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ORIGINAL ARTICLE



## Challenges and facilitators in supporting sustainable participation after rehabilitation: Experiences of immigrant parents and their children with disabilities

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### ABSTRACT

**Background:** Children with immigrant backgrounds and disabilities have lower rates of social participation compared with their non-immigrant counterparts. However, rehabilitation programmes offer an opportunity to promote a physically active lifestyle and increase home and community participation of children with disabilities.

**Objectives:** By exploring immigrant families' experiences of participation and associated challenges and facilitators after rehabilitation, the study intended to contribute to the development of potential pathways in supporting sustainable community-based participation.

**Methods:** The study used a qualitative approach with semi-structured interviews.

**Results:** The costs and lack of information, necessary skills, and local activities were among the barriers that families experienced after the rehabilitation. Local and rehabilitation professionals were not always aware of or prepared to address the challenges faced by families trying to become physically active. Parents expressed their needs for support and continuation of services after rehabilitation for moving towards an active lifestyle. Participation patterns among children highlighted the potential role of support contacts as facilitators for participation in physical activities among the families.

**Conclusions:** Establishing an efficient collaboration between local and rehabilitation professionals with identifying potential future challenges, adjusting the interventions, clarifying roles and responsibilities, and providing supportive follow-up services may support sustainable community-based participation among immigrant families.

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### KEYWORDS

Participation; immigrant families; parents; children with disabilities; rehabilitation; physical activity; local community

## Background

Participation is defined as involvement in life situations and is one of the outcomes of rehabilitation interventions outlined by the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) [1]. The physical and psychosocial health advantages of participation in physical activities for children and adolescents are well acknowledged [2–4]. Lately, an increasing international trend has emerged towards viewing participation as a measure of well-being and inclusion in community life among children with additional support needs and disabilities [5,6]. Despite the importance of participation and its positive impact on health outcomes and well-being,

participation of children and youth with disabilities is restricted in comparison to their typically developing peers [7–9]. Children with disabilities participate less frequently and are less involved in the community than children without disabilities [7,10]. They face complex barriers to participation [11] related to the child, family, and wider environmental factors [12]. Low level of motor, communicative, and adaptive behaviour skills are the most common factors associated with participation restrictions for children with disabilities [13,14]. Disadvantaged family circumstances including ethnic minority status, material, social, and educational deprivation are also showed to be consistently associated with reduced participation of these children. Interestingly, social disadvantage appears to affect participation irrespective of

children's disability type and health support needs [15]. Negative attitudes followed by the physical accessibility of the environment, services and policies and lack of support from staff and service providers are also suggested as the most common environmental barriers for participation of children with disabilities [16]. Children with immigrant backgrounds with and without disabilities have even lower rates of participation compared with their non-immigrant counterparts [17]. Household education, neighbourhood connections, and access to computer and internet are found to be significantly associated with social participation for children with immigrant backgrounds. However, disability status itself is not shown to be a significant independent predictor of social participation among children with immigrant backgrounds [17]. Generally, parents of children with disabilities experience it as very difficult to find appropriate leisure activities to their children due to limited choices and expenses. They experience that healthcare professionals hardly provide information about suitable leisure activities [11,18] and the information that they provide either is not specific enough to their child's situation or has little relation to enabling the child's daily activities. Parents also express a need for improved communication and documentation between professionals [18]. Immigrant parents of children with disabilities perceive that because of language difficulties they even receive less information and do not know how or where to seek the information [19].

Rehabilitation offers the opportunity to promote a physically active lifestyle and increase home and community participation of children with disabilities [20,21]. There is, however, evidence that physical training intervention by itself is not effective in improving and maintaining habitual physical activity among children and youth with disabilities [22]. Therefore, moving towards a goal-directed, activity and participation-focussed rehabilitation is suggested for promoting sustained participation and healthy active living among children and young people with disabilities [22–24]. Integrating physical activities into daily life and incorporating physical activity programmes in the home and local community are also needed for maintaining an active lifestyle after rehabilitation [21,25]. Although the importance of exercise and participation in physical activity immediately after rehabilitation has been emphasised [26], research on adults with disabilities show a gap between services offered in a rehabilitation setting

and those available in the community following discharge [26–28].

