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Perceived facilitators and barriers for participation in leisure activities in children with disabilities: perspectives of children, parents and professionals

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ABSTRACT

Background: There is limited knowledge about facilitators and barriers to leisure activity participation for children with disabilities in Norway, which is needed to improve rehabilitation interventions.

Aim: This study aims to explore the main facilitators and barriers for participation in leisure activities for children and youth with disabilities in Norway.

Methods: Semi-structured group interviews with 31 parents, 20 healthcare professionals, and nine children with disabilities were conducted. Qualitative content analysis with thematic coding was used, and the model of factors affecting the participation of children with disabilities developed by King et al. was applied for further deductive analysis.

Results: Child factors, as viewed by parents and professionals, worked primarily as barriers and tended to increase with the child's age. The children themselves focussed on their own preferences, friendship and enjoyment as their main facilitators for participation. Most environmental and family factors worked both as facilitators and as barriers, with parental support as the most important facilitator. Differences between urban and rural areas in the availability and accessibility of activities were reported.

Conclusion and significance: Knowledge from this study is important for the improvement of rehabilitation interventions that aim to increase participation in leisure activities for children and youth with disabilities.

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Introduction

Participation in leisure activities is important for the development of physical, social and mental health for all children and youth. It is a main goal and outcome for rehabilitation service providers [1–6]. Research has shown that children and youth with disabilities show different patterns of participation regarding recreational and leisure activities than their non-disabled peers [1,2,4,7–11]. The main differences are less participation in organized or physical activities, and more home-based, self-organized activities, or activities that include family members [4,10–13]. Patterns of participation also differ, depending on the country or region the child lives in, as shown by Ullenhag et al. [14] in an international comparison between children with and without disabilities living in

different European countries. Specifically, Norway shows quite unique patterns of participation in international comparison [15]. Green et al. [15] report both higher participation rates in cultural events and physical activity for Norwegian children and youth compared to other European countries. Since family and parents are much involved also in organized activities in Norway (volunteering as coaches or team managers), they contribute to these higher participation rates also due to sociodemographic factors like higher average income and less working hours, compared to other European countries. Therefore, it is of interest how children and youth with disabilities in Norway experience their participation.

Participation is a complex and still much discussed construct [4,16–20]. One of the widely used models is

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the biopsychosocial model incorporated in the ‘International Classification of Function, Disability and Health’ by the World Health Organisation [21]. There, participation is defined as ‘involvement in life situations’ [21, p.10]. However, despite its wide use the conceptualization of participation given in the ICF has received criticism from different researchers [11,17,18,20]. Main critique was a lack of theoretical clarity, or the individual’s subjective perspective on participation. In a recent comment, Mitra and Shakespeare [20] argue for a remodelling of the ICF to reflect the progress regarding the knowledge about the participation construct. This is in line with the argument of Adair et al. [22], who in their recent systematic review on participation measures conclude that the construct of participation is under constant development. This puts pressure on theory and measure development to adjust to this developmental process. In the view of the authors, participation is a multidimensional construct including both an objective and a subjective perspective. Therefore, when researching participation a focus on the individual’s perspective is of high significance.

Better understanding of the patterns of participation in leisure activities, including facilitating and hindering factors, is required [23]. Individual and environmental factors can be both barriers and facilitators, depending on the situation and the context [17,24–26]. However – to the knowledge of the authors – there is a lack of knowledge on barriers and facilitators for participation in leisure activities in children and youth with disabilities in Norway thus far. The ICF includes personal and environmental factors as either barriers or facilitators. This has been critiqued by Hemmingson and Jonsson [17]. Therefore, when researching facilitators and barriers a model, where factors can be seen as both facilitators and barriers is needed. King et al. [1] have presented a differentiated model of factors affecting the participation of children with disabilities, which identifies 11 factors divided into three main categories: child, family and environmental factors. The child factors include the ‘child’s perception of its own athletic and scholastic competence’, ‘the child’s physical, cognitive and communicative function’, ‘the child’s emotional, behavioural and social function’ and ‘the child’s preferences’. Family factors are the ‘financial and time impact of the child’s disability on the family’, ‘the family’s demographics’, ‘a supportive home environment’ and ‘the family’s preferences for recreation’. The third category of environmental factors includes ‘a supportive physical and institutional environment’,

‘supportive relationships for the child’, and ‘positive relationships for the parents’. In the view of the authors, this model gives a more detailed perspective on facilitators and barriers for participation in leisure activities – especially with a higher focus on the individual’s perspective – than the ICF. The model of King et al. is chosen as a theoretical framework for the present study. A more detailed definition of the model’s included factors is presented in the results.

So far, research on facilitators and barriers for participation has often focussed on the perspective of parents. However, different studies have found success in including other perspectives, such as professionals working closely with children and youth with disabilities [7,26–28]. Wright et al. [27] call healthcare professionals the perhaps missing link to improve an active lifestyle and encourage behavioural change in individuals. Moreover, in recent years it has become more and more important to include the perspective of the children themselves [29–35]. This is especially stated in article 12 of the UN Convention of the Rights of the Child (UNCRC):

[...] assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child [...] [29, p.4]

Therefore, it is of interest to explore the different perspectives of parents, professionals, and children and youth with disabilities regarding facilitators and barriers for participation.

The research question for this specific study was: What are main facilitators and barriers for participation in different leisure activities for children and youth with disabilities in Norway, based on the perspectives of parents, professionals and children and youth with disabilities?

Method

A qualitative design was used to explore and describe facilitators and barriers for participation in children with disabilities. Group interviews were conducted to explore the perspectives of parents, professionals, and children and youth. The study was approved by the Norwegian Centre for Research Data to meet all ethical research criteria (reference number 52305/3/STM).

