Experiences of immigrant parents and their children with disabilities interacting with the Norwegian health and rehabilitation services

Shahrzad Arfa

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Oslo, June 2021

Shahrzad Arfa

Abstract

Background: The present study explores the experiences of immigrant parents from non-Western countries and their children with disabilities interacting with the health and rehabilitation services in Norway. Immigrants and their Norwegian-born children comprise approximately 18% of the total population in Norway, and 80% of them come from non-Western countries. Increasing ethnic diversity in the population and differences in the use of healthcare services pose challenges to the authorities' stated goal of equitable healthcare. It is, therefore, important to conduct research focusing on diverse populations to provide health and rehabilitation services that meet the needs of immigrant families and their children with disabilities. This study comprises three articles, with the first one focusing on the experiences of immigrant parents navigating health and rehabilitation services, aiming to generate knowledge of how accessible and tailored the services were from their points of view. The second article explores the experiences of immigrant parents and their children with disabilities participating in a three-week rehabilitation program with a focus on participation in physical activity, aiming to generate knowledge of how beneficial, culturally adapted, and accessible the services were from their perspectives. The third article aims to generate knowledge on the experiences of immigrant parents and their children with disabilities regarding community-based participation and services available after the rehabilitation to contribute to developing potential pathways in supporting participation in the local community.

Methodology: The study has a hermeneutic design with semi-structured interviews (articles 1, 2, & 3) supplemented by participant observation (article 2). An inductive and reflexive thematic analytic approach was applied to explore the meaning patterns in the data produced by the interviews and observations. The findings are discussed in light of the family-centered theory, a conceptual framework for integration in the healthcare system, and intersectionality.

Results: The immigrant parents were mainly satisfied and grateful with regard to the services, particularly the follow-up services provided by the regional rehabilitation centers. They felt gratitude when comparing the healthcare services in Norway with those in their countries of origin. However, parents experienced several challenges while navigating the health and rehabilitation services, including the need for information, support, and timely help. They felt exhausted due to years of struggling to access the help and services they required and expressed how it had even affected their own health. The feeling of being treated differently from the ethnic Norwegian families was another challenge they experienced while navigating the services. The parents' experiences of communication with health and rehabilitation professionals were influenced by both their own language and communication skills and the professionals' intercultural communication skills and dominant organizational culture. The parents' and children's experiences of the studied rehabilitation program (article 2) showed several perceived beneficial aspects of the services, including learning new skills, raising awareness about the children's interests and capabilities, socializing and exchanging experiences, and information among the families. However, a lack of cultural adaptation, including insufficient information, as well as the location of the rehabilitation center, language barriers, and exclusion of siblings affected accessibility of the services to immigrant families. Back home after the rehabilitation (article 3), the families also faced several challenges for participation in activities, including the costs, lack of information, follow-up services, and local activities. The rehabilitation and local professionals were mostly not aware of or prepared to address the challenges faced by the immigrant families. The parents expressed their needs for support and continuation of services after the rehabilitation for participation and moving towards an active lifestyle.

Conclusion: This study highlights the importance of mobilization at the individual, systemic, and political levels in providing culturally adapted, accessible, and seamless health and rehabilitation services to immigrant families of children with disabilities. Further research is necessary to guide policy-makers and health professionals on determining effective strategies for facilitating and enhancing information transfer to immigrant families, transitioning of services from rehabilitation centers to the community-based service organizations, and the best ways of providing family-centered services (FCSs). The application of intersectionality within health research is also important for examining the power dynamics and existing discourses that can lead to health disparities among immigrant families.

Sammendrag

Bakgrunn: Denne studien utforsker erfaringene til innvandrerforeldre fra ikke-vestlige land og deres barn med nedsatt funksjonsevne relatert til samhandling med helse- og re/habiliteringstjenestene i Norge. Innvandrere og deres norskfødte barn utgjør omtrent 18% av den totale befolkningen i Norge, og 80% av innvandrerne kommer fra ikke-vestlige land. Økende etnisk mangfold i befolkningen og forskjeller i bruk av helsetjenester utfordrer myndighetenes mål om likeverdige helsetjenester. Derfor er det viktig å gjennomføre forskning som fokuserer på mangfoldet i befolkningen, for å kunne tilby helse- og re/habiliteringstjenester som tar hensyn til behovene hos innvandrerfamilier og deres barn med nedsatt funksjonsevne. Denne studien består av tre artikler. Den første artikkelen fokuserer på erfaringene til innvandrerforeldre med å navigere i norske helse- og re/habiliteringstjenester, med mål om å generere kunnskap om hvor tilgjengelige og tilrettelagte tjenestene var fra deres perspektiv. Den andre artikkelen utforsker erfaringene til innvandrerforeldre og deres barn med nedsatt funksjonsevne som deltok i et tre ukers rehabiliteringsprogram med fokus på deltakelse i fysisk aktivitet. Målet var å generere kunnskap om hvor nyttig, kulturelt tilpasset og tilgjengelig rehabiliteringsprogrammet var fra foreldrenes og barnas perspektiv. Den tredje artikkelen hadde som mål å generere kunnskap om erfaringene til innvandrerforeldre og deres barn med funksjonsnedsettelse om deltakelse og tilgjengelige tjenester etter rehabiliteringsoppholdet, for å bidra til utvikling av mulige måter å støtte familienes deltakelse i lokalsamfunnet.

Metodologi: Studien har hermeneutisk forskningsdesign med semi-strukturerte intervju (artikkel 1, 2 og 3) supplert med deltakende observasjon (artikkel 2) som metode. Induktiv og refleksiv tematisk tilnærming ble brukt for å analysere dataene både fra intervjuene og observasjonene. Resultatene er diskutert i lys av teori om familiesentrerte tjenester, konseptuelt rammeverk for organisatorisk integrasjon i helsevesenet og interseksjonalitet.

Resultater: Foreldrene var hovedsakelig fornøyde og takknemlige for tjenestene de mottok, spesielt oppfølgingen fra de regionale habiliteringstjenestene (artikkel 1). De følte takknemlighet når de sammenlignet helsetjenestene i Norge med tilsvarende tjenester i det landet de kom fra. Foreldrene opplevde likevel flere utfordringer med å finne fram i helse- og re/habiliteringstjenestene, inkludert behovet for informasjon, samt støtte og hjelp til riktig tid. De følte seg utslitt på grunn av flere års kamp for å få tilgang til hjelpen og tjenestene de trengte, og opplevde at denne kampen også hadde påvirket deres egen helse. Følelsen av å bli

behandlet annerledes enn etnisk norske familier var en annen utfordring de opplevde i kontakt med de ulike tjenestene. Foreldrenes erfaringer med kommunikasjon i konteksten av helse- og re/habiliteringstjenester ble påvirket av både deres egen språk- og kommunikasjonsevne, fagpersonenes interkulturelle kommunikasjonsevne og dominerende organisasjonskultur. Foreldrenes og barnas erfaringer med rehabiliteringsprogrammet (artikkel 2) viste at de opplevde flere nyttige aspekter ved programmet. Dette inkluderte læring av nye ferdigheter, bevisstgjøring om barnets interesser og evner, sosialt samvær og utveksling av erfaringer og informasjon mellom familiene. Mangel på kulturell tilpasning, inkludert utilstrekkelig informasjon, samt lokaliseringen av rehabiliteringssenteret, språkbarriere og ekskludering av søsken påvirket likevel tilgjengeligheten av tjenestene for innvandrerfamilier. Tilbake hjemme etter rehabiliteringsoppholdet (artikkel 3), møtte familiene flere utfordringer med videreføring av aktivitetsdeltakelse, inkludert kostnader, mangel på informasjon, oppfølgingstjenester og lokale aktiviteter. Rehabiliteringssenteret og lokale fagpersoner var stort sett ikke klar over, eller forberedt på å håndtere utfordringene som innvandrerfamiliene møtte etter rehabiliteringsoppholdet. Foreldrene opplevde behov for støtte og overføring av tjenestene etter rehabiliteringsoppholdet for å kunne videreføre barnas deltakelse og oppnå en aktiv livsstil.

Konklusjon: Denne studien viser betydningen av mobilisering både på individuelt, systemisk og politisk nivå for å kunne tilby kulturtilpassede, tilgjengelige og sømløse helse- og re/habiliteringstjenester til innvandrerfamilier med barn med nedsatt funksjonsevne. Ytterligere forskning er nødvendig for å veilede beslutningstakere og helsepersonell til å finne effektive strategier for å fremme informasjonsoverføring til innvandrerfamilier, overføring av tjenester fra re/habiliteringssentre til lokale tjenesteytere, samt de beste måtene å tilby familiesentrerte tjenester på. Bruk av interseksjonalitet innen helseforskningen er også viktig for å undersøke maktdynamikk og eksisterende diskurser som kan føre til helseforskjeller blant innvandrerfamilier.

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2. Shahrzad Arfa, Per Koren Solvang, Berit Berg & Reidun Jahnsen (2022) Participation in a rehabilitation program based on adapted physical activities in Norway: a qualitative study of experiences of immigrant parents and their children with disabilities, Disability and Rehabilitation, 44:9, 1642-1649.
DOI: https://doi.org/10.1080/09638288.2021.1907454.

3. Shahrzad Arfa, Per Koren Solvang, Berit Berg & Reidun Jahnsen (2022) Challenges and facilitators in supporting sustainable participation after rehabilitation: Experiences of immigrant parents and their children with disabilities, Scandinavian Journal of Occupational Therapy, 29:8, 631-644.
DOI: https://doi.org/10.1080/11038128.2020.1856183

Abbreviations

ICF: International Classification of Functioning, Disability and Health

ICP: Individual Care Plan

IMDi: Norwegian Directorate of Integration and Diversity

FCS: Family-Centered Service

GP: General Practitioner

PHN: Peer Health Navigator

RHAs: Regional Health Authorities

1. Introduction

The current study explores the experiences of immigrant parents from non-Western countries and their children with disabilities interacting with the health and rehabilitation services in Norway. Immigrants and their Norwegian-born children comprise approximately 18% of the total population of Norway. More than 80% of all immigrants in Norway come from non-Western countries (1). Immigrants, similar to the rest of the population, are not a homogeneous group (2, p. 4). They come from 221 different countries and independent regions for many different reasons (3). They vary in ethnic, cultural, educational, and socioeconomic backgrounds, as well as the length of their stay in Norway (1).

An inclusive and equal society is an important goal of the Norwegian government, both for the individual and for society. An equitable healthcare system is, thus, a particularly important part of and condition for achieving this goal (2, p. 3). However, the consumption of healthcare services in Norway varies both within different immigrant groups and between immigrants and the general population (4). Many immigrants have both limited Norwegian language skills and a lack of knowledge about the Norwegian healthcare and welfare system, potentially creating challenges for access and use of the services. These challenges would be more particular for immigrant families of children with disabilities (5, p. 7). Increasing ethnic diversity in the population and differences in the use of healthcare services pose challenges to the authorities' stated goal of equitable healthcare (4) and necessitates a great deal of flexibility, creativity, and professional expertise on the part of the healthcare services to provide equal access, use, and outcomes for the entire population (6). Research shows that a lack of service use has more to do with how the services are organized than with the families' characteristics (7-9). Therefore, improving knowledge of what influences immigrants' use of healthcare services will be beneficial for planning policies and delivering healthcare services (4).

Although a significant amount of research has been conducted on immigrants' use of healthcare services, immigrant families of children with disabilities are systematically underrepresented in international studies (9). There is an absence of information about their experiences of access to and use of healthcare services, particularly rehabilitation services (10, 11). A lack of knowledge of these families' experiences limits the cultural integrity of practices within health and rehabilitation services (12, 13). Formal procedures for developing approaches and treatment plans based on the interactions between professionals and immigrant families of children with disabilities are also absent, despite their importance for the support of those families (14). McKay (15) notes a lack of data about best practices for immigrant children with disabilities.

The legitimacy of the healthcare system is a product of its ability to provide timely and appropriate services to the entire population (16). It is, therefore, important to conduct research focusing on diverse populations to enhance the further development of the health and rehabilitation services to further meet the need of immigrant families of children with disabilities. The current study comprises three articles, as follows:

The first article reports the findings from the interviews with immigrant parents of children with disabilities navigating health and rehabilitation services.

The second article explores the experiences of immigrant parents and their children with disabilities who have participated in a rehabilitation program focusing on participation in physical activity.

The third article presents the experiences of immigrant parents and their children with disabilities about community-based participation and services available at least 6 months after participating in the rehabilitation program.

My focus throughout this study has primarily been to explore immigrant families' experiences of interacting with the services, without any intention to compare their experiences with native families. Even though immigrant and native families may both face some similar challenges, the experiences of the challenges and their impact on the families' lives may not be the same regarding the contextual differences and their minority and majority status in society (17). However, some common challenges are acknowledged within the first and third articles, without any intention to ignore how differently these common challenges might have affected or been experienced by the immigrant families.

This thesis is organized into seven chapters, with the first chapter briefly introducing the study, the three included articles, and this thesis' organization. Chapter two provides a background of the study in terms of its context and a brief review of the relevant research, followed by the knowledge gap and the study's rationale. At the end of chapter two, the overall aim of the study and each of the three articles is presented. In chapter three, the theoretical framework of the study is introduced.

The fourth chapter presents the methodology of the study, including the study design, methods, ethical considerations, and the researcher’s role and reflexivity. The findings from the three articles are briefly presented in chapter five. Discussion of the findings in the light of the study’s theoretical framework and previous research, followed by the methodological considerations, are presented in chapter six. The main conclusion of the study, its practical and scholarly implications, and suggestions for further research are provided in chapter seven.

2. Background

In this chapter, the political context of the study regarding Norwegian policies regarding the social inequities in health among immigrant families in the last decade is briefly explained. Then, the Norwegian healthcare system as the overall context of the study is presented. Moreover, the former developmental project “Active together, possible for us?” that the current study has been inspired by, and the studied rehabilitation program are described. Finally, a brief overview of the previous research followed by the research gap and the study’s objectives are presented.

2. 1 The political context

In Norway, the Coordination Reform was implemented by the government on January 1, 2012 to promote a high-quality, comprehensive, and coherent health service for all citizens tailored to each individual’s needs (18). The Coordination Reform was regulated by the new Public Health Act and the Health and Care Services Act. The purpose of this Public Health Act was to contribute to societal development that promotes public health and reduces social inequities in health (19). In October of the same year, the government presented the report “A comprehensive integration policy: Diversity and Community” to the Norwegian Parliament (20). The report deals with the opportunities and challenges that immigration poses to the country and society. It states that Norway must not become a society where people with immigrant backgrounds have poorer living conditions and participate less in the community than the rest of the population (21, p. 3). The report further states that children with immigrant backgrounds should not face more barriers than other children in the society, and all children must have the opportunity to participate in social and recreational activities. It also emphasizes the right to equitable public services, including equitable healthcare services for the entire population regardless of diagnosis, family background, gender, religion, ethnicity, and life situation (20, p. 65, 74-75). According to the report, equity in public services entails that everyone has access to good-quality services that are tailored to each individual’s needs. Public services must, therefore, follow the principles of user involvement and access to correct and clear information about the rights, duties, and facilities. The report notes the importance of access to information for all residents to have the same real opportunities to orientate themselves in the society. It underlines that inadequate communication and information dissemination may lead to indirect discrimination. According to the report, to reach the goal of service equity, service providers must also have sufficient cultural competence to interact with service users with a different background than themselves (20, p. 133-134).

As a follow-up to the Coordination Reform and the new Public Health Act, the government presented the Public Health Report “Good health – a common responsibility” to the Norwegian Parliament in spring 2013 (22). The report points out the existing social differences in health among the population, including immigrants. Later in August 2013, the Ministry of Health and Care Services published the “National strategy on immigrants’ health 2013-2017” (2). The strategy plan is intended to be a tool within all levels of healthcare services to facilitate effective services for the immigrant population. The strategy plan points out seven main challenges within the healthcare system regarding the immigrant population, including health-related challenges, cultural challenges, language difficulties, access to health information, access to and use of health services, the competence of health professionals, and research. The strategy plan underlines that there is limited knowledge about the use, accessibility, and quality of the existing healthcare services among immigrants (2).

Almost a week later to the strategy plan, the report “Equal opportunities for all children” was also published by the government. The report emphasizes that families of children with disabilities should have the same opportunity as other families to live an independent and active life. It also underlines the importance of participation in cultural and leisure activities among children with a disability and an immigrant background (23, p. 5).

2. 2 The Norwegian healthcare system

In Norway, the healthcare system is publicly funded (24, p. 49) and provided based on the principle of universal access for all legal residents in the country (25). It is semi-decentralized, with municipalities responsible for primary healthcare services under the Municipal Health Services Act, and the state responsible for specialist healthcare services, administered by four Regional Health Authorities (RHAs) (26, p. 15). Primary healthcare includes long-term care services, general practitioners (GPs), physiotherapists, community health nurses, and emergency care (26, p. 22). The specialist healthcare includes both public and private hospitals, specialized drug treatment, mental healthcare, ambulance services, and private specialists (27). All residents in Norway are assigned a GP who acts as a gatekeeper to specialist healthcare services. Patients, except children and pregnant women, pay a subsidized consultation fee when visiting their GP. Most medical specialists outside hospitals, as well as outpatient hospital services, require co-payments (28). There is also private healthcare in

Norway, where one can access specialists directly, but out-of-pocket fees are typically much higher. Private healthcare is relatively uncommon and mainly available in urban areas (29).

Within the Norwegian healthcare system, rehabilitation services are provided by both the municipality and specialist healthcare system, but the tasks are more specifically defined for the specialist healthcare services. The municipalities are responsible for identifying the need for rehabilitation by accomplishing a necessary examination (30). They also provide a wide range of health and social services important for the daily life of children with disabilities and their families; for example, physiotherapy, occupational therapy, speech therapy, home nursing, respite care, and support contact (31). Thus, the municipalities have the overall responsibility for the follow-up services and referring children with disabilities to specialist healthcare services if necessary (30). In addition, the municipalities have the overall coordination responsibility for children with disabilities. Each municipality needs to have a coordinating unit for rehabilitation activities, which must appoint a coordinator (31). This coordinator is a service provider who is responsible for ensuring the necessary follow-up and coordination of services as well as the progress in the work with the individual care plan (ICP). The ICP acts as a tool to map the service users' goals, resources, and needs in various areas; it also assesses and coordinates measures to meet the service users' needs and strengthens the interaction between both service providers and service users, and the service providers themselves (30, 32). Families in need of long-term and coordinated healthcare services are entitled to have a coordinator and ICP (30, 32, 33).

Children and adolescents aged 0–18 years with a congenital or early acquired disability, developmental disorders, or chronic illness may also be entitled to local interdisciplinary rehabilitation units for children within the specialist healthcare system (30). The function of these units is to supplement and enhance the services that children and their family receive in their local community (31). Multi-professional pediatric rehabilitation teams have the core responsibility to provide services and follow-up to children in accordance with their overall needs (30). Follow-up at local pediatric rehabilitation units is scheduled once or twice a year, and the evaluations are carried out to support the child in their daily life activities. Most of the services are provided as an outpatient but may also be offered at children's wards in hospitals (30). The rehabilitation units also arrange for intensive training periods (31), which are provided by the public or private rehabilitation centers (34). There are approximately 50 private rehabilitation centers that have agreements with the RHAs for offering services at the specialist health service level. The private rehabilitation centers have formed part of the specialist health service since 2006 (35).

2. 3 The former developmental project “Active together, possible for us?”

This study has been inspired by the experiences gained during a former developmental project “Active together, possible for us?”, which was established by a private rehabilitation center in 2014–2015. The project mainly intended to inform immigrant families living in the Oslo area about this rehabilitation center and its program, given the low participation among these families in the program. At the time, I worked as a pediatric physiotherapist in a multicultural district in Oslo and was appointed as a part-time project coworker to assist in conducting the project. In this position, I had the responsibility to distribute information about the rehabilitation program among immigrant families both directly and indirectly through the health professionals who worked with these families. My informal conversations with immigrant families while conducting the project gave me a broader insight into the challenges they faced while interacting with the health and rehabilitation services. The opportunity to be present during part of these families’ participation in the program also helped me to better understand the challenges related to the interactions between immigrant families and the rehabilitation professionals in the center. These experiences became an important part of the idea and inspiration for designing and conducting the present study. The rehabilitation program is further explained in the next section.

2. 4 The rehabilitation program

The program is provided by the aforementioned private rehabilitation center, located in the mountains, contracted by the RHAs and free of charge, within the specialist healthcare system. The eligibility criteria of the program are broad and include children aged 5–17 years with various functional levels, diagnoses, and disabilities, who are able to follow instructions and participate in the group-based activities. The program builds on intensive intervention and the principles of adapted physical activity (36, 37), reflecting Norwegian culture with a substantial focus on outdoor activities (38). The intervention is based on the child’s goals but is also designed to introduce families to novel and varied adapted physical activities (39). Depending on the season, families participate in summer or winter activities such as skiing, snowboarding, horseback riding, rock climbing, swimming, cycling, and canoeing. A multidisciplinary team of six professionals comprising a physician, physiotherapist, occupational therapist, sports pedagogue, nurse, and social worker provides the interventions for groups of 8–10 children and their parents, five hours a day, six days a week, for three weeks (36). The program also includes optional leisure activities—physical, social, and cultural events, such as picnicking, shooting with air rifles, painting, and playing bingo—provided by recreation workers in the afternoon and evening. Children and their parents reside at the center during the rehabilitation program. Children's activity preferences are identified before the intervention using ActiveYou I, a web-based self-report assessment instrument that is a Norwegian-adapted version of the Preferences for Activities in Children (PAC) (40). The goal-setting process applies an adapted code set based on the International Classification of Functioning, Disability and Health (ICF), including 40 categories mainly in Activities and Participation (38).

As a part of the program, parents participate in informative group meetings (39). One of the meetings, provided by the social worker, concerns the families' rights and the services to which they are entitled. A regional sports association consultant also informs parents about the different types of adapted physical activities available in their region. Additionally, a meeting is organized with a psychiatric nurse, who guides parents on how to overcome their daily challenges by using mastery strategies. The families are also introduced by the occupational therapist to assistive activity devices, which are available free and may facilitate activities in their local community.

Given the importance of implementing relevant interventions in the local community, local professionals have the opportunity to participate at the end of the program (39). However, the participation of local professionals in the program varies depending on municipalities' priorities and financial support. 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 has been established as an attempt to facilitate sustained participation among children back home in their local community. Previsits aim to further inform families about the rehabilitation program one month before the intervention and postvisits aim to discuss the families' experiences of participation three months after the intervention in their local community (36, 39).

2. 5 Previous research

This section provides an overview of previous research that has contributed to building the foundation of the present study, and directing the discussion chapter. It includes research about challenges to access and use of healthcare services among immigrant families of children with disabilities, barriers to participation among children with disabilities and an immigrant background, and community-based participation after rehabilitation.

2.5.1 Challenges to access and use of healthcare services among immigrant families of children with disabilities

Immigrant families of children with disabilities face health disparities and are at risk for unmet healthcare needs (15). They not only face the same barriers as native families to access and use the healthcare services but also encounter additional challenges (11). A narrative review of 39 articles, mostly from the US and UK, shows that immigrant parents of children with disabilities mainly face additional challenges due to language barriers (41). These language barriers influence service use in many interacting ways by affecting the awareness of available resources, comfort to seek out the services, acceptance of services, engagement in the family–professional relationship, and following the recommendations (10). Financial hardship, divergent perceptions of healthcare and disability, social isolation, lack of support system, and stigma are also among some additional challenges that these families may experience (10, 11, 41, 42). A recent review of 17 international articles reveals increased barriers for immigrant families of children with disabilities, partly due to the difficulty in navigating a challenging and changing healthcare system (15). Immigrant families reported frustration that they had to navigate uncoordinated healthcare systems with limited support (43).

Bailey et al. (44) point out that immigrant families also face challenges within the healthcare system due to a lack of familiarity with cultural expectations regarding how to correctly seek help. Furthermore, professionals may not be fully aware of the implications of ethnic and cultural diversity regarding values, goals, and behavior. Two studies of Pakistani and Bangladeshi families with a severely disabled child conducted in the UK reveal how service providers' stereotypical perceptions of immigrants created challenges for the families' interaction with the healthcare system (7, 8). A lack of cultural sensitivity in all levels of healthcare service provision can impact the families' ability to engage in and trust healthcare providers (10, 43, 45).

Research conducted in Norway and Denmark also shows how service providers largely explain the challenges they face while interacting with immigrant families as being the result of cultural and religious differences (12, 46). Service providers may, therefore, easily overlook other matters of importance and create stereotypical images of "the others" with reference to their culture or religion (12, 47, p. 111). This generalization can also hinder the building of individual relationships to meet the unique needs of each family. Söderström (6), in her study of minority parents of disabled children within the Norwegian healthcare system, highlights how language difficulties and stereotypical assumptions made it difficult for the families to access healthcare services. Although these studies illustrate the challenges that immigrant families face within the healthcare services in general, little is known about the families' experience of interacting with the rehabilitation services in particular.

2.5.2 Barriers to participation among children with disabilities and an immigrant background

Participation is defined as involvement in life situations and is an important outcome of rehabilitation (48). Recently, participation has been viewed as a measure of well-being and inclusion in community life among children with disabilities (49, 50). However, participation of children and youth with disabilities is restricted in comparison to their typically developing peers (51-53). They participate less frequently and are less involved in the community than children without disabilities (51, 54). Children with disabilities face complex barriers to participation (55), mainly related to child, family, and wider environmental factors (56). A low level of motor, communicative, and adaptive behavior skills are the main common factors associated with participation restrictions for children with disabilities (57, 58). Disadvantaged family circumstances, such as ethnic minority status, material, social, and educational deprivation are also consistently associated with reduced participation of children with disabilities. Social disadvantage appears to affect participation regardless of children's disability type and health support requirements (59). Negative attitudes followed by the physical accessibility of the environment, services, and policies and a lack of support from service providers and staff are also among the most common environmental barriers for participation of children with disabilities (60, 61).

Immigrant children with and without disabilities have even lower rates of social participation in terms of organized activities outside of school hours compared with their non-immigrant counterparts (62). This may indicate that sport club settings with their demands for material and cultural resources can exclude children with immigrant backgrounds (63). Although household education and neighborhood connections are shown to influence social participation among children with immigrant backgrounds, disability status itself is not a significant independent predictor of social participation among these children (62).

Generally, parents of children with disabilities experience that it is highly difficult to find appropriate leisure activities for their children due to limited choices and expenses. They experience that healthcare professionals cannot adequately provide information about suitable leisure activities (55, 64), and the information they provide is either insufficiently specific to their child's situation or is not relevant for enabling the child's daily activities (64). 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 (65). There is, however, a paucity of studies that have investigated participation among children with disabilities. Knowledge about the experiences of immigrant parents and their children with disabilities regarding participation in leisure activities is also lacking.

2.5.3 Community-based participation after rehabilitation

Rehabilitation offers the opportunity to promote a physically active lifestyle and increase home and community participation of children with disabilities (66, 67). There is, however, evidence that physical training intervention itself is not effective in improving and maintaining habitual physical activity among children with disabilities (68-70). This underlines the importance of shifting focus from the level of bodily functions to the level of participation and taking personal and contextual factors into account while providing intervention models for enabling participation and improving habitual physical activity (68, 69, 71). Therefore, moving towards goal-directed and participation-focused rehabilitation is suggested for promoting sustained participation and healthy active living among children and young people with disabilities (39, 69). A recent randomized controlled trial study of children with cerebral palsy who had participated in a highly tailored eight-week, goal-directed and participation-focused intervention documented a perceived improvement in the performance of self-selected leisure-time physical activity goals eight weeks after the intervention. However, the intervention did not translate into an improvement in habitual physical activity and community participation (72). Integrating physical activity into daily life and incorporating physical activity programs in the home and local community are, therefore, necessary for maintaining an active lifestyle after rehabilitation (67, 73).

Although the importance of exercise and participation in physical activity immediately after rehabilitation has been emphasized (74), research on adults with disabilities shows a gap between services offered in a rehabilitation setting and those available in the community following discharge (74-76). There is often a lack of formal links between rehabilitation practitioners and community physical activity programs (77), even though the pediatric rehabilitation literature has emphasized the value of community-based physical activity for positive psychosocial and physical skill development of children with disabilities (78). The role of local professionals, such as physiotherapists, in the promotion of community-based physical activity for children with a disability is also often unclear (77). Hence, the development of formalized linkages at the organizational level between the rehabilitation and local health and social services may facilitate a transition to community-based sport and physical activity among children with disabilities, particularly those with immigrant backgrounds (77). There is, however, a lack of research that focuses on the transition of services from rehabilitation to the local community. Knowledge is also lacking about parents' and children's experiences of community-based participation after the rehabilitation.

