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The coolest I know – a qualitative study exploring the participation experiences of children with disabilities in an adapted physical activities program¹

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ABSTRACT

Purpose: The first aim of the study was to obtain a broader understanding of how children 10-13 years old with disabilities experience participation in self-selected physical activities during an intensive group rehabilitation program. A second aim was to explore how new skills and experiences gained from intensive group rehabilitation can be transferred to meaningful participation in local environments.

Material and methods: Individual in-depth interviews obtained the perspectives on participation of a purposive sample of eleven children with disabilities. The study applied inductive thematic coding of the content associated with participation followed by deductive analysis.

Results: Five main themes were derived; “*to learn and to show others new activities*”, “*belonging, solidarity and friendship*”, “*activity and participation enjoyment*”, “*participation on my own terms*” and “*transfer to the local environment at home*”. To practice and learn physical activities during intensive group rehabilitation seemed to enhance transferring of meaningful participation to the local environment, and was related to the children’s activity competence, preferences and self-efficacy.

Conclusions: The rehabilitation stay created a setting where children learned diverse activities together with equal peers, which resulted in mastery, friendship and enjoyment. The children participated on their own terms, and continued to do so in their local environment.

Keywords: Adapted physical activity, children, disability, experiences, intensive rehabilitation, participation

IMPLICATIONS FOR REHABILITATION

- A context of freedom to learn preferred adapted physical activities on children’s own terms is important for transferring meaningful participation to local environments.
- A high intensity rehabilitation program with enough time to try and to learn diverse adapted physical activities is essential to increased activity competence in children with disabilities.
- Attendance in a group of equal peers provides opportunities to experience new roles and thus strengthens the sense-of-self and creates a feeling of belonging, solidarity, friendship and joy.

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INTRODUCTION

Providing a voice for the experiences of participation in physical activity in children with disabilities is crucial to identifying research knowledge gaps, guiding to improve intervention strategies aiming to optimize participation and thereby enhance health and participation outcomes for children (1).

This article aims to obtain new knowledge about the experiences of participation in self-selected physical activities for children with disabilities. Furthermore, we will explore how children can make use of these experiences and physical and social skills gained from intensive group rehabilitation regarding meaningful participation with peers in their home environment. By using a newly developed conceptual framework of the participation, the fPRC framework, we seek an in-depth understanding of the children's experiences

Clinical experiences and research literature emphasize that participation in physical activities is essential for the feeling of belonging and personal growth and development (2-4). Children with disabilities meet restrictions in their participation due to intrinsic individual factors, such as pain, mobility and communication disorders, and fewer social competences (5-9). Extrinsic factors like accessibility, availability and negative attitudes of others also restrict a child's participation (10-12).

The International Classification of Function Disability and Health (ICF) (WHO 2001) defines participation as a person's involvement in a life situation (13). Yet, ICF does not provide a clear definition of the construct of participation, and a conceptual inconsistency related to participation as an outcome seems still to exist (14, 15). A criticized aspect of the ICF is the overlap between the components of activity and participation. The suggestion is that activity is defined as execution of a specific task (the individual perspective of functioning) while participation will represent the societal perspective of functioning. The ICF provides nine categories for the users to differentiate activity and participation components as suits the situation (16, 17). However, the literature agrees, upon two dimensions of participation: the objective and the subjective perspectives (16-19). The objective dimension is seen as performing an activity and having the same opportunities to participate as others, whereas the subjective perspective includes the psychosocial experience while participating.

Consequently, without a distinct conceptualization of the construct, it is hard to design and evaluate interventions to improve participation. Imms et al. (18) have theorized participation

in the Family of Participation-Related Construct (fPRC) framework, and describe participation as two dimensions; *attendance and involvement*. Attendance, is defined as ‘being there’ whereas involvement is the ‘experience of participation while attending’. The components of attendance refer to the objective dimension of participation, such as frequency and diversity. Involvement represents the subjective dimension of participation including elements of emotional character, such as motivation, engagement, persistence and social connection.

The fPRC framework considers preferences, activity competence and the sense-of-self as individual intrinsic factors, which influence and regulate participation, but they are not participation per se (18). The child’s preferences for activities and activity competences are strongly related to involvement and represent intrinsic factors (1). When a child has appropriate or sufficient activity competences (mental and physical) for performance, it enhances the enjoyment of taking part and thereby increases the chances that a child will want to engage further in the activity (20). Positive participation experiences improve self-efficacy and thereby the child’s sense-of-self. The sense-of-self can be defined as confidence, satisfaction, self-esteem, and self-determination (18, 19). Finally, self-regulation, the ability to direct and monitor thinking, emotions, and actions on desirable achievements, is defined as the glue between intrinsic individual factors and the two dimensions of participation. The relationship between the different elements in the fPRC framework is bi-directional. This implies for example that participation in competitive and non-competitive activities requires certain activity competences, which a child will gain from previous experiences of attending and being involved in the activity (18). **FIGURE**