In Norway, the Coordination Reform was implemented by the government in 2012 to promote interaction and good cooperation routines between rehabilitation services and municipalities to ensure sustainable and continuous services of high quality tailored to each individual's need [29]. However, a recent study on adults shows that a cross-sectorial continuity from rehabilitation to municipality remains a challenge in Norway [28]. Therefore, the current study has chosen the following research question: How did immigrant parents and their children with disabilities experience participation and associated challenges and facilitators in the local community at least 6 months after a participation-focussed rehabilitation programme? By generating knowledge about immigrant families' experiences, the purpose of the study was to contribute to the development of potential pathways in supporting sustainable participation among children with disabilities and immigrant backgrounds after rehabilitation.

Immigrants and their Norwegian-born children comprise approximately 18% of the total population in Norway. They vary in ethnic, cultural, educational, and socioeconomic backgrounds, as well as the length of their residence in Norway. Over 80% of all immigrants in Norway come from non-Western countries [30]. It is, however, important to note that there might be cultural differences in conception of participation for children with disabilities across countries [17,31], and popular activities among Western children might not apply to children in other cultures [32].

### ***Rehabilitation and social services for children with disabilities and their families in Norway***

In Norway, rehabilitation services are provided by both the municipality and the specialist healthcare system for children with disabilities, but the tasks are more specifically defined for the specialist healthcare system [33]. The municipalities are responsible for a wide range of health and social services important in daily life of children with disabilities and their families, such as physiotherapy, occupational therapy, speech therapy, home nursing, respite care, and Educational and Psychological Counselling. The municipalities also have the overall coordination responsibility for children with disabilities. Each municipality must have a coordinating unit for

rehabilitation activities that has responsibility for appointment of a service coordinator [34].

The specialist health services are linked up with the regional health authorities and include local interdisciplinary rehabilitation units for children. The function of these units is to supplement and enhance the services children and their families receive in their local community. The rehabilitation units also provide medical follow-up and treatment and arrange for intensive training periods [34]. Intensive training periods are provided by public or private rehabilitation institutions [35] that are part of the specialist health services since 2006 with public funding, and thus free of charge for the service users [36].

Provision of good rehabilitation and social services demands coordination and cooperation between services, both internally in the municipalities and between municipalities and the specialist health services. Therefore, clarification of responsibilities and tasks must regularly be on the agenda both within the municipalities and in the cooperation between the specialist health system and municipalities to ensure good rehabilitation processes for each individual child and family [33].

### ***The rehabilitation programme***

The goal-directed programme is provided by a private rehabilitation centre within the Norwegian specialist healthcare system. A multidisciplinary team of professionals comprising physiotherapists, occupational therapists, and sport pedagogues provide physical activity and participation-focussed intervention for groups of 8–10 children (aged 5–17 years) with disabilities and their parents, 5 hours a day, 6 days a week for 3 weeks. Depending on the season, families participate in different types of summer or winter activities, such as skiing, snowboarding, horseback riding, rock climbing, swimming, cycling, and canoeing. The programme also includes optional leisure activities consisting of physical, social, and cultural activities, such as picnicking, shooting with air rifles, painting, and playing games in the afternoon and evening. Children and their parents stay at the centre during the rehabilitation programme. Families' activity preferences and rehabilitation goals are identified and set before the intervention [23,37].

Given the importance of implementing relevant interventions in the local community, local professionals have the opportunity to participate at the end of the programme [23]. However, participation of local professionals in the programme varies depending on

municipalities' priorities and financial restrictions. Groups of families from the same local community are also offered pre- and post-intervention visits from rehabilitation professionals in collaboration with local professionals, which is referred to as the Local Environment Model. The model was established as an attempt to facilitate sustained physical activity participation among children. Previsits aim to further inform families about the rehabilitation programme 1 month before starting the intervention and postvisits aim to discuss the families' experiences of participation in the local community 3 months after the intervention [23,37].

### **Materials and methods**

The study used a qualitative approach with semi-structured interviews as the method. Participants were asked about their experiences of participation, especially in leisure-time physical activities. Leisure time constitutes a considerable portion of the day; therefore, activity choices in leisure time have important implications for both the physical and mental well-being of children and adolescents [38]. The interview guide for parents explored three main domains of experiences: (a) children's participation in activities, (b) challenges and facilitators for participation, and (c) services available in the local community after rehabilitation. Children were asked about their participation in activities regarding the types of activities they participated in and activities they preferred to participate in after rehabilitation. The interview guide was grounded in the ICF model, acknowledging that participation is a complex construct resulted from a dynamic interrelation between a cluster of factors unique to the child, the family, and the wider environment [15]. The interview questions were developed based on the review of previous research and experiences gained during a former developmental project that intended to inform and encourage immigrant families to participate in the rehabilitation programme studied.

