Ableist Power Relations and Disabled People's Invisible Work during COVID-19

Hrafnhildur Snæfríðar- og Gunnarsdóttir

Thesis for the degree of Philosophiae Doctor

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Ableísk valdatengsl og ósýnileg vinna fatlaðs fólks í COVID-19

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Ágrip

Á tímum hamfara og samfélagslegra áfalla er fatlað fólk í sérlega viðkvæmri stöðu. Rannsóknir sýna að viðbragðsáætlanir og undirbúningur aðgerða miðar jafnan fyrst og fremst við þarfir og reynslu ófatlaðs fólks. Stuðningur sem virkjaður er á hættustund reynist fötluðu fólki því iðulega óaðgengilegur og eykur jafnvel hættuna sem að því steðjar. Þrátt fyrir ábendingar alþjóðlegra stofnanna og ákall samtaka fatlaðs fólks og rannsakenda um mikilvægi þess að viðbragðsaðgerðir tækju mið af þörfum og réttindum fatlaðs fólks, rötuðu þessi atriði neðarlega á forgangslista stjórnvalda í COVID-19 faraldrinum.

Meginkveikjan að rannsókninni var sú að margt benti til að ekki hafi verið tekið mið af þörfum fatlaðs fólks í undirbúningsvinnu og aðgerðum í faraldrinum og að þekking og framlag þess hafi verið vanmetin. Faraldurinn reyndi mikið á samfélagslega innviði og opinberar stofnanir sem ber skylda til að standa vörð um réttindi og velferð fatlaðs fólks. Vegna aðstæðnanna sem sköpuðust þótti mikilvægt að rýna í hvort og að hvaða marki fötlunarsjónarmið hafa verið innleidd og skilgreind sem forgangsatriði og hvað stæði í vegi fyrir því að það væri gert.

Markmið rannsóknarinnar var tvíþætt. Annars vegar að varpa ljósi á reynslu fatlaðs fólks í faraldrinum og auka með því fræðilegan skilning á ableísku regluverki og valdatengslum sem stuðla að undirskipun og jaðarsetningu fatlaðs fólks við aðstæður sem þessar. Hins vegar að stuðla að hagnýtri þekkingu sem nýst getur til að bæta viðbrögð í hamförum. Rannsóknin er hluti stærra rannsóknarverkefnis sem nefnist *Fötlun á tímum faraldurs* og miðar að því að varpa ljósi á áhrif heimsfaraldursins á líf fatlaðs fólks á Íslandi. Rannsóknin var styrkt af Rannsóknasjóði Íslands (nr. 217502-052).

Rannsóknin byggir á fræðigrunni femínískra sjónarmiðskenninga (e. feminist standpoint theory) og gagnrýnni fötlunarfræði (e. critical disability studies). Þessi fræðilegu sjónarhorn eiga uppruna í pólitískri baráttu jaðarsettra hópa (kvenna og fatlaðs fólks) og beina sjónum að félagslegum valdakerfum sem viðhalda undirskipun þeirra og kúgun. Gagna var aflað með eigindlegum viðtölum við fatlað fólk, fulltrúa samtaka fatlaðs fólks og foreldra fatlaðra barna. Fjallað er um niðurstöður rannsóknarinnar í fjórum ritrýndum greinum.

Niðurstöður leiddu í ljós að stuðningskerfi og viðbragðsáætlanir voru ekki undir það búin að mæta álaginu sem skapaðist í faraldrinum. Aðgerðir sem áttu að stemma stigu við áhrifum faraldursins komu illa til móts við þarfir þátttakenda og urðu oft til þess að þau fóru á mis við réttmætan stuðning. Fyrrum brotalamir í þjónustu komu enn betur ljós, svo sem langvarandi þjónustuskortur sem hafði grafið undan stuðningi, aukið ábyrgð fólks og í auknum mæli gert ráð fyrir ‚ósýnilegri‘ vinnu af þess hálfu. Krafan um ósýnilegt framlag fatlaðs fólks jókst enn frekar í faraldrinum þegar stuðningskerfi héldu að sér höndum og jók það mjög á erfiðleikana sem þátttakendur stóðu frammi fyrir. Þátttakendur voru því mörg ein á báti, þurftu að sjá fyrir vandamál og leysa þau án stuðnings.

Niðurstöður rannsóknarinnar endurspegla áhrif nýfrjálshyggjuhugsunar á velferðarþjónustu og áhrif þessa á fatlað fólk í heimsfaraldrinum. Fræðilegt framlag felst sér í lagi í því hvernig gagnrýnin fötlunarfræðisjónarhorn og femínískar sjónarmiðskenningar varpa ljósi á umfangsmikil kúgandi valdatengsl sem höfðu víðtæk áhrif á líf og aðstæður fatlaðs fólks í faraldrinum. Þekkingin sem af hlýst má nýta til að sporna gegn ríkjandi og kerfislægum ableisma. Niðurstöður varpa ljósi á brotalamir í þjónustu við fatlað fólk og verklagi sem því tengist og undirstrika mikilvægi þess að umbótastarf sé unnið í samvinnu við fatlað fólk og með reynslu þess og forgangsröðun að leiðarljósi.

Lykilorð:

Fötlun, Ableismi, Femíniskar sjónarmiðs kenningar, Gagnrýnin fötlunarfræði, ósýnileg vinna, nýfrjálshyggjuhugsun,

Abstract

Several factors render disabled people disproportionately affected in times of disaster. Research shows that they are often overlooked in emergency responses and that general aid and support to the public are often inaccessible or do not meet their needs. Although activists, researchers, and organizations of disabled people have highlighted the importance of involving disabled people in crisis management, evidence from the COVID-19 pandemic suggests that disability issues continue to be overlooked, and their knowledge and contributions are undervalued.

This study sought to investigate the power relations that govern and influence disabled people's lives. It is situated within the context of the pandemic, a period during which infrastructure was heavily tested, presenting an opportunity to explore the extent to which the rights and needs of disabled people had been integrated into decision-making and prioritization within institutions responsible for their welfare.

The study's overall aim was twofold: first, to contribute to theoretical understanding about the structural processes and oppressive dynamics that perpetuate the marginalization of disabled people yet remain opaque, and second, to gain important insight and practical knowledge about the impact of the pandemic on the lives of disabled people in Iceland. The study is part of a larger research project called *Disability in the Time of Pandemic*, funded by the Icelandic Research Fund (217502-052).

The study comprises four distinct lines of inquiry, featured in four peer-reviewed articles. It drew on qualitative data from disabled people, representatives of disabled peoples' organizations and parents of disabled children. The research, as a whole, is set within the theoretical paradigms of feminist standpoint theory (FST) and critical disability studies (CDS) which both originate from political struggle and share a commitment to highlight experiences of oppression and produce research that has practical relevance for marginalized communities. In this research, their complimentary alignment facilitated an analytical focus that highlighted and problematized ableist power relations while also bringing to the forefront and valorizing disabled knowledge and insights.

The findings demonstrate the persisting service inadequacies predating the pandemic and the increased responsibilization of disabled people and parents of disabled children, presupposing their invisible and unacknowledged work. These service inadequacies and normalization of invisible work persisted in the pandemic and exacerbated the challenges faced by disabled people and their families. Preventative measures implemented by official and service institutions predominantly centred the experiences and needs of non-disabled people, thereby resulting in service cancellations and endangering of the well-being of participants, and further complicating their lives during the pandemic. Recognizing that disability issues were being neglected and deprioritised by the institutions tasked with responding to the pandemic, participants had to anticipate problems and assertively advocate their rights and handle complicated issues without rightful support.

The thesis contributes to knowledge about experiences of disabled people during the pandemic. It corroborates and extends recent Scandinavian literature about the impact of neoliberal reasoning on welfare services and provides insights into the impact of this on disabled people during the pandemic. It provides theoretically informed insights into the complementary intersection of critical disability studies and feminist standpoint theory and how they, together, can facilitate important scrutiny into pervasive oppressive power relations and combat the way in which these relations suppress crucial evidence stemming from marginalized experience.

Keywords:

Disability, Ableism, Feminist Standpoint Theory, Critical disability studies,

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Contents

List of abbreviations

CDS	Critical disability studies
CRPD	UN Convention on the Rights of Persons with Disabilities
DPO	Disabled people's organization
FST	Feminist standpoint theory
PA	Personal assistance
SSRI	Social Science Research Institute
TA	Thematic analysis

List of original papers

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I, II, III, IV). As the first author of articles I, II, and III, I collected the data and had a leading role in data analysis and supervision over writing and editing. As a co-author of Article IV, I participated in data generation and contributed to the overall conceptualization and determining the theoretical context and analytical direction. I furthermore participated in writing and editing of the paper.

I. Snæfríðar- og Gunnarsdóttir, H., Ólafsdóttir, T. & Björnsdóttir, K. (2023). Risky obliviousness within fragmented services: Experiences of families with disabled children during the COVID-19 pandemic. *Social Inclusion, 11*(1): 5 - 15.

II. Snæfríðar- og Gunnarsdóttir, H. & Löve, L. E. (2024). Rights in crisis: Lived experience as knowledge in policy development during the Covid-19 pandemic. *Scandinavian Journal of Disability Research, 26*(1): 380 - 392.

III. Snæfríðar- og Gunnarsdóttir, H., Jóhannsdóttir, Á. & Haraldsdóttir, F. "I think they consider themselves free from all responsibility" Neoliberal Undermining of Welfare Services and its Implications for Personal Assistance Users During the Pandemic. Submitted for publication in *Nordisk välfärdsforskning/Nordic Welfare Research*.

IV. Björnsdóttir, K., Snæfríðar- og Gunnarsdóttir, & E, Gunnarsdóttir (2024). The digital exclusion of people with intellectual disabilities during the COVID-19 pandemic. *Scandinavian Journal of Disability Research*, *26*(1): 523 - 535.

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1 Introduction

This PhD project explores oppressive structural power relations that affected disabled people and their families during the COVID-19 pandemic. It is a contribution to critical disability studies (CDS) and is dedicated to the pursuit of disability justice.

When the first news of what would become the worldwide COVID-19 pandemic reached Iceland, few suspected that it would evolve in the way it did. On 27 January 2020, the Icelandic Department of Civil Protection and Emergency Management declared an "uncertainty phase" characterized by precautionary actions, such as regular risk assessments, monitoring, and consultation between the Department of Civil Protection and other institutions concerned (National commissioner's office, 2020). After the first domestic infection was announced on 28 February 2020 (Gunnarsson, 2020), things escalated quickly in Iceland, as in other countries. The response measures taken by the Icelandic government during the pandemic were based on the country's geographical traits and consisted of strict border controls and contact tracing. Heavy screening measures were emphasized, and intermittent bans on gatherings were implemented. Although a national lockdown was never imposed, the pandemic had a significant impact on infrastructure and the lives of citizens (Ólafsson, 2021).

As the pandemic unfolded, countries implemented distinct approaches in their responses, yet when it came to the prioritization of disability issues and rights – things seemingly progressed in similar ways. During the first months of the COVID-19 outbreak, it quickly became apparent that marginalized groups, such as individuals with low incomes, ethnic minorities, disabled people and those with underlying health conditions, were those most susceptible to dangerous viral infections (Inclusive Education Initiative, 2020; Kim et al., 2020). When it comes to disasters, research has shown that disabled people are a precarious group (United Nations [UN], 2020; United Nations for Disaster Risk Reduction, 2015). This goes hand in hand with their social status and the fact that disabled people are disproportionately poor and inhabit an ableist world (World Health Organization [WHO], 2011), and many need assistance in their daily lives to navigate that world. As a group, disabled people are at higher risk of having poor health than non-disabled people (WHO, 2022), and this contributed to their increased precarity during the pandemic. In part, these health disparities can be traced to the increased risk of secondary health conditions associated with impairments. However, they are also the result of disability discrimination and the social exclusion experienced by disabled people (Emerson & Hatton, 2014; WHO, 2011, 2022). Historically, disabled people have been marginalized in crisis and emergency responses. Research has consistently highlighted a pattern of neglect and deprioritization of disability considerations in emergency planning (Alexander, 2015). In response, international organizations, researchers, and disability activists emphasized the importance of promoting awareness and advocating for disability issues during the pandemic, urging governments to prioritize these concerns (Armitage & Nellums, 2020; Davis, 2021; Lisney et al., 2020; Mladenov & Brennan, 2021; UN, 2020).

Seemingly, recommendations and lessons learned from previous disasters had not been integrated into crisis response or emergency management. Despite the urging of international institutions such as the UN and WHO (United Nations, 2020; United Nations Human Rights, 2020; WHO, 2020), disabled people faced significant barriers to accessing health care and important pandemic-related information (Kubenz & Kiwan, 2022; McBride-Henry et al., 2023) and experienced a sudden loss of services (Jesus et al., 2021; Pearson et al., 2023; Read et al., 2023). News coverage shed light on numerous instances where disabled people did not receive adequate care, and healthcare rationing policies reflected unabashed devaluation of the lives of disabled people (Baker & Fink, 2020; Shapiro, 2020).

Disabled activists were vocal during the pandemic, both in Iceland and internationally, voicing concerns about their health, safety, and rights. They criticized disaster management procedures that failed to engage with disability-related concerns and how accessibility issues were overlooked (Haraldsdóttir, 2020; Lisney et al., 2020; Pulrang, 2021). They explained the way the pandemic exposed pervasive medical-ableist perspectives that considered their lives expendable – and the way this directly threatened their own lives (Beck, 2020; Coleman, 2020; Wong, 2020). Yet, disabled activists were unsurprised by the lacklustre way emergency planning addressed disability rights. As Andrew Pulrang (2020) explains: "Disabled people know better than most that in a crisis, in times of confusion, fear, and deprivation, rules and norms meant to protect us can disappear like wisps of smoke".

In this PhD project, the pandemic serves as an entry point into an exploration of structural processes and dynamics that generate and maintain the marginalization of disabled people - yet remain hidden or covert. As is delineated in the quote above, the pandemic, and the rapid onset of protective measures it necessitated, elucidate the underlying dynamics of ableism (Campbell, 2009). The responses within the service sector, and those of official entities, provide insight into the weight disability needs and rights were given – or lack thereof – in the balancing act of decision-making and the extent to which disability awareness and rights have been integrated into institutional processes.

The research was part of a larger project called *Disability in the Time of Pandemic*, the purpose of which is to identify and highlight the effects of the pandemic on the lives of disabled people in Iceland and provide information that may impact and improve their health and well-being and responses to future emergencies and disasters. The Icelandic Research Fund (217502-051) funded the project.

1.1 Purpose and aims

The thesis is grounded in the experiences of disabled people and their families and focuses on the structural processes that impacted their lives in the first months of the COVID-19 pandemic. The purpose of the research is to gain insights into issues deemed critical and important by disabled people and their families in the pandemic and contribute theoretical insights about ableist power relations and patterns of pervasive oppressive systems. To this aim, I developed four research questions/aims that guided my inquiry:

1. What are the main issues reported by disabled people and parents of disabled children during the COVID-19 pandemic?
2. How did structural factors interact to impact the experiences of disabled people during the pandemic?
3. How and to what extent were factors important to disabled people and their organizations addressed and acted on within service structures and other official institutions during the pandemic?
4. How did structural processes presuppose and sustain the need for disabled people's invisible work during the pandemic?

These four questions form my overarching commitment across the four academic articles comprising my findings. To guide me in addressing these questions, I employed qualitative methodology, grounded in feminist standpoint theory (FST) (Harding, 2004) and critical disability studies (CDS) (Goodley, 2013; Shildrick, 2019a). These critical theories are social justice theories that seek to bring about meaningful change and to that aim, provide critical insights into the scrutiny of social norms and patterns of pervasive, oppressive cultural systems. They provided an anchor for the PhD project as a whole, constituted the epistemological underpinnings of the study and informed how research aims were framed. They also guided the way in which data were collected and the lens through which they were then analysed. The findings are presented in four academic articles which engage in distinct inquiries:

Article I, "Risky obliviousness within fragmented services: Experiences of families with disabled children during the COVID-19 Pandemic", was published in *Social Inclusion* in January 2023. Grounded in FST and CDS, it explores issues reported by parents of disabled children during the pandemic and the way in which structural issues affected the families and increased their precarity. The findings highlight how preventative measures taken in the pandemic centred on non-disabled people's experiences and needs, which in turn intensified the already precarious position of the children and their families.

The second article, "Rights in Crisis: Lived Experience as Knowledge in Policy Development During the COVID-19" Pandemic, was published in the *Scandinavian Journal of Disability Research* in a special issue on disability human rights. It is grounded in interviews with representatives of Icelandic DPOs and is informed by FST, and the human rights approach to disability. It sheds light on the multifaceted knowledge that resides within disabled people's organizations (DPOs) as well as the institutional tactics and processes that affected DPOs' right to participate in decision-making during the pandemic.

The third article draws from semi-structured interviews with disabled adults and parents of disabled children with personal assistance (PA) services during the pandemic. Informed by FST and CDS, the findings highlight how neoliberal market ideology and austerity have influenced the implementation of PA services and how that attributed to many of the difficulties participants encountered during the pandemic. The article: "'I think they consider themselves free from all responsibility': Neoliberal Undermining of Welfare Services and its Implications for Personal Assistance Users During the Pandemic" has been submitted to *Nordisk välfärdsforskning/Nordic Welfare Research*.

Article IV is grounded in focus group and survey data from individuals with intellectual disabilities and focuses on the systemic barriers that contributed to the digital exclusion of people with intellectual disabilities during the pandemic – when remote technology played a pivotal role in assisting individuals in navigating daily life within the context of social restrictions. The article: "The Digital Exclusion of People with intellectual disabilities during the COVID-19 Pandemic" was published in the *Scandinavian Journal of Disability Research.*

1.2 Background and positionality

My involvement with the topic pre-dates my PhD project. In my former work at the Social Science Research Institute of the University of Iceland (SSRI), I participated in several research projects focusing on services for disabled people (Arnalds et al., 2013; Snæfríðar- og Gunnarsdóttir et al., 2016; Snæfríðar- og Gunnarsdóttir & Arnalds, 2016; Tryggvadóttir et al., 2016) and health-related issues (Snæfríðar-og Gunnarsdóttir, 2017; Tryggvadóttir et al., 2022). Throughout that work, I had the opportunity to interview and collaborate with several disabled people and representatives of DPOs. This, along with my previous studies in gender and disability studies, provided me with important insights and connections that proved a meaningful component of my PhD project. As I took on this project, I was motivated to get a chance to delve deeper into issues I had identified in my previous research but had not had the opportunity to scrutinize in detail.

I am a non-disabled, white woman focusing on the experiences of a group of people marginalized by societal power dynamics that privilege people like me. I recognize ubiquitous ableist societal dynamics and the fact that, within the scope of research, these have a history of accentuating and amplifying the already unbalanced relationship between the researcher and the researched. The role of the non-disabled researcher within disability studies has been debated (Morris, 1992; Oliver, 1992; Stone &

Priestley, 1996). Without a critical lens and a grounding in theory, research about disability and disabled experiences by non-disabled scholars may serve to perpetuate stereotypes and ableist understandings. At the same time, when it comes to undoing the ableist dynamics, it can be argued that the onus of responsibility should weigh most heavily upon non-disabled people (Shildrick, 2019a). Disabled scholars have urged non-disabled researchers to focus their gaze on prejudice and ableism ingrained in structures and social relationships (Morris, 1992; Oliver, 1992). That is what I set out to do at the start of my project: ground my research in the experiences of disabled people and direct the focus outward – on the complex interplay of structures and processes that affected them during the pandemic.

My choice of critical and feminist methodology was informed by my prior studies, research, and feminist activism, where my experience has resonated with the main claim of FST: that "the experiences of oppressed groups can become an important source of critical insight" (Harding, 2004, p. 5). As Collins and Stockton (2018) explain, theory coordinates research and its processes, permeating throughout its entirety – from the researcher's very disposition to the methods she uses and how she analyses data. In my case, and in this project, those permeating theories are FST and CDS, which I discuss in the next chapter. These complementary theoretical perspectives provide important insights into social scrutiny, "a sharp political edge and a vigorous critical punch" (Garland-Thomson, 2005, p. 1557). They are both rooted in emancipatory goals, and I hope that with my research, I can contribute knowledge that can be used to challenge underlying conditions that maintain the systemic marginalization of disabled people. My positionality will be further discussed in the chapter on ethical issues.

1.3 Terminology

I use the term "disabled people" in my project. This is based on the understanding that disability is a result of the interaction between individuals with impairments and the societal barriers that prevent their participation, as is emphasized in the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006). Therefore, although people with impairments are disabled in many situations because of environmental or attitudinal hindrances, they do not inherently possess disabilities. An exception to this is people with intellectual disabilities, for whom I use people-first language as advocated by the Icelandic self-advocacy group, Átak. In my thesis, I've chosen to use the term "intellectual disabilities," which is commonly used in international disability research (Björnsdóttir, 2009). It should be noted that disability constitutes a diverse array of embodied and cognitive variations. While I use the term "disability", I recognize that the scope of my research is limited and does not encompass the full breadth of experience. Following Shildrick (2019), I believe that the interrogation of ableist values and politics can justify setting aside intricate differential considerations: "in order to make the strong point that those with disabilities are 'othered'" (Shildrick, 2019, p.33). The critical inquiries of my PhD project focus on the oppressive structural power relations that ‘other’ people and render them disabled through discriminatory attitudes and practices.

Throughout my study, I refrained from using the term ‘vulnerability’. Although commonly used when referring to disabled people’s disproportionate disadvantage in many social contexts, it tends to shift focus to personal attributes as causes of inequalities or harm. I agree with Hughes (2009) that, when steeped in ubiquitous ableist and individualist social dynamics, the term becomes associated with the “ontology of human frailty“. This problem takes on a whole new dimension in the context of the pandemic, where frailty labels in triage protocols adopted in clinical settings were used as a means of excluding disabled people from critical care and lifesaving support (Scully, 2020). Furthermore, as Shuttleworth and Meekosha (2013) argue, the term can perpetuate a medicalized view of disability and contribute to the general rendering of disabled people as ‘less agentic’. This is particularly harmful and dangerous considering the deep-seated societal paternalistic and oppressive history. Because of criticism of the use of the term (Hollomotz, 2013; Hughes, 2009) and to affirm the structural focus of my study, I instead use the term ´precarity´. Following Butler (2012), the term places focus on oppressive social forces and structures at play facilitating disparate social circumstances and, consequently, the disproportionate risk for people. Although the allocation of precarity is not equal – as it disproportionately impacts certain people – the term underscores our interconnectedness, as it “exposes our sociality, the fragile and necessary dimensions of our interdependency” (Butler, 2012 p. 148). Like Davis and Aldieri (2021), I understand the term as a political provocation, underscoring the social and economic factors and infrastructure culpable in the disproportionate precarity of groups – such as disabled people.

1.4 Overview of the thesis

This thesis consists of six chapters. Following this introductory chapter, Chapter 2 introduces the interpretive frameworks for the overall thesis, namely FST and CDS. I furthermore discuss the concept of invisible work, which surfaced as a pivotal theme throughout my study, interlinking all the articles, and the human rights approach, which served as a foundation for the analysis in my second article. In Chapter 3, the study context is established, setting the scene for the findings. The chapter offers a review of existing literature on services for disabled people and, more specifically, how they have been implemented in Iceland. Furthermore, it delves into the literature on disabled people and crises and the COVID-19 pandemic. In Chapter 4, I present an overview of the research design, discussing the methodology and related issues, including ethical conduct and reflexivity. In the chapter, I make explicit the ways in which the project's theoretical underpinnings informed my research. Chapter 5 presents a summary of the findings, which consist of four articles. The sixth and final chapter discusses the findings and their relevance in greater depth and ends with a discussion of the strengths and limitations of the study.

