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ORIGINAL ARTICLE



'It's important that we learn too': Empowering parents to facilitate participation in physical activity for children and youth with disabilities

Claire E. Willis^a , Siobhan Reid^a, Catherine Elliott^{b,c}, Astrid Nyquist^d, Reidun Jahnsen^d, Michael Rosenberg^a and Sonya Girdler^b

^aSchool of Sport Science, Exercise and Health, The University of Western Australia, Perth, Australia; ^bSchool of Occupational Therapy and Social Work, Curtin University, Perth, Australia; ^cPaediatric Rehabilitation and Research, Child and Adolescent Health Service, Perth, Australia; ^dDepartment of Research, Beitostolen Healthsports Centre, Beitostolen, Norway

ABSTRACT

Aim: The actions and behaviors of parents have been identified as key factors that influence a child's participation in physical activity. However, there is limited knowledge of how parents can be supported to embody facilitative roles. This study aimed to explore how an ecological intervention encourages parents of children with disabilities to develop as facilitators, to enable ongoing physical activity participation in a child's local environment.

Methods: A qualitative design using grounded theory was employed. Forty four parents (26 mothers, 18 fathers) of 31 children with a range of disabilities (mean age 12y 6m (SD 2y 2m); 18 males) partaking in the Local Environment Model intervention at Beitostolen Healthsports Centre in Norway participated in the study. Data were derived from the triangulation of semi-structured interviews and participant observation. Data analysis was an iterative approach of constant comparison, where data collection, memo writing, open, axial and selective coding analysis, were undertaken simultaneously. Findings were consolidated into a model describing the central phenomenon and its relationship to other categories.

Results: Thematic concepts uncovered in this study describe a social process of parent learning and empowerment, comprising three primary components; (i) active ingredients of the intervention that enabled learning and empowerment to transpire, (ii) parent learning and empowerment as a process, and (iii) related outcomes.

Conclusion: A family-centered approach, encompassing family-to-family support, may enhance physical activity participation outcomes for children and youth with disabilities.

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family-centered; participation; environment; social learning; empowerment; cerebral palsy

Introduction

Participation in physical activity is necessary for the optimal physical, emotional, and psychosocial development of all children and youth. The experience of participation is influenced by child and family interests and priorities, and optimized by experiences that foster a child's engagement, connections with others, learning and skill development, and enjoyment [1]. Yet for children and youth with disabilities, it has been reported that 76% to 99% of their waking hours is spent in sedentary activity [2], and participation in physical activity is significantly less than their typically developing peers [3,4]. Alarming, the prevalence of obesity in children with disabilities has been documented to be up to six times higher than typically developing children [5]. An urgent call for action has recommended that research focus on developing physical activity promotion strategies across the lifespan,

and build an evidence base supporting the development of effective interventions [6,7]. Of particular importance is the development of approaches that enable the translation of practices acquired from interventions into sustained participation and lifelong habits [6].

The International Classification of Functioning, Disability and Health-Child and Youth version (ICF-CY) is frequently used to conceptualize the barriers and facilitators of participation in physical activity for children and youth with disabilities [8]. Systematic reviews document that factors across all levels of the ICF-CY influence physical activity for children with intellectual and physical disabilities [9,10]. The actions, behaviors and concerns of parents have specifically been identified as both barriers to and facilitators of physical activity [9,10]. While more barriers to participation are evident, there are a number of

identified supports that enhance a child's physical activity participation, including; the presence of parental support and motivation, participating in physical activity as a family, parents creating opportunities for their children to be active, and parental perseverance and assertiveness in advocating for a child's participation in physical activity [9,10]. As parents make up the immediate environment of a child and play the most influential role in their development and well-being [11], interventions attempting to optimize physical activity participation may be required to be family-centered.

Family-centered theory underpins many models of pediatric service delivery, recognizing and acknowledging the needs of all family members and not just those of the child with a disability [12,13,14]. Key principles of family-centered services are that families are central to the child's life and are the primary source of support, approaches are competency enhancing and strength-focused, and there is facilitation of family-to-family support and networking [14,15]. Despite the wide acceptance of the importance of family-centered approaches to health and functional outcomes of children with disabilities [13], few studies have examined the effectiveness of interventions founded on this theory to improve physical activity participation outcomes in children and youth [16,17]. In typically developing children, most evidence of effective physical activity interventions comes from those targeted at families [18]. While the development of facilitative parents has been proposed as a strategy that may improve participation outcomes for children with disabilities [19,20], our knowledge of how rehabilitation therapists can enable parents to embody facilitative roles is lacking.

An assumption of participation-based therapy is that the empowerment of families enables them to advocate for the full inclusion of their children in society [1]. Empowerment at an individual level refers to perceptions of personal control, participation with others to achieve goals, and an awareness of the factors that impede or enhance efforts to exert control in one's life [21]. Empowerment can be viewed both as a process (including actions, activities, and structures), and as an outcome, encompassing intrapersonal, interactional, and behavioral components [22]. While studies have focused on characteristics of the child and family that lead to a sense of empowerment in parents [23,24], there is limited research examining the influence of service or intervention-related factors on this outcome.

Understanding how an intervention triggers change is an essential component of the evaluation process [25].

