitate the interviews. The interview guide covered initial questions and key questions about the project with the addition of follow-up questions for further information. The participants were introduced, and the questions commenced with the following: What are your experiences of .........? What are your expectations regarding .........? What is your reflection regarding the project? What support do you need? Furthermore, prompt questions were used to gain a deeper understanding. The interviews were recorded digitally, and observational field notes were written and subsequently transcribed verbatim. The interviews were transcribed in Swedish, and after the analysis the categories were translated into English.

Data analysis

A conventional qualitative content analysis was applied in this study (Hsieh & Shannon, 2005). The analysis began with a constant reading and listening to the audio recordings. This was to understand what was expressed by the participants regarding PAP. The research group discussed and identified meaningful units in the data, and relevant meaning units were labelled with codes. These codes were re-read and sorted into sub-categories and main categories until consensus was reached (Table 2). The final findings in this study were developed from dynamic discussions between all authors (one pedagogue, one public health scientist, and one physiotherapist). The main categories that emerged were “Being a part of a collaborative effort”, “Growing with sports”, and “Individual reasons for participating in sports”.

Table 2. Example of the analytical process of the study, moving from meaning units to sub-category and main category.

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Condensed meanings units</th>
<th>Code</th>
<th>Sub-category</th>
<th>Main category</th>
</tr>
</thead>
<tbody>
<tr>
<td>That is, because otherwise you always work, as it were, in one place. And I'm thinking just like CAP and sports, they are completely different worlds. So, it is very important to get them together.</td>
<td>CAP and sports are completely different worlds and it is important to get them together.</td>
<td>Different worlds.</td>
<td>Bringing different worlds together.</td>
<td>Being a part of a collaborative effort.</td>
</tr>
<tr>
<td>It took time to get into the group, but they put just the right pressure on him.</td>
<td>It took time to get into the group, but they put just the right pressure on him.</td>
<td>Putting the right pressure.</td>
<td>Treating the child with respect.</td>
<td>Growing with sports.</td>
</tr>
</tbody>
</table>
The study was carried out in accordance with research ethical guidelines and was approved by The Regional Ethics Committee in Lund, Sweden (Dnr:2015/338).

**Results**

Parents moved on different levels when they described their experiences, ranging from how the intervention was organised to the child’s motivation for participating in sport. This was described as follows: 1) being part of a collaboration, including bringing two different worlds together and organising human and financial resources; 2) Growing with the sport, including treating the children with respect and creating social space and promoting sports skills for the children; and 3) Individual motivation for participating in sport, including feeling proud and capable and having a sense of belonging (Figure 1).

**Figure 1.** The three main categories, with six related sub-categories that emerged in the data analyses.

**Being part of a collaboration**

The parents described the collaboration as bringing two different worlds together, as it included Health care-CAP and sport movement, including CSC from the regional sport federation and various local sport clubs. However, the parents were aware of the limitations in the organisation and financing of the PAP intervention and collaborative effort.

**Bringing two different worlds together**

The parents described the sport culture of today as being too competition oriented, and not playful at all. They discussed further their child’s difficulties in being part of a competitive environment, as the child could become aggressive when losing a game and attack the winner. The parents agreed that participating in the PAP intervention offered a good opportunity for the children with NDDs to be able to participate in sports and be together with others. They stated that the PAP intervention brought two different worlds together and provided access to a safe world of sports. “I’m thinking CAP and sports, they are completely different worlds. However, it is very important to get them together” (Informant 3).

The parents found it important that professionals at the CAP introduce the different physical activities, as this legitimised their child starting and participating in activities in a local sport club. The sport coaches open attitudes and knowledge about how to treat and respond to the children, and the extra sport coaches during training, created a safe space, according to the parents. “Sometimes during training there has only been six children participating, and sometimes even fewer children. This is quite luxurious, then the sport coach can keep an eye on each child during training” (Informant 10).
The parents expressed how their child had tried out many different sports and activities in the past, but always left the sport or activity after just a short period of time. This had affected the family’s finances negatively as it involved expensive fees and new equipment. The parents stated that the PAP intervention was positive in terms of inviting the children to try out different sports for a low fee.