Since participation is the main goal for children with disabilities, families and physical and occupational therapists, special teachers etc, (21) a number of interventions have been implemented to improve participation (22-26). Few interventions, however, target efforts on the participation level. Imms et al. describe how participation can be seen both as a process to induce change and as an outcome of intervention, and thus participation can be seen as either the independent or the dependent variable in intervention studies (18). Viewed from a systems theory perspective, which seems adequate to use because of the complex nature of rehabilitation processes, participation emerges as an interaction among many different systems, each contributing to different aspects, such as intrinsic factors (i.e. skill competences, preferences, sense of self) and extrinsic factors (i.e. assistive devices, support,

climate) (27). Complex systems are constantly being influenced by, and adapting to, their environment. They respond to, and at the same time act upon, the multitude of elements that comprise their unique context (28). Understanding the interaction between the systems is important to gain knowledge about how and what changes occur over time, as well as the entry points for intervention. Thus, interventions aiming to improve the individual child's fitness or mobility (body function as an intrinsic subsystem) may enhance the child's overall activity competence necessary to participate in a particular physical activity. Environmental components, like the provision of assistive devices, such as a special wheelchair for power hockey, reflect extrinsic factors that also might contribute to optimize the conditions for the child's participation.

A significant body of empirical research has demonstrated that interventions, including tailored coaching and mentoring programs, may help to support children's participation in the home, school, and community (representing crucial subsystems for children's development and learning) (22). Interventions that involved a collaborative relationship with families, including mutually agreed goals that are highly motivating, as well as strategies of educating and supporting parents, and measuring the outcome seemed to be effective (29). Studies of interventions with a primary focus on body function or activity level outcomes did not demonstrate an effect on participation outcomes (22, 30, 31). A review of Henderson Skelton & Rosenbaum et al. (32) indicated that the use of assistive devices for children with disabilities increased their capacity for activity and participation. Several studies have demonstrated moderate levels of methodological quality, which indicates that caution is needed when interpreting and generalizing the results (19, 22).

To get a broader understanding of important prerequisite components for children's participation, it is necessary to heed children's own experiences. An intensive rehabilitation intervention, built on the ideas of the fPRC framework, which takes into account children's attendance to a diversity of activities and their involvement, using adapted physical activity and peer learning as main ingredients to enhance individual intrinsic factors such as; activity-competences, self-efficacy and preferences for activities have been conducted (33). The aim of this study was to investigate the following two research questions: 1) How do 10-13 years old children with disabilities experience participation in self-selected physical activities in a group-based rehabilitation program? 2) How can new physical and social skills and

experiences gained from intensive group rehabilitation be transferred into meaningful participation with peers in the local environment at home?

METHODS

Study design

A cross sectional qualitative design was applied to explore and describe the complex phenomena of participation in children with disabilities. Individual, in-depth interviews were used to explore subjective experiences. The analysis was consistent with an inductive and deductive approach. First, the categories were derived from the data in inductive content analysis, and the data moves from the specific to the general. This process includes open coding, creating categories and abstraction. The transcribed text is read through several times and main sentences are identified. Open coding means that keywords representing the content are detected. After open coding the keywords that are similar are grouped and combined into categories or general statements (35, 36). The purpose of creating categories is to provide a means of describing the phenomenon, to increase understanding and to generate knowledge. Secondly, a deductive content analysis was used and operationalized based on previous knowledge. The purpose was theory testing (36). The interpretation was guided both by the empirical interview data and by a strong conceptual framework, embedded in the ideas of the fPRC framework. The deductive content analysis involved a categorization matrix corresponding to the elements of the fPRC framework and the data were reviewed for content and coded for correspondence with the identified categories (36)

Ethics approval for this study (S-08658a 2008/18016) was obtained from the Norwegian Regional Committee for Medical and Health Research Ethics, section South-East C (REK Sør-Øst C).

Participants and intervention

Treating health professionals recruited the children during a standard rehabilitation stay at Beitostølen Healthsports Center (BHC) in 2010. The Local Environment Model (LEM) is an intervention developed by BHC dedicated to enabling physical activity participation for children with disabilities in local environments (33). The invited participants were a purposive sample of 11 children from urban and rural communities, both genders, of different ages, who were talkative and showed a genuine interest in participating in the study. The children were

eligible to participate in this study if they were a) participating in a Local Environment Model group at BHC b) between 10 and 13 years of age, c) had parents who also consented to participate, and d) had a cognitive and communicative ability. Each of the 11 children (five girls and six boys) accepted invitations to participate in the study and provided informed consent. The children had diverse childhood onset physical or complex disabilities and a mean age of 11y 8m. Diagnostic information is presented in Table 1. The rehabilitation period could take place any time of the year, and the children had two school lessons every day and contact with the local school on skype during the rehabilitation period.

Before the children arrive to the BHC, a multi-professional team from BHC travels to their local community. The purpose of this meeting is to engage children, parents, and local service providers in the preparation, intervention and follow-up stages of service delivery. Further, the aim is to find out what activities the municipality can offer, to secure that the children can continue an activity learned at BHC in their local environment. The field team also visits the families three months after they have returned home to map each child's participation, and discuss any barriers families maybe facing. In dialogue with the family and the local service providers strategies to overcome these obstacles are established.

