

The lived experience of immigrant parents of disabled adolescents and young adults transitioning into adulthood: A narrative inquiry

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Abstract

Background: Immigrant parents' perspectives on raising adolescents and young adults with intellectual disabilities during the transition to adulthood are the focus of this study. Disabled children demand more care and support as they mature and transition to adulthood. This increased care demand places significant stress on parents' wellbeing and participation in social and economic activities.

Methods: Qualitative interviews were undertaken with purposively sampled immigrant parents of adolescents and young adults with intellectual disabilities transitioning into adulthood. The study used inductive thematic analysis to identify common themes across the data set.

Findings: The birth of their disabled child marked a new beginning in a family's life, characterised first by shock and later by acceptance. Informants experienced challenges associated with language and information access, reduced service, social isolation, skewed gender roles and worrying about their children's future.

Conclusions: The intersection between migration and disability can aggravate the care burden. Knowledge about parents' experiences is crucial for designing rehabilitation programmes, promoting wellbeing and bridging gaps between services recommended by service providers and the actual needs of the family and child.

KEYWORDS

adolescence, adulthood, disabled immigrants, experience, immigrant parents, transition

Accessible summary

- This paper is about the stories of three immigrant parents raising children with intellectual disabilities in Norway.
- Moving to a new country and having a disability can increase the risk of vulnerability.
- The parents in the study faced challenges accessing services and being isolated.
- Knowing about their experiences is important for making services better.
- Transition to adulthood is an important milestone in an individual's life.

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1 | INTRODUCTION

This study is part of a larger study about the transition to adulthood for disabled immigrant adolescents and young adults aged 16–25. This research article is based on the perspective of parents. Exploring the views of immigrant parents raising disabled adolescents and young adults provides an important starting point for understanding their challenges. First, a considerable number of research studies related to immigrant children with disabilities in Norway (e.g., Fladstad & Berg, 2008; Kittelsaa & Berg, 2012) have focused on the challenges of raising disabled preadolescent children. This focus disadvantages research that covers the whole life course, including the transition into adulthood. Second, disabled adolescents and young adults experience complex physical, mental and behavioural changes as they transition into adulthood. These changes contribute to intensive parenting responsibilities. Third, service providers and policymakers need knowledge provided by parents about their everyday care experience. So, this study is about what immigrant parents of disabled adolescents and young adults experience.

Although the challenges of raising disabled children are undeniable, Gabel and Kotel (2015) and Green (2007) show that some parents have positive experiences caring for their disabled children. This group of parents does not deny that challenges exist, but they worry less and find self-fulfilment in caregiving (Beighton & Wills, 2019). However, regardless of whether care is burdening or enriching, the challenges of parenting disabled children are greater when disability and migration backgrounds intersect (Kittelsaa & Berg, 2012; Zhou, 2016). Not only do immigrant parents face the same barriers as majority families, but they also encounter postmigration challenges, including poverty (Søholt, 2016), discrimination and limited social networks (Kittelsaa & Berg, 2012) and insufficient cultural awareness by service providers (Rizvi, 2021).

Studies abroad (e.g., DuBay et al., 2018; Lindsay et al., 2012; Rizvi, 2021; Zhou, 2016) and Norway (e.g., Buzungu, 2022; Kittelsaa & Berg, 2012) indicate that language and cultural barriers present the greatest obstacles to accessing information about services and service delivery. Little information (Buzungu, 2022) and lack of cooperation between support agencies (Nyikach et al., 2022) are other obstacles to accessing information. Professional translators can help reduce language and information access gaps; however, these tend to be unavailable (Welterlin & LaRue, 2007), often untrained (Buzungu, 2022), or not used even when available (Schenker et al., 2011; van Rosse et al., 2016). Although many parents display resiliency, their challenges are further compounded by the loss of informal social support systems following migration (Friberg, 2019; Kittelsaa & Berg, 2012; Früh et al., 2016; Rizvi, 2021).

This study uses the gap model to explore the parents' experience. This model conceptualises disability as a mismatch between the person's capabilities and the context of the environment (Kassah & Kassah, 2009; Winance et al., 2007). Although the model recognises personal limitations imposed by disability, it insists that the challenges disabled persons experience are due to how the environment is designed and the support level available for special

needs persons. This conception represents a shift from, for example, the medical model, which considered disability a deficiency within the individual (Oliver, 1996). Unlike the deficit-based models, the gap model problematises society's inability to meet the needs of disabled persons.