Organising human and financial resources

The parents expressed the importance of society allocating resources for sports activity to all children and the collaboration between sports clubs and health care. They said that the administration of the region needs to provide the resources that are required for activities such as PAP intervention. The parents also pointed out the need for funding to sport clubs and coaches to be able to continue to initiate children with NDD in sports training.

The sport coaches do it for the sake of these children, give them the resources they need so they are able to continue the training, as this affects these children. I get so emotional and moved, I want to see that these children feel that they can succeed (Informant 7).

However, according to the parents, writing the prescription for physical activity and informing people about the PAP intervention did not occur routinely at the CAP. Instead, it was the parents themselves who occasionally had to ask for a written prescription. The parents commented on the information from the CAP as being unclear and not up to date. “We got information about the different activities at the CAP, and I think it was one of my boys’ classmates who went on climbing activities, that is how I found out more about the PAP intervention” (Informant 5). The parents describe that the contact with professionals at the CAP was obvious and important at the start of participating in the PAP-intervention, and the CSC from the regional sport federation was an important contact during the intervention. The parents found that the CSC was supportive, had further information about the PAP intervention, and was easy to contact. According to the parents, it was also easy to contact the sport coaches; this was important as the information about changes and cancelled sport activities were not always up to date. The parents also stated that they wished for a follow-up of the PAP intervention by the CAP, who then suggested a discussion with both parents and the children about how the children had succeeded in the sport activities.

Growing with the sport

The parents explained how the children’s participation in sports activities worked and why it was important for the children to be a part of a group. Different dimensions of participation in sports activity were highlighted by the parents, such as the sport coaches’ treatment of the children and treatment from other participating children. This created a safe social space and helped the children grow with sports.

Treating the children with respect

The parents explained that children with NDD are used to being on their own, and when the children joined a group, they had difficulties and did not dare be themselves. “I was very positive towards the PAP-intervention, that he would have some form of sport activity in addition to school and be able to meet children with the same problem or similar problems and not be alone” (Informant 2).

In the PAP intervention, the sport coaches’ attitudes towards the children enabled positive social interaction, and the children felt more confident, according to the parents. The relaxed way the sport coaches managed the activity was very educational for the
children. They spoke calmly and explained things clearly and with respect to the children. The parents described how the coaches did not force any of the children to participate in a group; instead, they look after the children, so no one felt excluded from the activity or failed. This created an ability among the children to join a larger group later on in the intervention.

Just the fact that he could take the time that he needed to enter the group. The coaches put just enough pressure on him and offered him a chance to play matches and so on. But he said no, and then the coaches continued to put just enough pressure on him and then they waited. Suddenly, he was ready and now he has entered the group (Informant 6).

According to the parents, the coaches took their time to help the children with the training and ensured that everyone had the best opportunities based on their circumstances. The activities took place based on each child’s condition. “The activities he has tested have worked out very well. All the sport coaches have been, after all, super cute and they have seen him, and I mean really seen him. They have been great in every way” (Interview 3).

The parents experienced being able to relax and be calm, as they were sure that their children were in a safe space and able to leave the children by themselves during training. The safe space included respect for the children and confidence in the coaches. Moreover, the children knew what was going to happen during training.

**Creating social space and promoting sports skills**

According to the parents, the most important thing about the PAP intervention was that the children were able to be physically active and at the same time train in being social. They wanted the children to come out and meet new friends, which was perceived as problematic in ordinary sports and other leisure time activities. The parents believed that the children associated with each other in a group and that the sport coaches could provide a structure that was acceptable by the children. “We thought a lot of good things about the PAP-intervention, one was that now she can have some contact with someone because she has problems making friends and social contact, she has difficulties with all this” (Interview 4).

The parents expressed that the individual support from the coaches during training was important and crucial as the children experienced the training as fun and joyful, as well as the group dynamic. The social interactions during the sport activity were not always observable but important and had a positive impact on the children, according to the parents. The positive dynamic in the group created a social space, and the children made friends during the training within the group, as the same children participated in the sport activity the same time every week.