2 Theoretical framework

In this chapter, I discuss the theoretical underpinnings of my PhD project, namely feminist standpoint theory (FST) and critical disability studies (CSD). These theories provided the critical anchor for the project as a whole, informing how research aims were framed, the way in which data were collected and the lens through which they were analysed. FST and CDS align well, sharing a critical focus on oppressive structures in society that perpetuate the unearned advantages of certain embodied experiences (specifically white, cis, male, able-bodied perspectives) and uphold this injustice as natural (Harding, 2004; Meekosha & Shuttleworth, 2009). Both hold a critical view on traditional research practices that have perpetuated the oppression of marginalized groups. Recognizing subjective experience as an important site of research – a topic of political importance – they propose an alternative approach to knowledge construction where marginalized experience is held at its centre (Goodley, 2013; Smith, 2005). This emphasis correlates with my strong belief that the voices, stories, and concerns of disabled people should be amplified and understood as important knowledge. Finally, FST and CDS share the common goal of using research and marginalized knowledge in practical ways, to enhance the social and material circumstances of disabled people and to promote social change (Goodley et al., 2019; Gurung, 2020).

Not all disability research is critical and feminist research devoid of nuanced disability understanding can be reductive, fall into ableist pitfalls, and contribute to alienation (Minich, 2016; Morris, 1992). The intersection of disability studies and feminist theories has been the subject of fruitful discussion as have the lingering barriers to such amalgamation in research (Garland-Thomson, 2005, 2011; Hughes et al., 2005; Kafer, 2013; Morris, 1993a). Both theories are essential to my project for the analytical and critical insights that are garnered through their integration and transformation (Garland-Thomson, 2011). Their complementary alignment of critical structural focus informs the analytical focus on ableist power relations in the PhD project and facilitates its emancipatory objectives. I will elaborate on these theories separately in subsequent sections.

Later sections of this chapter focus on invisible work, which I recognized belatedly in my research as a meaningful thread running throughout the project. The final subchapter discusses the human rights approach, anchored in and supported by the CRPD and utilized in the theoretical framework of my second article.

2.1 Feminist standpoint theory

FST is integral to my project. It signals the project's research aims, its theoretical underpinning, epistemological approach, methods used and analytical focus. FST is rooted in the feminist struggle to bring attention to and identify inequities faced by women – and the way in which they have been concealed by patriarchal power dynamics and structures (Harding, 2004; Smith, 2005). It critically engages with the power dynamics inherent in knowledge production, scrutinizing the relations and social structures that coordinate and determine whose experience is translated into knowledge and whose is not (Harding, 2004). FST problematizes conventional research upon which dominant knowledge claims rest. Traditional research has historically neglected the experiences of marginalized people as starting points for research and undervalued them as an important source of evidence under the guise of objectivity and keeping research value-free and impartial. By applying "the god-trick" (Haraway, 2004) – assuming a point of view outside of social context and removed from ubiquitous politics, interests, and underlying values – conventional research practices have facilitated and reinforced oppressive social dynamics. Feminist standpoint approaches call for a critical rethinking of this objectivity claim and argue that the conventional notion of objectivity should indeed be regarded as excessively weak, as it does not engage in a critical analysis of interests. Harding explains:

> The term "objectivism" is useful for the purposes of my argument because its echoes of "scientism" draw attention to ways in which research prescriptions called for by a value-free objectivity only mimic the purported style of the most successful scientific practices without managing to produce their effects. Objectivism results only in semi-science when it turns away from the task of critically identifying all those broad, historical social desires, interests and values that have shaped the agendas, contents and results of the sciences much as they shape the rest of human affairs. (Harding, 2001, p. 156)

Standpoint epistemologies call for the acknowledgement that all human beliefs – including those underlying conventional research practice – are socially situated. A standpoint (such as that of a researcher) is always located in a specific time and culture and can only ever produce partial and socially situated knowledge. *Strong objectivity* entails a critical and practical awareness that social positionalities impact how people experience the world (Harding, 2004). Feminist standpoint theorists, such as Haraway (2004), Harding (2004) and Smith (2005) argue that in order to create less biased and distorted understandings, research must take into consideration the social and historical context. Furthermore, this necessitates a critical evaluation of which social locations tend to generate the most objective knowledge claims. To this end, FST highlights the value of marginalized knowledge, as its interests are not tied to those of dominant ideologies. According to feminist standpoint scholars, drawing on the experiences of marginalized lives decreases the distortions provided by conventional research (Collins, 1986; Harding, 2004; Wylie, 2003). Research following FST, like mine, therefore starts from the experiences and cognitive frameworks of marginalized people.

A root argument of FST maintains that those socially marginalized and oppressed by unjust social systems, have a capacity to notice and understand things about those systems that people occupying privileged positions do not (or are invested in not knowing) (Wylie, 2003). Such an epistemic advantage is an oppositional consciousness (Collins, 1986) – marginalized people are outsiders to dominant societal institutions and conceptual schemes and correspondingly possess significant knowledge about them. This insight or knowledge is not generic or inborn but is achieved by coming up against and experiencing oppressive structures and relations (Elliott, 1994). It arises from the experience of mediating between two worlds: the lived experiences of oppression and the dominant worldview by which the oppression is accomplished (Harding, 2001; Sweet, 2023). To reiterate, in addition to their own cognitive frameworks – grounded in their lived experiences of navigating oppression and unjust systems – marginalized people can also be attuned to the distorted interpretation of reality upheld by those in power, which maintains and reinforces oppressive social dynamics. Because of this, knowledge derived from marginalized groups should be placed at the centre of research that aims to contribute to knowledge about power relations and social power structures (Collins, 1986; Harding, 2004; Wood, 2005; Wylie, 2003).

Several feminists have shed light on the procedures by which epistemic advantage is created. Dorothy Smith's (2004) term 'bifurcated consciousness' signals the rupture between 1) the dominant culture, which is the subject of social research, and 2) women's daily life experiences. Another important term is Patricia Hill Collin's (1986) 'outsider within', with which she describes black women's experiences working in white homes and their intricate understandings of the workings of racism. A more recent term, and relevant to my research, is Sara Ahmed's 'institutional plumbers' (Ahmed, 2012) which is how she describes diversity workers, and later, those who submit complaints within academic institutions (Ahmed, 2021). Institutional plumbers are those in marginalized positions in society (or within institutions) who, by coming up against systems and institutions, have become experts in their blockages and inner workings. This term proved important in the analysis for my second article, corresponding well to the experiences of people working within DPOs during the pandemic.

The objects of feminist standpoint inquiry are the covert yet omnipresent oppressive social power relations that affect people's experiences in everyday life (Rolin, 2009; Smith, 2005). While not necessarily explicitly linked to oppression, these power relations serve as instruments or mechanisms of domination and limit the choices available to individuals or groups (Rolin, 2009). They both facilitate social action and limit it; they coordinate and organize individuals in their daily lives. Furthermore, as they are deeply rooted in the dominant rationality and mindset, power relations are vested and routinized through, for example, traditions and bureaucratic action (Smith, 2005). They are ubiquitous and thus challenging to investigate. The way in which power relations manoeuvre suppresses and distorts evidence that opposes them (Rolin, 2009). As power is intrinsically tied with knowledge creation, oppressive power relations can facilitate epistemic injustices where the credibility afforded to speakers is clouded by prejudice and discrimination. People oppressed by such power relations may, therefore, be wronged in their capacity to be seen and understood as subjects of knowledge (Fricker, 2007). This is why centring marginalized experiences in social inquiry is imperative, as it is through their exertion and endeavours battling these 'ruling relations' (Smith, 2005) that marginalized individuals have gained valuable insight into them. As Rolin (2009, p. 219) explains: "Feminist standpoint theory outlines a method for producing scientific knowledge under social circumstances that, given all other conditions, undermine attempts to generate evidence".

In addition to providing insightful analytical tools, FST has important methodological implications for a project like mine. Arguing for the re-conceptualizing of "science as usual", FST raises fundamental challenges to conventional methodological practices and knowledge production, as I describe above. It calls for more inclusive research, increased self-reflexivity, and explicit attention to the responsibility of the researcher in the process of knowledge production (Gurung, 2020; Mulinari & Sandell, 1999; Smith, 2005). In Chapter 1, I discussed briefly what this means for my research and how I navigated these issues. They are further elaborated in Chapter 4.

2.1.1 Institutional mechanisms as manifestations of power relations

Standpoint theorists have contributed importantly to knowledge about the workings of covert yet pervasive oppressive social power relations and *how* they affect people's lives (Collins, 2017; Rolin, 2009; Smith, 2005). By delving into the experiences of diversity workers (Ahmed, 2012) and individuals filing complaints in universities (Ahmed, 2021), Ahmed has provided meaningful, inventive terms and analytical tools that shed light on how informal institutional mechanics, infused by oppressive power relations, can strategically manifest in blockages and barriers, undermining institutional commitments to justice and diversity. Ahmed's assertion (2019, p. 212), "Blockages can be how the system is working. The system is working by stopping those who are trying to transform the system" underscores the infiltration of oppressive power relations into institutional reasoning and norms, strategically perpetuating the status quo by privileging certain elements while silencing others and impeding change. Rooted in underlying norms and values, practices and mechanisms – which typically contradict an organization's public commitments – become natural to the institutions (Ahmed, 2021). Concepts and phrases such as *strategic inefficiency* and *exhaustion as a management technique* (Ahmed, 2021) contributed particularly to the analysis of my second article, which focused on institutional practices that affected consultation processes during the pandemic.

Other important power relations infusing the institutional tactics within the scope of my third article are neoliberalism and its practices of governance. Understanding of the term neoliberalism is shifting, but following Brown (2015), in this PhD project it is understood as an economic policy, a modality of governance and a system of normative reasoning. Rooted in the principle of affirming free markets, neoliberalism's overall aim is to reduce the government's role through deregulation, marketization, and privatization of public goods. Neoliberal goals also include reductions in welfare state provisions and social protection and the end of wealth redistribution as an economic or social policy (Brown, 2015; MacLeavy, 2016). As normative reasoning, neoliberalism has become deeply entrenched in both cognitive frameworks and institutional practices and mechanisms (Brown, 2015; Hayes, 2018) having extensive effects on political reasoning. Furthermore, marketization processes have gradually introduced market-like mechanisms into public sector care provisions, such as the purchaser—provider model and the outsourcing of services (Vaittinen et al., 2018). In Article III, we explore how the adoption of such private sector—inspired management practices in public services has influenced the way PA services are implemented in Iceland, in stark contrast to the social context and human rights understanding in which the services for disabled people are embedded.

2.2 Critical disability studies

Like other critical social research (Eakin et al., 1996; Harvey, 2022), CDS engages critically with traditional knowledge creation and the power dynamics that facilitate it. CDS scholars recognize the ways in which methodological practices within traditional research have historically legitimized ableist beliefs and call for a radical remodelling of research conventions and reflexive questioning of implicit assumptions. Importantly, CDC's critique of traditional research practices calls for meticulous attention to power—dynamics in research methodology (Minich, 2016) which influenced and guided my research practices throughout the project. CDS holds disabled people to be credible witnesses for their own experiences and establish disability and disabled people as the driving subjects of disability research — not its passive objects (Goodley et al., 2017; Shildrick, 2019a). Like those engaged in other critical social research, CDS scholars embrace emancipatory goals and their political and activist associations (Burghardt, 2011; Goodley et al., 2019; Meekosha & Shuttleworth, 2009; Shildrick, 2019a).

At its core, CDS is a theoretical framework which understands disability as intertwined in oppressive power relations that facilitate discrimination against and exclusion of disabled people in society (Meekosha & Shuttleworth, 2009). It engages in critically exploring and problematizing these power relations, scrutinizing the taken-for-granted assumptions and discourses that have traditionally shaped the way disability is understood and represented and the way in which these processes are invested in the construction and maintenance of normative ideas (Shildrick, 2019a). An important feature of CDS is problematizing normative assumptions based on the ubiquitous medical understanding of disability, which underlies much of what is traditionally held as truth regarding disability. The medical paradigm's focus on individuals and its obscuring of the social processes culpable in social inequality have provided fertile soil for stereotypes of passivity and dependence. By disrupting such normative understandings, CDS opens up new and seemingly radical yet self-evident possibilities as a starting point for research, such as the experience of living well with various types of impairments (Goodley et al., 2017; O'Dell et al., 2016; Shildrick, 2019a).

Recognizing the complex and manifold nature of social structures and their intersectionality, CDS encompasses a wide range of focus, drawing from material, discursive, psychological, and cultural understandings, as well as legal and social policies (Shildrick, 2017). It rejects simplistic approaches to identity and understands the non-normative body as an important site where oppressive, dynamic social forces, such as ableism, sexism, racism, classism and heteronormativity, intersect (Shildrick, 2019a). By drawing on other critical perspectives such as feminist, critical race, queer, and poststructuralist theories, CDS opens up new avenues for inquiry and facilitates a nuanced understanding of the dynamics of powerful and often intersectional and mutually constitutive oppressive social systems (Goodley et al., 2017; Shildrick, 2019a).

CDS is an important pillar of my project. It aligns with and strengthens the structural scrutiny of my project by placing the onus of change on biased and ableist policy, social processes and institutions (Goodley et al., 2019; Hosking, 2008; Meekosha & Shuttleworth, 2009). Its central concept, ableism, is an important analytical tool throughout my research project. Ableism is a central concept in CDS and refers to the oppressive social ideology that underscores and justifies the systemic discrimination and exclusion of disabled people. As with other oppressive dynamics, such as sexism and racism, ableism is covert and saturates society, its institutions and everyday life (Bogart & Dunn, 2019). Talila A. Lewis (2022), an abolitionist community lawyer and organizer engaged in social justice efforts, has developed the following understanding of ableism:

> A system of assigning value on people's bodies and minds based on societally constructed ideas of normalcy, productivity, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism and capitalism. This systemic oppression leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth and/or their ability to satisfactorily re/produce, "excel" and "behave".

Ableism is underpinned by the assumption that certain bodies (non-disabled bodies) are the unequivocal norm. Such compulsory able-bodiedness and the privileging of able-bodied knowledge renders disability abnormal and undesirable, dehumanized, and othered. Because of its omnipresent nature, ableist acts can be unintentional, as the people who commit them do so while unaware of their impact or harm (Dunn, 2019). It legitimates policies and institutional practices that segregate and exclude, and it validates inaccessible infrastructure – built to fail disabled people (Bogart & Dunn, 2019). Ableist assumptions also entail an epistemic injustice (Fricker, 2007), as they result in disregard of the knowledge that disabled people bring to the table, thus impoverishing everyone and perpetuating disabled people's marginal position. This is, for example, the case with disaster and risk management, where disabled people are at disproportionate risk, and barred from participation and consultation (King et al., 2019).

The relatively recent conceptualization of ableism and its widespread use has facilitated insightful and novel conceptions explicating the various manifestations of the oppressive power relations that prioritize able-bodied people. In my fourth article, we used the concept of "data ableism" (Charitsis & Lehtiniemi, 2023), which sheds light on the inherent ableist tendencies that exist in technology and technological advances. Specifically, data ableism refers to the way in which data-related politics, processes, and practices are grounded in normative frames of reference. Centring on non-disabled experiences, technological development and design are imbued with and maintain ableist power dynamics, rendering technology yet another social sphere that disables groups of people that don't conform to normative standards (Charitsis & Lehtiniemi, 2023). Another distinct yet related term is technoableism, coined by Ashley Shew (2023). Facilitated by individualism and market ideologies, technoableism renders the "problem of disability" as one of individuals, that should be addressed with market solutions, hence obscuring ubiquitous oppressive social dynamics and processes of injustice. In Shew's words: "Technoableism is a belief in the power of technology that considers the elimination of disability a good thing, something we should strive for" (2023, p. 12). Together, data ableism (Charitsis & Lehtiniemi, 2023) and technoableism (Shew, 2023) proved insightful analytical tools for Article IV, which focuses a critical gaze on the oppressive power relations infusing technology and hindering participants' digital use.

2.2.1 Neoliberal-ableism

CDS involve a critique of the political and economic factors that shape the experiences of disabled people, including neoliberal politics and globalization (Goodley et al., 2017). A pertinent concept for Article III in my dissertation is "neoliberal-ableism," as articulated by Goodley and Lawthom (2019). It underscores the significance of neoliberal politics in disabled people's lives and the centrality of able-bodiedness in the core message of neoliberalism. Privileging able-bodiedness and mindedness, neoliberal politics render disabled people collateral damage and "justifiably excluded because they simply cannot survive the demands of everyday living" (Goodley & Lawthom, 2019 p. 247). Neoliberal governance tactics mystify power and politics by constructing issues in terms of "efficiency" and "efficacy" (Brown, 2015). As a consequence, fundamental societal values, such as those pertaining to welfare, become divorced from their context and social justice history (Hoppania, 2019). This conceals social injustices and exclusions, and as a result, ableist, sexist, and racist connotations of the neoliberal imaginaries go unaddressed – as does the issue of interdependency and the fact that "freedom" relies on social solidarity because all people depend on social support to some extent.

Important also is the way in which neoliberalism fuels a strong moral discourse. As an emphasis on independence and self-containment has infiltrated normative reasoning, ableism has become integral to ubiquitous ideas of what constitutes meaningful contributions of citizens (Edmiston et al., 2017). Championing self-reliance and individualism, neoliberal- ableism shifts attitudes towards welfare systems and welfare goals and subsequently undermines them (Brown, 2015; Grover & Soldatic, 2013; MacLeavy, 2016). It criticizes those who need support from welfare systems and also the welfare systems themselves for facilitating dependency (MacLeavy, 2016). Having taken root in ubiquitous ideology, neoliberal-ableism has had devastating consequences for disabled people's lives. As, Shildrick notes: "We are all embroiled in the deadly politics of neoliberalism and need to keep chipping away at its claims and interrogating its effects, remembering always that it negatively impacts certain groups more than others" (Shildrick, 2019b, p. 596).

2.3 Invisible work

Feminist theorizing has problematized how common conceptualizations of work devalue and overlook women's work, both that which takes place at the end of the workday in the domestic sphere – women's "double day" or "second shift" – (Hochschild, 1989) and that which takes place in the work sphere (Acker, 1990). The pervasive devaluing of women's contributions is understood as being perpetuated by abstracted and inherently gendered notions, how the embodied nature of work is obscured, and the way in which women and their work are assigned to the "private sphere" of the home (Acker, 1990; Daniels, 1987). Important feminist research has focused on "making the work visible", drawing forth and highlighting the way in which power relations have framed, organized, and rendered women's contributions invisible (Craig, 2007; DeVault, 2014; Oakley, 1985). The significance attributed to work is deeply influenced by capitalist ideology, which has always been sustained by unpaid and invisible work (Smith, 2003). In fact, it is in the interest of the capitalist economy to organize itself in ways to increase the sphere of unpaid and invisible labour. Citing Glazer (1993), Smith (2003) explains how our social world is reorganizing by increasingly shifting tasks from paid to unpaid labour – as a strategy of efficiency. Jobs such as bank tellers and store clerks, traditionally held by women, have gradually been reassigned to other women as unpaid domestic work. Importantly, similar efficiency-driven responsibilization strategies could be gleaned in the analysis for Article III of my thesis.

Arlene Kaplan Daniel's (1987) conceptualization of "invisible work" provides an important contribution to theorizing about the unequal value assigned to work and brings to the fore the social processes that facilitate such power dynamics. She argues that certain work "disappears" from observations as gendered significance is attributed to tasks which are then expected to become the responsibility of women. Tasks related to nurturing, care, and comforting – attributed to "feminine proclivities" – are those that particularly lack validation. She further explains how the perpetuation of invisible work is intricately intertwined with "emotion work" (Hochschild, 1979), as women are expected to take responsibility for the comfort and well-being of others and adapt their demeanour accordingly. Hence, people tasked with carrying out invisible work, as well as the burden of emotional work, often find themselves compelled to conceal the exhaustive efforts associated with it to evade judgement. This is, however, an important element that facilitates the devaluing and invisibility of the work; as Harding (2001, p. 150) explains, "the more successfully women perform 'women's work', the more invisible it becomes to men".

Hatton (2017) brings clarity to the term for research purposes and defines invisible work as "labour that is economically devalued through cultural, legal and/or spatial dynamics" (p. 345). These dynamics, underpinned by oppressive social relations such as sexism, racism, and ableism serve to obfuscate the work being done and perpetuate its devaluation. Hatton (2017) further delineates three distinct dimensions (cultural, legal, and spatial) which intersect and mutually reinforce each other and perpetuate the devaluation of tasks. These conceptual distinctions are relevant to my project, as the theme of invisible work runs consistently through the first three articles of my dissertation. As will be discussed in Chapters 5 and 6, my analysis demonstrates a substantial amount of labour that participants were expected to do – or had to do – which was unrecognized or concealed.

Scandinavian research on disability services has highlighted a consistent "gap between the policy ideals and the practical realities" of disabled people (Tøssebro et al., 2012, p.141). Grue (2023) posits that the dissonance between the support disabled people require and the actual support they receive is perpetuated through the imposition of invisible work. Because support is insufficient, compliance with societal norms and participation in social activities necessitates work from disabled people – which is unrecognized and undervalued. This onus on disabled people, Grue (2023) argues, is, in fact, supported by the CRPD as it limits the requirements of states to that of reasonable accommodation and that which does not involve undue burden for states. This understanding constrains states' responsibilities to accommodations deemed "reasonable", thereby disregarding the accommodations needed for genuine societal participation. This, Grue (2023) warns, is an example of the way in which discourse surrounding rights and inclusion may inadvertently reinforce ableist expectations and is a manifestation of how the invisible work of disabled people perpetuates their marginalization.

If invisible work results from inadequate services, it becomes imperative to thoroughly examine the services and their implementation. Katzman and Kinsella (2018) illustrate how the self-management of PA services encompasses a multitude of administrative responsibilities and supplemental tasks that are overlooked in funding allocation and unacknowledged – rendered invisible. They problematize service providers' cost-saving efforts that reassign administrative tasks and responsibilities from paid service administrators to disabled service users and their support networks without remuneration. The undervaluation of the self-management work, they point out, is partly facilitated by the fact that it mainly occurs in users' homes and involves care work. Furthermore, self-management of PA services entails what Katzman and colleagues (2020) term "relational work," encompassing empathy, reflection, affirmation, and anticipation – all of which demand expertise and time but often go unrecognized, undervalued, and uncompensated. Much like women tasked with emotional work (Hochschild, 1979) Katzman and Kinsella (2018) found that users feel compelled to conceal the worry and efforts related to the administrative work of their PA self-management.

As an analytical tool, invisible work casts important light on the systems and mechanisms by which labour is made invisible and how disadvantage and marginalization are systemically created and perpetuated (Hatton, 2017). It is an insightful concept for exploring patterns of inequality, recognizing the tasks and labour thrust upon people and how that interlocks with oppressive power relations. In the context of my dissertation, it enables a critical analysis of the institutional mechanics that contribute to the responsibilization of disabled people. As Grue (2023) argues, the invisible work of disabled people needs to be acknowledged and deconstructed for the labour to be then shifted onto institutions.

2.4 The CRPD and the human rights approach

The CRPD is an international human rights agreement binding on ratifying states. The Convention's scope is broad as it comprehensively covers human rights, including civil, political, economic, social, and cultural rights, and it is specifically tailored to what is known about the marginalized social reality of disabled people (O'Mahony & Quinn, 2017). The CRPD is grounded in the advocacy of disabled people for equality and social justice and the social model of disability that originated from that struggle (Kayess & French, 2008). It rejects the idea that disability is manifested through an individual's attributes, positing disability instead as a product of societal oppression and disabled people as rights holders entitled to a protection of these rights. Underscoring society's responsibility in the construction of disability, it places the responsibility to prevent disability-based exclusion on signatory states, including through proactive measures. The failure of states to uphold these obligations is considered a breach of human rights (Degener, 2016; Kanter, 2006).