The participants were examined by a medical doctor and a multidisciplinary team at the arrival to BHC. On the second day, the team and the children made a detailed goal-setting plan for the rehabilitation stay at BHC. Goals were also set for the three-month follow-up period based on the children's activities preferences, directed at enhancing autonomy, activity adherence and self-efficacy. The rehabilitation programme at BHC is based on the ideology of Adapted Physical Activity (37), which means tailor-made physical activities adapted to the specific needs and preferences of each individual with a disability. The Local Environment Model includes collaboration, education and partnership with the children's families and local communities in order to facilitate continued local environment participation (29, 33).

The rehabilitation program includes social and cultural activities and extensive use of outdoor natural facilities on a year-round basis. A wide range of services is offered, including adaptation of environmental factors, assistive technology and individual instruction. The program is intensive with 2-5 hours of physical activity a day, six days a week during three weeks. Most activities are arranged in groups. Through the activities, the staff aims to improve the children's physical activity efficacy by facilitating mastery experience and

optimal challenge. The group setting is considered essential, enabling participants to work together, learn, give feedback to each other, and exchange experiences. The group constellations strive to consist of children from the same community with the hope that they can continue to meet when they come home,(33) Finally, a targeted teaching program, also for parents and local health and school professionals, and situated peer learning are considered important for handling chronic disease. The range of activities offered by the rehabilitation centre provides opportunity to determine the activities best suited to each child's preferences and the possibilities in the local community at home to continue with the activities.

Procedure and data collection

The interview procedure was piloted by the first author (AN) with a ten-year-old child with disability to ensure that the interview guide was applicable, and that it extracted the information required to meet the aims of the study and thereby strengthen the credibility of the results. Individual, face-to-face interviews were conducted with 11 children after a three week rehabilitation stay at the BHC. Medical record information was collected on diagnosis, age, gender, and demographic data (Table 1). The in-depth interviews consisted of open-ended questions focused on which factors children experienced as significant in relation to participation, and how the transfer of an activity from one context to another could affect the ability to participate in the home environment after the rehabilitation stay.

Insert Table 1 about here

The interviews were conducted at BHC by the first author (A.N). A parent was present when so desired. All interviews lasted for 40 to 60 minutes and were digitally recorded. Throughout the interviews, the first author (A.N) took notes to record factors of importance, as well as to reflect on the interview process, and summarized the interviews for the children to verify correctness (38) and enhance trustworthiness of the results.

Analysis

The data from the interviews were anonymised and pseudonyms were created by the authors. The interviews were then transcribed verbatim and analysed according to narrative synthesis and systematic content analysis with thematic coding associated with participation (39).

The first step of the analysis was conducted with an inductive approach. The first author (A.N) transcribed the interviews and extracted significant words and phrases, and representative keywords regarding the concept of participation. Thereafter, similar keywords were clustered, based on their meaning and became the themes. To gain a conceptual understanding of the phenomenon the research group discussed the themes. Previously analysed transcripts were reviewed and recoded if necessary, further adding to the development of meaning units. In case of disagreement, consensus discussions with the co-authors were conducted during the coding and interpretation process.

In a second step, the last author (A.U) applied a deductive approach using the fPRC framework. The researcher independently analysed the keywords, quotes and themes describing the experience of participation that had been extracted in the first step. Keywords and themes pertinent to the different concepts of participation described in the fPRC framework were identified using a categorization matrix (corresponding to the elements of the fPRC framework), and the data were reviewed for content and coded for correspondence with the identified categories. Table 2 provides an example of the analysis including phrases, keywords and themes from the extraction, reduction, and interpretation process. Only minor disagreements arose in the analysis from the two steps and were discussed among the researchers until consensus was reached.

In the second step of the analysis, it was important that the children's participation experiences were not neglected in the ambition to make the data to fit into the fPRC framework. Thus, the researchers revisited the extracted text several times and re-read it to become familiar with the children's voices and the language used. Through this iterating process, the authors found that the fPRC model worked well to describe factors that affected the children's participation.

Insert Table 2 about here.

RESULTS

The thematic analysis revealed five main themes. Four of the themes were related to the first research question about the children's experiences of participation in self-selected physical activities at BHC: *“to learn and to show others new activities”*, *“belonging, solidarity and*

friendship”, “*activity and participation enjoyment*”, “*participation on my own terms*”. The fifth theme “*transfer to the local environment at home*” addressed the second research question, on how children can make use of the experiences gained from intensive group rehabilitation in meaningful participation with peers in their home environment.

To learn and to teach others new activities

Through an intensive rehabilitation period, children experienced and had possibilities to learn several new physical activities and improve previously learned skills. The children described this freedom of choice as a new experience, unlike at home, where they had to opt out or withdraw from activities because participation was not possible. When the children participated in preferred activities in this safe and including setting, they used their current skills, and improved former skills, which they could transfer to other contexts and sometimes play an instructor role in relation to other children.

“Here we can try out many different things, almost anything we want. It’s also a good place to learn something new. And it’s cool that you can teach things to others. I may be good at something that the others cannot do so well, like riding a bike for example. Then they look at me and we learn from each other” (Ane).

Another boy experienced that it was by helping others with practical things that he got to know new people and expressed, “*it’s so good that I can help a little, besides being with the others*” (Sondre). The experience of being able to teach other children was a new and very satisfying experience for most of the children, which became part of the mastery experience and thereby a strengthened sense of self.

