Risky Obliviousness Within Fragmented Services: Experiences of Families With Disabled Children During the Covid-19 Pandemic

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Article

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Abstract

Living on an island in a pandemic has its obvious advantages. However, in a globalised economy, border restrictions cannot keep the Covid-19 virus completely at bay. Despite coordinated efforts at infection control and extensive vaccination, Iceland, a sparsely populated island in the north, was placed among the countries in the highest risk category by the ECDC. In this article, we report a qualitative study carried out at the peak of the fourth Covid-19 wave in 2021, when the pandemic had severely hit the Icelandic social and healthcare system, with a record-breaking number of infections. Semi-structured interviews were conducted with parents with seven disabled children. Guided by feminist standpoint theory and critical disability studies, we focused on how service structures affected and shaped parents' and children's experiences during the first waves of the pandemic. The findings suggest that the pandemic intensified the already precarious position of the families. During the pandemic, the gaps in the already fragmented services widened, and the families were left to navigate this new reality on their own. Preventive measures enforced by municipalities and healthcare services centred on non-disabled people's experiences and needs. Unprepared service systems distanced themselves from the families while maintaining governance and supervision over defining their need for support.

Issue

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1. Introduction

In March 2020, the way of life of people living in Iceland changed instantly, with a ban on gatherings, social distancing, polymerase chain reaction (PCR) testing, quarantine, and isolation due to the Covid-19 pandemic. Restrictions were lifted and reinstated in sync with the rise and fall of the infection waves, but all domestic Covid-related restrictions were dropped in February 2022, despite high infection rates.

There are limited available data regarding the pandemic's effects on different social groups, and disabled people have remained almost invisible in the media and public documents during the pandemic. Regardless of the advice and warnings from international experts and institutions (Armitage & Nellums, 2020; World Health Organization, 2020), the official Covid-19 guidelines published by the Icelandic Directorate of Health (2022) do not identify disabled people as at risk of suffering from the serious consequences of the disease. Prior to the pandemic, it has been widely reported that disabled people have poorer health outcomes and less access to health services (Allerton & Emerson, 2012; Snæfríðar- og Gunnarsdóttir, 2017). Research on past pandemics shows that disabled people find it harder to access critical medical supplies, which can be even

more challenging as resources become scarce (Campbell et al., 2009).

In this article, we report on a qualitative study grounded in the experiences of families with disabled children during the Covid-19 pandemic. These children also have long-term illnesses or underlying health conditions, increasing their risk of severe symptoms associated with Covid-19. Grounded in standpoint feminist theory (Smith, 2005; Wylie, 2003) and critical disability studies (Meekosha & Shuttleworth, 2009) we focus our critical gaze on the social structures and mechanisms that shape and coordinate the experiences of the parents. Iceland is a welfare state regime where healthcare and municipal services are universal, comprehensive, and mostly funded through taxation (Government of Iceland, n.d.). Disabled children and their families are, by law, entitled to services and assistance provided by municipalities (Althingi, 2018), and because of the children's health conditions, many also rely on a broad range of healthcare services. It is therefore important to explore how these service systems responded to the challenges that followed the outbreak of the Covid-19 pandemic.

1.1. Background

Prior studies focusing on the lives and circumstances of families with disabled children in Iceland have revealed that although parents value the services and support available to them and their children, collaborating with service providers often creates additional stress on family life. Services have been described as fragmented, and parents must demonstrate leadership and advocacy, taking on a supervisory role to maintain the necessary support for their disabled children (Egilson, 2015, 2022; Ingólfsdóttir et al., 2018).

According to disabled children and their parents (Egilson, 2015), an example of this fragmentation is the lack of collaboration between school and home support. Most disabled children in Iceland attend their neighbourhood school with their non-disabled peers (Ólafsdóttir et al., 2014). During school hours, assistance to disabled children is provided by the schools and funded by the municipalities, as is the support provided to their homes. However, these service provisions are organised by different departments of the municipalities, and with different budgets. Ingólfsdóttir et al. (2018) claim that parents' experiences of support and services do not align with the stated aims of the services provided by the state and municipalities. The reason for this gap, according to parents, is found in the system's structure that is centred around the professionals and the service providers instead of the children and their families. Parents in Egilson's (2015) and Ingólfsdóttir et al. (2018) call for better access to professionals and point out that increased collaboration between specialists and service providers would free the parents from the burden of serving as messengers within the service system. Although parents

want to maintain an active role in meeting their children's healthcare, social and educational needs, that role must be manageable and supported (Egilson, 2015; Ingólfsdóttir et al., 2018).