Iceland signed the CRPD in 2007 and ratified it in 2016, marking a significant moment and the Icelandic government's commitment to uphold the Convention and amend existing laws to ensure they align with its aims and goals. Laws pertaining to services for disabled people with long-term support needs *(Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir no. 38/2018*), and the Act on Protection of Rights for Disabled People (*Lög um réttindagæslu fyrir fatlað fólk, no. 88/2011*) are products of this commitment and are intended to align with the rights outlined in the agreement. The Icelandic government is currently in the process of bringing the CRPD into law (Ministry of Social Affairs and the Labour Market, 2024).

Since the adoption of the CRPD in 2006, the human rights approach has increasingly been employed in disability research (Arstein-Kerslake et al., 2020). This is evidenced by the breadth of articles featured in the special collection of the Scandinavian Journal of Disability Research, focusing on disability human rights, in which Article II of this dissertation was published. Such research engages with disability issues through the lens of the CRPD, incorporating the Convention's principles and requirements into its focuses and frameworks. The design and goals of such research foreground disabled people as rights holders oppressed by societal barriers and frame research findings as human rights issues (Arstein-Kerslake et al., 2020). The human rights approach was employed in Article II in conjunction with FST to facilitate a critical analysis of consulting processes during the pandemic. These approaches are aligned in firmly placing the responsibility of disability exclusion on state parties and official institutions and in their championing of the value that marginalized lived experiences bring to knowledge production. This emphasis is central to the Convention's call for DPOs' participation in policymaking (Article 4.3) and is furthermore highlighted in the Committee's guidance, where knowledge claims of disabled people are recognized "because of their lived experience and knowledge of the rights to be implemented" (Committee on the Rights of Persons with Disabilities, 2018, p. 2). Moreover, Article 11 of the Convention acknowledges the specific risk that disabled people face during emergencies and humanitarian crises. It emphasizes the obligation to uphold the human rights of disabled people in such scenarios, such as the obligation to "closely consult with and actively involve" disabled people through their representative organizations (UN, 2006, p. 6). Although the human rights approach is utilized solely in the analytical framework of one article, I reference the CRPD in all but one of the others. Its firm grounding in socio-political history and its emancipatory focus align with the critical and structural focus of my dissertation, acknowledging and emphasizing the responsibility that states bear for the injustices experienced by disabled people, as well as their role in resolving them.

3 The study context

This chapter delineates the current status of services for disabled people in Iceland and the principal developments since decentralization took place in 2011, when services for disabled people were transferred from the state to municipalities. It explores prominent themes in Icelandic research about services. Later subsections discuss the independent living ideology and PA services internationally and, subsequently, the implementation in Iceland. Later sections engage with research about disability issues and disaster, and then more specifically with evidence emerging from the COVID-19 pandemic. The chapter closes with a discussion about the COVID-19 pandemic in Iceland and the limited yet important information available regarding disability issues.

3.1 Disability services in Iceland

Services for disabled people in Iceland were first legislated by the Act on Idiot Asylum, in 1936 [lög um fávitahæli, nr. 18/1936]. Since then, in alignment with the focus in neighbouring countries, the implementation of services has undergone considerable evolution, moving from predominantly institutional provisions to services provided in people's homes, with an emphasis on facilitating independent living (Margeirsdóttir, 2001; Traustadóttir & Egilson, 2024). In line with decentralization trends observed in other Nordic countries (Tøssebro & Wendelborg, 2015), Iceland transferred responsibility for services to disabled people from the state to municipalities in 2011. The legislative and policy framework, however, remained under the central government's jurisdiction. The rationale for the transfer centred on the potential to optimize and simplify the service system, as municipalities could integrate the services with the general welfare services they already provided. The transfer would enhance accessibility to services, improve coordination, reduce overlap of administrative levels' responsibilities, and "ensure good use of funds" (Ministry of Welfare, 2010). Despite general agreement about the benefits of decentralization efforts, significant challenges have emerged, similar to those experienced in other Nordic countries (Brennan et al., 2018; Tøssebro et al., 2012). These challenges exemplify the complications that can arise when different entities assume responsibility for strategic planning and service implementation, resulting in a discrepancy between state policy and practical service delivery. Despite state policy and commitments to international agreements, local authorities have decision-making power regarding the implementation and prioritization of service options (Ehliasson & Markström, 2020). With the responsibility now resting with multiple municipalities, it can prove challenging to ensure that staff and elected representatives are well-informed and abreast of an ever-evolving ideology – which is a prerequisite for implementing the changes prescribed by the CRPD (Tøssebro, 2021). This has indeed been a challenge in Iceland (Jónsson et al., 2022a).

Since decentralization, tensions have sparked between the state and municipalities as the latter have been vocal, criticizing the government for making increasing demands while not providing the financial means to implement changes to services that align with national goals (Snæfríðar-og Gunnarsdóttir & Arnalds, 2016a). It seems there was and persists a radical underestimation of costs necessary to provide support that meets the needs of disabled people and aligns with national policy goals (Traustadóttir & Egilson, 2024). As argued by disability activists (Bjarnadóttir, 2021), the public debate perpetuates a neoliberal-ableist narrative, portraying disabled people as burdens on the welfare system. Such dynamics of blame-shifting and tensions between the state and municipalities following decentralization are not unprecedented and were described over twenty years ago by Andersen (2003) as a "strategic game" involving deflecting responsibility and shifting blame, creating a haven for doing nothing and ultimately leaving underlying issues unresolved. According to Andersen (2003), the tactics employed following decentralization could be interpreted as a method of reducing welfare services without being held accountable for the consequences.

Since the decentralization process, disabled people have voiced strong criticism regarding the problems in service implementation, particularly regarding limited access to services and discrimination based on place of residence (Guðnason, 2019; Þórisdóttir, 2023). Furthermore, due to differences in geography, population, political climate, and financial status among the municipalities providing these services, the quality of municipal services varies significantly (Jónsson et al., 2022a; Ministry of Social Affairs and the Labour Market, 2022).

3.1.1 Prominent themes in Icelandic disability research

Studies conducted prior to the pandemic revealed that the standard of care provided in residential care fell short of human rights regulations (Benjamínsdóttir & Stefánsdóttir, 2022; Jónsdóttir & Egilson, 2013; Stefánsdóttir et al., 2018). While staff members are committed to offering support to residents, they often lack the necessary resources and training, to deliver services that adhere to human rights and welfare policies. Factors such as financial restrictions, staff turnover, and limited professional expertise have significantly impacted service quality and hindered the decision-making and autonomy of disabled residents (Jónsdóttir & Egilson, 2013; Stefánsdóttir et al., 2018).

Icelandic research into people's experiences of disability- and other welfare services has demonstrated recurrent themes, namely that users of such services often find them fragmented, inflexible and lacking. As the support provided does not adequately meet people's needs, users have to rely to a significant extent on the help of family members (Arnalds et al., 2013; Ingólfsdóttir et al., 2018; Snæfríðar-og Gunnarsdóttir et al., 2016; Stefánsdóttir & Egilson, 2016). Furthermore, the scope and quality of services differ between municipalities and seem to depend partly on chance, or the individual professionals or consultants involved (Löve et al., 2018; Snæfríðar- og Gunnarsdóttir et al., 2016; Stefánsdóttir et al., 2022).

Importantly, the issues outlined in this section set the stage for the provision of services and support to disabled people and their families during the pandemic, which is the central focus of Article I. As the article's findings highlight, these critical themes were evident in the participants' experiences and became exacerbated during the pandemic.

3.1.1.1 Lack of accessible information about rights to services

A key theme in the findings of Icelandic research on the experiences of disabled people and their families is the inadequate availability of information about services and people's rights to them. The lack of readily available information appears to persist across various systems and organizations at the state and local levels, which seem to allocate minimal effort to ensure the accessibility of such information (Egilson et al., 2020; Egilson & Stefánsdóttir, 2014; Hjálmtýsdóttir & Ásmundsóttir, 2010; Óladóttir et al., 2024). As a consequence, service users frequently shoulder the burden of locating such information, even though they are unsure of where to seek it and must exert significant effort to retrieve it (Snæfríðar-og Gunnarsdóttir et al., 2016). There is, for example, a general lack of information available in easy-to-understand language and Braille (Jónsson et al., 2022b) as well as in languages other than Icelandic – which is especially concerning given the growing immigrant population and the associated difficulties in assimilating into an unfamiliar system and culture (Skaptadóttir et al., 2020).

Research conducted among individuals who depend on the system for financial assistance, such as rehabilitation or disability pensions, has brought to light the opaqueness, complexity, and unpredictability of the rules governing support services (Tryggvadóttir et al., 2016). The difficulties and lack of clarity in accessing information can lead to individuals not receiving the necessary services or forfeiting their entitlement to support. This predicament engenders significant stress and anxiety for many, potentially exacerbating existing health conditions (Hjálmtýsdóttir & Ásmundsóttir, 2010; Ingólfsdóttir & Sveinsdóttir, 2021; Tryggvadóttir et al., 2016).

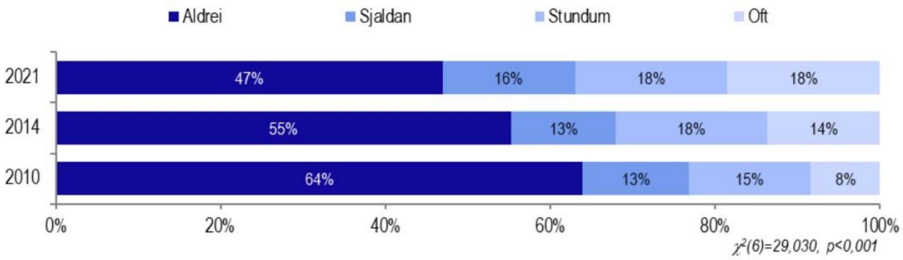
3.1.1.2 Fragmented system and random services

Despite the expectation that decentralization would establish a framework for improved integration and access to services, research consistently demonstrates the inconsistency, disjointedness, and haphazard nature of these services. This theme is commonly observed among research interviewees utilizing both health and social services, who express a sense of being "between systems" or "in a grey area" (Ingólfsdóttir et al., 2018; Snæfríðar-og Gunnarsdóttir et al., 2016; Tryggvadóttir et al., 2016). Similar themes can be found among parents of disabled children highlighting the way in which fragmented and poorly coordinated service systems contribute to the incompatibility of the services to families' daily lives, requiring parents to invest substantial effort in navigating the system and harmonizing the operational approaches of diverse service providers (Egilson, 2015; Ingólfsdóttir, 2023; Ingólfsdóttir et al., 2018). This can be attributed, in part, to the fact that services for disabled people and their families are managed by distinct entities and work units, including local authorities, the state, and non-profit organizations, each operating under different legal frameworks (Ingólfsdóttir, 2023). In response to growing public concern over these issues, a new law called the Act on the Integration of Services in the Interest of Children's Prosperity (No. 86/2021), commonly known as the Prosperity Act, was introduced in 2022 with the principle aim of providing children and families in need access to suitable integrated services without impediment. Recent data demonstrates that a substantial number of parents and guardians perceive that their children would have greatly benefited from receiving support and services at an earlier stage (Jónsson et al., 2022b). It is premature to determine whether and how the current legislation will bring about any changes.

3.1.1.3 Insufficient support and "battling" the system

Another prominent theme in Icelandic research is the lack of adequate support for disabled people and their families. Many face challenges when seeking support and perceive a need to substantiate and defend their eligibility for services. They often encounter scepticism and must expend considerable time and effort justifying their need for assistance (Bjarnason, 2009; Egilson & Stefánsdóttir, 2014). Research findings, both quantitative and qualitative, suggest that users frequently encounter inadequate support for their daily activities, work, or studies. This is exemplified by instances where users are not allocated sufficient funding for their direct payment contracts or are not provided with essential service options. The underlying reasons for this inadequacy may stem from service providers undervaluing support needs or from staffing shortages (Snæfríðar-og Gunnarsdóttir et al., 2016). Consequently, users may have to endure a waiting period for an employee to be found and hired, resulting in a lack of support during this interim period (Jónsson et al., 2022b). In some instances, service providers agree to provide services but place users on a waiting list, citing insufficient funding from the treasury as the reason for the delay (Jónsson, et al., 2022a). Consequently, users are placed in the midst of the "strategic game" (Anderson, 2003) between the state and local authorities.

Over the past decade, several surveys have been administered to disabled municipal service users to evaluate their satisfaction with the provided services. The following image was published in a report by the SSRI (Jónsson et al., 2022b). It compares the results of a survey conducted in 2021 with those from similar surveys conducted in 2010 and 2014 where the same question had been included. The question was as follows: Does lack of support hinder your participation in leisure activities or social life never (aldrei), seldom (sjaldan), sometimes (stundum) or often (oft)?



(Jónsson, et al., 2022b)

The image shows an increase from 23% in 2010 to 36% in 2021 of those who said that a lack of services sometimes or often hindered participation in leisure activities or social life. Those who claimed that lack of support never (aldrei) hindered participation decreased from 64% in 2010 to 47% in 2021. The results suggest a decline in service quality since the decentralization in 2011 – that the service meets users' needs to a lesser extent than they did.

As local government became core providers of disability services, discussions concerning the provision of services have been characterized by a focus on costs, the state's financial contributions, and the financial constraints of municipalities. This trend seemingly mirrors developments in other Nordic countries, signalling either municipal prioritization of issues other than disability services or what Tøssebro (2021, p. 57) describes as "an imbalance between expectations and available resources" limiting what municipalities can actually provide. Either way, it underscores austerity measures that have become evident in the allocation of services to individuals as financial considerations take precedence over the rights and needs of users, leading to inadequate support.

3.1.2 User-directed personal assistance

User-led PA services are rooted in the independent living ideology emerging from disability activism and its resistance to the power that professionals have wielded over disabled people (Mladenov et al., 2023). It proposed a new paradigm, highlighting choice and control as guiding principles. It centred on disabled people as holders of the same human and civil rights as non-disabled people and PA as a means to access those rights (Morris, 1993b). Since the initial conceptualization of the term by the independent living movement, the parameters of what independent living consists of have been constrained (Pearson, 2019). Article 19 of the CRPD (UN, 2006) asserts the right to live independently and to be included in the community. Although neither independent living nor PA is defined in the CRPD, disabled people's rights are further articulated in a general comment provided by the Committee on the Convention (CRPD Committee, General Comment No. 5, 2017) stating that: "The right to live independently and be included in the community can only be realized if all economic, civil, social and cultural rights enshrined in this norm are fulfilled" – implying that while PA can contribute to achieving independent living, the fulfilment of this right necessitates additional efforts from states.

PA and direct payment services have become mainstream service fixtures and have evolved differently, reflecting the varied cultures, service contexts, and economic conditions of the countries where they are implemented (Askheim et al., 2014; Branco et al., 2019; Nally et al., 2021; Pearson, 2019). Research has emphasized the importance of these services, and how implementation can increase the empowerment of users as regards the services and their own lives (Fleming-Castaldy, 2011; Hagglund et al., 2004; Stainton & Boyce, 2004). Due to the flexibility that the services allow, users can better adapt them to their changing service needs, thus ensuring that the resource meets users' needs more effectively (Stainton et al., 2009). Furthermore, users emphasize the significance of having control over the choice in selecting personal assistants (Mladenov, 2020).

The independent living grassroots movement's demand for rights and choice coincided with a powerful top-down emphasis on market model innovations, and so the implementation of the philosophy and PA services has, in many ways, been influenced by market ideology. The politically opposite discourses of market forces and social justice, as Askheim and colleagues explain (2014, p. 4) "found common ground in their demands for a more individual and consumer-friendly provision of services". The adoption of private sector-inspired management practices has influenced how PA services are implemented, in stark contrast to the social context and human rights understanding in which services for disabled people are embedded (Elder-Woodward, 2014; Mladenov et al., 2015; Morris, 2011). One outcome of this is the substantial influence of austerity politics and the utilization of PA to justify the retrenchment of services (Hande et al., 2020; Mladenov et al., 2015; Pearson & Ridley, 2017). The inherent individualization and responsibilization render disabled service users in increased precarity as risk is transferred from the state onto them (Ferguson, 2007). Furthermore, inadequate funding significantly limits the quality of services and the potential for user choice (Berggren et al., 2021; Katzman et al., 2022; Pearson & Ridley, 2017). In fact, in a comprehensive scoping review, Nally et al. (2021) found that no country offering a user-led PA model currently complies with Article 19 of the CRPD, as they all fail to provide adequately funded schemes.

PA service schemes where users oversee management themselves typically provide the highest degree of flexibility and user control. Nevertheless, this necessitates significant work from users, who have to recruit, hire, and train assistants and oversee budget administration and shift scheduling. As Katzman (2018) points out, these administrative and human resource tasks have been understood as users' responsibilities instead of work and have remained largely unacknowledged and uncompensated. Katzman's and Kinsella's discussion about the invisible work required of self-managers of PA services (2018) relates back to section 2.4 of the dissertation about invisible work and is a prominent issue in Article III.

Scholarly criticism has also focused on the broader impact of market forces and individualist political frameworks on the fundamental ideas underpinning welfare services, and collective responsibility and how key ideas of the independent living movement have been "colonized and corrupted" (Morris, 2011). As Mladenov et al (2015, p. 311) argue, efforts to "provide disabled people with greater voice and choice has, at times, appeared to be more of an appropriation of the movement's goals for reasons of political expediency than a sincere attempt to help meet these goals". In Article III of the dissertation, we delve into this important and critical work and examine the impact of market-influenced service adoption for disabled service users during the pandemic.

3.1.2.1 Implementation of user-led personal assistance in Iceland

In Iceland, the introduction of independent living and PA coincided with decentralization efforts. In June 2010, a parliament resolution regarding the implementation of personalized assistance passed unanimously, and shortly thereafter, in 2011, disability service jurisdiction moved from the state to municipalities. The same year, a trial programme was launched, and a few municipalities provided the services to a small number of users on a temporary basis. It wasn't until 2018 that the service form was finally embedded into Icelandic laws, making it mandatory for municipalities to offer it to their disabled citizens (Althingi, 2018). The reasons for this delayed uptake are multifaceted, partially attributable to decentralization and the complexities that arose as policy formulation and service implementation became the remit of distinct entities. Municipalities, which vary considerably in size and financial stability, could now make their own internal rules and assessment criteria for the PA scheme, resulting in a 'postcode lottery' (Snæfríðar- og Gunnarsdóttir et al., 2016). Moreover, although municipalities bear the majority of the costs for personalized assistance, they receive partial reimbursement through the Local Authority Equalization fund. Since decentralization, there have been constant tensions between the municipalities and the state regarding the extent of financial support.

An evaluation of the trial project conducted in 2015 revealed widespread satisfaction with the services as service users gained more control over their assistance and, thus, more independence in their daily lives (Snæfríðar- og Gunnarsdóttir & Arnalds, 2016b). The heightened flexibility afforded users the ability to adapt the support in accordance with their individual preferences and needs, such as increasing support during times of stress or greater need and reducing it during slower times. Interviewees furthermore underscored the importance of being able to select assistants personally. Similar findings were reported by Löve et al. (2018). Austerity politics have seemingly affected the implementation of the service, as well as the tension between the state and local governments. Despite high demand, less than 10% of those using disability services provided by the municipalities receive PA services (Jónsson et al., 2022b).

3.2 Disabled people and disasters

The disproportional risk to disabled people during crises or environmental hazards is recognized by official international entities (United Nations for Disaster Risk Reduction, 2015; WHO, 2013) and notably the CRPD (UN, 2006) Article 11, which specifies the duty of states to ensure the human rights of disabled people and to take "all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk". The precarious position of disabled people in such situations has furthermore been established by researchers (Abbott & Porter, 2013; Alexander, 2015; Görgens & Ziervogel, 2019; Spurway & Griffiths, 2016; Stough & Kelman, 2018).

Priestley and Hemingway (2007) remind us that, much like disability, human disaster — the damage to humans due to environmental or other types of hazards — is socially created and highly dependent on structural inequalities, rendering those marginalized by social injustice disproportionately affected. This has been illustrated in research that has shed light on the increased risk of damage and harm disabled people face in such situations. Research shows that disabled people's rights and needs are frequently overlooked during emergency planning and contingency stages, leading to significant oversights in the implementation of support and response measures (Alexander, 2015; White et al., 2007). As a consequence of faulty planning, emergency responses, general aid, and support provided to and for the public during disasters often do not meet the needs of disabled people. Built primarily to meet the needs of able-bodied individuals, structures such as temporary housing, shelters, and other built environments often prove inaccessible or inadequately equipped for disabled people (Alexander, 2015; King et al., 2019; Rooney & White, 2007). Furthermore, important information about disasters or relief support often fails to reach disabled people or is presented in an inaccessible format (Brittingham & Wachtendorf, 2013; Campbell et al., 2009). As a result of difficulties accessing and making use of disaster recovery services or material resources, disabled people's recovery from disasters is often further complicated (Stough et al., 2015). Despite often being just as, if not more, prepared for evacuation than their non-disabled counterparts, disabled people are more likely to experience fatalities or injuries in the event of disasters (Stough & Kelman, 2018). In the aftermath of a crisis, disabled people remain disproportionately affected, as infrastructure that they often depend more on than non-disabled people, such as social support and transportation, may be down or faulty due to the crisis (King et al., 2019).

Many, if not all, of the aforementioned issues stem from a deprioritization of disability issues and rights and a lack of inclusion of disabled expertise in disaster planning. The importance of involving disabled people in crisis management is recognized and noted in the Sendai framework (2015), an international accord on disaster risk reduction. In it, governments are reminded of the importance of engaging with disabled people and other marginalized groups in the design, planning, and implementation of policies regarding crisis management. The importance of involving and consulting disabled people in disaster planning has also been highlighted by several researchers (Abbott & Porter, 2013; Alexander, 2015; Görgens & Ziervogel, 2019; Pearson & Ridley, 2017). As Abbott and Porter (2013, p. 840) argue "disabled people's intricate, daily negotiations with risk, hazards and barriers make them extremely well placed to be at the heart of such forum". Harnessing disabled expertise for political and legislative actions can facilitate a deeper understanding of the complicated interplay of social and environmental factors that contribute to the heightened precarity of disabled people and would aid the development of effective solutions (Görgens & Ziervogel, 2019). In this regard, the notion of interdependency would particularly benefit and provide nuance to conceptualizations of resilience and vulnerability. For these reasons, Görgens and Ziervogel (2019) maintain that it does not suffice to merely include the voices and experiences of disabled people; they should, in fact, be prioritized and actively centred.

There seems, however, to be a prevailing credibility deficit (Fricker, 2007) and a systemic failure to recognize the value of the insights and knowledge disabled people bring to such work. According to King and colleagues, (2019) the lack of inclusion stems from deep-seated ableist societal attitudes and discrimination, which actively hinder disabled people's participation in disaster planning and management. The ableist assumptions underpinning the neglect of disabled knowledge impoverish everyone and perpetuate disabled people's marginal position and disproportionate risk in crisis events (Abbott & Porter, 2013). In Article II of this dissertation, I discuss the consultation that took place between DPOs and official entities in Iceland during the pandemic – or lack thereof.

3.2.1 COVID-19

International evidence emerging from the COVID-19 pandemic demonstrates that despite pressure from DPOs, researchers, and official entities (Brennan et al., 2020; Inclusion London, 2021; Lisney et al., 2020), disability issues remained systematically de-prioritized (Kubenz & Kiwan, 2022). Since the onset of the pandemic, research has highlighted the disparate and complicated effects of the COVID-19 virus and the social disruption of the pandemic on disabled people. A scoping review of the literature by

Jesus and colleagues (2021) about lockdown disparities in the first wave of the pandemic rendered two central themes as contributing to the problems faced by disabled people: the absence of disability-inclusive response and emergency preparedness and pre-pandemic structural disparities. Their findings furthermore outline the significant problems disabled people and their families faced during the pandemic, which included disrupted access to healthcare, increased social isolation, the disruption of important services, issues pertaining to the digital divide, and disabled children being disproportionately affected by school closures (Jesus et al., 2021). Findings from a survey sent out in the first months of the pandemic by Brennan and colleagues (2020), which reached disabled people in 134 countries, provided other important insights into the wide range of issues disabled people faced. They report on governments' failures to protect disabled people living in institutions, breakdowns of essential services, and the lack of accessible information about the pandemic. In the articles of my dissertation, I address some of these issues, including those related to service disruption, the prevailing digital divide, and inadequate support for the education of disabled children.