The project was registered with and approved by the Norwegian Centre for Research Data (NSD) and received permission for implementation (reference number 51764). The project was also submitted to the Regional Committees for Medical and Health Research Ethics (REC) but was considered to be outside the remit of the Medical Research; it could, therefore, be implemented without the approval of the REC (reference number 2016/1764).

Before participating, potential participants received an information letter describing the study, its purpose, and that participation was voluntary. The letter also stated they could withdraw their participation without giving any reason and that their contributions would be unidentifiable in the final report. Furthermore, potential participants received information verbally over the phone in simple language after they had received the letters and had the opportunity to ask questions if they wanted. The participants gave written consent to participate in the study. The consent form was approved by the NSD. The participants were informed in writing and verbally that the findings would be published in scientific journals.

### Participants

Applying purposive sampling, the study included non-Western immigrant parents and their children with disabilities who had participated in the rehabilitation programme between 2015 and 2017. Immigrants are persons born abroad of two foreign-born parents and four foreign-born grandparents [39]. Non-Western immigrants refer here to immigrants from Eastern Europe, Asia, and Africa [40]. Most of the Children were born in Norway to their two immigrant parents. Only four children had immigrated to Norway at a very young age with their parents.

Participants were recruited through the rehabilitation centre via an information letter about the study, sent either before or after their 3-week stay at the centre. In total, 66 families were approached in writing. The first author also informed potential participants who lived in the Oslo area about the study by phone and in simple language after they had received the information letter. Finally, 22 parents (6 fathers and 16 mothers) and 17 children including eight girls and nine boys (aged 8–17 years) with physical or developmental disabilities whose parents consented participated in the study. Three of the children were not diagnosed at the time but had participation restrictions identified by a general practitioner. Eligibility criteria for participating in this rehabilitation programme were broad and non-specific, thus no disability types were excluded in this study [23] (Table 1).

Parents were immigrants from 13 countries (Table 2) with varied educational and socioeconomic backgrounds, Norwegian language skills, and length of residence in Norway (Table 3). All but one family lived in the Oslo area.

**Table 1.** Number of children within each diagnosis.

Diagnosis	Number of children
Autism	2
Acquired brain injury	1
Cerebral palsy	6
Intellectual disability	2
Spina bifida	2
Vision impairment	1
No diagnosis at the time	3

**Table 2.** Number of parents and countries of origin.

Country of origin	Number of parents
Afghanistan	1
Bosnia	1
Bulgaria	1
Chechnya	2
Iran	1
Iraq	1
Jordan	1
Pakistan	4
Poland	1
Somalia	4
Sri Lanka	3
Tunisia	1
Zimbabwe	1

Some participants were familiar with the first author before the study because of her role in the prior developmental project. One family was also familiar with the first author because of her role as their child's physiotherapist. All but two families participated in the programme for 3 weeks: one participated for 1 week and the other for 2 weeks. Over half of the families in this study had pre- and postvisits from the rehabilitation professionals as part of the programme according to the Local Environment Model.

### Data collection

Twenty-one interviews with parents and 17 interviews with children were conducted from April to September 2017. One interview was conducted with both parents as participants. All interviews were conducted by the first author in Norwegian, except one conducted in English. Professional interpreters facilitated interviews with five parents at the parents' own request or based upon the first author's perception of their language skills during the initial telephone conversation and their ability to hold the conversation in Norwegian.

The first author, herself an immigrant from the Middle East, had worked as a paediatric physiotherapist in the primary healthcare system in a multicultural district of Oslo for several years. She, therefore, had the experience of working with culturally diverse families and consequently had familiarity with different cultures and values. This cultural familiarity became a



**Table 3.** Sociodemographic characteristics of the parents.

	Sex	Age	Education	Norwegian language skills (estimated by the first author)	Length of stay in Norway (years)
1	F	30–40	University	Very good	15
2	F	40–50	High school	Good	15
3	F	30–40	Primary school	Very basic	15
4	F	30–40	High school	Very good	28
5	F	40–50	High school	Very basic	18
6	M	50–60	University	Very basic	8
7	F	40–50	University	Very good	17
8	F	30–40	High school	Good	8
9	F	40–50	Primary school	Very basic	28
10	F	40–50	Primary school	Almost none	9
11	M	40–50	High school	Basic	29
12	M	50–60	High school	Basic	12
13	M	40–50	University	Very good	29
14	F	40–50	Primary school	Good	22
15	F	30–40	Primary school	Basic	15
16	M	40–50	High school	Good	20
17	F	40–50	University	Basic	8
18	M	30–40	High school	Basic	7
19	F	40–50	High school	Basic	23
20	F	30–40	University	Very basic	10
21	F	40–50	University	Very good	20
22	F	40–50	University	Very good	21

foundation for building trust between her as a researcher and the participants. Her experience as a paediatric physiotherapist contributed to helping the children feel safe and communicate freely while being interviewed.