According to UNESCO (2021), the pandemic has exposed the shortcomings in the education of disabled students worldwide. In the first wave of the pandemic, parents of disabled children in Iceland vocalised their fear regarding its effects, stating that many disabled children had not received the educational support to which they had a right (Einarsson et al., 2020). Icelandic law mandates that students who are either hospitalised or ill at home for longer periods should be offered education at home or in the hospital (Althingi, 2008). Björnsdóttir and Ásgrímsdóttir (2020) argue that although distance-learning solutions were used during the pandemic to help students keep up with their classwork, the implementation did not consider the children's social contexts or situations. Therefore, the use of such solutions was less available and less accessible to disabled children and children belonging to other marginalised groups. During the first waves of the pandemic, Icelandic teachers reported their difficulty in maintaining support for disabled children in schools, due to physical and social distancing rules (Björnsdóttir & Ásgrímsdóttir, 2020). Before the pandemic, these students were already at risk of missing out on learning and socialisation because of fragmented services provided during school hours (Ingólfsdóttir et al., 2018).

In recent years, there has been a shift to increased personalisation of services in Iceland. This is largely a response to the advocacy led by disabled people, calling for increased control over the services they receive as they have found traditional service arrangements to be lacking and inefficient (Snæfríðar- og Gunnarsdóttir & Arnalds, 2016). Examples of this new kind of service arrangement are direct payment contracts, which many Icelandic families of disabled children have with their municipalities. According to these contracts, the municipalities are not directly involved in service procurement, and the families themselves are responsible for hiring assistants. Such service schemes have been heavily tested during the Covid-19 global pandemic as serious questions have been raised about where the responsibility for infection control training and access to protective gear lies (Dickinson et al., 2020). In Iceland, disabled service users criticised authorities and municipalities for their inaction and slow response to the situations of disabled citizens who had to navigate pandemic-related problems on their own, such as managing support while shielding and securing assistance if they or their staff became infected (Haraldsdóttir, 2020).

Since pandemics are likely to exacerbate the precarious position of families with disabled children, it is important to gather information about how they were affected by the Covid-19 pandemic and ask what lessons can be learned from their experiences.

1.2. Feminist Standpoint Theory and Critical Disability Studies

Our project is grounded in feminist standpoint theory (Smith, 2005; Wylie, 2003) and the belief that centring marginalized knowledge and starting inquiries from the standpoint of disenfranchised groups in research, provides crucial knowledge about oppressive social structures. Feminist standpoint theory regards the critical reflections of marginalised groups, thinking from the outside-in, to hold a certain epistemic advantage, providing important insights into how social institutions and systems shape and affect people's experiences. This has methodological implications in our study, as we start our inquiry from the perspective of parents of disabled children and direct our critical focus outward, to the power relations and structures that coordinate and shape their experiences (Hundleby, 2020; Smith, 2005).

Furthermore, critical disability studies are a guiding framework for the study. Critical disability studies put social and cultural norms, conditions, and institutions under scrutiny as key drivers of the exclusion of disabled people (Meekosha & Shuttleworth, 2009). Ableism is a core concept within critical disability studies, highlighting the network of beliefs, social processes, and practices that produce and maintain narrow ideals of bodies as perfect and "normal." In a world of presumed able-bodiedness, disability and diversity are devalued and understood as less worthy (Campbell, 2009). Subsequently, critical disability studies provide a lens for scrutinizing and problematizing the discrimination and social exclusion typically faced by children growing up with disabilities.

Both feminist standpoint theory and critical disability studies are concerned with power relations and focus on uncovering processes of knowledge, power, and exclusion. Informed by these critical approaches we focus on the social structures and institutional processes that produce and maintain ableist social and cultural norms and shape the experiences of disabled children and their families. As academic research is not exempted from ubiquitous oppressive social relations, we wish to clarify that all the authors of this article are white, non-disabled academics with a background in social sciences, namely gender and disability studies. As Morris (1992) explains, knowledge production of non-disabled researchers in disability studies can become problematic if not grounded in reflexivity and self-awareness. We strive to work through these issues by actively engaging with reflexivity and collaborating with disabled people. We furthermore share a transformative research focus (Mertens, 2007) and aim to generate knowledge about social injustices and issues of importance for marginalized groups and use our platform to raise awareness about them.

