

## RESEARCH

# The Intersection of Childhood Disability and Migration in Family Lives

Snæfríður Þóra Egilson, Guðbjörg Ottósdóttir and Unnur Dís Skaptadóttir

University of Iceland, IS

Corresponding author: Snæfríður Þóra Egilson ([sne@hi.is](mailto:sne@hi.is))

Disability studies and migrant studies have largely operated on different tracks. Despite the growing diversity within Icelandic society, little is known about the lives of migrant families with disabled children living there. Inspired by critical disability studies, migrant studies and Bourdieu's concepts of capital and field, we focused on the daily experiences of three migrant mothers of disabled children and their encounters with the Icelandic service system. The migrant women's experiences reflected their diverse positions and needs in terms of their participation and possibilities to use their resources to build upon and apply their social and cultural capital. Initially, all three intended to stay temporarily in Iceland, but the intersection of the birth of their disabled children, their possibilities for balancing work and care, as well as their experiences with the service system, ultimately affected their decision to stay or leave. The paper concludes with a call for a more nuanced understanding of the intersection between disability and migration in family lives.

**Keywords:** critical disability studies; migration studies; Bourdieu; everyday lives; services

## Introduction

Disability studies and migrant studies have largely operated on different tracks, with the two being only rarely combined. Yet, the two academic disciplines have parallels as both have positioned themselves as counter paradigms that are critical of dominant discourses about disability (Shakespeare 2013) and the position of migrants (Castles, de Haas & Miller 2014) by highlighting the importance of the social, cultural, economic and political aspects of each field. This separation has also reduced opportunities for discussions on the ways in which childhood disability intersects with migration. Little is known about the lives of migrant families with disabled children living in Iceland. This gap was the inspiration for this study, which focuses on the everyday experiences of migrant families with disabled children living in Iceland.

Several Icelandic studies have focused on the lives and circumstances of families with disabled children (Egilson and Stefánsdóttir, 2014; Ingólfssdóttir, Jóhannsdóttir & Traustadóttir 2018; Egilson 2015; Bjarnason 2010). Their findings are in line with studies elsewhere, reporting that, although the birth or a diagnosis of a disabled child is a turning point in every family's life, families with disabled children face many of the same tasks and challenges as families with non-disabled children (Tøssebro & Wendelborg 2015; McLaughlin 2012; Breitzkreuz et al. 2014; Dowling & Dolan 2010). Having control and sustaining a sense of normality in relation to certain components of daily life, such as routine family activities, appear essential to families' well-being (Bjarnason 2010; McConnell et al. 2013; Traustadóttir 1995; Egilson 2008). Although parents value the services and supports available to them and their disabled children, collaborating with the service providers reportedly puts pressure on family life and often creates additional stress for parents (Tøssebro & Wendelborg 2015; Egilson 2015; Bjarnason 2010).

Studies conducted outside of Iceland show migrant families with disabled children face numerous challenges beyond those typically faced by families with disabled children, as their social position as migrants adds to the complexity of their situation (Berg 2012; Kramer-Roy 2012). In addition to language barriers, the challenges are believed to be related to migrants' lack of familiarity with the way of doing things within a new country, which may affect their access to and participation in various social spaces. Migrants' limited knowledge about the service fields and the different conceptions of families and service providers is, for example, frequently reported. Also, service organizations may not have sufficient insight into the needs of migrant families and, therefore, may not take them into account (Lindsay et al. 2014; Berg 2012; Kittelsaa 2012). Different family traditions and public service experiences in the countries of origin can also affect migrant families' expectations and their perceived need for support in a new country of residence (Khanlou et al. 2015; Lindsay et al. 2012; Berg 2015; Fellin et al. 2013).

In this paper, we focus on the experiences of three migrant mothers, particularly looking at how they experienced, remade, built and activated their social and cultural capital in their daily lives and in their encounters with the service system in Iceland. The study is part of a larger Icelandic research project that focuses on the lives and experiences of migrant families who have disabled children (Egilson, Skaptadóttir & Ottósdóttir 2019). Drawing upon critical disability studies and migration research, we aim to provide an understanding of what it means to be a migrant parent of a disabled child in a new country and to analyse the complexity of their situations. In our efforts to provide temporally, spatially and relationally sensitive notions of the three migrant mothers' experiences, we also draw on a few of Bourdieu's (1991) central organizing concepts to better understand the dynamics of their capital building. We highlight turning points in the mothers' lives that relate particularly to their disabled children's births, diagnoses and treatments, and subsequent changes over time and space. The paper concludes with a call for a more nuanced understanding of the intersection between disability and migration in families' lives.

### ***Critical disability studies and migrant studies***

Disability studies, as a scholarly discipline, developed in response to the increasing interest in disability in today's societies, accompanied by growing criticism towards traditional ways of understanding disability as an individual problem. Instead the attention is directed at the social, cultural, economic and political aspects of disability (Goodley 2010; Thomas 1999; Shakespeare 2013). In recent years, the term critical disability studies has been increasingly employed to reflect the growing critical theorising that has taken place in disability studies (Meekosha & Shuttleworth 2009; Goodley 2013; Goodley et al. 2019), characterized by 'rethinking of the marginalization of disabled people and an opening up of the field to a diversity of critical social and cultural theorizing' (Meekosha, Shuttleworth & Soldatic 2013: 320). Critical disability studies aims to promote an understanding of and challenge exclusionary and oppressive practices associated with disablism and to unpack the ways these intersect with other forms of marginalisation (Goodley 2014). The intersectional approach that is the hallmark of critical disability studies—focusing on mutual processes of exclusion—is of relevance in this study when considering the migrant mothers' marginalized and precarious positions.

