



Adaptation for participation!

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To cite this article: Berit Gjessing, Reidun Birgitta Jahnsen, Liv Inger Strand & Eli Natvik (2017): Adaptation for participation!, Disability and Rehabilitation: Assistive Technology, DOI: [10.1080/17483107.2017.1384075](https://doi.org/10.1080/17483107.2017.1384075)

To link to this article: <https://doi.org/10.1080/17483107.2017.1384075>



Published online: 09 Oct 2017.



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ORIGINAL RESEARCH



Adaptation for participation! *Children's experiences with use of assistive devices in activities*

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ABSTRACT

Purpose: To explore children's experiences with testing, acquiring and using assistive devices.

Methods: Nine children (six boys, three girls, 9–12 years old, with different physical disability and activity experience, participated in semistructured interviews. The interviews were audio-taped, transcribed and analysed using Systematic text condensation.

Results: Assistive devices were reported to contribute to cope activities that the children otherwise would not have participated in. Several subjects listed the need for a shielded environment when adapting to new equipment. The children highlighted "independence in activities" and "having the opportunity to participate in activities with family and friends" as important for frequent use. Need for assistance and lack of localizations to perform the activities were listed as reasons for less frequent use.

Conclusions: This study reveals that it is useful to map each child's opportunities for independency, appropriate locations for performing the activity and participation with friends, when considering obtaining assistive devices.

ARTICLE HISTORY

Received 30 November 2016

Revised 11 September 2017

Accepted 20 September 2017

KEYWORDS

Assistive device; children; disability; adapted physical activity; participation; qualitative

► IMPLICATIONS FOR REHABILITATION

- The use of assistive devices gives many children with physical disabilities the opportunity to participate in physical activity.
- Improving availability to assistive devices for physical activity should be a priority to help facilitate participation.
- Having opportunities to develop perceptions of competence may be essential for a child's long term participation in physical activity.

Introduction

The health benefits of being physically active are many, including physical fitness, improved quality of life and less risk of developing secondary health problems [1–4]. People with physical disabilities, children included, are less physically active than the population in general [5,6]. Physical activity early in life is important for having a physically active lifestyle as an adult [5,7]. Intrinsic motivation and identifying as a physically active person is considered important for choosing to be physically active, while impaired mobility and low physical function are factors that correlate with a low level of physical activity [8,9]. Intrinsic motivation is when you do something because you find it interesting or fun, while extrinsic motivation is doing something to achieve a desired outcome (i.e., lose weight or receive a reward), satisfy external requirements or get approval from others [10]. If intrinsic and extrinsic motivation is seen on a continuous line from one end to the other, most people are somewhere in between, dependent on the actual activity, the situation and the context [10].

The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) is a classification system of health and health-related components [11]. Health, function and disability are understood as a mutual interaction between body functions and –structures, activities, participation

and environmental and personal factors. Our understanding of the terms *activity* and *participation* is in line with the definitions given in the ICF; *execution of tasks and activities* and *involvement in a life situation*, respectively. The term participation has received considerable attention in the ICF-CY, because of the major development occurring in this component during the first two decades of life [11]. Children go from a close relation to one or a few people and environments early in life, to interaction with several people like relatives, peers, teachers, instructors and friends in an increasing number of environments as they get older.

Participation in activities for children with disabilities has been explored in a large survey in Norway including 300 parents of 3–12-year-old children, and in interviews with 31 parents and employees at kindergartens and schools [12]. It was concluded that many children experience challenges with social participation, including leisure activities. This seemed to be due partly to not mastering the same activities as their peers, leading to a lower rate of attendance in community activities. These activity limitations were largest when the children were 9–10 years old [12].

The importance of the environmental factors for participation is highlighted in an increasing number of scientific articles [13–16]. Real-life experiences facilitate individuals to develop skills that optimize their participation. Lack of suitable equipment is one of the several reasons for low activity levels [5,6].