The first author explained the purpose of the study and the regulations regarding confidentiality for both the children and parents before each interview, after which she obtained written informed consent from all participants. For children, informed consent from parents was also obtained. The first author emphasised that the participants could withdraw their consent without giving any reason if they later wished. The participants were informed of the interview procedure and the recording of the interviews. Interpreters also explained their roles and duty regarding confidentiality prior to each interview and signed a declaration form.

Interviews with the parents lasted for approximately 55–130 min and with the children for 10–25 min. One of the interviews was conducted on two different days and lasted for approximately 170 min in total. Children were informed that they could take a break, refuse to answer the questions, or even ask to end the interview whenever they wished. Interviews were performed at a place and time that were convenient for each participant, including their homes, a café, Oslo Metropolitan University, the rehabilitation centre, and the Family House health and educational centre in the participants' local district. Children could choose whether they wished to be interviewed in the presence of their parents. One

child was interviewed over the phone due to her parent's preference. During the interviews, the first author continuously asked participants if she had understood their statements correctly to ensure that she had captured their meanings accurately.

All interviews were recorded and transcribed verbatim by the first author. Transcription of interviews was an ongoing process after completing the interviews. The first four interviews were transcribed immediately after conducting the interviews, which was useful for reflecting on and modifying interview questions. Adjustments to the interview guide were constantly made while conducting the interviews depending on the participants' responses and the context of the interview.

### Analysis

An inductive thematic analytic approach [41] was applied to explore potential patterns in the data. The interview transcripts for both children and parents were read individually for deep familiarity with the content of the data. After repeated readings of the interview transcripts and searching for meanings and patterns, initial data-driven coding was performed. The initial codes were defined broadly to bring together a group of data extracts that could be related. As a result, data were organised into 13 codes, such as 'activity habits' and 'acknowledgment'. Six of these codes were commonly defined for both children and parents, and seven were only related to parents' transcripts. While defining the codes, a 'quotable quotes

file' was also created to ensure that the particularly powerful pieces of data would not either be lost or dominate the evolving analytic process [42]. Another file named 'reflection notes' was created at the same time to register the first author's reflections and thoughts through the analysis process.

After organising the data into the initial codes, the search for themes began. In this phase, the analysis involved making sense of the relationships among the groups of data within each code belonging to both parents and children, and merging them to identifying the themes. Repetitive thinking and shifting attention from similarities between certain cases to the differences between other cases led to the deconstruction of the initial groups, linking and merging data elements across the different codes. As a result, two themes ('transformation' and 'participation pattern') were identified by merging data across the codes related to both the parents and children, and two sub-themes ('services after rehabilitation' and 'challenges and facilitators to participation') were identified by linking the data across the codes belonging to only the parents.

As examples, the theme 'transformation' was identified by merging data across the codes ('acknowledgment' and 'experiences of changes after the rehabilitation') that were commonly defined for both parents and children. The data related to the three codes defined for the parents ('lack of services after rehabilitation', 'parents' expectation of services', and 'parents' experiences of postvisits') were merged and defined a subtheme ('experience of services after rehabilitation').

In the next phase, the data related to those initial subthemes related to only the parents ('services after rehabilitation' and 'challenges and facilitators to participation') were merged and formed a new theme ('transition to the local community'). Finally, representative quotes were selected for presenting the results under the three identified codes. In order to establish trustworthiness of the data analysis, all four authors reviewed and discussed the initial codes and themes to ensure that they were appropriate regarding the data set and the research question. Then agreement on the labels and the meanings of the codes and themes was achieved. The analysis process is described step by step to enhance its transparency and trustworthiness. Although the different phases of the analysis are described as being linear, the process of analysis involved moving back and forth throughout the different phases.