We talk a lot about the training and how positive it is, and he also feels how good it is. That the activity is part of a PAP intervention is nothing we talk about, because he is like anybody else in the group, and he is. This is something positive and he talks warmly about his training in jiu-jitsu (Informant 7).

The possibilities for the children to try both individual and team sport in the PAP intervention increased the children’s sport’s skills, according to the parents. Practice in team sports improved the children’s ability to play, for example, football during breaks at school and at leisure time.
He has a bit of adapted schooling, but he participates in sports at school, and this has become much better. Now he has got grades and so on in sports, so that's positive. I think that he is more active (Informant 13).

The parents also described that the PAP intervention gave a possibility for the children to learn more about sports and gain elementary skills that are needed to play them.

**Individual motivation for participating in sport**

The parents described that there was individual motivation to participate in the PAP intervention among the children. The opportunity to feel proud and capable was motivation to participate in the activity. The sense of belonging discussed by the parents referred to the children and the parents as a family in a community.

**Feeling proud and capable**

The children felt satisfied and enjoyed participating in sports activity, according to the parents. It appeared that the children experienced good times together with other children and that gave significance to other parts of life, such as school and other leisure time activities. Becoming skilled in a sport was explained as a great development for the children. "He is very proud that he has become so good at floorball and now he also plays football at school with his classmates. This was completely unthinkable six months ago" (Informant 6).

Parents expressed that the sport coaches had a major role in confidence-boosting in the children and encouraged them to try new activities. The parents described that the sports coaches had pushed just enough for the children to dare to do a little extra. "I feel that the PAP intervention has pushed him to dare to test new activities" (Informant 3). The increased self-esteem helped the children to develop and be proud, parents said, as before the PAP-intervention, from time to time the children rarely went outside. With the PAP-intervention, the children felt capable and wanted to tell peers at school that they were participating in different sport activities. "So, he knew that it was a PAP-intervention. He thought it was fun and he was happy to tell people that he had started archery and was doing things" (Informant 11).

Parents mentioned that they had recognised that the children had developed as persons and that their identity was shaped by the sport. "It almost becomes like an identity issue, she feels very proud when she says I'm boxing, and people respond, tough girl" (Informant 10). The parents also talked about how the children tried new things in everyday life, as in taking initiative on their own and being more independent. "I experience a change in him, that he has developed such that he can actually do something other than playing (computer games) after school" (Informant 1). The new sense of feeling capable among the children engaged them in being helpful towards new children joining the group.

**The sense of belonging**

The feeling of belonging to a group and having a place in it was described by the parents as a great benefit of participating in the PAP intervention, even though the children did not make friends to hang out with after training. It worked very well when they were in training together. The parents explained that the children got along and had a sense of belonging in a community. The parents also described that the children felt that they were all like-minded and had a sense of security and belonging in the activity. They were all allowed to participate in the activity and were accepted for who they were. "In any case, he has not been excluded from the group or been outside doing things on his own, or anything like that" (Informant 1). The membership in a sport club together with the right equipment was symbolic for belonging, according to the parents. The parents mentioned...
that belonging to the community also involved them as a parent, and they were invited to participate in the sport activity.

Yes, so it was very positive to participate in the activity. They were very welcoming, they thought that you should know what your child is doing. I had to shoot as well and my son thought it was great fun that his mother would shoot too, so then it became more positive (Informant 11).

The involvement in the activity also included giving a helping hand during the training and participating in education to learn more about the sport, involvement in the sport and motivating the children to participate. The experience that children and parents did things together felt good and fun for the family, according to the parents.

**Discussion**

This study shows that a designed environment, according to the individual's ability to function, in accordance with the environmental model, increased physical activity among children with neurodevelopmental disorders (Kristén, 2010; Lindqvist, 2020; Tideman, 2013). When parents’ described experiences about their child with NDD participating in a PAP intervention, they responded consistently that being part of a collaboration, and feeling that their child grew with the sport, were individual motivations for participating in sports. Previous research has presented factors that enable children’s participation, and these factors include coaches who are sufficiently trained to adapt the activities and accessibility of physical activity, and display non-discriminatory attitudes (Willis et al., 2018).