Recruitment and participants

Participants were recruited at a rehabilitation centre in Norway during a three-week intensive group

intervention based on adapted physical activity. Inclusion criteria for parents were having a child with disability aged between 5 and 17 years, and speaking Norwegian. Inclusion criteria for the children were being diagnosed with some kind of disability, being able to partake in the interview on their own, and being able to give informed consent (with support from parents). In order to handle the challenges of appropriately interviewing children with disabilities as a vulnerable population, the guidelines introduced by Lewis and Porter were applied [36]. These guidelines provide researchers with a checklist to adapt the research methods required when interviewing children with special needs for their specific research aim. The checklist includes how to get access to young interviewees, discuss questions of consent and assent, confidentiality and anonymity, recognition and feedback for the interviewees, and the researchers' social responsibility. It also provides guidance for sampling, design and proper communication.

Potential children and parents were invited to a short information meeting regarding the aim of the study. Consent forms and additional sociodemographic questionnaires were distributed. To further build trust and a positive relationship with the children, the first author participated in two days of intervention programme with each group.

The professionals were employees at the rehabilitation centre (e.g. physician, physiotherapist, occupational therapist, teachers), working with approximately 500 children and youth with disabilities per year. They were recruited in short information meetings where consent forms and a short sociodemographic questionnaire were distributed. Inclusion criteria were at least one year of working experience at the rehabilitation centre, and speaking Norwegian.

All together 61 people participated in interviews (32 parents, 20 professionals and nine children). The group of parents included seven fathers and 25 mothers. According to the sociodemographic questionnaires, 17 participants characterized their child's disability as physical, six as intellectual or emotional, and eight as complex.

Regarding the group of parents, in most cases (26), the child lived together with both parents. Most parents were of Norwegian heritage. Other heritages included the Middle East (4), other European countries (3), East Asia (2) and Africa (1).

Most parents worked full-time. Four parents, all mothers, were not employed in order to take care of the child with a disability.

The group of children, having a variety of impairments, was five boys and four girls. Their ages ranged

from seven to 15 years (mean 11.1 years). Often the parents of the interviewed children also participated in a separate interview for parents. However, this was not the case for all children. Furthermore, to assure anonymity – such connections between the children and parents interviewed were not recorded. Group size in the children interviews varied between two and four, with one individual interview, two interviews with two and one interview with four children.

The group of professionals was eight men and 12 women. Their average job experience was seven years. They comprised four physicians, four sports pedagogues (with a bachelor or master degree in sport-science and a focus on pedagogics and adapted physical activity), four leisure activity leaders, three physiotherapists, two teachers, two team assistants and one occupational therapist.

Once informed consent was received from parents, children and professionals, the group interviews were planned and conducted.

Data collection

The group interviews took place in a meeting room at the rehabilitation centre. Data collection took place during spring and summer 2017. The group size was set to a maximum of eight participants [37]. Other studies have successfully used similar methods in researching participation for children and youth with disabilities [2,7,9]. The interview guide used was inspired by that of Coster et al. [2] during the development of the 'Participation and Environment Measure for Children and Youth' (PEM-CY) and has been adapted to the different research groups (Table 1).

The first author conducted all 16 interviews: seven with groups of parents, five with groups of professionals and four with groups of children and youth. The interviews varied from 35 and 50 min, and were digitally recorded (both audio and video). For the interviews with children, parents were offered the opportunity to observe the interviews, or assist their children if needed. However, none of the parents did so.

Saturation for the interviews with parents and professionals occurred after six interviews (parents), respectively, five interviews (professionals), when no new aspects occurred in the interviews. To assure this assumption, one more interview for each group was conducted. In the case of the children, even though only nine children participated in the interviews no new themes occurred after the four conducted interviews.

Table 1. Interview-guide (translated from Norwegian to English).

	Parents	Professionals	Children/youth
1	What does 'participation' mean to you? (no correct or wrong answers)		
2	What kind of leisure activities does your child participate in at home, with friends, or in other organized or unorganized settings?	What kind of leisure activities do you think children with or without disabilities participate in at home, with friends, or in other organized or unorganized settings?	What kind of activities do you do at home, with friends or somewhere else during your leisure time?
a	-	-	Are there any activities you do, that you actually don't want to do?
b	-	-	Are there any activities you would like to do, but you can't do thus far? Why is that?
3	How do you evaluate your child's participation?	How do you evaluate a child's participation?	-
a	What are your key aspects to evaluate participation?		-
b	If you take an activity we mentioned before, what will give you the sense that your child is participating?		-
4	What facilitates your child's participation in leisure activities?	Which factors do you think can help children and youth with disabilities to participate in leisure activities?	What helps you to make it easy and fun to participate?
a	Which factors are helping (e.g. persons, physical environment, equipment, strategies, time...)?		Are there any persons, equipment or other things that help you?
b	In what kind of situations do these factors help your child participating?		Is it the same in all activities you do, or do things vary between activities?
5	Which factors hinder your child from participating in leisure activities?	Which factors do you think hinder children and youth with disabilities from participating in leisure activities?	What makes it difficult or boring to participate?
a	What kind of challenges or barriers are there (e.g. persons, physical environment, equipment, time...)?		Are there any persons, or other circumstances that make it difficult or boring for you to participate?
b	In what kind of situations do these factors hinder your child in their participation?		Is it the same in all activities you do, or would like to do, or do things vary between activities?
6	If you could design a questionnaire for children about participation in leisure activities, what would it look like (e.g. use of pictures, pictograms, symbols, language...)?		If you could decide what the new questionnaire should be and look like, what would be important for you?
7	Is there something else we haven't discussed today that you want to talk about?		Is there anything else you think we should talk about today?