2. 6 Knowledge gap and rationale of the study

As this research review shows, immigrant families of children with disabilities face several challenges to access and use healthcare services. Whereas research mostly focuses on experience of access and using the services in general, little is known about the experiences of immigrant families of children with disabilities interacting with the pediatric rehabilitation services. Exploring immigrant families' experiences of rehabilitation services is important, given the role of rehabilitation for improving health and social outcomes of children with disabilities. As this overview shows, children with disabilities and an immigrant background face increased barriers to community-based participation. However, little is known about how beneficial, accessible, and culturally adapted rehabilitation services are for these children from their own and their parents' perspectives. The voices of children with disabilities and immigrant backgrounds were almost absent in the reviewed research. There is also a lack of knowledge regarding immigrant families' experiences of community-based participation and services available after the rehabilitation. The present study seeks, therefore, to address the current research gap by exploring the experiences of immigrant parents (articles 1, 2, & 3) and their children with disabilities (articles 2 & 3) interacting with the health and rehabilitation services.

2. 7 Aims of the study

Based on the identified research gap, the overall aim of this study was to explore the experiences of immigrant parents and their children with disabilities interacting with Norwegian health and rehabilitation services to contribute to providing services that further meet the needs of immigrant families. The study comprises three research articles, and the aim of each article is as follows:

Article 1. By focusing on the experiences of immigrant parents navigating health and rehabilitation services, this study aimed to generate knowledge regarding how accessible and tailored the services were from their point of view.

Article 2. By exploring the experiences of immigrant parents and their children with disabilities with respect to participating in the studied rehabilitation program, the study intended to generate knowledge of how beneficial, culturally adapted, and accessible the services were from their perspectives.

Article 3. By generating knowledge about the experiences of immigrant parents and their children with disabilities in terms of their community-based participation and the services available after the rehabilitation, this study aimed to contribute to developing potential pathways for supporting sustainable participation in the local community among the families after the rehabilitation.

3. Theoretical framework

This chapter introduces the theoretical framework of the current study, including the ICF, the family-centered service theory, the conceptual framework for organizational integration in the healthcare system, and the intersectionality theory. Whereas the ICF has contributed to understanding the concepts of disability and participation within the present study, the three latter theories have assisted in understanding and analyzing the study's findings.

3. 1 The International Classification of Functioning, Disability and Health (ICF)

The ICF provides a common language for describing health, functioning, and disability (48). Within the ICF, disability is an umbrella term conceived as a dynamic interaction between health conditions and contextual factors, including environmental and personal factors (Figure 1). Environmental factors are the physical, social, and attitudinal environment in which each individual lives, such as the availability and quality of the services for children with disabilities. Personal factors are the particular background of an individual's life and living, composed of features of the individual that are not part of a health condition or health state, such as gender, age, education, and lifestyle (48).

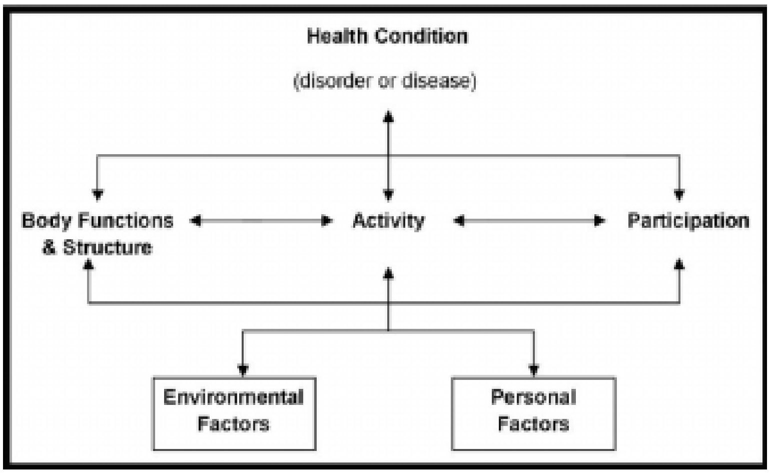

Figure 1. Interactions between the components of ICF (WHO, 2001, P. 18)

These contextual factors need to be identified and considered because they influence and modify the three other components of disability, including body functions and structures, activity, and participation. The significant value of the ICF model is its contribution to think beyond "fixing" primary impairments and provide a view that values facilitating the child's full participation in all aspects of life. At the same time, it acknowledges how the settings in which children live, including social and cultural environments, affect their participation in daily life activities (79). The WHO encourages application of the ICF internationally both as a classification tool, and as a framework for social policy, education, clinical practice, and research (48). This study has applied the ICF model as its framework in understanding disability as relational and the result of the interaction between the individual and environmental factors. Accordingly, the study acknowledges participation as involvement in a life situation resulted from a dynamic interrelation between a group of factors unique to the child, the family, and the wider environment. Whereas for young children, the environments of everyday life are closely connected to the home and school, these environments gradually become more diversified into the larger context of community and society for youth (80).

3. 2 The family-centered service theory

Family-centered service (FCS) is an approach that has gathered the interest of parents, healthcare providers, and researchers (81). FCS is both a philosophy and method of service delivery originated from Carl Rogers' idea of client-centered therapy in psychiatry back in the 1940s (82). Rogers defined client-centered therapy as a practice, in which the therapist treats each client as a person of worth and respects the client's uniqueness, capacity, and right to self-direction (83). Over the years, Rogers's idea of client-centeredness was embraced and taken to the next level that emphasized the importance of the family in children's well-being. Late in the 1960s, the concept of FCS emerged from a strong advocacy movement where parents of children with disabilities demanded a shift from the dominant expert model to more involvement in their child's health and related care (82). Although the concept of FCS became increasingly adopted at the time, many clinicians were unsure about its precise contents. In 1988, Rosenbaum et al. (84) noticed the need for describing a conceptual framework and constructed a three-level framework based on the review of existing literature on FCS at the time (Table 1).

Central to this framework are three basic assumptions focusing primarily on the family. Each assumption is followed by a number of guiding principles directed to the service providers describing the context in which the parent–professional interaction should take place. The framework also includes a series of elements complementary to parent-focused dimensions in order to increase accessibility and feasibility of the model to service providers.

The first basic premise of the model is that parents know and want the best for their children. Therefore, service providers need to encourage parental decision-making by providing appropriate information, clarifying child and family needs, and building upon their strengths through a collaborative partnership. Services should also be offered in an accessible manner regarding both the services' location and each family's ability to comprehend and absorb information and advice based on a shared understanding of the child's situation.

The second assumption of the framework refers to families' diversity and uniqueness, arguing for the necessity of individualizing the services for each family and its members. This assumption's immediate implication for service providers is to acknowledge and accept the diversity of families' values and cultures within the multicultural communities and adapt their communication styles to be consistent with each family's understanding and needs. This assumption also demands that service providers listen carefully to the families, try to understand their difficulties from their points of view, and trust their observations and opinions about their child.

Table 1. Premises, principles, and elements of family-centered service (Rosenbaum et al. 1998, p. 6)

Premises (basic assumptions)		
• Parents know their children best and want the best for their children.	• Families are different and unique.	• Optimal child functioning occurs within a supportive and community context. The child is affected by the stress and coping of other family members.
Guiding principles ("should" statements)		
• Each family should have the opportunity to decide the level of involvement they wish in decision-making for their child.	• Each family and family member should be treated with respect (as individuals).	• The needs of all family members should be considered.
• Parents should have ultimate responsibility for the care of their children.		• The involvement of all family members should be supported and encouraged.
Elements (Key service provider behaviors)		
• To encourage parent decision-making	• To respect families	• To consider psychosocial needs of all members
• To assist in identifying strengths	• To support families	• To encourage participation of all members
• To provide information	• To listen	• To respect coping styles
• To assist in identifying needs	• To provide individualized service	• To encourage the use of community support
• To collaborate with parents	• To accept diversity	• To build on strengths
• To provide accessible services	• To believe and trust parents	
• To share information about the child	• To communicate clearly	

The third and last premise of the FCS framework states that optimal child functioning occurs within a supportive context of family and community. Therefore, within FCS practice, the involvement of all family members and considering their needs has to be encouraged and supported by service providers. The use of community services and support system and the facilitation of family-to family support and networking as the contributors to the child and family well-being should also be considered within FCS (84).

The FCS approach offers an important conceptual foundation for a developed model of health service delivery (82), and its principles are often aligned with a vision of effective healthcare delivery (85). Therefore, the present study applies the FCS approach as an analytical framework to interpret the immigrant families' experiences of interacting with the health and rehabilitation services and suggests how to improve service provision to these families and their children with disabilities.

3. 3 Conceptual framework for organizational integration within the healthcare system

Integration has become an important issue in the developing and modern healthcare system with an increasing differentiation of roles, tasks, and responsibilities caused by the driven forces of specialization, decentralization, and professionalization (86, 87). The concepts of differentiation and integration were first introduced by the organizational researchers Lawrence and Lorsch in 1967 (88), who concluded that a major part of the current knowledge about organizations could be reduced to these two concepts. Differentiation takes place because of the need for adaptation to the complexity of the environment, and increasing differentiation necessitates the integration of the services to make the organizations viable (88, p. 10-11). Differentiation as a concept includes both functional and structural aspects and differences in behavior and attitudes as the consequence of variation of the roles and tasks. Therefore, integration is generally a difficult task for the management of the organization, particularly inter-organizational integration in terms of integrating the activities of different organizations (87), which is within the scope of the current study.

Ahgren et al. (89) have illustrated different forms of integration along a continuum model of integration (figure 2). This continuum can be used for analyzing integration both within organizations (intra-organizational integration) and between separate organizations (inter-organizational integration) (89). Learning about this continuum is important and relevant to the current study because different types of integration within the healthcare system are often pictured along this continuum of integration; this point will be further explained later in this section (87). The continuum begins with a zero point, namely full segregation with almost the absence of any form of integration and extends through intermediate forms of integration including linkage, coordination, cooperation, and collaboration to the full integration point where resources are totally merged (86, 87, 89).

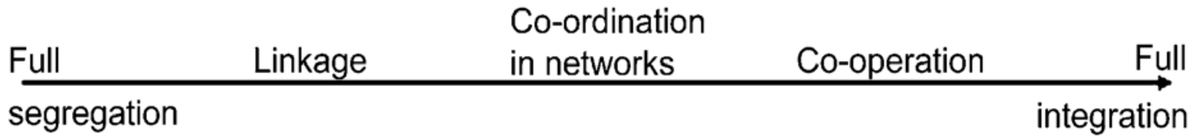

Figure 2. Continuum of integration (Ahgren & Axelsson, 2005)

Linkage is a form of integration that promotes continuity of care by good communication between the involved organizational units to ensure that referrals reach the most appropriate recipients without delay (86). Coordination is a more structured form of integration that intends to coordinate the various services, produce common information, and facilitate the transfer of service users between different organizational units. Another intermediate form of integration is the cooperation that takes place to improve contact between involved organizational units (89). Finally, collaboration is another intermediate type of integration, not shown in Figure 2, accomplished through voluntary agreements and mutual adjustments between the organizations involved (87).

To clarify the relationships between these different forms of integration, a distinction needs to be made between two main dimensions of integration— vertical and horizontal. Vertical integration takes place between organizational units on different levels of a common hierarchical structure, and horizontal integration occurs between more or less independent organizational units at the same hierarchical level or with the same status (87, 89). Different forms of integration have a varying emphasis on vertical and horizontal integration (87). Coordination is a form of integration with a high degree of vertical integration but a low degree of horizontal integration; hence, integration is mainly achieved within a common management hierarchy. This means that decisions on integration are made at the top of the hierarchical structure and implemented on lower levels. Cooperation, with a high degree of both vertical and horizontal integration, is based on a hierarchical management combined with voluntary agreements between the involved organizations. In other words, decisions of the management hierarchy give room for informal contacts and communications between the organizations. Within collaboration, most of the integration is achieved through horizontal integration or voluntary agreements between the involved organizations but with a low degree of vertical integration (87). According to Axelsson et al. (87), coordination, cooperation, and collaboration mostly find a place somewhere in the middle of this continuum of integration.

The continuum does not indicate the optimum form of integration, (89) and each of these forms of integration can be effective depending on the objectives, environment, and degree of differentiation of the organizations involved (87, 89). Whereas a low degree of differentiation can be managed through vertical integration, higher degrees of differentiation between organizations that may not be part of a common management hierarchy demand more horizontal integration. Coordination, with a high degree of vertical integration, may therefore be an effective form of integration within a low degree of differentiation, whereas cooperation and collaboration can otherwise be more effective when there is a high degree of differentiation between organizations (87). On the inter-organizational level, it is necessary to achieve a state of integration required to deal effectively with the state of differentiation by implementing effective forms of integration through management hierarchy, market competition, or the network mode of integration (87). Whereas the management hierarchy takes place in the form of a top-down coordination of organization, market competition occurs through contractual relations between the organizations, and the network mode of integration occurs based on voluntary cooperation or collaboration between organizations belonging to a different hierarchy or market (87, 90). Because most of the service organizations involved in the Norwegian healthcare system are not market oriented (24, p. 17), the inter-organizational integration of the services will mainly take place either according to the hierarchical management in terms of coordination, or according to the network mode in terms of collaboration and, to some extent, cooperation (87).

When it comes to the provision of rehabilitation services in Norway, which is within the focus of this study, inter-organizational integration between the specialist healthcare system and municipalities is primarily a question of collaboration according to the network mode and accomplished by the voluntary agreements and mutual adjustments between the service organizations involved (91, p. 13, 31) because the municipalities are not part of the hierarchical structure of the state administration (92, p. 75). Inter-organizational collaboration for the provision of seamless rehabilitation services to immigrant families of children with disabilities will be further discussed in chapter 6 of this thesis based on the presented conceptual framework for integration.

3. 4 Intersectionality theory

This study applies intersectionality as the theoretical framework to understand how the intersection of immigration and disability can affect the health and rehabilitation outcomes of immigrant families of children with disabilities and their experiences of interacting with the services (93-95). The theory of intersectionality was originally developed by Kimberlé Crenshaw in the 1980s to capture how different types of discrimination intersect to oppress people in multiple and concurrent ways and contribute to systemic injustice and social inequality (96). Intersectionality as a critical approach provides the mind-set and the language to consider interconnections and interdependencies between social categories and systems of power or oppression (97). Within intersectionality, it is possible to explain the simultaneity and mutual co-constitution of diverse categories of social differentiation and emphasize the particularity of the experiences shaped by these interactions (98, p. 2). The concept of intersectionality confronts a particular dimension of social complexity by focusing on the interaction between different groups of social structures, such as class, race, and sexual orientation (99, p. 193). These social structures are constructed through the institutionalized rules of authority and subordination, the social organization of labor and production, and the organization of desire and sexuality (100). As Collins (101) points out, these social groups are created by a common location within the hierarchical power relation, rather than a collective decision-making of individuals within them. Inside these social groups, some individuals may encounter relative constraints in their material well-being and freedom because of the cumulative effect of their positions, whereas others may have more options and easier access to benefit and fortune (102, p. 21). Therefore, intersectionality is not just a concept applying to marginalized groups but, rather, an aspect of social organization that shapes all of our lives, and nearly everyone may be privileged in some ways and disadvantaged in others (99, p. 195).

There are different ways of understanding and using the concept of intersectionality (99, p. 193). However, Else-Quest et al. (103) have summarized the three most common assumptions underlying the intersectionality as follows: (1) recognizing that all people are characterized simultaneously by multiple interconnected or intertwined social categories, such as gender, ethnicity, class, and sexual orientation; (2) within each of these socially constructed categories is a dimension of inequality or power; (3) all social categories have both individual and contextual facets that are linked to personal identities, institutional processes, and structural systems. These assumptions reveal how intersectionality draws attention to the individuals' and groups' multiple positionalities at both individual and socio-structural levels (97). By this, an intersectional approach decreases the risk of essentialism (97) in which certain categories (e.g., ethnicity) have an underlying reality that forms the individuals' identities and is responsible for similarities that category members share (104). This categorization and drawing of boundaries as a result of the categorization process leads to stereotyping and constructing the ‘otherness’ and the ‘sameness’ (105). Intersectionality, on the other hand, facilitates exploring nuanced and complex within-group comparisons and challenges the assumptions of within-group homogeneity (97). The intersectional approach highlights that immigrants are a diverse group, and their experiences are shaped by intersecting multiple social structures, including race, religion, and disability (106, p. 21-22), all of which will be further discussed in chapter 6. The categorization of immigrant families may affect the services accessible to them and their relations with the service providers. Therefore, improving the health and well-being of the immigrant families of children with disabilities demands an intersectional lens that focuses on the varied circumstances and contexts in which they are situated, which is within the scope of the current study (107).

This chapter presented the study’s theoretical framework, including the ICF model, FSC theory, conceptual framework for organizational integration, and intersectionality, and the three latter approaches together with the relevant research will be applied to discuss the findings in chapter 6. With this in mind, the next chapter presents the study’s methodological choices, including the study’s design, methods, analyses, ethical considerations, and the researcher’s role and reflexivity.

4. Methodology

Methodology forms and is formed by research objectives, questions, and design. It directs and justifies the choice of method, which produces the data and analyses (108). This chapter presents the methodological choices, including the study’s hermeneutic design, qualitative methods, reflexive thematic analyses, ethical consideration, and the researcher’s role and reflexivity.

4. 1 Hermeneutic design

Different designs exist within qualitative studies, and each provides a specific direction for the research procedures (109, p. 12). This study applies a hermeneutic design towards the school of Gadamer (110). Emerging in the nineteenth century in the dominance of positivist scientific approaches, Gadamerian hermeneutics refrained from a positivist paradigm by anticipating that knowledge is influenced by the researcher’s preunderstanding (111). Preunderstanding emerges from past experience and prompts questioning that keeps open the possibility of new understanding (112). However, it may also obstruct understanding and reduce the capacity to come to new ways of being. Therefore, while conducting hermeneutic research, preunderstandings must be explored for how they enable or limit understanding rather than being denied or identified and bracketed (113).

As a philosophical perspective, hermeneutics seeks to understand human experiences rather than describing them, paying particular attention to the context in the human sciences (110, 114, p. 84). Hermeneutics highlights that understanding is generated from a certain perspective that is situated in a cultural and historical context (114, p. 85), and this situatedness would not hinder interpretation and understanding (115). In hermeneutics, contexts and preunderstandings are, in fact, researchers’ interpretative tools for entering the inquiry and throughout the circular process of understanding (116). During this circular process of understanding, the researcher remains open to the other’s perspectives, adjusts her or his preunderstanding according to new insights, and re-encounters the inquiry with a new set of preunderstandings. Through this process of understanding, preunderstanding will be continually visited and adjusted (117). This cyclical process continues until the researcher and participants reach a fusion of horizons, and the researcher gains a profound understanding of the experiences being studied (110). This study chose a hermeneutic design because it is particularly advantageous while conducting multicultural research by providing the space to identify and understand various perspectives on human experiences. Hermeneutics also raises researchers’ awareness about how their preunderstanding as well as their linguistic capacity and cultural identity may influence the multicultural research process and the findings. Furthermore, the integration of interpretation and critical reflection in hermeneutic inquiry allows researchers to reexamine practices that are closely defined by traditions and cultures, which is exactly within the scope of the current study (118).

4. 2 Qualitative methods

Qualitative methods are applied in research to answer questions about experience, meaning, and perspective from research participants’ points of view (119). In this study, a semi-structured interview was applied as the main method for exploring participants’ experiences. Participant observation was also used as a supplementary method in the second part of the study (article 2) (120, P. 24), mainly to gain insight into the interactions between professionals and the participants (121). In the following sections, recruitment and participants followed by the process of data production are presented.

4.2.1 Recruitment and participants

This study applied purposeful sampling to include parents from Non-western countries and their children with disabilities who participated in the studied rehabilitation program between 2015 and 2018. Purposeful sampling selects participants whose study will illuminate the research questions and provide useful information regarding the study’s objective (114, p. 169). Immigrants are persons who are born abroad of two foreign-born parents and four foreign-born grandparents (122). Non-Western countries refer here to countries within Asia, Africa, and Eastern Europe (123). Participants were recruited through the rehabilitation center via an information letter about the study, sent either before or after their three-week stay at the center. Two levels of written information were made available for the children taking part in the study, one each for children aged between 8–12 and 13–18 years. In total, 66 families were approached in writing. After sending the information letter in Norwegian, I contacted potential participants who lived in the Oslo area by phone to additionally inform them about the study in simple language. Forty families did not respond, and two declined because of their work and life schedules. Several studies have reflected on the difficulties of recruiting immigrants to participate in research and suggest different reasons, including lack of time, trust, fear, attitudes towards research, employment constraints, language barriers, and cultural differences (124-126). However, based on experiences from the recruiting process and conversations with the potential participants, I believe that language and literacy difficulties, together with the number of daily responsibilities and challenges faced by immigrant families of children with disabilities, might have influenced the low response rate in the current study.

In total, 25 parents (seven fathers and 18 mothers) and 17 children (aged 8–17 years), including eight girls and nine boys with physical or developmental disabilities, participated in this study. 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. At the time, three of the children were not diagnosed but had participation restrictions identified by a general practitioner (GP) (Table 2).

Table 2. Characteristics of the children

Diagnosis	Autism	2
	Acquired brain injury	1
	Cerebral palsy	6
	Intellectual disability	2
	Spina bifida	2
	Vision impairment	1
	No diagnosis at the time	3
Sex	Female	8
	Male	9
Age (years)	8–12	8
	13–17	9

As mentioned previously (chapter 2), the eligibility criteria for participating in the rehabilitation program were broad and nonspecific; therefore, no disability types were excluded from this study.

Parents were immigrants from 14 different countries, with varied educational and socioeconomic backgrounds, Norwegian language skills, and length of residence in Norway (Table 3). All but three families lived in the Oslo area. Within one family, both parents participated in the study. Some families were familiar with me before the study because of my role in the prior developmental project. One family also knew me as their child’s physiotherapist. All but two families participated in the rehabilitation program for three weeks; one participated for one week and the other for two weeks due to the child’s and job’s conditions. Six families in the study had participated in the program more than once, and four of them had experienced both winter and summer activities. The broader range of these families’ experiences may have contributed to produce richer data and, thus, influenced the results. Other families had mostly participated in the program in the warm seasons, finding summer activities more attractive and culturally familiar. Over half of the families in this study had participated in the pre- and post-intervention meetings with the rehabilitation professionals as a part of the Local Environment Model.

Table 3. Sociodemographic characteristics and country of origin of the parents

Sex	Female	18
	Male	7
Age (years)	31–40	10
	41–50	13
	51–60	2
Education	University	9
	High school	10
	Primary school	5
	Not available	1
Norwegian language skills (estimated by the first author)	Very good	7
	Good	4
	Basic	6
	Very basic	7
	Almost none	1
Length of residence in Norway (years)	2–10	8
	11–20	10
	21–29	7
Country of origin	Afghanistan	1
	Bosnia	1
	Bulgaria	1
	Chechnya	2
	Iran	1
	Iraq	2
	Jordan	1
	Pakistan	4
	Poland	2
	Serbia	1
	Somalia	4
	Sri Lanka	3
	Tunisia	1
	Zimbabwe	1

4.2.2 Semi-structured interviews

The qualitative interview has become a key method in many types of sciences, such as in the health sciences (127). Depending on the study’s aim, the degree of structure within the interviews varies, contributing to the formation of either structured, semi-structured, or unstructured interviews (128). Brinkmann (127, p. 18) believes that this distinction should be considered as a continuum ranging from relatively structured to relatively unstructured formats because a completely structured or unstructured interview does not exist. He argues that in structured interviews, participants always talk about subjects beyond the structure, and even in unstructured interviews, the interviewer always has an idea about the subject of the conversation (127). Building on hermeneutics, this study chose an individual semi-structured interview that allows the researcher to pursue a less structured questioning approach while interviewing and, at the same time, enabling elaborate spontaneous topics raised by the participants (108, 129). Semi-structured interviews are frequently applied in healthcare settings (128) to explore interviewees' experiences and embrace their varied perspectives.

Prior to conducting the interviews, the interview guides, including open-ending questions that covered specific topics of interest, were prepared. These guides were developed based on a review of previous research and experiences from the former developmental project at the rehabilitation center with informal conversations and observations of the families, some of whom were later recruited to the present project. However, adjustments to the interview guide were constantly made while conducting the interviews, depending on the participants' responses and the context. The interviews with the parents and children were conducted from April 2017 to January 2018. As an immigrant from the Middle East myself, I had experience working as a pediatric physiotherapist in the primary healthcare system in a multicultural district of Oslo for several years. I therefore experienced working with culturally diverse families and, consequently, some familiarity with different cultures and values. My own immigrant background and the cultural familiarity became a foundation for building trust between me as a researcher and families as the participants. Furthermore, my experience of working with children as a pediatric physiotherapist facilitated building a relationship with the children in a way that they mostly felt safe and comfortable to communicate freely. Prior to each interview, I explained the study's purpose and the regulations regarding confidentiality for both children and parents; I then obtained written informed consent or assent from all participants. For children, written informed consent from parents was also obtained. I also emphasized that both children and parents could withdraw their consent without giving any reason if they later wished to. They were also informed of the interview procedure and that audio recordings would be made of the interviews. All but one of the interviews were conducted in Norwegian. One interview was conducted in English. Six interviews were facilitated by interpreters. Interviews with the parents lasted for approximately 55–130 minutes and with the children 10–25 minutes. One interview with a parent was conducted on two different days and lasted for approximately 170 minutes in total. Interviews were performed at a time and place convenient for each participant, including their home, a café, Oslo Metropolitan University, the rehabilitation center, and the Family House health and educational center in the participants' local district. Three participants' spouses were partly present while the interviews occurred in their homes. While interviewing some parents, the conversations were interrupted several times because their cell phones were ringing. I had not initially asked the parents to turn off their cell phones, and I took it for granted that they would do this themselves. One of the parents' phone rang three times during the interview because she was expecting a visitor and was guiding her to find the address. When the visitor finally arrived, we had to stop the interview and make a new appointment with the interpreter and the parent, which was both frustrating and challenging. Although these interruptions might have affected the quality of the produced data, I still experience that it is difficult to predict and avoid all kinds of potential disruptions while interviewing, particularly when it takes place in participants' homes. However, all parents were welcoming and showed a high degree of hospitality. They always offered coffee or tea and acted in a way that made me feel as if I was visiting family or friends. One family also served me dinner after the interview. The families' kindness, honesty, and willingness to share their stories of vulnerability, strength, and harshness have become an unforgettable part of my journey as a Ph.D. student. All interviews were recorded and transcribed verbatim by myself a short time after the interviews. The recordings performed in a café had poor sound quality with a noisy background and made the transcription process challenging and additionally time consuming. Transcription of the interviews that were assisted by the interpreters was also demanding and considerably time consuming. Therefore, transcription was an ongoing process even after completing the interviews. The first four interviews were transcribed immediately after conducting the interviews, which was useful for fostering reflection on the interview questions and the applied terms. As a result, the interview questions were modified. In the two following sections, my experiences of conducting interviews assisted by an interpreter and conducting interviews with the children are described.

4. 2. 2. 1 Interviewing through an interpreter

Language is a methodological challenge when participants and researchers do not speak the same language. However, the forces of globalization necessitate conducting health research that is linguistically and culturally representative of the entire population in order to improve the quality of care and reducing health inequities (130, 131). In this study, parents were from 14 different countries and spoke 12 different languages. They had also varied Norwegian language skills; whereas some spoke fluently, some others struggled significantly. Therefore, professional interpreters facilitated interviews with six parents, determined by the candidate's perception of their language skills during their prior conversations or by participants' own mention of the need. However, while interviewing some other parents, I realized that the interviews could have been improved by using interpreters. Unfortunately, the participants had not mentioned the need for an interpreter themselves, and I had overestimated their Norwegian skills because they managed to speak adequately during our initial conversation. These experiences may show how determining the need for an interpreter remains a challenge in cross-language qualitative studies.