## Results

Families' experiences of participation in the local community after rehabilitation varied. Although some experienced improvements in their children's activity and participation habits, others expressed that they reverted to their old habits. Some children participated in their preferred activities, whereas others did not participate in any leisure activities. However, after analysing the data three themes were identified: 'transformations', 'transition to the local community', and 'participation pattern'. The theme 'transition to the local community' represents only the parents' perceptions.

### Transformations

After rehabilitation, some parents experienced that their children were more confident and social. They noticed that their children sought contact with their peers, found friends, and were more engaged with their siblings. They explained that their children took responsibility to follow their daily tasks, such as brushing their teeth or organising their rooms. Some experienced that their children were more motivated and less afraid of trying activities at school or during leisure time. They explained that their children took more initiative for participating in activities, and some of them regularly participated in physical activities that they had tried in the rehabilitation centre, such as rock climbing, swimming, or horseback riding. One parent explained what she considered as progress in her child's capacity for participating in physical activity:

She is active, she has gym classes twice a week [at school] that she handles well, this makes me pleased. It is progress. (P. 7)

Similar to their parents, some children also described themselves as more social and explained how they even took initiative for going to the gym. They were all aware of which activities they were interested in after rehabilitation and wished they could participate in their preferred activities in the local community. One child explained his experience of participating in activities after rehabilitation:

I feel confident and I like to do activities, running, cycling .... before I was very scared, I was afraid of drowning, I was afraid of horses, I was even afraid of meeting new people at the rehabilitation centre.... (C. 8, 12 years)

This child's experience highlights how participating in different activities, learning new skills, and having

the opportunity to socialise at the rehabilitation centre helped him to overcome his fears and inspired him to participate in activities back home in his local community.

Parents themselves also expressed their awareness of the importance of their children's participation. They explained how they had searched to find adapted activities for their children after the rehabilitation programme. For instance, some parents contacted local professionals to seek information about available activities or facilities for their children. Some also explained that they planned to enrol their children in leisure activities or do activities, such as cycling, together with their children in the summertime.

### ***Transition to the local community***

Although parents expressed their awareness of the benefits of participation, they faced challenges to participation in their local community. They explained that they had participated in many activities at the centre but had few options in their local community. Some parents explained how motivated they were initially but after a while of facing challenges, they struggled to stay motivated. Some got frustrated and explained how they returned to their old routines. One parent expressed the need for support to overcome the challenges for participation in the local community:

Sometimes your motivation is not increasing but decreasing because you feel exhausted. You know what is best for your child and you wish the best for her, but you are alone with all these responsibilities .... (P. 8)

This parent's statement shows her awareness of the importance of participation and she is frustrated about not being able to manage the challenges for her child's participation by herself and without any support.

Parents expressed their need for information and guidance about adapted activities available to them and experienced it as difficult to carry the entire responsibility of the children's participation by themselves. Adapted activities were often limited in both diversity and availability. Some parents explained how impossible it was to use the swimming pools nearby, because the wardrobes were too cold, or there was no wheelchair available, and the water was often too cold for their children's conditions. Parents experienced it as exhausting that they had to participate in adapted activities far from home, given that their children were already tired after a long day at school. A far

travelling distance to attend activities sometimes ruined the whole experience of participation for both children and parents. The children's physical and mental condition also affected their participation in activities. Some parents of children with developmental disabilities explained how their children's lack of motivation and adaptive behaviour hindered them from participating in activities. These parents expressed need for support and guidance to enable their children's participation.

Some parents also explained how they struggled with affording the costs of organised activities despite their awareness of its benefits for their children. Participating in activities, such as skiing, that required special equipment was extra challenging. One parent explained the financial challenges they faced related to their daughter's participation:

Our financial situation is not sufficient to afford the costs of organised activities for her because my husband is the only one who works .... And my daughter has other kinds of expenses as well. (P. 10)

As this participant explained, the costs hindered especially those families with one parent as a sole financial provider, which is a common pattern among non-Western immigrant families in Norway [43]. Being a single parent in a host country with no network was an extra challenge to participation for some families. Time restriction and amount of responsibilities in daily life limited single parents' abilities to ensure their children's participation in leisure activities. Furthermore, some cultural challenges including parents' lack of skills and/or interests to participate in certain activities with their children, such as skiing that are particularly popular in Norway, or religious restrictions for participation of girls in mixed gender swimming courses were raised by a few parents.