Due to recruitment difficulties, an additional interview to confirm this presumption was not conducted.

Transcription took place the week following the interviews. Qualitative data were transcribed verbatim into Microsoft Word by the first author. Transcriptions were imported into MAXQDA 12 for further analysis. The participants' names were exchanged with participant-numbers. If participants mentioned their child's name, these were replaced with 'my son', 'my daughter', or 'my child'.

Analysis

Descriptive analyses were performed to describe the sociodemographic data and the setting for the leisure activities of the children. Sociodemographic data, anonymized by a codename, were analyzed using SPSS 24 (SPSS Inc., Chicago, IL).

The qualitative analysis followed established recommendations for qualitative content analysis [38]. All quotations from the interviews were translated from Norwegian to English, with the intent to stay as close as possible to the original quotes in use of language, formal and informal expressions, and so on. In the article, names of the participants (children, parents, or professionals) have been changed into pseudonyms. The transcripts were read through, parallel with the video and audio files, adding comments on non-verbal communication (gestures, facial expressions, expressions of emotions). The reduction phase began with a basic content analysis of the transcripts based on the interview guide. Text passages were marked according to the question in the interview guide. The model of factors affecting the participation of children with disabilities, developed by King et al. [1], was used for further deductive analysis of the interview data. Table 2 gives an example of the analysis process.

After several rounds of coding, the results were summarized in a table by category and group of participants to enhance the interpretation and reporting process. Mainly the first author, with several consultations with the last author (ASD) until consensus was reached, conducted analyses.

Results

First, the different activities from the interviews were: (1) physical activities such as individual activities as horseback riding and swimming), team sports as for example football and handball, and family activities as go for a walk/hiking, cross-country skiing and downhill skiing. (2) Cultural activities like playing an

Table 2. Examples of the analysis process.

Original quote	Extraction	Factor according to the framework from King et al. [1]	Conceptual theme
'We are lucky, having a very capable occupational therapist, who has experience with problems regarding inclusion. Based on that he could make specific suggestions that worked for us. In this way we did not need to experiment too much'.	Experienced and motivated occupational therapist; suggestions from professionals help to find good opportunities for participation	Environmental factors – relationships for the parents – formal support	Facilitating participation due to support from motivated and experienced professionals
'For example, when we are at the sports-club. It's not just for him (<i>refers to his son</i>), but I also get to talk with other parents. [...] These activities also work as a think-tank and in order to exchange ideas for us parents. We can't think about everything on our own. We have to exchange experiences. This is really important'.	Activities not just for own child; importance of exchange of experiences with other parents with similar challenges	Environmental factors – relationships for the parents – informal support	Facilitating participation by exchange of experiences with other parents

instrument, singing in a choir and dancing. (3) Hobby and outdoor recreation activities as playing outdoors, fishing, being a member of a scout-group and hunting. (4) Recreational activity like use of PCs, tablets or smartphones; gaming; watching TV and just 'relaxing or taking a break'.

A major focus in leisure activities was within computer and media (e.g.). The use of PCs, tablets and smartphones included social media and use of streaming providers.

In the following the findings on barriers and facilitators are described in categories related to the frame of King et al. [1]. Table 3 gives an overview of all categories.

Child factors

Child's perception of his or her own athletic and scholastic competence

King et al. [1] refer to the children's perception of their own athletic and scholastic competence.

In this study, all participants (children, parents and professionals) provided information from their perspective.

Barriers: The main barrier for all parents and professionals was the child's own perception of his or her ability gap in comparison to peers without disabilities. As the gap increased with increasing age, low motivation, low self-esteem or even dropout from the leisure activity were experienced. One mother exemplified this:

'My child participated in gymnastics for one year. And then it became like, things got too fast, so she couldn't keep up. And so... well... she became almost ashamed that she didn't manage to do as much as the others. Even though the trainer was really good at adapting the activity, so she could participate, she withdrew [...]' Sara

The children themselves did not necessarily perceive their own impairment as a barrier. Often they

saw other children's impairments as more disabling, compared to their own.

Facilitators: Some parents explained that their children tried to find activities in which their impairment was invisible. Another strategy was to find a niche or role within the activity according to their capabilities. One father exemplified this with his son's participation in handball:

'My son – he is quite weak – withdraws if things get too physical, or if the other guys in a way start shoving, bopping and tossing. Especially when he should start with handball, where things can get a bit rough, he wanted to participate as a referee, see? Because in this way he could stand on his own, did not have to fight for the ball – he just stands there with his whistle. So, this was his reasoning for being the referee...' Teodor

Child's physical, cognitive, and communicative function

King et al. [1] define this factor as how the child functions on a physical, communicative and cognitive level, perceived by external (professional) observers.

Barriers: As the child got older, the parents and professionals perceived an increased gap between the child's physical, cognitive and communication functions and their non-disabled peers. This included physical functions, complex sets of rules, or complexity in strategies and tactics.

Another aspect mentioned was the child's overall level of energy. Many children use most of their energy to keep up at school, as parents and professionals explained.

Consequently, some children had an increased need for rest and sleep, affecting their opportunities for participation in leisure activities. Especially parents pointed out that clear priorities are necessary, as one mother explained:

Table 3. Overview on facilitators and barriers found in this study (categorized according to King et al. [1]).