To find qualified interpreters, I applied the national interpreter register guideline provided by the Norwegian Directorate of Integration and Diversity (IMDi) (132). At the time (spring 2017), the guideline was classified into five categories (1–5), where interpreters within the first three categories (1–3) were recommended. Therefore, I only assigned interpreters within these first three categories to assure the quality of the interpretation. Category 1 included interpreters with state authorization, who had also passed "the introductory course to interpretation in the public sector". Category 2 included interpreters with only state authorization, and category 3 contained those who had only passed "the introductory course to interpretation in the public sector". Since spring 2020, IMDi has launched a new national interpreter register with five new categories (A–E), where category A, the highest one, demands both state authorization and a bachelor's degree in interpreting (132).

The process of contacting and assigning interpreters within the first three categories, who had time and interest to assist in conducting the interviews, was demanding. Conducting interviews facilitated by an interpreter involves several considerations regarding both the interviewee and the interpreter. The interpreter's competence and role, the style of interpreting, the assurance of confidentiality, positioning of the parties during the interview, cultural factors, and the type of person to serve as an interpreter are among some important considerations (133, 134). At the time, I was not aware of all these considerations and did not have experience of conducting interviews facilitated by an interpreter. I only had experience cooperating with interpreters to interact with immigrant families when I worked as a physiotherapist. None of the assigned interpreters had contributed to interviews within a research setting either. However, they mostly expressed their interest in cooperating within the research context and found it to be a unique experience.

Prior to each interview, I communicated with the interpreters about the study, its objective, and the interview process, and let them familiarize themselves with the keywords in the interview guide. I chose to use female interpreters while interviewing female participants due to cultural considerations (131). Four interpreters, three females and one male, facilitated interviews in four different languages, including Arabic, Urdu, Dari, and Somali. One and the same female interpreter assisted three interviews that were conducted in Arabic. Through all interviews, the interpreters sat beside the participants, and I sat in front of them. Before beginning the interviews, the interpreters explained their roles and duty regarding confidentiality and signed a declaration form. All interpreters used consecutive interpreting styles, meaning that only one person spoke at a time. While conducting the interviews, I experienced that not only the interpreter's professional qualifications but also their personal characters influenced the interaction between all three parties. The interpreter's professional and personal characters influenced the openness of participants and how free they felt to share their experiences.

Through the interviews, I mainly looked at the parents and was sensitive to non-verbal signs they made through eye, hand, and body gestures. I also was aware of regulating my pace while speaking or asking a question to allow the interpreters to translate the conversation. The interpreters also often guided the participants to slow down or pause to manage interpreting their statements. Some interpreters communicated not only with words but also via transferring the parents' emotional expressions by gesture and varying intonations, as has been recommended (133, 135). In coordination with the parents and interpreters, we took several breaks while interviewing. Conducting interviews through an interpreter is time consuming and can be tiring for all parties without taking a break (136).

Despite all these considerations, some issues were raised while conducting the interviews. I noticed that some interpreters did not interpret participants' statements completely but summarized and/or modified them. Although exact translations are not the goal of interpreter-facilitated conversation (134), it is important that interpreters remain as close as possible to the words and meaning of participants' statements (137). One interpreter only interpreted what she considered as relevant to the interview questions. I explained how vital it was that the interpreter translates the parent's statements completely. Freed (133) points out that an interpreter has to be a natural party, linking the interviewer with the interviewee without adding or subtracting from their conversation. Some interpreters guided the parents if they perceived that their responses were not relevant without mentioning it to me. However, an interpreter is responsible for informing the interviewer or the interviewee when a question or statement is unclear, without interfering with their communication (133). I noticed that one interpreter even asked the parent some questions of her own curiosity or interest that had nothing to do with the study. After ending the interview, the same interpreter expressed her regret about accepting such a tiring and financially unprofitable task. These experiences may show how the interpreter's role has a substantial impact on the interview situation and its outcomes (136), and even assigning interpreters within the three recommended categories by the guidelines is not a guaranty for the quality of the task they accomplish.

4. 2. 2. 2 Interviewing children with disabilities

Children with disabilities have the right to express their views and participate in research, rather than relying on adults as proxies (138). Thus, this study chose to explore the experiences of both the children and the parents. There is also little research that reflects these children's own experiences of services provided to them. All children in this study communicated with verbal speech, and informed consent or assent together with informed consent from their parents was obtained. The interview guide included broad, open-ended questions, using clear, simple language with words that were familiar to the children. During the initial stage of each interview, I tried to further adapt the questions according to the children's responses to facilitate the flow of the conversation.

Some children in this study were familiar with me due to my role in the prior developmental project. I was present during parts of their stay at the rehabilitation center and had informal conversations with them at the time. This familiarity, together with my experiences of working with children as a pediatric physiotherapist, facilitated the interviews and made them feel comfortable expressing themselves. Prior to each interview, I used a sufficient amount of time to inform the children in simple language about the nature and purpose of the study, my role as the interviewer, and the interview procedure. I particularly emphasized that they could not be identified in the research outputs. I also informed the children about audiotaping of the interviews and asked them if they had any questions before beginning the interview process. The children also received information about how to contact me later on if they had any questions or if they wished to withdraw their assent. I provided all this necessary information to the children prior to each interview to enable them to make an informed decision about their participation in the study (138).

Although all the children were informed that they could take a break, refuse to answer questions, or ask to end the interview whenever they wished, only one child asked to end the interview almost at the ending of that interview. Creating safe spaces in which children can feel free to express themselves and share their experiences is important while conducting interviews (139, p. 114, 140). During the interviews, I listened carefully to the children and gave them time to think and respond without feeling any kind of pressure (139, p. 114). They could also choose to be interviewed alone or in the presence of their parents. As a result, all but three children were interviewed in the full or part presence of their parents. Having their parents nearby was reassuring for the children and might have helped them to express themselves easily. Two parents also assisted their children's contributions by reminding them about their shared memories of participating in the rehabilitation program or activities they participated in back home after the rehabilitation. However, one of these parents was too engaged and interfered with the interview several times. At that moment, I found it difficult to ask the parent to not interrupt the interview and instead chose to ask the child the same question again. While interviewing another child, she asked her mother whether it was okay to tell me about some of her memories regarding participating in the rehabilitation program. As these experiences may show, although parents' presence was comforting to the children and might have facilitated producing richer data, it might also have disturbed some children's views being heard (141). One of the children was also interviewed by phone because of her mother's preference. Although the phone interview went well, I experienced that it affected the natural flow and quality of the conversation to some extent. At the end of each interview, I appreciated the children's willingness and interest in sharing their experiences and explained how their participation could contribute to improving the services for other children with similar challenges.

4.2.3 Participant observation

Participant observation can offer important contributions in research within the healthcare setting involving children and families by providing insights that are not as accessible through other research methods, such as interviews (142). According to Söderström et al. (121), observations provide the opportunity to grasp interactions that are lived but not conscious or articulated. Participant observation is also an analytical tool that enhances the quality of the interpretation of data, whether they are produced through participant observation itself or other methods (142, 143). Therefore, participant observation was considered to be a supplementary method together with semi-structured interviews in the second part of the current study (article 2) (144). Applying observation in this research offered the opportunity to obtain insights into the context of the study, the interaction between the families and professionals, between the families themselves, and the families and their surroundings as well (145, p. 432). It also stimulated reflections and provided a wider perspective for interpreting the data during the analysis process.

The initial idea of applying observation began during the former developmental project. As a project coworker at the time, I was responsible for producing a report about the experiences obtained through the project. To accomplish this, I decided to reside at the center during part of the immigrant families' stay and participation in the program. The families were divided into two groups, each including seven parents and their children who participated in the program in May and October 2015. Spending time at the center, observing the families in the varied settings, and having informal conversations with them helped me to better understand the daily routines, the program, and the interactions in which families were involved. I also became familiar with the staff, established trust, and gained insight into the organizational culture that influenced their practice. Some families also gave consent verbally to be observed during their individual conversations with the rehabilitation professionals, including the goal-setting process and evaluation of the intervention. Doing these informal observations and writing notes raised my awareness about the benefits of applying observation to gather insight into the ongoing interactions between families and rehabilitation professionals and families themselves. These experiences encouraged me to apply observation as a supplementary method within this study.

Because most of the families consented to participate in the study after their stay at the center, the opportunity for observation of the participants was limited. Therefore, only three families who gave consent prior to their stay at the center were observed during parts of their stay in December 2017 and January 2018. However, as explained earlier, observation was used only as a supplementary method. Morse (144) points out that the supplementary component within a study is not a complete project and is not publishable by itself. The supplemental component is conducted only to the extent that the researcher obtains the information required (120 p, 24), and its results can only be interpreted within the core component of the study. According to Morse (144), the supplementary method can be observations in particular settings, which may have not reached saturation per se, but a particular question might have been answered to the satisfaction of the researcher (144). In this study, observation as a supplementary method provided important knowledge, particularly regarding the interactions between the professionals and families, and how the professionals handled the families and the challenges they faced in the context of the rehabilitation center.

Observations took place at a range of occasions, such as the arrival of the families, conversations with the rehabilitation professionals, intervention activities, leisure activities, informational meetings, meals, and periods of informal conversations. As Carnevale et al. (142) notes, it is often challenging for a researcher to specify what to observe in advance and/or to what degree to participate in the setting. In the current study, the experiences gained through the developmental project enabled me to refine the areas of observation and what to observe (145, p. 432). Thus, I mainly focused on the interactions, patterns of communication, decision-making, and parents' role and involvement in the rehabilitation process of their children. In terms of the degree of participation and the researcher's role, I inevitably played different roles during the observations. Sometimes, the professionals or the parents asked for help or engaged me in their interaction, which made me shift between different roles and varying degrees of participation (146, p. 85, 87). Furthermore, despite spending time in different settings to make my presence familiar to the families and professionals, it was not possible to completely remove the observer effect (145, p. 432). I experienced that in my presence, some professionals were more concerned about the quality of their conversation with the parents than they would typically be. After one of the conversations regarding the goal-setting process, a health professional told me how sorry he was that the conversation was conducted without an interpreter. He felt bad that he had to adjust his language and use simple words that hindered having a deep, quality conversation with the parent.

Following each observation period, the descriptions of events, conversations, and reflections were written. Two of the observed parents were also interviewed later. One of these parents had grown up in Norway; the two others spoke little Norwegian. I experienced that the observations, as a supplementary source, enriched the data developed by the interviews by providing insight into the context of the studied rehabilitation center and interactions between the families and professionals and the families themselves.

4.2.4 Data analysis

In this study, an inductive and reflexive thematic analytical approach was applied to explore the meaning patterns in the data produced by the interviews and the observations. Such an approach highlights that the starting point of the analysis is within the data rather than existing concepts or theories. A reflexive thematic analysis emphasizes the active role of the researcher in the process of producing the knowledge (147). Thematic analysis, with its theoretically flexible approach, is applicable across a range of descriptive or interpretative designs in qualitative research and is widely used within health and well-being research (147, 148). This flexibility stems from its status as an analytical method rather than a methodology that is informed by a particular theoretical framework. Thematic analyses also offer flexibility around data collection and allow applying different methods, including interviews and observations (147). Therefore, thematic analysis was chosen as a compatible analytical method for the present study and its hermeneutic approach. Thematic analysis was applied following a six-step reflexive and recursive process, rather than a strictly linear process, to develop initial codes and themes (147). In this section, the analysis process conducted in all three articles is first explained. Then, the process within each article is further explained in detail.

At the first step, the interview transcripts (articles 1, 2, & 3) and field notes (article 2) were read and reread individually to develop a deep familiarity with the content of the data and noticing interesting features. A "quotable quotes file" was also created to ensure that particularly powerful pieces of data would not either be lost or dominate the evolving analytical process (149, p. 149). Another file named "reflection notes" was also created to register my initial impressions and thoughts regarding both individual data items and the entire dataset together with further reflections throughout the whole analysis process (147).

Then, the data-driven coding was performed by paying attention to make sense of the data systematically. Except for the first article, in which the codes were defined in Norwegian, the codes, themes, and final report were all provided in English to reflect upon the linguistic nuances within the key concepts early on. The initial codes were also defined broadly to bring together a group of data extracts that could be related. Then, these data extracts were collated for each code to facilitate the subsequent phases of the analysis. In this phase, the analysis involved making sense of the relationships among the various groups of coded data belonging to parents (articles 1, 2, & 3), children (articles 2 & 3), and the field notes (article 2) by moving within and across the groups of data extracts within each code to develop potential themes. A repetitive thinking and reasoning process and shifting attention from similarities between certain cases to the differences between other cases led to linking data elements together across the different codes. Thus, data extracts were reorganized into preliminary themes related to the research questions in each article, as the result of an intersection of the produced data, the research questions, and my own experience and subjectivity (147).

Next, in the refining phase, the codes and initial themes were reviewed by all three of my supervisors and me to ensure that the coded data within the themes cohered meaningfully, that the initial themes and theme names concisely and comprehensively captured what was meaningful about the data and the research question, and whether there was a clear distinction between the themes. Consequently, the theme that was not relevant to the research question was discarded (article 1), some themes were merged and formed new ones, and some were divided into new themes and subthemes (articles 2 & 3), themes names were changed, and new themes were identified. Finally, I created a report as the preliminary results, including the themes and representative quotes to describe the participants' experiences within each theme.

This initial report was reviewed by all three supervisors for further checking of how well the themes worked regarding the data set both individually and together. Revisions of the themes' content, structure, and order was an ongoing process that continued through working on the results and discussion (147). The codes and the initial and final themes for each article are presented separately below.

Table 4. Illustration of the analysis process in article 1

Codes	**Initial themes**	**Refining**	**Final themes**
Parents' transcripts			
- Immigrants may be difficult to reach - Services that are not adapted	1) The alienation of immigrants	Discarded	
- Experience of communication - The interpreter - The organizational framework	2) Communication between immigrant families and healthcare professionals	Refined	1. Communication beyond the language
- Satisfaction with the services - Gratitude - The strengths of the services	3) Gratitude towards the healthcare system	Refined	2. Immigrants' grattitude for the services
- Underestimating parents' worries - Back and forth in the health system - The parents' stories of struggling - The limitation of the services	4) The battle to access help	Merged with initial theme 5	3. Accessing help as a battle
- Perceived attitudes - Perceived discrimination	5) Prejudice as an additional challenge while navigating the healthcare system	Merged with initial theme 4	
- A lack of information - A lack of support - Social workers as facilitators	6) Access to information	Refined	4. Finding a way through the service system

As has been demonstrated (Table 4), data within the first article were ultimately organized into 17 codes. By linking data elements together across the codes, data extracts were reorganized into six initial themes. Through the refining phase, the first theme was discarded because it did not fit with the other themes and was considered irrelevant to the research question. Two initial themes (4 & 5) were also combined, and a new theme "Accessing help as a battle" was defined. Two initial themes (3 & 6) were also renamed after refining. The following is an example of the coding of the data extracts related to a parent's transcript (Table 5).

Table 5. Coding of the data extracts related to a parent's transcript

Data extract	Coded for
I have lived in Norway for several years, but I kind of feel that if I go somewhere where they do not know me enough, they just set a lable on me, a mother with a hijab and from Somali, right, then you do not get the best services, you do not get the most qualified person working there, right…(P 4)	Perceived attitudes Perceived discrimination

As illustrated below (Table 6), the parents’ transcripts in article 2 were organized into 14 codes and those of the children into six codes. The field notes were also organized into three main codes. Data extracts within each code related to the field notes, and the interview transcripts of both the parents and the children were merged and formed the first initial theme “A multidimensional program”. This theme was then refined and divided into two final themes, “Learning through participating” and “Sharing the same experience”. The coded data extracts related to the field notes and the parents’ transcripts were also linked together, and the theme “Gaps in the service delivery” was developed. This theme was then further analyzed, and three subthemes were generated to give structure to the results and help readers to follow its key components.

Table 6. Illustration of the analysis process in article 2

Codes			**Initial themes**	**Refining**	**Final themes**
Parents’ transcripts	*Children’s transcripts*		1) A multidimensional program	Divided into two main themes	1. Learning through participating 2. Sharing the same experience
- Connecting to nature - Trying varied activities - Becoming aware of the children’s interests and capabilities - Improving and learning new skills - The goals	- Learning new skills - Trying varied activities - The goals				
Parents’ transcripts	*Children’s transcripts*	*Field notes*			
- Socializing with other parents - Exchanging information - Meeting other children with similar challenges - Safe environment	- Making friends - Having fun - Safe environment	- Group dynamic			
Parents’ transcripts	*Field notes*		2) Gaps in the service delivery	Divided into three subthemes	3. Gaps in the service delivery - Lack of information about the services - Unmet needs of the family as a whole - Communication difficulties
- Knowing about the center for the first time - Communication experiences - Making an inclusive program - Challenges for participation in the program	- Goal-setting process - Communication challenges - Group dynamic				

The following is an example of the coding of the data extracts regarding the field notes within the second article (Table 7).

Table 7. Coding of the data extracts related to the field notes

Data extract	Coded for
The health professional explained to the family (mother with both of her children) that she had assigned a telephone interpreter for the consultation, but she had to share the interpreter with a colleague who would also have a conversation with the family; therefore, she (the health professional) had to be quick. The phone connection was poor, and it was challenging to follow the conversation through the interpreter. It seemed that the health profession did not have much experience working with the telephone interpreter, which further affected the flow and quality of the conversation... (field notes, the rehabilitation center)	Communication difficulties (time restriction, poor connection, a lack of experience working with the interpreter)

In article 3, as illustrated below (Table 8), the data were organized into 13 codes, six of which being commonly defined for both the children's and parents' transcripts, and seven only being related to the parents' transcripts. Linking and merging data elements across the different codes related to both the parents and children resulted in developing two main themes—"transformation" and "participation pattern". Two initial themes were also identified by merging data across the codes related only to the parents' transcripts; these themes were merged within the refining phase, and a new theme "Transition to the local community" was defined.

Table 8. Illustration of the analysis process in article 3

<table>
<tr><th colspan="2">Codes</th><th>Initial themes</th><th>Refining</th><th>Final themes</th></tr>
<tr><td colspan="2">Parents transcripts</td><td rowspan="2">1) Experience of services after rehabilitation</td><td rowspan="2">Merged with initial theme 2</td><td rowspan="3">1) Transition to the local community</td></tr>
<tr><td colspan="2">- Lack of services after rehabilitation
- Parents' expectation of services
- Parents' experiences of post-visits</td></tr>
<tr><td colspan="2">- Challenges
- Facilitators</td><td>2) Challenges and facilitators to participation</td><td>Merged with initial theme 1</td></tr>
<tr><td>Parents transcripts</td><td>Children transcripts</td><td rowspan="2">3) Transformation</td><td rowspan="2"></td><td rowspan="2">2) Transformation</td></tr>
<tr><td colspan="2">- Acknowledgment
- Experiences of changes after the rehabilitation</td></tr>
<tr><td>- Activity habits
- Activity types
- School activities
- Physiotherapy
- Support contacts
- Parents' lack of demanding skills</td><td>- Activity habits
- Activity types
- School activities
- Physiotherapy</td><td>4) Participation pattern</td><td></td><td>3) Participation pattern</td></tr>
</table>

An example of coding of the data extracts related to a child's transcript is also presented below (Table 9).

Table 9. Coding of the data extracts related to a child’s transcript

Data extract	Coded for
Before [rehabilitation], I was like a child. I feel like I am wiser now. I do my homework. I do sports now…Yesterday, I went to the Dragen [youth sport club] and played basketball with other children there… (C 3, aged 16 years)	Experiences of changes after the rehabilitation.

In this section, the analysis process conducted in all three articles was explained and illustrated in detail with examples of coding data extracts (Tables 5, 7, & 9) regarding the observation and interview transcripts of both the children and their parents to enhance the transparency of the analysis. In the following section, the ethical issues within the current study will be discussed.

4.3 Ethical considerations

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

However, ethical issues arise during different phases of a research process, including the research design, beginning a study, data collection, analysis, and reporting the data (109, p. 95). In the following, some ethical issues that I faced in the initial phase and though conducting the study are discussed.

4.3.1 Ethical issues regarding “informed consent”

Most guidelines for ethical research demand all participants to agree to research before its commencement (150, p. 60). Accordingly, NSD requires the researcher to give information about the research and gain consent from the participants before beginning. To fulfill this demand, the researcher has to prepare a consent form including information about the project to request participation (151). For the consent to be valid, it must be both informed and voluntary. Thus, informed consent entails two related activities; first, participants need to comprehend it, and second to agree voluntarily to the nature of the research and their role within it. However, written consent forms can be rather difficult to follow and often require participants to have high levels of literacy and language ability (150, p. 59). Researchers need to provide potential participants with a substantial amount of information about the purpose, methods, demands, risks, and possible outcomes of the research, including whether and how results might be disseminated.

Following these demands, I ended up with a consent form in Norwegian comprising five pages. Although I consciously avoided using difficult terms, it was not easy to find substitutes for some key concepts such as “confidential” or “anonymizing”. Although such concepts may be difficult to comprehend for any participants, they would be more challenging to understand for non-Norwegian ones. Smith (152, p. 99) points out how the principle of informed consent causes problems for both researchers and participants. She discusses what it really means to be informed for people who may not be literate or well educated or who may not be able to speak the researcher’s language. She further refers to those people who potentially cannot even differentiate the invitation to participate in research from the required compliance in signing official forms for welfare and social services. Some potential participants in the current study told me how they initially perceived that the consent form was an invitation from the rehabilitation center for another participation in the program. These experiences illustrate how the demand for informed consent in practice and in some situations could be quite difficult to follow (150, p. 54). To overcome these challenges, I gave the potential participants information verbally over the phone in simple language after they had received the consent forms. In this way, the potential participants also had the opportunity to ask questions if they had something on their mind. Some participants explained how hearing my voice, probably my foreign accent, and having a conversation, made the study and me as the researcher trustworthy to them in order to participate.

Assessing the voluntary nature of participants’ consent as a demand for validation of the consent was another ethical issue in the current study. Some potential participants were familiar with me due to my role in the former developmental project “Active Together, Possible for Us?” with which they were highly pleased. Furthermore, participants in the current project were mostly from cultures where it is not usual or polite to give an explicit decline. Both these factors may have influenced the nature of their consent to this study. As Israel et al. (150, p. 60) indicate, it is difficult for the researcher to assess the true extent of the “voluntariness” of participants’ consents. All these issues show that the claim to universal principles is one of the difficulties with ethical codes for conducting research (152, p. 99). According to many social scientists, the principles of informed consent have been adopted mechanically by research ethics governance structures and created an artificial and culturally inappropriate bureaucratic process (150, p. 55, 64). Therefore, an indigenous approach to research that offers alternative ways of knowing and thinking about ethics that are unique to each culture will be necessary for overcoming these types of challenges (152, p. 101).

This study also included children with physical and varied types of developmental disabilities. The ethical concerns regarding researching children with disabilities are similar to typically developing children (154, 155, p. 97). However, it is particularly difficult to be confident that procedures for gaining informed assent are adequate for those children with intellectual disabilities. There are no specific methods available for ensuring their capability of providing assent either (155, p. 101). Therefore, judgment regarding the capacity to give assent or consent needs to be made on the basis of each study, rather than by an overall decision about an individual's capacity (155, p. 101, 156). The purposes and requirements of some research, such as the current study, are more easily understandable compared to others. The capacity to understand what a study entails will also partly depend on the vocabulary used to explain it (155, p. 101). In this study, prior to each interview, the study's purpose and contents were explained to the children with a simple language adapted to their understanding level to assure that they were informed and comfortable with participation in the study. As Kellett et al. (157) point out, it is important that the push and demand for informed assent do not lead to excluding children with disabilities from research because researchers may perceive that it is difficult to include these children.

4.3.2 Interviewing participants experiencing disparities and marginalizing

Interviewing participants experiencing marginalizing and disparities may be emotionally challenging for both researchers and participants. Therefore, researchers need to be flexible and adequately prepared to face ethical dilemmas before conducting these kinds of sensitive interviews (158). However, participants' reactions to the terms and topics will be highly individualized, and it is not always possible to be well prepared as a researcher with relatively little experience. Within the present study, I experienced how some parents became emotional and even cried while conducting the interviews. One of the parents was agitated and reacted to the term "immigrant" when I was explaining the study and its aim prior to the interview. The parent stated immediately that she did not consider herself as an "immigrant" because she had a high level of education and a successful job in Norway. As an immigrant myself, I did not expect this kind of reaction from another "immigrant". I considered myself an absolute "insider" and did not expect that a participant would react to what we actually had in common, being an "immigrant" in Norway. I actually did not know how possible and dynamic it was to be both an "outsider" and an "insider" as a researcher (159, p. 177). The notion of "insider/outsider" status is understood as the extent to which a researcher is located either within or outside a group being researched because of a shared lived experience or status as a member of that group (160). Seeing myself as purely an insider because of my “immigrant” status was, in fact, oversimplifying the complexities of my relationship as a “researcher” with the participants (161). To this participant at that moment, I was most likely a total “outsider” who had attempted to simply classify her as an “immigrant” in Norwegian society. Thus, she strongly resisted being identified as an “immigrant” and not “the person” she really was. She was, and still is, a successful member of the society and a caring mother of three children. She had to constantly fight through the legal, healthcare, and educational system for the best interests of her child with a disability, and I had unintentionally reduced her identity to only be an “immigrant” in the society.

According to Johnson et al. (162), the groups and social categories in which people belong play an important role both in the development of their self-concept and in perceptions of others. Hence, accepting to be labeled as an “immigrant” might cause this group of people to be confronted and influenced by the stereotypes associated with the term “immigrant” (162). Media and political narratives that link migration to insecurity and other social disorders have hardened attitudes towards the immigrant population over the years (107). This participant later explained how society typically applies the term “immigrant” only related to those who do not have any education or recourses and are dependent on the social and welfare system. Although I argued how this participant with all her qualities could show the society another side of being an “immigrant”, she strongly refused to be categorized as an “immigrant”. This experience raised my awareness about the importance of paying attention to using terms such as “immigrant” for people who may have experienced marginalization due to being labeled as an “immigrant”. As a researcher, I should have reflected upon what the term “immigrant” could possibly mean to the different people involved in this study. I was not aware how understanding of the term “immigrant” might have changed over time, and applying it uncritically could cause tensions and consequences.

Some other participants who had experienced disparities or perceived attitudes while interacting with service providers also became highly upset and even cried during the interviews. They described years of struggling to obtain the help they required and perceived that their immigrant status influenced the way they were treated by service providers and the services they received. I was not always prepared for the intensity of emotions expressed by the parents and was a little hesitant about how to handle the situation. My attempt to maximize the space for parents to tell their story without being influenced or interrupted was the main reason for my hesitation. However, I listened to the parents with compassion, allowed them to express their feelings, and asked them to take a break if necessary (158). As these experiences demonstrate, participating in the interviews might have caused emotional burdens for the parents. However, they were mostly pleased that they had the opportunity to speak up and express their feelings, needs, and experiences. Some even articulated their satisfaction about raising, what they considered to be, important subjects by conducting this kind of research. Furthermore, parents had the opportunity to access the information about the services they needed by asking me questions after the interviews. I also had to emotionally deal with parts of the interview material that covered the struggles, grief, and pain that some parents had been through. Conducting sensitive interviews requires, therefore, the development of reflective research skills that enable the researcher to be prepared for overcoming these emotional challenges.

4. 4 The researcher’s role and reflexivity

Reflexivity is an integral part of ensuring the quality and transparency of qualitative research and is commonly viewed as the process of a continual self-appraisal of a researcher’s position within the research and how it may affect the research process and outcomes (153, 163). In hermeneutic research, it is especially important for researchers to be reflexive and be able to clarify their own preunderstanding and move beyond it to comprehend the phenomenon of interest (117). Preunderstanding includes the values, assumptions, experiences, academic perspective, theoretical knowledge, and even expected findings that the researcher brings into the project (164, p. 45). Reflexivity is crucial throughout all phases of the research process, including the formulation of a research question, producing and analyzing data, drawing conclusions, and finally reporting the research (153). In this section, I will reflect upon my personal and work experiences and my position within the current study because they have directly impacted the knowledge co-created between me and the participants (161).