Belonging, solidarity and friendship

The analysis generated another important theme related to participation in a group with other children of the same age and with various disabilities. Belonging in a group setting and feeling equal to others was very important. Most children expressed that this desire was crucial for maintaining participation in their home environment. One boy had a pronounced goal to find activities that he could perform with peers. As the boy said, “*I do more things with my mother and father, and sometimes with a physiotherapist, but preferably, I want to be with the other children. When they play football, I would also like to do it*” (Hakon).

A feeling of solidarity, not being the only one with special needs, was a common theme in the children's reasoning about being in a rehabilitation setting that gave freedom to adapt ways

and means, and enough time to master. *"Here, it's not just me who has problems. All of us need some help to succeed. Look at Ida, for example, she has learned to ride a bike. Just think how proud she must be. I would have been, anyway"* (Heidi)! To share frustrations and joy creates a connectedness. As two children said, *"we learn a lot from each other, and finally there are some others that know how it is"* (Erik and Morten). To obtain sufficient competence, and thus be "good enough" among significant others, appears to be crucial for participation. Or, as one girl expressed, *"When there are others with disabilities, it's not so obvious what problems you have. It gives you the feeling of being accepted and you can make mistakes without the consequences being so visible"* (Ida). Another child's statement focused on being in a group where she felt safe enough to participate in activities she could not master. *"We accept each other and then try things our own way, and it doesn't matter if you don't get it right anyway. Somehow, this has become my safe haven"* (Hilde).

For some of the children, this was the first time they experienced an opportunity to make friends. As one boy said, *"We have become friends and will have contact later. We will at least attend swimming both of us"* (Morten). Another statement concerning friendship was *"It's very important to make friends with peers in the same situation, especially when you become older"* (Martin). Being part of a group and doing activities was a way for the children to experience different situations with peers. It gave them opportunity to build friendships, which strengthened the experience of being able to participate.

Activity and participation enjoyment

The third theme concerns the importance of enjoyment while participating in an activity. When the children were engaged in activities of their own choice it promoted a sense of joy and fulfilment. All the children expressed a feeling of pleasure, which was associated, for them, not only with participation in new activities, but also with the connection between group participants. Participation in adapted physical activities made it possible for the children to experience mastery and success that they would not have otherwise experienced. When describing the experience of participation in the rehabilitation setting, the children often mentioned; *"We have so much fun"* (Erik and Morten) or, *"I can't wait to participate in the activities"* (Kristin). *"Now it's more meaningful"* (Heidi). With great exuberance, the children referred to experiencing joy during the activities. They had fun and they stated that it was *"just so good"* (?NAVN?) to participate.

Participation on my own terms

The children described a feeling of being free from the worries of their disabilities and of not being good enough, as they were not subjected to stigmatization associated with their disabilities. One boy said, *"I would say that here, no one is different, and things are adapted for us, so somehow we can be like others. It's easier to talk to others here too, since everyone has something"* (Atle).

A girl felt the same way and said, *"I suppose that everyone has something, isn't that true? And somehow then it seems like your shortcomings are not noticed. I can be myself and relax. It is not so difficult to fit in either"* (Ida).

The shared experiences of learning and performing individually adapted physical activities developed a social connection among the children helping the individual child to overcome an experience of inadequacy that might be prominent in their everyday life. In previous not adapted activities it was difficult to keep up with friends, since the activities were either too physically demanding or the pace or tempo was too high, which could trigger a sense of lack of involvement. Being a valued participant contributed to a feeling of meaning in the activity and increases a sense of participation.

Transfer to the local environment at home

The final theme "*transfer to the local environment at home*" can be illustrated by Morten's story, which points out how children in different contexts can experience participation as both attendance and involvement. The coolest Morten knows is soccer, but he does not really play soccer. It is his brother, who plays soccer, but even without attending the game, Morten is very involved, since his brother and all his friends play soccer. He is a passionate supporter and thinks that soccer is fun, even if he never gets to play real matches. He is engaged in his brother's victories and probably also in his losses. But Morten has won real power-hockey matches! He learned it at his first stay at BHC. Now he exercises once a week and plays tournaments during week-ends, sometimes with his brother and friends.

A.N. (first author) asks him: Is there something you really like to do?

Morten answers: The coolest I know is soccer. They play a lot of soccer at school, and I play a little by myself in the garden at home. Before I played at "After school" but now none of my friends are there anymore... I don't play on a soccer team, you know, that's only my brother who is on a team. I can't do the same as the others, you know.

What is it that makes soccer so much fun?

That's because all my friends do it! Before they let me be a referee, but not anymore. The others become like a little annoyed if I made mistakes... I can't move the wheelchair fast enough, you know, not on the grass anyway.

A.N. asks further: Do you play soccer now, then?

Yes, a little, at school it happens that my teacher makes sure that I am allowed to play. I am placed as a striker, but some say it's unfair.... But soccer is fun even if I never get to play real matches. My brother often wins. Last time they won 6-0!!..... But, do you know, I have won a real power-hockey match!

So you play power-hockey? You haven't told me that.