The identification of active ingredients and understanding how they exert their effect is required for the design of more effective interventions, and to enable their application across settings [26]. Beitostolen Healthsports Centre (BHC) is a rehabilitation center in Norway, seeking to enable lifelong activity and participation in local environments for people with disabilities. The pediatric program (the Local Environment Model, LEM) is a goal-directed, family centered intervention that enables children and youth with disabilities to participate in physical activities in their local communities [17]. The family-centered context of the LEM attempts to ensure that knowledge, skills and experiences of children and caregivers acquired during a stay at BHC are translated into family lifestyles and local settings following the intervention. This is driven by a derivative of situated learning theory known as 'Communities of Practice' [27]. Parents of children with disabilities from the same municipality are actively engaged in the preparation, intervention and follow-up stages of service delivery, connecting through mutual engagement, a joint enterprise and a shared repertoire [27]. Given the multiple components of this intervention, the original question of this study was broad and unassuming [28], asking 'how do parents experience the LEM?' As the research progressed, and parents described a process of evolving as facilitators, the research question gradually became more focused [28]. Subsequently, this study aimed to explore how the LEM encourages parents to develop as facilitators of a child's participation in physical activity.

Methods

Design

A grounded theory approach was used for this study. Grounded theory has a realist orientation and is intended to produce knowledge of processes [28,29]. The full version of grounded theory [29] was utilized in this study, and sources of data were derived from ethnographic data collection methods, including semi-structured interviews and participant observations. Grounded theory and ethnography are highly compatible, in that ethnographic studies can provide a thick description of data that is required for grounded theory analysis [30,31]. Through application of these methods, we described the process that enabled parents to adopt roles as facilitators of their child's participation in physical activity.

Ethics approval for this study was obtained from the Princess Margaret Hospital Human Research

Ethics Committee (2013099), The University of Western Australia (RA/4/1/6556), and the Norwegian Regional Committee for Medical and Health Research Ethics, section South-East C (2014/1342-1).

Participants

Purposive and theoretical sampling was used to select participants for this study. In phase one of data collection, participants were selected to participate if they were (i) the accompanying guardian and (ii) the primary caregiver of a child participating in the LEM intervention at BHC (children participating in the LEM are 5–17 years of age and typically have a range of disabilities). Primary caregivers who met the inclusion criteria were first informed about the study by the Director of Paediatric Teams, and received an information sheet that had been translated into Norwegian. In phase two of data collection, participants were theoretically sampled to refine emerging categories relating to how participation in physical activity was, or would be, maintained following the intervention. Theoretical sampling ceased upon reaching theoretical saturation, when no new properties of the categories were identified [32].

Description of intervention

The LEM is an intervention developed by BHC that focuses on enabling participation in physical activity for children and youth with disabilities. The inclusion criteria of the LEM are broad and nonspecific. The LEM is intended for children and adolescents aged 5–17 years with activity limitations and participation restrictions (at home, school or in the community) identified by a medical practitioner. Children do not need to have a formal diagnosis to receive this service.

One month prior to the program, representatives from BHC travel to the community of the group of families coming to stay, to prepare and engage local communities in the service delivery cycle. The intervention is delivered at BHC, where groups of 8–10 children and their parents stay for 19 days. The intervention is based on the child's goals, but also designed to introduce children and their families to novel physical activities and participation experiences. The children's stay is intensive; activities are scheduled for 2–5 hours a day, six days a week.

At BHC, parents participate in the 'Parental Guidance Program', to learn how to facilitate their child's participation in their home and community. Additionally, a short training course (optional) is provided to service providers involved with the child in their local communities to encourage environmental adaptation and collaborations between service providers from the same municipality.

Three months after families return to their local communities, the same field team travels back to the community for a follow up meeting with children, their parents, service providers, and the region's representative from the Norwegian Confederation of Sport. This meeting is used to map each child's progress towards achievement of their follow up plan, and discuss any barriers and facilitators families may be experiencing, which will continue to be followed up by local communities. The second objective of this meeting is to begin the plan for the child's second stay at BHC that occurs approximately 1.5 years after the first, in the opposite season. The intervention timeline can be seen in Figure 1.

Data collection

The first author spent a total of 15 weeks at BHC undertaking data collection. This occurred over two

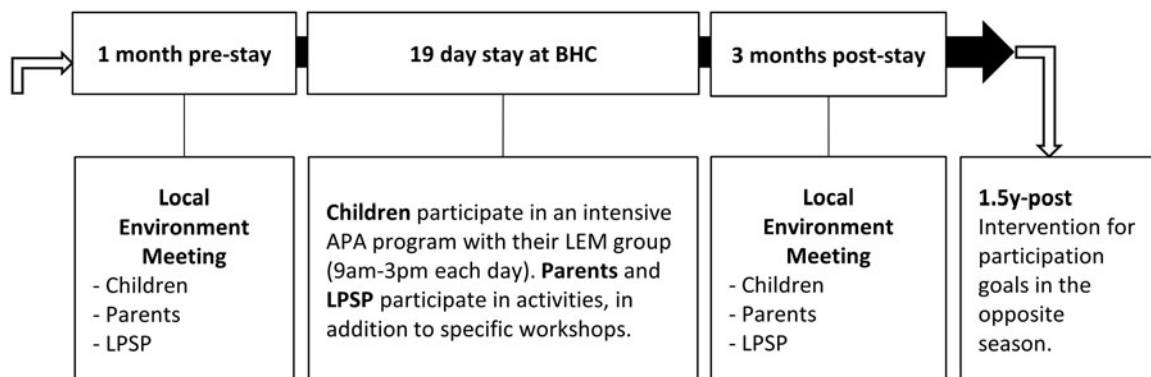


Figure 1. Timeline of the Local Environment Model (LEM) intervention. BHC: Beitostolen Healthsports Centre; LPSP: local pediatric service provider; APA: Adapted physical activity.