Factors (King et al. [1])	Barriers	Facilitators
Child factors		
Child's perception of own athletic and scholastic competence	<ul style="list-style-type: none"> • Demotivation/lower self-esteem due to perceived ability gap to non-disabled peers 	<ul style="list-style-type: none"> • Finding activities where disability is not visible • Finding 'niches' within activity to compensate for/hide ability gap
Child's physical, cognitive, and communicative function	<ul style="list-style-type: none"> • (Increasing) gap to non-disabled same-age peers (with age) • Overall level of energy and increased need for rest/sleep 	<ul style="list-style-type: none"> • Adaption of activity/rules according to the child's needs
Child's emotional, behavioural and social function	<ul style="list-style-type: none"> • Attention deficits • General resistance/negative attitude towards (new) activities • Unpredictable situations that lead to resistance against further participation 	<ul style="list-style-type: none"> • Increased focus in individual activities or one-on-one support
Child's preferences	<ul style="list-style-type: none"> • Parents/assistants not capable/able to support the child due to own lack of ability/skills • Child's abilities make participation (in the view of the parents or other adults) not possible 	<ul style="list-style-type: none"> • Considering the child's preferences in activity choices
Family factors		
Financial and time impact on the family	<ul style="list-style-type: none"> • Long distances • Child's need for support while participating • Expensive one-on-one support/lessons 	<ul style="list-style-type: none"> • Gaming to support social participation (e.g. online gaming) or physical training (e.g. training using Wii-Sports, EA Sports Active, Xbox Your Shape, or Happy Rehab™) • Support from Norwegian welfare system
Family demographics	<ul style="list-style-type: none"> • Working hours of parents • Family income in conflict with high costs 	<ul style="list-style-type: none"> • Support from Norwegian welfare system
Supportive home environment	<ul style="list-style-type: none"> • Problem in Coordination of activities (especially with several siblings) • Social isolation • Exhaustion due to everyday life/work • Protecting child from negative experiences/emotions • Physical/mental restrictions due to disability/illness of a parent • Patronizing attitude of parents during participation • Inactive home environment 	<ul style="list-style-type: none"> • Supporting autonomy of the child during participation
Family preferences for recreation	<ul style="list-style-type: none"> • Inactive home environment 	<ul style="list-style-type: none"> • Parents or siblings as active role models
Environmental factors		
Supportive physical and institutional environment	<ul style="list-style-type: none"> • Physical barriers • Little variety of activities (especially rural areas) • Little range of activities adapted for disabled children • Restrictive (local) legislations/regulations • General organization/structure of sport clubs in Norway/missing resources • Focus on competition especially in sports • General lack of thoughtfulness in society • Perceived barriers by others, which are not really barriers or can easily be overcome 	<ul style="list-style-type: none"> • Adapting public areas to the needs of disabled people • Living in urban areas • General legislation connected to the Norwegian welfare state
Supportive relationships for the child	<ul style="list-style-type: none"> • Inactive/unavailable parents • Child's wish for autonomy with increased age that stands in conflict with the child's realistic perspectives to be independent • Activity leaders with a negative attitude/lack of knowledge towards inclusion • Peers with a negative attitude towards the disabled child 	<ul style="list-style-type: none"> • Active/supporting parents • Leisure assistance • Inclusive/competent activity leaders • Peers with an inclusive attitude • Peer group both within the disabled and the 'non-disabled' community
Positive relationships for the parents	<ul style="list-style-type: none"> • Lack of informal support • Unmotivated/stressed local professionals • Lack of clear responsibility 	<ul style="list-style-type: none"> • Support from relatives/friends • Exchange with other parents • Motivated/experienced local professionals • Advocacy groups • Local welfare offices

'My child enjoys pretty much everything she participates in. Her problem lies in the aftermath. If she cannot go to school for two days afterwards, it may not have been the right activity... Then we have to find something that enables us to keep balance in everyday life. This is a challenge we've met...' Ella

Facilitators: Parents and professionals pointed out that often already small adaptations of the setting, equipment or activity rules could enable a child's participation.

Child's emotional, behavioural, and social function

This factor refers to how the child is functioning emotionally, behaviourally and socially in leisure activities [1].

Barriers: Parents mentioned an attention deficit due to too much stimulus, especially in group activities. This could cause missing different instructions, or spending less time on tasks compared to the peers without a disability.

Some parents also mentioned their children had a general resistance towards new activities, until they get started, as one father explained:

'There are for sure several children like that: everything is "no" – right until you get started and try a bit; then it may be a bit "yes" – with the exception of some things that are 'yes' all the time.' Ulrik

Additionally, unforeseeable triggers appearing while participating can lead to the child refusing all further participation or cooperation. Often even professionals or parents had no explanation for these incidents, making it even harder for them to deal with these situations.

Facilitators: Parents especially mentioned that their children often coped better with individual activities (e.g. climbing, swimming), where they solely could focus on themselves and/or had one-to-one support.

Child's preferences

King et al. [1] refer to the child's own priorities and affinities regarding leisure activities. These preferences can include both organized and unorganized activities.

Barriers: Parents experienced that their own lack of knowledge or ability to follow up an activity could hinder the child's participation. Another perceived barrier appeared in situations when children had unrealistic thoughts about their own capabilities, as one mother explained: her son was using a wheelchair and wanted to play football (as a field player on the pitch, scoring goals):

'I have a boy that grew up with a father playing football on a high level and he has been to football matches since he was born, in a way... So football has high priority. So, when spring is coming, he will likely want to participate in "football school". Even though the other parents say they want to adapt so he can participate, that might be difficult... Maybe, we have to take this fight, that this is something he cannot do... just because he does not have the abilities.' Hedda

The children themselves mentioned disliking activities and not having chosen activities themselves as barriers. Examples included household chores that they were ordered to do, cleaning a pet's cage, helping with the dishes or walking the dog in bad weather.