I am an immigrant from the Middle-East and mother of two children with experience of working as a physiotherapist in the specialist healthcare system in my country and as a pediatric physiotherapist in the primary healthcare system in Norway for several years. As an immigrant and physiotherapist, I approached the current study with some insights and preunderstanding. Shortly after beginning to work as a pediatric physiotherapist in a multicultural district in Oslo, I noticed how my colleagues simply classified the service users into two main groups; “disadvantaged” or “resourceful”. The “resourceful” group referred mostly to ethnic Norwegian families who were cooperating and easily accessible. The “disadvantaged” group, on the other hand, mainly included immigrant families who were difficult to get in touch with and problematic to collaborate with. To my surprise, this way of classifying the service users was also uncritically and commonly used among our coworkers in the other service organizations and sectors. I also noticed how all those challenges of working with a "disadvantaged" group, or in other words, immigrant families, were easily explained by their cultural backgrounds. These experiences, over time, increased my sensitivity about the concept of "culture" and how it had gradually become a negative loaded concept among service providers to explain all difficulties of interacting with immigrant families. I then became interested in looking further into the nature of the challenges related to the interaction between immigrant families and healthcare services. In 2014, I was appointed as a project coworker connected to the former developmental project. I had a responsibility to inform and encourage immigrant families in the Oslo area to participate in the studied rehabilitation program. During the initial stages of the project, I noticed that whereas immigrant families' main concern was to overcome their challenges to participate in the rehabilitation program, rehabilitation professionals were mainly concerned about how to cope with the cultural differences. All these experiences became an important part of the inspiration for and influenced designing and conducting of the current study.

As an immigrant myself, I had experience coping with the hardships of re-establishing my credentials as well as my financial and social status, becoming familiar with a completely different society, learning to live in a different culture and new language, and coming to terms with my dual identity (153). The shared immigration experience with the study participants positioned me primarily in an "insider" role and brought me some advantages in studying the familiar. Being an "insider" helped me gain trust and facilitated establishing rapport with the participants. It also increased the participants' level of comfort and openness during the interviews and observations, facilitating the production of deep, rich data. Some of the participants even expressed satisfaction and confidence that I, as both an immigrant and researcher, was able to understand and represent these families' experiences and struggles within the current study (153, 161).

Despite all those benefits, being primarily in an "insider" position increased the possibility of overlooking some aspects of the produced data or taking them for granted (161). However, my three Norwegian supervisors with their different professional backgrounds in the health and social sciences as the "outsiders" were engaged in the analysis process and description and discussing the results to ensure that varied aspects of the data were considered and presented. Drawing upon their knowledge and experiences, the supervisors guided me through the research process into the topics at hand. Furthermore, although I emphasized that the families’ responses would not influence the services they would receive, my connection to the rehabilitation center and my prior position within the developmental project might have affected their responses, particularly regarding the rehabilitation program (article 2).

5 Results

In this chapter, the results of the three articles that constitute the basis of this study are briefly reported. At first, the results of the interviews with immigrant parents of children with disabilities regarding their experiences of navigating the Norwegian health and rehabilitation services are presented (article 1). Then, the findings from observation and interviewing immigrant parents and their children with disabilities about their experiences of participating in the rehabilitation program focusing on participation in adapted physical activity are provided (article 2). Lastly, the results of the interviews with the parents and their children concerning their experiences of community-based participation at least six months after the rehabilitation are described (article 3). The aim of each article is mentioned prior to the results to facilitate the reading.

5. 1 Article 1

The aim of the first article was to explore the experiences of immigrant parents seeking care for their children with disabilities and generate knowledge of how accessible and tailored the services were from their point of view. Four main themes were identified after analyzing the data: (1) immigrants' gratitude for the services, (2) communicating beyond language, (3) finding a way through the service system, and (4) accessing help as a battle.

The first theme "immigrants' gratitude for the services" shows how satisfied and grateful the parents were with regard to the services, particularly the follow-up services provided by the regional rehabilitation centers. They experienced these follow-up services as continuous, predictable, and well organized, which took care of several important dimensions of their children's development. Parents also appreciated how attentive the healthcare providers were with their children and how well they handled them. They also valued how the healthcare providers talked to them and informed them about their children's conditions and planned interventions, which was quite unfamiliar in their countries. Parents compared health services in their home countries with Norwegian services, potentially reinforcing their gratitude and satisfaction.

The second theme "communicating beyond language" describes how parents experienced communication with the healthcare providers differently. Some experienced communication difficulties because of language barriers and emphasized how disturbing and frustrating it was to communicate through interpreters, whom they perceived as unprofessional. Some others experienced that communication in the context of the healthcare system was beyond speaking the same language. They believed that the healthcare providers’ engagement, empathic listening, experiences, and even their body language influenced the experience of the communication. Parents also noted how the dominant organizational culture, especially time pressure, influenced communication in the context of the healthcare system despite management of the language barrier. There were, however, parents who stated that their ability to ask questions together with the healthcare providers’ patience and ability to explain and adjust their language contributed to overcoming language barriers and made them feel satisfied with the communication. Some parents also overcame language difficulties by communicating with healthcare providers through their spouses or children who could speak Norwegian.

The third theme, “finding a way through the service system” is about the parents’ experiences of not receiving the necessary information required to manage navigating the services. The parents experienced that healthcare providers did not provide them with information about the rules or their rights. Lack of information about the services together with the lack of support to navigate the services limited parents’ ability to access the services. Some experienced that they received information randomly by meeting other parents because the healthcare providers were not always aware of the services available to them. It was not easy for parents to know what to ask from healthcare providers either. Parents stated that the healthcare system was structured in a way that only benefited privileged clients who were already able to fully navigate the services. Parents typically received information and support from social workers only in the very early years after their children had been diagnosed. Considering that family situations and healthcare options vary over the years, the parents’ need for information was not completely met by the social workers.

The last theme, “accessing help as a battle” indicates the parents’ struggle back and forth in the healthcare system through the years of seeking help and services. Parents felt that their concerns had been underestimated and not taken seriously by the healthcare providers. They experienced that the struggle over the years had even affected their mental and physical health. Some explained how they occasionally chose to take their children to private emergency care or specialists in order to obtain appropriate and timely help, even though they had to pay additionally for the consultations. Language barriers and inadequate knowledge about medical conditions and terms hindered some parents when describing their children’s conditions and made it even more challenging for them to access timely help. Some parents also perceived that their skin color and religion influenced how they were treated and the services they received.

In summary, the immigrant parents were mainly satisfied with the follow-up services provided by the regional rehabilitation centers. They felt gratitude when comparing the healthcare services in Norway with those in their countries of origin. Parents experienced communication difficulties because of language barriers, perceived unprofessional interpreters, and perceived time restrictions. They also expressed unmet needs for support and information about their rights, the rules, and the services available to them and to which they were entitled. The parents felt that their concerns were not taken seriously by the healthcare providers and explained how several years of struggling to access help affected their own health. Some parents brought up their position as immigrants and believed that this impacted the way they were treated by the healthcare providers.

5. 2 Article 2

The aim of the second article was to generate knowledge of how beneficial, culturally adapted, and accessible the rehabilitation services were from the perspective of immigrant parents and their children with disabilities. Analyzing the families' experiences revealed several aspects of the services that are presented within the three following themes: (1) learning through participating, (2) sharing the same experience, and (3) gaps in the service delivery. The last theme reflects only parents' experiences and is presented within the three subthemes: lack of information about the services, unmet needs of the family as a whole, and communication difficulties.

The first theme "learning through participating" presents parents' and children's experiences of the opportunity to try some new and different activities during their participation in the studied rehabilitation program. Doing activities intensively was an opportunity for the children to learn new skills and made them more confident about their abilities. Participating in varied activities also made them aware of their interests and capabilities. Furthermore, parents became aware of their children's strengths, capabilities, and interests by participating in activities together with them. The experience of performing physical activities together with their children outdoors in nature was also new and thrilling to the families. Although some parents were initially skeptical about participating in the program in the mountains, they experienced a connection with nature soon after their arrival. However, some parents stated that performing many activities during the day made it difficult to keep focusing on and cooperating with the professionals for achieving their rehabilitation goals. Similar to their parents, some children also wished that they could participate only in their preferred activities.

The second theme “sharing the same experience” is about immigrant families’ opportunities to socialize with other families in similar situations. Parents felt safe to speak about their experiences, challenges, and even frustrations. By exchanging experiences with each other, parents also gained useful information about the assistive devices and services they were entitled to. Learning about and observing how other families coped with their challenges gave parents the strength to keep going, acknowledging that they were not the only ones. For children, participating in the program was also an opportunity to socialize, make friends, and have fun while doing activities together.

The last theme, “gaps in service delivery” is presented via three subthemes. The first subtheme *‘lack of information’* shows how parents received information about the studied rehabilitation program randomly through the developmental project in 2015, despite their connection to the healthcare system for several years. They noted that health professionals did not always inform them about the available services and believed that the first step to make services inclusive was to make information available to immigrants. The second subtheme ‘*unmet needs of the family as a whole’* is about the challenges that some families faced to participate in the program for three weeks far from where they lived due to the fact that siblings were not included. Although these parents brought the siblings to the center after explaining their situation, they faced other kinds of challenges during the program. They had complete responsibility for taking care of and entertaining the siblings, subsequently affecting their engagement in the program and their ability to socialize with other families. The last subtheme ‘*communication difficulties’* concerns how language barriers affected some parents’ ability to actively take part, follow, and benefit from the program optimally. Communication difficulties particularly affected parents’ ability to participate in the shared decision-making through their children’s rehabilitation process, including goal-setting.

In sum, participation in physical activities together with their children at the rehabilitation center made parents aware of their children’s capabilities and interests and the available resources, such as the Norwegian natural environment. Parents also had the opportunity to socialize and exchange experiences and information with each other. Children also learned new skills, became aware of their preferences and capabilities, built friendships, and improved their social skills. However, a lack of information, language barriers, the location of the center far from home, and excluding siblings affected accessibility of the services to immigrant families.

5. 3 Article 3

The purpose of the third article was to contribute to the development of potential pathways in supporting sustainable participation among children with disabilities and immigrant backgrounds after the rehabilitation. The final analysis resulted in three main themes, (1) transformations, (2) transition to the local community, and (3) participation pattern among children. The second theme represents only parents' experiences.

The first theme "transformations" indicates the parents' experience of progress in their children's social skills and interest in participating in activities. Some parents explained how their children took more initiative for participating in activities both at school and during leisure time. Parents were aware of the importance of their children's sustained participation and explained how they had searched to find adapted activities in their local community. Children also expressed their interest in continued participation in their preferred activities and described themselves as more social.

The second theme "transition to the local community" indicates the challenges that parents faced for continuity of their children's participation in the local community after the rehabilitation. Lack of information, follow-up services, adapted activities, social support, parents' activity competence, children's adaptive behavior, cultural challenges, distances, time restriction, and costs were among the challenges they faced. Parents explained how motivated they were initially, but after facing the challenges, they reverted to their old routines. They expressed their needs for support and services and wished that the rehabilitation center could stay in touch with them until their children managed to participate in their preferred activities in the local community. Some parents suggested or even expected that the rehabilitation center, with or without cooperation with the local professionals, could offer activities in their local community as well.

The final theme "Participation pattern among children" illustrated how participation patterns varied among children after the rehabilitation. Some participated in one or several types of organized and/or unorganized activities, whereas others did not participate in any type of leisure activity. However, there were only a few children who participated in their preferred activities. Some parents only counted on the school activities or were dependent on the services offered by the local professionals, which limited opportunities for participation among their children. Children’s participation patterns showed the potential role of support contacts as facilitators to participation among immigrant families because some children participated in leisure activities only with their support contacts.

To conclude, families became aware of the importance of participation, and some described progress in their children’s activity and participation habits after the rehabilitation. However, facing challenges, such as a lack of information and costs, affected children’s participation back home in their local community. Although parents expressed their needs for support and follow-up services for sustained participation for their children, the local and rehabilitation professionals were not always aware of or prepared for addressing the challenges the families faced to enable them to remain physically active after the rehabilitation.

6. Discussion

In this chapter, the findings of the three articles in the light of the study's theoretical framework and relevant research are discussed first. Then, the methodological considerations in terms of the study's dependability, confirmability, transferability, credibility, and choice of theory are addressed. The discussion of the findings takes place within the following three main themes. The first theme "enhancing provision of healthcare services for immigrant families and their children with disabilities" discusses the findings of all three articles by applying family-centered service (FCS) theory. The second theme "improving rehabilitation outcomes of children with disabilities and immigrant background by improving inter-organizational collaboration" will discuss our findings in article 3, inspired by the conceptual framework for organizational integration within the healthcare system. The last theme "immigrant parents' experience of interacting with the healthcare system through an intersectionality lens" discusses the families' experiences of certain challenges to access and interacting with the services from the perspective of intersectionality.

6. 1 Enhancing provision of healthcare services for immigrant families and their children with disabilities

The findings of this study in all three articles underscore the need for providing accessible, culturally, and linguistically adapted health and rehabilitation services for immigrant families. Access is a major concern in healthcare policy that represents the degree of fit between the characteristics of health services and the nature and expectations of service users (165). As our findings revealed (articles 1, 2, & 3), service offering to immigrant families was not always based on a reasoned consideration of their characteristics and needs (166). The findings also demonstrate how the healthcare system still lacks the necessary flexibility to adapt the services in accordance with the increasing population diversity (6). Research suggests that the FCS approach has the potential to be more responsive to the particular needs of culturally diverse families (167). However, immigrant parents of children with disabilities report significantly lower levels of FCSs compared with their non-immigrant counterparts (168, 169). In this section, the importance of practicing the FCS approach for enhancing service provision for immigrant families and their children with disabilities with reference to our findings will be discussed (169, 170). The FCS approach builds on the three main assumptions, each followed by guiding principles and elements (see chapter 3), which together have been used to address our findings and direct the following discussion.

One of the main assumptions within the FCS approach is acknowledging families' diversity and uniqueness and the necessities of individualizing the services for each family (84). Consequently, cultural sensitivity is a fundamental element of FCSs that contributes to providing individualized and high-quality health and rehabilitation services for families regardless of ethnic and cultural background (170-173). Cultural sensitivity is defined as knowledge, consideration, understanding, and respect for each individual, and making adaptations to meet the individual's needs as a result of gaining awareness of one's own and other's differing cultural perspectives (174). Training in cultural sensitivity is shown to result in health professionals' increased open-mindedness, cultural awareness, and ability to communicate with service users from minority populations (175). Health professionals who practice FCSs are trained to critically reflect on their own culture and preferences and the specific cultural context in which services are embedded (6, 175).

As our findings also demonstrated (article 2), health professionals typically take the cultural context of the service delivery for granted (6) without considering how it can affect the accessibility and benefit of the services for immigrant families. Our findings revealed how providing a three-week rehabilitation program in the mountains far from where the families lived, in a context that fully represents the Norwegian culture, reduced its accessibility for some families, who had no network to take care of their children at home. Some parents were also initially skeptical about participating in the rehabilitation program because of its location in the mountains, which were culturally unfamiliar to them.

Within FCSs, health professionals are aware of communicating with the families in a culturally sensitive manner to explore and identify their preferences and needs and adapt the services accordingly (175-177). The findings of this study in all three articles showed how the professionals' lack of awareness or skills in applying culturally sensitive communication to identify the immigrant families' needs affected those families' ability to access or optimally benefit from the services. In the context of the healthcare system, communication with the families is frequently embedded in the professionals' perspective and sense of reality, and there are often professionals who ultimately direct the flow in the conversation (6, 178). This power imbalance particularly affects communication between Western healthcare professionals and non-Western immigrant families in which language difficulties together with certain assumptions about families, such as a lack of knowledge, may also exist (178). Our findings in articles 1 & 2 showed how the professionals steered communication with the families and even set the goals they recognized as important for their children's rehabilitation (article 2). Some families (article 1) experienced that the professionals were not always interested in listening to them or did not take their concerns seriously. As the findings revealed (articles 1 & 2), immigrant parents may not be able to express themselves as precisely and nuanced as necessary in their non-primary language (6) so that they can receive timely and appropriate health and rehabilitation services. Applying culturally sensitive communication as a crucial assumption within the FCS approach will lead health professionals to focus on listening and capturing the intent and meaning behind the words and ensure that they have understood immigrant parents' concerns.

Culturally sensitive communication also makes professionals responsible for ensuring that families have fully understood the content of the conversation and use professional interpreters if necessary (179). Our findings (articles 1 & 2) revealed how a lack of professional interpreters, or using perceived unprofessional interpreters, or even spouses and children affected parents' access to appropriate services and engagement in their children's rehabilitation process. Language barriers are known as one of the main obstacles to accessing and utilizing health and rehabilitation services for immigrant families (6, 45). The use of professional interpreters for both linguistic and cultural reasons is emphasized within FCSs and may, therefore, enhance immigrant families' access to and use of the health and rehabilitation services (177). Research also suggests that the use of culturally sensitive communication within FCSs is associated with increased family satisfaction, improved health outcomes, and better engagement of the families (177).

The other core assumption within FCSs is that parents know their children best. Hence, each family should have the opportunity to take part in the shared decision-making and goal-setting for their children (84). Provision of information and professional support are, therefore, key components of FCSs for enabling and empowering parents to take control and participate in the decision-making for their children (173, 180). In the current study, a lack of information and support were constantly brought up by the parents as the main challenges to access and navigating the services (6, 181-184). Some parents experienced that healthcare professionals were not always aware of the services available to them (184), and parents received information by chance (article 1). Provision of information about services and their availability is suggested as an important determinant for parents to take an active role in the care process, obtaining appropriate help, and decision-making (181, 182). Providing families with both general and specialized information relevant to their children's condition is also highly correlated with families' ratings of their sense of empowerment (185). Support from health professionals has also been shown to be highly correlated with families' positive experiences of care (185). Providing support and encouraging immigrant parents to take part in the decision-making about their children's healthcare is also necessary for shared decision-making. As our findings (article 1) revealed, immigrant parents may come from countries where health services are provided within a paternalistic model of medicine, in which health professionals are viewed as experts and parents are used to solely rely on the decisions made by the professionals (186). Therefore, the health and rehabilitation professionals need to inform immigrant parents about the elements of the FCS approach and explicitly communicate about the parents' roles as the partners in the shared decision-making for their children's healthcare within FCSs (187). Furthermore, as our findings in all three articles demonstrated, immigrant parents may face additional challenges, including a lack of social networks, financial difficulties, and language barriers that can negatively affect their ability to participate in decision-making for their children's healthcare (186). Research suggests that shared decision-making within goal-setting may increase families' sense of ownership and motivation to achieve the rehabilitation goals (188). Therefore, practicing an FCS approach with its associated empowering qualities can enable immigrant families to seek and access resources and actively participate in decision-making (173), which may positively impact their children's health and rehabilitation outcomes (186).

Lastly, the FSC approach acknowledges that optimal child functioning occurs within a supportive context, and stress and coping of other family members affect the child. Within FCSs, the needs of all family members should, therefore, be considered (84). Our findings revealed how the lack of a holistic approach among professionals (articles 1, 2, & 3) and their attempt to maintain strict boundaries around their roles (articles 1 & 3) hindered some of the families' access to the help and support they needed to overcome the challenges they faced. Some parents explained how several years back and forth in the healthcare system for accessing the help they required was an additional burden and had affected their own physical and mental health (article 1). Immigrant parents of children with disabilities are vulnerable to physical and mental distress and decreased health because they face additional challenges, including a lack of social support. Access to the healthcare and welfare systems is, therefore, important for their handling of everyday life and their own health and quality of life (183). Research shows that living with a child with a disability can also affect siblings' health and development (189). Within FCSs, the unique requirements of siblings are also considered, understood, and supported (84, 190). This consideration is particularly important while providing services to immigrant families, who often do not have a social network in their host countries (62) and have to cope with the conflicting needs of their children on their own. Our findings demonstrated how excluding siblings from the studied rehabilitation program hindered some families' access and ability to optimally benefit from the services (article 2). Therefore, there is a need to implement FCSs sufficiently to integrate immigrant families' needs within the services and make them accessible and culturally adapted for immigrant families. However, providing FCSs is time consuming and resource demanding (167). Policy-makers and funding agencies need, therefore, to acknowledge the time necessary for counseling, building rapport, sharing information, care coordination, and other areas of importance for family support within FCSs (85). Health professionals must also be supported and resourced to practice FCSs that are responsive and flexible to the varied needs of families (167, 191). There is also a requirement to educate health professionals about FCS theory and its principles (85, 191-193). Research suggests the need to reach a shared understanding about what FCS means and how it should be implemented (167). It is documented that the use of educational materials can increase the perceived knowledge about FCSs, irrespective of whether or not the recipients have familiarity with the topics (193). Whereas written materials can increase awareness and knowledge, active approaches including interactive workshops or educational outreach visits may have better potential for facilitating changes in practice (194).

6. 2 Improving rehabilitation outcomes of children with disabilities and an immigrant background by promoting inter-organizational collaboration

In this section, the importance of inter-organizational collaboration between the specialist healthcare system and the municipality for providing comprehensive and continuous rehabilitation services and improving rehabilitation outcomes of children with disabilities and immigrant backgrounds with reference to our findings in article 3 will be discussed (30). As explained previously (chapter 2), the rehabilitation services in Norway are provided by both the municipality and the specialist healthcare system (30) at different organizational levels and financed through varying budgets (195). The discussion is, therefore, mainly inspired by the conceptual framework for organizational integration in the healthcare system presented in chapter 3.

Optimizing home and community participation of children with disabilities, particularly those with immigrant backgrounds, is an important outcome of rehabilitation (66). However, our findings revealed that insufficient inter-organizational collaboration between the rehabilitation center and community-based rehabilitation services made it challenging for the families to integrate activities into their daily lives. Back home in the local community, the families experienced that they were left on their own and expressed their needs for support and continuation of services for moving towards and maintaining an active lifestyle. Some families even returned to their old routines and habits. Although adopting and maintaining behavior change is often difficult for any family (196), certain challenges unique to immigrants made it more challenging for these families. Language difficulties to access local activities, a lack of required skills, low income, and a paucity of social support were among the challenges the families faced. Therefore, identifying potential future challenges for each family and developing a multifaceted approach to overcome them is necessary when planning interventions and associated behavior-change strategies (197, 198). Clarifying future roles and responsibilities, providing follow-up services, and partnering with families after rehabilitation and throughout the process of changing behavior are all recommended for overcoming the possible challenges and achieving long-term maintenance of an active lifestyle (75, 76, 197, 199). However, our findings demonstrated how providing the intervention in the rehabilitation center without sufficient collaboration with the local professionals to map families' resources and their surroundings hindered the rehabilitation professionals to consider families' future challenges, adjust the intervention accordingly, and provide facilities collaboratively to support families overcoming the challenges back home. The lack of clarifying future roles and responsibilities, and follow-up services affected families' transition to the local community and their ability to overcome the challenges for integrating activities in their everyday lives. As these findings may demonstrate, sustainable participation demands seamless rehabilitation services by establishing an efficient inter-organizational collaboration between community-based rehabilitation services and rehabilitation centers (74, 76).

To ensure inter-organizational collaboration and integration of rehabilitation services, the Norwegian government introduced the mandatory individual care plan (ICP) in 2001 (200, 201). Years later, in 2012, the Coordination Reform, a national policy attempt for better integration of the services, was also implemented to promote interaction and good collaboration routines between municipality and specialist healthcare systems. Accordingly, changes were made to the health legislation, including clarifying the duty to appoint a coordinator by the municipality for those who require coordinated services to ensure the necessary follow-up and coordination of rehabilitation services (202). However, as our findings also demonstrate, collaboration and continuity of rehabilitation services still remain a challenge (76, 203, 204). Despite the strong political imperatives, ICP has been significantly underused (183, 200, 205), and service users, relatives, or parents often have to take over the coordination task themselves (183, 206). These findings may reveal that the change of legislation may not necessarily facilitate collaboration between service organizations at the operational level (200, 203, 204, 206, 207).

Collaboration is a form of integration that requires an effort and will be mainly achieved by voluntary agreements and mutual adjustments between the involved organizations (87, 208). Although environmental and structural factors, such as existing legislation and administrative boundaries may affect the inter-organizational collaboration (208, 209), different organizational cultures and interests, and variations in the commitment of the involved organizations and professionals are the main barriers to the collaboration (87, 210). Overcoming these barriers demands professionals and leaderships who are able to see beyond their own organizational cultures (87, 208) and collaborate for a shared purpose of providing comprehensive and user-centered services (209, 211). Facilitating contacts and communication across organizational boundaries by the leaderships is, therefore, highlighted as the key factor for a successful collaboration (87, 209, 212). Both formal and informal communication carried out on a regular basis will enhance trust and the exchange of information between organizations (203, 204, 209, 211, 212). Professional roles and tasks must also be clarified and formalized because a lack of clarity may hinder the collaboration across the organizations and create confusion for service users, as our findings also revealed. Formalizing collaboration through established collaborative processes is highlighted for a sustained inter-organizational collaboration (209, 212, 213).

Community-based rehabilitation services and rehabilitation centers need, therefore, to prioritize and facilitate collaboration across their boundaries towards the shared goal of supporting sustainable participation among the families. This collaboration is crucial both prior to and after the intervention for mapping the families' resources and needs, identifying potential future challenges, adjusting interventions, clarifying roles and responsibilities, and providing supportive follow-up services. Coordinators must also be involved and support the families on their journey towards an active lifestyle. They can play an important role in families' transition from specialist to community-based rehabilitation services by ensuring that professionals sufficiently cooperate across their organizational boundaries. In the current study, pre- and post-intervention visits by the rehabilitation program have the potential to evolve into formalized collaborative work with local professionals, including coordinators, by applying ICP as a coordination tool and action plan in supporting community-based participation among immigrant families. Applying the ICP that contains an outline of the rehabilitation goals, families' resources, and required follow-up services for each family may facilitate the transferring of information between the professionals across organizational boundaries and contribute to providing coordinated services that support families to cope with the challenges they face towards an active lifestyle after the rehabilitation (214).

6. 3 Immigrant parents' experience of interacting with the healthcare system through an intersectionality lens

This study's findings in all three articles revealed how living a life at the intersection of immigration and disability made it challenging for parents to access and navigate the services. The results may also reveal how the experience of interacting with the services as a parent of a child with a disability is intertwined with the experience of being an immigrant (95). Hence, in this section, at first, the complexity of the challenges faced by the immigrant families while interacting with the healthcare system will be discussed through an intersectionality lens. Then, the discussion continues to show how intersecting immigration and parenthood of a child with a disability within a context of privilege disparities in the society influenced the way parents appraised and even appreciated the services despite all the challenges they faced.

As our findings revealed (articles 1, 2, & 3), parents experienced specific challenges related to being an immigrant that exacerbated the difficulties to access and navigating the services, including communication barriers, unfamiliarity with the services and how to seek them, a lack of social support, and low socioeconomic status (6). This latter factor itself is one of the particular reasons for health inequity in Norway (215) and could further impact the parent's own health status (216).

In addition to all these challenges, perceived stereotypical attitudes among healthcare providers further complicated access and interaction with the healthcare system for some of the families (217, p. 227) (article 1). Some parents perceived that they were treated differently from native Norwegian families within the context of the healthcare system (218, 219). They experienced that their interactions with the healthcare professionals were embedded in different forms of discrimination related to their immigrant status, religion, skin color, and race (article 1) (220, p. 110-111).

These perceptions may not be surprising considering the current anti-immigrant sentiment in Western countries (221) and how media and political narratives link immigration to terrorism, insecurity, and other social issues (107). Although in Norway, attitudes towards immigrants have become more positive over time, there is still 16% of the population who quite agree that immigrants are a source of insecurity in the community (222). Approximately half of the Norwegian population are skeptical about Muslims, potentially explaining why many immigrants from Muslim countries (e.g., some parents in the current study) experience discrimination (223). This skepticism can be a result of the current framing of Islam in mass media, social media, and politics in a negative and stereotypical manner within Western countries (178). Therefore, healthcare professionals need to be aware of their attitudes while interacting with immigrant families, who might have experienced many years of stigma and discrimination in the society. Even the feeling of being treated differently than the natives may be experienced as offensive and cause emotional distress among immigrant families. In Norway, a life condition survey of immigrants revealed that six percent of immigrants had experienced discrimination due to their immigrant background within the healthcare system (224). Such a sense of discrimination, in addition to other barriers related to being an immigrant, can even cause the families to avoid using the healthcare system (218). Discrimination because of skin color, race, ethnicity, or religion has been considered a driver for inequities in healthcare (219, 225).