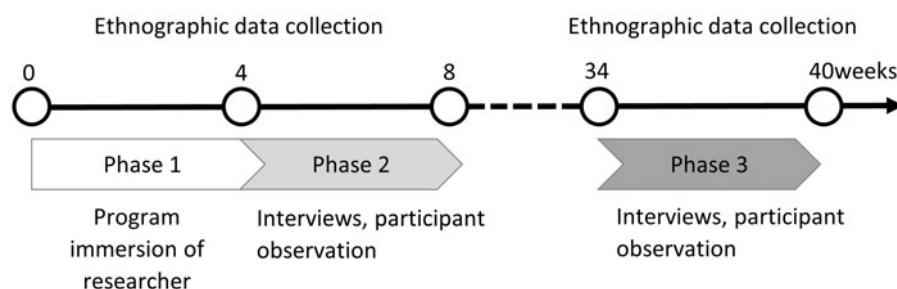


Figure 2. Timeline of data collection in weeks.

separate time periods (summer/autumn and winter/spring). As well as accounting for intervention-specific seasonal differences, this also enabled the researcher to return to the field to validate the theory that emerged from the initial stages of data analysis [28]. The first author lived at BHC during this time, and participated in the daily intervention and leisure practices of parents and children staying at the Centre. Proficiency in the Norwegian language aided in the cultural immersion of the researcher. Data collection involved the triangulation of semi-structured interviews and participant observation, employed over two time points (Figure 2).

Interviews and focus groups

Interview guides were developed in collaboration with a consumer-driven steering group, including parents of children with disabilities. The interview guide was piloted with a manager at BHC to obtain feedback of utility prior to use in data collection. The interview guide covered broad topics relating to the experience of the parents in the program, and was revised when new topics were raised during the interviews. Topics discussed during the interviews with parents at BHC are outlined in Table 1.

The first author, a female researcher proficient at qualitative data collection, undertook all interviews. The interviewer had no relationship to participants prior to their involvement in the LEM. Semi-structured

interviews explored the parents' experience in the LEM, and as it emerged, their role in their child's participation in physical activity. Interviews were conducted with parents at a mutually convenient time in a private meeting room at BHC. Norwegians have a very high proficiency in English [33], thus participants were offered the choice to conduct interviews in Norwegian or English. Most parents elected to undertake interviews in English, with three parents choosing to conduct the interview in Norwegian. As Norwegian is not the primary language of the first author, a translator (MM) was present in these interviews to ensure accurate interpretations.

The first author transcribed each interview from the recordings verbatim. Norwegian interviews were transcribed in Norwegian and translated to English by the first author. Whilst researchers who also act as translators are rare, this method enhances the validity of interpretations as it allows close attention to cross cultural meanings and interpretations [34]. English translations were then back-translated by the translator that was present in the interviews (MM). Approximately half of the interview participants had the opportunity to review their transcribed interview, and made no changes.

Participant observation

During phases 2 and 3, overt observational methods were used to describe and link emerging categories

Table 1. Key topics forming semi-structured interview guide.

Guiding topic	Key prompts
Experiences of participation generally	Reasons for applying for a stay at BHC Expectations of the program Description of experience
Experience in the program at BHC	Influence of service-related factors Influence of the human and physical environment Managing other commitments Recommendations for change
Experience in local communities	Barriers and facilitators (experienced, or perceived) Role of parent/BHC/LEM group Role of local pediatric service providers Outcomes from previous stay (if applicable) For parent/family
Outcomes of the stay	

BHC: Beitostolen Healthsports Centre; LEM: Local Environment Model.

proposed in the interviews to actual parent behaviors during the intervention [35]. Observations of parents in this study occurred in a range of settings; (i), in the local communities of families participating in a stay at the center, during the pre- and post-intervention meetings; and (ii), at BHC, during the intake and evaluation interviews, during structured intervention activities, and periods of informal interactions and communications. Conversational interviews with parents also occurred spontaneously in these settings. Observations of parents at BHC occurred during the hours of their typical day, 8am–8pm.

Detailed field notes were documented following each observation period, containing descriptions of events, conversations and reflections. Alongside this, memo writing throughout the process of data collection maintained a record of preliminary thoughts in relation to observation and interviews, and provided reflections on the adequacy of the research question [36]. Daily contact with participants meant it was possible to check and confirm the meanings of participant behaviors, and adjust or add to the categories and their properties explored in the memos accordingly [36]. Memos were both original and integrative (of earlier memos or ideas), and used both words and diagrams that documented the emerging theory [36].