2. Methods

This article draws from a qualitative study undertaken in Iceland among a group of parents with disabled children. The study is part of a larger research project where the experiences, health, and well-being of disabled people during the Covid-19 pandemic are explored. The project is funded by the Icelandic Research Fund.

2.1. Data Collection

Qualitative interviews were used for data collection as they provide means for gathering the thorough and detailed information necessary for exploring social processes and how they, formally and informally, organize different aspects of daily life (Smith, 2005). Interviews were conducted with parents with disabled children by the primary investigator, who is a PhD student and a seasoned researcher. The interviews were semi-structured and therefore provided flexibility to follow up on interviewees' answers while still anchored in an interview guide with predetermined topics (Braun & Clarke, 2013). The interview guide was developed by the primary investigator and revised as the project progressed. At the beginning of each interview, broad questions were asked about the family and their daily lives before the pandemic. Participants were asked about the services they had received prior to the pandemic and their experiences with different service providers, offering municipal, school, and healthcare services. The principal part of the interview focused on the family's experiences during the first waves of the pandemic, up until the time of the interviews. When all families had been interviewed once, additional interviews were carried out with the first two families, to follow up on themes that emerged in later interviews and had not been a part of the initial interview guide.

Each interview took about 60–75 minutes, through videoconferencing technologies. Consequently, it was recorded and transcribed verbatim. The interviews took place from September to November 2021 against a backdrop of a rapid spread of infections and subsequently stricter domestic prevention measures in November, following prior relaxation of prevention measures in the end of August (Government of Iceland, 2021).

2.2. Data Analysis

A thematic analysis approach (Braun & Clarke, 2019) was used. After being thoroughly read by all authors, the interviews were coded by the primary researcher, where in which data segments relevant to the study aims were identified and labelled. The codes were revised in collaboration with the second author, who is also a PhD student. Subsequently, themes were developed by identifying patterns among the codes, reassessed in collaboration with all authors, and reviewed by going back to the initial codes and the full dataset (Braun & Clarke, 2013; Creswell, 2008). The analysis was finalised by the primary investigator and the third author who is a professor of disability studies. In line with critical disability studies and standpoint feminist theory, the analytical

focus was aimed at the social structures and mechanisms that affected and shaped parents' and children's experiences during the pandemic, to form a broad picture of the power relations affecting the lives of families (Meekosha & Shuttleworth, 2009; Smith, 2005; Wylie, 2003). Examples of critical questions that guided the analysis were: What characterizes the institutional service structure and processes that shape and affect the families with disabled children? How did service systems and institutional processes shape the participants' experiences during the pandemic? How was participants' daily life framed or coordinated by power relations during the pandemic? To validate the accuracy of our findings, we triangulated among different data sources (participants), multiple researchers (authors), and through member checking where participants in the study were asked to determine the accuracy of the findings (Creswell, 2008). The interviews were conducted in Icelandic, and direct quotes were translated by the primary investigator.

2.3. Participants

In total, eight parents, six mothers and two fathers, participated in the research. In two instances both parents took part in the interviews and one family had two disabled children (Table 1). Initially, a purposeful sampling strategy was employed to recruit participants who would be able to provide in-depth information about the experiences of families with disabled children during the pandemic (Creswell, 2008). This was done by placing an advertisement about the research in a Facebook group for parents with disabled children. Five individuals answered the call, all of which participated. Snowball sampling was then used, where participants forwarded information about the research to other parents. This resulted in the recruitment of the last family. No participants opted to drop out at any time. In total, eight interviews were conducted, as two families were interviewed twice. All participants were white, native Icelanders between the ages of 34 and 52. All the children needed support in their daily lives and had physical impairments, but seven of them also had complex health issues. Three families lived in the capital region; the other three resided in towns with under 20,000 inhabitants. The children, three girls and four boys between 7 and 16 years old, all lived in two-parent households. Table 1 provides an overview of the participants.