Within migration studies, questions about assimilation and integration are being replaced by critical analyses of processes of inclusion and exclusion and growing attention to discriminatory processes. Scholars increasingly apply an intersectional approach, exploring how gender, ethnicity, racialization and class are often dynamically interrelated and intermeshed in constituting social positions and power differences (Erel 2015; Anthias 2015). Combining a Bourdieusian and intersectional approach, Erel (2015), for example, emphasised the importance of acknowledging the interplay between differential social positionings of migrant women and their access to, and creation of, forms of capital.

### ***Field and capital in the context of migration***

Bourdieu's key concepts of field and capital (Grenfell 2014; Bourdieu 1991) can be helpful in analysing people's fluid situations over time and space. Field is Bourdieu's term for the social space in which interactions, transactions and events take place, such as in the family, the welfare system, the education system or the healthcare system (Bourdieu & Wacquant 1992). Fields have their own set of understandings, rules, players and histories, and the term *doxa* reflects the self-evident rules, behaviours and ideas that are taken for granted within any particular field (Bourdieu 1977).

A person's position in a field is determined by the field-specific capital she or he has. Capitals are resources that are acknowledged as valuable within a given field, and as such, they are both the process in and product of that field. Bourdieu highlights three forms of capital, economic, social and cultural, that can be converted into advantageous positions in social fields (Bourdieu 2006). Economic capital is reflective of financial wealth and convertible into money and property. Cultural capital refers to the transmission of linguistic and cultural competence, while social capital reflects the value of the social relationships and networks individuals have and can utilize (Bourdieu 1977; Moore 2014).

Social, cultural and economic capital are interrelated as one can be converted into the other. For example, by providing access to social networks and resources, cultural capital can be converted into social capital. Similarly, cultural capital is reproduced by social networks insofar as these depend on a sense of commonality. Built into Bourdieu's ideas is a recognition of people's agency in dealing with situations and resources in their efforts to increase their capital.

In their studies of migrant capital, Erel and Ryan (2019) called attention to the fact that migration to a new country may result in a loss of cultural and social capital due to the mismatch between the contexts where specific capitals were formed and the new contexts where they may be differently valued. The authors, nevertheless, caution against jumping to the conclusion that, after an initial loss of capitals, migrants gradually begin to accumulate cultural, social and economic resources. Instead, they point out that gains, losses and reorientations of capitals are connected across different social fields, classes and genders, as well as in the wider context of the society of residence (Erel 2010; Erel & Ryan 2019). To address the three mothers' different experiences and the dynamism of their capital formation, it is important to focus on changes over time and space.

### ***The Icelandic context***

As one of the Nordic countries, Iceland has received international attention for its high standard of living, gender equality, high participation of women in the labour market, emphasis on human rights in policies and legislation, and extensive public welfare provisions (Kangas & Kvist 2013). This context is important because resources and

opportunities available to migrants depend in part on the socio-economic, cultural and physical particularities of the local context in which they live and work (Hickman, Mai & Crowley 2012). A fundamental aim of the Icelandic welfare system is to provide quality services that meet the needs of diverse social groups to ensure equal access to services for all residents (Stefán Ólafsson 1990). Despite legislative intentions, evidence suggests Icelandic families with disabled children generally experience added challenges in comparison with other families. This is reflected in their difficulty in accessing information and supports and in the fact that the services available only meet their needs to a certain extent (Bjarnason 2010; Egilson 2015).

Over the last 20 years, Iceland has experienced large demographic changes, including an aging population, growing migration to the country and a declining birth rate (Stefán Hrafn Jónsson 2013). Since 1998, the percentage of migrants has increased from 2% to 14.1% (Statistics Iceland 2019). The demographic changes have required support systems to become competent in working with an increasingly diverse population in terms of cultural and social background. Recent legislative efforts promote diversity and equal access to social participation in areas of welfare, employment and education (Lög um málefni innflytjenda nr. 116/2012; Lög um jafna meðferð óháð kynþætti og þjóðernisuppruna nr. 85/2018; Lög um útlendinga nr. 80/2016; Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir nr. 38/2018), but the implementation of the legislation on practical and service levels remains unknown.

## **Methods**

### ***Participants***

To recruit migrant families for the larger qualitative research project about migrant families with disabled children, contact was made with gatekeepers at large Icelandic municipalities and institutions that provide services to disabled children and their families. These gatekeepers introduced the study orally and in writing to prospective participants and then passed on the names and telephone numbers of parents who wanted to participate. Thus, we recruited 12 first-generation migrant families to the study. They had been living in Iceland from 18 months to 20 years when the first interview took place, the average duration was 10.5 years. The families had a total of 16 disabled children between the ages of 2 and 17 and included 5 single parent families and 7 2-parent families from diverse countries of origin in southern and eastern Europe, central America and northeastern Asia. According to information provided by the parents, many of the children had more than one diagnosis, and most of them were diagnosed with autism spectrum disorder.

In this paper, we settled on using data from three of the mothers: Agnes, Johanna and Lisa (pseudonyms). When the study took place, these women had all lived in Iceland for 16 years or more and spoke Icelandic quite well. Agnes and Lisa were single mothers, while Johanna was married. Altogether, the women had five disabled children between the ages of three to seven, all born in Iceland. These three women were selected because of the richness of the data acquired from them and because of the similarities and differences in their experiences. While each of the three cases is unique in its own way, they also reflect wider patterns found across our broader datasets.