Data analysis

Interviews

Data analysis was an iterative approach of constant comparison, where data collection, coding and analysis were undertaken simultaneously [30]. NVivo (QSR International Pty. Ltd., 2015) software assisted with handling interview data and field notes. Discussions were transcribed verbatim and constantly compared with field notes and memos. Transcripts, field notes and memos were read multiple times, with this inductive approach allowing meanings to emerge from the data [35]. Initial coding of the interview data was conducted via a grounded theory approach in exploration of emerging categories and their properties [30,32]. Data were coded using an open coding model, with attention to constant comparison between participants [28,30]. Analysis of deviant or negative cases enabled the revision, broadening and confirmation of the patterns emerging from data analysis [37]. During open coding, data were triangulated with observation data to identify additional subcategories and agreement amongst source material [28]. Axial coding was used to group

ideas based on the constituent clusters addressed by participants, with constant comparison of categories and relationships with ongoing additions of ethnographic evidence [28]. Selective coding allowed the detailed development of categories, around the core categories and central phenomenon of the study [28]. The emerging theory guided additional data collection (e.g. new interview topics, such as the role of multiple stays) to support further development of the theory and to reveal discrepancies that needed clarification. As grounded theory suggests, the core category and its unification with other categories directly informed the creation of the model presented in the results section (Figure 3) [36]. One author coded all interviews first and a second author reviewed and checked the coding.

Participant observation

Descriptive and coding analysis of observation data recorded in the form of field notes occurred away from the clinical field, but onsite at BHC. This involved elaborating upon, completing and refining descriptions of fieldwork experiences, reflecting upon the emotional responses of parents, and examining patterns in behavior. Observation data was coded in the same manner as the interview transcripts.

Memos

Throughout the process of data collection and analysis, the first author kept a written record of theory development. This included the exploration of categories, tracing their emergent relationships with other categories, and keeping a record of the progressive integration of higher- and lower-level categories [36]. The memos captured the first authors progressive synthesis of the data as analysis occurred concurrently with data collection [36].

Trustworthiness

A number of procedures were employed to ensure the trustworthiness of these methods. Prolonged engagement, persistent observation and the triangulation of data sources strengthened the credibility of interpretations [38]. Purposive and theoretical sampling enhanced the transferability of the data. Dependability was enhanced by the researcher documenting reflections in memos and demonstrating an audit trail of the research methods [39]. Additionally, emerging and final results were presented to the steering group in Australia as a method of confirmability [39].

Table 2. Participant demographics.

Characteristic	Category	Total
Parent relationship to child	Mother (<i>n</i>)	26
	Father (<i>n</i>)	18
Residential setting of family	Population 500,000–1,000,000 (<i>n</i>)	9
	Population 250,000–499,999 (<i>n</i>)	5
	Population 50,000–249,999 (<i>n</i>)	9
	Population <50,000 (<i>n</i>)	8
Characteristics of children	Age, y:m (SD)	12:6 (2:2)
	Age range, y	6–17
	Gender (<i>n</i>)	
	Male	18
	Female	13
	Child's primary health condition (<i>n</i>)	
	Cerebral Palsy	12
	GMFCS I/II/III/IV/V	5/4/1/1/1
	Acquired brain injury	2
	Intellectual disability ^a	17
	Number of stays at BHC (<i>n</i>)	
	<i>n</i> = 1st	20
	<i>n</i> > 1	11

GMFCS: Gross Motor Function Classification System; SD: standard deviation; BHC: Beitostolen Healthsports Centre.

^aIncluding Down Syndrome, Fragile-X syndrome, and craniosynostosis.

Results

Forty four parents of 31 children participated in the study. All caregivers that were approached were parents, and all agreed to participate. Of the 44 participants, 13 were parent dyads. A total of sixteen mothers and two fathers participated in semi-structured interviews. Of these, 5 were single parents, and 7 of the parents had another caregiver (partner, grandparent, or carer) stay at BHC for one week or more. Family demographics and characteristics of children (*n* = 31) are detailed in Table 2.

The social process of parent learning and empowerment

The thematic concepts uncovered in this study describe a social process of learning and empowerment for parents participating in the LEM. This encompasses three primary components; (i) active ingredients of the LEM intervention that enable learning and empowerment to transpire, (ii) the central phenomenon of learning and empowerment, which refers to the process through which parents gained knowledge, understanding and control over their role as facilitators to their child's participation in physical activity and (iii) outcomes of the process, including how the practices acquired from the intervention continued as a part of family lifestyles in local communities, and the relationship to parent satisfaction with service delivery. Perspectives did not differ between mothers and fathers, and were independent of the age, gender and disability type of children. The process and outcomes of parent learning and empowerment are described in detail below and illustrated in Figure 3.