These experiences demonstrate challenges that immigrant families faced in the local community. Even parents who had participated in the Local Environmental Model did not describe the postvisits as purposeful or helpful for facilitating for their children's participation at home. According to some parents, the rehabilitation professionals mostly intended to evaluate the programme rather than facilitate the children's participation. These parents wished that the rehabilitation centre would stay in touch with them for a period until the children were able to participate in their preferred activities in the local community. Some parents suggested or even expected that the rehabilitation centre with or without cooperation with local professionals should have



offered them local activities to facilitate their children's participation back home:

I think there should have been a mandatory and targeted activity plan after the rehabilitation programme, but that did not happen. ... they should make an agreement with the local community and link the local community and the rehabilitation centre together in a way that parents had to follow the plan. (P. 13)

This parent not only experienced the need for an activity plan as a facilitator for participation but also believed in the importance of established cooperation between the rehabilitation centre and local community. Although the rehabilitation centre had sent a final report to local professionals with a list of appropriate activities for each child, families did not experience any related intervention. As this participant pointed out, making an intervention plan that would be actively followed up in cooperation with parents may be beneficial and facilitate participation among children back in the local community. As some parents described, participating in the rehabilitation programme might be experienced as an opportunity for doing activities intensively only once a year if families do not receive the support and services that they need in their local community.

### ***Participation pattern among children***

Participation patterns among children varied; some participated in one or several types of organised and/or unorganised activities, whereas others did not participate in any leisure activities. Some parents only counted on school activities and were satisfied that their children regularly participated in physical activities, such as playing football or swimming, at school. Yet, others were frustrated that their children could not even participate in swimming at school because the water was too cold for their conditions. In accordance with their parents, some children explained that they participated in physical activities at school regularly. They also expressed their interests for being able to participate in their favourite activities in their leisure time. Only a few children explained they participated in their preferred activities. Although the children were not always aware of why they did not participate in their preferred activities, they offered possible reasons. For instance, some explained that they did not know where to find those activities or were unsure about availability of those activities in their local community. One of the children who

played basketball instead of volleyball—her favourite activity—explained:

I play basketball with my friend ... it is for free. Volleyball training is a bit expensive; it costs about 4500 kroner. (C. 5, 15 years)

This child's explanation shows how the costs hindered her participation in an activity meaningful to her. In response to whether she enjoyed and planned to continue playing basketball, she explained that she enjoyed it and would continue playing basketball despite not being good at it. However, her mother later explained that she did not play basketball any longer because she preferred to stay at home after school to take care of her homework.

One parent, whose child had participated in an art course only twice, explained how the same course was introduced by the local professionals to some families after the rehabilitation. This participant believed that it was important the children could keep participating in their favourite activities to make progress. She explained:

If they [local and rehabilitation professionals] want to follow up the services delivered by the rehabilitation centre, they should offer us the same or similar activities here in the local community ... We would like to participate in physical activities because art is a subject that children can work on it at the school as well. (P. 4)

This parent's statement shows that it is not only the participation that matters to her but also the type of activity. She further explained that her child no longer participated in any type of leisure activity because local professionals did not provide them with physical activities at the time. As this parent's explanation illustrates, being dependent on services offered by local professionals limited participation among some children in this study.

The children's participation patterns also show the potential role of support contacts as facilitators to participation among immigrant families. Support contacts help children with disabilities spend their free time actively and in a meaningful way. All municipalities in Norway must provide support contact services for free. Parents can apply for the services through the municipality that decides whether they are granted a support contact. Support contacts may be assigned individually, in groups, or in cooperation with a voluntary organisation [44]. Some children in this study participated in leisure activities only with their support contacts. Although support contacts played an important role in children's participation, children's opportunity to participate in activities

became limited to their support contacts' possibilities or even personal interests. One parent explained how her daughter had to participate in a group activity defined by the municipality instead of swimming, which was her preferred activity. This parent further explained that neither she nor her spouse could swim, and therefore they perceived it as important that their child could participate in swimming with her support contact. The child herself also explained that swimming and cycling were activities she preferred to do in her leisure time. These experiences reveal the potential role of support contacts as a facilitator for participation among immigrant children by considering families' resources and interests.