Assistive devices for leisure activities is equipment that is specifically designed to help people with disabilities to participate in play and sports [17]. Examples are sit-ski, arm-cycle, bike with assistive motor, motorized chair for floor ball and frame for cross-country skiing. These technical aids belong in the “environmental factors” domain in the ICF classification [18].

To our knowledge, there is a lack of studies capturing experiences with assistive devices in activities both for children and for adults. Kurtze and Hem [19] conducted a systematic review and interviews with key employees within deliverance and adaptation of assistive devices in Scandinavia. However, their understanding of assistive devices was broad and included devices for sensory loss, cognitive impairment and mental health as well as for physical disabilities. Assistive devices for leisure activity were not mentioned in the study. The authors stated that there is little research on this topic and that the quality of the existing research is of varying quality. Furthermore, few qualitative studies on children are conducted with the children themselves [20]. Many studies have interviewed adults who know the children well, for example, parents or teachers, to gain knowledge about the children’s world, but the children’s own voice in expressing their lived experiences is scarce.

In this study, we aimed to explore and describe children’s experiences with the use of assistive devices in leisure activities, including feelings of mastery, inclusion with peers in activities and feelings related to different-looking equipment. The overall aim is that dissemination of such experiences will contribute to increased competence among parents and health professionals about the challenges and benefits of using assistive devices in leisure activities. Increased competence may contribute to more focus on how to succeed in adapting and using this equipment and eventually lead to increased meaningful participation in physical activity among children with physical disabilities.

Methods

Design

A retrospective qualitative design was applied, using semistructured interviews [20] to generate knowledge on the impact of environmental factors, here assistive devices, for participation in physical activities for children with disabilities. The authors designed an interview guide with open-ended questions like “When do you use your bike?” and “Tell me what it means to you to have this bike”. The language was adapted so that children should understand the meaning of the questions, as recommended by Kortessluoma [20]. Adapting the language and conducting a pilot interview on one child contributed to trustworthiness in the study.

Participating children

Participants were recruited from Beitostolen Health Sports Centre (BHC), which is a rehabilitation centre offering publicly funded,

secondary rehabilitation stays to children, adolescents and adults with disabilities. Adapted physical activity is the main rehabilitation tool, including compensatory adaptations to reduce disabling barriers in the environment. Part of the philosophy of the rehabilitation programme is to ensure continued physical activity after discharge. For many people, this includes environmental adaptations, such as the use of assistive devices. Professionals at BHC recruited a purposive sample of children. Inclusion criteria were age 9–12 years (this is when activity in the same environment as peers often becomes more challenging), at least six months experience with having an assistive device for use in leisure activities, and ability to understand and respond adequately to questions. Children with different age, sex, physical functioning and experience with using assistive devices for activity were included to facilitate credibility and transferability [21]. In total, 11 children met the inclusion criteria and were asked to participate. Two children did not want to participate. One of them gave no reason while the other believed that he had little relevant information since he scarcely had used the equipment.

The participants had access to the following assistive devices for use in leisure activities; five tricycles (some with an assistive motor), four bikes with training wheels and an assistive motor, two tandem bikes (two or three wheels, with or without an assistive motor), three sit-skis for cross country skiing, one frame for cross country skiing, two sit-skis for downhill skiing and two motorized chairs for floor ball (Table 1).

Data collection

The first author (B.G.) conducted face-to-face interviews with each participant, without their parent present. The interviewer had met the children once before, informing the child and parent about the study. The interviews were conducted in a quiet room at BHC, with no disruptions, and were digitally recorded. Each interview lasted for approximately 30 min. The data collection was done with an inductive approach, where the children’s knowledge and experiences were in focus. The participants were asked about the following themes:

1. Motivation for physical activity in general (2 items)
2. Self-assessment of social belonging (3 items)
3. Self-assessment of physical functioning (2 items)
4. Experience of getting and using assistive devices (6 items)
5. Significance of having assistive devices (3 items)

The priority was to identify the participants’ experience of using an assistive device in the context of their everyday lives, for instance “tell me about the last time you used your bike”. The researcher who conducted the interviews had extensive experience and well-developed skills in facilitating conversations with children, in the same context as the interview took place. Control questions were asked to ensure that the children answered in relation to what the researcher meant to ask them about, and that the researcher understood what the children intended to

Table 1. Characteristics of the participants (names are made up).