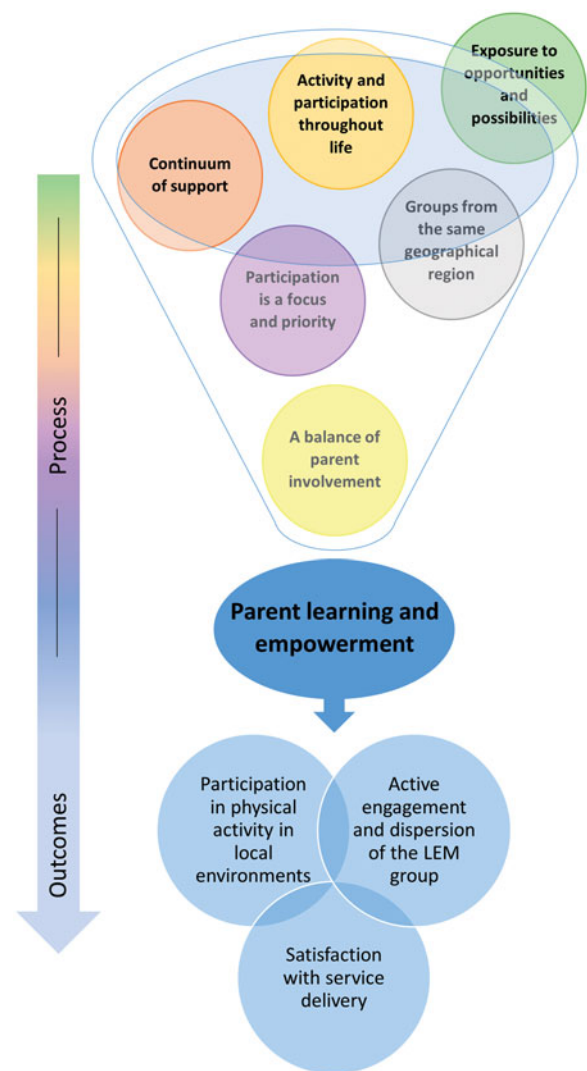


Figure 3. The process of parent learning and empowerment to facilitate physical activity participation for children with disabilities. Local Environment Model, LEM.

Active ingredients of the intervention

Six active ingredients were described by parents that enabled them to learn and be empowered as facilitators of their child's participation in physical activity. These included; a balance of parent involvement in the intervention, a continuum of support, groups from the same geographical region, participation as a focus and a priority, exposure to opportunities and possibilities, and activity and participation throughout life. Active ingredients, operational definitions and sample quotes are described in detail in Table 3. Quotations are defined with mother or father (capital letter) and participant number (figure). Quotes referencing children are accompanied by the child's age (y), and whether they have a physical disability (PD) or intellectual disability (ID).

Parent learning and empowerment

So now, I think [to myself] "it is possible". It helps me to understand [child] can do it, of course she can. And when some other parent at home says to me my child cannot climb – of course she can climb. Maybe only 50cm but she can do it if she wants to. Everybody can do a little bit. And [that's why] I think that it's important that we [parents] learn too. We see that it is possible. Just go for it. And even if the results are small, it might not be so small for that person. And over time, you learn, and you can do more. You build. – M11

Learning and empowerment was the process by which parents obtained access to knowledge, skills, and resources that enabled them to gain positive control over their roles as facilitators of their child's physical activity participation. From the active ingredients of the LEM, it was clear that parent learning and empowerment was a social process. Learning evolved from social engagement, where parents could '*discuss differences and similarities and what we can do better, and how we can cooperate with each other to make it better*'. Similarly, exposure to a variety of opportunities enabled parents to master new understandings about the possibilities for physical activity for the whole family. Participation in physical activity, the focus of the intervention, facilitated the growth of new knowledge for parents, and this typically stimulated the prioritization of physical activity for families. Empowerment was initiated alongside other parents through whom support and affirmation of understandings and experiences were received. Empowerment was a result of not only meeting a family's needs (i.e. being provided with skills and knowledge about how to facilitate physical activity

participation, support pre- and post-intervention), but also from highlighting the existing abilities of themselves and their child, and the resources already available in a family's local environment (support and relationships, services). Following the intervention, ongoing participation was anticipated to continue as a shared enterprise of the parent group ('*now I know we can do it*'), particularly in their desire to '*show the local communities how to see our kids better*'. Ultimately, the process of learning and empowerment increased parents' belief in their ability to enable their child's participation in physical activity in their local environment.

Outcomes following intervention

Participation in physical activity in local environments

Feeling confident and equipped with the skills, knowledge and support to enable their child to participate in physical activities at home and in the community was a primary outcome for parents. Parents for whom it was their first time participating in a stay at BHC described strategies and plans in relation to what would happen when they returned home in an assured manner. When conveying this, parents were exhilarated, uplifted and excited about the possibilities this would now create for their child and their family:

[Child, 14y, ID] likes to kayak. So we are going to get a kayak. We have talked before about buying a canoe. But [at BHC], trying them both, we have learnt that a kayak is better for him. So we are going to get a kayak! – M8

Parents whom had previously visited BHC typically described positive physical activity experiences in their home communities. Many described that coming to BHC helped them to realize that '*most of the activities we learn here are things we can do at home*'. Parents felt participating in physical activity in their local communities as a family was a more manageable process:

It's amazing. Since BHC we have been able to do lots of cross country skiing, and bicycling and swimming and other activities like that. – M2

A number of environmental barriers existed in local community settings. Parents explained that often, '*the biggest problem is distance*', particularly for seasonal activities where '*we have to travel a long way to get to the ski slopes*'. For goals relating to structured physical activity programs, negative attitudes and access to specialized staff were reported to be an ongoing barrier. However, parents described BHC as

Table 3. Active ingredients of the intervention identified by parents that promote learning and empowerment.