Facilitators: Considering the child's preferences in the choice of activities was seen as a main facilitator by parents and professionals. Parents explained how this prevented discussions and conflicts, since children looked forward to participating. Professionals

mentioned that prioritizing a few activities the child is motivated for would lead to better outcomes.

The children themselves focussed mainly on their preferences and activities they were interested in, as the comment of one boy exemplifies:

'If you choose an activity, you choose one that you really want to do. So it's always fun.' Sebastian, 15 years

When participating with their friends, their preferences were often formed by the group's current interest.

Family factors

Financial and time impact on the family

According to King et al. [1], this factor refers to how the child's disability effects the family on a day to day basis. This can include time aspects (e.g. extra time for daily care, support in activities of daily living), or additional expenses connected to the child's disability (e.g. accessible home environment, adapted transportation).

Barriers: Parents and professionals lay most attention on the time aspect. This included time to travel long distances to activities suitable to the child's needs, or increased time need to support the child during participation, especially compared to non-disabled siblings (parent perspective) or non-disabled peers (professional perspective).

For the financial aspect, parents referred to additional expenses due to the child's need for one-to-one support during participation, as one mother exemplified with the activity of horseback riding:

'It becomes expensive, if you have one-to-one support during lunge lessons [in horseback riding]: You have one standing in the middle and one assistant takes care that he [her child] does not fall asleep, or falls down, and that he does what he is supposed to do. Then it becomes expensive, if it's organized activity, and you have to pay for it, since there are two adults.' Selma

Facilitators: Investing in gaming equipment (e.g. PC, gaming-consoles, motion-control applications) was seen as a very effective strategy to facilitate social participation with non-disabled peers (e.g. multiplayer games both online and stationary), and/or joyful training (e.g. training using Wii-Sports, EA Sports Active, Xbox Your Shape, or Happy RehabTM), in the perspective of the parents and professionals. This is reflected in the argument of one father:

'My son is playing online with a headset and microphone, talking with the others. They are playing Warcraft and other such things. There he is as social

as everyone else is. Even if there are 10,000 that are sitting in each their own room, there is a common activity going on in this digital space, you understand. Then it does not matter if you are sitting in a wheelchair, where you are, or whether you maybe don't have the best pronunciation. Yes, this is a really good arena.' Theodor

Family demographics

This factor incorporates the parents' education, employment, and family income [1], and how these affect the child's participation in leisure activities.

Barriers: The level of employment was a main topic within this category in the interviews with parents and professionals. This included activities already starting within working hours of the parents, or changing working hours when parents were working shifts.

Professionals talked more about how a low family income could hinder participation, especially in case of activities that required cost-intensive equipment (e.g. downhill skiing) or was bound to high fees for participation (e.g. paying for lessons, payment for entrance in swimming pool, skiing resort).

Facilitators: Main facilitators were connected to financial support from the Norwegian welfare state, such as caregiver benefit for care that helped parents working less hours to support the disabled child.

Supportive home environment

This factor refers to the physical, mental and social well-being of the parents and how well the family interacts and corporates with each other [1].

Barriers: Siblings with different interests were perceived as a barrier by both parents and professionals, since coordinating all these interests was challenging. Parents also talked about how the child's disability affected the social functioning of the family, isolating or excluding not only the child, but sometimes also the whole family from participation and social life.

Another aspect mentioned by parents was that they often felt exhausted after working days or weeks, without energy left to motivate their child to engage in specific leisure activities, or participate together with them.

Parents also reported protecting their child from negative experiences and emotions, which affected their own emotional well-being, as shown in a communication between two mothers:

Aurora: 'It is well known – to say it like that – that children with special needs are often standing on the side-line. They do not have the same group of friends – we parents have to compensate for a lot of that.'

Tea: 'Like my seven-year old – he said "Why is it always me calling the others? Why is there nobody calling me?" [Other participants nod their heads and agree] This is hard.'

Aurora: 'It is hard to be a parent in such situations. I said to the other parents [in her home community] "How shall I respond to this?" This is very sad. My daughter wants so desperately to be a part ...'

In one case, a parent had a disability and perceived that his own restrictions affected the child's participation negatively.

Family preferences for recreation

This factor incorporates preferences for engaging in specific activities by the parents and the rest of the family [1].

Barriers: According to the professionals, mainly inactive parents or a family with an inactive lifestyle would hinder the child's participation in leisure activities.

Facilitators: Both parents and professionals agreed on how the preferences of the parents and siblings could work as a facilitator for the child's participation, working as positive role models, by participating in a variety of leisure activities themselves. As one father explained:

"Well, another aspect is that it helps to be active oneself. We really enjoy cross-country skiing and this has also passed over to my son. Going cross-country skiing or hiking, and that we are doing this regularly, made it become a part of his activities." Tobias

Environmental factors

Supportive physical and institutional environment

King et al. [1] define this factor as the physical environment, policies, and public institutions facilitate or hinder participation in leisure activities.

Barriers: Some participants mentioned that some community facilities still display physical barriers for children with disabilities (e.g. missing elevators or wheelchair ramps). Living in rural areas was also often perceived as a barrier, with longer distances to suitable activities or institutions, and generally little variety of available activities.

Some parents were critical that their specific communities had different minimum ages to apply as a leisure assistant. They wished for a young energetic person their child could relate to. Unfortunately, most communities had set a minimum age of 18 years or provided primarily elderly people.