Child	Years	Sex	Place of living	Mobility ^a	Assistive device(s)
Tyler	12	Boy	City	1	Bike with training wheels and assistive motor.
Emma	9	Girl	City	2 + 3	Bike with training wheels and assistive motor, sit-ski (cross country), chair for floor ball.
Eric	10	Boy	City	2	Tricycle, sit-ski (cross country).
Victor	10	Boy	City	3	Tricycle with assistive motor, tandem bike, sit-ski (downhill), chair for floor ball.
David	9	Boy	Small city	1	Bike with training wheels and assistive motor, frame for cross country skiing.
Thomas	11	Boy	Small city	1	Tricycle with assistive motor, tandem bike, sit-ski (cross country).
John	10	Boy	Rural	1	Tricycle with assistive motor, sit-ski (downhill).
Sarah	11	Girl	City	1	Tricycle.
Claire	9	Girl	Rural	1	Bike with training wheels and assistive motor.

^a1 = Walking without assistive devices (some with ankle orthoses).

2 = walking with assistive device, 3 = using manual wheelchair.

convey. One example is "To make sure that I understood you correctly; you said that using your bike makes it possible for you to participate in biking activity together with your classmates?" This method increased the level of credibility and trustworthiness of the study [21].

Data analysis

The recordings were transcribed verbatim and de-identified by the first author (B.G.). The transcribed interviews were analysed using an inductive approach, searching for new knowledge about a previously underexposed topic. The analyses were carried out using Systematic text condensation [22]. This is a descriptive method for thematic analysis of qualitative data and consists of four steps: (1) total impression; (2) identifying and sorting meaning units; (3) condensation; (4) synthesizing. The first author had the main responsibility for the logistics and the progress of the analysing process, but the whole research group contributed in each of the four steps. Several perspectives on the same data material, contribute to increased credibility of the findings [21]. Reading through the interviews gave a total impression. Meaning units from each interview were identified and coded into appropriate groups with the headings *confident or a bit sceptic*, *acceptance of different physical functioning and assistive devices for activity* and *independence equals opportunity to participate*. Then, meaning units within the same group were divided into subgroups, and statements that resembled each other were put together and reformulated to artificial quotes. These artificial quotes were then gathered and rewritten into a continuous text, and direct quotes from the children were used to illustrate the analysed text. A last theme "motivation" was lying under and covering the three other themes, as this theme could fit in all the other themes. Therefore, "motivation" was not analysed as a separate theme, even though different aspects of motivation are prominent in the data analysis. During the analysis process, members of the research team discussed titles and content in different subgroups, in order to include a variety of perspectives. To ensure trustworthiness, we searched to find statements from the children that referred to the aim of this study.

Ethics

Regional Committee for Medical and Health Research Ethics approved the study (ref.nr.: 2012/1076/REK vest). Prior to the interviews, all participants and their parents were informed about the aim of the study, how the interview would be conducted, and how the results would be used. They were assured that the results would be presented without single persons being identifiable and that they could withdraw their consent to participate at any time, without any explanation. Both parents and children gave written informed consent. While conducting the study the interviewer had a child-centred approach, and each child's well-being was in focus. Analyses were conducted while focusing on representing the children's views justly, which is a factor to ensure trustworthiness. Since several of the participants had rare diagnoses and could be recognizable, each child's diagnosis is not linked to age and gender in the presentation of demographic information.