2.4. Ethical Issues

Researchers are obligated to ensure that their research is scientifically sound. Furthermore, ethical justifications for research lie in its scientific and social value (CIOMS, 2016). We affirm that we have adhered to scientifically sound and ethical research practices and believe this work to be a valid contribution to scientific and practical knowledge about the topic. The research proposal was reviewed by the Research Ethics Committee for Public Higher Education Institutions (SHV2021–009) as is required when interviewing families from a marginalized population. As stated in their guidelines, the committee emphasises four core values in research: respect for human dignity, beneficence, non-maleficence, and justice (University of Iceland, 2014). All parents participated willingly in the research and were informed of the study's purpose and their right to terminate their participation at any time. Attention was paid to power relationships, and trust and security in interactions during the interviews were emphasised. An example of this were the measures taken to protect anonymity. This was, understandably, an important concern for participants, who many lived in tight-knit communities. In collaboration with participants, it was decided to forgo pseudonyms in analysis and published findings and omit certain demographic and background information about the families.

3. Findings

Three main themes emerged from the data. The first theme, "fragmentary services," describes the support system (healthcare, school, or other municipal services) encountered by the families before the Covid-19 pandemic. The second theme, "risky obliviousness," and its subthemes, "faulty response measures," "unprepared systems," and "service providers distance themselves," depict the circumstances in which the families found themselves during the first wave of the pandemic, when gaps in the fragmentary services widened. The final theme, "on their own," offers insights into the parents' concerns about the ongoing pandemic.

3.1. Fragmentary Services

All the participants described having limited trust in the healthcare system prior to the pandemic. Because of

Table 1. Information about the participants.

Participants	Region	Disabled children	Siblings	Interviews
Mother and father	Rural	1	2	1
Mother	Rural	1	2	1
Mother	Urban	2	2	1
Mother	Rural	1	2	2
Mother and father	Urban	1	1	2
Mother	Urban	1	1	1

their children's health conditions, five of the six families had regular contact with the healthcare system for monitoring their children's health. This included several doctors who all limited their interest and involvement to issues within their fields of expertise. Due to limited collaboration among these doctors, they had little oversight, resulting in fragmentary services. As one mother (id.2) explained: "I've never felt that the [healthcare] system is keeping track of us at all."

Because of this disjointed nature of services and the lack of oversight, the parents felt that it was up to them to stay vigilant and ensure the necessary follow-ups. Lapses in care could have serious consequences, as described by one mother. While a neurologist on call in the ER had recommended regular monitoring of her daughter's blood levels, her main specialist dismissed this and minimised the mother's concerns. This led to the daughter's long and dangerous seizure, which could have been avoided had her blood levels been monitored. The mother (id.6) explained:

> I said: "Well [neurologist on call] said that we need to monitor this regularly, you know. Don't we have to do that?" And he just: "No, no, no, no, no, it's all good." He just could have sent her to this damn blood test and this wouldn't have happened six weeks later. And it was just, we were so incredibly hurt and angry at him.

Other parents had similar stories to tell, of how being advocates for their children often meant that they doubted or second-guessed the doctors' opinions. Their advocacy role was often complicated by limited access to doctors and other gatekeepers. These hurdles not only lengthened the process of obtaining sufficient care and support but also cost energy for the parents. The parents were nevertheless adamant that they had to take matters into their own hands, oversee their children's healthcare and fight for the latter's rights and health. A mother (id.3) said:

> My experience of the Icelandic healthcare services is that I have to be her specialist because she has a rare disease, and no one has the time to monitor or follow up on things regarding what is best to do and ensure that everything that needs to be done gets done.

Parents' experiences with municipal service providers were also described as one-sided interactions. For example, service providers rarely showed initiative, anticipated the children's or the families' needs or provided practical information beforehand. This was a substantial barrier as it is difficult to ask for something you don't know exists. A mother (id.2) explained:

> It's a kind of a one-way street. We always have to let them know or wish for or ask for something. And you don't always know what is within your right or what

you can ask for, and sometimes, I just don't know what they can offer.