Oh, yes, that's great fun, and it goes really fast!! Me and my dad learnt it last time we were here at the center. Now we are training once a week, and then we go to play tournaments. My brother sometimes comes with us, and Iver, that's my friend, you know. He also joins even if he doesn't have a wheelchair. He can borrow one, but not as cool as mine, though. I have a special wheelchair just for power-hockey. Have you ever tried power-hockey?!? (Morten)

Several children expressed that they had learned something new and found an activity they can do at home. For one of the children (Sondre) the main goal of participating in the intensive group rehabilitation program was to find a cool activity that he could do together with friends at home. In previous activities he had done at home, he could not keep up with friends, thus the activities were either too physically demanding or the pace or tempo was too high. All the children expressed that it was important to be able to continue to do the activity at home and to have someone to do it with. *"We have become so well-known and it is important that we continue to meet. We'll find things together afterwards when we get home, me and Sigurd"* (Martin).

Several children also stated that the time aspect was crucial for transferring participation to the local environment. It was important that it did not take too long before they could continue to do the activity at home. *Sondre: "Things must happen quite soon after I have come home, otherwise you lose the desire to continue. .. For example, now I think it's fun to swim, so I have to continue swimming when I come home while I remember why I thought it was fun."* Or as Atle expressed: *"It may happen that time just goes and I will lose my desire."*

DISCUSSION

The dimensions of the fPRC framework were reflected in the transcribed texts from each interview, revealing the five described main themes, four related to the first research question

about children's experiences of participation in the intensive group rehabilitation, and one addressing the second research question on the transfer of these experiences to meaningful participation with peers at home.

To learn and to show others new activities

According to the fPRC framework, there is a bi-directional link between participation and activity competence, including a process of acting and learning. The children need certain cognitive, physical and social abilities to perform an activity, which they learn, practise and improve by participating in the activity (18). The context is also essential, as the program provides the children with the time needed to be able to learn new skills in a social context where all the children are struggling with the learning process (table 2). The experiences of learning new skills have been highlighted in the literature to be important to children for their participation in daily activities (40). However, it is not only the acquisition of new skills that is meaningful for the children's participation, but also to learn more about their own abilities and limitations among other children with disabilities (41). Self-perception is shaped through others' reflections, and to be able to help others with similar impairments created new roles in the group, and thereby a new self-understanding.

In the fPRC framework, the group setting comprises extrinsic factors like people, place, activity objects and time, and the relationship between the context and the person is seen as transactional. The relationship can be illustrated by the children's positive experiences in the group setting, where they could not only choose and learn a number of different activities, but also have the time, the assistance and the devices necessary to utilize the opportunities. In addition, the activity experiences provided a feeling of mutual acceptance among the children. If the attitudes of the social environment are supportive and understanding, not judgmental, it strengthens the sense of acceptance, which affects the sense-of-self (41). These results were confirmed by the review of elements contributing to meaningful participation by Willis et al. (2016).

Belonging, solidarity and friendship

Group based interventions, built on a supportive atmosphere that inspires social connections, where children have role models, and where activities are adapted to the children's competences seem to be important ingredients for meaningful participation (41). The sense of belonging was an important element for the children to experience meaningful participation. A feeling of connectedness to others developed through shared experiences and diminished

the child's sense of isolation (41). The statements of belonging, solidarity and friendship highlight that the social component of participation was very important and gave the activities meaning. According to the fPRC framework, involvement is strongly related to social connections, affection and motivation (18). Consistent with the children's experiences of participation, it appears to be crucial to establish opportunities for children to connect with peers and make friendships. Willis et al (2016) concluded that a group setting where children had possibilities to develop and confirm their identity among equal peers with disabilities is essential to fostering a feeling of relatedness (41). The opinions expressed of the children in this study are in line with such a perspective.

Activity and participation enjoyment

Enjoyment and fulfilment can be achieved in a variety of ways including intrinsic and extrinsic factors according to the fRPC model. Activities chosen by the children, experience of mastery, support received from therapists, friends and family, and socialisation with peers were recognized as internal and external contributors to having fun. Intrinsic concepts in the fPRC framework such as *Sense-of-self*, and *preferences*, are both antecedents to, and consequences of, participation enjoyment (18). Sense-of-self is influenced by our participation experiences, such as having fun, and this is predicting future involvement. Several studies have demonstrated the importance of choosing preferred activities in order to enhance children's motivation, focus, and participation enjoyment (20, 42). There seems to be a dynamic relationship between, preferences, enjoyment and the sense-of-self, which is based on previous participation experiences and which will predict future involvement. To be involved and engaged in an activity will also promote a more solid perception of wellbeing and happiness, and thereby enhance the person's intensity and focus in the activity while participating.

Participation on my own terms

Attending an activity does not automatically guarantee involvement in the activity. Rather, the feeling of involvement is dependent on the behaviours of others and the subjective experience of being an actor in a particular situation. The possibility to perform activities on your own terms in an accepting and supporting context is crucial to developing a feeling of mastery. The adaptive context in combination with children's preferences and experience of skill-competences form children's sense-of-self, which in turn affects which activities they want to attend and be involved in.

Studies have described the importance of social interactions between individuals with similar disabilities to explore and strengthen an identity (40, 41, 43). The others will become role models and help the children to understand themselves better. They will also experience being role models to others, which will strengthen the feeling of mastery further.