Results

Interviewing the children gave varied information about obtaining, having and using assistive devices for physical activity. The participants seemed delighted that an adult was interested in their opinions. For the most part, the children seemed eager to talk about

their assistive devices. However, a couple of the children answered with few words, and needed follow-up questions to provide more complete answers. Some did not remember much, especially from obtaining their equipment. Most children willingly told stories about using their equipment, some more detailed than others.

Analysis of the interview transcripts revealed three overarching themes:

- Confident or a bit sceptical?
- Acceptance of different physical functioning and assistive devices for activity
- Independence equals opportunity to participate

The following sections report the findings relative to each theme. The quotes were translated into English by the first author, and then discussed with the research team and a native English speaking colleague, to ensure that the participants' statements were properly quoted.

Confident or a bit sceptical?

When it comes to testing new and novel assistive devices, the group of children was ambiguous in their opinions. Six of the participants were sceptical about using one of their new equipment when they tried it the first time. For instance, John expressed:

I had an accident when I was younger, I rode into the ditch! So I was concerned about how fast the bike with the assistive motor would run.

Albeit speed was a bit frightening for a couple of the biking children, it was also an important motivational factor for all the children. The feeling of wind in their face was most of all exhilarating. Victor, who used his sit-ski in holidays and some weekends during the winter, explained:

In my sit-ski I think I'm running in 50 km/h! We are down in no time! Then I feel more wild and alive, than when I sit in my wheelchair.

Four of the children told that it took them some time to get used to the speed, for instance on a tandem bike, a bike with an assistive motor or a sit-ski for down-hill skiing. On the other hand, Thomas, who had much and varied activity experience, talked about trying his new sit-ski for cross country skiing to be unproblematic:

It was quite obvious how I would use it. I could just test it together with my dad.

David was used to ride a bike with three wheels, but his father challenged him to learn to ride on a two wheeled bike (with an assistive motor), because it was better balance training. Claire also said that dad made her try activities and equipment that she was sceptical about trying and that she got a reward when she dared to try.

Even though feelings of trying out novel assistive devices were different among the children in this study, all of them had at some point become comfortable with using their equipment and expressed satisfaction using it.

Three of the children told that they were motivated by role models, often older persons, who managed the same assistive device as they were learning to use. One example is John, who was learning sit-ski together with his father in the alpine hill, and who watched and was inspired by an adolescent with the same disability as himself managing the sit-ski on his own:

I was on the alpine slopes together with another guy who also uses a wheelchair. And he's very good at sit-ski. I observed how he used his crutch skis when performing downhill turns. That was how I learned to do it.

Acceptance of different physical functioning and assistive devices for activity

Four children spoke openly about being a bit different and having different needs than their peers. Some could not participate in ballgames and other activities with high intensity. They accepted that they did not have the same physical skills as their peers, but they had a wish to have opportunities to be together with their friends in activity. Victor said:

I is difficult to play soccer with my classmates. But that is ok. They know that I am a bit different. And I can be the referee or commentator!

None of the children in this study talked negatively about their equipment, even though it looked different. Eric, who used his bike regularly at school, said:

I think my bike is cool. It's not like the others tease me and stuff, because they know why I have it.

Victor saw some positive sides of having the special equipment:

The advantage of having this disease and using a sit-ski is that I can come first in the lift queue. Jumping the queue is allowed!

Independence equals opportunity to participate

The children had most experience in using their assistive devices together with family members. This was both due to the need many of them had for assistance and that the equipment was used in natural family activities, such as biking, and downhill and cross country skiing. David, who rarely goes cross country skiing told about when he had to go the long track even though he did not want to:

All the others wanted to go the long track, so I had to join. I got a bit mad for a while. But it was good to come in to the TV afterwards. And I think I lost some weight!