## Discussion

The purpose of this study was to explore immigrant families' experiences of participation and associated challenges and/or facilitators in the local community after taking part in a participation-focussed rehabilitation programme in Norway. By generating knowledge about participants' experiences, the study intended to contribute to the development of pathways towards supporting sustainable community-based participation. Immigrant families in this study expressed their awareness of the importance of participation for their children. Some described their experiences of progress in their children's activity and participation habits after the rehabilitation programme. However, challenges affected families' participation after rehabilitation and participation patterns varied among families. A lack of information, local activities, and necessary skills and costs were the challenges parents experienced. Parents' experiences revealed that local professionals were not always aware of or prepared for addressing the challenges to enable families to become physically active. Parents expressed their needs for support and continuation of services after rehabilitation for moving towards an active lifestyle. In this section, the importance of local professionals' involvement during the rehabilitation, clarifying the roles and responsibilities, providing supportive follow-up services, addressing immigrant families' challenges, and integrating facilitators for sustainable participation will be discussed.

Identifying potential future challenges for each individual and developing a multifaceted approach to overcoming them when planning interventions and associated behaviour change strategies have been highlighted in research [45,46]. Providing intervention in the rehabilitation centres where professionals are

not familiar with immigrant families, their resources, or their surroundings may hinder rehabilitation professionals from considering potential future barriers that families may face for participation in similar activities in their local community. Therefore, local professionals who are familiar with the families and their surroundings need to get involved early in the rehabilitation process to inform rehabilitation professionals about resources available to each family and potential future challenges for participation back home. This information may enable rehabilitation professionals to adjust the intervention by introducing activities that are available to the families and can be followed up in their local community. The need to individually assess and plan interventions to facilitate participation among families of children with disabilities is already highlighted by Anaby et al. [16]. Identifying potential challenges may also assist local and rehabilitation professionals to cooperate in providing strategies for addressing future challenges and enabling families to overcome them [47]. Overcoming challenges that restrict families' participation in activities is a critical element for promoting physical activity after rehabilitation [27].

Clarifying local and rehabilitation professionals' future roles and responsibilities before ending the rehabilitation programme may also assist families transitioning to their local community [28,48]. Our findings indicate that lack of clarity makes a discrepancy between families' expectations and available services after rehabilitation that may affect participation among the children.

Providing follow-up services and partnering with families after the rehabilitation programme are also recommended through the process of changing behaviour and achieving long-term maintenance of an active lifestyle [27,46]. Although maintaining behaviour change is often difficult for any family [49], certain challenges that are unique to immigrant families, such as the lack of a social network and support, may exacerbate these difficulties [50]. Resources available to these families, therefore, play an important role for maintaining new health behaviours and not reverting to old habits [49]. Some parents in this study explained they were motivated right after the rehabilitation but the challenges they faced afterwards made it difficult to stay motivated and keep participating in activities. Some parents admitted they went back to their old habits. A study of adults with disabilities showed how providing supportive follow-up interventions that focussed on identifying physical activity possibilities, overcoming challenges, and integrating

facilitators increased sport participation even 1 year after rehabilitation [21]. As our findings revealed, a lack of supportive follow-up services may affect participation among families [16]. For instance, some families explained how difficult it was to find information about local facilities and available activities after rehabilitation. Although needs for services and information may affect participation among all families [16,51], language difficulties make it more challenging for immigrants to find services and information [50,52]. Therefore, to follow up and support families, local and rehabilitation professionals need to familiarise themselves with the leisure activity options available in the local community, as parents continuously need to access the information about activity opportunities [20,25,47,53]. Local professionals are a trusted source of information for families and are in the position to act as the facilitators by linking families to community opportunities for activities [53].

Local and rehabilitation professionals also need to consider how socioeconomic factors influence immigrant children's participation in leisure activities [17]. Social participation among immigrant children with and without disabilities is significantly influenced by household socioeconomic factors [17,52]. In Norway, like other countries, immigrants have incomes lower than the average population [54]. Expenses hindered some parents in this study from enrolling their children in their preferred physical activities. Research reports how parents with lower incomes experience stress when they lack the resources necessary to enrol their children in leisure activities [55]. In line with our findings, research on non-immigrant families of children with disabilities also shows that living in socio-economically disadvantaged and single-parent families is associated with reduced participation in leisure activities [15]. Local and rehabilitation professionals may lessen the financial burden on parents and facilitate participation among these families by developing partnerships with sport and leisure activity sectors, providing affordable local opportunities, or introducing flexible payment options [56,57].