As discussed earlier in this chapter, training in cultural sensitivity and providing culturally sensitive services are suggested for promoting equitable health outcomes responding to the needs of immigrant families, regardless of their culture, religion, or origin (226, 227). Culturally sensitive health professionals are aware of their own attitudes and behavior, try to explore immigrant families' views and values, and resist stereotyping (175). However, although cultural sensitivity is important while interacting with immigrant families, this alone is not sufficient to address the multilevel factors affecting access and use of healthcare services among diverse immigrant groups (228, 229). Some of the factors driving health inequities, such as structural racism and nativism are shaped by socio-political contexts (225), and policy reforms are required to reduce structural discrimination and 'othering' to improve immigrant families' access to services and health equity (228). Healthcare professionals also have a central role and responsibility to transform the dominant discourse surrounding immigrant families and facilitate their access to the health and rehabilitation services (227). A recent research study conducted in Belgium revealed how healthcare professionals frequently mentioned certain groups of immigrants as ‘the others’, including Muslim patients and those with roots in Northern African and Middle Eastern countries (178). Another study conducted at a Danish hospital showed how most healthcare professionals considered immigrant patients to be a specific strain on the Danish healthcare system (230). By overcoming ‘othering’, healthcare professionals can also better understand their own biases and assumptions that hinder intercultural interaction and mutual trust while interacting with immigrant families (231).

However, despite all these challenges, parents in this study were mainly satisfied with the services they received (articles 1 & 2). Some parents were even hesitant and cautious about discussing the challenges they had experienced because they were afraid of being perceived as ungrateful or demanding (article 1). Comparing the services with those in their home countries made parents even more appreciative of the Norwegian healthcare system. Previous research also illustrates how immigrant parents from non-Western countries felt gratitude when comparing the services in their host countries with their own countries (95, 232, 233). Research shows that immigrant parents appreciated the services, even if they did not meet their expectations (233). Sandhu et al. (233) interpreted immigrant parents’ appreciation as a reflection of their assumptions that health services are privileges that can be withdrawn rather than rights. Immigrants may also have lower expectations of healthcare systems (234) because of not knowing about their rights in their host countries, as noted by the parents in this study (article 1) (85). These findings may show how intersecting immigration and parenthood of a child with a disability within a context of privilege disparities, where those capable and resourceful parents with knowledge about their rights and services will expect more and receive more services (25), influence the way immigrant parents appraise and even praise the services. This may also explain why immigrant parents respond to the challenges they face with a stoicism that is less usual among native families (233). Hence, there is a need to inform immigrant parents about the rights and services entitled to them so that they can advocate for their children and make informed decisions (181, 182). Healthcare professionals must be aware of immigrant parents’ need to be informed and supported, even though they may not ask for it. As our findings reveal (article 1), immigrant parents may find it difficult to define and express their information needs and wait for the professionals to address a subject (235, 236). This is also important to enable the parents to meet the complex demands of navigating the healthcare system in their host countries. Peer health navigator (PHN) interventions are a promising approach to breaking down barriers to navigate the complex and often fragmented healthcare delivery systems for immigrant families. PHNs are individuals from the target population with shared lived experiences, who have been trained to support and assist others to navigate the services (237). Providing PHN programs adapted to meet the needs of immigrant families of children with disabilities may, therefore, help them to overcome some barriers to their care, particularly those newly arrived families. As our findings demonstrated (article 1), interprofessional collaboration and connecting immigrant families with social workers is also important for enabling them to navigate the health and social systems and connect with appropriate resources (11, 238). Lindsay et al. (238) argue that social workers act as cultural brokers to enhance care for immigrant families by building rapport and spending time listening and understanding the families' cultural backgrounds, priorities, needs, and advocating for their needs through linking them to the resources and helping them with paperwork to manage navigating the services.

6. 4 Methodological consideration

A researcher must make essential decisions about applying an appropriate methodology and methods of data production relevant to the research question, participants, and context of the research as soon as the initial research question is identified. The process of analyzing also raises several considerations. A researcher, therefore, must constantly reflect upon any threats to the research's validity and be conscious of the ethical responsibilities during the entire research process (239). Within qualitative research, the methodological correctness of a study is typically evaluated by its trustworthiness, assessed with the criteria of dependability, confirmability, transferability, and credibility that are discussed in this section (240, p. 236-243). There is, however, a disagreement between researchers about applying universal criteria for judging trustworthiness of the qualitative research (108, 241-243). Some researchers believe that the quality of the research cannot be assured by the application of a set of previously agreed criteria, and each study has to be appraised on its own merits (241, 243). Qualitative research should rather be able to explain itself by presenting and arguing for an internally consistent set of research epistemology, methodology, and methods (108). Reflexivity and transparency throughout the research process become, therefore, significantly important and need to be emphasized even while applying these four criteria (241). I agree with the latter approach and have emphasized transparency and reflexivity throughout the entire research process, regardless of applying these standard criteria. In this section, the four universal criteria for assessing the trustworthiness of this study will be first discussed. At the end, the choice of theory applied for discussing the findings in the current study will be critically addressed.

6.4.1 Dependability

Dependability involves the aspect of consistency and documenting the logic of the research process and method decisions (240, p. 242). One way in which a research study may be shown to be dependable or consistent is for its process to be audited (115). In the current study, dependability was undertaken by transparency and providing detailed descriptions of the research's aim, process, context, analyses, and ethical and methodological challenges and considerations along the process (see chapter 4). Saturation was also evaluated and considered achieved in terms of the information power of the produced data to enlighten the study objective (244), rather than as a fixed point or information redundancy (147).

6.4.2 Confirmability

Confirmability is concerned with assuring that data, interpretation, and outcomes are grounded in the participants' narratives and words (240, p. 242). Confirmability as well as dependability is established through auditing the research process and was ensured by transparency and a description of the process and the context of data production regarding both interviews and observations, the use of an interpreter, analyzing, and data interpretation. All four authors of the articles also reviewed and discussed the initial codes and the final themes to ensure that they were appropriate regarding the data set, and an agreement on the labels and the meanings of the codes and themes was gained among the authors. A detailed description of the findings by giving participants voice through using direct quotes was also undertaken for the reason of confirmability. According to Wallin et al. (134), if interpreters have been involved in the study, the quoted passages must be provided in the third person to make the interpreter's role visible in the produced narrative. However, in this study, the interpretation while interviewing was done in the first person (131), and I found it more natural to present the related quotations in the first person as well.

Although the findings of the current study (articles 2 & 3) represent the children's own experiences of the rehabilitation program and social participation after the rehabilitation, the themes were dominantly merged from the coded data belonging to the parent's experiences. Because a high number of mothers compared to fathers participated in this study, our findings represent an overweight of mothers' experiences.

6.4.3 Transferability

Transferability involves the aspect of applicability (163). A research study is transferable when its findings can “fit” into contexts outside the study situation, and its audience views its findings relevant and applicable in terms of their own experiences (242). Transferability depends, therefore, on the degree of similarity between two contexts. In this study, I provided sufficient contextual information about the Norwegian healthcare system (2.2) and the studied rehabilitation program (2.4) to facilitate a judgment of transferability by the readers (115). However, the findings may be relevant for understanding immigrants’ experiences interacting with the healthcare system elsewhere because the Norwegian healthcare system is comparable to those in the Nordic and some other Western countries. Additionally, our findings were discussed in the light of previous studies on immigrant families’ experiences of health and rehabilitation services in different countries.

6.4.4 Credibility

Credibility is concerned with establishing the match between the constructed realities of participants and those realities that are represented by a researcher (240, p. 237). Credibility can be operationalized through the process of member-checking (245), by which participants can provide continuous feedback during the data production, within the transcription and analysis stage, and finally when the study is prepared (240, p. 239). Member-checking in the current study was accomplished in terms of follow-up questions to ensure a mutual understanding of the interview questions and the responses (246, p. 193, 247, p. 279). However, the fact that Norwegian is not the first language of mine or the participants, and six interviews were conducted assisted by the interpreters might have affected the quality of the produced data, the analysis and interpretation of the results, and the study’s credibility (130).

Following each interview, I asked each of the participants, including both children and parents, if they had experienced any concepts or questions as unclear or difficult to understand. Ensuring that interview questions are understandable is an important part of establishing rapport and producing rich data (114, p. 309). While transcribing two of the interviews, some areas of vagueness arose that made me confirm with the participants, over the phone and in person, for the accuracy of their statements (248, p. 182). Conducting a thematic analysis by repeatedly re-contextualizing the data extracts, codes, and themes into the context of the overall interview, and the total data set also increased the credibility of the findings (246, p. 194). However, member-checking in terms of asking participants to review the interview transcription or sharing research findings with them was not undertaken due to language difficulties, level of literacy (163), participants' restricted daily schedules, and amount of responsibilities. Several researchers are questioning the sharing of findings with participants as a way to document the credibility of the research (242, 246, 249). Malterud (246, p. 194) suggests that it is the researcher's role and responsibility to interpret the produced data and not to introduce exactly the participants' stories (246, p. 194).

Peer debriefing or the process of engaging with a disinterested peer candidate is another strategy for increasing the credibility of the research (240, p. 237). I discussed the identified themes regarding the first part of this study (article 1) with a non-involved peer, a physiotherapist with a Ph.D. in qualitative research methods, that contributed to further reflections and enhancing the rigor of the final analyses. Applying participant observation as a supplementary method in the second part of the study (article 2) also improved the quality of the analyses (142, 143) and credibility of the findings by providing a wider perspective for interpreting the produced data. The credibility of research is also enhanced as a result of a researcher's reflexivity and self-awareness (115), which has been explained earlier in the methodology section (chapter 4).

6.4.5 Choice of theory

In this section, the selection of the FCS theory, conceptual framework of organizational integration, and intersectionality theory as the study's theoretical framework for discussing the findings will be respectively discussed. The FCS theory has been chosen as the theoretical framework in this study because of its relevant and comprehensive approach for understanding and interpreting different aspects of the experiences of immigrant families in this study. Furthermore, FCS theory has the potential to reduce racial and ethnic disparities within the healthcare system and improve equitable utilization of the services (170, 172, 250). However, the theory focuses only on encounter-based provider behavior without addressing the context of the community or the system of care (85). As discussed briefly earlier in this chapter, it is also challenging to implement FCS theory and its principles in practice (85, 167, 192, 251). Research shows that although FCS theory has been widely acknowledged as the standard within pediatric healthcare, it has been insufficiently implemented in practice (81, 85, 166). A lack of shared understanding and clarity about what specific actions constitute FCS on both a professional and family level within a partnership is one of the main challenges. Families may not understand what they can or should expect in a partnership with professionals (85, 187), and some professionals may consider it as delegating more responsibility to families (85, 167). A review of 15 studies in both developed and developing countries found that the FCS approach was not always implemented correctly, and the collaborative process for partnerships became a devolution of responsibility to parents without any role negotiation (252). Some professionals may feel threatened by sharing power and responsibilities with families and prefer to keep practicing according to the traditional biomedical model (251, p. 242). Furthermore, institutions and policies do not adequately support the time and effort required to implement FCS theory in practice (85, 252). Finally, a lack of high-quality research to guide healthcare systems and policy-makers is another hindrance for practicing FCSs (85). However, transformation to full and effective operationalization of FCS theory can begin with small changes by an inter-playing of theory, research, education, and practice that are contextually relevant to the population (85, 252).

The conceptual framework for organizational integration within the healthcare system with its contribution to defining and clarifying the main concepts of integration was also applied for discussing the importance of inter-organizational collaboration in the provision of seamless and comprehensive rehabilitation services and supporting community-based participation among the immigrant families. Although integration has become a significant issue in the growing modern welfare society, there has been a conceptual confusion regarding applying different and even contradictory definitions of main concepts, such as collaboration, within the literature (87). The conceptual framework of organizational integration by clarifying the concepts and their theoretical relationships has provided a guide not only for conducting research and analyzing the integration of services across different organizations and sectors in the society but also for practical work on the integration of health and welfare services. However, despite its contribution to clarifying the concepts and better understanding of the complexities of integration, it provides only a simplification of reality (87). The model does not provide insights into the key challenges faced by policy-makers, organizational managers, and healthcare professionals in planning, implementing, or evaluating inter-organizational collaboration. The increased failure of inter-organizational collaborations may highlight the importance of paying attention to the existing and potential challenges in collaboration and establishing resolution strategies in the collaborative process early on. Failing to identify, diminish, or respond to the challenges leads to unsuccessful collaborative efforts and frustration among the involved organizations in the collaborative process within the healthcare system (253).

Lastly, intersectionality theory was applied in this study because of its contribution to highlighting how the intersection of immigration and disability within the discourse of oppression and otherness together with other types of challenges related to being an immigrant can affect families' access, interaction, and the way they experience the services. Intersectionality has the potential to enrich health research by increasing attention to the different intersections of identity, social position, processes of oppression or privilege, policies, institutional practices, and how these intersections cause health inequities among the population (254-257). Bowleg (257) identifies intersectionality as an important theoretical framework for public health research.

Despite the growing interest in applying intersectionality in health research (254), there have been debates concerning its vague and open-ended definition, its parameters, and how it exactly should be used (258). Davis (258), on the other hand, argues that the vagueness and open-endedness of intersectionality, in terms of which categories to use and when to stop the analyzing intersecting of the social categories, may be the main reasons for its success. According to her, a lack of clear-cut definition or specific parameters has, in fact, enabled intersectionality to be drawn upon in almost any context of inquiry. I agree with Davis that intersectionality, with its vagueness and inherent open-endedness, initiates a process of continuous discovery that may contribute to new and more comprehensive and reflexively critical insights into the world around us. As she points out, intersectionality may not provide concrete and unalterable guidelines for doing research, but it stimulates the researcher's creativity in looking for new and different ways of doing analysis while conducting research (258).

7. Conclusion

In the following, the main conclusions from the study are presented, followed by the study's implications for clinical practice and further research.

7. 1 Main conclusion

This study explored the experiences of immigrant parents and their children with disabilities interacting with the health and rehabilitation services. This study's findings show that there is still a gap between the Norwegian government ideal of equitable healthcare services and the reality of the everyday lives of immigrant families of children with disabilities. A coordinated approach to the assessment of the families' needs that take account of all aspects of each family as a whole is, therefore, important for the provision of comprehensive, accessible, and culturally adapted health and rehabilitation services to immigrant families. There is also a need to support and inform the families about the rights and services entitled to them so that they can advocate for their children and make informed decisions. The study suggests that practicing FCS theory, which acknowledges families' diversity with its empowering nature and a comprehensive approach to the family as a whole, has the potential to be more responsive to the particular needs of immigrant families.

By applying an intersectionality perspective, the findings of this study also highlight the uniqueness of the families' experiences of services shaped at the intersection of immigration, disability, culture, language, race, religion, and socioeconomic status. The findings show how the families' interactions with the healthcare system were embedded in different forms of perceived discrimination related to their immigrant status, religion, and race. Attention is, therefore, necessary to the inequities shaped by socio-political contexts and existing stereotypical discourse about immigrants. Our findings also demonstrate the need to improve inter-organizational collaboration between rehabilitation centers and community-based services towards the shared goal of supporting immigrant families on their journey towards increased participation in the local community and an active lifestyle.

7. 2 Implications for practice

This study’s findings are derived from the Norwegian healthcare context, even from the particular context of the studied rehabilitation program (article 2). However, these results may be applicable elsewhere because the Norwegian healthcare system is comparable to those in the Nordic and some other Western countries. By exploring the experiences of the immigrant parents and their children with disabilities, this study contributes to the opportunity to provide accessible, culturally adapted, and seamless health and rehabilitation services. Educating health professionals about FCS theory and its principles is important to reach a shared understanding about its principles and how to implement it. Policy-makers and funding agencies must also acknowledge the resources and time required for practicing FCSs and support health professionals to provide services that are responsive and flexible to the different needs of immigrant families. Providing PHN programs adapted to meet the requirements of immigrant families of children with disabilities can also help those families overcome some barriers to navigate the services, particularly those newly arrived families. Improving interprofessional collaboration and connecting the families with social workers is also important for enabling them to access and navigate the health and rehabilitation services.

Policy reforms that reduce ‘othering’ and structural discrimination are also necessary for improving immigrant families’ access to services and health equity in the society. Health professionals need also to take responsibility and transform the dominant discourse surrounding immigrant families and facilitate their access to the services. Policy-makers and health professionals need to be aware that practicing cultural sensitivity is important but is not sufficient to address the multilevel factors affecting access and use of healthcare services among diverse immigrant groups.

Establishing inter-organizational collaboration between rehabilitation centers and local community services is also crucial for mapping the resources and needs, identifying potential future challenges, adjusting interventions, clarifying roles and responsibilities, involving coordinators, and providing supportive follow-up services in the local community for increased community-based participation among immigrant families.

7. 3 Implications for research

This study adds to the current literature by exploring the experiences of immigrant parents and their children with disabilities within the health and rehabilitation services. However, this study did not include newly arrived families; therefore, it was not possible to determine whether certain challenges were more likely to be reported by newer immigrant families. Research that includes newly arrived families can provide new insights into their experiences and needs regarding the health and rehabilitation services.

Further research is also required to guide policy-makers and health professionals regarding the best ways of providing FCSs to meet the diverse needs of immigrant families and their children with disabilities. Determining effective strategies for facilitating and enhancing information transfer to immigrant families is a relevant topic for future research. In addition, there is a need for research to develop PHN interventions adapted to meet the requirements of immigrant families of children with disabilities, considering their success across diverse populations.

The application of intersectionality within health research is also important because it has the potential to inform embedded policies by creating a space to examine power dynamics and existing discourses that can lead to health disparities among immigrant families (256). Research within pediatric rehabilitation should also focus on the transition of services from the rehabilitation centers to the community-based service organizations to inform policy-makers and practice for providing comprehensive and seamless services to immigrant families and their children with disabilities.

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Appendices

1. Information letter and consent form to children 8–12 years

Har du lyst til å delta i et prosjekt om erfaringene til barn og ungdommer med nedsatt funksjonsevne og innvandrerbakgrunn om intensivt treningsopphold på Beitostølen helsesportsenter?

Til prosjektdeltakere fra 8-12 år

Bakgrunn og formål

Jeg vil gjerne spørre deg om å delta i et forskningsprosjekt fordi vi ønsker å få vite hvordan innvandrerfamilier med funksjonshemmede barn opplever å delta på et tre ukers intensivt treningsopphold på Beitostølen Helsesportssenter (BHSS). Jeg spør deg fordi du deltok eller skal delta i et intensivt treningsopphold på BHSS, og har gjort deg erfaringer om det. Jeg er interessert i å vite hvordan du opplevde oppholdet på senteret, hvilke aktiviteter du likte best og hvilke aktiviteter du har lyst til å gjøre når du er tilbake hjemme. Det er BHSS som sender dette informasjonsbrevet til deg.

Hva innebærer deltakelse i forskningsprosjektet?

Jeg ønsker å høre på fortellingene dine om oppholdet ditt på BHSS og vil derfor gjerne snakke med deg hvis du har lyst til det. Det betyr at du kan velge å snakke med meg eller ikke. Samtalene skal gjennomføres i løpet av 2017-2018. Hvis du velger å snakke med meg vil du sammen med dine foreldre være med på å bestemme hvor og når vi skal snakke sammen. Du kan velge å være alene, eller sammen med foreldrene dine når vi snakker sammen. Du kan også velge å snakke med meg i en gruppe sammen med andre barn som du kanskje kjenner fra oppholdet ditt på BHSS. Vi skal snakke sammen i omtrent en time, men du kan si ifra hvis du blir sliten slik at vi kan stoppe samtalen vår. Du kan også velge å la være å svare på noen av spørsmålene. Jeg vil gjøre et lydopptak av det vi snakker om, og senere kommer jeg til å skrive det på papir. I tillegg, dersom du skal til BHSS for første gang eller du skal dit igjen på re-opphold, ønsker jeg å være med og se deg sammen med andre barn i gruppen din mens du deltar i ulike aktiviteter på BHSS. Etterpå kommer jeg til å skrive ned noe av det jeg har sett. Jeg vil bare notere det jeg ser om de barna som på forhånd har sagt ja til å delta i prosjektet. Det du forteller meg vil ikke påvirke tilbudet til deg på BHSS.

Hva skjer med informasjonen om deg?

Alt det du forteller meg eller det jeg skriver etter å ha sett deg på BHSS skal skrives på en sånn måte at ingen kan kjenne deg igjen når prosjektet er ferdig i 2021. Navnet ditt vil ikke bli skrevet noe sted.

Frivillig deltakelse

Det er frivillig å delta i prosjektet og du kan når som helst ombestemme deg uten å fortelle om grunnen. Hvis du velger å snakke med meg og delta i dette prosjektet, kan du og dine foreldre skrive under på siste side i dette brevet og sende det til BHSS, Shahrzad Arfa, Sentervegen 4, 2953 Beitostølen, eller dere kan gjerne ta direkte kontakt med meg på telefon: 975 62 846 eller via e-mail; shahrzadarfa@yahoo.no. Hvis du eller dine foreldre ønsker å vite mer før du bestemmer deg for å delta eller ikke, eller du senere ombestemmer deg er det bare å kontakte meg eller min veileder Reidun Birgitta Jahnsen på telefon: 415 13 839 eller via e-mail; reijah@ous-hf.no.

Med vennlig hilsen,

Shahrzad Arfa

Stipendiat ved Beitostølen helsesportsenter

Høgskolen i Oslo og Akershus

Samtykke til deltakelse i forskningsprosjektet

Jeg er villig til å delta i prosjektet

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Som foresatte til_ (Fullt navn) samtykker vi til at hun/han kan delta i prosjektet

Sted og dato

Foresattes signatur

Foresattes navn med trykte bokstaver

Sted og dato

Foresattes signatur

Foresattes navn med trykte bokstaver

2. Information letter and consent form to children 13–18 years

Vil du delta i et prosjekt om erfaringene til barn og ungdommer med nedsatt funksjonsevne og innvandrerbakgrunn om intensivt treningsopphold på Beitostølen helsesportsenter?

Til prosjektdeltakere fra 13-18 år

Bakgrunn og hensikt

Med dette spør jeg deg om å delta i et forskningsprosjekt som har til formål å bygge opp kunnskap om erfaringene til innvandrerfamilier med funksjonshemmede barn som deltar i et tre ukers intensivt treningsopphold på Beitostølen Helsesportssenter (BHSS). Det er veldig få barn og ungdommer med nedsattfunksjonsevne og innvandrerbakgrunn som deltar i habiliteringsopphold på BHSS. Dette prosjektet vil undersøke om intensive treningstilbud er tilgjengelige, og til nytte for barn med nedsatt funksjonsevne og innvandrerbakgrunn. Jeg spør deg om å delta i dette forskningsprosjektet fordi du deltok eller skal delta i et habiliteringsopphold på BHSS. Forskningsprosjektet er en doktorgradsstudie ved BHSS og Høgskolen i Oslo og Akershus. Det er BHSS som sender dette informasjonsbrevet til deg.

Hva innebærer deltakelse i forskningsprosjektet?

Jeg ønsker å intervjue deg 1 eller 2 ganger, det vil si at jeg ønsker å snakke med deg. Samtalen handler om erfaringer du har gjort under ditt opphold på BHSS, for eksempel hvordan du likte deg på BHSS, hvordan du opplevde treningsøktene og liknende. Intervjuene vil ta mellom 45 til 90 minutter, men du kan si ifra hvis du blir sliten slik at vi kan stoppe samtalen. Du kan også velge å la være å svare på noen av spørsmålene. Det vil bli gjort et lydopptak av det vi snakker om, og senere kommer jeg till å skrive det på papir.

Du kan også delta i gruppeintervju sammen med andre barn og ungdommer dersom du har lyst til det. Intervjuene er tenkt å gjennomføres i løpet av 2017-2018 og du vil kunne være med å bestemme hvor og når vi skal snakke sammen.

I tillegg, dersom du skal til BHSS for første gang eller du skal dit igjen på reopphold, ønsker jeg å kunne observere deg når du deltar i ulike aktiviteter eller ved andre sosiale sammenhenger under oppholdet på BHSS. Etter å ha observert deg kommer jeg til å skrive ned notater om mine observasjoner. Jeg vil bare notere ned opplysninger om de som på forhånd har samtykket til å delta i prosjektet. Informasjonen som framkommer i prosjektet vil ikke ha noen konsekvenser for tilbudet til deg/dere på BHSS.

Hva skjer med informasjonen om deg?

All informasjon om deg skal behandles konfidensielt, det vil si at det kun er jeg som har tilgang til personlige informasjon og jeg har taushetsplikt. Personopplysninger og opptak oppbevares innelåst i brannsikkert arkivskap på BHSS. I prosjektperioden vil alt informasjon om navn og andre personlige kjennetegn blir fjernet, men det vil være mulig å spore informasjonen tilbake til personen det gjelder med en kode som er koblet til en navneliste. Navneliste/koblingskode og informasjon/datamaterialet skal oppbevares atskilt fra hverandre, og det er kun jeg som har tilgang til disse. Prosjektet skal etter planen avsluttes i 2021 og informasjon/datamaterialet skal anonymiseres etter prosjektslutt. Det vil si at når jeg skal presentere det du har fortalt meg, muntlig eller skriftlig, skal ingen kunne kjenne igjen deg ut fra det som beskrives.

Mulige fordeler og ulemper

Det er ingen kjente fordeler ved å delta i prosjektet utover at du bidrar med viktig kunnskap som kan brukes til utviklingen og forbedring av habiliteringstilbudet for barn og ungdommer med nedsatt funksjonsevne og innvandrerbakgrunn. Jeg vil tilstrebe å ikke være til bry eller forstyrrelser underveis i prosessen, og oppfordrer deg til å si fra dersom det skulle medføre noen ulemper for deg.

Frivillig deltakelse

Deltakelse i prosjektet er frivillig, og du kan når som helst trekke deg fra prosjektet uten å fortelle om grunnen. Siden du er under 18 år trenger jeg også tillatelse fra foreldrene dine til at du kan delta i prosjektet. Hvis du ønsker å delta og foreldrene dine er enige i det, undertegner du samtykkeerklæringen på siste side og sender den tilbake til BHSS, Shahrzad Arfa, Sentervegen 4, 2953 Beitostølen, eller du kan gjerne ta direkte kontakt med meg på telefon: 975 62 846, eller via e-post; shahrzadarfa@yahoo.no. Hvis du ønsker å vite mer før du bestemmer deg for å delta eller ikke, eller du senere ønsker å trekke deg er det å bare kontakte meg eller min veileder Reidun Birgitta Jahnsen på telefon: 415 13 839 eller via e-post; reijah@ous-hf.no

Godkjenning

Prosjektet er meldt til Personvernombudet for forskning, NSD – Norsk senter for forskningsdata AS.

Med vennlig hilsen

Shahrzad Arfa

Stipendiat ved Beitostølen helsesportsenter

Høgskolen i Oslo og Akershus

Samtykke til deltakelse i forskningsprosjektet

Jeg er villig til å delta i prosjektet

Sted og dato　　　　　　　　　　　Deltakers signatur

Deltakers navn med trykte bokstaver

Som foresatte til_ (Fullt navn) samtykker vi til at hun/han kan delta i prosjektet

----

Sted og dato　　　　　　　　　　　Foresattes signatur

Foresattes navn med trykte bokstaver

Sted og dato　　　　　　　　　　　Foresattes signatur

----

3. Information letter and consent form to parents

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

Erfaringene til innvandrerfamilier med funksjonshemmede barn i samhandling med helse og habiliteringstjenester.

Foreldre som deltakere

Bakgrunn og formål

Med dette spør jeg deg om å delta i et forskningsprosjekt som har til formål å generere kunnskap om erfaringene til innvandrerfamilier med funksjonshemmede barn som deltar i et tre ukers habiliteringsopphold på Beitostølen Helsesportssenter (BHSS). Det er veldig få barn og ungdommer med nedsatt funksjonsevne og innvandrerbakgrunn som deltar i habiliteringsopphold på BHSS. Dette prosjektet vil undersøke om intensive habiliteringstilbudet er tilgjengelige, og til nytte for barn med nedsatt funksjonsevne og innvandrerbakgrunn. Jeg spør deg om å delta i dette forskningsprosjektet siden du og ditt barn skal delta eller har deltatt i et habiliteringsopphold på BHSS. Forskningsprosjektet er en doktorgradsstudie ved BHSS, avdeling for forskning, utvikling og undervisning og Høgskolen i Oslo og Akershus. Det er BHSS som sender dette informasjonsbrevet.

Hva innebærer deltakelse i forskningsprosjektet?