Several researchers (e.g., Mittner et al., 2021; Thompson et al., 2010) have used the gap model. Motivating this usage is the recognition that disability is not an inability but a lack of empowerment. Inaccessible buildings or the inability to adequately fund special education prevents disabled persons and their parents from bridging the gap. For example, Thompson et al. (2010, p. 172) argue that 'the purpose of special education is to close the gap between personal capacity and environmental demands', not to fix the pupil. Physical and mental conditions do not necessarily widen the participation gap; having fewer opportunities does. However, the number of opportunities will decrease rapidly, and challenges will increase significantly when disability and migration backgrounds intersect (Kittelsaa & Berg, 2012; Lindsay et al., 2012; Zhou, 2016).

We hypothesised that immigrant parents of disabled adolescents and young adults experience different challenges and barriers, such as language and information access, increased risk of vulnerability and increased care burden. This may affect their parenting abilities as the children transition into adulthood. We endeavoured to address this issue through the following research question:

What challenges do immigrant parents raising adolescents and young adults with intellectual disabilities face during their children's transition into adulthood?

The authors will try to answer this question by analysing qualitative data from interviewing immigrant parents raising adolescents and young adults with intellectual disabilities. The data collected are stories of their lived experiences. This type of interview aims to encourage and stimulate the interviewee to tell something about important events in their life (Butina, 2015).

2 | MATERIALS AND METHODS

2.1 | Study design

The study adopted the narrative approach to explore how informants describe their experiences. According to Creswell and Poth (2016, p. 71), '[the] narrative [approach] is best for capturing the detailed stories or life experiences of a single individual or the lives of a small number of individuals'. Clandinen and Connelly (2000) first used this method of inquiry to obtain and describe the personal experience of teachers. They believed the approach was appropriate for uncovering detailed stories and life experiences of informants. Butina (2015) believes that narratives benefit research because participants reveal themselves in their stories. English and Irving (2015, p. 51) maintain that 'the process of sharing stories and giving voice to individual experience can be used for collective and critical analysis to support

social action'. According to Goodley and Tregaskis (2006), the lively storytelling atmosphere allows disabled people or their parents to speak, define, describe and interpret their environments. Furthermore, stories are also easy to tell, understand and read. These characteristics make stories an important research approach.

The narrative approach differs from other methods because it uses stories and storytelling as research materials. The objectification of these stories allows the experience to be understood by the researcher. However, the researcher focuses exclusively on the parts that answer the research question rather than on the minutiae of the informants' life stories. This approach suits the present study, which focuses on the experience of immigrant parents raising disabled adolescents and young adults. The narrative approach also acknowledges human experiences as dynamic entities in constant flux (Overcash, 2003). The parenting experience continually changes and adapts to the child's multifaceted needs as they develop and mature. The informant's story is not just another way of describing these events but a part of the informant's day-to-day experience of these events. Their stories are situated in the social context in which they happen. The authors chose the method because it allowed them to understand the lived experience of informants through their stories.

2.2 | Informants

The Norwegian Centre for Research Data (NSD Ref: 61283 AMS/LR) permitted the study. The authors recruited informants through institutions and interest organisations working with immigrant parents raising disabled adolescents and young adults. The selection was criteria-based. Participants were immigrant parents living in Norway for the last 5 years and receiving state support for their children. The inclusion criteria allowed researchers to select informants with relevant information about the topic (Malterud et al., 2016). Ten informants were invited for interviews. However, five of them participated in the study, and the other five were prevented from participation due to the Covid-19 pandemic. The narratives are from three of the five informants: two females and one male between 45 and 57 years old. The authors gave them pseudonyms: Khamsila from East Africa, Dhalmisa from North Africa and Zalman from the Middle East. They were selected from among the five participants interviewed because they had lived longer in Norway, had better Norwegian language skills, were more knowledgeable about the support apparatuses and represented cultural and national diversity. Importantly, they were parents raising children with intellectual disabilities. This, in effect, means that they and their children had similar needs and challenges.

Qualitative research experts assert that sample size is based on several factors relating to epistemological, methodological and practical issues (Baker & Edwards, 2017). Sandelowski (1995, p. 183) suggests that qualitative sample sizes can be large enough to enable the emergence of a 'new and richly textured understanding of the phenomenon under study, but small enough to enable the

deep, case-oriented analysis of qualitative data'. Morse (2000) asserts that the more useful data are collected from each participant, the fewer participants are needed. And that was the case in our study; we got new, usable and rich data from the three informants.