Operational definition and outcome	Active ingredient
1. Parent involvement in the intervention: a balance	
Parents are involved in some parts of the structured physical activity program:	
<ul style="list-style-type: none"> Parent involvement in the activity program: <ul style="list-style-type: none"> Enabled learning and recognition that they would be able to facilitate the child's participation in the same activity in their home and community. Allowed parents to witness capabilities of their child, an important process for alleviating concerns and fears associated with safety, skills of professionals and the ability of the child to manage the activity. Components of the intervention whereby parents were not involved allowed parents to understand: <ul style="list-style-type: none"> Children can often be more motivated by staff members, students, and peers to try an activity or achieve a goal. It is important for children to have opportunities to do things without their parents present. Time without children allowed time for their own respite, self-reflection and social activities. 	<p><i>'I feel that it is so important for [child, 17y, ID] that we are with her to see this, so we can continue when we go home' – M1</i></p> <p><i>'But mostly, it has helped me become less protective of my son. Now I can see he can do things on his own. So a part of this has been me letting go, after seeing he can do things by himself' – M6</i></p>
2. Continuum of support	
Parents receive support pre-, during and post-intervention from a service, systems and policy level:	
<ul style="list-style-type: none"> Support pre-intervention: <ul style="list-style-type: none"> Provided an opportunity for parents to raise their concerns and uncertainties, and receive answers to questions. Support during the intervention: <ul style="list-style-type: none"> Resulted in minimal difficulties in taking time away from their workplace to participate in the stay at BHC. Due to government policies, there is no financial contribution required from families, and parents continue to receive their wage from their employer during the intervention. Families of all socioeconomic positions can access the service. A model of service that was accommodating to the individual needs and preferences of each child and family elicited a high level of satisfaction from parents. Provided parents with knowledge of services in their own communities and encouraged parents to create ongoing opportunities for their child to be active. Support post intervention: <ul style="list-style-type: none"> Encouraged parents to implement practices acquired at BHC into their lifestyles, knowing the support from BHC was available. Fostered the transition of the role of support to be adopted by local communities (e.g. NSF regional representative, local rehabilitation centers, parent group). 	<p><i>'We met as a group much before. But I was skeptical to come [to BHC] you know. But I thought, let's just give it a try. And after that meeting, I was a little bit like "why didn't we come [to BHC] before?"' – M5</i></p> <p><i>'We have good arrangements for this ... it's our rights' – M10</i></p> <p><i>'I think it's great because you have this conversation with the whole team when you get here, and you have this conversation when you are halfway to see if the goals are still right and if there is anything you want to change, and then you have a conversation before you go home' – M3</i></p> <p><i>'We are getting help [at BHC]. They know the places in our community that are doing those activities, so they can lead us in the right direction or link us to the right group' – M9</i></p> <p><i>'[The follow up] makes you feel like you are being taken seriously, and that [BHC] really want to do this the right way. You don't just come and then you go home and then everyone forgets you' – M3</i></p>
3. Groups from the same geographical region	
Groups are assembled from the same regional area to unite families and community members who have similar experiences, without the benefit of a shared practice:	
<ul style="list-style-type: none"> The development of an ongoing support network for parents: <ul style="list-style-type: none"> Enabled the exchange of experiences between parents of children of a variety of ages and abilities and encouraged parents to learn from each other. Facilitated the development of a social group and enjoyment in physical activity. Parents adopt a role of knowledge broker: <ul style="list-style-type: none"> Parents become confident in their ability to impart their knowledge to other community members, for the benefit of the community. Developed an attitude of 'strength in numbers': parents were no longer alone in their quest to advocate for opportunities for their child. 	<p><i>'We are able to talk to other people who have the same problems. We are all in different stages I think. And we learn from each other when we talk' – M7</i></p> <p><i>'From being a group [at BHC], we know each other very well and we go on many trips together at home. We know each other's kids very well and we cooperate together. We are a very good team' – M5</i></p> <p><i>'I think this is a good idea for us to come here as a local community. Because it means we have more people that come here and learn about more activities and how we can do them, and then we can teach others in our community' – F2</i></p>

(continued)