In the beginning of the pandemic, international institutions seemingly foresaw governmental responses (and inherent systemic ableism) and promptly dispersed policy briefs and official statements reminding states of their obligations to protect disabled people's rights. In a policy brief issued in May, the UN (2020) warned of the deepening of pre-existing inequalities in the pandemic and called on governments and institutions to provide a disability-inclusive response and recovery by utilizing both targeted measures and the mainstreaming of disability issues in all plans and efforts. On a similar note, the United Nations Human Rights Office of the High Commissioner (2020) alerted states to the disproportionate risk to disabled people in the pandemic and the impending impact it could have on their rights. They urged states to undertake several key actions, such as prohibiting the denial of treatment on the basis of disability, ensuring that information about the pandemic prove accessible, and seeing to it that support persons of disabled people be exempted from restrictions so support could be provided. Many heeded warnings of ableist values guiding health rationing of resources and care early in the pandemic (Houtrow et al., 2020; Scully, 2020), urging health professionals to employ anti-discriminatory approaches and disability ethics in triage protocols (Singh, 2020). Others pointed out how language in public health communication was indicative of oppressive biopolitics and thanatopolitics, perpetuating ablest ideas about disabled lives being less valuable (Abrams & Abbott, 2020; Goggin & Ellis, 2020). Despite this, the measures implemented to combat the pandemic heightened the risk for disabled people (Mladenov & Brennan, 2021). Research and grey literature have highlighted the various ways in which this manifested. Disabled people lost access to important services due to the fact that important support or disability services were classified as nonessential (Brennan et al., 2020; McKinney et al., 2021). Their access to healthcare, such as regular treatments and rehabilitation, was hindered (Brennan et al., 2020; Jesus et al., 2021). The lockdowns of the pandemic caused isolation and loneliness among disabled people (Dickinson et al., 2023; Kavanagh et al., 2022), furthered the economic hardships of many people, and increased employment precariousness (Brown & Ciciurkaite, 2023; Cobley, 2024). Some people were trapped and abandoned without support and necessities (Brennan et al., 2020).

Governmental inaction, health care rationing, and limited access to care and treatment underscored systemic ableist conceptions. As Kamran Mallick, CEO of Disability Rights UK explained (2023), "We found ourselves dismissed and patronized as 'vulnerable', we were last in the queue for health care, our social care was removed or reduced, our rights were restricted, and our reasonable adjustments denied". News of resource shortages, limited hospital beds, and triage protocols for allocations of critical care elicited fears in disabled people who foresaw discriminatory practices and compromised access to health resources (Liddiard et al., 2022). Parents feared that protocols for ventilator allocation and health practitioners' value judgements when allocating services would reflect ableist views and pose a threat to their children (Houtrow et al., 2020). Similar fears were reported by Icelandic participants in Article I of this dissertation.

Paulauskaite and colleagues (2021) reported on the difficulties parents of disabled children had in maintaining the support that their children needed during the pandemic. Approximately three out of every four participants described an abrupt disruption to their access to adequate healthcare support, and 90.9% reported a disruption in the child's education. Disruptions in inclusive practices in education also proved to be barriers as education moved online or into the home (Dickinson et al., 2023; Sims, 2021). Indeed, the pandemic introduced much change to the daily lives of people, and with social distancing and lockdowns, communication, work, and education became increasingly dependent on technology and online participation. Digital technologies were proposed as a solution to mitigate the pandemic's negative impacts on daily life, benefiting health and well-being while keeping with social distancing rules. Normalization of the use of technology brought hope of more inclusivity. In fact, some technical options that disabled people had long called for quickly became accepted and widely used (Goggin & Ellis, 2020; Hankerson & Brown, 2020). Although this opened new possibilities for many disabled people, the shift to digital options served to complicate the lives of others (Hannam-Swain & Bailey, 2021) and exacerbate existing structural disparities and digital divisions between disabled and non-disabled people (Cho & Kim 2022; Hankerson & Brown 2021; Scanlan 2022). This issue, and in particular its implications for people with intellectual disabilities in Iceland, was discussed in Article IV of the thesis.

In a policy brief in 2020, the UN urged governments to ensure meaningful and active consultation with disabled people through their representative organizations in all response and recovery stages. Research and grey literature, however, show that DPOs were involved in consultation processes to a limited degree (Cobley, 2024; Mladenov & Brennan, 2021), although their participation increased in later stages at the behest of DPOs themselves (Uldry & Leenknecht, 2021). They further demonstrate that DPOs and community-led initiates played a crucial role in advocating for and securing disabled people's rights during the COVID-19 pandemic. The valuable efforts of DPOs and community-led initiatives often served as the most meaningful and, in some cases, only source of assistance as state responses were insufficient (Cobley, 2024; Mladenov & Brennan, 2021b; Uldry & Leenknecht, 2021). This was also the case in Iceland, as discussed in the findings in Article II of the dissertation.

Research findings unequivocally demonstrate a systemic failure of governments in safeguarding the lives and rights of disabled people in the pandemic. By disregarding the needs and rights of disabled people, ableist societal structures, policy responses and measures to counteract the spread of the virus in many ways proved to be more harmful than the pandemic itself (Jesus et al., 2021; Mladenov & Brennan, 2021). In their systematic review of empirical and grey literature emerging in the first ten months of the pandemic Kubenz and Kiwan (2022) emphasize that recommendations and lessons learned from previous disasters had clearly not been integrated into crisis response or emergency management. They contend that, in light of that and the admonitions heeded, oversight of disabled people's rights during the pandemic should be framed in terms of active exclusion rather than passive neglect.

3.2.2 COVID-19 in Iceland

Compared to many European countries, pandemic responses in Iceland included relatively mild restrictions. Measures focused heavily on strict border controls, contact tracing, and screening measures. Although there were no national lockdowns there were intermittent bans on gatherings that took a considerable toll on infrastructure. The first such ban took place in March 2020 (Ólafsson, 2021). Iceland lifted all national COVID-19-related restrictions in February 2022 (Guðnason, 2022).

Although little Icelandic research exists about the effects of the pandemic on disabled people and their families, news reporting during the pandemic gives some insight into issues and complications disabled people encountered. Importantly, the advocacy and vocal criticisms of DPOs and disability activists during this time inspired my research project and influenced the lines of inquiry chosen in the project. In the early months of the pandemic, DPOs criticized decisions to close disability service facilities and schools for disabled children, advocating instead the use of preventative efforts that had been adopted generally in schools, such as shortening school days and compartmentalizing school premises. They urged officials to ensure that disabled children and their families had the support they needed (Friðjónsdóttir, 2020; Öryrkjabandalagið, 2020). A disability activist, Steinunn Ása Þorvaldsdóttir, criticized the fact that people with intellectual disabilities were not prioritized in vaccinations. She furthermore pointed out that due to the digital acceleration taking place – namely the recent uptake of electronic IDs – many disabled people's access to vaccination and health-related information was hindered (Fréttablaðið, 2021, p.4). An interview in the early months of the pandemic with Freyja Haraldsdóttir, a disability activist, provides an important insight into emerging problems for disabled people and their families (Beck, 2020). Freyja explained how information about the pandemic for disabled people was inaccessible, inadequate, and centred on residential settings, overlooking those who received assistance at home such as users of PA services. She discussed the general lack of consultation with DPOs on matters such as disaster planning, management, and implementation and noted that disabled people have important insights and valuable knowledge that could prove useful to such work. In the interview, Freyja argued that the general neglect of disability issues reflects how those in official institutions did not view it as their responsibility to address the needs and rights of disabled people: "You can see that those responsible for the public are not necessarily those responsible for us, so our organizations need to react, which is of great concern" (Beck, 2020).

The issues emphasized by Icelandic DPOs and disability activists became integral to my research project. Grounded in these critical insights and those of participants, my dissertation positions the pandemic as a catalyst of sorts that provided an important opportunity to scrutinize ableist social structures under duress and to what extent disability rights and needs had been taken up as priorities within the institutions tasked with responding to the pandemic.

4 Study design and methodology

This chapter discusses the methodology and methods employed in the project. Capitalizing on the flexibility qualitative research projects provide and their element of craft (Taylor & Bogdan, 1998), I opted for a flexible research design which will be described throughout the chapter. At the start of the project, research aims were clear. In line with those objectives, I developed an initial draft of the research questions aimed at structural oppression and ableism, rooted in the theoretical underpinnings. The research questions evolved throughout the research process, and in the next subsection, I return to them and discuss how I went about answering them. The chapter then delineates how the research evolved, resulting in four distinct lines of inquiry and the four academic articles of this dissertation. The chapter ends with a discussion about ethical issues and the project's strengths and limitations.

4.1 Aims and research questions

The purpose of the study was to explore how oppressive power structures impacted the lives and experiences of disabled people and the parents of disabled children during the pandemic and imposed increased burdens on them. Furthermore, to inquire how disability issues and rights were addressed, prioritized, and integrated within service structures and other official institutions. The theoretical lenses described in Chapter 2 provided the cornerstones of my project and coordinated it as a whole, including, importantly, the research questions posed and the methods employed to answer them. As is the nature of research questions, mine developed throughout the project, starting broader and gradually refining as my understanding of the issues at the heart of the research gained a clearer focus (Agee, 2009). Initial questions, while at first unfocused, were inspired by my theoretical framework and centred ableist power relations. They ultimately proved a fertile starting point and instrumental in helping me find and maintain focus in my analysis and data generating. It wasn't until the editing phase of Article II that I realized the significance of invisible work as a key theme in my project and constructed the fourth question.

The research questions in the project were as follows:

1. What are the main issues reported by disabled people and parents of disabled children during the COVID-19 pandemic?
2. How did structural factors interact to impact the experiences of disabled people during the pandemic?

3. How and to what extent were factors important to disabled people and their organizations addressed and acted on within service structures and other official institutions during the pandemic?
4. How did structural processes presuppose and sustain the need for disabled people's invisible work during the pandemic?

Table 1 presents an overview of how each article contributed to addressing the four research questions.

Table 1. Overview of papers within the overall project

	Paper I. Risky obliviousness within fragmented services: Experiences of families with disabled children during the COVID-19 pandemic	**Paper II. Rights in Crisis: Lived Experience as knowledge in policy development during the COVID-19 pandemic**	**Paper III. "I think they consider themselves free from all responsibility"**	**Paper IV. Digital Exclusion of People with intellectual disabilities during the COVID-19 Pandemic**
Topic	Focuses on the experiences of parents with disabled children and critical issues raised by them concerning support during the pandemic.	Examines concerns presented by representatives of disabled people regarding the capacity of Icelandic DPOs to effectively participate in policymaking during the pandemic.	Explores how disabled people with PA services fared in the pandemic and addresses critical issues raised by them.	Addresses factors contributing to the digital exclusion of individuals with intellectual disabilities during the pandemic.
Data	Eight interviews with parents of seven children.	18 interviews with 15 participants	Eight interviews with eight individuals and seven interviews with parents of three children	Survey data from SSRI and three focus groups with 16 participants
Theoretical perspectives	Standpoint feminist theory and Critical disability studies	Standpoint feminist theory and Human Rights Approach	Standpoint feminist theory and Critical disability studies	Critical disability studies and Data Feminism
Research questions	1, 2, 3, 4	1, 3, 4	1, 2, 4	1, 2
Findings	The pandemic and measures taken by municipalities and healthcare services exacerbated the already precarious situation of participants. Preventive measures centred on non-disabled experiences and needs. Unprepared service systems distanced themselves from the families.	Institutions tasked with responding to the pandemic failed to recognize the value of DPOs' expertise and to collaborate with them effectively. Institutional practices that impeded consultation indicate non-performative commitments to consultation.	The implementation of self-managed personal assistance services in Iceland has been influenced by neoliberal market ideology and austerity, which played a part in exacerbating the precarity of disabled service users during the pandemic.	During the pandemic, people with ID living in residential care had less contact with friends and families via digital technology. Barriers to digital access and use for the group included paternalistic attitudes, insufficient support, limited access to education, and a lack of inclusive technological design.

4.2 Critical qualitative lens

It is important that methodological practices are aligned with the theoretical framework and conceptual assumptions underpinning research projects. FST is in some ways distinct from other theoretical frames in that it can be understood as an epistemology, a methodology, and a method of research "appearing to conflate or even confuse fields standardly kept distinct" (Harding, 2004, p. 2). In my study, this was indeed the case. FST and CDS informed the epistemological underpinnings of the project, the focus of the project's overall analytical gaze, and the methods employed – such as decisions pertaining to data generation. They informed the data analysis and interpretation, contributing to the achievement of research aims, facilitating the insights to address the research questions. Corresponding to FST, participants in my study were held as subjects of knowledge and their experiences were placed at the centre of the project (Harding, 2004).

The PhD project employs reflexive thematic analysis (TA) (Braun & Clarke, 2021). Embodying the principles of qualitative research and centring researcher reflexivity, TA aligned well with the context and purpose of my research. Its core assumptions highlight the subjective and situated researcher who engages in knowledge generation through interpretive analysis – not a quest for objective scientific truths. As Clarke and Braun (2019) argue, fully incorporating qualitative sensibilities in the methodology and framing of the research as well as engaging in reflexivity, are important — not only with regard to research quality but also the underlying feminist goals to produce emancipatory knowledge. This is in line with FST's and CDS's critical approach to knowledge creation and call to researchers to reflect on and engage with pointed and important questions such as those regarding their own complicity in sustaining oppressive power dynamics and the ethical ramifications of adhering to traditional research processes (Goodley et al., 2019; Gurung, 2020; Harding, 2001; Minich, 2016). Importantly, reflexivity is not done after-the-fact or once-and-for-all but is an ongoing process of engaging in self-awareness (Finlay, 2002). Throughout this chapter, I aim to clarify my presence as the researcher; my decisions and actions, and the way in which they informed the project.

4.3 Methodology and implementation

My involvement with the topic began prior to my decision to pursue a doctoral degree, during my tenure at the SSRI. At the onset of the pandemic, I was in the middle of collecting data for a project contracted by the Ministry of Social Affairs and Labour (Jónsson, et al., 2022a). The project involved conducting interviews with parents of disabled children to gain insight into their experiences with the services they received. This was not my first project of this kind, and the emerging themes were consistent with the findings of previous reports and other Icelandic research (Snæfríðar- og Gunnarsdóttir et al., 2016; Snæfríðar- og Gunnarsdóttir & Arnalds, 2016). Specifically, the services provided were often inadequate and service entities did not work together cohesively, requiring parents to exert significant time and effort to make everything work out. As the pandemic started spreading, the virus and the complications it caused became prominent themes in the interviews. The inadequacies in the service system prior to the pandemic became more pronounced, the gaps in the services exacerbated and this intensified the workload and anxiety experienced by the parents. What also became evident in the interviews was the keen and critical understanding parents had of these system weaknesses and flaws, they anticipated issues and foresaw problems before they arose. Having become familiar with the workings of the poorly coordinated and often uncollaborative services, they drew the ominous conclusion that they were on their own. The last interviews I conducted for the SSRI coincided with the beginning of my PhD project, and I decided that this would be an important place to start and form the basis for my first line of inquiry. The pandemic had made explicit the systemic faults in the service structures that had been discussed by many researchers, and a deeper analysis could potentially provide novel understanding into its workings. When I began my PhD research, I contacted a few parents whom I thought would be interested in participating in interviews about their experiences during the pandemic. Their stories became the foundation of my first article, "Risky Obliviousness within Fragmented Services: Experiences of Families with Disabled Children during the COVID-19 Pandemic".

Through my engagement in disability research for the SSRI I have come to appreciate the importance of engaging with representatives of DPOs. Their direct insights into emerging issues and challenges, gained through close contact with their members and advocacy work, always proved extremely insightful and valuable to my work. Their knowledge about structural problems and barriers faced by disabled people was instrumental in shaping my research approach. Therefore, I made interviewing DPO representatives one of my first priorities for data generation and conducted those interviews simultaneously with those with parents of disabled children for my first article. With this line of inquiry, my objective was to explore what the DPO representatives perceived to be the critical issues in the pandemic and manifestations of structural oppression so as to ensure that those issues be included within the scope of my research. At this time, Dr Laufey E. Löve was also conducting interviews with representatives of DPOs focusing on consultation processes, for a research project called *Disabled people's effective participation in the development of law and policy (2021-2023)* – which coincidentally was one of the topics that the representatives repeatedly brought up during my interviews with them. Given the alignment of our research interests and focus, Laufey and I decided to combine our datasets and collaborate on my second article, "Rights in Crisis: Lived experience as knowledge in Policy development during the COVID-19 pandemic".

Some of the families I interviewed for Article 1 were users of PA services. Their accounts prompted questions regarding the perceived lack of municipal involvement during the pandemic, an issue also underscored by representatives of DPOs in their interviews. Some years earlier I participated in an extensive research project that focused on the implementation of PA services in Iceland (Snæfríðar- og Gunnarsdóttir & Arnalds, 2016b), and the issues raised in the interviews were reminiscent of the cautions and challenges highlighted by contributors in that earlier study. Subsequently, I decided to further explore this topic and generate more interview data with users of PA services. The analysis focused on structural factors that impacted users with PA services during the pandemic such that they called for increased invisible work and further exacerbated the users' precarity. At this stage, I discerned patterns in the analysis that correlated with other research and academic writing about the influence of neoliberalism on welfare services, the responsibilization it fosters and its undermining of values of collectivism (Soldatic, 2019; Hoppania, 2019; Morris, 2011) and more specifically how that relates to PA services (Mladenov et al., 2015; Pearson & Ridley, 2017). This resulted in what became my third article, "'I Think They Consider Themselves Free From All Responsibility': Neoliberal Undermining of Welfare Services and Its Implications for Personal Assistance Users During the Pandemic".

The larger research project, *Disability in the Time of a Pandemic*, afforded me the privilege of being able to participate in academic endeavours led by fellow researchers. In this context, I collaborated with Dr Kristín Björnsdóttir collecting focus group data with people with intellectual disabilities. I felt this to be an important addition to my PhD project, as the other articles had mostly been grounded in the experiences of people with physical impairments; this collaboration provided an opportunity to focus specifically on challenges that people with intellectual disabilities had faced in the pandemic. A project I contributed to during my time at the SSRI about the health and wellbeing of disabled people during COVID-19 had rendered interesting results, namely that people with intellectual disabilities had been less likely to engage in digital technology to communicate with friends and family than people with other impairments. Results furthermore showed that people with intellectual disabilities who lived in residential settings – supposedly providing them with personalized support – engaged in such digital use to a lesser extent than people with intellectual impairments living independently. Dr. Björnsdóttir and I decided to collaborate on a study utilizing the quantitative data and adding focus group data to dive deeper into a field that had not been researched in Iceland. By comparing and contrasting different types of datasets, we aimed to gain insight into the structural factors that impeded people with intellectual disabilities' use of information and communication technology during the pandemic. This became the fourth article in my thesis, "Digital exclusion of people with intellectual disabilities in the COVID-19 pandemic." My contribution to the project involved collaborating on the conceptualization of the article, participating in qualitative and quantitative analyses, and taking an active part in the writing and editing.

4.3.1 Qualitative interviews

In-depth qualitative interviews have maintained their significance as an important methodological approach in feminist research, despite the evolving landscape of research methodologies and approaches embraced by feminist scholarship over time (Doucet & Mauthner, 2008). In my PhD project, data for the first three articles were generated through semi-structured, in-depth interviews, as they provide means for acquiring the thorough, close-to-the-ground, and detailed information necessary to delineate the systemic yet covert ways oppressive power relations operate (Smith, 2005).

Through my previous work in disability research, I cultivated valuable contacts who acted as facilitators in identifying potential study participants and disseminated information about the research. These contacts, for example, assisted in recruiting participants for Articles I and III by posting advertisements on Facebook groups dedicated to disabled people and parents of disabled children.

Prior to the interviews, individuals received an introductory letter about the purpose of the research and the voluntary nature of their participation (see appendices A and B). In the letter, it was made clear that they should feel free not to answer any question they were uncomfortable with and that they could withdraw from the study at any point without having to provide any justification. At the beginning of the interviews, this information was reiterated and efforts made to ensure that the participants fully comprehended the nature of their participation, such as by giving participants a chance to ask questions that they had regarding the study.

I used semi-structured interviews, which were anchored in an interview guide (see appendices C, D and E) with predetermined topics yet provided flexibility to follow up on interviewees' answers and new lines of inquiry that came up (Braun & Clarke, 2013). The interview guides furthermore evolved and changed throughout the data generation process as new important issues were identified during the interview phase. Consequently, when conducting interviews for my first and second article, I decided to re-interview participants whom I had talked to earlier in order to follow up on new themes that had not been a part of the initial guide or ask more specifically about aspects that had surfaced in other interviews.

During the interviews, I was mindful of the importance of flexibility and of creating space for explorations of the research topics, as urged by feminist scholars (Devault, 1990). Carving out space and time for participants to be able to link to and expand on accounts rooted in their experiences is particularly important when the aim is to gain insights into lived experiences. Cognizant of this, I tended to minimize the structuredness of the interviews, following to a greater extent the lead of participants (Hesse-Biber, 2007). In the interviews, I strived to establish rapport by carefully listening and showing signs of engagement by probing and using non-verbal cues such as nodding (Hesse-Biber, 2007). Due to the pandemic, most of the interviews were conducted remotely with the help of technology. The use of technology enabled me to reach people in other parts of the country whom I would not have been able to reach otherwise. Establishing rapport with participants can be challenging in remote interviews (Hesse-Biber, 2007). In fact, it sometimes took longer to establish a good flow and ease in conversations in interviews where this technology was used. To remedy this, I took care to create an inviting space and allowed more time for interviews than usual. I also gave the participants the option of longer or follow-up interviews if they felt we had not been able to discuss issues they felt were important. Being knowledgeable about the service systems and the common issues faced by disabled people and their families appeared to facilitate the depth of discussions.

Apart from eight interviews gathered by Dr. Laufey Löve for Article II, all individual interviews in the research project were conducted by me. For Article I I gathered eight interviews, nine for Article II and 15 for Article III.

4.3.2 Qualitative analysis

In the analysis, I employed TA and the six steps it entails (Braun & Clarke, 2021). It provided an important theoretical flexibility which accommodated the critical focus derived from the theoretical framework. For each line of inquiry, I constructed critical questions (preliminary research questions) that were rooted in the theoretical framework provided by FST and CDS and guided the analysis. These critical questions evolved throughout the analysis but retained a focus on oppressive social forces and structures that perpetuate unearned advantages of certain embodied experiences (namely non-disabled experiences) and how they formally and informally shaped the participants' lives and experiences during the pandemic. Examples of critical questions guiding the analysis were: "How did service systems and institutional processes shape the participants' experiences during the pandemic?" (Article I); "What characterizes the mechanisms encountered by participants and that effected the consultation processes in the pandemic?" (Article II); "How were participants' experiences navigating daily life during the pandemic framed or coordinated by power relations?" (Article III); and "What characterized the power relations that framed or hindered participants' digital engagements during the pandemic?" (Article IV).

For each article, I used the six steps of analysis provided by Braun and Clarke (2021). The clear descriptions of the tasks associated with each step provided an important frame and guidance that aided me in the analysis. My analytical endeavours proved not as linear as the steps imply, and oftentimes the steps became integrated (or tangled - which was the case for the analysis of Article III).

In the first phase, I familiarized myself with the datasets (Braun & Clarke, 2021). After transcribing the interviews verbatim, I read and re-read them thoroughly. Using a text-to-speech app, I also listened to a reading of the data, sometimes in their entirety and other times in segments. At this stage, I furthermore wrote down memos, thoughts and reflections, that arose during the reading and flagged portions of the data that stood out to me – such as when I encountered contradictions or interview excerpts I believed to be important.