Our findings also highlighted the potential role of support contacts as facilitators for participation among immigrant families after rehabilitation. While sport participation can be culturally described as an extension of family life in the Norwegian context [58] and introducing children to sports at a young age is perceived as a sign of good parenting [59], immigrant parents' own lack of necessary skills prevented them from participating in some of their children's

preferred activities, such as skiing. To optimise support contacts' contributions, professionals can support families when communicating with municipalities about their needs and interests when assigning support contacts and planning activities. Research shows that considering children's activity preferences is important for increasing participation in leisure activities [60]. Children participate and continue to participate when they are having fun and activities are meaningful to them [53,61]. Participating in leisure activities provides an opportunity for enjoyment, making new friendships, and social cohesion among children [52,62]. Immigrant families, especially those raising children with disabilities, may not have a developed social network in their host countries and are at risk of becoming socially isolated [17,19]. Therefore, offering varied and adapted services that also take cultural and religious values into consideration and support these families to participate in activities in the local community is important [19]. Religion is a part of culture and one of the most important concerns in European literature on sport participation of girls with immigrant backgrounds [63]. Our findings also revealed how lack of equipment, availability and adequacy of services hindered some families from participating in leisure activities in their local community [7].

Lastly, the findings suggest that pre- and post-intervention visits from the rehabilitation centre in this study may have the potential for improvement to act as a facilitator for immigrant children's participation by focussing on mapping families' resources, local activity options, and supporting families to overcome the challenges after rehabilitation through close collaboration with local professionals.

## Limitations

Norwegian is neither the first language of the first author (interviewer) nor the interviewees, which might have affected the quality of the produced data. Some interviews were also conducted through interpreters. Therefore, the first author continuously asked participants questions to ensure a mutual understanding of the interview questions and the responses during the interviews. However, member checking after the interviews was not done due to participants' restricted daily schedules and amount of responsibilities. Furthermore, the study included immigrant families who had participated in the rehabilitation programme between 2015 and 2017 due to the low number of immigrant families who participated in the

rehabilitation programme and the difficulties in recruiting those who participated. Consequently, duration of families' experiences of participation in their local community and associated challenges and facilitators varied between six months and two years when the interviews took place. Although, this variation may have influenced the results, our findings revealed that the overall experience of participation and associated challenges and facilitators in the local community was similar regardless of the time that had passed from the rehabilitation programme. Since this study did not intend to evaluate the effect of the rehabilitation programme, the variation in the time duration passed after the rehabilitation was not considered as decisive for the quality of the results. Another limitation is a high number of mothers compared to the fathers who participated in this study. Although, the study also represents the children's own experiences of social participation after the rehabilitation, the themes are dominantly merged from the coded data belonging to the parent's experiences. Thus the findings of the study represent an overweight of mothers' experiences regarding their children's participation after rehabilitation.

## Conclusions

This study was conducted to generate knowledge about immigrant parents' and their children's experiences of participation and associated challenges and/or facilitators after rehabilitation in the local community. The results showed that participation patterns varied among families and multiple individual and environmental factors affected children's participation in the local community. While many of these factors may commonly affect participation of any child with a disability, our findings revealed that certain challenges that are unique to immigrant families including language difficulties, low income, and lack of activity competence and social support exacerbated the difficulties for participation among these families. Furthermore, the results of this study highlighted the importance of individually assessment and planning interventions within the rehabilitation services to facilitate participation among immigrant families. Finally, our findings revealed that continuity of services from rehabilitation centres to the local communities remains a challenge despite the health authorities' ideal of providing sustainable and continuous services after rehabilitation.

Sustainable participation in community-based activities demands seamless cross-sectoral services.

Establishing an efficient collaboration between local and rehabilitation professionals to identify potential future challenges, adjust interventions, clarify roles and responsibilities, and provide supportive follow-up services may be the potential pathways in supporting sustainable community-based participation. Therefore, dissemination of this knowledge is essential to influence municipalities and rehabilitation centres to prioritise and facilitate the involvement of local professionals during families' rehabilitation and build a long-lasting collaboration. Knowledge translation is necessary to ensure policy-makers and key healthcare decision-makers acknowledge the value of community-based services after rehabilitation and invest in providing varied, low-cost, and adapted activities to immigrant families. Finally, raising awareness of the need to provide a seamless transition is important within clinical practice and may facilitate cooperation between local and rehabilitation professionals.

This study highlights the need to fill the current gap between services offered in a rehabilitation setting and those available in the community as a step towards sustainable participation after rehabilitation. Research needs to focus on the transition from rehabilitation to the local community to inform professionals and policy-makers about the best ways to meet the needs of families after rehabilitation for achieving long-term maintenance of an active lifestyle. These findings provide essential information for occupational therapy researchers and practitioners.

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