### ***Data generation***

Two interviews were conducted with each woman, with each interview lasting 50–70 minutes. Two interviews took place in the first author's office at the women's request, while the remaining interviews took place in their homes. The women were asked about their background, education, reasons for relocation to and staying in Iceland and about their lives in Iceland, their communication with and experiences of the service system, and about their thoughts and plans for the future. All interviews were conducted by the first author in Icelandic, in line with the women's wishes. Although the interviews were in a conversational style, an interview guide was used to obtain comparable information. Observations were also made in the women's homes and in one child's school.

The interviews were recorded with the women's permission. The audio files and field notes from observations were then transcribed. For the purpose of this paper, a traditional inductive approach was not used for data analysis. The three women had already made meaning out of their experiences, which they expressed in their selection of stories to share, what they emphasized and what they chose not to reveal. Inspired by a critical disability studies lens (Goodley 2013) and some of Bourdieu's theoretical constructs (Bourdieu 1986), we analysed the women's stories. Thus, we read the interview and observation transcripts over and over, keeping in mind theoretical concepts that would promote sensitivity to temporal and spatial dynamics and enable us to highlight capitals, hierarchies and the intersection of the women's marginalities within specific fields.

### ***Ethics***

Inexperience with participating in research, cultural differences and language barriers can affect people's understanding of what participating in a research study entails (Birman 2005). The three women were well informed about the purpose of the study and willingly participated. During interviews and observations, attention was paid to power relationships and emphasis was placed on developing trust and minimizing the distance between the researcher and the women. A written summary from interviews and participant observations of about two pages was provided to each woman for them to review and agree to before the analysis took place. Identifiable information was removed to prevent the results being traceable. Nevertheless, the three women were informed that, due to their unique circumstances and the small

population of Iceland, it would be difficult to maintain full anonymity. They all agreed to this. The study proposal was reviewed by the University of Iceland Ethics Committee.

## Findings

This chapter includes a vignette of each woman's experience based on the summaries they approved. Then, certain aspects of the women's experiences are further explored from a critical disability studies' perspective and Bourdieu's concepts of field and capital.

### *Johanna*

Johanna is from Eastern Europe and had a professional education before migrating to Iceland. In her early twenties, she came to Iceland to join her partner who had moved there to work. Johanna described her first years in Iceland as hard and demanding. She found it difficult to adapt to the cold and the darkness and difficult to get acquainted with people and make friends.

Because I had been living in a big city with maybe one million people ... I just found everything impossible. I just felt everything was so small and that the people were introverted. It was, yes, difficult to connect, few shops and movies in the cinema. Just so little and inadequate ... I would rather have liked to live in Spain.

Johanna initially took a job as an unskilled worker but got a job within her professional field a few years after arriving in Iceland. Although 'the people there were just lovely and it was a good place to work', still she was not happy. Becoming more proficient in speaking Icelandic and making new friends gradually contributed to more positive views about living in Iceland. During the interview, Johanna highlighted the importance of learning and speaking Icelandic.

I think it is imperative for migrants. If you want to live here and get services, then you must learn the language. Otherwise, everything becomes much more difficult.

Her triplets, Patryck, Tumi and Tina, were born preterm and were very small at birth. Johanna described the health services before and around the birth of her children as excellent. Collaboration between the health and social services was good, and when the family returned home from the neonatal intensive care unit, services and supports were in place. Nevertheless, the following years were difficult. The children were constantly sick, so Johanna hardly slept at night. The change was almost overwhelming. 'Everything had been stable and then the three of them were born and everything became unstable'.

The children were diagnosed with autism spectrum disorder at the age of two years and six months. Johanna was content with the diagnostic process and the services that followed. The diagnosis meant more supports were put into place. The family received extra help from the municipality, and their former babysitter took care of the children one weekend a month. Johanna described her as 'the best babysitter in the world, and she helps a lot. And, if I have any questions, then she's just the person who answers'.

After the children were born, Johanna stopped working outside the home. Consequently, she lost valuable social connections as her contact with former work colleagues diminished. On the other hand, she got to know new people through the services the family received. Currently, the family socializes mostly with Icelanders, not with people from their country of origin. Since the birth of the triplets, Johanna's partner worked longer hours, so Johanna is often alone with the children and has very little time to socialize. Taking care of the three children can be challenging at times. 'I pick them up [from preschool] at four, and then at twenty past four, I occasionally just want to cry as they fight and fight and fight'. In a later interview, Johanna described how the situation had improved as the children grew and developed.

Today, Johanna appreciates many of the aspects of living in Iceland that she disliked when she first arrived, such as the smallness and the simplicity of their Icelandic community.

Everything that wasn't good in 2001, I find really good today. It changed with the birth of the children. When I am constantly wondering how little time I have, then it is so convenient that it just takes no time to go to the store and to preschool to pick up the children ... Now I am very happy to live in Iceland ... I don't think I will ever return to [country of origin] with three young children. It would be just impossible ... everything there is too big and complicated ... It is much easier to continue to live in Iceland.

The family spends all summers in their country of origin, but they have no plans to return there permanently as of now.

### *Lisa*

Lisa comes from Central America and had a vocational education before arriving in Iceland. In her early twenties, she moved to Iceland for adventure, and shortly thereafter, she met and married an Icelandic man. The marriage lasted a few years. Initially, Lisa took a job in a factory, but as she became more proficient in Icelandic, she got a job within her

field of expertise. Although she lost her valued job following the Icelandic financial crash in 2008, she decided to stay on in Iceland.

In 2010, Lisa had a daughter, Anna, and two years later, Jacob was born. Soon after his birth, Lisa realized that something was different, and at the age of 14 months, Jacob got a diagnosis of autism spectrum disorder and severe intellectual disability. Later on, he was also diagnosed with epilepsy. Lisa described his diagnoses as a shock as she had no experience with disability. Everything was new to her, and it took time to learn about her right to support. 'Initially, I didn't know about any services and such. But Sólveig [social worker] told me and helped me apply for care allowances and respite services'.