Jeg ønsker å intervjue deg rett etter og ett år etter oppholdet på BHSS. Jeg er interessert i dine erfaringer med habiliteringstjenester generelt, og intensiv habiliteringsopphold på BHSS spesielt. Spørsmålene handler om erfaringer du har gjort i forkant av oppholdet, under oppholdet og i etterkant av oppholdet på BHSS. Intervjuene vil hovedsakelig gjennomføres individuelt, men du kan gjerne delta i gruppeintervju sammen med andre foreldre dersom du har lyst til det. Intervjuene vil ta mellom 45 til 90 minutter og du vil selv kunne være med på å bestemme hvor og når intervjuene skal gjennomføres. Det vil gjøres lydopptak av intervjuene og intervjuene er tenkt å gjennomføres i løpet av 2017-2018. I tillegg, dersom du skal til BHSS for første gang eller du skal dit igjen på re-opphold, vil jeg være tilstede under deler av oppholdet på BHSS for å observere samhandlingen mellom foreldre og personalet på BHSS, samt foreldre og barna seg imellom. I den forbindelse vil jeg skrive feltnotater underveis. Jeg kommer bare til å notere ned opplysninger om de som på forhånd har samtykket til deltakelse i prosjektet. De opplysningene som framkommer i prosjektet vil ikke ha noen konsekvenser for tilbudet til deg og/eller ditt barn på BHSS.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Det vil si at det kun er jeg som vil ha tilgang til personopplysninger og jeg har taushetsplikt. Personopplysninger og opptak oppbevares innelåst i brannsikkert arkivskap på BHSS. I tillegg vil alle opplysninger avidentifiseres i prosjektperioden. Dette innebærer at navn og andre personlige kjennetegn blir fjernet, men det vil være mulig å spore opplysningene tilbake til personen det gjelder med en kode som er koblet til en navneliste. Navneliste/koblingskode og opplysninger skal oppbevares atskilt fra hverandre, og det er kun jeg som har tilgang til navneliste/koblingskode. Prosjektet skal etter planen avsluttes i 2021 og datamaterialet skal anonymiseres etter prosjektslutt, og du vil ikke kunne gjenkjennes ved publikasjon av resultatene.

Mulige fordeler og ulemper

Det er ingen kjente fordeler ved å delta i prosjektet utover at du bidrar med viktig kunnskap som kan brukes til utviklingen og forbedring av habiliteringstilbudet for barn og ungdommer med nedsatt funksjonsevne og innvandrerbakgrunn. Jeg vil tilstrebe å ikke være til bry eller forstyrrelser underveis i prosessen, og oppfordrer deg til å si fra dersom det skulle medføre noen ulemper for deg.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli slettet. Dersom du ikke vil delta i studien eller senere velger å trekke deg skal det ikke få innvirkning på oppholdet ved BHSS hverken nå eller senere. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side og sender den tilbake til BHSS, Shahrzad Arfa, Sentervegen 4, 2953 Beitostølen, eller du kan gjerne ta direkte kontakt med meg på telefon 975 62 846 eller via e-post; shahrzadarfa@yahoo.no Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet er det å bare kontakte meg eller min veileder Reidun Birgitta Jahnsen på telefon: 415 13 839 eller via e-post; reijah@ous-hf.no

Godkjenning

Prosjektet er meldt til Personvernombudet for forskning, NSD – Norsk senter for forskningsdata AS.

Med vennlig hilsen

Shahrzad Arfa

Stipendiat ved Beitostølen helsesportsenter

Høgskolen i Oslo og Akershus

Samtykke til deltakelse i forskningsprosjektet

Jeg har mottatt informasjon om studien og vil samtykke til å delta i prosjektet.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

4. Interview guide children (articles 2 & 3)

Each interview begins with providing information about my role as the interviewer, the project and its aims, interview process, and research ethics.

The experience of the rehabilitation program

- It has been a while since you have participated in the rehabilitation program, right? How did you like it at the rehabilitation center? Can you tell me more about it? What was your typical day like at the center? Can you tell me about it?
- What was it like for you to participate in all of the different activities? Can you tell me about those activities? Which one did you like the most? Was there any activity that you did not like that much? Why? If yes, what did you do about that? Did you tell anyone about it?
- How did you experience those who organized the activities you participated in? Were they helpful? In which way? Can you tell me more about it?
- Can you tell me what the best thing about participating in the program was? Why? Can you explain it more?
- Was there anything about the program that you would like to change? Why do you want to change it? Can you tell me more about it?
- How was it like for you to meet other families and children at the rehabilitation center? Did you find new friends? Are you still in touch with them?
- Do you have any memories of those days at the center with other families and children that you want to share with me?
- Did you tell your friends at the school about your participation at the program back home? If yes, can you tell me how you explained it to your friends?

The experience of participation in activities after the rehabilitation

- How are your days back home now? Do you experience any changes in your daily activities compared with before the rehabilitation? Can you explain it more?
- Do you participate in any kind of activities back home now? If yes, which type of activities do you participate in? Are they the same activities that you liked the most at the center? Or not? Can you tell me about it?
- Which activities do you like participating in the most? Are you participating in your favorite activities now? If not, can you tell me why?
- Is there anything that you would like to share with me before we end our conversation? Was there any question that you experienced as difficult to answer or understand?

5. Interview guide parents (articles 1, 2, & 3)

Each interview begins with providing information about my role as the interviewer, the project and its aims, interview process, and research ethics.

The experience of navigating the health and rehabilitation service

- How long have you been in touch with the healthcare system regarding the follow-up services of your child with a disability within both the primary and specialist healthcare system?
- How accessible did you experience the services within both the primary and specialist healthcare system? What about the pediatric rehabilitation services? How accessible were they?
- How did you experience the pediatric rehabilitation services in terms of both challenges and facilities? What did you find to be the strengths of the services? What did you experience as limitations?
- Do you have any suggestions for improvement of the rehabilitation services in particular? What about the healthcare services in general; do you have any ideas for improving the services?
- How did you experience your interaction with the healthcare providers in terms of relationship, cooperation, and communication? Did you experience any challenges? Did you communicate with the healthcare providers through the interpreter? If yes, how did you experience communicating assisted by an interpreter?
- How would you describe the consultations with the pediatric rehabilitation team? Any challenges?
- How did you experience receiving the information that you consider important for your family or/and your child’s best interests from the healthcare providers? Did you receive the information that you need in order to navigate the services?

The experience of participating in the rehabilitation program

- You participated in the rehabilitation program a while ago; do you remember when and how you received the information about the program in the first place? How did you experience the information you received? Was it clear?
- Did you participate in the pre-intervention meeting with the rehabilitation team before participating in the program? If yes, how did you experience it?
- Did you experience any difficulties to participate in the program? Can you explain it? How did you manage to overcome them and participate in the program anyway?
- What was motivating for participating in the program? Can you explain it more?

- How did you experience the daily plan at the rehabilitation center? Was it easy for you to follow the plan? Or did you need help? Did you experience any difficulties? What about the meetings; how did you experience participating in the meetings? Were there any language difficulties?
- How did you experience the activities in which your child participated? Can you tell me more about the type of activities? Did you experience any challenges? Were there any activities that you wish they could change or add to the program?
- How did you experience participating in the activities yourself? Can you explain which kind of activities you participated in?
- How would you describe the program as a whole? How did you experience your participation in the program in general? Was there anything that you could change to make the program more inclusive for immigrant families?
- How would you describe your interaction with the rehabilitation professionals in terms of relationship, cooperation, and communication? Did you experience any challenges? How did you manage them?
- How did you experience the goal-setting process? Could you describe your experience collaborating with the professionals through the goal-setting?
- What was it like meeting other families at the center? How did you experience interacting with them? Were there any challenges? Do you have any preferences of what kind of family group you want to be a part of if you would choose to participate in the program again?

The experience of participation in the community-based activities after the rehabilitation

- How is it going now after the rehabilitation; do you experience any differences or progress regarding her/his (child) participation? Does she/he participate in any type of activities now? If yes, which types of activities does he/she participate in? Can you explain this further? If no, can you explain why?
- Were there any challenges for her/his participation in physical activity in her/his free time? Can you explain it?
- What could facilitate her/his participation? Can you explain how?
- How did you experience services back home in the local community after the rehabilitation? Was there any type of services for supporting your child’s participation in activities after the rehabilitation? Did local professionals contact you after the rehabilitation to provide services or support? Did you participate in a post-intervention meeting with the rehabilitation team? If yes, how did you experience the meeting?

Reflective and ending questions

- At the end, I wish to know whether you have any thoughts/reflections regarding why some of the healthcare providers experience it as challenging to reach out to immigrant families, the children of whom need services?
- Do you have any further comments that you want to add? Any questions? Please let me know if there is something on your mind that you want to add or discuss.
- Was there any concept or question that you experienced as difficult to understand or answer during the interview? Do you have any suggestions for modifying any of the interview questions?
- May I (the interviewer) contact you again if I realize that I have forgotten to ask you a question or if something is unclear to me?

6. Response letter from REC

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Tor Even Svanes	22845521	21.11.2016	2016/1764/REK sør-øst C
			Deres dato:	**Deres referanse:**
			20.09.2016	

Vår referanse må oppgis ved alle henvendelser

Reidun Jahnsen
Oslo universitetssykehus HF
Postboks 4950 Nydalen
0424 Oslo

2016/1764 Funksjonshemmet eller 'informasjonshemmet'? Erfaringer til innvandrerfamilier med funksjonshemmede barn i møte med habiliteringstjenester.

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 27.10.2016. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: Beitostølen helsesportsenter
Prosjektleder: Reidun Jahnsen

Prosjektomtale (original):
Studien vil generere kunnskap om erfaringene til funksjonshemmede barn med innvandrerbakgrunn og deres foreldre som deltar i et tre ukers habiliteringsopphold på Beitostølen Helsesportsenter (BHSS). Studien skal ha en kvalitativ tilnærming med bruk av kvalitativt intervju som hovedmetode og deltakende observasjon som tilleggsmetode. Prosjektets skal besvare spørsmålet om intensive habiliteringstilbud er tilgjengelige og til nytte for funksjonshemmede barn med innvandrer bakgrunn. For å besvare spørsmålet skal studien belyse deltakernes erfaringer i møte med habiliteringstjenester generelt, i forkant av deres opphold på BHSS, samt deres erfaringer under selve oppholdet og i oppfølgingsprosessen etter oppholdet. Prosjektet gir dermed økt kunnskap om innvandrerfamilienes behov, forventninger og ønsker i møtet med habiliteringstjenester generelt og Beitostølen helsesportsenter spesielt.

Vurdering

Under søknadens del **2.4.2 Beskrivelse av forskningsdeltakere/utvalg**, angir søker følgende om utgangspunktet for prosjektet: *Ved å rette fokuset mot innvandrerfamiliene og deres erfaringer med habiliteringstjenester generelt og tilbudet på Beitostølen helsesportsenter spesielt vil denne studien fremme økt kunnskap om innvandrerfamiliers ønsker, behov og forventninger i møte med habiliteringstjenester. Kunnskapen kan benyttes til utvikling og forbedring av habiliteringstjenester generelt, og helsesportenterets tilbud med fokus på tilpasset fysisk aktivitet spesielt, noe som kan bidra til at disse familiene i større grad opplever at tjenestene er tilgjengelige og helhetlige.*

Komiteen viser i den forbindelse til hvordan kvalitetssikring av etablert behandling avgrenses mot medisinsk og helsefaglig forskning i Helse- og Omsorgsdepartementets veileder til helseforskningsloven:

Kvalitetssikring kan defineres som prosjekter, undersøkelser, evalueringer o.l. som har som formål å kontrollere at diagnostikk og behandling faktisk gir de intenderte resultater. Nasjonale tiltak for å sikre og forbedre kvaliteten i tjenestene inkluderer utvikling av nasjonale kvalitetsindikatorer, samordning og *styrking av medisinske kvalitetsregistre og å utarbeide gode faglige retningslinjer. Kvalitetsarbeidet må baseres på systematisk dokumentasjon.*

Komiteen mener formålet med det omsøkte prosjektet nettopp er å evaluere et etablert tiltak, med henblikk på å videreutvikle gode, faglige retningslinjer. Prosjektet omfattes dermed ikke av helseforskningslovens bestemmelser.

Komiteen antar for øvrig at prosjektet kommer inn under de interne regler for behandling av pasient-/helseopplysninger som gjelder ved ansvarlig virksomhet. Søker bør derfor ta kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende.

Vedtak
Prosjektet omfattes ikke av helseforskningslovens virkeområde, jf. helseforskningslovens § 2. Prosjektet er ikke fremleggelsespliktig, jf. helseforskningslovens § 4 annet ledd.

Komiteens avgjørelse var enstemmig.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. Forvaltningslovens § 28 flg. Eventuell klage sendes til REK Sør-Øst. Klagefristen er tre uker fra mottak av dette brevet.

Med vennlig hilsen

Britt-Ingjerd Nesheim
prof.dr.med.
leder REK sør-øst C

Tor Even Svanes
seniorrådgiver

Kopi til: astrid.nyquist@bhss.no

7. Ethical approval from NSD

Shahrzad Arfa
Beitostølen Helsesportsenter

2953 BEITOSTØLEN

Vår dato: 06.02.2017 Vår ref: 51764 / 3 / HJP Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 22.12.2016. Meldingen gjelder prosjektet:

51764	*Funksjonshemmet eller "informasjonshemmet? Erfaringer til innvandrerfamilier med funksjonshemmede barn i møte med habiliteringstjenester*
Behandlingsansvarlig	*Beitostølen Helsesportsenter, ved institusjonens øverste leder*
Daglig ansvarlig	*Shahrzad Arfa*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 31.12.2021, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Hanne Johansen-Pekovic

Kontaktperson: Hanne Johansen-Pekovic tlf: 55 58 31 18

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Article 1

Arfa S, Solvang PK, Berg B, Jahnsen R. Disabled and immigrant, a double minority challenge: a qualitative study about the experiences of immigrant parents of children with disabilities navigating health and rehabilitation services in Norway. BMC Health Services Research. 2020;20(1):1-16. doi: 10.1186/s12913-020-5004-2

Arfa *et al. BMC Health Services Research* (2020) 20:134
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BMC Health Services Research

RESEARCH ARTICLE Open Access

Disabled and immigrant, a double minority challenge: a qualitative study about the experiences of immigrant parents of children with disabilities navigating health and rehabilitation services in Norway

Shahrzad Arfa[1,2*], Per Koren Solvang[3], Berit Berg[4] and Reidun Jahnsen[1,5,6]

Abstract

Background: Immigrants and their Norwegian-born children make up approximately 18% of the total population in Norway. While several studies have been conducted on immigrants' utilization of healthcare services, immigrant families are systematically underrepresented in international studies of children with disabilities. By focusing on experiences of immigrant parents of children with disabilities navigating health and rehabilitation services in Norway, this study generated knowledge of how accessible and tailored the services were from their point of view.

Methods: This study took a qualitative approach, using semi-structured interviews to explore the experiences of immigrant parents of children with disabilities from non-Western countries. The interviews were transcribed, coded, and analyzed via an inductive thematic analytic approach.

Results: The findings show how the "immigrant experience" influenced the way the parents looked at, experienced, and even praised the services. The parents appreciated the follow-up services provided by the pediatric rehabilitation centers, which they experienced as predictable and well-organized. While navigating the services, they experienced several challenges, including the need for information, support, and timely help. They felt exhausted because of years of struggle in the healthcare system to access the help and services they needed. They expressed how this struggle had affected their own health. The feeling of being treated differently from the majority was another challenge they experienced while navigating the services. The findings also show how parents' experiences of communication with healthcare providers were influenced not only by their own language and communication skills but also by the healthcare providers' intercultural communication skills and dominant organizational culture.

Conclusions: The parents' experiences show that there is still a gap between the public ideal of equal healthcare services and the reality of the everyday lives of immigrant families of children with disabilities. By exploring immigrant parents' experiences, this study highlights the importance of mobilization at both the individual and systemic levels to fill the current gap and provide tailored and accessible services to the entire population.

Keywords: Immigrant parents, Children with disabilities, Healthcare system

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Background

The composition of the Norwegian population, as in other countries in Europe, has been changing [1], p., 3. Immigrants and their Norwegian-born children comprise approximately 18% of the total population in Norway. More than 80% of all immigrants in Norway come from non-Western countries [2]. Immigrants, like the rest of the population, are not a homogeneous group [1], p., 4. They come from 221 different countries and independent regions for many different reasons [3]. They vary in ethnic, cultural, educational, and socioeconomic backgrounds, as well as the length of their stay in Norway [2].

An inclusive and equal society is an important goal of the Norwegian government, important both for the individual and for society. An equal healthcare service is a very important part of and condition for achieving this goal [1], p., 3. However, the consumption of healthcare services in Norway varies both within different immigrant groups and between immigrants and the general population [4].

Increasing ethnic diversity in the population and differences in the utilization of healthcare services pose challenges to the authorities' stated goal of equitable healthcare. Improving knowledge of what influences immigrants' use of healthcare services will therefore be beneficial for planning policies and delivering healthcare services [4]. While much research has been conducted on immigrants' utilization of healthcare services, immigrant families are systematically underrepresented in international studies of children with disabilities [5].

A critical review of the international literature on immigrant and refugee families of children with disabilities revealed an absence of information about their access to, utilization of, and experience with community-based healthcare and rehabilitation services [6]. Bailey et al. [7] studied 100 Latino couples parenting young children with disabilities in the United States (US). They found that awareness and utilization of services varied among these families, and high awareness was associated with high use of services. Interestingly, their findings showed that none of the demographic variables, such as the education of parents, were correlated with awareness and use of services. The results revealed how parents with low awareness and utilization tended to be satisfied with the services they had received, and did not actively pursue additional information. Thus, the authors suggested that family variables such as feelings of control, which could influence an individual's ability to gather information and use necessary services, might be more important determinants of awareness and use.

A recent review of 17 international articles revealed increased barriers to care for immigrant families of children with special healthcare needs, partly due to the difficulty in navigating a challenging and changing healthcare system [8]. A qualitative study in Canada also showed that immigrant parents of children with disabilities not only faced the same barriers as majority families but also encountered additional challenges [9]. Additionally, a narrative review of 39 articles, mostly from the US and United Kingdom (UK), showed that immigrant parents of children with disabilities mainly face additional challenges due to language barriers [10]. According to Bailey et al. [7], parents in minority ethnic groups may also face challenges due to lack of familiarity with cultural expectations of the proper way to seek help, and professionals who are not fully aware of the implications of ethnic diversity with regard to values, goals, and behavior. Fellin et al. [11] interviewed 43 clinicians within two pediatric centers in Canada. They highlighted the need for clinicians to provide culturally competent care to immigrant families of children with disabilities, by being aware of their own cultural and/or professional worldviews and the views and experiences of these families. Two UK studies of Pakistani and Bangladeshi families with a severely disabled child revealed how service providers' stereotypical perceptions of immigrant families created challenges during these families' encounters with the healthcare system [12, 13].

Research conducted in Norway and Denmark also showed how service providers largely explain the challenges they face while interacting with immigrant families as being the result of cultural and religious differences [14, 15]. Because of this, service providers may easily overlook other important matters and instead create stereotypical images of "the others" with reference to their culture or religion [14]. This generalization can hinder the building of individual relationships to meet the unique needs of each family. In a study of minority parents of disabled children within the Norwegian healthcare system, Söderström [16] highlighted how language difficulties and stereotypical assumptions made it difficult for minority families to access healthcare services.

The legitimacy of the healthcare system is a product of its ability to provide timely and appropriate services to the entire population [17]. Increasing ethnic diversity in the population necessitates a great deal of flexibility, creativity, and professional expertise of healthcare services to provide equal access, usage, and outcomes for the entire population [16]. Research shows that lack of service use has more to do with how the services are organized than with the characteristics of the families [5, 12, 13]. However, limited literature has told the stories of immigrant families who have children with disabilities [18]. A lack of knowledge of these families' experiences interacting with the healthcare system limits the cultural integrity of practices within healthcare services [14, 18].

McKay [8] noted a lack of data about best practices with regard to immigrant children with special healthcare needs. According to Fellin et al. [11], formal procedures are absent for developing approaches and treatment plans based on interactions between professionals and immigrant families who have children with disabilities, despite their importance for the support of those families.

It is, therefore, important to conduct research focusing on diverse populations to enhance the further development of healthcare services and provide appropriate care and guidance to immigrant families who have children with disabilities. This study reveals the experiences of immigrant parents of children with disabilities who are navigating the Norwegian healthcare system, particularly pediatric rehabilitation services.

The Norwegian healthcare system

The Norwegian healthcare system is publicly funded [19] and characterized by universal coverage and public provision of services [20]. It is semi-decentralized, with municipalities responsible for primary healthcare services and the state responsible for specialist healthcare services [19]. Primary healthcare includes long-term care services, general practitioners (GPs), physiotherapists, community health nurses, and emergency care. Specialist healthcare includes both private specialist healthcare providers and hospitals [21].

Residents are assigned a GP who acts as a gatekeeper to specialist healthcare services. Patients, except children and pregnant women, pay a subsidized consultation fee when visiting their GP. Most medical specialists outside hospitals, as well as outpatient hospital services, require co-payments [22]. There is also private healthcare in Norway where one can access specialists directly, but out-of-pocket fees are typically four times higher [21]. Private healthcare is relatively uncommon and mainly available in urban areas [20].

The primary and specialist healthcare systems both provide pediatric rehabilitation services, but the tasks are more specifically defined for specialist healthcare services. The primary healthcare system has the overall responsibility for follow-up, providing the necessary examination to identify the need for rehabilitation, and if necessary refer these children to specialist healthcare services. Children and adolescents from 0 to 18 years with congenital or early acquired disability, developmental disorders, or chronic illness may be entitled to pediatric rehabilitation services in the specialist healthcare system. Multi-professional pediatric rehabilitation teams have the core responsibility to provide services and follow-up to children in accordance with their overall needs. Most of the services are provided as outpatient services, but may also be provided at children's wards in hospitals [23].

Methods

This study was conducted with a qualitative approach, using a semi-structured interview guide (Additional file 1) to explore the experiences of immigrant parents seeking care for their children with disabilities. Parents were asked about their experiences with both primary and specialist healthcare services in general, and pediatric rehabilitation services in particular. By focusing on the experiences of immigrant parents from non-Western countries, this study generated knowledge of how accessible and tailored the services were from their point of view.

Participants

Applying convenience sampling, this study included immigrant parents of children with disabilities from non-Western countries. The participants were recruited through a rehabilitation center between 2015 and 2017 via an information letter about the study. The potential participants who lived in the Oslo area were additionally informed about the study verbally by phone by the first author in simple language after they had received the information letter. The sample included 23 parents, with six fathers and 17 mothers who were immigrants from 14 different countries (Table 1). One potential participant declined to participate in the study, because of family difficulties.

Some participants were familiar with the first author prior to the study commencement, due to her role in a prior developmental project intended to inform and encourage immigrant families to participate in a pediatric

Table 1 Number of participants and countries of origin

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

rehabilitation program at a Norwegian rehabilitation center with adapted physical activity as the main intervention. One of the families was already familiar with the first author due to her role as their child's physiotherapist.

Although we used convenience sampling, the participants varied in their educational and socioeconomic backgrounds, Norwegian language skills, and length of residences in Norway (Table 2). Because the healthcare system in Norway is organized similarly across the whole country, the experiences of the services would remain largely the same regardless of the city of residence.

Data collection and analysis

Twenty-three interviews were conducted from April 2017 to January 2018. All interviews were conducted by the first author in Norwegian, except one that was conducted in English. Data saturation was discussed with the co-authors and considered achieved. The first author is an immigrant from the Middle East herself. She worked as a pediatric physiotherapist in the primary healthcare system in a multicultural district in Oslo for several years. Both as an immigrant herself and as a health professional, she was familiar with some of the challenges that the participants may have experienced while navigating the Norwegian healthcare services. The shared experiences and cultural familiarity were a foundation for building trust between her as a researcher and the participants.

Professional interpreters contributed while interviewing six participants. The use of interpreters was based on the first author's perception of the participants' language skills during the telephone conversation prior to the interviews, if the participants did not mention the need themselves. The interpreters explained their role and their duty regarding confidentiality, and signed a declaration form prior to each interview.

Prior to each interview, the first author explained the study purpose and regulations regarding confidentiality, then obtained written informed consent from all participants. She also emphasized that they could withdraw their consent without giving any reason if they wished to later. The participants were informed of the interview procedure and the recording of the interviews. Interviews lasted for approximately 55–130 min and were conducted at a place and time convenient for each participant, including participants' homes, a café, Oslo Metropolitan University, the rehabilitation center, and

Table 2 Sociodemographic characteristics of the participants

	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	High school	Basic	15
16	F	40–50	University	Basic	8
17	M	30–40	High school	Basic	7
18	F	40–50	High school	Basic	23
19	F	30–40	University	Very basic	10
20	F	40–50	University	Very good	20
21	F	40–50	University	Very good	21
22	F	30–40	High school	Very good	19
23	M	30–40	University	Very basic	4

the Family House health and educational service providers in the participants' local districts. One of the interviews that was conducted in two different days lasted for approximately 170 min in total. While interviewing two participants, their spouses were present during parts of the interviews.

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. Two participants were contacted and interviewed again by the first author to obtain further clarity about some subjects. All interviews were recorded and transcribed verbatim by the first author. Transcription of the first four interviews took place immediately after conducting the interviews, which was useful for fostering reflection on the applied terms and construction of interview questions based on participants' understanding and responses. Then, the interview questions were modified, and new questions were added to the interview guide. However, adjustments of the interview guide were constantly made while conducting the interviews, depending on the participants' responses and the interview context. The interview guide explored three domains: (1) the experience of services in terms of both strengths and challenges, (2) the experience of interacting with healthcare providers, and (3) the experience of receiving information. The interview guide was developed based on experiences from the former developmental project at a rehabilitation center, with informal conversations and observations of the participants who were later recruited to the present project.

The transcription of interviews was an ongoing process, as was conducting the interviews; the process of transcribing the interviews continued for some time after completing the interviews. Therefore, the first author listened to all audiotapes again right before analyzing the transcripts to refamiliarize herself with the context of each interview and the content of the data as a whole. An inductive thematic analytic approach [24] informed by interpretive description [25] was applied to explore the potential patterns in the data. Each interview transcript was read individually in an active way, searching for potential patterns, and 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, the data were ultimately organized into 17 codes, such as the strengths of the services, the experience of communication, and the interpreter. At the same time, a "quotable quotes" file was created, including particularly powerful pieces of data to ensure that they would not be lost, while also preventing them from dominating the evolving analytic process [25], p., 149. A "reflection notes" file was also created to register the first author's reflections and thoughts while analyzing the data.

After organizing the data extracts into different codes, the analysis involved making sense of the relationships among the various groups by moving within and across the groups of data extracts within each code. A repetitive thinking and reasoning process, and shifting attention from similarities between certain cases to the differences between other cases, led to the deconstruction of the initial groups. By linking data elements together across the different codes and discarding some codes, data extracts were reorganized into six initial themes: (1) the alienation of immigrants, (2) communication between immigrant families and healthcare professionals, (3) gratitude towards the healthcare system, (4) the battle to access help, (5) access to information, and (6) prejudice as an extra challenge while navigating the healthcare system. Thereafter, the data within each initial theme were further analyzed, and subthemes were generated to give structure to the themes by elucidating the variation and details within them. For instance, three subthemes were identified within the theme "access to information": "lack of information", "challenges to accessing information", and "facilitators of accessing information". Next, the initial themes and subthemes were reviewed by all four authors to ensure that they were appropriate with regard to the dataset, that the data within the themes cohered meaningfully, and that there was a clear distinction between the themes. Subsequently, the themes were refined; one theme that did not fit with the others was discarded ("alienation of immigrants"), and two themes were combined to form a new one ("the battle to access help" and "prejudice as an extra challenge while navigating the healthcare system"). Finally, four themes were identified, and representative quotes selected to generalize the descriptions of the participants' experiences. The first author discussed the identified themes with a non-involved peer, a physiotherapist with a PhD in qualitative research methods, which contributed to further reflections and enhancing the rigor of the final analyses.

The four themes were further interpreted in the context of previous literature. Although the different phases of the analysis are described here as being linear, the process of analysis was actually done by moving back and forth throughout the different phases.

Results

Each participant had a unique story, and their experiences of the services and challenges were diverse. However, four main themes were identified after analyzing the data: (1) immigrants' gratitude for the services, (2) communicating beyond language, (3) finding a way through the service system, and (4) accessing help as a battle.