2.3 | Data collection

Data collection was conducted through narrative interviews using semistructured questions that the authors developed to guide the process. The guide contained open-ended questions. This method allows participants to freely story their life experiences in the context of research interviews (Polkinghorne, 2007). The lived experience areas covered the diagnosis process, coping and adjustment, the family's socioeconomic status, accessing information and support services and transition plans. Questions proceeded chronologically to maintain the built-in connections. The narrative environment or contexts in which people speak are fundamental to the meaning that they are creating (Gibson & Brown, 2009). Informants in this study chose the venue and time for the interviews.

Participants received information about the study's aim and sample questions before the interview. To gain a credible story, the researcher needed to ensure that the participants 'are genuinely willing to participate and prepare to offer data freely' (Shenton, 2004, p. 66). The authors obtained written consent from the informants and informed them about the right to withdraw if they so wished. The interviews were conducted in the participants' preferred languages: Arabic, English and Norwegian. However, they were free to switch between languages if they felt that was the best way to bring forward their story. They were also at liberty to answer or not if they felt uncomfortable about a question. The interview was a one-time face-to-face interview that lasted 75–90 min and was audio-recorded with the participants' permission. Participants had unlimited time to narrate their stories. This allowed them to recall events that gave meaning to their experiences.

2.4 | Data analysis

This study uses thematic analysis. Braun and Clarke (2006) propose two methods of analysis: deductive analysis, which is a top-down analysis, and inductive analysis, which is data-driven. The authors used a data-driven inductive approach. Analysis of the stories progressed through the four stages of data organisation, familiarity, coding and theming and reporting (Creswell & Poth, 2016). Data transcription was verbatim. The authors checked the transcripts and compared them to the audio recordings. Next, they translated data not in English from the source languages into English. The translations were thoroughly checked for meanings and contents to ensure that they matched the original texts' explicit and implicit meanings. This is a complex and complicated task for researchers when cultural contexts differ.

Although the rigorous examination of the translated texts reduces incidences of data misrepresentation, it does not eradicate incongruities resulting from linguistic and cultural differences (Helmich et al., 2017). Besides, gestures, cues, humming or hesitations cannot be transcribed into texts. After transcription, the authors analysed each interview as a case. The interviews were examined for statements, concepts and issues that were central and around which codes were assigned (Braun & Clarke, 2006). Finally, the analysed text was reread, checked for consistency and themed. These themes were compared across the participants to identify patterns of shared experiences. Disagreements were discussed, and an agreement was reached. The analysis generated five themes: *language and information access, reduced services, social isolation, skewed gender roles and worry about the children's future*.

In a qualitative study, *trustworthiness* means that the qualitative research process and the outcome reflect the phenomenon studied (Birt et al., 2016). Four strategies were applied to increase trustworthiness. First, after each interview, informants had the opportunity to listen to the audio recording, thus verifying that the data collected were accurate reflections of their stories. Second, researchers must acknowledge the power imbalance between them and their informants (Alase, 2017). The authors were thoughtful, reflexive and self-aware about their position throughout their interactions with the informants. Participation was voluntary, and there was no attempt to distort or influence the participants' stories. Informants own their stories. Third, despite their knowledge position and experience working with special needs persons, the authors came to this study as learners, not experts. Lastly, Nowell et al. (2017) stress the importance of peer checking to provide an external check on the research process. The authors presented this study at two international conferences and the national research school of which the authors are members. Valuable feedback obtained from these presentations is incorporated into the present version.

3 | FINDINGS

The authors presented the stories of three informants separately. Although they are individuals with different backgrounds, they are linked by their shared experiences as immigrants and parents raising disabled adolescents and young adults. However engaging, compelling or emotive the stories might be, they are only meaningful if they help us understand the experience of informants.

3.1 | Dhalmissa

Dhalmissa came to Norway 13 years ago with her children and husband. She has not been to the language school and is unemployed. She complained that it was difficult to access information when one comes from an Arabic-speaking country.

I access little information here. There was nothing during the first seven to eight years of our lives in this country (Norway). The hospitals do not give any information about services, nothing. They said there is more information online. How do I get that? No, I cannot.

The birth of her disabled child led to immediate social changes in her life. She stopped visiting people. When she does visit people, it must be because of something special, and such visits are usually very brief.