After Jacob was diagnosed, Lisa temporarily relocated to her country of origin but soon discovered that resettling there was not an option due to the difficulty of balancing work and care, as well as the limited availability and low quality of therapy and education services. Thus, she moved back to Iceland with her two children.

Lisa has a sister who lives in Iceland and who helped her greatly after Jacob was born, but now the sister has moved to another part of the country. Otherwise, all of Lisa's family and the father of her children live in her country of origin. Lisa has many friends in Iceland, and she has formed important relationships with the staff who have provided her with emotional and practical support throughout the years.

There is this one person at [Jacob's former preschool], I just lack words to describe Birta. She has done so much for us and constantly advises me to do this or that. And also Halla [a physiotherapist]. I just ask: "What should I do? Or, this or that happened, what can I do?" ... So, I have got a lot of help from them, [these two] have been so important to me. Sometimes, I just feel like I am in 1,000 pieces and then get such a smile and hugs ... just like: "this is going to be okay". It is so important!

During the interviews, Lisa was positive and hopeful for the future. For a while, she has run a catering service, which she finds very enjoyable. Looking back, Lisa describes how she worked hard on everything that needed to be done for years. Now, she is doing more of what she wants to do, such as 'cooking and working with flowers and doing things with the children'.

Overall, Lisa found the living conditions and opportunities in Iceland much better than in her country of origin, not the least for single mothers and families of disabled children. 'Back home, the situation is very difficult ... much more difficult than in Iceland. In fact, I don't find it difficult here in comparison'. She added

The quality of life here [in Iceland], you know, there is much more quality. Yes, you can work in [country of origin], but still, it's hard to get a job and to be able to work with what you have trained for, what you want to do.

Nevertheless, life is not altogether easy. After two car accidents, Lisa has chronic back pain, which makes it difficult for her to care for Jacob. She must be careful with her money as the mortgage payments for her apartment are heavy, and Jacob is on an expensive diet. Lisa also describes how, despite her right for support, her situation is often fluid, depending on specific people around her.

I had a support family, but they moved to [other town in Iceland] last year, very good people, and it has been very difficult for me because they were like a family, so losing them was very difficult. I'm looking and there's just no one, no people ... it is hard.

When asked to further compare Iceland with her country of origin, Lisa replied

It just can't be compared! I come from a country where we are many millions of people, so at first, it felt a bit strange. Empty when you go out and meet so few people and see no one outside ... But sometimes, I love it being so small and being alone, and I can really enjoy being.

Asked about the future, Lisa says that she really tries not to think too much about it but she intends to stay in Iceland in the near future.

Initially, the lack of social and cultural capital within a new country affected Lisa and Johanna, who could not apply their education or earlier work experience. Both described their changing social position as they acquired more cultural capital through learning Icelandic and being able to pursue jobs within their fields of expertise. Johanna connected much of her success in regard to employment and in communication with professionals in the service fields to speaking Icelandic. 'Because we are rather good with the Icelandic language, we really cannot complain'. Johanna gradually formed important social relationships at her second workplace, characterized by shared interests and frequent contact within and outside of work hours. But maintaining relationships requires effort (Bourdieu 1986), and after the triplets were born, she neither had the time nor the opportunity to nourish these relationships. Lisa, on the other hand, appeared to be more successful in forming and holding social relationships by drawing support from friendships and

networks after having her children. Although social capital may be generated through social relationships, it is not identical with them in that social capital involves the ability to mobilise social relations and networks to build social or other forms of capital (Anthias 2015).

The birth and diagnosis of Lisa's and Johanna's disabled children made them reconsider their options, values and priorities about living in Iceland. Although they had initially planned their migration to be temporary, it had turned into a long-term, if not permanent, stay as resettling in their countries of origin was no longer considered to be an option. Easy access to and availability of important resources and supports made it much easier for them to live and care for their children in Iceland as compared with their countries of origin. In Lisa's case, economic reasons were also important, as there were scarce employment opportunities in her country of origin. Thus, a cumulative and combined intersection of factors affected her choice.

Agnes' experience was, in many ways, different and sheds light on her complex and difficult situation and on being devalued and not heard due to the different values and attitudes of particular professionals and service systems within different cultures.

### **Agnes**

Agnes comes from northeast Asia and had a university degree when she migrated to Iceland in her late twenties. Upon arrival, Agnes studied further at the University of Iceland. After graduation, she worked part time within her professional field and part time in a care home.

Due to a mistake during labour, her son Andri suffered extensive loss of oxygen. As a result, he has almost no control over his body movements and no functional speech. Agnes later went to court and sued the hospital and consequently received benefits. She filed the case with the help of lawyers and stood alone in the litigation as she received no information or support from the service system on how to deal with the court.

In hindsight, Agnes was very happy with many of the services offered to her and her son throughout the years. Care allowances balanced the loss from her restricted work, as after Andri was born she was only able to work every other weekend while he was in respite care. Agnes was particularly pleased with Andri's preschool and elementary school and with the therapy services that he received over the years. She also appreciated the variety of support services available to her and her son, such as respite services.