Four families had direct payment contracts, where they organised the services themselves and hired assistants, with the budget from the municipality. Participants described how the support they received through these contracts was insufficient as the contract hours did not cover the needs of families. As an example, one mother explained that the municipality had assessed her daughter's support needs to be 720 hours a month, or around-the-clock care. However, citing a limited financial budget, the municipality only provided the family with a service contract that amounted to about a third of assessed hours. The mother (id.5) recounts:

> She [the social worker] said to us: "I managed to get you a 240-hour service contract." I think I remember her saying word-for-word: "Can you just please take it and be happy with it. It's the best I can do for you now. Just take it."

Although support in school is also provided by the municipality, in the parents' experience, it was organised more or less independently of the circumstances in the child's home and limited collaboration with other municipal services. The school support is tied to the school premises and limited to the school's work hours, leaving little room for flexibility. This posed a problem for children who needed around-the-clock support, as their parents had to be prepared to care for them when schools were closed due to discretionary days or when school days were shortened. One mother (id.4) explained that according to school administrators, there need to be two or three assistants available to her son at school, at all times. When assistants became ill or there was a staff shortage, the school called to let the parents know that the boy could not attend school that day, regardless of whether any assistant was at home with the child:

> Well, they [the school] believe that there should always be two assistants by his side and that....Well, they do it somehow like, there are three assistants with him and two are always by his side and the third is [elsewhere] then they change and take turns. If...well they have allowed him to come when there were only two assistants at the school, but if two assistants are off work then it's just: "Sorry, you know, it just isn't, there is no one else that can see him today."

Other parents encountered similar problems regarding the support their children were allocated at school. One participant (id.1) explained how the problem was rooted in the ways that the support was organised. Namely, rather than being arranged around children's needs the support was tied to school facilities: "Assistants belong to particular buildings; really, it's just

unbelievable that it remains that way. The support needs to be more flexible.''

The parents described how insufficient and fragmentary services before the onset of Covid-19, left them with limited trust in the different systems with which they had to interact. They had become used to taking matters into their own hands to ensure the necessary support for their children. According to the parents, these issues would become more prevalent in the pandemic. The families described themselves as in a state of shock in the first weeks of the Covid-19 outbreak. Six of the seven children had comorbidities that left them susceptible to severe infection. Their parents were particularly frightened, and so six of the families were shielded early on when news of the infection broke, before any lockdown measures had been taken by the authorities. This meant taking all their children, including siblings, out of school and taking leave from work or working from home if possible. During the first wave, these families lived more or less in isolation until May 2020, when the infection rates decreased. Although one family did not shield, their situation was similar to those of the others as they had to quarantine several times in a relatively short period and subsequently isolate themselves because of a family member's infection. When shielding themselves from the pandemic, participants did not meet close family members who resided outside their homes or their assistants. Trying to keep up with schoolwork for their children, as well as maintaining physiotherapy schedules, housework, and remote work, many parents soon felt overwhelmed, as described by a mother (id.2): "We just closed our doors. And then we were just at home and saw to everything ourselves, and it indeed ended with the two of us having to take sick leave. It was just such awful pressure."

3.2. Risky Obliviousness

From the interviews, the theme "risky obliviousness" emerged, as parents described how seemingly unprepared support services did not reach out or provide meaningful support to the families in the first wave of the pandemic. The subthemes "faulty response measures," "unprepared systems," and "support providers distance themselves" depict how, inadvertently, the deprioritization of the needs of disabled children and their families in response measures, increased participants risk of isolation and exhaustion.

3.2.1. Faulty Response Measures

According to the parents, neither healthcare providers nor doctors contacted the families beforehand in the wake of the pandemic. Not anticipating much support, the parents themselves did not refer to any specialist before deciding to shield. There was one exception; when news of the pandemic broke, one mother asked her daughter's main doctor how the family should proceed.

He replied that he did not see shielding as especially beneficial for her daughter, who was in fact, no different from anyone else. In the mother's view, this response was irresponsible and most likely incorrect since the child had serious health issues and comorbidities. She explained (id.6): "I was baffled. What kind of answer is that? After that, I just didn't talk to anyone." Not only did the doctor dismiss her concerns, but he also did not contact her again to follow up on or revise his response when further knowledge about the seriousness of the pandemic emerged.