Transfer to the local environment at home

To transfer new skills and experiences gained from intensive group rehabilitation into meaningful participation with peers at home will be easier to realize with past experience of enjoyment and success, through which preferences are established. By means of adapted physical activity and peer learning on their own terms, the children developed activity competence during the intensive rehabilitation period. An appropriate activity competence reinforces a child's self-efficacy and sense-of-self to handle a certain situation, which, in turn stimulates the child to seek for new available settings to participate in. The continuity seemed to be essential for the children to transfer their participation in an activity at home, otherwise there was a risk that the children lost their motivation in doing the activity. The range of activities offered by the rehabilitation centre should also be activities the municipality can offer, to secure that the children can continue an activity learned at BHC in their local environment. Furthermore, several children expressed that it was important to have a friend to do the activity together with.. The Local Environment Model at BHC has the ambition to create groups consisting of children from the same community, with the hope that the children can continue to meet when they come home.

To be able to transfer physical activity participation into the local community it was essential to understand the nature of transactional processes between elements: how intrinsic factors such as activity competence, preferences and sense of self, and the context are linked. The Local Environment Model at BHC is goal-directed and family-centered, with focus on collaboration, education and resource-building in partnership with local communities to facilitate long-term physical activity participation (29, 33).

Strengths and limitations

A qualitative design with individual in-depth interviews and content analysis was considered to be the most appropriate approach to obtain a broader understanding of how children experience participation in physical activities. Even though the participants were a purposive sample of only 11 children, they were boys and girls of different ages, who had various

disabilities with different functional levels, and come from different rural and urban regions of Norway. This was believed to be rather representative for the population group of children with disabilities, and strengthens the transferability of the results. However, the intensive inpatient rehabilitation blocks may not be transferable to other countries due to policy differences, but as described by Willis et al (2018) (32), the active ingredients may be transferable to other contexts in different countries.

A limitation could be that children potentially did not understand the questions or give the expected answers. The interviewer, however, who is an experienced sports pedagogue working with children with disabilities for many years, and with a master degree and PhD in adapted physical activity, verified her interpretations of the children's responses using summaries and follow-up questions to strengthen the trustworthiness of the results. Credibility was also strengthened by parents being present who confirmed the children's statements. Social desirability, however, could also affect the children's answers, and thus the presence of the parents could reduce credibility.

In the content analysis process, it was important to interpret the children's experiences as correctly as possible and therefore a manifest abductive approach was used. Reflective commentaries after each interview illustrated the researcher's immediate impression of the data collected and were utilized to verify the interpretations of the children's experiences, which are considered to establish credibility (38). Further, the researchers revisited the extracted text several times, re-reading it to become familiar with the children's voice and the language used. Debriefing sessions between researchers (A.N, A.U & R.J) concerning differences in the analysis from the two steps were discussed until consensus was reached. Finally, similar results in the research literature (20, 41, 44) and with rich descriptions of the phenomenon and the participants strengthen the assumption that the results can be transferred to other situations and contexts.

Conclusion and implications

The themes emerging from in-depth interviews and the analysis using the fPRC framework contributed to a broader understanding of the elements that created meaningful participation experiences in this group of children with disabilities. Intrinsic factors, such as freedom of choice, increased activity competence, and the feelings of belonging and enjoyment, as well

as extrinsic factors including the group setting and collaboration with local communities seem to be essential for transferring meaningful participation to the local environment.

As previous research has stated (42, 45), it seems to be important to consider the children's freedom of choice, as their preferences for activities will create motivation and enjoyment for children to participate (19). Further, therapists should use strategies to increase children's activity competence (46). Building activity-competences into physical activities enhances a child's self-efficacy and has a positive impact on their sense-of-self when they can perform activities on their own terms. Therefore, different aspects need to be considered, such as, intensity of training, children's different functional levels, adaptation of activities and the need for assistive devices.

In general, integration of children with disabilities has been advocated, but these qualitative data suggest that children may need temporary settings where they come together with equal peers, get enough time and support to learn new skills, and where activities are adapted to a child's ability, create opportunities to experience fulfillment and happiness (3, 20, 41). These adapted settings seem to be required in order for the children to develop physical and social skills that are valuable for participating in their everyday environment together with peers. Further, group-based interventions where children experience connectedness and solidarity with peers with disabilities provide possibilities to develop identity and a sense of belonging where children feel that they are accepted for who they are and not stigmatized according to their disability. Saebu et al. (34) emphasized that experiences of relatedness was the most important need for participation in physical activities among adults with disabilities.

To transfer skills and experiences gained from intensive rehabilitation into meaningful participation with peers in the local environment at home, intervention strategies need to apply a systems theoretical perspective. Seeing that children's experience of involvement depends on extrinsic and intrinsic factors, the activity and the context, implies that all elements in the fPRC framework need to be considered.