Table 3. Continued

Operational definition and outcome	Active ingredient	Sample quote
<ul style="list-style-type: none"> ○ Awareness of the role of communities. ○ Enabled parents to recognize that without the support from health professionals, services and systems in their home communities, barriers surrounding accessibility and accommodation may still be present. 		<i>'It's just as important that the local service providers, and the team around the child at home, come to a place like this and learn'</i> – M14
<p>4. Participation is a focus and a priority Participation is the focus of the intervention. This encouraged parents to:</p>	<p><i>'To get in the bubble, to focus on physical activities and participation... I think that's important in life. And we forget about that sometimes in the routines at home. So it's good to come in a new bubble that helps you focus on that'</i> – M9</p> <p><i>'That is what is so great about this place - you make many small steps, and while you are here they build up to a really big one'</i> – M1</p>	
<ul style="list-style-type: none"> ● Reflect on the importance of participation amongst other priorities. ● Accept that changes in participation outcomes requires time. ● Understand that creating opportunities for a child to participate in physical activity impacts other aspects of their lives in a positive way. 		
<p>Participation in physical activity is (or becomes) a priority for parents:</p>	<p><i>'I just wish we had known about this place a long time ago, when [child, 16, ID] was a little girl. So we could have got the benefits earlier'</i> – M15</p> <p><i>'We will start on Monday. And I'll buy ten personal training sessions. They are expensive but it will be worth it'</i> – M12</p>	
<ul style="list-style-type: none"> ● Parents become aware of the benefits of physical activity. ● Parents are motivated and inspired to continue participating in physical activity. ● Parents are determined to explore and access opportunities in their community to transfer their acquired knowledge and experiences into lifestyle changes. 		<p><i>'What also would be great, would be if we had something like this near to us, and you just came for the day'</i> – M13</p>
<p>5. Exposure to opportunities and possibilities Exposure to, and the opportunity to participate in, a range of physical activities with the appropriate supports (specialized staff, adaptive equipment and personalized instruction), enabled families to:</p>	<p><i>'My children have a big platform of activities they can try here, with a lot of good equipment and assistants who make sure we learnt how to do the activities correctly. So then we have a lot of different activities to continue with at home'</i> – M9</p> <p><i>'We wouldn't be quite as motivated for skiing if we hadn't been here'</i> – M3</p> <p><i>'At home, we don't often get invited to things with other children, but here, we are included in everything'</i> – M3</p> <p><i>'[BHC] is all of the possibilities you can think of'</i> – M4</p>	
<ul style="list-style-type: none"> ● Learn how to facilitate participation in a variety of activities for their child. ● Find enjoyment in physical activity, and find activities that the family can do together. ● Experience an 'out of the ordinary' feeling of inclusion. ● Gain new understandings of possibilities that were not previously considered or believed to be achievable. 		<p><i>'And yesterday after the [formal program], me and another mother taught him [child, 14, PD] to ride a bike with only two wheels!'</i> – M5</p>
<p>Opportunities for informal and unstructured activity time within the intervention allowed parents to:</p>		
<ul style="list-style-type: none"> ● 'Practice' facilitation of physical activity pursuits with the supports (parent group) of the intervention environment. 	<p><i>'I think it's important that these opportunities exist throughout life for people to be active'</i> – M11</p> <p><i>'There will always be steps made with each stay. Not only that [children] try different things because of the seasons, but because they build on what they have already learnt'</i> – M1</p> <p><i>'So right now we feel like we are on track to start the swimming group and we feel like after being here, we can do that. But later the kids might want to do new activities, and we might need some guidance in how to do that'</i> – M14</p>	
<p>6. Activity and participation throughout life The LEM intervention entails children and families returning to BHC to participate in activities available only in the opposite season (e.g. winter for skiing). Additionally, parents and children can return to BHC through other programs. This enables parents to understand and recognize:</p>		
<ul style="list-style-type: none"> ● The importance of physical activity participation throughout the lifespan. ● The value of what the intervention provides to a child and their family. ● That a child's activity and participation preferences will change throughout the course of their life. ● That further support and guidance may be required to facilitate this. 		

BHC: Beitostolen Healthsports Centre; LEM: Local Environment Model; NSF: National Sports Federation; PD: Physical disability; ID: Intellectual disability; M: mother; F: father.

'an engine that gives us new spirit to go on', and that the LEM enabled them to continue to persevere in facilitating their child's participation in local communities.

Active engagement and dispersion of the LEM group

The life cycle of each LEM group was determined by the value it provided to parents and children. Parents who had previously been to BHC as a part of the LEM described the ongoing engagement of the group for the children as vital, because *'being able to maintain these connections is so important for [child], and his motivation and participation when he goes home'*. Support and relationships within the group commonly facilitated ongoing participation:

We went skiing, walking in the forest, we were sleeping outdoors without a tent in the summer time ... we have done a lot of things together with all of the kids. – F3

One group described that the initial coalescing of the group when its members were young children had been highly influential for their futures as adolescents and young adults:

So there are five kids, and we are looking to build a house together, with six apartments. Five for the children together, and one for a person who is working in the house [as a carer]. It has taken a lot of time but things are happening now. And that's really comforting to think of, because the kids know each other so well, and the parents as well, and it's so safe to think we have a future together. – M9

Some explained the gradual dispersion of the group over time, from regularly engaging in joint activities and being *'a very tight group'*, to no longer engaging as intensely. Parents did not describe this in a negative manner, explaining that the group was still alive as a center of knowledge, and continued to communicate with members as the *'exchange of experiences is useful'*.

Of the parents for whom this was their first time participating in the LEM intervention, a number of strategies, including electing one parent to be the group coordinator and *'a Facebook group, where we can share our photos but also stay in touch'* were enthusiastically implemented at BHC in the hope to keep the group active and connected after the intervention.

Satisfaction with service delivery

Parents expressed an extremely high level of satisfaction regarding all aspects of the LEM throughout their

time in the intervention. The most common word to describe the experience at BHC was *'perfect'*. The operationalization of the active ingredients contributed to the positive experiences:

I think the whole package is important and it works.
– F2

Parents attending their first stay were often unsure and hesitant coming into the program. Upon leaving, all parents (regardless of how many times they had visited BHC), felt equipped, self-assured and satisfied with the outcomes of the intervention:

I can't think of anything more I would want to get out of this whole experience. – M4

Parents were often very emotional when describing what the experience meant to them, their child and their family. It was extremely important to parents that other parents of children with disabilities were informed about the Centre, and were made aware of its impact:

We didn't know about Beitostolen Healthsports Centre. But now we do. And now we shall recommend it to all of the other parents who have children who have special needs. – F1

Discussion

This study describes novel findings as to how parents can be empowered to embody facilitative roles to enable their child's participation in physical activity. The family-centered nature of the intervention was pivotal to this process, adding empirical support to previous research that emphasizes the need to consider the whole family if we are to improve the participation outcomes of children with disabilities [1,40,41]. Active engagement in parts of the intervention enabled parents to learn and practice facilitation in situ, which simultaneously alleviated parents' concerns and fears associated with their child, the activity, and the environment. This is a unique approach for participation interventions, which typically focus solely on the child during the intervention component [42,43]. The involvement of parents in the participation-focused intervention supported the development of awareness of the benefits of physical activity, prompting reflections on the importance of participation, amongst other priorities. This is an important finding, as if families do not inherently value physical activity, they are unlikely to engage in, or sustain, physical activity behaviors [44]. Engaging parents in interventions to optimize physical activity participation may not only empower them to adopt facilitative

roles, but also address many family-related barriers that previously hindered this.