I think there is a change in attitude, not least from me also. Before I had my son, it felt a lot freer. I went out, visited people and places, and had fun. Not anymore. Now it is different. I have no time for social things and no contacts. We live by ourselves.

The condition of her son is a source of constant worry. Although her faith tells her that her son is a gift (God's gift), she feels overwhelmed by a sense of guilt. It is unclear whether she meant that the disability, the son, or both were God-given gifts. However, the idea that children are God-given gifts to parents is anchored in religious beliefs. This belief helps parents continue to see their disabled child as a gift.

It is usually tough to talk about how you feel when a dramatic event happens. The inner wounds take longer to heal; the invisible scars remain big and painted in your mind until you accept the situation. It is not an easy process.

She continued to explain further:

The first that came to my mind was: What did I do wrong? Did I eat something that caused him this? After some time, the doctor told me that the condition is in the family. I do not know which is which because no one in the family has it (disabled).

Dhalmissa wakes up at 05:30, says her prayers and begins the day. She does everything alone. It was not always like this. She and her husband were once a couple that other couples in the neighbourhood envied. All she has now are nostalgic memories.

When my husband is not out with his friends, he sits in the living room or sleeps. I run around with children to school, kindergarten, all over (--). I go from one meeting to the other (long silence). I take my son to swim, play football, and do other activities. When I tell him we go together, no, he says he is cold, tired, or unwell. I go alone. If I do not, who else will?

Dhalmisa's family have older children who have assumed helping roles. They accompany her to some of the meetings when they can. They also act as translators for words she does not understand.

I do not know what I would have done without my daughters. They are my eyes and ears. I feel guilty about how much time I take away from them. They should be living their lives instead of spending it on me.

The family has 40 h of support. Most of the son's activities are organised and subsidised. The family also gets some assistance during the school holidays.

It is strange to think that he will live independently one day without me. I am happy about the things he can do for himself. When I was coming for the interview, I told him I was going to a meeting and the nurse would come to see him in my absence. He told me it was fine. He is beginning to care for himself.

The most crucial part of a transition is not necessarily the changes but managing the changes and turning them into opportunities.

As he grows, the demands and care increase. We would have wanted to decide how and which activities to use the hours (-). A contact assistant comes every Saturday for four hours. We are satisfied with the services we get. It is not perfect. Seventy-five per cent right is fine for me.

Being able to socialise and to make and maintain friendships encourages parents to have positive expectations. What worries Dhalmisa most is her husband's lack of concern. It scares her. She wishes he could be like he was before they came to Norway. They have no transition plan and do not know what the future will look like for their child.

3.2 | Khamsila

Khamsila came to Norway over 20 years ago. She gave birth to what she thought was a healthy baby boy. He was her second child. Not long after, she discovered something unusual about her child. She believes in God and believes there is a purpose for her son. Focusing on her spiritual beliefs seems to impact her understanding of disability positively. Supporting her son wholeheartedly today is down to two things: fulfilling her maternal role and bringing spiritual closeness to God.

First, the nurse said, 'psykisk utvikling' (intellectual disability). I did not know what she meant or what it

was. They sent me to Ullevål Hospital. The doctor said, 'Ah, your son will need help for the rest of his life'. Then I asked, 'What help?' He could not give me an answer. They said I should check for more information on the net.

Khamsila was not satisfied with the diagnoses handed to her by the medical practitioners in Norway. She wanted to know more.

My son is not a mistake. I believe that God does not give you something you cannot manage. I called home. I said, 'My son was not talking'. I will come home so they can find out what was ailing him. We went home. They checked and said, 'No, he will be okay'.

Emboldened by the verdict from home, Khamsila came back from holidays determined to see her child through the challenges of growing up. But, at the end of her day, she would be exhausted.

My husband works 24/7. He has just stopped now, but he worked night and day when I came to Norway. It is difficult to sit and talk if someone works night and day. He is tired. It would help if you had someone to talk to outside the home.

Khamsila wished her husband were more understanding and cooperative. Unfortunately, he fails to understand the difficulties she is undergoing. 'That has always been my life since we married', she said.

I remember I would go to Ullevål alone. It is as if it was my fault that our child is disabled. Our son enjoys being out in the open. He likes to exercise. It is difficult for me to do this all alone. We have no relatives here; we are alone.