The parents were aware that they were part of a collaboration that included different stakeholders, such as the CAP, CSC from the Regional sport federation, and sports coaches from local sports clubs. They were also aware of this opportunity for the children to be active in sports and engage in physical activity because their children had difficulties in being part of contemporary sports culture. Based on the environmentally-relative model, the children and parents experienced smaller barriers; for example, the sports coaches adapted their activities and showed favourable attitudes towards the children (Kristén, 2010; Tideman, 2013; Tossebro, 2004). The structure and resources of the collaboration created a sense of security and contributed to a safe space for their child to be active in sports. Willis and colleagues (2018) have reported on the enabling factors for children with disabilities to participate in sport, including coaches who are sufficiently trained to adapt activities, the accessibility of physical activity, and non-discriminatory attitudes. In further discussion, and in line with the Convention on the Rights of Persons with Disabilities (CRPD), where "enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities” (UN, 2006), the PAP intervention was seen as an alternative for playing sports by the parents. This was because the sports coaches had made adaptive routines for the children such as having more coaches and fewer children. The parents were aware that the activities demanded more organization and more human and financial resources, but promoting and ensuring opportunity and access to sporting activities is one of the rights of persons with disabilities.

The parents described how the sport clubs contributed to developing the child’s sport skills by creating space and time for learning. The child perceived that they fitted in, due to the sport coaches welcoming and treating the children with respect. In previous research, problems with social communication and motor skills have been shown to be common among children with neurodevelopmental disorders, and this might contribute to the child losing their temper during sport participation, thus creating further difficulties fitting in (Beckman et al., 2016; Kaiser et al., 2015; Petrina et al., 2014). The respectful treatment from both sport coaches and other participating children was thus an important aspect of
being able to develop sport skills in the sport context. This shows that sport coaches had an important role, which has also been described by McConkey and colleagues (2013).

According to the environmentally-relative model, sports activities must be designed according to the children’s abilities and needs (Lindqvist, 2020). However, the attitudes towards the children were an important issue, but because this is a personal trait, it is difficult to succeed in ensuring all sport coaches to work the same way (Rosenbaum & Gorter, 2011). The structural conditions of society can certainly play a role in how different actors can adapt activities and conditions for children with neurodevelopmental disorders. It is thus important to assume that obstacles do not lie with the individual but with the structure and design of society, according to the approach in the environmentally relative model (Kristén, 2010; Tideman, 2013; Tøssebro, 2004). Nevertheless, the sport clubs need to use their best sport coaches for good social interaction with the children.

For the parents, this meant that they could relax during training because they knew that the sport coaches saw their children and had a calm way of speaking to them. The parents also said that the children learned from each other, and therefore it was good that the activities did not involve large groups. Children with these diagnoses often have difficulty adjusting to large groups (Kristén et al., 2020). Hence, it takes time for these children to dare to be themselves because many of them tend to be alone for most of the time. The children felt confident in the coaches, thanks to the fact that they respected every child as he or she was. It is thus of great importance to have small and calm groups, like PAP, and understand the needs of all children so they do not feel like they are failing all the time (McConkey et al., 2013).

Several parents considered that the individual support in the training was important because the children thought it was fun to go to their training. Being able to train both individually and in team sports was mentioned by several parents as having affected their children’s ability to play team sports when they, for example, played football during breaks at school. It was a great benefit that participating in PAP also strengthened the children in participating in sports during school breaks, which confirmed findings by Ayvazoglu and colleagues (2015). In order to be able to participate in physical activities at school, the environment is also important, as advocated by the environmentally-relative model (Lindqvist, 2020). The activities took place based on each child’s health condition, both individually and as a group, as seen in Rosenbaum and Gorter (2011). Research has shown that being involved in sports activities is important, and that was also the parents’ opinion regarding PAP (Jeong et al., 2015). Sports with adaptive routines can be used as a bridge to complement rehabilitation for these children (Eriksson & Saukkonen, 2021).

The parents discussed how sports influenced their children’s perceptions of themselves and believed that their children felt satisfied with the sports, and this can add value to other parts of life such as health and well-being, in accordance with (Coster & Khetani, 2008; King et al., 2003; Law et al., 2006). From an environmental perspective, the adaptations a sports association makes for children can lead to an increased experience of feeling included and like one of the participants in a larger context (Danermark, 2005; Lindqvist & Sauer, 2007). The parents felt that the coaches’ ability to encourage the children’s self-esteem played an important role in the children trying new sports activities.