On the other hand, Agnes distrusted the Icelandic healthcare system, especially the doctors. She said, 'Iceland is so small. We cannot choose a doctor or hospital. I do not trust Icelandic doctors'. She reported Andri had not thrived the first few years, and when he was four years old, a digestive specialist had decided he would need to be solely tube fed. In Agnes' visits to her country of origin, however, she sought the advice of doctors who considered it to be important for the boy to eat as it would enhance his life quality and the possibility of him creating sounds and potentially using oral speech in the future. Thus, Agnes continued to give Andri a little bit of food in addition to the tube feeding. Subsequently, she was twice reported by healthcare professionals to child protection services in Iceland for neglect. The case was finally dropped when she presented a written statement from a doctor who had followed the boy in her country of origin. Eventually, Agnes moved back to her country of origin after living in Iceland for 20 years. She said, 'It is better to work in Iceland, but I want Andri to eat, and he cannot eat here in Iceland'.

When the article was written, mother and son had been living for a year in her country of origin. Agnes said Andri was content. His teachers had been trained to feed him orally, so he did not use a tube at school. Every month, mother and son visit a doctor who monitors Andri's progress and listens carefully to what Agnes has to say. She stated

But it is not so that [country of origin] is better than Iceland. Andri got much more physiotherapy and occupational therapy in Iceland. I think Icelandic preschools and elementary schools are better, and it was a great experience for Andri to attend school in Iceland. But it's horrible to know that he would have been tube-fed his whole life if we had continued living in Iceland.

Agnes had settled in Iceland and had planned to live there permanently before Andri was born. After the conflict with the healthcare system and the inequalities and abuse of power she believed she and her son had been subjected to, she changed her mind.

The cultural capital that Agnes brought to the country in the form of a university education and upon which she continued to build until her son was born was of little use within the healthcare field, where she had limited access and no power. Her priorities as a mother, building on expert knowledge from her country of origin, were of limited value, possibly because Agnes' place in the social order was shaped by and reflected the social position and conditions imposed on her as a migrant in Iceland. The trauma became even greater as, prior to her son's birth, Agnes had valued and had had great faith in most aspects of Icelandic society.

### **Everyday experiences**

As already noted, the birth or diagnosis of a disabled child is a turning point and a disruption in every family's life (Tøssebro & Wendelborg 2015; McLaughlin 2012; Bjarnason 2010). For families with disabled children, various practical issues typically take much time and energy. Mothers often carry the major responsibility for childcare, and mothers of

disabled children are even more likely than other mothers to engage in complex, skilled and prolonged aspects of care (Traustadóttir 1995; Runswick-Cole 2013).

Mothers often reorganize their lives after the birth of a disabled child by quitting their jobs, working part time or by seeking jobs that allow them to be flexible and to prioritise the caretaking demands within the family (Traustadóttir 1995; Egilson & Traustadóttir 2015; Ryan & Runswick-Cole 2008). This was true for all three mothers in this study. Jóhanna quit working outside of the home, and six years after the birth of the triplets, she was still busy with the many practical aspects of childcare. After the birth of Jacob, Lisa took on a new career path, which gave her more flexibility in her working hours. Agnes gave up the professional part of her work and only worked outside the home while Andri was in respite care.

Adapting to changes in family rhythms and routines is easier if families with disabled children have strong social networks and supports (Bjarnason 2010; McConnell, Savage & Breitreuz 2014; Breitreuz et al. 2014). Being able to build and sustain social capital through the mobilization of formal and informal social support networks can be key for adapting to changes following the birth or diagnosis of a disabled child. Although both Jóhanna and Lisa had family members in Iceland, they were not receiving much help from them when the study took place, either due to long distances or to the relatives' busy schedules. Agnes had no relatives around.

Interestingly, none of the three mothers belonged to networks of co-ethnics. In Lisa's and Agnes' cases, there were simply not that many people from their countries of origin around. Yet, Lisa had a strong connection to people of various ethnicities. Drawing on her outgoing disposition, she had mobilized her resources of friends and service providers and built social capital that strengthened her position and provided her with emotional and practical support. Nevertheless, she emphasized 'friends are not the same as family'. Jóhanna came from a larger ethnic group with more possibilities for socializing with co-ethnics. Nevertheless, she chose to focus on building social connections with Icelanders. All three women identified important relationships with former or current professionals who had worked with them and their children and provided them with useful information and emotional or practical support. However, these relationships were rarely strong enough for the women to make them part of their social support network that could be mobilised into social capital.

Parents of disabled children often describe how helpful and supportive they find other parents of disabled children to be and how easy it is to spend time together (Bray et al. 2017; McCabe 2008). This was not the case with the three women. Although they knew other parents of disabled children, all three reported having little time or opportunity for socialization, especially not for attending meetings at parent organizations.

The comparison of the opportunities available for them and their children in their countries of origin was central when the three mothers described their everyday experiences and the choices they had made. Although both Lisa and Agnes claimed life for single mothers was much easier in Iceland in terms of work opportunities and balancing work and family care, Agnes relocated to her country of origin as she felt staying in Iceland was no longer an option due to the discrimination and abuse of power she believed she had been subjected to as a migrant.

### ***Dealing with the system***

Throughout the years, all three women had gradually built and strengthened important cultural capital that included a good grasp of Icelandic, which turned out to be imperative in their dealings with services, especially because most of the information about support entitlements was only available in Icelandic (Egilson et al. 2019). All three knew and understood the basic rules of the social and educational service fields (Bourdieu 1986), trusted and valued those systems and highlighted the important benefits of the supports they received as compared to what was available in their countries of origin. However, the situation was fluid, as they were often dependent on certain individual professionals for support. If these left their employment, there was occasionally no good replacement to be found, such as when Lisa lost her valued support family.

Parents of disabled children often report the support they are provided with depends on the professionals they meet rather than what legislation says. The variation from one professional to the next may influence the nature of the information provided, the interpretation of regulations, what services are provided and the decisions professionals make about needed support. Some professionals act mainly as gatekeepers, others as gate openers. Meeting the right person is of the utmost importance in navigating and accessing services (Tøssebro & Wendelborg 2015; Egilson & Stefánsdóttir 2014).