Immigrants' gratitude for the services

The participants were mainly satisfied and grateful with regard to the services, especially the follow-up services provided by the pediatric rehabilitation centers. They experienced the follow-up services as continuous, predictable, and well-organized. They also felt safe that their children were in good hands and would receive follow-up services from caring and competent healthcare providers. Some participants were even cautious of discussing the challenges they had experienced while navigating the healthcare system because they were afraid of being perceived as ungrateful or demanding.

One participant explained how satisfied she was with her son's checkup routines and her ability to stay in touch with his physicians over many years. She expressed her trust in and gratitude for the healthcare providers:

> *They [the healthcare providers] have done the best they could do … I feel that one should not criticize and be very picky about things that are unnecessary because people who are ungrateful to humans are ungrateful to God, too. (P 9)*

A culture of gratitude and appreciation is a major part of the values that this participant, like many others in this study, grew up with and believe in. Thus, this participant, like many others, was initially hesitant to talk about what she had struggled with over the years while navigating the healthcare system.

Some participants experienced that the follow-up services had a holistic approach and included several important dimensions with regard to their children's development. They were satisfied with how their children's wellbeing and progress at school had been followed by the healthcare providers. Their experience was that the healthcare providers supported them in overcoming the challenges that their children faced at school by cooperating and participating in the school meetings. One participant explained his satisfaction with the services:

> *I am satisfied with the follow-up services. You know for sure how the pediatric rehabilitation works; they follow the children's health conditions, behaviors, and schooling. (P 11)*

This participant noted his appreciation of how the follow-up services comprehensively took care of his child's needs.

The immigrant experience was highlighted when the participants praised the services. One explained that in her home country, her child could not even go to the ordinary school with the other children, and they had to pay a substantial sum of money to buy her a wheelchair.

> *I'm satisfied with everything … we have different assistive devices and exercise equipment. She is riding, she is very happy, she goes to the physiotherapy, and she goes to the school, which is also important. We cooperate with the school and the hospital, and there is a lot of responsibility. (P 8)*

She deeply appreciated the services, acknowledging that her child would not have the same opportunities in their home country because of her disability. She appreciated her child's happiness in participating in different activities like other children. Similarly, several participants compared their experiences of services in their home countries with Norwegian services, which reinforced their gratitude and satisfaction. Some appreciated being involved and informed about their children's condition while receiving well-organized follow-up services, which was not common in their home countries.

> *They always plan what the next step is going to be and how. The doctor discusses her [condition], and they inform us of what they think has to be done. We are grateful for it because not all countries give these opportunities. (P 1)*

Coming from countries in which the doctor–patient relationship is based on the idea that doctors exert professional authority through medical expertise, the participants appreciated the opportunity to be involved in the physicians' decision-making and follow-up procedures. Some experienced being involved in this process as informative and educational. Participants also appreciated how attentive the healthcare providers were with the children and how well they handled and took care of them. One participant explained how she, as a newcomer to Norway, experienced their first meeting with the healthcare providers:

> *The way they talk to the kids; the kids feel so safe here. They are not afraid. I don't know; it was a total shock. And in the beginning, when they started talking, I wanted to cry. Because I felt like a human being, like a real human being. This was really new to me. Also when you feel that everyone will help you... I'm so grateful. (P 16)*

The participant was grateful for the way the healthcare providers approached her and her child calmly and with respect. She explained that she was very emotional in the beginning because this type of approach was unfamiliar to her, and how differently they were treated by the healthcare providers in their home country. She recalled the day that she was kicked out of the hospital because she complained about what she perceived to be wrong treatment of her child. She experienced that those healthcare providers did not listen to her at all. She explained how in their first meeting with the physician here in Norway, she did not talk because she was afraid of being treated the same way as in her home country.

The participants' statements illustrate how the immigrant experience made them look differently at the services available to them in Norway. Comparing the services with those in their home countries made them even more appreciative of the Norwegian healthcare system, knowing that their children's needs were being met by qualified and empathic healthcare providers.

Communicating beyond language

The participants experienced communication with the healthcare providers differently; while some perceived it to be good or very good, others perceived it to be difficult or stilted.

Several participants experienced communication difficulties because of language barriers, especially during their first years in Norway. They experienced communicating through interpreters as challenging and emphasized how disturbing and frustrating it was to communicate through interpreters, whom they perceived as unprofessional. One participant who was dependent on an interpreter to communicate with healthcare providers shared her experience:

> *Sometimes they [the healthcare providers] order a good interpreter, but sometimes they order an interpreter who misinterprets! Then, the healthcare providers misunderstand, and it bothers me for the rest of the day … It is important that they order a professional interpreter … It is about a human life. (P 10)*

The experience of being misinterpreted by unprofessional interpreters, given the importance of the content of the conversation, was disturbing to the participants. They also felt insecure about how correctly the information from the healthcare providers was relayed to them. Participants stated that they did not give feedback to the healthcare providers about their experience with the interpreters, rather relying on the hope that they would have a different interpreter the next time. However, one participant was frustrated at having the same interpreter several times in a row.

Participants also occasionally communicated with healthcare providers through their spouses or children who could speak Norwegian. Although they did not complain about that, the following experience shows how damaging it could be to communicate through relatives in the context of the healthcare system.

> *They found out that the baby was not normal when they did an ultrasound [during pregnancy]; however, my husband asked them to not tell me about it because it could upset me! Also, when the baby was born, his face was different! A week after birth, the doctor told me about the baby's condition. (P 9)*

While interviewing this participant, her husband confirmed that he knew about the baby's condition before the birth. Although the participant justified her husband's decision to not inform her, the fact that she had the right to know about the baby's condition during her pregnancy is undeniable.

Other participants were satisfied with their communication with their healthcare providers despite the language difficulties. They explained how their ability to ask questions and the healthcare providers' patience and ability to explain contributed to overcoming language barriers while communicating. A participant with basic language skills who was satisfied with the communication shared his experience:

> *We had good communication. We did not have communication difficulties! But if I do not understand what they say in Norwegian, I'm not just going to pretend I understand. I have to understand what this is about... I ask them to explain. (P 11)*

Although these participants were confident about their communication with the healthcare providers, there is no guarantee that they truly understood the conversation completely. Speaking a language partially can be more challenging than not speaking the language at all. The reason for this is that neither the clients nor the healthcare providers ask for a professional interpreter, which could lead to the loss of important information.

Some participants believed that communicating in the same language was not enough to experience good communication in the context of the healthcare system. They believed that the healthcare providers' engagement, empathic listening, and even their body language influenced the experience of the communication. A participant who could speak a little Norwegian explained what he believed about communication:

> *I remember there was a professional doctor at the hospital, where we communicated through an interpreter, but it was still difficult to get to the point and communicate. Conversely, there was a social worker who was also professional, and we understood each other quite well and were on the same page, even though we did not use an interpreter... I think culture plays an important role. Possibly, the doctor has not been in touch*

> *with immigrants like me, perhaps we communicate differently, maybe they have been educated differently … (P. 6)*

This participant noted culture and experience as important dimensions of communication. To him, experiencing good communication was not only about speaking the same language but also about the healthcare providers' intercultural communication skills, because culture and communication are strongly intertwined. One of the participants even perceived that belonging to different cultures affected the communication with healthcare providers by making both parties more cautious than they might otherwise be. Some participants also noted how the dominant organizational culture, especially time pressure, influenced communication despite management of the language barrier. A participant who spoke fluent Norwegian shared her experience related to her child's routine checkup by a rehabilitation team:

> *Even though we are physically present, mentally we are almost not there, because it is an unfamiliar language and things happen very quickly, and it is not natural to stop very often and ask them what something is, because they have to go through everything in an hour and a half … It's too short a time … The last few times, it became more like writing what they need in relation to the CPOP [The national Cerebral Palsy Surveillance Program]. It was the program that was the focus rather than what we would need in the future. (P 20)*

Time pressure, routine tasks, and the surveillance program were perceived as challenges by this participant in communicating with healthcare providers. She also experienced medical terminology as an unfamiliar language, which affected her ability to completely follow the conversation. Participants' experiences reveal that communication in the context of the healthcare system depends not only on the communication skills of both the clients and the healthcare providers at an individual level but also on the dominant organizational culture at a systemic level.

Finding a way through the service system

Knowledge of the law, their rights, and the services they were entitled to was important to the participants. They experienced that healthcare providers did not inform them about the rules or their rights. Furthermore, language barriers made it difficult for them to access and comprehend this type of information themselves. One participant who experienced that information was not made available to immigrants reflected on the possible reasons:

> *There is no information, or if there is, it is hidden, maybe it is in Norwegian. I don't know, but a lot of information is not readily available to immigrants, I don't know why. Perhaps the health caregivers just assume that you know what to do or where to get the information from. (P 19)*

This participant's statement reveals the need to make information available in different languages. Furthermore, healthcare providers need to be aware of the importance of informing and enabling immigrant families who are trying to navigate the services. Several participants also experienced that they received information randomly by meeting other parents. Some said that they received information by being associated with organizations for children with disabilities. A participant who had tried to access services to which they were entitled, through their GP, shared her experience:

> *We have experienced that many healthcare providers, even our regular GP, who is absolutely fantastic, do not have information about our rights … So I think if healthcare providers who are supposed to provide information to us do not know about it themselves, it would be very random how multicultural families get access to information. (P 20)*

This participant noted the importance of being prepared as a healthcare professional to provide the information that immigrant families need to access the services to which they are entitled. Lack of information about the services available and how to access them limited the participants' abilities to navigate the services. It was not easy for some of them to know what to ask healthcare providers. Some participants stated that the healthcare system was structured in a way that only benefited privileged clients who were already able to participate fully. They emphasized the importance of tailoring the services to different groups in society to offer accessible and equal services to the entire population. A well-educated participant who defined herself as a resourceful and well-integrated citizen noted the need to enable the immigrants she defined as disadvantaged:

> *There are immigrants who have less knowledge and do not know what to ask about. They do not know which services are available, so maybe it would be good to inform them … I think society expects that this group of immigrants will integrate well, but the society is responsible for informing them. (P 7)*

This participant's statement highlights the importance of enabling the immigrants to not only navigate the services but also integrate into society. As she noted, access to the services is an important element of integration.

Among the professionals discussed, social workers stood out. Participants met social workers mainly after their children were diagnosed. The participants were mostly satisfied with the information and support they had received from the social workers. Some noted that receiving the information was not helpful if they did not receive the guidance and help they needed to access and navigate the services:

> *I was in touch with a social worker earlier; she told me about our rights, and how to access the services … I cannot write very much, like proper letters, so after receiving the necessary medical documents from the GP, I used to go to the social worker and she helped me with that. (P 15)*

As this participant noted, navigating the services demands special skills, such as an appropriate level of writing skills to apply for services. Application letters have to be well-documented and convincing. This participant used the social workers to not only obtain the information but also navigate the services. However, other participants experienced that the information provided by social workers was not comprehensive. Despite the fact that the participants' need for information was continuous as their children grew up and entered new stages of development, their relationship with the social workers was not continuous. They stated that they met the social workers only a couple of times in the very early years after their children were diagnosed. Considering that family situation and healthcare options vary over the years, the participants' need for information was not completely met by the social workers.

Accessing help as a battle

Some participants described years of struggling to get help. They felt that their concerns had been underestimated and not taken seriously by the healthcare providers. They described how they consistently had to insist on their need for help, and even wondered if they had been perceived as nagging or rude. They felt exhausted and experienced their attempts to get help as stressful, frustrating, and demanding in terms of resources. They stated that the struggle over the years had affected their mental and physical health. Some participants described it as challenging to obtain access to the specialist healthcare system through GPs, who acted as gatekeepers. One participant felt that her worries about her daughter had been underestimated by their regular GP for several years:

> *We really experienced from the beginning that she was very uneasy, cried a lot, and was delayed in her motor skills, so we arranged an appointment with our regular GP, and she told us that there was no reason to worry … When she turned three years old, we still experienced challenges; then we arranged a new appointment with the GP, and she still said that it was normal until she turned five years old. (P 20)*

This participant explained that they were worried because they observed that their child fell a lot. They decided to reach out to their regular GP again to obtain a referral to the orthopedic outpatient clinic. Although the GP referred their child to a specialist this time, she was not prioritized.

> *...But we did not receive any response, so we called them, and they said she was not a priority... Again, we went back to our regular GP. It was already over one year later, so she sent a reminder of the referral … Then we got an appointment at the orthopedic outpatient clinic, and the physician recognized what was wrong, so she sent us to the children's department at the hospital immediately... She was five at the time. (P 20)*

Five years of being sent back and forth to access help from the healthcare system was a burden on this family. This participant described how they could not pay enough attention to their son because they were focused on getting help for their daughter. She believed that this entire burden could have been alleviated if their concern had been taken seriously by the healthcare providers in the beginning.

Another participant who described accessing help as a battle wondered whether healthcare providers perceived the parents' concerns as excessive. She recalled how even after her child was finally hospitalized with a swollen and painful knee, it took almost two months before an orthopedist visited and referred her for further examinations. It had been several years since her child was diagnosed, but she still experienced attempts to access help through emergency care and their regular GP as continually "hitting a wall". Another participant even generalized her experience of not being taken seriously by the doctor as a common pattern while seeking help in Norway. She further explained how years ago when her child was only 18 months old, they had to take her to emergency care three times, and each time they were sent back home. Finally, they had to take her to the hospital, where she went into a coma and was hospitalized for a month. According to this participant, the child was never the same after that, and they struggled to get the help they needed for several years.

> *We used to receive an appointment with the doctor. We went there and talked to the doctor [about our child], but as you may know, he kept saying that everything is fine. As you may know in Norway, the doctors always say that everything is fine. (P 5)*

Some participants with similar experiences explained how they occasionally chose to take their children to private emergency care or specialists in order to get proper and timely help, even though they had to pay extra for the consultations.

Other participants felt that healthcare providers did not always pay attention to their concerns or were not interested in listening to their worries. They described how healthcare providers interrupted them or changed the subject of the conversation, which they might have thought to be irrelevant. One participant described worry about his family's situation not interesting healthcare providers:

> *I have experienced that it is not important for them to know or hear about my financial situation or about my residential situation, or when I am talking about transport, I have noticed that they do not care. In my opinion, our financial and residential situation is related to my children's health, but they do not see it, they do not understand it. I have always talked about it to our regular GP... (P 11)*

This participant felt that the healthcare providers ignored and overlooked what the family truly struggled with. He believed that the healthcare providers did not consider his worries to be of interest or relevant to their jobs. He then described how exhausting it had been not to receive timely help:

> *… The problem is that it takes so long, you get help when you have become completely exhausted. You have to approach them and complain again and again; they do nothing until you fall down... Then they will help you. (P 11)*

He finally described how the demanding and stressful process of getting help over the years had caused him a lot of stress and disturbed his mental balance.

Language barriers and lack of knowledge of medical conditions made it even more challenging for some participants to access timely help. One participant, whose daughter experienced seizures for several months before receiving help, shared her frustration:

> *Every time I went to the hospital, I explained how she used to lose consciousness and started kicking and how disturbing it was for her. Every time I told them, they replied that it has something to do with her nerves. (P 10)*

She explained that she did not know anything about seizures, and this condition was quite unfamiliar to her. The participant's difficulty in precisely describing her child's condition caused significant delays in receiving a proper diagnosis and specialized services for her daughter. The participant explained how, after several months of suffering and trying to navigate the healthcare system, her daughter finally received the treatment that she needed. This family's experience illustrates how important it is for healthcare providers to be aware of language barriers and inadequate knowledge about medical terms among immigrant families. Being curious as a healthcare provider and paying enough attention while interacting with immigrant families would prevent others from experiencing what this family went through.

When interpreting and reflecting on their experiences with healthcare services, some participants brought up their position as immigrants. They believed that the way they were treated by the healthcare providers was important. Some participants perceived that their skin color and religion influenced how they were treated and the services they had received. One of the participants discussed frustration about how a physician had alerted the child protective services immediately after she and her child left the hospital:

> *I feel like if I was Norwegian it wouldn't happen, but because we are different skin color from everybody, then people just think that immigrants come here without knowledge and they are not educated enough to understand things, and they beat their children and they do not have good homes. (P 19)*

She described how her child was intimidated by a blood test and kept crying, hiding himself under the physician's table and saying that he did not want to go home. The participant believed that the physician had misinterpreted the child's behavior; she explained that her child feared the needles badly since he had been through a lot of examinations. She was frustrated that the physician did not express her concerns or inform her about the decision to alert the child protective services:

> *I feel like if I was Norwegian she would have spoken to me first, to say what is going on … because we came out, then I did not know what she is going to do. (P 19)*

This statement shows how the physician could have handled the situation differently by clarifying her concerns and making an informed decision.

Discussion

This study reveals the experiences of immigrant parents of children with disabilities navigating the Norwegian healthcare system, particularly pediatric rehabilitation services. The aim of the study was to generate knowledge of how accessible and tailored the services were from the parents' point of view. Although the findings of this study are derived from a Norwegian healthcare context, they may be relevant for understanding immigrants' experiences elsewhere, because the Norwegian healthcare system is comparable to those in the Nordic and some other Western countries.

Previous studies of immigrant families have mostly explored their experiences of challenges while utilizing services. This study aimed to explore experiences of the services' strengths as well as challenges. The immigrant parents were mainly satisfied with the follow-up services provided by the pediatric rehabilitation centers. Although participants' satisfaction may reflect the quality of the health services provided to them [26], it is important to consider that these participants came from countries with very different services or even lacking a public welfare system. They had varied experiences of healthcare services in their home countries, which may have influenced their expectations, the way they experienced the Norwegian healthcare service, and their level of satisfaction [27]. Mangrio et al. [28] similarly showed how non-European parents felt gratitude when comparing the services received from child healthcare centers in Sweden with those in their countries of origin. They appreciated the way the service was organized and how well the children were cared for, the same way the parents in our study did. They expressed that the Swedish child healthcare system was good and that they could not find similar healthcare in their home countries. Czapka et al. [29] also noted how most of the Polish immigrants in their study compared the Polish and Norwegian healthcare systems and drew both positive and negative conclusions about the services provided to them in Norway.

Interestingly, a study of Turkish-speaking families of children with disabilities who were immigrants in the UK showed that parents appreciated the services they were given, even if they did not meet their expectations [30]. Sandhu et al. [30] interpreted these families' appreciation as a reflection of their assumptions that health and social care support are privileges that can be withdrawn, rather than rights. This interpretation may also explain why some participants in our study were so grateful and hesitant to talk about the challenges they faced while navigating the services. Sandhu et al. [30] perceived that assumptions of the services as privileges, rather than rights, could also explain why immigrant families tended to respond to the challenges they faced with stoicism, which was less usual among non-immigrant families.

Despite their satisfaction with the follow-up services, participants in our study experienced several challenges while navigating the services. The challenges spontaneously shared were mostly about accessing help before their children were diagnosed. At that time, they felt that their concern had not been taken seriously by the healthcare providers and they did not receive the help they needed. A previous study conducted in the Netherlands also showed how mutual understanding and compliance is often worse in doctor–patient consultations with ethnic minority parents of pediatric patients than with their socially dominant counterparts [31]. That study suggested that the large differences in explanatory models of health and illness used by physicians and ethnic minority parents could be a reason for this poor mutual understanding. The same study found that consultations that ended without mutual agreement more often resulted in noncompliance with the prescribed therapy. As Van Wieringen et al. [31] stressed, healthcare providers' communication skills when exploring the explanatory model with parents, and their open attitude to models other than a scientific medical paradigm, are important when interacting with immigrant families.

Eriksen et al. [32] also explained how some immigrants express their symptoms in a way that reflects their cultural background, which is minimally influenced by Norwegian medical thinking. These immigrants are unable to express themselves in a way that a Norwegian doctor is likely to take seriously. They struggle with accessing the treatment they need over a long period of time. Eriksen et al. [32] noted how Norwegian doctors and immigrant patients used the same word to describe two different conditions. According to them, in these cases, misunderstandings persisted partly because the doctors never tried to determine what the patient truly intended to say, and their conversation was not constructive.

The participants in our study also expressed unmet needs for information about their rights, the rules, and the services available to them and to which they were entitled. Sandhu et al. [30] found that although immigrant families of children with disabilities expressed gratitude for the services they were receiving in the UK, they felt that they were overlooked and not kept informed by service providers.

The experiences of needing information [33–36] and facing challenges due to a lack of access to timely help do not only affect immigrant families. Sloper et al. [37], in their study about the service needs of families of children with severe physical disabilities, showed how the difficulties in obtaining appropriate help caused these parents additional anxiety. Surprisingly, what Sloper et al. [37] noted in 1992 about the need for information, help in obtaining services, and a coordinated approach to providing services appropriate to all aspects of the family is still relevant and consistent with our findings.

Providing information about services and their availability is a crucial determinant for parents to take an active role in the care process, obtaining appropriate help and decision-making [37–39]. However, research has shown that healthcare providers are not always aware of the resources available to the families of children with disabilities [34, 40]. In addition, parents may find it difficult to define and express their information needs and may instead wait for healthcare providers to address a subject [41, 42]. These challenges explain how some participants in our study experienced accessing information by chance.

While providing information itself seems to be a challenge for service providers [43], immigrant parents in our study expressed the need for guidance and support in addition to information. Paperwork and the need for adequate writing skills, as well as knowing where to go or whom to contact, were challenges faced by several families in our study. Consistent with our findings, Fellin et al. [9] found that social workers acted as facilitators of services by assisting immigrant families in navigating the health and social systems. Interprofessional collaboration and connecting immigrant families with social workers is therefore important for their ability to manage navigating the health and social systems and connect with the appropriate resources [44].

Peer health navigator (PHN) interventions have also shown to be a promising approach to breaking down barriers to care for people from underserved populations, such as immigrants and ethnic minorities [45]. PHNs are individuals from the target population with shared lived experiences, and who have received specialized training to support and help others to navigate the complex and often fragmented healthcare delivery systems [45]. Providing PHN programs adapted to meet the needs of immigrant families of children with disabilities may therefore reduce barriers to their care, particularly for newly arrived families.

Navigating systems with multiple organizational and access issues has also been indicated as difficult for parents belonging to the majority of the population [33]. While these common challenges can complicate gaining access to and navigating the healthcare system for any family, certain challenges that are unique to immigrant families exacerbate the difficulties. Language barriers were noted by Lindsay et al. [40] as one of the main obstacles to accessing, receiving, and utilizing healthcare services for immigrant families of children with disabilities. Our findings show that language difficulties, issues with perceived interpreter quality, and issues of accuracy of translation are barriers to navigating the healthcare system [46, 47]. Therefore, while communicating with immigrant families in their nonprimary language or through an interpreter, healthcare providers should be aware of how this process may influence the quality of care and services provided to the families. It is the healthcare providers' responsibility to ensure that their clients have understood the content of the conversation and to use a professional interpreter instead of relatives. Improvement of access to and use of professional interpreters is also important for both linguistic and cultural reasons [48].

The use of medical terminology [48, 49], lack of intercultural communication skills, and lack of training pertaining to working with families from diverse backgrounds were also communication challenges that immigrant families in our study faced. Healthcare providers may unintentionally devalue immigrant families' perspectives and perceptions, assuming that the "Western way" is the "best and only way" [50]. According to Söderström [16], communication between healthcare workers and minority families occurs in the context of the healthcare providers' perspectives and sense of reality. Healthcare providers need, therefore, to use culturally sensitive communication. This involves listening to and respecting the family, reflecting on their own knowledge and biases, and sharing their beliefs with the family [51]. Although ensuring equal access to public healthcare services for culturally diverse families of disabled children involves applying culturally sensitive communication [16], it is widely recognized that healthcare providers lack the skills to have culturally sensitive conversations with these families [52]. Therefore, enabling healthcare providers to use culturally sensitive communication by equipping them with the required knowledge and skills is important [51, 52].

Another important barrier to communication was the parents' perceptions of the lack of adequate time to address their questions and concerns. Improving communication with immigrant families requires new and innovative solutions at the systemic level to provide enough time and/or make more efficient use of the time spent with these families, ensuring that their needs are met [40, 51]. A systematic review of 37 articles showed how the perceptions and practices of healthcare providers in providing services for immigrants were mainly influenced by cultural and language differences, as well as restricted institutional capacity in terms of time and/or resources [53]. King et al. [54] also noted how the context of the workplace can strongly affect the ability of therapists to deliver culturally sensitive care. They noted how the structured and time-limited therapeutic sessions and the organizational methods in the practice could restrict the time therapists had to get to know the family situation and build a collaborative relationship. However, it has been documented that time constraints also negatively affect ethnic majority patients' experiences of communication in medical contexts and make them feel vulnerable. A systematic review of 57 qualitative studies targeting patients' experiences in communicating with primary care physicians revealed negative experiences related to feeling vulnerable due to time constraints, regardless of patients' ethnicity. Physicians were perceived to ask fewer questions or ask more closed questions, seemed disinterested, and tended to use jargon to rapidly explain the condition. Consequently, patients reported feeling dehumanized or "like a number". Although experiences were similar among all patients, ethnic minority groups raised distinctive experiences relating to language barriers and differences in values and beliefs that further exerted a negative influence on their experience of communication [55].

Last, the findings of this study, in accordance with those of other research, show how perceived stereotypical attitudes towards immigrants can act as a barrier to these families navigating the healthcare system [29, 46]. Even the feeling of being treated differently than the majority may be experienced as offensive and can cause emotional distress among minority families. Such a sense of discrimination, in addition to other barriers related to the immigrant experience, can even cause immigrants to avoid using the healthcare system [29]. Thus, healthcare providers must be aware of their attitudes while interacting with people such as immigrants who have experienced many years of stigma and discrimination. This would be a step toward providing the services that are available and appropriate for the whole population, regardless of ethnicity, religion, function, or social status. A survey conducted at a Danish hospital showed that most healthcare providers considered immigrant patients to be a specific strain on the Danish healthcare system, which affected the attitudes towards immigrants of some providers. The same study showed that healthcare providers characterized some immigrant patients as being overly dramatic when ill [56].

As Penchansky et al. [57] noted, access to services is about the fit between the characteristics of providers and health services and the characteristics and expectations of users. Our findings show how the characteristics of healthcare providers and of immigrant families influence the families' access to and utilization of the services. Therefore, practicing strategies that contribute to increasing the coherence between healthcare providers and immigrant families is important. Our findings also show how the discrepancy between the organization of services and the needs of immigrant families makes it challenging for families to use and navigate services. This underlines the importance of listening and responding to families' perceptions of their own resources, challenges, and needs.

Study strengths and limitations

While previous research conducted in Norway and internationally has mainly focused on particular minority populations, the participants in this study were immigrant parents with varied linguistic, cultural, and religious backgrounds. They came from different parts of Africa, Asia, and Eastern Europe, which together compose the largest immigrant group in Norway. There has also been little research exploring the experiences of immigrant families with pediatric rehabilitation services [9], as this research did.

It was not possible to parse out whether certain challenges were more likely to be reported by newer immigrant families, because this study did not include newly arrived families. The study included only immigrant families who had participated in an intensive pediatric rehabilitation program at a rehabilitation center. Applying for this program demands familiarity with the healthcare system and some language skills. Thus, the participants did not face the same challenges as newly arrived families might, and the results do not reflect the challenges and experiences of newly arrived families when seeking assistance from the healthcare system in Norway. However, the participants described their experiences of navigating the services during the very first years of their time in Norway, and those were included, analyzed, and reported in the results of this study.

Furthermore, member checking was not carried out. Norwegian is not the first language of the first author (interviewer) or the interviewees. This might have affected the quality of the produced data, despite the fact that the first author did her best to ensure a mutual understanding of the interview questions and the responses.

Conclusion

This study was conducted to generate knowledge of how accessible and tailored the Norwegian healthcare system is from the perspective of immigrant parents of children with disabilities. The immigrant parents were mainly satisfied with the follow-up services provided by the pediatric rehabilitation centers, but they experienced several barriers while navigating the healthcare system. The barriers from the perspective of immigrant parents were associated with both the systemic and individual levels. At the individual level, the barriers were related to characteristics of both the families and the healthcare providers. Insufficient competence in the majority language, a lack of knowledge of the services, and a lack of understanding of how to navigate those services were some of the barriers related to family characteristics. Applying medical terms, a lack of experience and intercultural communication skills, and perceived attitudes were among the barriers related to the service providers' characteristics. At the systemic level, the barriers were related to the use of interpreters who were perceived as being unprofessional, organizational routines, and insufficient time allotted for interactions with immigrant families. The lack of effective strategies to inform, empower, and enable immigrant families to manage navigating the complex and growing healthcare system was another barrier at the system level.