The second phase consisted of generating initial coding wherein I systematically went through all the data and labelled data excerpts in meaningful ways that described their content. The overall coding was abductive (Alvesson & Skjöldberg, 2018), meaning that it was grounded in and started from the empirical data but drew on the critical scrutiny of the theoretical framework of my overall project. There was a notable evolution in my coding throughout the project, as the coding of the data used in articles I and II was more inductive but in my later articles became more deductive and influenced by the interpretive lens. In this work of coding I used Atlas.ti (Friese, 2019) as it made the oversight of codes more accessible and facilitated their generation by allowing me to modify and develop them more easily. At this stage, I engaged with co-authors of the articles and discussed with them the construction of the initial codes and their relationship to the critical questions at hand. Importantly, this was not to increase coding accuracy or consensus but to gain diverse and deeper insights – and often led to codes being reevaluated or sharpened. As emphasized by Braun and Clarke (2021), coding is interpretative, a process of meaning – making, not truth seeking or discovery.

The third phase of data analysis consisted of theme generation – whereas I scrutinized the codes that had been generated and synthesized and organized them into themes, "defined by meaning unity and conceptual coherence" (Braun and Clarke, 2021, p. 77). Finding a meaning that united codes into themes proved rather straightforward in some cases, but in others – for example, for Article III – theme generation proved arduous. This was, in most part, due to the fact that I was relatively new to the concept of neoliberal reasoning and to scholarly writing about the ways in which it impacts welfare services. During the coding stage, retrenchment practices had become a prominent thread, but it took time – and a lot of reading and familiarization with the issue, to understand and grasp the way in which codes related to each other and could cohere into overarching themes and subthemes. Discussions with my co-authors, particularly Freyja Haraldsdóttir, who is herself a user of PA services, furthermore proved helpful in conceptualizing how the codes could be integrated meaningfully into themes.

In phase 4, the themes were reviewed by revisiting how they were configured with the dataset as a whole. I used software such as MindManager and Miro to visually map out the codes and themes and aid my understanding of the ways in which they related to each other and to the critical questions guiding the analysis. This phase sometimes resulted in a revaluation of themes and clearer definitions of their boundaries. Furthermore, in this step, critical analytical questions at the core of the analysis were often refined. Further refining of themes continued in phase 5 and the final phase, 6, consisted of writing up findings.

During the analytical/meaning-making process, I consistently wrote memos and documented interesting data excerpts, both to promote reflection and thinking about the data and to facilitate a writing flow in English, which is not my native language. Therefore, writing was an ongoing part of the project. As emphasized by Braun and Clarke (2021), I kept a record of my reflections and wrote memos which often engaged in thinking through the ways in which the empirical data could be understood in light of the critical interpretive framework underlying the project.

4.3.3 Quantitative data and analysis

In the fourth article, we utilized quantitative data to supplement our qualitative analysis. The data was derived from a health survey with the objective of gathering important health-related information and monitoring the impact of the COVID-19 pandemic on the health of disabled people in Iceland. The survey was developed from a health questionnaire used in previous research focusing on health and disability (Snæfríðar-og Gunnarsdóttir, 2017), with supplementary questions specifically related to COVID-19. It had furthermore been customized and edited in collaboration with members of the disability movement in Iceland. The SSRI published an extensive report encompassing the findings of the survey (Tryggvadóttir et al., 2022), and exploring those results sparked our interest in delving deeper into the technology-based participation of people with intellectual disabilities. We, therefore, requested access to a specific segment of the dataset with variables regarding type of impairments, a subjective measure of economic strain, living arrangements, and the frequency of communication with friends and family through phone or social media during the pandemic. We used the Chi-square test in Jamovi 2.2.5 to determine whether differences in the frequency of communication with family and friends through technology were statistically significant between people with intellectual impairments and people with different impairments. Furthermore, the Chi-square tests were used to examine whether any differences in the frequency of such communication manifested between disabled people who reported financial difficulties and those who did not. Finally, we examined whether there were differences in technological communication between those living independently and those in residential care.

4.4 Ethical issues

The research proposal of the larger research project, *Disability in the Time of Pandemic*, was reviewed by the Research Ethics Committee for Public Higher Education Institutions (SHV2021–009). Throughout the research process, my supervisors and the doctoral committee provided ethical oversight for my project.

Ethical scrutiny and awareness of power relations inherent in research are particularly important when the focus of research is the experiences of marginalized groups. Throughout my work at the SSRI and previous studies, I gained experience pertaining to the research topic and research ethics that proved useful for my study. My understanding of the service systems facilitated depth in the interviews and analysis and helped me better comprehend the complex situations participants were describing. I, however, remained attentive, aware of the fact that my prior knowledge could potentially lead to preconceived notions. The epistemological underpinnings of my projects locate the expertise with the participants, stemming from their lived experience, and in light of the FST inversion thesis, a natural question follows: Who am I to theorize about the experiences of individuals who have an epistemic advantage over me? Borrowing useful framing from Elliott (1994), I have not experienced on my own skin how ableist oppression *make the familiar strange*. I, indeed, have "the privilege of being shielded from the gory details" of ableism (Elliott, 1994, p. 429). However, standpoint can also be achieved through critical engagement with oppressive ruling relations, and I agree with Shildrick (2019) that due to our complicit nature in the normative paradigms and ableist values we live by and within everyday life, it is researchers like myself, non-disabled, that perhaps have the "weightiest responsibility".

Choosing FST as underpinnings for the study embeds it in a tradition of informed and reflexive self-aware writing. It compels me to elaborate on my position in relation to the power dynamics under investigation. Throughout the study, I remained mindful of power differences between myself, and the participants and the authority imbued in the role of the researcher and aware of the fact that disabled people have felt alienated by disability research (Morris, 1992). There is a long tradition of non-disabled people theorizing and articulating about disabled people's lives and casting themselves as the 'knowers', often maintaining and reinforcing the theoretical paradigms that oppress disabled people (Stone & Priestley, 1996). I have strived to not fall into such ableist academic entrapments by embedding my research within theoretical frameworks that problematize oppressive power relations, understanding the personal experiences of disabled people as a political issue and engaging in a topic that has social justice aims (Morris, 1993a).

Furthermore, ethical justifications for research projects lie in their scientific and social value. It is the ethical duty of researchers to ensure that their research is scientifically rigorous and valuable and that it does not compromise the safety of participants (CIOMS, 2016). Safety and ethical considerations were central to decision-making in the project. I am aware of the potential inconvenience and risks involved in my research as I ask people to critically scrutinize support from institutions that they have to rely on in daily life. Throughout the research, I prioritized trust and security in interactions with participants and have been mindful of power dynamics.

Anonymization and confidentiality are important in all research but can prove a distinct challenge in areas with such a small population as Iceland and thus require specific consideration. As interviews were transcribed, names and identifying information were left out. In many cases, substantial background information and demographics were excluded to ensure the anonymity of participants. I did not use names or pseudonyms in the analysis and published findings to prevent readers from possibly drawing conclusions about participants based on the information in the written findings. Audio files with interviews were destroyed as soon as they had been transcribed.

4.5 Strengths and Weaknesses

The strengths and weaknesses of projects such as mine emanate from decisions made throughout the research process, encompassing both significant methodological considerations as well as seemingly trivial ones. The research takes place within a particular context and at a particular time, and although it provides valuable insight into certain issues, it is limited to that perspective, time, place, and participants. Importantly, generalizability in a probabilistic sense is not a meaningful objective in research such as this one and does not cohere with the epistemological assumptions underlying the PhD project. The relatively small number of participants who took part in each of the four papers poses limitations in the sense that findings are limited to their experiences. In this context, it is important to note that all participants were white, native Icelanders who, for the most part, lived in urban areas. The study, therefore, does not provide insight into the experiences of those who are multiply marginalized by their social locations – such as disabled people of foreign descent.

The decision to focus on critical issues brought forth by disabled people, their families and DPOs meant that the project adopted a broader scope than it otherwise would have. Although I understand this as a strength of the project, it can also be understood as a limitation in the sense that a more focused gaze could have provided a deeper understanding of one specific topic and possibly rendered a deeper analysis – such as an intersectional analysis focusing on the experiences of disabled women especially or people with specific impairments. Such lines of inquiry would be interesting to follow up on in future research.

Despite these limitations, my analysis was able to provide robust critical insights into the experiences of disabled service users during the pandemic. To date, such research in Iceland is scarce, yet important to glean valuable lessons that can be used to improve future disaster management planning and preparation. Iceland is a small country, which enabled important oversight of the issues at hand during the pandemic. The country's small size facilitated, for example, access to nearly all DPOs in the country, providing valuable insights into issues deemed most pressing and critical. Such insights, that challenge the underlying structures that perpetuate ableism and social injustices, are of great importance to projects with emancipatory goals. The thesis also contributes to a growing body of research in the Nordic countries on the impact of neoliberalism on welfare services and, in that regard, has implications for policy and activism aimed at safeguarding social provisions. Theoretically, the research contributes informed insights about feminist disability research, namely the integration of FST and CDS.

5 Summary of the findings

The research progress and findings are showcased in the four peer-reviewed articles of this PhD project. Each article adopts a distinct line of inquiry with the aim of contributing an understanding of the way in which oppressive ableist power relations affected participants during the pandemic. The project's overall findings demonstrate that prior to the pandemic, service structures were fragmented, support to participants inadequate, and their relationship with service providers taut. During the pandemic, these factors compounded and exacerbated the precarity of participants' situations. Furthermore, official institutions proved unprepared. Their measures to counteract the pandemic centred on able-bodied and able-minded experiences which further complicated the situation of disabled people and placed them at risk of service cancelations and isolation. Official responses and the lack of meaningful consultation with DPOs reflected a deprioritization of disability issues. The invisible work imposed on disabled people and their families stood out as an important theme throughout the PhD project. Although identified belatedly in the research process, the term provides an important way to conceptualize the onus placed on participants pre-pandemic and during the pandemic.

Article I, titled "Risky Obliviousness Within Fragmented Services: Experiences of Families With Disabled Children During the COVID-19 Pandemic" was published in the *journal Social Inclusion* in January 2023. Grounded in eight interviews with parents of seven disabled children, it critically examined the challenges confronted by the families during the pandemic and the structural issues that exacerbated their precarious situation. Analysis rendered insights pertaining to research questions about important issues raised by parents of disabled children (research question I), how structural factors impacted their experiences (research question 2) and how these were addressed by official institutions (research question 3). Utilizing the theoretical insights about invisible work furthermore serves to deepen the analysis presented in the article, bringing into focus the way in which official institutions, support entities, and service implementation placed increased onus and responsibility on the parents of disabled children, both before the pandemic and during in.

In line with findings of prior Icelandic research (Ingólfsdóttir et al., 2018; Snæfríðar-og Gunnarsdóttir et al., 2016; Stefánsdóttir & Egilson, 2016), the article found the pre-pandemic service structure to be fragmented and that support often did not align with the actual needs of participants. The findings demonstrate how long-lasting service inadequacies facilitated and normalized a burden of invisible work on participants, which increased during the pandemic. The inadequacy and disjointed nature of the services led to a lack of trust and confidence among the parents. Due to the fragmentary nature of the services, parents had become adept at integrating various components of systems. Furthermore, as their children's advocates, they had come to recognize the importance of questioning the advice provided and taking matters into their own hands. During the pandemic, these inadequacies within the disjointed service system were exacerbated at a time when families were grappling with anxiety about the potential health implications of viral infections for their children and the challenges that shielding brought about. The families experienced little support from professionals and staff within health and service institutions. The disjointed nature of the pre-pandemic services and the role ambiguity it facilitated enabled professionals and those within service entities to distance themselves and adopt a narrow perspective about their involvement and responsibilities towards the families – which further increased the invisible work of the parents. Unprepared official institutions' measures aimed at mitigating the spread of the virus, predominantly catered to the experiences and needs of non-disabled people and worsened the already precarious situation of the children and their families. Securing support, getting their message across and thriving necessitated considerable labour on the part of participants.

Article II, "Rights in Crisis: Lived Experience as Knowledge in Policy Development During the COVID-19 Pandemic", was published in July 2024, in a special issue about disability human rights in the *Scandinavian Journal of Disability Research*. It draws on 18 interviews with representatives of DPOs and examines the institutional tactics and processes that affected DPOs' right to participate in decision-making during the pandemic. The article addresses research questions 1, 3 and 4 and the critical questions guiding analysis focused on the mechanisms participants encountered in their advocacy that presupposed invisible work and hindered the uptake of their knowledge and insights. In the article, we argue that consultation practices during the pandemic reflected and reinforced ableist power dynamics. The findings underpin the immense work of DPOs during the pandemic in campaigning for issues they predicted would be deprioritized and providing support to their members. They also illuminate the valuable knowledge residing within the DPOs, drawing on their experiences as disabled people navigating barriers and risk and as representatives who, in their work, had encountered institutional mechanics and ableist power relations. The uptake of DPOs' messages was, however, often conditional and tokenistic, as official institutions obliged to participate in consultation seemingly did not recognize the value of the knowledge that DPOs could bring to planning and risk management. Their input was only sought and used haphazardly and to the extent that it aligned with authorities' interests. As institutions defined the scope of the consultation in restrictive and limiting ways, collaboration was mostly limited to solving immediate problems and was rarely effective or meaningful as defined by the Committee on the Convention (CRPD Committee, General Comment No. 7, 2018). DPOs were rarely involved in planning or decision-making processes that addressed broader issues, as mandated by the CRPD Committee's General Comment

No.7 from 2018. In the article, we argue that the institutional practices that impeded the consultation processes during the pandemic are indicative of the non-performative nature of commitments to consultation. Additionally, the findings underscore the invisible work of representatives who, recognizing that disability issues were being neglected and deprioritized by the institutions tasked with responding to the pandemic, had to anticipate problems and assertively advocate that disability issues be considered in pandemic response measures.

Article III is titled "'I think they consider themselves free from all responsibility': Neoliberal Undermining of Welfare Services and its Implications for Personal Assistance Users During the Pandemic" and is under review at *Nordisk Välfärdsforskning*. Drawing on semi-structured interviews with eight disabled adults and the parents of four disabled children, it explores their experiences in light of their self-managed PA services during the pandemic. The analysis contributed insights for research questions 1, 2 and 4.

The findings highlight how neoliberal market ideology and austerity have influenced the implementation of self-managed PA services and how that attributed to many of the difficulties that participants encountered during the pandemic. Prior to the pandemic, the relationship between participants and the municipalities responsible for their services was strained and marred by mistrust as financial restrictions took precedence over support needs in service provisions. Participants perceived a general lack of engagement from the municipalities in the outcomes of the services and their implication for participants' daily lives. Furthermore, the implementation of PA services presupposed substantive unacknowledged work from participants regarding the management of the services. This invisible work became more pronounced as users had to navigate the uncertainties and practical complications brought about by the pandemic. During the first waves of the pandemic, municipalities provided little or no information or support to users of self-managed PA services. Seemingly framing the services as a private sector—inspired contract enabled municipalities to evade their responsibilities towards disabled service users during the pandemic who, as a consequence, were seriously affected by service cancellations, stress, and insecurity. The inadequate services and taut collaboration with municipalities hindered participants from seeking help. The findings illustrate how the influence of market-ideology on the welfare services has fostered increased responsibilization of disabled people, undermining the very goals at the heart of the CRPD and disability legislation.

Article IV was published in the *Scandinavian Journal of Disability Research* and is titled "Digital Exclusion of People with intellectual disabilities during the COVID-19 Pandemic". It drew on survey and focus group data from people with intellectual disabilities and highlighted structural power dynamics that contributed to their digital disparities in the pandemic – contributing insights for research questions nr. 1 and 2. Survey findings showed that people with intellectual disabilities were less likely to have been in contact with family members, friends, or other people via phone or digital technology during the pandemic than people with other types of impairments. Results also showed that their digital engagement did not statistically vary between individuals experiencing economic strain and those who did not, contrary to prevalent digital divide literature (Scheerder et al., 2017). Importantly, however, there was a difference in digital participation between people with intellectual disabilities living independently and those in residential care, as the latter group were less likely to have used a phone or digital technology frequently or very frequently to contact family members, friends, or other people during the pandemic – indicating that social interactions, such as through digital devices, are not prioritized within the service entities.

The qualitative data underlined four main barriers to the use of information and communication technology by people with intellectual impairments. These were analysed in view of data ableism (Charitsis & Lehtiniemi, 2023) and technoableism (Shew, 2023) and furthermore reflected cognitive ableism (Carlson, 2001). These main barriers were paternalism, lack of digital training and access to education, the quality of disability services and support, and lack of inclusive digital design and data presentation. Furthermore, the findings shed light on how digital acceleration within public administration proved inaccessible to participants and posed barriers for them during the pandemic. The study furthermore underscored the importance that researchers engaging with digital disparities include the experiences of disabled people and a critical examination of the social forces and structures that underlie and perpetuate technological inequalities. Otherwise, there is a risk of perpetuating prevalent stereotypes and excluding disabled people. Many participants in the focus group demonstrated digital use that differed from typical definitions of digital access and use, reflecting broader, more relational digital engagements. Had the study adopted a narrow understanding of digital use – which is common for such research – focusing solely on acts such as retrieving information from the Internet or posting on social media or excluding relational participation, it would easily have overlooked participants' diverse digital technology uses.

6 Concluding discussion

This PhD project sought to examine the challenges faced by disabled people and their families during the pandemic, employing critical frameworks rooted in the analysis of oppressive structures and processes within society (Harding, 2004; Meekosha & Shuttleworth, 2009). It rendered three key findings which will be discussed in this chapter.

6.1 Pre-pandemic undermining of services and responsibilization

My findings demonstrate pre-pandemic problems and service inadequacies, in line with previous Icelandic research (Jónsdóttir & Egilson, 2014; Ingólfsdóttir, 2023; Snæfríðar- og Gunnarsdóttir et al., 2016), underscoring a misalignment between support provided and policy commitments and aspirations. Emblematic of neoliberal restructuring (Soldatic, 2019), the service inadequacies and fragmented support have contributed to the responsibilization of disabled people and the parents of disabled children, where the requirement of their continual efforts to manage the services has been normalized. In the pandemic, service inadequacies and misalignments deepened further and so did the responsibilization of disabled people and the parents of disabled children, as demonstrated in the articles. In Article I, fragmented services and lack of collaboration between service entities compounded the challenges faced by participants in the pandemic and facilitated a distance between participants and service providers and professionals, allowing the latter to abstain from taking initiative or assuming responsibility. With no clear accountability, families with disabled children were left with little or no support. Similarly, the implementation of self-managed PA services enabled municipalities to evade responsibilities towards PA service users, as is evident in Article III. The lack of adequate support, coupled with the resulting mistrust among participants, exacerbated the challenges faced during the pandemic and diminished their inclination to seek assistance. Article II shows how it came down to DPOs to monitor and remain vigilant of disability issues, as authorities and institutions responsible for disability support and for responding to the pandemic systematically overlooked disabled people in response planning and deprioritized disability issues.

The findings of Articles I, III and IV indicate that service implementation prioritizes budget constraints over users' needs. This is in line with the neoliberal restructuring of welfare services (MacLeavy, 2016; Soldatic, 2019) which renders retrenchment as the apolitical result of "management processes" and the pursuit of efficiency, thereby fostering a general acceptance of underfunding essential services. Irrespective of the social justice goals underpinning them, in law and the CRPD, the services provided seem to be undermined by ableist retrenchment politics, causing increased responsibilization, as demonstrated in articles I, III and IV – reinforcing the very ableist dynamics that the services are meant to counteract and rendering institutional commitments to policy goals and the CRPD nonperformative (Ahmed, 2021).

The ways in which neoliberal welfare services counteract and undermine the very fundamental values they build on is uniquely and intuitively described by Hannah Gadsby (2022, p.274):

> Welfare systems don´t accommodate for transience because welfare systems are not built to be accessible; they are built to be temples of administrative doom because, apparently, welfare is a treasure that must be protected.

The neoliberal eroding of welfare services, delineated by scholars such as Hande et al. (2020), Hoppania (2019), and Soldatic (2019) shifts democratic principles into economic terms, and divorces welfare issues from the social justice foundations and historical roots which are fundamental for the successful implementation of the services. With neoliberal rationality comes responsibilization and intensified individualism where political problems and social injustices are framed as individual issues requiring market-based solutions (MacLeavy, 2016), eroding the consensus underlining fundamental values – such as welfare – (Brown, 2015) and undermining social justice movements built on principles of social solidarity (Mladenov et al., 2023). In light of my findings, I share the concerns of those who are apprehensive of the weakening of social services due to the influence of market ideology, which leaves disabled people exposed to increased financial and personal risk, and agree with Morris, (2011, p.3) who says:

> My concern is that – in engaging with the dominant policy agendas – we have lost touch with more fundamental issues concerning the welfare state, and that we have, unintentionally, contributed towards a steady undermining of collective responsibility and redistribution.

I believe it's crucial to strengthen our support system, engage in the required work, and allocate the necessary resources for our services to align with our commitments. In that work, prioritizing rights and social justice over cost-effectiveness is essential.

6.2 Invisible work in the pandemic

The findings of articles I, II, and III showcase how long-lasting service inadequacies and a deprioritization of disability issues facilitated and normalized a burden of invisible work on participants, which increased during the pandemic. The fragmented and inadequate services provided to disabled children and reported in Article I presupposed much invisible work of the families who had to ensure follow-ups, monitor procedures, and facilitate and oversee collaboration. Instead of this being done by a paid professional, it became a part of the parents' second and third shift (Hochschild, 1989) – ultimately invisible work (Daniels, 1987). According to Hatton (2017), the devaluation of their labour can also be attributed to the historical feminization and undervaluation of care work. Furthermore, it took place in the domestic sphere, a site intrinsically associated with invisible work. Similarly, the unacknowledged self-management of PA users in Article III can be understood as adjacent to care-work and took place in their homes. The findings of Article III corroborate research by Katzman and Kinsella, (2018) and demonstrate the substantial invisible work expected of PA users. Although users of PA in Iceland receive a fee for administrative work, it is minimal, and users are not viewed as working for wages. As Katzman and Kinsella (2018) argue, it is ethically questionable that "cost-efficiency" of self-managed services, first and foremost entail shifting administrative tasks and responsibilities from paid municipal staff onto disabled people and their families with little or no remuneration. In Article II, the work of DPO representatives remained unacknowledged as they shouldered responsibility for issues which had been neglected in official discussions and by institutions tasked with responding to the pandemic. In some cases, they assumed tasks for which non-disabled individuals were remunerated, yet they themselves did not receive compensation. The palpable frustration and discouragement of representatives of DPOs, stemming from their relentless advocacy and mistrust towards official institutions to integrate disability issues into pandemic responses and recovery, underscores the burden of the invisible work they have to endure.

A recurring theme in Nordic disability research is the enduring gap between policy ideals and the services provided to disabled people (Brennan et al., 2018; Ingólfsdóttir, 2023; Rice et al., 2015; Tøssebro et al., 2012). This was discernible in the findings of Articles I and III, which showed that policy commitments and ideals do not readily translate into effective practice. This was furthermore gleaned in results of article IV which showed that disabled people residing in residential settings engaged less with their loved ones through phone or digital means than other disabled people during the pandemic – indicating that communication with friends and family through such channels was deprioritized in residential service settings.