Lack of cultural capital in the form of knowledge about her entitlement to services and supports initially impacted Lisa's ability to effectively navigate the service field. Jóhanna, on the other hand, experienced the social and healthcare fields as proactive in providing her with information about the rules of the game and these two service fields collaborated well from before the birth of her children by setting timely and important supports in place.

The different experiences of the three women in their meetings with the healthcare field is noteworthy. While Lisa and Jóhanna were overall pleased with the medical services provided to their children, Agnes' experience was quite the opposite. It is noteworthy how harshly the healthcare field reacted when she, in consultation with experts in her country of origin, did what she considered to be best for her son. Whether or not this was due to arbitrariness—as her dealings involved one digestive specialist mainly—is difficult to say. Specialists who occupy important positions within a specific service field set the rules and understandings on how to behave. This understanding, that may feel natural

and correct, can be explained by the doxa that are common within the field. Possibly, there is little flexibility towards that considered to be evidence within this specific realm of the medical profession in Iceland. Possibly, this reflects other aspects of the prevailing culture or specific structures or mechanisms of power that cannot be identified in this instance. We want to highlight Agnes' experience was unique, also, for the larger study, all the families appreciated the health services their child received in Iceland as compared with what the situation would be in their countries of origin. It should be noted, however, no other family had challenged professional knowledge and power in the way Agnes did.

## Conclusion

Drawing on empirical data from Iceland, this article contributes to theorizing about the nature of the intersection of migration, disability, field and capital by promoting a nuanced understanding of the complex situation of three migrant mothers of disabled children. Their experiences reflect their diverse positions in terms of participation and possibilities to use their resources to build and apply their social and cultural capital. The critical disability studies lens helped unpack and illuminate the complex interconnections between each woman's migration experience and contextual factors, such as her employment opportunities, access to formal and informal supports, attitudes within the service systems, as well as her child(ren)'s impairment. Although the three mothers' experiences were, in some ways, similar to that of native born mothers of disabled children (Egilson & Stefánsdóttir 2014; Bjarnason 2010), adding the position as a migrant to the equation clearly complicated the situation.

Ryan (2018) describes how temporary, uncertain and circular migration may slowly evolve into something approaching long-term staying, if not permanent settlement. For these three women, who all intended to live temporarily in Iceland, the intersection of the birth of their disabled children, their possibilities for balancing work and care, as well as their experiences with the service system, ultimately affected their decision to stay or leave.

It is important to delineate ways to promote migrant parents' of disabled children societal participation by, for example, focusing on their opportunity structures, belonging, connections and supports. Within the fields of education, social services and healthcare, this calls for increased knowledge, flexibility, creativity and compound professional expertise to ensure equal access for all (Söderström 2014; Lindsay et al. 2012).

## Acknowledgements

We sincerely thank the three migrant women who shared their experiences. The study was funded by Miðstöð margbreytileika og kynjarannsókna [Center for diversity and gender studies] and Þróunarsjóður innflytjendamála [Development fund for immigrant affairs].

## Competing Interests

The authors have no competing interests to declare.

## References

- Anthias, Floya. 2015. "Foreword." In *Migrant capital: Networks, identities and strategies*, xi–xiii. Basingstoke: Palgrave Macmillan.
- Berg, Berit, ed. 2012. *Innvandring og funksjonshemming*. Oslo: Universitetsforlaget.
- Berg, Berit. 2015. "Immigrant families with disabled children in Norway." In *Childhood and disability in the Nordic countries: Being, becoming, belonging*, edited by Rannveig Traustadóttir, Borgunn Ytterhus, Snæfríður Þóra Egilson and Berit Berg, 215–230. Basingstoke: Palgrave Macmillan.
- Birman, Dina. 2005. "Ethical issues in research with immigrants and refugees." In *The handbook of ethical research with ethnocultural populations and communities*, edited by Joseph E. Trimble and C. B. Fisher, 155–177. London: Sage.
- Bjarnason, Dóra Sigrún. 2010. *Social policy and social capital: Parents and exceptionality 1974–2007*. New York: Nova Science Publishers.
- Bourdieu, Pierre. 1977. *Outline of a theory of practice*. Cambridge: Cambridge University Press. DOI: <https://doi.org/10.1017/CBO9780511812507>
- Bourdieu, Pierre. 1986. "The forms of capital." In *Handbook of theory and research in the sociology of education*, edited by J. G. Richardson, 280–291. New York: Greenwood Press. DOI: <https://doi.org/10.1002/9780470755679.ch15>
- Bourdieu, Pierre. 1991. *Language and symbolic power*. Cambridge: Polity Press.
- Bourdieu, Pierre. 2006. "The forms of capital." In *Education, globalisation and social change*, edited by Hugh Lauder, Phillip Brown, Jo-Anne Dillabough and A. H. Halsey. Oxford: Oxford University Press.
- Bourdieu, Pierre, and Loic Wacquant. 1992. *An invitation to reflexive sociology*. Chicago: The University of Chicago Press.
- Bray, Lucy, Bernie Carter, Caroline Sanders, Lucy Blake, and Kimberley Keegan. 2017. "Parent-to-parent peer support for parents of children with a disability: A mixed method study." *Patient Education and Counseling* 100(8): 1537–1543. DOI: <https://doi.org/10.1016/j.pec.2017.03.004>
- Breitkreuz, Rhonda, Laura Wunderli, Amber Savage, and David McConnell. 2014. "Rethinking resilience in families of children with disabilities: A socioecological approach." *Community, Work & Family* 17(3): 346–365. DOI: <https://doi.org/10.1080/13668803.2014.893228>