A major topic for both parents and professionals was how most leisure activities were organized, especially physical activities. In Norway, most sport clubs are run on a voluntary basis, often by parents during their own leisure time. According to the participants, this led to a lack of knowledge on how to include children with disabilities, or a lack of additional resources to facilitate their participation, delegating most of this work to the parents of the disabled child. Further, most organized physical activities aim towards competition, leaving no room for including children with disabilities.

Many parents said that they missed sensitivity in how to interact with children with disabilities, or perceived that others saw non-existing barriers and a lack of trying, because of such self-constructed barriers. One mother explained this in regard to the attitude of other parents towards dealing with her son, who uses a wheelchair:

'I think many parents build up their own barriers. They see a set of stairs as a problem – this is no problem. I can lift him [talks about her son], I can carry him, I can help them, if they would just give it a shot.' Aurora

Facilitators: Professionals argued that a lot has been done to include disabled people in society, as one professional explained:

'I think, as I reflect on the last decade, there has been a significant increase in customizing and adapting the physical environment. Everywhere – adapting school buildings and others. There has been a lot of construction work everywhere the last years; the last decade, actually.' Mikkel

Living in urban areas was perceived as a facilitator, with lower distances to activities and particularly adapted activities close by, for example organized by advocacy groups. Children articulated that they thought they had a lot of opportunities in their local communities, no matter if they came from urban or rural areas.

Parents and professionals mentioned different supports connected to the Norwegian welfare state. These included cash benefit for care, or different possibilities for assistance such as respite care or leisure assistance.

Supportive relationships for the child

According to King et al. [1] this factor describes how relations between the child and different persons (e.g. parents, peers, teachers, trainer, assistants) facilitate or hinder participation in leisure activities. Parents and professionals argued for the parents being the most relevant relationship for the child in order to facilitate participation in leisure activities.

Barriers: Parents with less engagement were perceived as a major barrier, according to the professionals. Conversely, too much engagement was perceived as a hindering factor with increasing age of the child, since older children want to be more autonomous in their participation. Another aspect mentioned by professionals was a regulating or dictating attitude from parents during participation.

Activity leaders, who have a negative attitude towards inclusion, or lack knowledge, also hinder the child's participation. This may lead to dropout or loss of interest in the activity. Parents and professionals also talked about how peers with excluding attitudes work as barriers.

Facilitators: Parents supporting their children to participate in leisure activities, mentally, emotionally and physically, had a large facilitating effect. A teacher explained the general role of parents in participation, reflecting also on being a mother herself:

'Well, this is really crucial, that we as parents take part: driving, picking them up, stay on the side and cheer them on, let children do the things they are excited to do. It really depends on the parents partaking, or that parents organize that the child can participate together with others.' Julie

Supporting the child's autonomy while participating and a cautious attitude when supporting the child were perceived as facilitators, especially by professionals. With increasing age, leisure assistance was perceived as a facilitator, supporting the child's increasing wish for autonomy and independence from their parents.

Parents perceived that a third party often had better chances to motivate the child. These could be personal or leisure assistants, instructors at organized activities or other older teenagers or adults.

Activity leaders with high knowledge and a positive attitude towards inclusion were perceived as facilitating the child's participation. One mother exemplified this with her daughter's participation in a theatre club:

'We attend a theatre club and my daughter really enjoys herself there... For us it is working perfect. And this is because of the women leading the club: she writes some roles including a chair, so my daughter can sit a bit. She writes those roles especially for my daughter.' Ella

Positive peer relationships facilitate participation, as one father explained using the adapted athletics group his son and other children who know each other quite well took part in:

'What I experienced is parents coming saying they would never have thought that their children would run a single metre, you know. But then, all of a

sudden, they ran a whole lap on the athletics track as a warm-up. Just because they meet others, they are friends with and start running because "That's what we are here for..." So it is this social arena, you can use for so many activities.' Tobias

This is in accordance with the children's perspective. For them positive peer relationships were among the most important factors for participation, as two girls from different interviews stated clearly:

'It's about being with my friends when you do things that I really like doing.' Elinor, 12 years

'Everybody is nice to each other, that's what makes it fun to play handball. And at the team I play in, it's a lot of fun.' Signe, 11 years

Parents and professionals argued for the importance of interacting with both disabled and non-disabled children, to reflect the diversity of the 'real world' and prepare them for their future lives.

Positive relationships for the parents

This factor refers to the support the parents of the disabled child receive [1]. This includes informal social support (relationships with friends, relatives and neighbours) and professional support.

Barriers: Parents often reported a lack of informal support, or perceived social isolation, and having to rely on formal support. They said they lacked information on available activities, support and legal rights. Parents often felt left alone by local professionals, as expressed in a communication between several mothers:

Elise: 'We are a really active family with two older siblings doing sports, and only he [her son with disability] cannot partake. And so I asked the paediatrician, 'Can you give me some tips?' and he was like, 'Just try to find out yourself.'"

Mia: 'And they should know. It is not the first child with cerebral palsy they meet. Yet, it is my first child with CP - I don't have a clue what children with CP can do, or master.'

Parents often perceived a lack of clear responsibilities between different professionals in their local setting.

Facilitators: Informal support from relatives or friends was perceived as a major facilitator. One parent explained this concerning downhill skiing:

Victoria: 'Sitting downhill skiing. We are not experienced in downhill skiing and we don't have the possibility to learn. So it is difficult to find possibilities for my child to do it.'

Researcher: 'How do you solve this challenge? Do you have an assistant or something like that?'

Victoria: 'We have another family, our friends that are experienced in downhill skiing. They take my daughter with them and then bring her back to us.'