Findings from this study demonstrate that parent learning and empowerment evolved from social engagement. Parents were exposed to, and had the opportunity to participate in, a range of physical activities with their children, other families, and with and without the presence of program staff. The group-based design not only created a social and support network for parents, but enabled them to learn from and empower each other. This aligns with the work of Parsons et al. who described that empowerment is initiated with others through mutual support and confirmation of experiences [45]. Interestingly, models that describe parent empowerment as a primary goal alongside child participation outcomes do not include elements describing the support parents may require from other parents in order to achieve this outcome [1,41]. In this study, it was the support from others in similar situations that empowered parents to advocate for the full inclusion of their child in their community. For parents, empowerment may not only be a matter of their needs being met [46]; the accessibility to social support may act as a key determinant to this process and its outcomes.

A child (and family's) ongoing participation in physical activity in local environments was a central outcome of the learning and empowerment process. While rehabilitation therapists are documented to be primary facilitators of change [1], this research proposes a model whereby collaboration with families encourages parents to take on this role. For this to occur, our findings emphasize the significance of the 'community of practice' of which the intervention was entrenched in [27]. Prior to a stay at BHC, families faced similar situations without the benefits of shared practice. The LEM brought families together, enabling them to explore their connectedness, negotiate their 'community' and develop a 'practice'. Following the stay at the center, not all families engaged as intensely, yet each group continued to stay connected, producing a resource for knowledge and encouragement for ongoing participation in physical activity upon their return home. While it is widely acknowledged that children and adolescents will experience health and psychosocial benefits from participating in physical activity, interventions alone are not enough to sustain these benefits [47]. The application of communities of practice to foster participation in physical activity is unexplored across typically developing and disability literature, but may represent an effective

approach for sustaining participation in physical activity for children with disabilities and their families.

Parents in this study reported a high level of satisfaction regarding the process and structure of service delivery at BHC. These results are consistent with other family-centered and service evaluation literature, describing positive and directional relationships between empowerment, service delivery satisfaction, and parent and child outcomes [48,49]. As satisfaction is an outcome that can be measured easily across settings [50], this could also be considered as an indicator of effectiveness for future interventions. Further, while the process of empowerment is most often studied using qualitative methods [22], there are a tools that can quantify the outcome of parent empowerment [51]. The Family Empowerment Scale can provide information relating to the changing status of empowerment of family members caring for children with disabilities [51]. Future research in family-centered participation interventions should attempt to measure the relationship and impact of parent empowerment to child, parent and service-related outcomes of interest.

It is important to note that the continuum of support families that received in this intervention was largely due to standards in place at a policy level. Reducing social inequalities in health and access to care and services is a central theme of health policy in Norway, and reflected in the active ingredients identified in this study. As parents recognized in this study, a child's participation preferences and needs change over time, and access to support across the lifespan is required. Encouragingly, these policies are not exclusive to this country; current trials of the National Disability Insurance Scheme represent a groundbreaking reform of disability support services in Australia [52]. This was initiated by campaigns from advocates, whereby evidence describing the lived experience of disability, including identification of strategies to support participation, contributed to momentous and pervasive policy change [52]. Support at a service, systems and policy level may be essential for parents to continue to receive the support they require to facilitate their child's physical activity participation, and for children to do this independently in the future.

While the uniqueness of the services available at BHC must be highlighted, the practices and insights gained from this study should encourage therapists working in more conventional settings to consider alternative approaches when attempting to improve outcomes relating to physical activity participation.

How these are operationalized are likely to differ across contexts, but may include connecting families through a network of schools or rehabilitation centers in the same regional area, encouraging the child's whole family to participate in activities in interventions, and facilitating participation opportunities in partnership with community-based leisure services and other families. These are merely some examples of ways in which family-to-family support and networking, and delivering services that meet the needs of families, may enable parents to learn and be empowered to facilitate and advocate for a child's participation in physical activity.

Limitations

The findings from the current study should be interpreted within the parameters of a number of considerations. This research was conducted in one rehabilitation center in Norway, which may limit our interpretation of parents' collective perspective and resulting experiences. Our understanding may be further limited without data describing parent educational level and socioeconomic status. However, all identifiable characteristics of the study sample were reflective of the demographics of caregivers staying at BHC, as were those of the children. Finally, we were not able to perform a complete member checking process of interview participants. The triangulation of data sources and prolonged engagement at the site enhances the credibility of the data and subsequent results.

Conclusion

This study describes a social process of parent learning and empowerment, of which encouraged parents to adopt facilitative roles to enable their child's participation in physical activity. A family-centered approach, including developing family-to-family support and networking, may be required to optimize physical activity participation outcomes for children and youth with disabilities. Outcomes from this study may be of particular value for health professionals, researchers, and policy makers, for further testing and utilization.

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ORCID

Claire E. Willis  <http://orcid.org/0000-0002-3794-2902>

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