Khamsila has two other children. When they were younger, they would complain and accuse her of giving them less attention. Now they understand. Her challenge is explaining to her son why he is going to another school.

He asks me, 'Mommy, Mommy, why am I in a different school? Why am I not going to my sisters' school?' Then you tell him, 'You are in another school, and you are not sick'. That is the challenge I am facing: explaining the situation as he matures.

The extent to which parents raising disabled children can participate in paid employment closely relates to the child's care needs and the family's capacity to meet those needs.

Our finances are not sound. I had full-time work before my son was born. Now I spend time caring for

him. I started working again when he was about a year. I would work weekends. I cannot manage 100%. I work extra when I feel that I must.

She explained the situation further:

When he was younger, we got different things (help). Now, they said that the service is no longer available. They told me to pay. I have no money, I said. They said, 'You should try to apply'. I applied twice but received negative responses. I applied for the third time, and then gave up.

Khamsila's request for help came through because of an unfortunate incident involving her son. She explained:

You know, it is a long story. My son got into problems with some boys. He was in bad company against my wishes. They (service providers) are giving me support. He now has personal helpers accompanying him wherever he goes.

Accessing certain help from support agencies without help from an advocacy group can at times be difficult. Joining a peer support group of parents with similar difficulties can lessen the burden of doing it alone.

I wish I had had this group of parents earlier. We all have similar problems and challenges. We have a doctor, a psychologist and a nurse helping the group. They understand us better because they are also immigrants like us. You ask them; you do not wait for an appointment. I am not a racist, but I lack people who understand what I say.

She highlighted the difficulties of raising a disabled child in the following words:

It is not easy being an immigrant and parent of a child with disabilities. Then the language? Many doctors, some are from the North. They talk dialects. It is not easy to understand. In the group, we talk about our experiences. You understand that some get better help than others. It is as if we live in different countries.

Children with a disability, like all of us, have strengths and weaknesses when it comes to doing schoolwork, their personality or mastering motor skills. They may be slow to comprehend yet have internal motivation to succeed.

He can make tomato soup, butter his bread, and take public transport alone. He has fixed assignments at home,

such as taking the kitchen garbage to the main garbage bin and cleaning on Saturdays. He does them well. I am no longer scared because I see that he will manage.

Parents can use the child's strengths to build up their capacity to overcome challenges in other areas. They must be trained to care for themselves and help with housework. The focus must always be on the children's abilities, not their disabilities.

3.3 | Zalman

Zalman came to Norway over two decades ago. He arrived traumatised, exhausted and sickly. He still remembered the first days vividly in the new country. Then, after a year, his wife joined him. Life in Norway started well, but the birth of his child and the medical conditions that followed changed everything.

It is always challenging to be available to children when the painful past does not go away. Having a disabled child increases the difficulties. Every day is a challenge, and no two days are the same. How does one relate or react to things she does? It is not easy. We do not have much contact with other people like we had before.

Many parents raising children with intellectual disabilities encounter practical challenges that demand support from service agencies. However, the process of accessing support can be frustrating.

It was easier to get support when she was younger. Every office wanted to help. Not anymore. We received a letter from NAV (The Norwegian Labour and Welfare Administration) a year ago about her transition to independence. That was it. We have not heard anything again. Our daughter is always with us, and we receive nothing. It is good to hear that there is help. I will contact the council.

Some immigrant parents of disabled children may lack the resources and the networks, and they are probably unaware that they can get help.

We do not know what help we are entitled to receive for our daughter. No one provides information. Do you know, 'you are entitled to this and that? Come to us, and we will give you'.

When asked why he was not seeking help or was aware he could get help, he had this to say:

No, he said. My wife works. I am unemployed. I stay home and do house chores for the family. She only

does the things I am not able to do. I must go there to ask what help I can get for my daughter. I realise now that I will fail her if I do not do everything.

After overcoming the initial shock of having a child with intellectual disability, parents begin to imagine and worry about the child's future. Parents naturally understand that they, because of old age and decline in physical health, will not always be there for their children.

Yes, I am worried about the future. I tell my daughter to believe in herself, because she can do much better than she thinks. It is difficult, she tells me. Sometimes, I felt that we pushed her too much.

He explained further:

I try my best to do the right things. I know that someday my daughter may have to take care of herself. I tell her, 'You can be much better than you think. You are good enough. Believe in yourself'. I say that to her every single day. I have pushed her a lot. Sometimes you think, 'Maybe we are applying more pressure than she can take'.