On the other hand, motorized floor ball chairs were exclusively used with peers, and many also used their bikes (especially those with an assistive motor) together with friends. All of the children highlighted the importance of the opportunity to be independent in activity. Six of them, who were dependent on others to use their assistive devices, reported it to be a barrier for using the equipment. For those who were independent while using their equipment, it gave them opportunity to participate with friends in leisure activities. The children expressed joy and said that use of assistive devices with friends were one of the best aspects about using the equipment. For example, Sarah, who used her bike daily, said:

I love using my bike because I can be with my friends, and I think it's cool to be with them!

Six of the children pointed out that some activities could not have been done without their assistive devices, especially floor ball and sit-ski. Three of them had participated in the process of applying and trying out the equipment and were very happy to get one. For example Emma, who said "Yes!" and punched both her arms in the air. She was happy to join the others in activity, instead of just watching.

The most important factor that motivated the children to use their assistive devices in leisure activities was being with friends and sharing experiences with them. All interviewed children had experienced the feeling of not being able to keep up with peers in activity. Four of them had even stopped participating in

organized leisure activities like soccer. For some, the feeling of mastering an assistive device to keep up with others was the best feeling of all. Tyler said:

I was biking to school with my classmates. It was uphill and some of them had to walk. I had to use the motor while I was pedaling, but I managed to follow the fastest boys to the top!

All of these three themes contain many examples of different aspects that motivate the children to be active with their assistive devices. Some are examples of extrinsic motivation, like children who go cross country skiing with their family to satisfy external requirements (mum told him to join) and to lose weight, children who get rewarded for trying new equipment or the boy who tried a two wheeled bike because dad said that it was better balance training. There are also many examples of intrinsic motivation, like Victor who found it interesting to be a referee or commentator on the soccer-field, Sarah and Tyler who could enjoy being with their friends while biking, or Victor that found it fun to feel the high speed when using his sit-ski.

Discussion

The aim of this study was to explore experiences of children with disabilities when using assistive devices in leisure activities. The interviews revealed many positive experiences from using assistive devices, especially when mastering the equipment independently together with friends. Still, some children were initially sceptic to the activity or to the assistive device, because they had previous experiences of not mastering the activity, or they were uncertain of how the equipment worked. These children may have started trying the new assistive devices with low self-efficacy (belief in own ability to perform actions), which is an extra challenge when trying to learn new skills [23]. In such situations, children can benefit from favourable environmental factors, such as extra time to practice in a safe environment, with expert professionals and preferably also role models. Such opportunities, like some of the participants had experienced during a rehabilitation stay at BHC, gave time to try out the novel equipment over some time, with role models present, so that the children had mastery experiences before returning to peers in their local environment. Since lack of suitable equipment is one of several a reasons for low activity level [5,6], it is important that professionals focus on this essential environmental factor when working with patients in a phase in life where participation with an increasing number of people is of great importance [11]. It may also enhance self-efficacy to watch others learning, someone that you can compare yourself with, in order to master the same type of activity [24]. An example of peer learning is John, who was inspired to improve his sit-ski skills when he watched an adolescent with the same disability as himself run down the hills. The result was an opportunity for John to participate both with his role model and, after returning back home, with his friends in the local alpine slope.

The children's acceptance of their need for assistive devices, and their possibility to be independent in activity, gave them a possibility to participate actively with their friends. Six of the children in the study ascertained that a well-adjusted assistive device was essential for their opportunity to undertake an activity. Heah et al. demonstrate that it becomes more and more challenging to keep up with peers in physical activity, as the children grow older [15]. At the same time, ICF-CY states that participation in the first two decades of life is of great importance [11]. Most children in this study had experiences with not keeping up with peers. As they grow older, comparison with peers will most likely be more and more important, which may lead to the children feeling more

isolated. In the treatment of children with physical disabilities, there is now more focus on the importance of identifying each child's functions and skills and build on these in the treatment [13,14,16]. Darrah and colleagues describe "context therapy" as a suitable approach in the treatment of children with cerebral palsy. The method is characterized by not focusing on changing the child's impairment, but rather on facilitating the task and/or adapting the environment, so that the task can be implemented with success. This method has similarities with adapted physical activity, where the purpose is to adapt activities and environments to the children's conditions [25].