This study therefore highlights the importance of mobilization at both the individual and systemic levels. A need exists to reach out and educate immigrant groups to enable them to meet the complex demands of navigating the healthcare system in modern Norwegian society. Healthcare providers should particularly be aware of immigrants' need to be informed and supported, even though they may not ask for it, so that they can make educated decisions while navigating the services. Healthcare providers should also be aware of the importance of effective communication and engagement and the impact of their interaction style on immigrant families of children with disabilities. Workplace teaching strategies and other training methods can be used to provide healthcare professionals with the training they need to develop the approaches needed to deliver care in a culturally sensitive manner.

This study adds to the current literature on the experience of accessing and utilizing healthcare services by showing how the immigrant experience affects the way the parents look at, experience, and appraise the services. The study reveals immigrant parents' need for support in addition to information to manage navigating complex and changing services. The study also highlights the need for a coordinated approach to the assessment of need and the provision of services appropriate to all aspects of the family as a whole.

Our findings show that there is still a gap between the public ideal of equal healthcare services and the reality of the everyday lives of immigrant families of children with disabilities. The current gap challenges public policy on both the disability front and the immigrant front. By exploring the immigrant parents' point of view, this study contributes to the opportunity to improve and adjust the services and the overall health and quality of life of these families and their children with disabilities.

Further research is needed to guide service providers and inform policymakers about the best ways of meeting the needs of immigrant families and their children with disabilities. Determining effective strategies for enhancing information transfer to immigrant families of children with disabilities is a relevant topic for future research. In addition, there is a need for research to develop PHN interventions adapted to meet the needs of immigrant families of children with disabilities, considering their success across diverse populations.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12913-020-5004-2.

Additional file 1. Interview guide.

Abbreviations

CPOP: The national cerebral palsy surveillance program; GP: General practitioner; NSD: Norwegian Centre for Research Data; PHN: Peer health navigator; REK: Regional Committees for Medical and Health Research Ethics; UK: United Kingdom; US: United States; WHO: World Health Organization

Authors' contributions

SA contributed to the study design, conducted the interviews, performed the transcription, analyzed the data, and prepared the manuscript. RJ contributed to the study design, analyzed the data, and prepared the manuscript. PKS contributed to the study design, analyzed the data, and prepared the manuscript. BB contributed to the analysis of data and prepared the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets generated and analyzed during the current study are not publicly available due to the need for participant anonymity but are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

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

Prior to participating, potential participants received an information letter describing the study, its purpose, and that participation was voluntary. The letter also stated that they could withdraw their participation without giving any reason and that their contributions would be unidentifiable in the final report. Furthermore, the 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 desired. The participants gave written consent to participate in the study. The consent form was approved by the NSD.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

Article 2

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Participation in a rehabilitation program based on adapted physical activities in Norway: a qualitative study of experiences of immigrant parents and their children with disabilities

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ORIGINAL ARTICLE

Participation in a rehabilitation program based on adapted physical activities in Norway: a qualitative study of experiences of immigrant parents and their children with disabilities

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ABSTRACT

Purpose: By exploring immigrant families' experiences of participating in a three-week rehabilitation program focused on adapted physical activity in Norway, this study investigated how beneficial, culturally adapted, and accessible the services were from the families' perspectives.

Methods: A hermeneutic design with semi-structured interviews supplemented by participant observation was applied. Inductive thematic analysis was conducted.

Results: Three themes were identified: "learning through participating," "sharing the same experience," and "gaps in service delivery." By participating in physical activities together with their children, parents became aware of their children's capabilities and interests, as well as the available resources. Parents also socialized and exchanged experiences and information with each other. Children learned new skills, became aware of their preferences and capabilities, built friendships, and improved their social skills. However, a lack of cultural adaptation, such as insufficient information, as well as the location of the rehabilitation center, language barriers, and exclusion of siblings affected accessibility of the services to immigrant families.

Conclusions: Although the beneficial aspects of the services were demonstrated, the cultural adaptation and accessibility of the services were limited. Providing flexible and culturally adapted services that meet immigrant families' needs may improve the accessibility of rehabilitation services to immigrant families.

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➤ IMPLICATIONS FOR REHABILITATION

- Making information available to immigrant families, mapping their resources and needs well before the intervention may improve the accessibility of the services for these families.
- Rehabilitation professionals need to consider families' perceptions of their own role through the goal-setting process when engaging with families from cultural backgrounds different from their own.
- When planning the intervention, grounding physical activities in the diverse cultural background of participants may increase immigrant families' sense of belonging and inclusion, and thereby facilitate interaction between families regardless of cultural differences.

Introduction

Physical activity is associated with improved health, psychological benefits, and social development among young people [1]. However, participation in physical activities varies within the young population and occurs considerably less frequently among children with disabilities compared to their peers without disabilities [2–4]. Children with disabilities face complex barriers to participation [5], mainly related to the child, family, and wider environmental factors [6]. Children with disabilities and immigrant backgrounds have even lower rates of participation in organized social activities, such as sports, dance, and youth groups compared with their non-immigrant counterparts [7]. Household socioeconomic factors, such as education, as well as household connectedness with the neighborhood significantly influence the participation of children with immigrant backgrounds [7]. 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. More than 80% of all immigrants in Norway come from non-Western countries [8].

In recent years, research has shown the potential of interventions based on adapted physical activity and involving parents in improving physical activity participation among children and youth with disabilities [9,10]. Such interventions encourage parents' active engagement in physical activity sessions, which is an essential consideration for the continuation of physical activity behavior once interventions have ceased [11]. Given the low

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participation in physical activity among children with disabilities and immigrant backgrounds [7], this study explored the experiences of immigrant parents from non-Western countries and their children with disabilities who participated in a rehabilitation program built on the same principles of involving parents and focusing on adapted physical activity. The purpose of the study was to generate knowledge of how beneficial, culturally adapted, and accessible the services were from the immigrant families' perspectives.

Access is a multidimensional concept and a major concern in healthcare policy, representing the degree of fit between the characteristics of families and health services [12]. Access is optimized by accounting for its dimensions, which include accessibility, availability, acceptability, affordability, adequacy, as well as awareness in service design, implementation, and evaluation [12,13]. The knowledge produced in this study may contribute to providing inclusive and accessible rehabilitation services for immigrant families with children with disabilities.

Materials and methods

The present study used a hermeneutic design. This approach is especially advantageous for conducting multicultural research in that it provides the space to identify and understand various perspectives. Hermeneutics also raises researchers' awareness about how their own preunderstandings, linguistic capacity, and cultural identity may influence the multicultural research process and the findings. Furthermore, the integration of interpretation and critical reflection in hermeneutic inquiry allows researchers to reexamine practices that are closely defined by traditions and cultures, which is precisely within the scope of the current study [14]. A mixed-method qualitative study was chosen, with semi-structured interviews as the main method and participant observation as the supplementary method [15]. Participant observation was applied as a supplementary method to gain insight into the interaction between professionals and families as well as inter-family interactions [15,16]. Observations give the opportunity to grasp interactions that are lived, but not conscious or articulated [16].

The study was registered with, and approved by, the Norwegian Center for Research Data (NSD) and received permission for implementation (reference number 51764). The study 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 Act; it could, therefore, be implemented without the approval of the REC (reference number 2016/1764). 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 [17], the study included immigrant parents from non-Western countries and their children with disabilities who participated in the pediatric rehabilitation program between 2015 and 2018. Immigrants are persons born abroad of two foreign-born parents and four foreign-born grandparents [18]. Non-Western immigrants refers here to immigrants from Eastern Europe, Asia, and Africa [19]. Most of the children were born in Norway to two immigrant parents. Only four children had immigrated to Norway, arriving at a very young age with their parents.

Participants were recruited through the rehabilitation center *via* an information letter about the study, sent either before or after their three-week stay at the center. In total, 66 families were approached in writing. After receiving the information letter in Norwegian, potential participants who lived in the Oslo area were additionally informed by phone about the study in simple language by the first author. Forty families did not respond, and two declined because of their work and life schedules.

The rehabilitation program

The context of the study was a private rehabilitation center, located in the mountains, within the Norwegian specialist healthcare system, which provides services to both children and adults with disabilities. The eligibility criteria of the program were broad and included children aged 5–17 years with various functional levels, diagnoses, and disabilities. The program was based on intensive intervention and the principles of adapted physical activity [20,21], reflecting Norwegian culture with a particular focus on outdoor activities [22]. The intervention was based on each child's individual goals but was also designed to introduce families to novel and varied adapted physical activities [9]. Depending on the season, families participated in summer or winter activities, such as skiing, snowboarding, horseback riding, rock climbing, swimming, cycling, and canoeing. A multidisciplinary team of six professionals—comprising a physician, a physiotherapist, an occupational therapist, a sports pedagogue, a nurse, and a social worker—provided the interventions for each group of 8–10 children and their parents, five hours a day, six days a week, for three weeks [20]. The program also included optional leisure activities comprising physical, social, and cultural activities, such as picnicking, target shooting with air rifles, painting, and playing games provided by recreation workers in the afternoon and evening. Children and parents resided at the center for the duration of the program. Children's activity preferences were identified before the intervention using ActiveYou I, a web-based self-report assessment instrument that is a Norwegian-adapted version of the Preferences for Activities in Children (PAC) [23]. The goal-setting process used an adapted code set based on the International Classification of Functioning, Disability and Health and included 40 categories, most of which were subsumed within Activities and Participation [22]. The goals were mainly to improve children's participation in their preferred physical activities, such as learning to swim or ride a bike. Parents were involved in some of the activities to learn about possibilities for facilitating their children's participation back home in their local community [10].

As a part of the program, parents also participated in informative group meetings. One of the meetings, led by the social worker, was about the families' rights and the services to which they are entitled. A regional sports association consultant was also present to inform parents about the different types of adapted physical activities available in their region. Additionally, a meeting was organized with a psychiatric nurse who guided parents on how to overcome daily challenges by using mastery strategies. Another meeting was organized with a nutritionist about the importance of healthy food in maintaining good health. The families were also introduced by the occupational therapist to assistive activity devices, which are available free of charge and may facilitate activities in their local communities.

Data collection

Twenty-three interviews with parents and 17 interviews with children were conducted from April 2017 to January 2018, between one month and nearly two years after the program. The authors discussed data saturation, and consensus was achieved. All interviews were conducted by the first author in Norwegian, except one interview that was conducted in English. Professional interpreters facilitated interviews with six parents; this necessity was determined by the first author's perception of these parents' language skills during the initial telephone conversation or at the participants' own request.

The interview guide for parents explored five main domains of experience: (1) receiving information about the rehabilitation services, (2) challenges to, and motivation for, participation in the rehabilitation program, (3) the program itself, (4) collaboration with rehabilitation professionals, and (5) meeting other families at the center. The two main domains of the interview guide for children were the experience of the program and getting to know other children and families. The interview guide was developed based on the review of previous research and experiences from a prior developmental project involving informal conversations and observations of the immigrant families. The project was intended to inform and encourage immigrant families to participate in the rehabilitation program studied. The interview guide was not further pilot-tested.

The first author, herself an immigrant from the Middle East, had worked as a pediatric physiotherapist in the primary healthcare system in a multicultural district of Oslo for several years. She therefore had experience working with culturally diverse families, and consequently some familiarity with different cultures and values. This cultural familiarity became a foundation for building trust between her as a researcher and families as participants. Furthermore, her experience as a pediatric physiotherapist contributed to helping the children participating in the study to feel safe and to communicate freely.

Prior to each interview, the first author explained the purpose of the study and the confidentiality regulations to both children and parents, then obtained written informed consent from all parents. For children, informed consent or assent was obtained in addition to informed consent from their parents. The first author also emphasized that the participants could later withdraw their consent without giving any reason if they wished to. The participants were informed of the interview procedure and that audio recordings would be made of the interviews. The 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 for 10–25 min with the children. One interview with a parent 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 questions, or even ask to end the interview whenever they wished. Interviews were performed at a time and place convenient for each participant, including their home, a café, Oslo Metropolitan University, the rehabilitation center, and the Family House health and educational center in the participants' local district. Three participants' spouses were partly present while the interviews occurred in their homes. Children could choose to be interviewed alone or in the presence of their parents. Only five children were interviewed in the full presence of their parents. Having their parents nearby was reassuring for these children and helped them to express themselves easily. Two parents also assisted their children's contributions by reminding them about their shared memories. Although the parents' presence might have influenced the findings by producing richer data, it might also have limited the expression of the children's views [24]. All interviews were recorded and transcribed verbatim by the first author.

In addition to the interviews, observation was applied as a supplementary method in this study [15]. Since most of the families consented to participate in the study after their stay at the center, the opportunities for observation were limited. Therefore, only three families who gave consent prior to their stay at the center were observed by the first author during parts of their stay, in December 2017 and January 2018.

Observations occurred at a range of occasions, such as the arrival of the families, conversations with the professionals, intervention activities, leisure activities, informational meetings, meals, and periods of informal interactions and communications. Field notes were written by the first author following each observation period and contained descriptions of events, conversations, and reflections. Two of these parents were also interviewed by the first author. One of the observed parents had grown up in Norway and thus spoke fluently; the two others spoke little Norwegian. Several of the families in this study were also observed by the first author during the former developmental study at the center, prior to the commencement of the present study. These families had consented to be observed during parts of their stay. Those observations provided the first author with a deeper understanding of the context of the study, the program, and the interactions in which these families were involved. All the observations, as a supplementary source, enriched the data developed by the interviews [15].

Analysis

An inductive thematic analytic approach [25] was applied to explore the potential patterns in the data. The interview transcripts and field notes were read individually, and then the codes were defined broadly to bring together a large group of data extracts that could be related. As a result, the field notes were organized into three codes: "language difficulties," "goal-setting process," and "group dynamic." The parents' transcripts were also organized into 14 codes and those of the children into six codes.

Next, in searching for themes, data extracts within each code related to the field notes and the interview transcripts of both the parents and the children were merged and formed two initial themes: "a multidimensional program" and "gaps in the service delivery." Whereas the first theme was identified by merging data extracts related to only the transcript data, the second theme was identified by merging the data extracts related to the field notes and the parent transcripts.

Reviewing the initial themes in the next phase led to breaking the first theme into two new themes: "learning while participating" and "sharing the same experience." The second initial theme of "gaps in the service delivery" was also further analyzed, and three subthemes were generated to give structure to the theme and assist in directing readers to its key components. The subthemes are presented in the Results section. The codes and the final themes were reviewed by all four authors to ensure that the themes were appropriate with regard to the dataset and the research question. Finally, three main themes and three subthemes were identified, and representative quotes were selected for presenting the results.

Results

In total, 24 parents (7 fathers and 17 mothers) (Table 1) and 17 children (aged 8–17 years) with physical or developmental disabilities participated in the study. At the time, three of the children were not diagnosed but had participation restrictions identified

Table 1. Sociodemographic characteristics and country of origin of the parents.

Sex	
Female	17
Male	7
Age (years)	
31–40	9
41–50	13
51–60	2
Education	
University	9
High school	10
Primary school	4
Not available	1
Norwegian language skills* (estimated by the first author)	
Very good	7
Good	4
Basic	5
Very basic	7
Almost none	1
Length of residence in Norway (years; median 16 years)	
2–10	8
11–20	9
21–29	7
Country of origin	
Afghanistan	1
Bosnia	1
Bulgaria	1
Chechnya	2
Iran	1
Iraq	2
Jordan	1
Pakistan	4
Poland	2
Serbia	1
Somalia	4
Sri Lanka	2
Tunisia	1
Zimbabwe	1

*Very good: communicates fluently in Norwegian; good: communicates with varied vocabulary; basic: communicates with limited vocabulary; very basic: communicates with very limited vocabulary; almost none: can only use a few Norwegian words.

Table 2. Characteristics of the children.

Diagnosis	
Autism	2
Acquired brain injury	1
Cerebral palsy	6
Intellectual disability	2
Spina bifida	2
Vision impairment	1
No diagnosis at the time	3
Sex	
Female	8
Male	9
Age (years)	
8–12	8
13–17	9

by a general practitioner (Table 2). All but three families lived in the Oslo area. Some participants were familiar with the first author before the study, due to her role in the prior developmental project.

One of the families was also familiar with the first author because of her role as their child's physiotherapist. Six families in the study had participated in the program more than once, and four of these had experienced both winter and summer activities.

Other families had participated in the program mostly during the warm seasons, finding summer activities more attractive and culturally familiar. Analyzing the families' experiences of participating in the rehabilitation program revealed several aspects of the services, which are presented within the three themes: "learning through participating," "sharing the same experience," and "gaps in the service delivery." The last theme builds only on parents' experiences and the field notes and is presented within the three subthemes: "lack of information about the services," "unmet needs of the family as a whole," and "communication difficulties."

Learning through participating

Parents and children discussed the opportunity to try new and different activities during rehabilitation. Horseback riding, canoeing, and skiing were some of the activities introduced at the center that were new to some of the children and parents. Parents experienced that doing activities intensively facilitated learning new skills and made their children feel more confident about their capabilities. One parent explained how her child overcame his fears and mastered new activities during their stay:

> He feared height so much, but by the time we came back, he was climbing up and down. He was feeling confident in himself. (P 19)

The children also discussed all the different activities that they had tried and the new skills they had learned. The opportunity to participate in the activities made them aware of their interests and capabilities. They spoke about their favorite activities and those that they wished to continue back in their local communities.

> It was a good experience to be able to do many different activities that I do not usually do in Oslo… Back home I wish I could continue swimming and cycling. (C 7, 17 years)

Although the children were mostly excited about participating in the varied activities, some expressed that they would rather participate only in their preferred activities. They were frustrated that they had to participate in all activities, even though they did not enjoy them.

> I did not like that sometimes we had to do the activities, that we could not choose, sometimes we could choose, like after dinner [leisure activities], maybe it was a little silly that we had to do some activities. (C 11, 13 years)

Like their children, some parents also experienced difficulty remaining focused and collaborating with the professionals on their children's goals and preferred activities. This was largely due to hectic daily routines and participation in different activities.

> They [the professionals] were experts on organizing and accomplishing all those different activities, but there was not so much focus on what she [the child] wished to improve, or what we [the family] preferred to focus on… (P 1)

However, parents experienced that doing activities together with their children made them aware of their strengths, capabilities, and interests, and were pleased to know exactly which activities they would invest in back in their local communities. Participating in the rehabilitation program as an immigrant was also an opportunity to experience Norwegian nature differently. Despite their initial skepticism about staying for three weeks at a totally unknown place in the mountains, far from where they lived, parents felt close and connected to nature soon after beginning their stay at the center. Parents described how peaceful it was to listen to the birds, walk through the woods, sit by the bonfire, and chat with each other. The experience of performing physical activities together with their children outdoors in nature was also new and thrilling to the families.

Sharing the same experience

Parents talked about the opportunity to socialize with other families, and how observing the other parents coping with their challenges gave them the strength to persevere. They also exchanged information about assistive devices and services they were entitled to, which they believed was important for their children. One of the parents explained how she had received information from fellow parents that she had never received before:

> You receive information from parents, that you have never heard from physicians or the government … It is not like you are intending to take advantage [of the system], but you wish to do the right thing for your child. (P 22)

To the children, having fun and socializing with friends was one of the best parts of participating in the program. They described it as an opportunity to make friends, spend time with them and have fun while doing activities together.

> It was exciting to be there, doing different activities, making good friends … I felt energized. (C 4, 14 years)

Gaps in service delivery

This theme is presented within three subthemes that are intended to assist in directing readers to the theme's key components.

Lack of information about the services

Parents experienced that information about the services was not easily available to them. Most of the parents had first received information about this rehabilitation program through the prior developmental project, which started in 2015. They knew nothing about it before that time, despite their connections to their local pediatric rehabilitation center and the primary healthcare system over several years. One parent, who was frustrated about not knowing about the opportunity before, explained:

> I am still wondering why her physiotherapist did not think about that. Why didn't she mention it? We have the same rights [as the rest of the population]; why were we not informed [about this] sooner? (P 14)

This participant had experienced that health professionals did not always inform families about the services they were entitled to, which made it impossible for them to benefit from such services. The parents believed that in order to make the services inclusive of immigrant families, it was important to begin by making information available to them.

Unmet needs of the family as a whole

The program was limited to parents and their children with disabilities that make it difficult for immigrant families who lack a social network in Norway to participate in it. However, some parents were permitted to bring their other children to the center after explaining their situations. Although bringing siblings to the center was a relief for these parents, it also posed new challenges. Parents had to care for the siblings and entertain them during the stay at the center, since they were not included in the program. This limited the parents' opportunity to actively participate in the rehabilitation process of their children with disabilities and to socialize with other families. One such parent even explained how her child who was not included in the program experienced her time at the center as boring and perceived it to be unfair that she was not allowed to participate in the activities with the others. Some parents believed that making an inclusive program for immigrant families demands services that meet the needs of the family as a whole:

> I think the place [the rehabilitation center] is originally established to take care of ethnic Norwegians' needs, this was the idea, but now there are so many immigrants in the country, then there is need for cultural facilitation [of the services] in a way that immigrants also feel more included. (P 6)

Communication difficulties

Because most conversations with the professionals were conducted without interpreters, language barriers hindered some of the parents from optimally benefiting from the program during their three-week stay at the rehabilitation center. According to the parents, the conversations went well because their children assisted with the interpretation or because the professionals adjusted their language by speaking slowly and using simple words. Some conversations were also conducted with the assistance of a phone interpreter, but the professionals' lack of experience working with phone interpreters negatively impacted the quality of the conversation. Although the parents did not complain, language barriers nevertheless made it difficult to communicate thoroughly about important topics, and communication therefore remained superficial. As a result, the professionals themselves steered the rehabilitation process and even set the goals they considered useful and meaningful for the children. One of the parents who spoke only a little Norwegian explained her experience of goal-setting for her child's rehabilitation:

> It was a goal that they [the professionals] set, because they read the reports and recognized what was missing. (P 9)

This statement reflects the passive role of the parent, who is supposed to be actively engaged and cooperating in the goal-setting process and shared decision-making.

Informative group meetings were also held in Norwegian without interpreters, which affected some parents' ability to follow and understand the information provided. One parent with basic Norwegian language skills even chose not to participate in the group meetings due to language difficulties.

Discussion

This study explored the experiences of immigrant parents from non-Western countries and their children with disabilities of participating in a rehabilitation program in a context that reflected Norwegian culture in all its aspects. It is about not only the entire intervention but also the culture that dominates planning the program and running the center in the mountains. The purpose of the study was to generate knowledge of how beneficial, culturally adapted, and accessible the services were from the immigrant families' perspectives. In terms of experienced beneficial aspects of the services, our findings—in line with prior research on ethnic Norwegian families in the same context—showed that the group-based design of the intervention created a social support network for parents and enabled them to learn from and empower each other [20]. These findings are particularly important when providing intervention for immigrant families, given that they may not have a developed social network in their host country [7]. Our findings also revealed how participation in a variety of activities provided parents with insight into the possibilities and resources available to them [20]. Interestingly, our findings showed how getting close to nature awakened a new desire in immigrant parents to explore and enjoy outdoor activities as a family. Although nature plays a vital role in human health and wellbeing [26], immigrant families participate significantly less in nature recreation [27,28]. Therefore, providing interventions that connect immigrant families to other families, introduce them to outdoor activities, and facilitate their participation in activities in their host countries, such as hiking and camping, will be valuable [29].

Furthermore, in alignment with earlier research on ethnic Norwegian children, our findings showed the beneficial aspects of the services in terms of children's experience of enjoyment, connectedness, and skill development after participating in the studied rehabilitation program [30]. However, our study also revealed how some immigrant parents and children preferred to focus on learning and participating in only their chosen activities rather than a wide range of activities. Previous research has highlighted the importance of considering children's freedom of choice and learning self-initiated activities [31,32]. Preferences for activities will create motivation and enjoyment, which are important for continued participation following rehabilitation [31,33]. Therefore, a more flexible and individualized approach within the group-based interventions that thoroughly engages parents and children may improve rehabilitation outcomes.

Activity choices within the rehabilitation program were also mainly derived from Norwegian culture without consideration for cultural diversity among the families. This supports the current critique that physical education in Norwegian schools does not accommodate cultural diversity among children [34]. Physical activity has the potential to act as a tool for promoting social inclusion of the immigrant population, and it is also beneficial in that it fosters cultural interaction between immigrants and the native population. However, the inclusivity—and thus, the social benefits—of physical activity may be greatly diminished in an environment that is not based on acknowledging and accommodating cultural differences [35]. Therefore, when planning interventions, physical activities must be grounded in the diverse cultural backgrounds of the participants in order to increase immigrant families' sense of belonging and inclusion, and facilitate interaction between families regardless of cultural differences.

In terms of cultural adaptation and accessibility of the services, the results also showed that most of the families were unaware of the rehabilitation services to which they were entitled. It has been documented that immigrant families have unmet needs for information and are largely unaware of the rehabilitation services they may benefit from [36–38]. Awareness is an important and two-sided dimension for access to health services: families who are aware of the services may better access and use them, and professionals who are aware of the families' needs may provide appropriate and effective services that are easily accessible [13]. As the findings showed, the professionals were not aware of the families' needs or resources. The informative group meetings, conversations, and even the goal-setting process were accomplished without consideration for families' language skills or perceptions of their own role through the process of goal-setting. Insufficient use of professional interpreters and the exclusion of siblings from the program consequently reduced the availability of the services for the families. Availability is another important dimension of access in terms of services' sufficiency to meet the needs of the families [13]. The location of the center, which was far from where the immigrant families lived, also reduced its accessibility for the families, who had no network to care for their children left at home for three weeks. Some parents also explained that they were initially skeptical about participating in the program because of its location on the mountain, which was culturally unfamiliar to them. According to Penchansky and Thomas [12], an accessible service is within reasonable proximity to the consumer in terms of both time and distance. Therefore, increased support and resources are needed to provide flexible services that meet immigrant families' needs and improve their access to the services [39]. The use of professional interpreters is critical for promoting effective communication and improving immigrant families' access to rehabilitation services. Providing information about services to immigrant families and mapping their resources and needs are also important for raising awareness and increasing access.

Study strengths and limitations

To our knowledge, this is the first study to explore the experiences of immigrant families from non-Western countries in a rehabilitation program focused on participation in adapted physical activity in a Norwegian context. It suggests strategies to provide services that are culturally adapted and accessible within the rehabilitation context based on reasoned consideration of immigrant families' needs.

Six families in this study had participated in the program more than once. The broader range of these families' experiences may have contributed to generating richer data, thereby influencing the results.

Forty families did not respond to the information letter in this study, and two declined. Several studies have remarked on the challenges in recruiting immigrants to participate in research and have suggested different reasons for the phenomenon, including fear, a lack of trust, and negative attitudes toward research [40,41]. However, we believe language and literacy difficulties, together with the volume of daily responsibilities and challenges faced by immigrant families of children with disabilities, may have influenced the low response rate in the current study [42].

Norwegian is not the first language of the first author (interviewer) or the interviewees, which may have affected the quality of the produced data. Some interviews were also conducted through interpreters. Therefore, the first author continuously asked participants questions to verify mutual understanding of the questions and responses during the interviews. However, due to participants' restricted daily schedules and responsibilities, neither the interview transcripts nor the findings were subjected to a member check.

The study included immigrant families who had participated in the rehabilitation program between January 2015 and January 2018 due to the low number of immigrant families participating in the program and difficulties in recruiting them. This caused a delay of between one month and nearly two years from the end of the program to conducting the interviews. Although this discrepancy may have influenced the results, our findings revealed that the overall experience of the services and participation in the program was similar, regardless of how much time had passed.

Conclusion

The findings demonstrated the empowering and beneficial aspects of the services for immigrant families. However, the services' accessibility and cultural adaptation were limited. Making information available to immigrant families and mapping their resources and needs well before the intervention may improve the accessibility of the services for these families. Rehabilitation professionals need also to consider families' perceptions of their own role through the goal-setting process when engaging with families from cultural backgrounds different from their own. When planning the intervention, grounding physical activities in the diverse cultural background of participants may increase immigrant families' sense of belonging and inclusion, and thereby facilitate interaction between families regardless of cultural differences. This study contributes to the existing literature by demonstrating the need to provide accessible and culturally adapted rehabilitation services for immigrant families of children with disabilities. Research still needs to explore immigrant families' needs and expectations of services within the rehabilitation context.

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Data availability statement

The datasets generated and analyzed during the current study are not publicly available due to the need for participant anonymity. However, they are available from the corresponding author on reasonable request.

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Article 3

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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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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

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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 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
Aquired 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 subthemes ('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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