The Zalman couple try to maximise future outcomes by making their children as responsible and independent as they can be.

I want to bring her up the way I was, but it is not easy. We give her pocket money to shop for some of her things. She cooks now and then, does the dishes, cleans the whole house, and takes care of her room. I ask her, 'we are going to do this; do you want to? What do you think?' For me, what matters is what she wants. However, I do not know what she wants most of the time.

Zalman shares common challenges parents of disabled children face, for example, concerns that they as parents will not be able to give support in the future. However, the level of vulnerability goes up when challenges associated with caring for a disabled child intersect with other postmigration stressors.

Another important thing I want to say is this: I am not like an ordinary ethnic Norwegian who has a disabled child. I am a foreigner with painful experiences of wars and torture. I have experienced strange things that I cannot tell you. Every single one of them was traumatic. These things have made me suspicious of authorities. I can say that my daughter is also a victim of the terrible situations I went through. I worry about her future.

With instinctive fear for the state and limited or no access to information about support services, parents like Zalman will

experience challenges. They may not seek help because of past painful experiences in the hands of people with power, or they might, in some cases, have tried and failed to get help. Being unable to self-advocate and living incognito will only worsen their conditions. Their challenges are further compounded by the inability of the support systems to discover them.

4 | DISCUSSION

Data analysis yielded five themes: *language and information access, reduced services, social isolation, skewed gender roles and worry about their children's future*. These themes reflect participants' daily interactions with their ecosystems and how they experience these interactions.

4.1 | Language and information access

Moving to a new country comes with many challenges, and the challenge of learning a new language is the most difficult of them all. Results indicated that informants were eager to be engaged but were incapacitated by a lack of information and limited language proficiency. They experience communication challenges and frustration because they are unable to make themselves understood or do not understand the messages that are given. They also experience inadequate or, in some instances, a complete lack of information about services. Immigrants' language proficiency and information access are repeated themes in most immigrant research studies (e.g., Akram et al., 2003; Buzungu, 2022; Kittelsaa & Berg, 2012; Lindsay et al., 2012) but little is mentioned about how professionals use language with immigrants and why information inaccessibility persists. It is obvious that immigrants' skills in reading and speaking in the host's language are of central importance to accessing written and verbal information. Furthermore, such skills enable and strengthen active participation in a society that places increased demands on the population's reading and verbal language skills. However, the lack of access to information about services for immigrant users is also more of an institutional problem than a matter of immigrants' inability to speak the language. Cooperation between support agencies is a necessary condition for knowledge concerning what services and benefits might be available and where to find those services (Nyikach et al., 2022).

Language and cultural barriers increase the risks of being misdiagnosed (Karliner et al., 2007; van Rosse et al., 2016). Employing certified translators or language and cultural brokers who are competent in the language and culture of the source language reduces this risk. But professional translators are either in short supply (Welterlin & LaRue, 2007) or not frequently used even when they are available (Le et al., 2013; Schenker et al., 2011; van Rosse et al., 2016) or often less competent (Buzungu, 2022). In the absence of professional interpreters, using children to translate for their parents overrides the reluctance to have them involved (Finlay

et al., 2017). However, using children as translators, as was the case with an informant in this study, can lead to incorrect interpretation of what is said (Guan et al., 2014). Regardless of their abilities, children lack the maturity and experience to correctly interpret and translate complex information. Additionally, they may not possess the vocabularies needed to translate professional terminologies successfully. Although discouraged, using children as translators is widespread. Some parents prefer their children to translate for them (Finlay et al., 2017). That said, translation, however proper, does not eradicate inconveniences resulting from linguistic and cultural differences (Helmich et al., 2017).

We must avoid reducing challenges immigrants face in accessing services to simple and general explanatory models such as lack of integration, language difficulties and cultural differences or indifferences, that is, to attribute to the individual full responsibility for the challenges that arise in the contact. The responsibility can just as much lie with the overall support services as with the postmigration difficulties that immigrants encounter. A lack of cultural competence and understanding among professional service providers is the most prominent barrier to the access and provision of services to immigrant parents of disabled children. There is a need to strengthen health-relevant cultural competence among service providers both through in-service education and through field training. Services that are culturally and linguistically adapted to the needs of immigrants can greatly contribute to increased use. Whenever and wherever possible, information should be given in the users' own language. This is important considering the need for immigrants to understand their new environment and develop mechanisms to mitigate effects and appropriately adjust. This adjustment, or the lack of it, plays a vital role in accessing and using services. For example, the lack of culturally appropriate services can interfere with timely mental diagnosis or utilisation of mental services (Kirmayer et al., 2011; Popovac, 2020).