The children had more experience with participation in leisure activities together with family than with friends. ICF-CY points out that the children are dependent on their family the first years of their lives. They are the most important facilitators for both social interaction and activity. When children turn 9–10 years old, it becomes increasingly more important to join peers and "significant others", at the expense of immediate family [26–28]. It has been shown that children with disabilities participate less frequently and have less environmental support in the community, compared to children without disabilities [5,12]. At the same time, it is clear that support from peers promotes participation [27,29]. Children with disabilities, who are less physically active with friends, do not get the advantage of peer support to join activities, and they do not participate as much in environments where friendships are developed. However, those who do participate with friends, have even better opportunities for peer support that might lead to even more activity.

The children made it clear that motivation for the activity was essential for a positive and meaningful activity session. Assistive devices were one of several environmental factors that often contributed to increased motivation among the participants, both because the activity became more enjoyable, and because being active lead to other positive aspects, like the opportunity to participate with peers. Heah et al. [15] found that experiencing joy, preferably with friends, was the most motivating factor for children to participate in physical activity. In this study, we found several examples of that, for instance Sarah, who wanted to use her adapted bike in order to join friends biking. She started using her novel equipment, because she then expected a positive result; that the others would include her in the activity. Situations such as this are described by Bandura as outcome efficacy [30], where motivation depends on whether the result of the action performed is what one wishes to achieve.

According to Deci and Ryan, we can distinguish between intrinsic and extrinsic motivation [10]. The data in this study show examples of both. For instance, those who used assistive equipment because peers expected them to join or to be rewarded from parents were extrinsically motivated. Examples of intrinsic motivation are the children who used their assistive devices in leisure activities because of the nice feeling of high speed or mastering an activity or simply because they liked it, especially in situation when being with friends. Intrinsic motivation is found to be the only type of motivation that can be associated with children's physical activity levels [9]. Since it is important to maintain physical activity from childhood and youth into adulthood [5,7], it's beneficial to identify and encourage activity behaviour that is driven by intrinsic motivation.

Limitations of the study

All participants were recruited from the same rehabilitation centre. However, factors that increase the credibility of the study are that the children represent a wide range of experiences with use of

assistive devices in leisure activities in their local communities. They also come from both urban and rural areas of Norway. Some information might be absent, since children who were not able to communicate verbally were excluded from the study, and since one child who had used his/her equipment very little, chose not to participate. In addition, those who were included might have omitted relevant information, telling what they thought the interviewer wanted to hear. A pilot interview to ensure well-adapted questions to children, and use of follow-up questions were efforts that encouraged the participants to share their experiences, in order to increase trustworthiness of the study.

The participants of this study were living in Norway. The transferability of the study results may be questioned as the need and possibilities for having access to and using assistive devices in activity may differ between countries.

Conclusions

This study of nine children with disabilities revealed varied, but positive experiences of using assistive devices in leisure activities. Although some needed extra time to get used to their novel equipment, assistive devices helped them master and participate in activities they would not otherwise have managed. The opportunity to be independent in activity was important to them, much more important than to participate with the same looking equipment as others. The most motivating factor for using assistive devices was the possibility of being included in activities with peers. Keywords like time to get used to new equipment, opportunity to be independent and possibility to participate with peers seems to be essential in health professionals' work on choosing, adapting and teaching children how to use assistive devices for leisure activities. The experience of accomplishment and enjoyment in activity during childhood and adolescence, may contribute to a more active lifestyle into adulthood.

Acknowledgements

The authors thank the children who participated in the study and the employees at Beitostolen Health Sports Centre who contributed with the recruitment of participants.

Disclosure statement

The authors report no declarations of interest.

Funding

Authors thank The Norwegian Fund for Post-Graduate Training in Physiotherapy, for funding the research and writing of this article.

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