Another important informal support for parents was the exchange with other parents in the same situation, such as during a rehabilitation intervention or in the local community or sports club.

Parents also talked about motivated local professionals as a significant support in finding the right activities for the children, including other therapists or sport clubs, and at times advising against certain activities or settings based on their experience. These facilitating experiences could also often be extended to advocacy groups, such as user organizations.

Professionals named local Norwegian Labour and Welfare Administration (NAV) offices, and the appointed persons in charge of inclusion in the local municipality, as facilitators.

Discussion

The purpose of this study was to explore and describe key barriers and facilitators for participation in leisure activities for children and youth with disabilities in Norway. The framework, provided by King et al. [1] has proven to be an adequate tool to use when structuring and analyzing the collected data. Consequently, In this study, there were no aspects of the data that could not be structured and analyzed using this model.

The results show that a methodological approach including children, parents and professionals provides different perspectives. The focus of professionals was the children-parent relationship, combined with physical and institutional aspects, influencing participation in leisure activities. For example, the family engagement and different supports connected to the Norwegian welfare model. This is in line with the finding of other researchers that included the perspective of professionals or clinicians [27,28]. As the clinicians interviewed by Wright et al. [27], professionals in this study were able to both reflect on their point of view and put themselves in the perspective of the children and youngsters they worked with. The parents focussed on the child's abilities, peer relationships and equal participation for their child, and formal and informal support for the child, themselves and the whole family. The participating children's attention was on positive aspects of participation, such as participating in preferred and enjoyable

activities and being with friends and less on what might inhibit their participation. As Jaarsma et al. [28] showed in their study in the Netherlands, children focussed mostly on fun, peers as facilitators.

The results have shown that both facilitators and barriers vary between individuals and are often tributary to the setting they live in. As many authors have observed, several factors can be seen as both facilitators and barriers, depending on the individual and the situation [7,9,17,24,26–28].

Child factors

Increasing age was found to work as barrier for sub-dimensions within child factors. The participation gap increased between children with and without disabilities with increasing age, where low motivation, low self-esteem or even dropout from the leisure activity were experienced by parents of children with disabilities. This supports the results of many other studies [26,39,40]. Strategies to work around own restrictions – called ‘masquerading’ in a recent scoping review by Krieger et al. [11] on the participation of adolescents with autism spectrum disorder. Such ‘masquerading’ strategies were used by some of the children in this study, when choosing activities making their disability invisible and participating within the activity according to their capabilities.

An important factor restricting the child’s participation mentioned by parents and professionals was the general level of energy of the child. Fatigue was one of the main barriers for participation. Fatigue as a barrier for participation has been reported in relation to many diagnoses [27,28,41–43], therefore, careful planning of the activities to be prioritized during a day is required.

The child’s increasing wish for autonomy and independent participation with age was another challenge mentioned by parents and professionals in this study. This has also been reported by Dolva et al. [10] in their research on children and adolescents with Down syndrome in Norway. Internationally, this is a tendency also observed by Krieger et al. [11]. Jaarsma et al. [28] also have reported autonomy to be an important factor that was mainly reported by professionals and children in their study, while no parents reported on this barrier. In our study several parents reported this barrier, reflecting both on unpleasant situations that appear because of this barrier and expressing empathetic understanding to their child’s wish for autonomy.

The child’s own activity preferences were discussed intensively by parents and professionals. Beside the facilitating effect when following these preferences, they could also have a hindering effect, as reported by multiple studies [9], when preferences and planned activities were in conflict.

Overall child factors have been foremost characterized as barriers in previous research, besides the child’s preferences [9]. This study could show that a positive attitude (e.g. adapting rules) and a focus on opportunities (e.g. finding ‘niches’ within the activity) could bring forward more facilitating strategies. This was most apparent in the group of children. While in other studies [27,28] children reported their own disability or health as limitations, the participating children in our study never mentioned their own disability as a barrier. However, they mentioned other children’s disability as possible limitations for participation in certain activities. It is not clear if this is a general tendency in Norway, or if this is due to the child’s age, which was significantly lower in other studies [27,28]. There is a chance that the participants of this study were – due to their younger age – not capable to reflect on their own participation limitations. Another explanation may be the sample of children – all participating in an intensive rehabilitation programme focussed on adapted physical activities and the child’s possibilities. The children’s participation in the rehabilitation programme may have given them activity competences and a sense of success to overcome barriers.

Family factors

Family factors were often seen as ‘either-or’ factors by the parents and professionals of this study. Examples were discussions about the effect of an active versus an inactive family environment. This supports the results of other studies [7,11,12,27,28,44].

Another major factor mentioned during the interviews was time. Time has also been mentioned as a main barrier by other authors [9,26,39,40]. In this study, time was related to the financial and time impact on the family (e.g. longer distances to suitable activities, increased need for support during participation), family demographics (e.g. the parents’ level of employment and working hours), and home environment (e.g. coordinating everyday life and activities in the family), all in line with the conceptualization by King et al. [1]. Financial aspects were mostly mentioned in situations where families did not receive support from the Norwegian welfare state or needed

expensive one-to-one support during participation in leisure activities. As in the study from Wright et al. [27] financial aspects were mostly mentioned by adults. Children, on the other hand did not mention financial limitations. Contrary to Rimmer et al. [7], financial constraints played a much lesser role in the present study. Factors like paying club-memberships were not perceived as barriers. Only expenses that were more or less directly related to the child's disability (e.g. special equipment, additional support) were perceived as barriers. This could be a result of generally lower membership-fees in Norway, for example for the participation in sports-clubs; at least in a European comparison [45,46].