Grue (2023) argues that such failed commitments and policy ideals, thrust upon disabled people invisible work as a prerequisite for their integration into society. This, he argues, is furthermore facilitated by the CRPD which employs language that constrains state obligations to that of reasonable accommodation without imposing an "undue burden" on states (Grue, 2023). In Icelandic law, similarly, appropriate accommodations are limited to that which is necessary to facilitate the equitable enjoyment of rights for disabled people on par with non-disabled people, without exceeding what can be deemed normal or unduly burdensome (Althingi, 2018). Importantly, this all takes place within a ubiquitous neoliberal and ableist reasoning. Within the realm of neoliberal ideology, laws can serve as mechanisms for the propagation of its principles. Legal reasoning in a neoliberal context will inevitably change the understanding of democratic principles (Brown, 2017). This is, for example, evidenced by cutbacks to PA services in Sweden after the country's ratification of the CRPD (Brennan et al., 2016). Considering the oppressive power dynamics and intricate circumstances of disabled people in their dealings with service providers, as well as their precarious role in the "strategic game" (Andersen, 2003) between municipalities and the Icelandic government – it isn't hard to understand how such phrasing can be employed for retrenchment purposes.

Changes in law and social policy can undoubtedly yield important material gains for disabled people. Yet,– as Shildrick (2019a) notes – such formal structures alone cannot effectively address the discrimination and oppression experienced by disabled people and the underlying ableist attitudes, values, and deep-seated prejudices that fuel intolerance towards them. For research purposes, I find that the human rights approach can be expanded and fortified through the integration of feminist theory and CDS. Grounded in marginalized insights, activism and emancipatory objectives, these frameworks provide important and necessary depth to critical inquiry into prevailing ableist relations. Their interests are not tied to those of dominant ideologies. Employing them in research can facilitate identification and confrontation of the opaque and insidious ableist power relations that saturate structures (including law, policy and their interpretation) and hinder real change.

6.3 A systemic undervaluing of disabled peoples' expertise and knowledge

Pandemic responses largely centred the needs of "normal" bodies and minds – as demonstrated in this PhD project – leading to service cancellations, barriers to education, inadequate and inaccessible information, and heightened stress and anxiety for disabled people and the parents of disabled children during times of great uncertainties. The deprioritization of the needs and rights of disabled people during the pandemic is both a product of, and a testimony to, their exclusion from emergency planning and the systemic devaluation of disabled expertise. When undermined as epistemic subjects (Fricker, 2007), disabled people cannot contribute to shared knowledge. Their social experience becomes obscured from collective understanding – impoverishing everyone and posing a threat to disabled people's safety and well-being.

Through the framework of FST (Harding, 1993, 2004; Smith, 2005), my findings illuminate the valuable experiential disabled knowledge, that remains underappreciated. In Article II we borrowed the term *institutional plumbers* from Ahmed (2021) when delineating the important work of DPO representatives during the pandemic. The term underscores the valuable insights achieved by coming up against and experiencing oppressive structures. The advocacy and work of representatives was grounded in important insights, stemming from their experiences as disabled people as well as understanding harnessed through their advocacy work as activists. Because of these insights and because of their close contact with the grassroot, representatives of DPOs could speak directly to various needs and barriers disabled people encountered during the pandemic and foresee issues before they progressed into serious problems. Similarly, participants in the other three studies (Articles I, II and IV) can be understood as holders of such oppositional consciousness (Collins, 1986). They had come to critically question the messages they got from service providers and professionals – understanding the intricate workings of the ableist relations that could potentially pose barriers for them. An example of this are participants in Article IV who recognized and understood the way in which paternalist reasonings hindered their digital engagements as well as how such ableist tactics were grounded in flawed reasoning. Through their experiences of navigating a fragmented service system, working with and against service entities, participants in my PhD project had developed important insights and knowledge into the workings of the service systems and the ways in which ableist relations were embedded in institutional tactics and habits. As highlighted by FST, marginalized knowledge can contribute novel insights about power relations and social power structures that more privileged frameworks cannot. Power is intrinsically tied with knowledge creation, and it is an important research objective to center marginalized insights and experiences in order to reform distorted monolithic knowledge derived from privileged social locations.

Currently, the pandemic feels like a lingering uncertainty. Looking back at the drastic departure from daily life that took place during its height, its absence now is stark. Yet, the virus persists and poses a threat, in particular to disabled people, and this has, in some sense become disquietingly mundane. There is a concerning lack of reflection and introspection in the aftermath of the crisis. Copious issues remain understudied and a great need for empirical research that contributes to transformative knowledge. It is imperative that lessons be drawn from the pandemic and that disabled people be an integral part of that process. Their knowledge must be prioritized and funnelled into the design, planning and implementation of policies of crisis management.

6.4 Contributions

At the core of research with emancipatory aims lies the aspiration that research findings can prove valuable in improving the material and social circumstances of those marginalized by social injustices. To this aim, issues deemed most pressing and critical by disabled people, DPOs and parents of disabled children during the pandemic, were placed at the centre of this project. One of its key contributions lies in the theoretical insights it offers, into the workings of pervasive ableist social relations that influence and govern disabled people's lives and suppress evidence derived from their experience. The complimentary integration of FST and CDS, facilitated an analytical focus that brought to the forefront and problematized ableist power relations, building on and valorizing disabled knowledge and insights. FST and CDS are critical frameworks grounded in political struggles for rights, with the aim of achieving equity and ending oppression. They hold an important social critique that enriches critical research with emancipatory objectives, like mine. Both aim to produce knowledge about the conceptual practices of oppressive power relations and facilitate an understanding that can be used to challenge the underlying conditions that maintain systemic marginalization (Harding, 2004; Shildrick, 2019). I believe their integration in research to be an important way to challenge the ubiquitous and covert ableist power relations and the systemic undermining of disabled expertise embedded within societal constructs.

The pandemic brought about significant disruptions and complications in disabled people's daily lives and the insights garnered in this research can prove valuable and practical to strategic planning and preparedness for future disaster management. Furthermore, by scrutinizing the way in which market ideology and service retrenchment have imposed additional responsibilities and invisible work on disabled people, the PhD project contributes to a growing body of research in the Nordic countries which focuses on the impact of neoliberalism on welfare services. These critical insights carry significant implications for policy considerations and serve as an important means to examine how and to what extent national and institutional goals are realized in practice and translate into support for disabled people. I believe disability research and policy research stand to benefit significantly from this perspective which critically considers the impact of neoliberal reasoning on welfare services.

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Article

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

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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.

Keywords

Covid-19; disabled children; family support; Iceland; social inequality

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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Paper II

SJDR SCANDINAVIAN JOURNAL OF DISABILITY RESEARCH
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Rights in Crisis: Lived Experience as Knowledge in Policy Development During the COVID-19 Pandemic

COLLECTION:
DISABILITY HUMAN RIGHTS

RESEARCH

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HRAFNHILDUR SNÆFRÍÐAR- OG GUNNARSDÓTTIR
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ABSTRACT

The Convention on the Rights of Persons with Disabilities recognises the value of knowledge derived from lived experience with disability as a vital part of the co-production of policy affecting disabled people. Furthermore, Article 11 of the Convention specifically highlights the need to safeguard the rights of disabled people during times of crisis. This paper draws on interviews with representatives of Icelandic disabled people's organisations conducted from 2021 to 2023. Informed by the human rights approach and feminist standpoint theory, it explores critical issues raised by representatives of disabled people regarding the capacity of Icelandic DPOs to effectively participate in policymaking during the pandemic. The findings demonstrate the value of the lived experience of disability, which enabled DPOs to promptly advocate for effective solutions. However, collaboration and consultation were limited, and DPOs were not involved in important decision-making, suggesting their role as knowledgeable stakeholders remains undervalued.

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Evidence emerging from the COVID-19 pandemic demonstrates that despite pressure from disabled people's organisations, researchers and official entities (Brennan 2020; Inclusion London 2020; Sisters of Frida 2020; WHO 2020), disability issues remained systematically deprioritised (Kubenz and Kiwan 2023). Disabled people were both disproportionately affected by the COVID-19 virus and the measures put in place by authorities to contain infections (Eurofound 2022).

The precarious position of disabled people in times of emergency is recognised in Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD), which asserts the responsibility of state parties to ensure that their rights are upheld under such circumstances (United Nations 2006). Noting the socially precarious situation of disabled people and lessons from previous disasters, the United Nations warned that the pandemic could lead to a deepening of pre-existing inequalities. In policy briefs and official statements issued in the first months of the pandemic, states were reminded of their obligations to protect disabled people's rights and to ensure meaningful and active consultation with disabled people through their representative organisations in all stages of response and recovery (United Nations 2020). Despite this, disabled people's organisations (DPOs) were only involved by governments in consultation processes to a limited degree (Brennan 2020; Kubenz & Kiwan 2023; Uldry & Leenknecht 2021), echoing previous research demonstrating a lack of inclusion of the rights and needs of disabled citizens in government responses and planning in emergency situations (Abbott & Porter 2013; Alexander 2015; Grove et al. 2010; WHO 2011).

As acknowledged by the UN, disabled people are important stakeholders who must and should contribute to all aspects of disaster risk management and reduction during planning, design and implementation (UNISDR 2015). Furthermore, disabled people's contributions to such work can be highly valuable, as their experiences of navigating risk and inaccessibility while adapting to an ableist society bestow on them multifaceted insight and understanding that are uniquely practical and important to the task of planning responses to hazards and crises (Abbott & Porter 2013). Yet, in accordance with the power relations inherent in knowledge production and value systems, their contributions to emergency planning and management have been and remain overlooked (Kubenz & Kiwan 2023; Lord & Waterstone 2009). However, drawing on these insights and experiential knowledge, DPOs played a key role during the COVID-19 pandemic, providing crucial support and securing and advocating for disabled people's rights. The findings of a survey conducted in the early months of the pandemic across 134 countries highlighted the valuable efforts of DPOs and community-led initiatives, often serving as the most meaningful and, in some cases, the only source providing crucial support and securing and advocating for disabled people's rights (Brennan 2020).

Pandemic response measures in Iceland drew on the country's geographical traits, with emphasis on strict border controls, contact tracing and heavy screening measures with intermittent bans on gatherings (Ólafsson 2021). Although a national lockdown was never imposed, the pandemic had a significant impact on infrastructure. Seemingly ill-prepared, the educational and social service systems often fell short of meeting the requirements of disabled individuals and families with disabled children, who did not receive their rightful support (Snæfríðar-og Gunnarsdóttir et al. 2023). Arguably, the situation that arose reflected the lack of consideration for disabled individuals and disability-related issues in Icelandic civil defence material and contingency planning (Björnsdóttir & Jóhannsdóttir 2021).

This paper is grounded in the experiences of representatives of Icelandic DPOs and focuses on critical issues raised by them regarding their role as valued contributors and their capacity to effectively participate in policymaking during the pandemic. Drawing on the disability human rights approach and feminist standpoint theory, the aim of this article is twofold. First, it is to elucidate DPOs' knowledge area and how expertise stemming from participants' lived experience as disability advocates informed their advocacy work and furthered disability issues during the pandemic. Second, it is to explore power relations that affected and conditioned the DPOs' right to full and effective participation in consultation processes during the COVID pandemic.

FULL AND EFFECTIVE PARTICIPATION

Article 4.3 of the CRPD asserts the right of disabled people, through their representative organisations, to full and effective participation in the development of policies that relate to and affect their lives and rights. The right to effective participation derives from the demand that disabled people be recognised as subjects and citizens with full rights and capacity to make decisions regarding their own lives and affairs, rejecting what has been the often-unquestioned norm that decisions be made by others on disabled people's behalf (Quinn 2009; Keys 2017). What counts as meaningful and effective participation has been discussed by several scholars. In her landmark article, Arnstein (1969) points out that fully inclusive consultation processes must entail an actual redistribution of power in decision-making processes. Securing a seat at the table does not suffice, and tokenistic gestures merely serve to maintain the status quo while allowing those in power to claim that all sides have been considered. Indeed, research on the role of DPOs and access to participation in policy development has shown that participation is often rendered 'illusionary', a mere formality, where a platform and opportunity to express opinions is provided but the expertise and knowledge residing in the DPOs are not actually taken into account (Kumpuvuori & Virtanen 2017). To bring about effective participation, Young (1990) argues that marginalised groups must have a role in setting the agenda and defining the issues involved. The CRPD reflects this concern, emphasising that the views of disabled people should be given due weight in consultation processes and not only be heard as a mere formality or a tokenistic approach to consultations (CRPD Committee, General Comment No. 7 2018). In fact, the Committee on the Convention provides guidance to member states on what constitutes full and effective participation. First, it highlights that participation should be broadly interpreted, not limited to disability specific policy but 'to cover the full range of legislative, administrative and other measures that may directly or indirectly impact the rights of persons with disabilities' and extend across all levels and branches of government (CRPD Committee, General Comment No. 7 2018). Second, consultations should be initiated in a timely manner, be continuous, result in input to the final product and not be regarded 'as an individual one-time event'. Third, access to all relevant information must be ensured in a timely manner and in accessible formats. Finally, the Committee emphasises that authorities have a duty to inform DPOs of the outcome of consultation processes, including an explicit explanation in an understandable format of the findings, the reasoning behind decisions and how their views were considered and why (CRPD Committee General Comment No. 7 2018).

THE ROLE OF DPOs

The lived experience of disabled people is central to the Convention's call for DPOs' participation in policymaking, as highlighted in the Committee on the Convention's guidance (2018), which recognises knowledge claims of disabled people 'because of their lived experience and knowledge of the rights to be implemented' (CRPD Committee, General Comment No. 7 2018). Kumpuvuori and Virtanen (2017) argue that this effectively results in DPOs functioning as both interest and expert groups. On the one hand, DPOs claim legitimacy through their representation of disabled people's interests and rights and, on the other, through their unique expertise, experience and understanding of the lives and needs of disabled people (Kumpuvuori & Virtanen 2017). In many respects, these dual functions are intertwined and fundamental to ensuring the centrality of disabled people themselves in accessing and implementing their rights.

In this context, it is important to note that the obligation on states parties to ensure the realisation of the right to participation in policymaking, includes a derivative obligation to support the capacity of DPOs to serve as effective contributors and collaborators in consultation processes (CRPD Committee, General Comment No. 7 2018). The Committee stresses that this includes ensuring funding and other necessary support to secure DPOs' independence and ability to function as monitors of the Convention and to provide meaningful input. Particular attention is drawn to the need to ensure that this support takes note of and reflects the diversity of impairments and, thus, the diversity of disabled people's organisations.

In Iceland, public funding for DPOs is limited. Funding for the largest DPO, and one of two DPOs that have legally protected consultation status, is secured through their ownership stake in the national lottery. The other DPO that has consultation status is partly funded through project-based government funding. The remaining DPOs are predominantly independently funded through the sale of various lotteries, merchandise and grants, with limited public funding.

THEORETICAL PERSPECTIVE

The research draws on the human rights approach to disability and feminist standpoint theory.

The human rights approach to disability both reflects and is driven by the CRPD. It draws on the social approach to disability and its emphasis on society's role in constructing disability while adding a rights-based focus, claiming disability as a human rights issue (Degener 2016; Kanter 2007; Quinn & O'Mahony 2017). The two approaches support and complement each other, firmly placing the responsibility to address disability-based exclusion on states parties. As rights holders, disabled people are entitled to the protection of their rights, including through proactive measures taken by governmental authorities. Failure to live up to these obligations is identified as a human rights violation (Degener 2016; Kanter 2015; Office of the High Commissioner for Human Rights 2010; Stein & Stein 2006).

Furthermore, the human rights approach and the CRPD provide a roadmap for states parties on the effective implementation of disabled people's rights, including via guidance provided by the CRPD Committee in its General Comments. As such, the human rights approach and the Convention serve as tools to support disabled people in their claims to full and effective inclusion and participation in society (Degener 2016; Skarstad & Stein 2018).

FEMINIST STANDPOINT THEORY

A second pillar of our theoretical perspective is feminist standpoint theory, which stems from the feminist struggle to cast light on and give name to inequities faced by women. Feminist standpoint theorists argue that marginalised lived experience can establish different ways of knowing, providing critical insights into the processes of oppression (Collins 1998; Harding 1993; Harding 2004; Smith 2005; Wylie 2003). Indeed, a main argument of feminist standpoint theory maintains that groups oppressed by unjust social systems have an epistemological advantage over privileged groups when it comes to understanding those systems. By virtue of their lived experience, marginalised groups have a capacity to know and understand things regarding oppressive dynamics and systems that privileged individuals do not know (or have a vested interest in ignoring or not knowing) (Wylie 2003). Therefore, placing the experiences of marginalised groups at the centre of research provides a fuller view of oppressive social structures and power relations and how they shape and condition people's lives (Collins 2009; Harding 2004; Smith 2005). A recent term encapsulating the value arising from marginalised experience is Sara Ahmed's (2012; 2021) 'institutional plumbers', describing marginalised individuals who, by coming up against institutional blockages and the inner workings that reproduce oppressive power relations, become experts in them. Ahmed's (2012; 2021) writing about the various informal institutional mechanics experienced by marginalised individuals brings valuable analytical insight into how power dynamics are manifested through them, rendering institutional commitments to justice and diversity nonperformative.

Drawing on feminist standpoint theory has both methodological and analytical implications for this research project. As argued by Smith (2005), the inquiry starts at the margins, from the perspectives of disabled people, is grounded in their understanding and cognitive frameworks and probes critical issues raised by them. In line with feminist standpoint theory, our analysis focused on the power dynamics and institutional inertia that participants came up against in their advocacy work during the pandemic. Mindful of the importance of the social position individuals occupy and the power dynamics between researchers and participants, we, the authors, feel it is important to briefly note our position. We are both non-disabled, white, cis women and disability scholars. Throughout the project, we remained cognizant of the power relations inherent in it and committed to remaining true to the experiences of the participants in our research project.

METHODS

This was a qualitative interview study aimed at gathering comprehensive information about the consultation processes during the COVID pandemic based on the experiences of representatives of Icelandic DPOs. The interviews were conducted separately by the authors as a part of their individual projects. The first author's research is part of a larger project, *Disability in the times of pandemic*, funded by the Icelandic Research Fund. The second author's data gathering was part of the project *Disabled peoples' effective participation in the development of law and policy*, funded by the University of Iceland Research Fund.

PARTICIPANTS AND PROCEDURES

Altogether, 15 representatives of established DPOs, grassroots and activist groups were recruited through purposeful sampling: nine women and six men. Participants worked for seven DPOs, which all serve as interest and expert groups (Kumpuvuori & Virtanen 2017), and all are based in the capital area of Iceland. Using the classification by Löve et. al. (2018), four of the DPOs were identified as established organisations and three as activist or grassroot organisations. The established organisations included two large umbrella organisations and two DPOs that have legally protected consultation status.

In total, 18 interviews were conducted from January 2021 to February 2023, nine by each author. Ten representatives of established DPOs were interviewed; six of them were disabled and four were non-disabled. The five representatives of activist organisations were all disabled. Three participants were interviewed twice to delve deeper into aspects that had emerged in prior interviews. The interviews were semi-structured, allowing flexibility for follow-up questions while staying within the framework of predetermined topics (Braun & Clarke 2013). The interviews began with general inquiries about the DPOs' advocacy efforts and their experience with consultation processes before the pandemic. The main part of the interviews centred around the DPOs focus and advocacy work during the pandemic and their engagement with the institutions tasked with responding to the pandemic.

The duration of the interviews was about 60 minutes. Due to the pandemic, six interviews were conducted via Zoom, but others took place in a location of participants' choice as restrictions had been lifted. All the interviews were conducted in Icelandic, recorded with participants' consent and transcribed verbatim.

DATA ANALYSIS

Reflexive thematic analysis (Braun & Clarke 2013) was employed by reason of its theoretical flexibility, making space for the centring of analytical aspects brought about by the theories guiding the research, namely the disability rights approach and feminist standpoint theory. Critical questions guiding the analysis focused on social structures and mechanisms encountered by participants, affecting successful consultation processes in the pandemic. Furthermore, whether and how the lived experiences of participants informed the advocacy work of DPOs and furthered disability issues during the pandemic. Initially, the first author coded and developed the themes. The authors collaborated on the further development and refining of themes. Direct quotations were translated into English by the first author.

ETHICAL CONSIDERATIONS

Research holds ethical value in its scientific and social significance. It is the responsibility of researchers to ensure that their work is scientifically sound and generates valuable information (CIOMS 2016). As authors, we affirm that we have adhered to sound and ethical practices in the project design, analysis, and data interpretation. We believe that our work contributes to both scientific and practical knowledge on the subject matter. All participants were informed of the purpose of the study and participated willingly. In order to maintain the anonymity of the participants, we refrain from the use of pseudonyms and omit any identifiable background information in the analysis and published findings. The research proposal was reviewed by the Research Ethics Committee for Public Higher Education Institutions (SHV2021–009).

FINDINGS

Data analysis yielded two main themes that are presented in the first two sections of the findings. The first theme, lived experience as knowledge guiding DPO advocacy, brings into focus how the lived actualities within the DPOs bestowed them with valuable multifaceted insights and informed their advocacy work and efforts. The second, institutional mechanics impeding consultation, describes the informal institutional mechanics experienced by representatives of the DPOs that impeded the consultation processes, seemingly undervaluing the asset of the DPOs' knowledgebase and their role as experts. The last theme, 'We were our own civil defences' – Skewed responsibility leads to invisible work, provides further insight into the consequences and conclusions drawn from the two main themes.

LIVED EXPERIENCE AS KNOWLEDGE GUIDING DPO ADVOCACY

Participants described realising as soon as news of the pandemic broke that it would most likely impact their people in manifold ways. Foreseeing, based on previous experience, that their interests would be neglected or deprioritised by authorities, DPOs quickly refocused their work to prioritise advocacy on behalf of their members, keeping in close contact with them through their organisational channels to learn about problems arising and often aiding individuals in precarious situations. Throughout the interviews, it became clear how their advocacy and work were informed by multifaceted experiential knowledge, ranging from an understanding of specific barriers that particular groups might face to detailed insight into how institutional habits of service systems might impede the uptake of disabled people's concerns. Three separate knowledge bases informed the DPOs work and advocacy in important ways.

First, based on their lived experience of disability, the disabled DPO representatives had intricate knowledge of the needs, barriers and issues the group they represented faced in daily life. Furthermore, they were aware of how circumstances could affect diverse groups differently, for instance, how the shift to online teaching could disadvantage, in particular, children with intellectual disabilities.

Second, through their organisational channels, DPOs were in close contact with their members and had access to first-hand information about emerging issues and challenges. To maintain and facilitate this flow of information, DPOs made their consultation services available through remote technologies and organised special online and peer support forums. Through these mediums, DPOs gained information about issues that were meaningful and important to their grassroots and placed them at the forefront of their advocacy work, as one participant described:

> This all comes from, all or most of it, from the grassroots, or our people. They ask questions, and we, while answering them, start thinking: Where are the answers?

Third, through their prior experience dealing with these systems and advocating for disability issues and rights, the disability representatives had a keen insight into the service systems, institutions and official entities that collaborated to respond to the pandemic. Like Ahmed's institutional plumbers (2012; 2021), they knew the cracks and the gaps in the systems, as well as the informal institutional mechanisms that had so often deprioritised the disability issues they had been advocating for. This insight and understanding was evident in the way DPOs expressed their concerns when the pandemic started. Although concerned about the potential health repercussions of the virus for their members, the primary source of apprehension shared by the representatives was whether or how the basic rights and safety of disabled people would be impacted, potentially ignored or disregarded in the actions taken by officials. Through their long-time advocacy work, they had experienced the ways in which disability issues were often rendered ad hoc within the same institutions that were now tasked with reacting to the virus. Having repeatedly come up against such institutional tactics, they deduced the potential hurdles or threats to disabled people's safety and rights. For example, being well acquainted with the fragmented nature of services, which are often tied to specific premises but not the individuals who use them, one representative envisaged that closing schools and workplaces could result in the loss of necessary support by many individuals. They explained:

> Immediately when we realised where things were heading in the pandemic when they started to close nursing homes, and we saw that they were closing workplaces for disabled people, we wrote a letter urging authorities to be careful, and we emphasised that they had to ensure services provided on the grounds of law. Because although preschools, schools and workplaces were closed, the need for support didn't disappear. The support had to follow individuals to their homes, whether children or adults.