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References

1. Shikako-Thomas K, Dahan-Oliel N, Shevell M, Law M, Birnbaum R, Rosenbaum P, et al. Play and be happy? Leisure participation and quality of life in school-aged children with cerebral palsy. *International journal of pediatrics*. 2012;2012:387280.
2. Bjornson KF, Belza B, Kartin D, Logsdon R, McLaughlin J, Thompson EA. The relationship of physical activity to health status and quality of life in cerebral palsy. *Pediatric physical therapy : the official publication of the Section on Pediatrics of the American Physical Therapy Association*. 2008;20(3):247-53.
3. Dahan-Oliel N, Shikako-Thomas K, Majnemer A. Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 2012;21(3):427-39.
4. Fowler EG, Kolobe TH, Damiano DL, Thorpe DE, Morgan DW, Brunstrom JE, et al. Promotion of physical fitness and prevention of secondary conditions for children with cerebral palsy: section on pediatrics research summit proceedings. *Physical therapy*. 2007;87(11):1495-510.
5. Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, et al. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental medicine and child neurology*. 2006;48(5):337-42.
6. Shikako-Thomas K, Shevell M, Schmitz N, Lach L, Law M, Poulin C, et al. Determinants of participation in leisure activities among adolescents with cerebral palsy. *Research in developmental disabilities*. 2013;34(9):2621-34.
7. Ullenhag A, Bult MK, Nyquist A, Ketelaar M, Jahnsen R, Krumlinde-Sundholm L, et al. An international comparison of patterns of participation in leisure activities for children with and without disabilities in Sweden, Norway and the Netherlands. *Developmental neurorehabilitation*. 2012;15(5):369-85.
8. Engel-Yeger B, Jarus T, Anaby D, Law M. Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *The American journal of occupational therapy : official publication of the American Occupational Therapy Association*. 2009;63(1):96-104.
9. Lindsay S. Child and youth experiences and perspectives of cerebral palsy: a qualitative systematic review. *Child: care, health and development*. 2016;42(2):153-75.
10. Bult MK, Verschuren O, Jongmans MJ, Lindeman E, Ketelaar M. What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Research in developmental disabilities*. 2011;32(5):1521-9.
11. Shields N, Synnot AJ, Barr M. Perceived barriers and facilitators to physical activity for children with disability: a systematic review. *British journal of sports medicine*. 2012;46(14):989-97.
12. Anaby D, Hand C, Bradley L, DiRezze B, Forhan M, DiGiacomo A, et al. The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability and rehabilitation*. 2013;35(19):1589-98.
13. Organization WH. *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY*: World Health Organization; 2007.
14. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. *Archives of physical medicine and rehabilitation*. 2010;91(9 Suppl):S5-16.
15. Coster W, Khetani MA. Measuring participation of children with disabilities: issues and challenges. *Disability and rehabilitation*. 2008;30(8):639-48.
16. Whiteneck G, Dijkers MP. Difficult to Measure Constructs: Conceptual and Methodological Issues Concerning Participation and Environmental Factors. *Archives of physical medicine and rehabilitation*. 2010;91(11):S22-S35.
17. Coster W, Khetani MA. Measuring participation of children with disabilities: Issues and challenges. *Disability and rehabilitation*. 2008;30(8):639-48.

18. Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Developmental medicine and child neurology*. 2017;59(1):16-25.
19. Imms C, Adair B, Keen D, Ullenhag A, Rosenbaum P, Granlund M. 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Developmental medicine and child neurology*. 2016;58(1):29-38.
20. Powrie B, Kolehmainen N, Turpin M, Ziviani J, Copley J. The meaning of leisure for children and young people with physical disabilities: a systematic evidence synthesis. *Developmental medicine and child neurology*. 2015;57(11):993-1010.
21. King G, Tucker MA, Baldwin P, Lowry K, LaPorta J, Martens L. A life needs model of pediatric service delivery: services to support community participation and quality of life for children and youth with disabilities. *Physical & occupational therapy in pediatrics*. 2002;22(2):53-77.
22. Adair B, Ullenhag A, Keen D, Granlund M, Imms C. The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Developmental medicine and child neurology*. 2015;57(12):1093-104.
23. Imms C, Mathews S, Richmond KN, Law M, Ullenhag A. Optimising leisure participation: a pilot intervention study for adolescents with physical impairments. *Disability and rehabilitation*. 2016;38(10):963-71.
24. Zwinkels M, Verschuren O, Lankhorst K, Ende-Kastelijin K, Groot J, Backx F, et al. Sport-2-Stay-Fit study: health effects of after-school sport participation in children and adolescents with a chronic disease or physical disability. *BMC Sports Sci Med Rehabil*. 2015;7.
25. Baxendale J, Lockton E, Adams C, Gaile J. Parent and teacher perceptions of participation and outcomes in an intensive communication intervention for children with pragmatic language impairment. *International journal of language & communication disorders*. 2013;48(1):41-53.
26. Anaby DR, Law M, Feldman D, Majnemer A, Avery L. The effectiveness of the Pathways and Resources for Engagement and Participation (PREP) intervention: improving participation of adolescents with physical disabilities. *Developmental Medicine & Child Neurology*. 0(0).
27. Wachs TD. Necessary but not sufficient: The respective roles of single and multiple influences on individual development: American Psychological Association; 2000.
28. Brown CA. The application of complex adaptive systems theory to clinical practice in rehabilitation. *Disability and rehabilitation*. 2006;28(9):587-93.
29. Willis CE, Reid S, Elliott C, Nyquist A, Jahnsen R, Rosenberg M, et al. 'It's important that we learn too': Empowering parents to facilitate participation in physical activity for children and youth with disabilities. *Scandinavian journal of occupational therapy*. 2017:1-14.
30. Shikako-Thomas K, Kolehmainen N, Ketelaar M, Bult M, Law M. Promoting leisure participation as part of health and well-being in children and youth with cerebral palsy. *Journal of child neurology*. 2014;29(8):1125-33.
31. Tatla SK, Sauve K, Virji-Babul N, Holsti L, Butler C, Van Der Loos HF. Evidence for outcomes of motivational rehabilitation interventions for children and adolescents with cerebral palsy: an American Academy for Cerebral Palsy and Developmental Medicine systematic review. *Developmental medicine and child neurology*. 2013;55(7):593-601.
32. Henderson S, Skelton H, Rosenbaum P. Assistive devices for children with functional impairments: impact on child and caregiver function. *Developmental medicine and child neurology*. 2008;50(2):89-98.
33. Willis CE, Reid S, Elliott C, Rosenberg M, Nyquist A, Jahnsen R, et al. A realist evaluation of a physical activity participation intervention for children and youth with disabilities: what works, for whom, in what circumstances, and how? *BMC pediatrics*. 2018;18(1):113.
34. Timmermans S, Tavory I. Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory*. 2012;30(3):167-86.
35. Chinn PL, Kramer MK. *Theory and Nursing Integrated Knowledge Development* 1999.