Parents explained how universal response measures aimed at health and safety usually did not consider disabled children's needs. Preventive efforts sometimes served to complicate things further or create new problems. Examples include measures taken in Icelandic schools during the first two waves, when school days were shortened, and school premises were compartmentalised to limit the risk of infections. One mother described how the compartmentalisation in her son's school resulted in his impossibility to return to school. His three assistants had been vaccinated early, being his allocated support staff. They were then separated into different compartments, making it impossible for them to work together to organise and provide him support. The mother (id.1) explained:

> He was totally forgotten in the first wave…and it was really awkward of the school to do that [split up the assistants] because then, there was never a chance for us to get any assistance. And everyone lost track, and no one made any contact because everyone was separated.

Furthermore, schools had seemingly no plans in place to provide the children with the support that they were allocated in school or to find ways to extend the support to their homes, for example through remote learning. One mother (id.3) explained how, during the shortened school days her son was sent home, without his allocated support or any consideration for the situation at home:

> They were just two hours at school or something, and then they went home. My son needs one-on-one support, both on account of his physical and emotional needs. He was sent home at twelve o'clock. His support staff was at the school, at work, probably getting paid to be at work, but the child was sent home. And we got nothing [no support].

Parents recounted several incidences of such responses and preventive measures that proved to be "awkward" or "stupid," organised without taking the needs or considerations of disabled children into account.

3.2.2. Unprepared Systems

Most of the municipal service support to the families was put on hold as soon as the virus started spreading.

As the pandemic progressed, it became clear to the parents that the municipalities and school services had no measures in place to ensure important support for the children and their families. As noted previously, support that the children were allocated during school hours was not extended to their homes. Physiotherapy, occupational therapy and speech and language therapy were cancelled, with no protocols in place to ensure these specialised services. The loss of these services could have long-term effects on the children, as one mother (id.1) explained: "He is learning to use [assistive communication device] but if there isn't continuity the training becomes unfocused and futile. We feel that we are losing precious time." Furthermore, the families had no support in their homes for extended periods. Afraid that support staff could bring infection into the home, some of the parents did not reach out to schools or municipalities for assistance. Others, however, contacted schools or municipalities to seek ways to secure support for the families. For those who had direct payment contracts, the municipalities provided little help. After much advocacy, one family was allowed to bring assistants into their home for a few days if the assistants wore protective clothing. The municipality quickly withdrew this exemption as the home was not equipped with the necessary features: two bathrooms and a special room for the assistants to change into protective clothing. The mother (id.5) explained: "There were no clear instructions on what you could or couldn't do. No one knew anything, and you always had the feeling that people were just guessing what would be okay and what wouldn't."

Because the hospitals were overloaded and the healthcare system was under pressure, some parents were concerned that their children would not be safe if hospitalised. One mother (id.3) inquired whether there was a protocol regarding the allocation of ventilators, that is, if any group was prioritised over others. The answer was that there was no protocol, but "everyone hoped it would not come to that." In her view, this was both emblematic of the system that commonly overlooked her child's needs and could probably pose a danger to him. She said:

> Worst-case scenario and all ventilators are in use, then you have to trust that the doctor you get isn't full of disability prejudice or thinks his [her son's] life isn't worth living. I mean, really? There are no protocols. I know that everyone hopes we won't get there, but this needs to be written down and decided beforehand….I mean, I don't think my house will catch fire, but I've still told my children what to do if it catches fire in the middle of the night.

Participants described their feeling of being on their own as no one seemed to have oversight or take responsibility regarding support for disabled children and their families. Although aware of the complicated situation in which the families found themselves, doctors and other service providers seemingly distanced themselves.

3.2.3. Support Providers Distance Themselves

In the middle of March 2020, the Children's Hospital of Iceland sent a message to the families of children with underlying risk factors, advising them to keep their children at home while little was known about the virus. At that time, the families who had decided to shield had started already. The hospital never followed up with further recommendations, and no institution or authority seemed to have oversight, take charge of streamlining information, or coordinate efforts. As a mother (id.6) pointed out: "It was like no one knew who was supposed to provide information [for families of disabled children] or, you know, take charge regarding this group."