As the DPO representative foresaw, this would become a serious problem for many disabled individuals, children and their families who did not receive their rightful support during the pandemic (Snæfríðar-og Gunnarsdóttir et al. 2023). Another participant described her apprehension when hearing of impending vaccination prioritisation. Being acquainted with the limited databases of institutions and the faulty understanding of officials, she anticipated hasty and streamlined outcomes that wouldn't take the important physical and social issues of disabled people into consideration. She explained:

> I just thought: On what grounds will they prioritise? Will they prioritise on the grounds of what services people use or on the grounds of medical records? And how safe is that, then? What about when a person has reduced lung capacity because of their impairment but they don't have a disease? Will they recognize that? I, of course didn't know, but then again, knowing how it usually goes for our group, we always end up on the margins.

Many of the issues that the DPOs foresaw potentially progressing into serious problems in the pandemic stemmed from the failure of institutions to work together in a cohesive manner. They had experienced how gaps in services between individual governmental institutions and municipalities had often served to complicate and thwart responses to disability issues. Accordingly, these unaligned service structures, coupled with the atmosphere of panic arising from the pandemic, created conditions where important issues could possibly, if not in all likelihood, fall between the cracks. One participant explained:

> It was such a daunting realisation that even between different institutions of the state, like the health clinics and the Directorate of health, there wasn't that much collaboration. And the panic kind of shone through.

Since disability issues had not been successfully integrated into the work and routines of various governmental institutions and organisations, it remained the task of DPOs to be vigilant and to advocate for important disability issues related to the pandemic or the measures taken to counter the spread of the virus. Indeed, a lack of collaboration and consultation during the pandemic often made it difficult for DPOs to get important messages across to, or to establish a dialogue with, the authorities.

INSTITUTIONAL MECHANICS IMPEDING CONSULTATION

Overall, the DPO representatives considered consultation processes during the pandemic to have been limited and faulty. Institutions very seldom initiated contact with DPOs. When invited to collaborate or consult, it most often involved immediate problems, usually issues raised by the DPOs themselves, but not involving them in important decision-making processes or in planning focusing on pandemic-related issues with a broader scope, as called for by the CRPD committee (CRPD Committee, General Comment No. 7 2018). A number of participants described engaging in collaboration, which they perceived to be 'tokenistic gestures', where the methods of collaboration were restrictive, defined and delineated by the institutions. Sometimes this was done under the guise of information gathering, where DPOs were asked to partake in time-consuming efforts, such as regularly filling out long questionnaires or participating in meetings, without any assurance as to how or whether their views or the information they provided would be taken into consideration. To participants, these consultation processes were opaque and felt like a placation. As an example, one interviewer had attended a meeting that seemed to be primarily aimed at letting participants vent, allowing officials to claim that all sides had been considered and everyone had been heard:

> We were called by the ministry. It was the kind of consultation that they used in order to be able to say they had been consulting us. But it was just ridiculous.[…] But it didn't really matter what was said, it was just to tick some box: 'We've listened to that and now we can start thinking about the issues that really matter'.

The method employed by the ministry to promote consultation, as described by the participant, had the apparent aim of not to collaborate but to appease DPOs and 'tick a box'. Furthermore, as the quote shows, such tactics left participants with the understanding that disability issues were not those 'that really matter'.

Although, at times, institutions' responses indicated a recognition of the practicalities of the experiential knowledge of disabled people, the capacity of DPOs to act as expert groups, as defined by Kumpuvuori and Virtanen (2017), was undermined as their contribution was seemingly devalued and used selectively when aligning with the officials' own priorities. This manifested in various ways. After being criticised by DPOs for overlooking large groups of disabled people in the material they disseminated, rendering it unusable for many users of disability services, the Department of Civil Protection and Emergency Management hired a non-disabled person to serve as a specialist in disability issues. An interviewee explained how 'instead of us just being hired to do the job', it was assumed that they, the DPO representatives, would participate in numerous meetings and volunteer advice to help this specialist who lacked knowledge on issues of importance to the group she was supposed to be working for:

> It was just a little absurd that she, the non-disabled person who had little or no understanding of the topic, was the only one at the table on the payroll while we were there to feed her with facts and information and all the things that needed to be thought through, and we all were unpaid.

Overall, the DPOs that officials were obliged by law to consult with appeared to be involved to a greater degree than others. In particular, one such DPO stood out in the interviews, as its consultative experiences had been more fruitful than those of other DPOs. They characterised their collaboration with one specific municipality as having been successful:

> In my opinion, [the municipality] did a very good job of always keeping in touch, looking for advice and including us. And we were often helping them solve problems, which was just self-evident, we were somehow all in this together.

As the interviewee explains, the municipality had kept the DPO updated regarding impending actions or changes in their services and consulted with them when tackling infections in assisted living residences. Municipality staff furthermore asked for and accepted immediate help and expertise from the DPO when reacting to infections and by reaching out to 'and just calling me, often during evenings', as one representative from the DPO explained. This DPO reported having cultivated a collaborative relationship with the municipality in question in previous years, with regular consultative meetings that seemingly facilitated a consultative relationship during the crisis. However, this specific DPO differed from others in meaningful ways. It is fronted mainly by non-disabled people and has, in their advocacy work, been particularly mindful of how they got their messages across, taking care not to be perceived as imposing or difficult to work with, as one interviewee explained: 'It's important to be solution-oriented. I think it's a very effective way to make the system want to work with you'.

As the quote illustrates, the representative understood collaboration as being dependent on the willingness of the institutions. Despite authorities' obligation to consult, it was seemingly understood as fleeting and that being regarded as negative could have potential ramifications for your cause.

As interviewees describe collaboration with authorities during the pandemic, it was rarely effectively meaningful as defined by Young (1990) or the committee on the Convention (CRPD Committee, General Comment No. 7 2018), and DPOs were kept out of important decision-making processes. Collaboration was mostly limited to solving immediate problems, and rarely were DPOs asked to take part in organised planning or decision-making processes that focused on issues with a broader scope, as called for by the CRPD committee (CRPD Committee, General Comment No. 7 2018). This also remained the case for DPOs, whom officials were obligated to consult with. Even DPOs with a collaborative history with authorities reported being left out of collaborative processes where important decisions were made. One participant explained how a DPO's invitation to participate in a consultation team aimed at disaster risk planning and management had been rescinded as it was deemed too burdensome for the institution.

> They established a response group in the ministry which we were told that we would be represented in. Then, when they started meeting, we were told we couldn't participate because if we were allowed to, then everyone would have to be allowed to participate, and then the group would become too big.

Apparently, 'practicalities' outweighed the obligation to consult disabled people and the value of the knowledge the DPOs brought to the consultation.

‘WE WERE OUR OWN CIVIL DEFENCES’ – SKEWED RESPONSIBILITY AND INVISIBLE WORK

Recognising that important disability-related issues were being neglected in official discussions, disability representatives were cognizant of the importance of their advocacy. Several participants spoke of the invisible work rendered by this, as DPOs found themselves shouldering responsibility for disability-related issues. Due to their experience and insight into institutional mechanics and habits, like Ahmed’s (2012; 2021) institutional plumbers, they were often one step ahead of officials regarding important issues, as examples in the previous chapters show. When describing the work of DPOs in the first months, one participant used the analogy of emergency workers trying to contain the potential damage: ‘We were a lot like firefighters, trying to distribute information, suggestions and instructions’.

Participants noted that the challenges faced during the pandemic were largely due to the lack of involvement of DPOs in disaster planning before the pandemic; in fact, none of the DPOs had been invited to participate in consultation regarding such matters. In their view, many important issues would have been easier to implement and take into consideration if ‘you just do it from the start’. This was reflected in official plans and procedures as explained by a participant:

> Naturally there need to be plans beforehand, you know. When you look into all the plans from the Department of Civil Protection and Emergency Management, they barely mention disabled people.

Thus, for participants, the situation that arose in the pandemic was predictable, in line with their experience in advocacy work. When authorities and institutions responsible for disability support systematically overlook disabled people and DPOs in response planning and deprioritise disability issues in times of crisis, it all comes down to disabled people themselves. One participant explained the burdensome nature of such invisible work:

> I find it interesting to think of it in terms of women’s third shift. Disabled people have the third, the fourth and the fifth shift, you see. And I find it so frustrating that we can’t even be safe in a fucking pandemic when other citizens can just: ‘Ok, I can trust that officials are doing the right thing with all the scientists’. Disabled people always must have the initiative to protect themselves, plan and just do everything themselves [...] I’m no specialist in this, you know? I don’t want to be planning reactions to a pandemic while other groups can just rest assured that someone is taking care of things for them.

Although DPOs had managed to successfully navigate important issues during the pandemic with relentless advocacy work, such sentiments of frustration and discouragement were common and discernible among study participants. While important disability issues and commitments to consultation were overlooked and deprioritized, DPOs were forced to shoulder responsibility during the pandemic, which they firmly believed should lie elsewhere.

DISCUSSION

This study explores the experiences of representatives of Icelandic DPOs in consultation processes and how expertise stemming from DPOs’ lived experience as disability advocates informed their work and furthered disability issues during the COVID-19 pandemic. In line with reports from other countries (Brennan et al. 2020; Kubenz & Kiwan 2023), our findings reveal shortcomings in Icelandic authorities’ responses when it came to ensuring the needs and rights of disabled people. According to the interviewees, collaboration with the authorities during the pandemic was rarely effective or meaningful, as defined by Young (1990) or the Committee on the Convention (CRPD Committee, General Comment No. 7 2018) but mostly limited to solving immediate problems. Rarely were DPOs asked to take part in organised planning or decision-making processes that focused on issues with a broader scope, as called for by the CRPD committee (CRPD Committee, General Comment No. 7 2018). This also remained the case for DPOs whom officials were obligated to consult with. Methods of consultation were, for the most part, tokenistic, not acknowledging DPOs as co-producers of policy and decision-making. Thus, we argue that authorities did not sufficiently fulfil their obligations, stated in Article 4.3

of the Convention, to 'closely consult with and actively involve' disabled people through their representative organisations (United Nations 2006).

The dual function of DPOs as both interest and expert groups, as defined by Kumpuvuori and Virtanen (2017), was evident in the pandemic. In their role as interest groups, DPOs pressured the authorities to actualise the rights of disabled people, reminding them of their obligations and responsibilities in accordance with the CRPD. As expert groups, DPOs drew on their experience of navigating institutional mechanics embodying ableist power relations, campaigned for issues they foresaw would be deprioritised by authorities and provided support to their members. However, institutions tasked with responding to the pandemic seemingly failed to recognise the value of DPOs role as experts, as their input was only sought and used haphazardly and to the degree to which it aligned with authorities' interests. Institutions rarely initiated contact, and collaboration mostly involved solving immediate problems brought to light by DPOs. The methods of engagement were defined, restricted and delineated by the institutions, often aimed at appeasing or letting participants vent while providing no assurance as to how or whether their issues would be addressed. The methods by which consultation was enacted, we argue, counteracted the actual redistribution of power that meaningful consultation entails, as called for by the CRPD (Löve et al. 2017).

By employing feminist standpoint theory (Harding 1993; Harding 2004; Smith 2005), the valuable experiential knowledge residing within DPOS was illuminated, as were the power relations that hindered its uptake by institutions tasked with responding to the pandemic. In their advocacy work, the DPOs had intricate first-hand knowledge, in many cases as disabled persons themselves, and, thus, the ability to speak directly to the various needs and barriers disabled people face. They served as channels for the voices, opinions, and concerns of their members. Furthermore, through their experience advocating for disability rights and issues, they gained important insights into the institutions and organisations mandated to provide services for disabled people. Much like Sara Ahmed's 'institutional plumbers' (2012; 2021), the study participants knew the informal institutional mechanisms that served as barriers to the uptake of their causes, the tactics that allowed some aspects to be prioritised and others to be silenced. These insights informed their advocacy work in the pandemic, enabled them to foresee and predict hurdles and barriers and advocate for effective responses.

The institutional practices that impeded the consultation processes indicate that commitments to consultation remain, to a great degree, nonperformative—an institutional slogan that does not 'bring into effect what they name' (Ahmed 2021: 30). Overall, DPOs' participation can be categorised as having 'a seat at the table,' but not as the full and effective participation called for by the CRPD, as defined by Kumpuvuori and Virtanen (2017), or as reflecting the shift in the balance of power needed to change how disability policy is made (Arnstein 1969; Löve et al. 2019). The lone example about a collaborative relationship with one municipality does not contradict our claim but instead supports it, not least since the DPO in question is fronted mainly by non-disabled people. We understand this to be a representation of how the methods of collaboration overlooked and reinforced the underlying power disparities that the obligation to consult in the CRPD is intended to combat. Nevertheless, the findings do suggest that, when a successful consultation relationship has been established and cultivated, it may facilitate collaboration in such circumstances.

Due to the shortcomings of consultative processes, DPOs assumed a proactive role during the pandemic, pressuring the authorities to include disability rights in their responses to the crisis and reminding them of their duties and obligations according to the CRPD. As important issues regarding the health and safety of disabled people were deprioritised, it remained the task of disabled people and DPOs to foresee the problems and the solutions and work tirelessly to ensure those issues were addressed by the relevant entities. This burden of invisible work was referred to as 'the third, the fourth and the fifth shift', citing the term 'second shift', coined by Arlie Hochschild (1989) to give name (and political presence) to the unequal burden and labour women face. The metaphor illuminates the arduous work placed on disabled people and disability representatives during the COVID-19 pandemic in order to safeguard disabled people's needs and rights.

Being bound by the CRPD to safeguard the rights of disabled people, states must closely consult with DPOs and make a concerted effort to consider disabled people's needs in all planning and measures aimed at protecting their citizens. The right to participation by DPOs in decision-making is truly at the heart of the Convention and is in great part derived from the decisive role disabled people themselves played in the negotiation, development and drafting of the Convention, reflecting the international rallying call, 'nothing about us without us' (Kanter 2015). The obligation to consul is grounded in the understanding that disabled people's political participation has been obstructed by ubiquitous structural inequality. It is imperative that the ways in which these commitments are realised do not reflect and reinforce the very oppressive dynamics they are supposed to counteract. The call of the CRPD for the lived experience of disabled people to be embedded in law and policy relates, importantly, to the emphasis of feminist standpoint theories on the value of the insight of those oppressed or marginalised by systemic inequity. Drawing on disabled knowledge can significantly enrich our collective understanding and is, indeed, a matter of urgent practical concern.

CONCLUDING REMARKS

This paper sheds light on how the CRPD's obligations regarding consultations fared during the COVID-19 pandemic in Iceland, a country that has ratified the Convention and written into its core disability legislation an emphasis on the state's obligation to closely consult with DPOs in matters that concern disabled people's interests. The findings demonstrate that consultation processes in Iceland fell well short of the requirements of the CRPD. The DPOs' role as experts and the value of their input were overlooked and mostly went unrecognised by the institutions that were tasked with responding to the pandemic.

This study raises important critical questions about the institutional practices that hinder and impede consultation processes and highlights the need to scrutinise the way in which consultation is practised so that it does not inadvertently fortify the very oppressive dynamics it is intended to combat. It is imperative that such critical inquiries be based on the experiences of disabled people. Further implications drawn from this study illuminate the importance of investigating and responding to critical issues raised by disadvantaged groups and bringing into focus the social relations that emerge from their accounts. There is a continued need to funnel knowledge drawn from lived experience of disability into policy and decision-making processes. Importantly, disaster planning, management and implementation must include disabled knowledge to prepare for future crises.

COMPETING INTERESTS

The authors have no competing interests to declare.

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Paper III

Paper III

“I think they consider themselves free from all responsibility” Neoliberal Undermining of Welfare Services and its Implications for Personal Assistance Users During the Pandemic

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Abstract

The pandemic brought to the surface various structural and systemic problems facing disabled people. Drawing from semi-structured interviews with eight disabled adults and parents of three disabled children this paper explores the experiences of disabled users of personal assistance (PA) services in Iceland during the pandemic. The findings show that participants encountered significant difficulties during the pandemic, in great part due to the influence of neoliberal market ideology and austerity on the implementation of PA services. Framing the services as a private-sector-inspired contract enables municipalities to evade their responsibilities towards disabled service users, in stark contrast to the social justice and human rights understanding in which the services are embedded. The article is a contribution to research problematizing neoliberal undermining of welfare services and the commodification of fundamental values such as welfare and the human rights of disabled people.

Keywords: Covid-19, Iceland, personal assistance, neoliberalism, responsibilization

“I think they consider themselves free from all responsibility”: Neoliberal Undermining of Welfare Services and its Implications for Personal Assistance Users During the Pandemic

Disabled people were at exacerbated risk in the Covid-19 pandemic for many reasons. It became evident early on that, besides the virus itself, the social and policy responses would serve to jeopardise disabled people’s safety (Shakespeare et al., 2021; Yates & Dickinson, 2021). In the years since, research has highlighted how preexisting systemic barriers and social inequities faced by disabled people and their families played a part in their precarious position in the pandemic (Pearson et al., 2023; Underwood et al., 2021). The onset of the pandemic wrought significant disruption to social infrastructure and welfare services. Governments and service institutions were slow to address disability issues and when they eventually did, their primary focus was on residential services, leaving those with home-based services, such as user-led personal assistance, largely overlooked and left to their own discretion (McAllister et al., 2023; Pearson et al., 2023). Users of self-managed personal assistance (PA) were in a unique position during the pandemic, having difficulties retrieving protective equipment (Kennedy et al., 2021; Leverton et al., 2023) and facing service cancellations (Koon et al., 2022).

Research has highlighted the impact of consumerist, individualistic trends and austerity on the implementation of PA schemes (Hande et al., 2020; Mladenov et al., 2015). The aim of this paper is to explore how disabled people with PA services fared in the pandemic and to address critical issues raised by them. We argue that the implementation of independent living in Iceland has been marked by neoliberal market ideology and austerity and that this placed users of PA in increased precarity during the pandemic.

We begin by delineating the characteristics of neoliberal reasoning and its ramifications on welfare systems. Subsequently, we focus on the Scandinavian welfare systems and Iceland in particular. Finally, we discuss the independent living ideology, PA services, and how they are affected by market ideology before we discuss our study and findings.

Neoliberalism, austerity and welfare systems

Neoliberal ideology has significantly influenced welfare services and disability policy in various ways, involving the implementation of increasingly punitive measures, the imposition of stringent eligibility criteria, and the adoption of workfare activation policies (Soldatic, 2019). Market-based mechanisms have been implemented in the provision of public sector care, such as the purchaser-provider model and the outsourcing of services (Vaittinen et al., 2018) and austerity politics have led to retrenchment and budget cuts under the guise of reform (MacLeavy, 2016; Soldatic, 2019). Austerity-driven reforms have seen a decrease in support and deprivation of choice and autonomy for disabled people reliant on these services (Malli et al., 2018) and have adversely affected the human rights agenda (United Nations, 2017).

By shifting democratic principles into economic terms, neoliberal processes divorce welfare issues from their social justice roots. Bureaucratic and technocratic approaches present cutbacks and anti-welfare rhetoric as apolitical results of management processes, shaping policies to favour neoliberal models as the only feasible options available (Brown, 2015; Hoppania, 2019). Moreover, omnipresent neoliberal reasoning has influenced attitudes towards welfare objectives, placing blame on those who experience structural disadvantage. Accompanying neoliberal restructuring is a robust moral discourse to garner public support for its agenda of welfare reform - its moral justification (Hughes, 2015). It portrays disabled people as potential fraudulent claimants and criticises the system itself for fostering dependency with "hand-outs", rendering it in a recurrent need of reform (MacLeavy, 2016; Soldatic, 2019). Championing self-reliance and individualism, neoliberal restructuring has shifted institutional policies towards increased responsibilization (Frericks, 2014).

The pervasive uptake of neoliberal values is an urgent issue, as disability scholars have reminded us (Goodley & Lawthom, 2019) and poses a danger to disabled people. As Shildrick notes (2019, p. 603) "Precarity may be the default condition under contemporary capitalism, but the slow death to which it consigns individuals and distinct populations remains discriminatory". It is important to recognize how the protections in the Convention of the Rights of Disabled People [CRPD] and disability laws can be undermined by neoliberal principles and values influencing the interpretation of laws, legal reasoning and judgments (Brown, 2017), thus posing a threat to disabled people.

Scandinavian welfare states

The Scandinavian welfare states are considered among the social democratic welfare states - where principles of universalism and collective provision are emphasized. According to Esping-Andersen (1990, p. 47), the crux of the social democratic project consists of 'emancipation from market dependency´. There has been considerable academic focus on the "Nordic model" and its capacity to leverage the productive aspects of capitalism while mitigating its more destructive tendencies as well as a growing scepticism about these mitigating abilities (Oppegaard & Nosrati, 2024). Increased commercialization represents a shift in the dynamics between capitalist and non-capitalist logic (Innset & Rudberg, 2024), leading to the "reorganisation of previously de-commodified welfare services through the implementation of capitalist and marked-based logics and dynamics" (Oppegaard & Nosrati, 2024, p.7).

Recent Scandinavian research has examined the impact of neoliberal restructuring on the Nordic model, such as the widespread privatization of services to older people (Hoppania et al., 2024) and how ableist austerity discourses ignite feelings of shame and guilt (Falster & Ringø, 2023). Norberg (2022) asserts that neoliberal austerity could be construed as a form of bureaucratic violence, implemented in the name of rationality and through administrative procedures and decision-making processes, irrespective of its outcomes and consequences, ultimately resulting in dire repercussions for individuals.

Iceland is perceived to be among the social democratic welfare states, despite having historically been less influenced by social democracy politics than their Scandinavian neighbours and more by liberal individualistic notions (Jónsson, 2019). When it comes to disability policy, Iceland has gone through similar motions as its neighbouring countries: through deinstitutionalisation, decentralization, the adoption of independent living and the CRPD, and, most recently, following the trend towards neoliberalist policies (Tøssebro, 2016). Despite the lack of Icelandic research on the topic, this article argues that the presence of market-like mechanisms in the implementation of welfare services is evident.

Independent living and personal assistance

Independent living ideology emerged from the grassroots movements and its critique of the power professionals wield over disabled people and their authority under traditional service schemes (Mladenov et al., 2023). It is upon the principles of independent living that personal assistance service schemes have been implemented. Article 19 of the CRPD (United Nations, 2006) asserts the right to live independently and community inclusion. Although neither independent living nor personal assistance is defined in the treaty, a general comment provided by the Committee on the Convention (CRPD Committee, General Comment No.5, 2017) states that achieving independent living requires fulfilment of all economic, civil, social, and cultural rights – implying that while personal assistance can contribute to achieving independent living, the fulfilment of this right necessitates additional efforts from the states. Furthermore, the committee stresses the shift from viewing disabled people as 'objects' of charity, medical treatment and social protection towards viewing them as 'subjects' with rights, capable of making decisions on their free and informed consent (CRPD Committee, General Comment No.5, 2017).

Many have warned of the effects of neoliberalist reasoning and austerity on the implementation of PA schemes (Elder-Woodward, 2014; Mladenov et al., 2023). According to Mladenov and colleagues (2015), there is a discernible trend wherein marketization trends supersede the social justice dimensions in the implementation of the services. Furthermore, underfunding has severely curtailed the advantages of the services and the potential for user choice. Norberg (2019) explains how, through "the quiet implementation of austerity", Sweden's austerity measures and strict eligibility criteria have resulted in an increasing number of people losing their PA services. Similarly, efforts to contain costs in Iceland have manifested through alterations in eligibility criteria for accessing PA services (Brennan et al., 2017). In their comprehensive scoping review, Nally et al. (2021) observed that currently, no country offering user-led PA services complies with Article 19 of the CRPD, as they fail to provide adequately funded schemes.