- Castles, Stephen, Hein de Haas, and Mark J. Miller. 2014. *The age of migration. International population movements in the modern world*. 5 ed. Palgrave: McMillan.
- Dowling, Monica, and Linda Dolan. 2010. "Families with children with disabilities – Inequalities and the social model." *Disability & Society* 16(1): 21–35. DOI: <https://doi.org/10.1080/713662027>
- Egilson, Snæfríður Þóra. 2015. "User perspectives on support services to disabled children and their families." In *Childhood and disability in the Nordic countries: Being, becoming, belonging*, edited by Rannveig Traustadóttir, Borgunn Ytterhus, Snæfríður Þóra Egilson and Berit Berg. Basingstoke: Palgrave Mcmillan.
- Egilson, Snæfríður Þóra, and Rannveig Traustadóttir. 2015. "Familier med funksjonshemmede barn: Dagligliv in en sosial kontekst." In *Utviklingshemming: Hverdagsliv, levekår og politikk*, edited by P. Kermit, A. Gustavsson, A. Kittelsaa and B. Ytterhus, 92–104. Oslo: Universitetsforlaget.
- Egilson, Snæfríður Þóra, and Sara Stefánsdóttir. 2014. "Velferðarþjónusta og fötluð börn: Reynsla foreldra af starfi fjölskyldudeildar Akureyrarbæjar." *Stjórnmal og stjórnsýsla* 10(2): 587–610. DOI: <https://doi.org/10.13177/irpa.a.2014.10.2.19>
- Egilson, Snæfríður Þóra, Unnur Dís Skaptadóttir, and Guðbjörg Ottósdóttir. 2019. Innflytjendafjölskyldur með fötluð börn: Reynsla foreldra [Migrant families with disabled children: Parent perspectives]. *Tímarit um uppeldi og menntun/Icelandic Journal of Education* 28(1): 2019: 1–22. DOI: <https://doi.org/10.24270/tuuom.2019.28.1>
- Erel, Umut. 2010. "Migrating cultural capital: Bourdieu in migration studies." *Sociology* 44(4): 642–660. DOI: <https://doi.org/10.1177/0038038510369363>
- Erel, Umut. 2015. "Thinking migrant capitals intersectionally: Using a biographical approach." In *Migrant Capital: Networks, identities and strategies*, edited by L. Ryan, U. Erel and A. D'Angelo, 19–32. Basingstoke: Palgrave Macmillan. DOI: [https://doi.org/10.1057/9781137348807\\_2](https://doi.org/10.1057/9781137348807_2)
- Erel, Umut, and Louise Ryan. 2019. "Migrant capitals: Proposing a multi-level spatio-temporal analytical framework." *Sociology* 53(2): 246–263. DOI: <https://doi.org/10.1177/0038038518785298>
- Fellin, Melissa, Gillian King, Victoria M Esses, Sally Lindsay, and Anne Klassen. 2013. "Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability." *International Journal of Migration, Health and Social Care* 9(3): 135–145. DOI: <https://doi.org/10.1108/IJMHC-07-2013-0024>
- Goodley, Dan. 2010. *Disability studies: An interdisciplinary introduction*. London: Sage.
- Goodley, Dan. 2013. "Dis/entangling critical disability studies." *Disability & Society* 28(5): 631–644. DOI: <https://doi.org/10.1080/09687599.2012.717884>
- Goodley, Dan. 2014. *Dis/ability studies: Theorising disablism and ableism*. Abingdon: Routledge. DOI: <https://doi.org/10.4324/9780203366974>
- Goodley, Dan, Rebecca Lawthom, Kirsty Liddiard, and Katherine Runswick-Cole. 2019. "Provocations for critical disability studies." *Disability & Society* 34(6): 972–997. DOI: <https://doi.org/10.1080/09687599.2019.1566889>
- Grenfell, Michael, ed. 2014. *Pierre Bourdieu: Key concepts*. 2 ed. Oxon: Routledge.
- Hickman, M. J., N. Mai, and H. Crowley. 2012. *Migration and social cohesion in the UK*. Basingstoke: Palgrave Macmillan. DOI: <https://doi.org/10.1057/9781137015174>
- Ingólfssdóttir, Jóna G., Thuríður Jóhannsdóttir, and Rannveig Traustadóttir. 2018. "Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland." *Nordisk velfærdsforskning/Nordic Welfare Research* 3(01): 33–46. DOI: <https://doi.org/10.18261/issn.2464-4161-2018-01-04>
- Jónsson, Stefán Hrafn. 2013. "Af akri lýðfræði Íslands." *Stjórnmal og Stjórnsýsla* 8(2): 17–35. DOI: <https://doi.org/10.13177/irpa.a.2012.8.1.10>
- Kangas, Olli, and Jon Kvist. 2013. "Nordic welfare states." In *The Routledge handbook of the welfare state*, edited by Bent Greve, 148–160. London: Routledge.
- Khanlou, Nazilla, Nasim Haque, Sinead Sheehan, and Gail Jones. 2015. "It is an issue of not knowing where to go': Service providers' perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities." *Journal of Immigrant Minority Health* 17: 1840–1847. DOI: <https://doi.org/10.1007/s10903-014-0122-8>
- Kittelsaa, Anna. 2012. "Erfaringar fra møter mellom familier og hjelpeapparatet." In *Innvandring og funksjonshemming*, edited by B. Berg, 103–128. Oslo: Universitetsforlaget.
- Kramer-Roy, Debbie. 2012. "Supporting ethnic minority families with disabled children: Learning from Pakistani families." *British Journal of Occupational Therapy* 75(10): 442–448. DOI: <https://doi.org/10.4276/030802212X13496921049581>
- Lindsay, Sally, Gillian King, Anne Klassen, Victoria M. Esses, and Melissa Fellin. 2012. "Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers." *Disability & Rehabilitation* 34(23): 2007–2017. DOI: <https://doi.org/10.3109/09638288.2012.667192>
- Lindsay, Sally, Sylvie Tétrault, Chantal Desmaris, Gillian King, and Genevieve Piérart. 2014. "The cultural brokerage work of occupational therapists in providing culturally sensitive care." *Canadian Journal of Occupational Therapy* 8(12): 114–123. DOI: <https://doi.org/10.1177/0008417413520441>