In later waves, support from doctors proved to be important, particularly regarding vaccinations, yet quite inaccessible. Securing a place on a vaccination priority list for their children and themselves was arduous; the participants received little help from their specialists and encountered gatekeepers who were supposedly preventing misuse of the priority lists. Although they recognised the children's precarious situation, few healthcare providers showed particular interest in the families' position or provided meaningful support. In the parents' view, the Children's Hospital and healthcare specialists took a step back as the pandemic progressed, and they then withdrew, citing that this was not their field of speciality and seemingly not wanting to take responsibility. A mother (id.4) explained: "His [specialist] team just withdrew and said, 'You just have to assess the situation. If you need a medical certificate, we will write it, but you just have to assess the situation.'"

The municipal and school services also remained at a distance; nobody called to check and hear how the children were doing. Although most schools remained open, the participants chose to keep their children at home during the first wave and periodically in later waves, when infection rates rose. Some parents found it hard to send their children back to school when infections decreased, as they did not trust the schools to undertake the necessary precautions for their children's safety, such as following the two-metre distancing rule. In some cases, schools overtly shied away from responsibility. When discussing with school officials what arrangements could be put in place to facilitate their son's return to school, one family experienced limited cooperation and felt that the school staff were finding ways to bow out of their obligations. The mother (id.1) explained: "The school said at some point in time: We cannot protect anyone, that is, we cannot 100% protect anyone. And then, you know, we just backed off even more." After this response, which the parents interpreted as a distancing technique of sorts, it became difficult for them to trust that their son's needs would be considered.

3.3. On Their Own

At the time of the interviews, Covid-19 had lasted for many months, with fluctuations. The parents felt that during the pandemic they had been overlooked and forgotten, many using metaphors such as "on our own" or being "alone on a boat" when discussing their experiences. One mother (id.2) explained:

> I just feel like we've had to be on our toes completely to monitor and follow everything, but there isn't somehow, I don't feel like, I don't get the sense like there is someone that would possibly catch us or support us. Not at all.

The families who had shielded in the first waves of the pandemic had, now, relaxed their restrictions somewhat, although remaining very careful. With new variants posing less health threats, concerns about infections decreased among the general population, while annoyance with protective measures increased. However, the participants remained worried about their children's health and situation, and the growing dismissal of the pandemic's dangers only increased their concerns. An increasing number of people were brushing off the dangers of the virus, unconcerned about the precarious position of many people and families, as a father (id.1) explained:

> It's infuriating to hear people say that this is just a flu and that only a small percentage of people will have any problems when you precisely have someone who will have problems. You know, it's difficult listening to people talk about this so carelessly.

Some participants described similar obliviousness by healthcare staff and specialists who were quite versed in the children's situations. One mother had encountered healthcare staff's dismissive attitude and lack of understanding while she was taking strides to maintain protective measures when taking her daughter for regular bloodwork and check-ups at the hospital. Another family was asked to participate in an annual meeting and check-up at the Counselling and Diagnostic Centre, targeting families from rural towns. When the mother (id.4) declined, pointing out that her son had not been vaccinated and it would be unwise to risk infection, the specialist was surprised, seemingly forgetting about the child's situation. She believed that this probably would not have happened at earlier stages of the pandemic, when adults had not been vaccinated. "Even the specialists have forgotten. But in the earlier wave, when the infection rates were this high, everything was closed. But now, because they [the specialists] are vaccinated, everything is just supposed to be moving along."

The families criticised the authorities whom they felt had overlooked the situation of people and families who needed assistance in daily life, prioritising measures for the benefit of the economy. Many voiced their irritation and concerns about travel industry lobbyists who called for limited restrictions and more governmental support. As the parents explained, prolonging preventive measures was imperative since infection rates were still rising and the consequences on their children's health were unforeseen and potentially deadly. As one mother (id.6) explained:

> I just don't feel that anyone *needs* to go to Tenerife, you know. I think it's more important that my children get to go to school. But there is no point in discussing it because it's such a small group [who has to shield]. Naturally, if the majority was in this position [having to shield] then it would be different.

Similarly, a father (id.1) pointed out: "It is important that the government play their cards right, which we are quite scared they won't do….I think that too much money is at stake." In his view, financial and political interests seemed likely to win over the health concerns of a minority group. Being in a minority and "on their own," participants found it difficult to trust that politicians would prioritise their children's welfare.