The parents also reasoned about the importance of the environment up to the involvement of the coaches in their various sports activities, which is in line with Kristén (2010) and Tideman (2013). It also seems that the approach to carrying out sports activities could increase children’s feelings of independence and autonomy, although parents pointed out the different challenges that exist for children with disabilities in the surrounding community (Hurley & Burt, 2015; Obrusnikova & Miccinello, 2012). The parents talked about the importance of the children feeling a sense of belonging in the
group and equal to the other participants. This was seen as a great step forward for children who often seem to experience the opposite situation in, for example, school and sports associations. Being included and feeling seen is one of the health factors that can play a big role during development (Arim et al., 2012; King et al., 2003; U.S. Government Accountability Office. 2010). Furthermore, it is not possible to ignore the parents’ own role in enabling participation in the various sports and being supportive of the children in connection with the activities (Nichols et al., 2019).

Study strengths and limitations

There are different meanings about concepts regarding trustworthiness, and some researchers are positive about using them when discussing trustworthiness in qualitative studies (Graneheim & Lundman, 2004; Lincoln & Guba, 1985). Other researchers believe that it is not necessary to replace well-established concepts such as validity, reliability, and generalisability (Long & Johnson, 2000; Morse et al., 2002; Sandelowski, 1996). Therefore, the methodological issues were evaluated in relation to strengths and limitations.

A limitation of the study could be that there were only 13 participants included, yet they all had quite similar experiences. The data from the two last interviews resembled data from the earlier interviews, which could indicate that saturation had been reached, where a recurring pattern begins to emerge in the data and experiences and words return without any new information (Malterud et al., 2016). The fact that most of the parents were positive could have changed if there were more participants. However, the PAP-intervention was a long-awaited activity. The lack of male parents in the study was a limitation, and perhaps a broader sampling that included male parents might have resulted in more variation in the interviews. Furthermore, data analysis was described as accurately as possible, and quotations from the interviews were used to strengthen the findings (Graneheim & Lundman, 2004).

Conclusions

The collaboration between the CAP, the Regional Sport Federation, and local sport clubs was perceived as important by the parents. Cooperation is dependent on the sports federation’s resources. This in turn contributes to conversations about physical activity and leisure time, which then, according to the parents, contributes to a holistic view of the children. The collaboration between the CAP and local sport clubs may be an opportunity for children with NDD to receive support in a safe environment that encourages participation in physical activity during leisure time. The collaboration intervention also provides a step toward inclusion by allowing children to leave home and meet other children both with and without disabilities. However, challenges within the intervention must be addressed, and continuous feedback through dialogues between stakeholders is necessary for sustainability. Training initiatives should be made for both the CAP staff and sport coaches about the importance of physical activity for children with NDD, as well as the knowledge about disabilities and the different conditions of different sports. Directed support from the community should be set aside to facilitate inclusion in sports. A CSC that works between the healthcare and sports movement is a success factor in collaborative efforts within PAP.

Perspectives

The findings from this study provide us with further understanding of the factors that influence sports activities in the form of physical activity for children with NDD. Parents perceived obstacles, such as the attitudes and social aspects of the environment, as well as possibilities, such as coaches’ support, when participating in group sports activities, e.g.
archery, bowling, table tennis, rowing, shooting, climbing, jiu jitsu and skateboarding. Also, a lack of knowledge from sport coaches and the cost of sports activities was reported to be an obstacle for children and families. This study was in some ways different from previous research in that it identified collaborative strategies within society for children with neurodevelopmental disorders. The environmentally-relative model was used because it emphasised the interactions between the individual with impairment and surrounding society, instead of only considering disability as an individual condition or societally created phenomenon. Collaboration between the CAP and sports federations in the southwest of Sweden was perceived as important by the parents. The collaboration intervention provided an opportunity to get away from home, meet other children both with and without disabilities and be part of a community. Conversations about physical activity and leisure contribute to a holistic view of the children, according to the parents.

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