4.2 | Reduced services

As children mature, their social and material needs also change. For example, weight gain and increased outdoor activities for disabled adolescent children may increase physical and financial stress on parents. Thus, parents and service providers must adjust to the changing demands accompanying the transition phase (van den Akker et al., 2010). The research participants acknowledged receiving plenty of support when their children were younger. However, support gradually decreased as children approached adolescence. Service providers told parents to reapply or purchase some items previously provided for them from retail stores. This advice serves no purpose for parents experiencing financial difficulties. Several studies (e.g., Früh et al., 2016) show that immigrant parents of disabled children are often unemployed. They either cannot find jobs or are conflicted between seeking employment and staying home caring for their children.

Additionally, informants expressed frustration and thought caseworkers did not trust or ignore their opinions. They also felt

pressured to comply with what the service providers had decided. This compliance reflects how professionals exercise control through expert authority. Family-centred support principles emphasise that professionals recognise the family's strengths, experience and expertise. Studies (e.g., Jegatheesan et al., 2010; Kalyanpur & Harry, 1997; Zhang & Bennett, 2003) show that some parents might disagree with experts' understanding of their children's conditions. They may feel that service providers are deficit-focused or promoting initiatives that conflict with the family's needs. Therefore, acknowledging the interface between cultural attitudes towards disabilities and parents' knowledge, beliefs and priorities for their children is imperative for sustainable service provision. Paying less attention shows a lack of trust in parents' knowledge about their children's conditions (DuBay et al., 2018).

4.3 | Social isolation

Our results show that informants have limited social engagements outside those provided by service providers. This finding is consistent with Kittelsaa and Berg's (2012) and Friberg's (2019) studies that immigrants often have limited social networks. Parents' links with their immediate surroundings influence parenting (Lanigan, 2009). This informal social link within the encapsulated community acts as a platform for information sharing and transmission. However, Abbas (2004) shows that restrictive social connectivity hinders acculturation and prolongs adaptation to the new environment. The apparent disconnect between informants and their environment is attributable to the level of care needs (Rizvi, 2021) and negative community attitudes towards disability (Kang-Yi et al., 2018; Kassah et al., 2012). These demands intersect with other factors, denying parents opportunities for leisure and socialisation (Akram et al., 2003; Rizvi, 2021).

The informants' stories represent the experience of mainstream parents of disabled children, especially mothers. They grieve, feel burdened, rejected and perhaps even blamed for bearing disabled children (Gabel & Kotel, 2015; Sousa, 2011). Interestingly, the blame game is a belief rooted in cultural conservatism that imagines disability as a product of spirits and witchcraft. For example, Ameen (2005) reveals that many people in traditional Islamic societies believe curses, evil spirits and witchcraft cause disability. Although this view has no basis in Islam, it contributes to the isolation of people with disabilities (Bhatty et al., 2009). On the other hand, many parents believe that caring for their disabled children brings them great spiritual significance and closeness to God (Rizvi, 2021). Whether or not this is one way of accepting a situation they cannot change, it seems clear that it brought them peace.

Many communities have negative cultural beliefs and attitudes towards people with disabilities and their parents. For example, Kang-Yi et al. (2018) show that Korean parents hide their disabled children because of negative cultural assumptions surrounding disability. However, Rizvi (2021) argues that families do not think disability brings shame, but they are conscious of negative attitudes

towards disability from some community members. Despite the psychosocial and material difficulties associated with raising disabled children, studies (e.g., Beighton & Wills, 2019; Green, 2007) show that some parents find comfort in caring for their disabled children. This alternative perspective challenges the widespread assumption that associate parenting disabled children with parental grief and care burden. Instead, these parents recognise challenges related to extreme parenting stressors but find self-fulfilment in caregiving by focusing on those situations that contribute to positive adaptation.