4. Discussion and Concluding Remarks

In this article, we explored the experiences of families with disabled children during the Covid-19 pandemic. Consistent with previous research results (Egilson, 2015, 2022; Ingólfsdóttir et al., 2018), the findings expose a flawed system of support, prior to the pandemic, best characterised as fragmentary. Through their experience of navigating uncollaborative systems and constantly fighting for the health, education, and safety of their children, the parents had become used to taking matters into their own hands, honing the problem-solving skills that they subsequently used to tackle the difficulties that arose during the pandemic.

In our analysis, we set out to examine the service structure and processes from the standpoint of parents with disabled children and how participants' experiences were shaped and coordinated by institutional power relations. We argue that the service system responses and preventive measures taken during the pandemic were ableist in nature as they centred on non-disabled bodies and experiences (Campbell, 2009). This was particularly prominent regarding organizations of restrictions in school settings and the prioritisation in the health care system. The disregard for the importance of education and other specialised services for disabled children during the pandemic reflects ableist notions about children who are fully valued and those who are not. The deprioritisation of disabled children and their families, described by participants, is emblematic of the marginalised position they hold in society. Indeed, the problems and barriers encountered by the families during the pandemic were not alien to them but perpetuated and

highlighted systemic issues and problems that they previously faced.

The parents' fear for their children's safety was exacerbated by their limited trust in healthcare and municipal services, which in many ways overlooked and underestimated disabled children's needs and complex situations. Since the interviews were conducted, the National University Hospital of Iceland (2021) published guidelines for critical care, allowing the rejection of critical care for frail patients, regardless of age, during the Covid-19 pandemic. Based on these guidelines, disabled people who rely on support in daily life, and may therefore be categorised as frail, are at risk of being refused intensive care treatment. Grounded in ableist perceptions and judgements about the quality of people's lives, such decisions confirm that the participants' anxiety regarding their children's safety was warranted. Similar issues have been raised elsewhere (Inclusion London, 2020; McKinney et al., 2021; Rockwood & Theou, 2020). Recognising that societies' structures and institutions are offsprings of existing ableist power relations, this is undoubtedly a global issue.

This article contributes to emerging literature about the experiences of disabled children and their families during the pandemic. Our findings highlight the importance of prioritising the needs and concerns of disabled people, children, and their families in policy measures taken by institutions and authorities in response to pandemics and other disasters. Covid-19 remains a threat, particularly to those with serious health issues. The long-term outcomes of the virus and the social conditions it has fostered are not yet fully known. It is important to draw lessons from the experiences of disabled children and their families and use them to improve support and ensure access to rights and social inclusion at all levels of society. The findings have implications for the service systems and institutions and indicate practical issues that need to be addressed. The fragmented nature of the service systems, established in prior research (Egilson, 2015, 2022; Ingólfsdóttir et al., 2018), remains a substantial barrier to services for disabled children and their families. Although inclusive education is the official policy in Iceland and mandated by law (Althingi, 2008), school support shows limited regard for the social or familiar context of the children. This results in a gap between the support provided in schools and in homes, which has further jeopardised the families' situation during the pandemic. It is imperative that services be more flexible and adjustable to the different needs of children. Rules must ensure children's rights to assistance and not be limited to the school grounds or particular facilities. Furthermore, service providers must fulfil their legal obligations and make certain that support is provided. Whereas direct payment contracts have introduced an important alternative to inflexible traditional service arrangements and have enhanced users' autonomy and well-being (Snæfríðar- og Gunnarsdóttir & Arnalds, 2016), in this study, current arrangements conveniently provided space for municipalities to distance themselves, seemingly exempt from legal obligations in the face of a serious event—a pandemic. This not only resulted in children and their families not receiving the support to which they are entitled by law, but also put them at risk for further marginalisation and isolation.

Limitations of the study stem from the small sample size, which is to be expected from such a small population. Notwithstanding, the study offers important insight into the experiences of these families. There was much agreement in the participants' accounts which are also in accordance with previous studies about families' experiences of services. Another limitation are the fluctuations in the pandemic and the fact it is still ongoing when this article is written. This issue is superseded by the fact that Covid-19 is an ongoing global threat. Our study is a contribution to the continuing endeavour to uncover and understand the effects of the pandemic and responses to it from institutions and service systems.

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Conflict of Interests

The authors declare no conflict of interests.

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