36. Elo S, Kyngäs H. The qualitative content analysis process. *Journal of Advanced Nursing*. 2008;62(1):107-15.
37. Hutzler Y, Sherrill C. Defining adapted physical activity: international perspectives. *Adapted physical activity quarterly : APAQ*. 2007;24(1):1-20.
38. Guba EG. Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Technology research and development*. 1981;29(2):75-91.
39. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today*. 2004;24(2):105-12.
40. Goodwin DL, Lieberman LJ, Johnston K, Leo J. Connecting through summer camp: Youth with visual impairments find a sense of community. *Adapted physical activity quarterly : APAQ*. 2011;28(1):40-55.
41. Willis C, Girdler S, Thompson M, Rosenberg M, Reid S, Elliott C. Elements contributing to meaningful participation for children and youth with disabilities: a scoping review. *Disability and rehabilitation*. 2016:1-14.
42. Sansone C, Thoman DB. Maintaining activity engagement: individual differences in the process of self-regulating motivation. *Journal of personality*. 2006;74(6):1697-720.
43. KristÈn L, Patriksson G, Fridlund B. Conceptions of Children and Adolescents with Physical Disabilities about Their Participation in a Sports Programme. *European Physical Education Review*. 2002;8(2):139-56.
44. Palisano RJ, Chiarello LA, King GA, Novak I, Stoner T, Fiss A. Participation-based therapy for children with physical disabilities. *Disability and rehabilitation*. 2012;34(12):1041-52.
45. Law M, Darrah J. Emerging therapy approaches: an emphasis on function. *Journal of child neurology*. 2014;29(8):1101-7.
46. Heah T, Case T, McGuire B, Law M. Successful participation: the lived experience among children with disabilities. *Canadian journal of occupational therapy Revue canadienne d'ergotherapie*. 2007;74(1):38-47.

Table 1 Sample characteristics

Child	Gender	Age (year)	Diagnose/mobility*	Personal assistant	Number of stays at BHC
Håkon	boy	13	CP/walking	No	2
Erik	boy	12	Spina bifida/walking	Yes	3
Morten	boy	11	CP/wheelchair	Yes	2
Kristin	girl	10	ADHD + epilepsy/walking	No	1
Hilde	girl	12	Spina bifida/wheelchair	No	1
Heidi	girl	13	CP/walking	Yes	1
Sondre	boy	13	Syndrome/walking	No	3
Atle	boy	10	Neuromuscular disorder/ wheelchair outside	No	2
Ida	girl	12	CP/walking	No	2
Martin	boy	13	CP/wheelchair	Yes	1
Ane	girl	11	Spina bifida/wheelchair	No	1

*= Mode of mobility

Table 2. Example of content analysis including data extraction, reduction, and interpretation

Verbatim text	First extraction of opposite phrases	Second extraction of keywords and phrases	Constructs according to the fPRC framework	Conceptual theme
<i>“Here I get to try out many different things. We can try almost anything we want. It is such a good place to learn something new. And it's good that you can show things to others. I can certainly do something that the others cannot so well, like climbing and cycling, for example. Then they look at me and we learn from each other.” (Sondre)</i>	Try almost anything, good place to learn, you can show things to others, and learn from each other	Good place to learn and show others how to do things	Context Activity competence	To learn and to show new activities to others
<i>Oh, yes, that's great fun, and it goes really fast!! Me and my dad learnt it last time we were here at the center. Now we are training once a week, and then we go to play tournaments. My brother sometimes comes with us, and Iver, that's my friend, you know. He also joins even if he doesn't have a wheelchair. He can borrow one, but not as cool as mine, though. I have a special wheelchair just for power-hockey. Have you ever tried power-hockey?!? (Morten)</i>	That's great fun, me and my dad learnt it last time we were here. Now we are training once a week. Iver, that's my friend, He also joins even if he doesn't have a wheelchair. I have a special wheelchair	It's fun and I learned it last time at the centre, now training at home with a friend in a special wheelchair	Involvement Activity competence Context	Transfer to the local environment at home