4.4 | Skewed gender roles

A family home is a place of significant inequality. Although this reflects gender equality in each country (Glick & Fiske, 2001), the present study, like previous studies, for example (Kavli & Nadim, 2009), found that cultural values surrounding gender roles in some immigrant communities in Norway are less egalitarian. However, there is a global dimension to the phenomenon. For example, Tai and Treas (2013) show that women suffer inequality in all European societies. Similarly, in their studies on South Asian carers, Katbamna et al. (2004) show that mothers could not rely on their husbands for practical support in caring for their disabled children. While there are notable improvements, gender equality in family homes remains a work in progress (Sullivan et al., 2018). In Norway, the significant presence of many immigrant women in higher education and the workforce reflects this progress (Cools & Schøne, 2019).

Gender inequality and repression do not exist in a vacuum. It intersects with other power systems to increase women's vulnerability. The housework arrangements witnessed in our informants' homes reveal the underlying gender ideology that considers childcare feminine (Katbamna et al., 2004). Even the male participant admitted that although he did house chores, his wife was responsible for what he could not do. As the data show, mothers in this study feel exploited and powerless. They are overworked from labouring at the highest level on two demanding jobs: parenting and house chores.

4.5 | Worry about their children's future

Even though many parents would consider the transition to adulthood a routine life event, it is nothing like routine for parents raising disabled children. They understand that the children will live without them someday, but they are also aware that theirs is a lifelong obligation. Informants in this study are constantly worried about what life their children will live as adults. Their children are physically grown-ups, but their psychosocial development is lagging. The discrepancy troubles parents. Parents also expressed a need for a transition plan to guide future progress. A study by Mazzotti and Plotner (2016) found a positive correlation between transition planning and future outcomes. The absence of a plan causes despondency, uncertainty about the future and anxiety to parents as their children transition to adulthood.

Furthermore, the transition to adult living comes with challenges that no prior preparations can anticipate. For example, a child moving from paediatric to adult healthcare may involve losing familiar contacts, including social workers and nurses that parents and child have known for many years. These changes may scare both parents and children. Parents want assurance that their children will be fine when they are no longer there to support them (Gabel, 2018). They should feel confident their child is in safe hands, and significantly so when the child's disability affects their ability to convey feelings and needs. This positive feeling is essential because it removes parental anxiety about their child's future wellbeing.

4.6 | Limitations

Translation from the source language into the new language is only sometimes accurate (Helmich et al., 2017). This factor might have resulted in the loss of valuable information. Therefore, to minimise imperfections from translation and increase trustworthiness, all informants had the opportunity to verify and validate the contents after the interviews. Lincoln and Guba (1985) argue that giving data back to participants helps ensure accuracy and completeness. This is widely considered the gold standard for establishing trustworthiness in qualitative research.

As a scholar and experienced special needs educator with an immigration background, the first author comes to this study with personal and insider perspectives about the daily challenges confronting many immigrant parents of disabled children. Prior information can influence how data are gathered, interpreted and presented (Sparkes & Smith, 2014). However, as a scholar, I am constantly conscious of these preconceptions, knowing well that what is important is not what I know and feel about the topic or my informants' experience, but their lived experiences as research material. I was always cognisant of the scholarly and objective impression I wanted to project. Future researchers can build on the findings in this study by exploring immigrant parents' experiences of raising disabled adolescents and young adults with emphasis on, for example, the nature of their child's disability.

5 | CONCLUSION

The birth of a child with an intellectual disability affects parents' experiences in diverse ways. Some parents show great openness, acceptance and coping abilities, while others are reserved, cautious or resigned. Informants in this study missed a familiar environment and the dependable social networks of families and friends. They experienced language and communication barriers, limited information, financial constraints and worry about their children's future. Arguably, some of these challenges would be recognisable by ethnic Norwegians raising disabled children. Yet compared to native parents, immigrant parents' experiences are often shaped by other dimensions, including cultural and racial prejudice and poverty. These challenges increase their vulnerabilities during this crucial phase in their children's lives.

However, it is important to avoid reducing challenges that immigrants face in accessing service to simple and general explanatory models such as lack of integration or language and cultural barriers that arise in contact with support apparatuses. The responsibility can lie just as much in the overall support services as in the postmigration challenges that immigrants encounter. This study suggests holistic approaches to the intersecting challenges immigrant parents of disabled children face. Importantly, it recommends that service providers pay attention to parents' knowledge about their children's needs. Informants in this study are optimistic and forward-looking. After the initial shocks, they accepted the situation and adjusted family life accordingly. They handle that duty with faith, stamina, grit and limitless commitment. The parenting obligation and the physical intensity it requires may yet take its toll, but what will not change is their determination to persevere.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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