- Lög um jafna meðferð óháð kynþætti og þjóðernisuppruna [Act on equal treatment regardless of race and ethnic origin nr. 85/2018.
- Lög um málefni innflytjenda [*Immigration act*]nr. 116/2012.
- Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfarir [Act on services to disabled people with longstanding service needs] nr. 85/2018.
- Lög um útlendinga [*Act on foreigners*] nr.80/2016.
- McCabe, Helen. 2008. "The Importance of parent-to-parent support among families of children with autism in the people's republic of China." *International Journal of Disability, Development and Education* 55(4): 303–314. DOI: <https://doi.org/10.1080/10349120802489471>
- McConnell, David, Amber Savage, and Rhonda Breitreuz. 2014. "Resilience in families raising children with disabilities and behavior problems." *Research in Developmental Disabilities* 35(4): 833–48. DOI: <https://doi.org/10.1016/j.ridd.2014.01.015>
- McLaughlin, Janice. 2012. "Understanding disabled families. Replacing tales of burden with ties of interdependency." In *Routledge handbook of disability studies*, edited by Nick Watson, Alan Roulstone and Carol Thomas, 402–413. New York: Routledge.
- Meekosha, Helen, and Russell Shuttleworth. 2009. "What's so 'critical' about critical disability studies?" *Australian Journal of Human Rights* 15(1): 47–75. DOI: <https://doi.org/10.1080/1323238X.2009.11910861>
- Meekosha, Helen, Russell Shuttleworth, and Karen Soldatic. 2013. "Disability and critical sociology: Expanding the boundaries of critical social inquiry." *Critical Sociology* 39(3): 319–323. DOI: <https://doi.org/10.1177/0896920512471220>
- Moore, Rob. 2014. "Capital." In *Pierre Bourdieu: Key concepts*, edited by Michael Grenfell, 98–113. London: Routledge.
- Ólafsson, Stefán. 1990. *Íslenska leiðin (The Icelandic way)*. Reykjavík: Háskólaútgáfan.
- Runswick-Cole, Katherine. 2013. "'Wearing it all with a smile': Emotional labour in the lives of mothers and disabled children." In *Disabled children's childhood studies: Critical approaches in a global context*, edited by T. Curran and K. Runswick-Cole, 105–118. Basingstoke: Palgrave. DOI: [https://doi.org/10.1057/9781137008220\\_9](https://doi.org/10.1057/9781137008220_9)
- Ryan, Louise. 2018. "Differentiated embedding: Polish migrants in London negotiating belonging over time." *Journal of Ethnic and Migration Studies* 44(2): 233–251. DOI: <https://doi.org/10.1080/1369183X.2017.1341710>
- Ryan, Sara, and Katherine Runswick-Cole. 2008. "Repositioning mothers: Mothers, disabled children and disability studies." *Disability & Society* 23(3): 199–210. DOI: <https://doi.org/10.1080/09687590801953937>
- Shakespeare, Tom. 2013. *Disability rights and wrongs revisited*. 2 ed. London: Routledge.
- Söderström, Sylvia. 2014. "Lost in translation? Communication challenges in minority families' and healthcare workers' interactions." *Disability & Society* 29(5): 807–820. DOI: <https://doi.org/10.1080/09687599.2013.848783>
- Statistics Iceland. 2019. *Immigrants and persons with foreign background 2019*. Sótt á <https://statice.is/publications/news-archive/inhabitants/immigrants-and-persons-with-foreign-background-8903/>.
- Thomas, Carol. 1999. *Female forms: Experiencing and understanding disability*. Buckingham: Open University Press.
- Tøssebro, Jan, and Christian Wendelborg. 2015. "Ordinary or not? Families of children growing up with disabilities." In *Childhood and disability in the Nordic countries: Being, becoming, belonging*, edited by R. Traustadóttir, B. Ytterhus, S. T. Egilson and B. Berg. Basingstoke: Palgrave. DOI: [https://doi.org/10.1057/9781137032645\\_13](https://doi.org/10.1057/9781137032645_13)
- Traustadóttir, Rannveig. 1995. "A mother's work is never done: Constructing a 'normal' life." In *The variety of community experience: Qualitative studies of family and community life*, edited by Stephen J. Taylor, Robert Bogdan and Zana Marie Lutfiyya, 47–65. Baltimore: Brookes.

**How to cite this article:** Egilson, Snæfríður Þóra, Guðbjörg Ottósdóttir and Unnur Dís Skaptadóttir. (2020). The Intersection of Childhood Disability and Migration in Family Lives. *Scandinavian Journal of Disability Research*, 22(1), pp. 25–34. DOI: <https://doi.org/10.16993/sjdr.689>

**Submitted:** 23 November 2019    **Accepted:** 07 February 2020    **Published:** 09 March 2020

**Copyright:** © 2020 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/4.0/>.



*Scandinavian Journal of Disability Research* is a peer-reviewed open access journal published by Stockholm University Press.

**OPEN ACCESS**