Environmental factors

Environmental factors varied the most between being facilitating or hindering, according to the interviews with parents and professionals. While some parents experienced a supportive and adapted environment, others met many barriers to the child's participation in leisure activities. Moreover, parents and professionals identified a difference in the physical and institutional environment, when comparing urban and more rural areas. Rural areas were associated with longer distances to suitable activities or institutions, and generally little variety of available activities. This is in agreement with Rimmer et al. [7] and Shields et al. [9]. Unfortunately, this study did not collect data on whether the participants lived in urban or rural areas, so that the collected information could not be specially reviewed in light of their place of residence.

Additionally, professionals experienced parents themselves to be either facilitating or hindering to the child's participation, depending on their engagement in the specific leisure activities. Parents supporting their children to participate in leisure activities, mentally, emotionally and physically, had a large facilitating effect while parents with less engagement were perceived as a barrier. While parents with less engagement or with a dictating attitude were perceived as a major barrier, according to the professionals. This family factor has previously been reported in different studies [11,27,28].

There was a consensus in the interviews of parents and professionals that policy restrictions were not that apparent in Norway. However, they mentioned multiple supports offered by the Norwegian welfare state that facilitated participation in leisure activities for children and youth with disabilities. This agrees with Ullenhag et al. [14], who referred to Norway as

a state with generous policy towards including individuals with disabilities, compared to other European countries. Barriers within legislation were mostly reported on a local level in this study. Moreover, a European research project on the policies and characteristics for sports clubs discuss facilitating policies and structures in Norway, like supporting and strengthening voluntary work [45]. Anaby et al. [44] also saw bureaucracy as one reason for segregation and thereby a barrier to equal participation in their scoping review. It seems that in general, Norwegian policies also support participation and lower barriers not just for non-disabled, but also for disabled children.

Parents had an important function in the child's participation in leisure activities, and Krieger et al. [11] describe this as an 'anchoring' function. This is also in agreement with other studies [26,40]. Other supporting relationships for the children, expressed by parents and professionals, were leisure assistants, or activity leaders with a positive attitude towards inclusion. This is in line with both Shields et al. [9] and Krieger et al. [11]. For children, positive peer relationships were the most important factor for their participation. Social acceptance and positive relationships to peers have also been reported as one of the main facilitators from the perspective of children and adolescents with disabilities in other studies [27,28].

In regard to the environmental factor of the importance of relationships for the parents, information varied considerably. While some experienced a lot of formal and informal support from relatives and professionals in their community, and had information easily accessible, others experienced significant struggles. Most variation was expressed in regard to knowledge, motivation and commitment of local professionals such as paediatricians, occupational therapists, or welfare workers and the collaboration between these service providers. This is common with the results of Rimmer et al. [7], who found a lack of information or lack of knowledge and commitment from professionals as barriers to participation. The most facilitating relationship for the parents was with other parents of other children with disabilities. Wright et al. [27] describe clinicians as a missing link to support an active lifestyle, participation and behavioural changes. This underlines the importance of motivated and knowledgeable professionals, also found in this study.

The present study must acknowledge some limitations. One is the limited number of child and youth participants, due to recruitment difficulties. Multiple

authors have discussed the challenges that come with interviewing children [36,47,48], especially within the additionally vulnerable demographic of children with disabilities, which this study tried to take into consideration. In regard to the children's age, Docherty and Sandelowski [47] argue that children (in general) at the age of six have the cognitive and language abilities to be interviewed. This might not apply for all children in this group, especially those with learning disabilities, which needs to be taken into consideration as discussed by Lewis and Porter [36] and stated in article 12 of the UNCRC [29]. In this study, children were aged between eight and 11 years, which seemed at times somewhat too young. Other studies, that included the perspective of children and youth [27,28], generally worked with a sample with a higher age. Although saturation was reached with the current sample the question stands, if an older sample could lead to more perspectives.

Another limitation was the cooperation with a single rehabilitation institution. Since the cooperating institution focussed mainly on adapted physical activity, participants, including parents, children and professionals, also focussed during the interviews mainly on physical activities and took some time to include other leisure activities in their considerations. Moreover, since the interviewed parents and children already had been involved in an intervention and thereby committed to their participation in leisure participation, they – especially the parents – might already fall into the group of an active and involved family environment. This possibly could have affected their reflections on barriers and facilitators and their own role. Therefore, it might be wise for future studies to include parents and families that might not be as much committed to active participation or increasing participation.

A third limitation was the dominance of female participants in the interviews with parents. During analysis, it became clear that fathers often brought a slightly different, more pragmatic and practical perspective to the interviews, while mothers focussed more on relationships, experiences and emotions connected to participation in leisure activities. A more balanced sample of male and female participants would be a point of improvement for further research. This was not the case with the professionals interviewed.

In conclusion, this study provides an overview of the main facilitators and barriers for participation in leisure activities for children and youth with disabilities in Norway. Facilitating and inhibiting factors are

found to vary depending on the context, and may thus serve as both a facilitator and a barrier. Consequently, participation measurements need to be context specific.

The main findings of the present study are in accordance with international studies, and of significance to occupational therapy. However, a difference may be the effect of the Norwegian welfare system, compensating for many financial barriers experienced in other countries. Thus, when developing a new instrument to measure participation in leisure activities in a Norwegian context this must be taken into consideration.

Future studies in the Norwegian context should evaluate these factors on a larger scale in order to achieve more generalizable results. Among others, studies could look at the differences between urban and rural areas in more depth in order to identify strategies to facilitate participation in all settings. Finally, involvement of children and youth with disabilities in future studies is of greatest importance in understanding their perspective of participation opportunities and wishes.

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