Furthermore, the widespread uptake of the term 'independent living' has seen its misinterpretation and misuse. When divorced from its political history and social justice claims, independent living can be wrongfully construed as being about "living on one's own and without support" (Mladenov et al., 2023). Such strategic use of the term serves to undermine its social justice aims and can render PA services an economically efficient way to marketize the services and facilitate austerity measures. Cost-cutting strategies, marketisation and administrative procedures undermine the core concepts of user autonomy and choice (see for example: Mladenov et al., 2015; Norberg, 2019; Pearson & Ridley, 2017).

PA service schemes in which users themselves oversee the management typically offer the greatest flexibility and user control. They do, however, require substantive work and responsibilities of the user, who must administer budgets, hire and train assistants, and schedule shifts. According to Katzman & Kinsella (2018), these responsibilities remain, for the most part, unfunded and unacknowledged, invisible work. The challenges posed by the pandemic further complicated the managerial and administrative tasks, introducing additional uncertainties and complications (Leverton et al., 2023).

According to official policies and regulations in Iceland (Althingi, 2018a; 2018b) municipalities are responsible for drafting user-led personal assistance schemes and implementing them, regardless of how the assistance is organised and who is responsible for managing the services. The needs-based nature of the service schemes is clearly stated, as "the agreement on support hours is based on an assessment of the user's support needs for the necessary support to live a meaningfully independent life, regardless of disability." [authors translation] (Althingi, 2018b). Previous research on the implementation of PA services demonstrates the service scheme's success. The main challenges have involved the underestimation of users' needs for support, resulting in insufficient funds for the services, and the underestimation of the administrative work and responsibilities that fall on disabled service users

Although previous research demonstrates the service scheme's success, underestimation of users' needs for support has also been reported resulting in insufficient funds for the services, underestimation of administrative work, and responsibilities that fall on disabled service users (Snæfríðar- og Gunnarsdóttir et al., 2016).

The study

Our study is grounded in feminist standpoint theory (Harding, 2004) and critical disability studies (Goodley et al., 2017; Shildrick, 2019) which share an analytical focus on power relations that produce and maintain oppressive social and cultural norms. These frameworks provide the epistemological underpinnings of our project, mark its theoretical orientation and carry methodological implications. In accordance, we place the experiences of disabled people at the centre of the study, not as its object for scrutiny but as its "point of entry" (Goodley et al., 2017; Smith, 2005). Our critical focus was aimed at the social structures and mechanisms experienced by participants during the pandemic. Grounding our analysis in their understanding and cognitive framework, we probed critical issues raised by them and traced the way in which their experiences and daily lives were coordinated and conditioned by oppressive power relations (Smith, 2005).

Mindful that ableist social relations are not exempt in academic research, we the authors, feel it important to briefly note our position. Two of the authors are non-disabled, white, cis women and disability scholars, and the third author of this paper is a disabled white cis woman, a disability scholar who uses PA services in daily life and was a user of such services during the pandemic. Our study is part of a larger project funded by the Icelandic Research Fund that examines the experiences of disabled people during COVID-19 in Iceland (217502-052).

Participants

A purposeful sampling strategy was utilized to enlist participants who could offer comprehensive insights on the topic. An advertisement about the research was posted in a Facebook group for parents with disabled children, disabled people's organizations were approached, and snowball sampling was employed. Semi-structured interviews were used to gather information from eight adult PA service users and parents of three disabled children. The adult PA service users were between 27 and 50 years old and all had physical impairments. In the interviews with parents, two mothers took part and, in one instance, both the father and mother. The children, two boys and one girl were between 6 and 15 years old. They had physical impairments and complex health issues, and all lived in two-parent households. All participants were white, native Icelanders. All but two of the participants lived in the capital region; the other resided in towns with under 20,000 inhabitants.

Data collection and analysis

The first author conducted interviews from September 2021 to April 2023, adhering to an interview guide that centred on participants' experiences during the initial stages of the pandemic. While guided by pre-established topics, the interview guide provided the necessary flexibility to pursue new avenues of inquiry and follow up on interviewee responses (Braun & Clarke, 2021), and a means for acquiring the thorough and detailed information called for by our theoretical framework (Smith, 2005).

A total of fifteen interviews were conducted, two families were interviewed twice and one family thrice, to further explore emergent themes that were not initially part of the interview guide. All interviews were conducted in private settings, primarily through videoconferencing technologies, each about 60-80 minutes long. The first author audio-recorded and transcribed the interviews verbatim.

The interviews were conducted in Icelandic, and direct quotes were translated by the first author. Thematic analysis approach (Braun & Clarke, 2021) was employed and was led by the first author. Co-authors took part in deliberations and in revising the analysis. The third author, a user of PA services, participated in deliberations and the analysis and provided valuable inputs to ensure the accuracy of the findings.

Ethical issues

Prior to the interviews, participants received an introductory letter explaining the research's purpose and the voluntary nature of their participation. It was made clear that they could decline to answer any question and withdraw from the study at any point. This information was reiterated at the beginning of each interview.

Preserving anonymity and confidentiality can prove a distinct challenge in regions with limited populations, such as Iceland. To ensure confidentiality, names and identifying information were left out during transcriptions, and audio files were promptly destroyed after transcription. We furthermore opted to refrain from utilizing pseudonyms or names in both the analysis and the published outcomes. The research proposal was reviewed by the Research Ethics Committee for Public Higher Education Institutions (SHV2021—009).

Findings

In the first months of the pandemic, users experienced unprecedented challenges and uncertainties. The work required of them as self-managers increased exponentially as they were required to adapt to new and unknown circumstances. This involved acquiring protective equipment and guidelines on how to use it, developing new cleaning protocols and directing assistants in navigating daily tasks in ways to ensure safety. Additionally, plans had to be made for how services would continue in the event of illness. In line with Leverton et al. (2023), participants were often uncertain of how to adapt to the frequent changes in rules and restrictions and were acutely aware of their responsibilities as employers. The practical complications brought about by the pandemic disrupted their daily routines, and many had grave concerns about the potential health implications of contracting the virus and how they would manage their services in the event of illness. Although only a few contracted the virus, several participants were seriously affected by service cancellations and the stress and insecurity that unfolded during the pandemic as articulated by a participant:

> There was so much stress and you just prayed to God every night – I the atheist - not because I was afraid for my health but because I was afraid what would happen If I got Covid. Who would assist me and how? What do I do if someone refuses to come to work? Do I just lie here in bed and starve, you know?

In the ensuing sections, we posit that their precarious position in the pandemic can be largely attributed to the neoliberal principles shaping the implementation of PA services in Iceland. Framing the services as a private-sector-inspired contract enabled municipalities to evade their responsibilities towards disabled service users in stark contrast to the social justice and human rights understanding in which the services are embedded.

The three following sections outline the way in which neoliberal principles manifested in users' experiences, prior to and during the pandemic. First, we explain how financial restrictions took precedence over support needs, facilitating a relationship of distrust between the users and the municipalities. The second section discusses the limited institutional knowledge about PA services and independent living ideology within the municipalities which undermined the relationship between them and the users. In the final section, we delineate how – through ideas akin to market relations – municipalities outsourced their responsibility to users.

Resource-based funding and mutual distrust

The relationship between the participants and their municipalities was complex and strained. From the initial meetings, where the users' service requirements had been determined and discussions about funding for the assistance had taken place, mutual distrust soon became a predominant factor. It was clear to participants that municipal staff efforts aimed mostly at keeping costs to a minimum. Met with suspicion and positioned as potential counterfeit claimants (Hughes, 2015), participants were required to incessantly justify and prove their support needs. Ultimately, however, the municipalities' financial restraints took precedence over their needs in the design of the schemes. Demonstrative of this is a dismissive comment a participant got when requesting an increase in their funding: *"she said: 'Yes, but there is very little mood for raising contracts right now' (stemming / humör)"*. Discussions about service provisions were revisited annually and were emblematic of the municipalities' resource-based emphasis in service provisions. One mother likened those meetings to contractual business negotiations: *"It's like it's this business or something. Not like: ´This is what we need´. But it's a business that they're in"*. Despite municipal responsibility towards the disabled service users, their strategies prioritized budget constraints over users' needs

(Berggren et al., 2021). Municipal financial hardships were frequently cited as the rationale for why the service funding was not adapted to their needs and in consonance with those in Norberg's research (2022), participants experienced a sense of powerlessness when confronted with the welfare bureaucracy and its clear efforts to deprioritise their needs and rights. This sense that the municipal staff mistrusted them and did not have their best interests at heart was articulated by one participant:

> I think that [the municipality] was hoping I would just give up and say no. But I never will. And I never got any support from them or anything, this was just kind of thrown at me. And I was just supposed to take care of it myself. Which I am doing.

During the pandemic, inadequate services further exacerbated participants' precarious position. Complications related to assistants taking sick days, quarantine rules and isolations often proved costly to underfunded service schemes. Furthermore, the complicated and taut collaboration with municipalities and the mutual mistrust hindered participants from seeking help from them. As one participant noted: *"it wouldn't be a good idea to tell them that things weren't going well"*. Perceiving that the municipalities distrusted them and were primarily driven by their financial considerations rather than a commitment to supporting users, they believed divulging information about the challenges they faced during the pandemic could result in adverse consequences.

"They don't understand independent living"

One of the main reasons for service cancellations for participants during the pandemic can be attributed to the absence of accessible and clear information about users' rights to services and support during social distancing, quarantine or isolation. The municipalities seemingly did not view it as their responsibility to provide users with any instructions. In fact, the little information users received was provided by other public institutions and by the Icelandic Centre for Independent Living. This information, although important, often proved contradictory and left many users with questions unanswered. Furthermore, participants had limited or no access to support or guidance to help them navigate the fast-changing rules and adapt instructions to their situations. This led, in some cases, to service cancellations as users were unsure of whether they had a right to receive services or were afraid of inadvertently posing a risk to their PA's safety.

The first information users received was from the Quality and Supervisory Agency of Welfare at the beginning of March 2020. The information was targeted towards supervisors of welfare services and included guidelines on how quarantines and isolation should be handled within group homes and residential services. The instructions presupposed institutional house layouts, with separate entrances for staff and spare bathrooms and rooms, which caused some participants to assume that they were ineligible for the services since they could not fulfil those requirements. One participant extrapolated from the information that she wasn´t allowed support and consequently, went without PA assistance when she got ill early in the pandemic: *"I would have had to build partition walls in my apartment, would have had to have a contractor on standby, really, [...]and I just couldn´t put my staff through it, to bring them into such a situation. I mean, I just wasn´t allowed to, and I didn´t want to."*

Some municipalities seemed to have adopted this misunderstanding. One family contacted their municipality about receiving assistance during a family member's quarantine but was told they couldn't bring in assistants as their house did not meet the requirements. As a result, the family was without support for several weeks, during which they were ill and had difficulty providing support for their daughter. They explained:

> We [the family] were quarantined three times, this was when the quarantine was 14 days, and we didn't get any services to our home the first two times. The second time, we all got Covid except for [name of child], and as we didn't get any services or help. She just remained inside the house with all of us who had Covid.

This lack of engagement with users of PA services corresponded with participants' overall experiences of limited municipal knowledge about the service scheme and the independent living ideology as explained by a participant, "*they just don't know anything. They don't understand independent living*". After receiving their PA contracts, participants had been referred to administrative agents within their municipality who then served as their main point of contact. Although responsible for annual contract renewals, they lacked sufficient knowledge and understanding to be of any help when issues arose. The high turnover of administrative staff further hindered these consultants from building relationships with users and gaining the necessary knowledge to support them. This turnover was so notable that some participants found it comical, as evidenced by the account of one participant:

> I have a consultant, but its really only when I have to renew the contract or something like that. There's a new one just starting now, but before that, well I really have no idea who has been my consultant for some time. Well, they change them regularly so I have no idea (laughs).

This lack of engagement with the outcomes of the services does not align with the principles of independent living and hinders municipalities from determining whether the support suffices for users "to live a meaningfully independent life, regardless of disability" (*Reglugerð um notendastýrða persónulega aðstoð 1250/2018*). It furthermore implies that service implementation is divorced from the political underpinnings of the service schemes (Hoppania, 2019) and that municipalities view the services as "technical solutions providing basic needs" (Rice et al., 2015, p.137). Illustrative of this was a participant's experience of municipal administrative staff trying to persuade her to accept a decrease in her funding. Using condescending flattery and conflating the idea of independence with self-sufficiency and ultimately, not needing support, their priority was on cutting costs (Mladenov, 2023):

> She was trying to decrease my contract and said something like: 'But you just look like you are so independent and cool'. You know, they are always trying to take this from me.

Participants understood the limited institutional knowledge within municipalities to be part and parcel with their overall lack of engagement with PA users.

"They´re just off the hook"

Garnered from their experience and communication with the municipalities, participants understood that, by opting for the PA scheme, they could not seek any further support from the municipalities. This was the case, even in situations such as a pandemic, which could reasonably change their service needs. As one mother of a disabled child elucidated, users had to manage with the resources available to them:

> No, its just this budget. Like during Covid when we all got sick and there were these three or four weeks where we all got Covid and then his PAs got Covid and we had no one – and I can't go to the municipality for any support or anything. I think they consider themselves free from all responsibility.

This understanding permeated throughout the data, that by providing (often insufficient) PA schemes, municipalities had fulfilled their duties towards them so that "*we can't use any of their other services and they´re just off the hook*". This understanding was also evident in municipalities' responses in the pandemic and can be gleaned in the lack of information provisions to PA service users discussed in the previous section. It was furthermore evident in a municipality's response to a participant, who got ill in the early months of the pandemic and couldn't procure protective equipment. She called her municipality offices to see if they could spare any protective equipment, but they clearly signalled their limited responsibility: *They said no, they just said I was responsible for my own services*".

It seems that the implementation of the PA services is perceived by the municipalities as a form of outsourcing. Users' rights to services are exhausted, and the users' welfare becomes their own self-responsibility (Frericks, 2014) – the municipalities are "off the hook" - irrespective of the social justice goals underpinning the services. Instead of being viewed as 'subjects with rights' (CRPD Committee, General Comment No.5, 2017) users are construed as contractors with responsibilities. If the users needed additional or more help, they would have to forfeit their PA and opt for residential services:

> I've never felt that I could look to the municipality for anything. It's just like: If I want this [PA], I have to bear the brunt, or I can move to a group home or residential services and get a supervisor to assist me.

During the pandemic, the municipalities turned a blind eye to various difficult and often dangerous situations that arose among disabled people with PA contracts as they apparently understood their obligations to these disabled citizens having been fulfilled by PA service contracts. This was a recurring theme among the participants as underlined by one participant:

> I just found it unbelievable to hear, you know, how many people weren't getting any assistance because of fear of infection for example. And I just thought it was awful to hear. Because the municipalities took no responsibility. So, people didn´t have any assistance or very little assistance.

Concluding discussion

The unique circumstances that unfolded in the pandemic exacerbated the precarious position of disabled people, exposed ableist social structures under duress, and rendered users of self-managed personal assistance in a unique position. Our findings demonstrate that their precarity was exacerbated by the influence of market ideology and individualism on the implementation of PA services, leaving users with underfunded services (Nally et. al., 2021) and unacknowledged administrative tasks (Katzman & Kinsella, 2018), and enabling municipalities to distance themselves, evading responsibility (Frericks, 2014). When operating from neoliberal reasoning, disability services are untethered from their political history, undermining the very goals at the heart of the CRPD and disability legislation. This "depolitization" (Hoppania, 2019) furthermore facilitates the widespread misinterpretation of independent living ideology. Instead of recognizing the services as disabled people's right and a means to ameliorate their systemic discrimination and exclusion, PA services have seemingly been embedded in the realm of market logic (Brown, 2015) where service users are understood as contractors that, first and foremost, have contractual obligations. The relentless and unchecked pursuit of efficiency has furthermore led to the general acceptance of underfunding essential services. Importantly, as Mladenov et al. (2015, p.35) argue "sometimes, emancipation costs more, not less".

During the pandemic, the managerial and administrative tasks increased exponentially, as did the uncertainties, risks and complications PA users faced. However, accountability and responsibility cannot be outsourced from governing bodies and municipalities cannot contractually delegate their responsibilities towards social justice objectives to service users. Furthermore, PA services do not shield disabled people from the structural factors that have served to marginalize them, and providing such services does not let municipalities "off the hook".

It is evident that ubiquitous market ideology influences and undermines welfare services in the Nordic countries (Berggren, et al., 2021; Hoppania; 2024; Norberg, 2022). We are concerned about the increasing punitive focus and responsibilization this has fostered, as well as the accompanying ableist rhetoric that justifies and perpetuates it. Furthermore, as researchers examining the experiences of disabled people during the pandemic, we are left with a disquieting apprehension about the absence of reflection and introspection in the aftermath of the crisis. It is important that the Nordic welfare systems reflect on the impact of the pandemic and learn from the experiences of disabled people to determine what changes need to be made and how we proceed from here.

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Paper IV

Scandinavian Journal of Disability Research
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The Digital Exclusion of People with Intellectual Disabilities During the COVID-19 Pandemic

RESEARCH

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ABSTRACT

This article aims to explore whether and how people with intellectual disabilities in Iceland were using information and communication technology during periods of COVID-19-related social restrictions, as well as examine barriers to their access to and use of such technology. The study uses two sets of data. Survey data were collected from disabled people (n = 412) and data from focus group interviews with people with intellectual disabilities (n = 16) were used to expand and elaborate on the survey results. Contrary to previous research findings, socioeconomic status was not a significant barrier to digital access for the participants. However, the study's results shed light on several intersecting socio-cultural hindrances that contributed to the digital exclusion of participants. The study is a contribution to a critical discussion on technological advancements, digital access, and uses that highlight the barriers derived from ableism.

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KEYWORDS:
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INTRODUCTION

Iceland lifted all national COVID-19-related restrictions in February 2022, two years after they were first imposed. Initially, the authorities implemented relatively mild restrictions compared to other European nations, despite high numbers of tests and confirmed cases (The Directorate of Health and The Department of Civil Protection and Emergency Management n.d.). Nevertheless, the pandemic strained Iceland's healthcare, education, and social service systems, exposing multiple layers of discrimination faced by disabled people (Snæfríðar- og Gunnarsdóttir, Ólafsdóttir & Björnsdóttir 2023; Tryggvadóttir, Snæfríðar- og Gunnarsdóttir & Sævarsson 2021). In this article, we explore the experiences of people with intellectual disabilities during the pandemic, focusing on their use of digital technology and the barriers they faced during a period of rapid digitalization through the lenses of data feminism and critical disability studies.

During the pandemic, digital technologies emerged as a proposed solution to mitigate the pandemic's negative impacts on daily life and support well-being during social distancing. This led to increased digitalization, with remote platforms evolving significantly for work, education, and social interactions (Galea, Merchant & Lurie 2020). While many disabled people benefitted from this, research shows that the shift to digital options during the pandemic exacerbated existing structural disparities for others, deepening the digital divisions between disabled people and non-disabled people (Cho & Kim, 2022; Hankerson & Brown 2021; Scanlan 2022).

When it comes to access to and use of technology, a persistent disparity exists, commonly called the digital divide (Van Dijk 2017; Gorski & Clark 2002). Digital disparities are embedded in a broader social power dynamic as disenfranchised groups are left underrepresented in education, employment, and healthcare (Goggin 2017; Hankerson & Brown 2021; Ragnedda 2017; Saeed & Masters 2021; Sostero et al. 2020). Importantly, research suggests that the disability digital divide is most prevalent among people with intellectual disabilities (Chadwick, Wesson & Fullwood 2013), who consequently were at exacerbated risk of being negatively affected by the acceleration of digitalization during the COVID-19 pandemic (Chadwick et al. 2022). For these reasons, the pandemic provided a unique opportunity to learn from the experiences of people with intellectual disabilities and revisit the concept of the digital divide.

BACKGROUND

The understanding of social disparities in technology access and utilization, commonly called the digital divide, has progressed over the past few decades in tandem with the rapid pace of advancements in digital technologies and use. Since the 1990s, Internet use has become commonplace with the widespread availability of digital devices. In the early days of the Internet, limited and costly access resulted in disparities in Internet infrastructure availability, known as the first-level digital divide (van Deursen & Helsper 2015; Lutz 2019). These disparities have decreased since the Internet became widely used (Hargittai & Hinnant 2008). However, socioeconomic factors remain significant barriers to access to digital technology (Scheerder, van Deursen & van Dijk 2017).

Digital divide research has been criticized for the oversimplification inherent in the binary distinction between those with access and those without access to technology (Brock 2016; Hargittai & Hinnant 2008). To capture a more nuanced scope of digital disparities, Hargittai and Hinnant (2008) suggest focusing on different types of Internet use and digital skills, describing them as the second-level digital divide. Given the unique barriers faced by disabled people, such as a lack of adaptive devices, educational disparities, and non-inclusive digital design, it is essential that conceptualizations of the digital divide incorporate an understanding of their social circumstances and experiences specific to them.

A more recent conceptualization of the digital divide concerns its third level, which extends the first two levels and focuses on the offline impact of Internet use (Blank & Lutz 2018; van Deursen & Helsper 2015; Lutz 2019). The third-level digital divide conceptualizations address Internet use and outcomes in economic, social, political, and cultural terms (Lutz 2019). It shifts away from a deficit-based digital divide model, which posits that barriers to digital use stem primarily from individual characteristics (Brock 2016). Although the third-level digital divide literature brings more depth to the concept, perspectives of disabled people remain excluded for the most part. A nuanced understanding of digital disparities that incorporates the experiences of disabled people is imperative, not only for research purposes but because these concepts serve as crucial measurements taken up and utilized by policymakers (van Dijk 2006). Therefore, researchers must scrutinize the social forces and structures that underlie and perpetuate technological inequalities and disparities. This is the aim of this paper, where we approach the digital divide concept from critical disability studies (CDS) and data feminist perspectives.

At its core, CDS is a critical theory that scrutinizes societal structures that perpetuate discrimination and exclusion of disabled people in society and the ableist assumptions and norms that underlie them. Ableism is manifested in various forms, including inaccessible spaces, damaging discriminatory policies, and attitudes that view disabled people as inferior or abnormal (Bogart & Dunn 2019; Meekosha & Shuttleworth 2009). CDS recognizes the non-normative body as a site where dynamic social, symbolic, and materialist forces merge to challenge and disrupt conventional understandings and illuminate ableist standards. By doing this and drawing on diverse critical perspectives, CDS opens up new avenues of critique and potential lines of inquiry to explore and articulate the intricate and intersectional nature of ableist power dynamics (Goodley 2013). Thus, CDS provides a framework for understanding how people with intellectual disabilities are made to 'feel abnormal, dependent, and excluded' within society (Peddogrew 2023: 146). It works to deconstruct notions of norms by revealing ableist standards formed upon political, cultural, and social structures (Goodley et al. 2017) and re-think who should be included in the discussion on disability and, for example, technology.

Ableism significantly influences technological imagination. Shew (2023) coined the term 'technoableism' to describe the pervasive belief that technology can eliminate or solve all disability issues. This form of ableism arises from a societal focus on individual fixes rather than addressing underlying social injustices (Jaeger 2012; Shew 2023). Similarly, Charitsis and Lehtiniemi (2022) introduced data ableism to describe ableist norms embedded in technology. Data ableism involves data politics, processes, and practices that prioritize the non-disabled experience, thereby privileging specific data-related abilities and digital engagement forms. The technoableism and data ableism concepts align with data feminism (D'Ignazio & Klein 2020a), which urges examining how power operates in data science and challenges injustice and oppression. In this article, we respond to D'Ignazio and Klein's (2020b) call for equitable and actionable COVID-19 data by attempting to unpack the nuances and power relations in digital use for people with intellectual disabilities. By adopting a data-feminist approach, we can identify and challenge technological practices and understandings that perpetuate inequalities and work towards more inclusive and equitable digital futures for people with intellectual disabilities from their perspectives.

MATERIAL AND CONTEXT

The study was carried out in Iceland, which maintains a Nordic social welfare system. Universal healthcare is provided, and disabled people are, by law, entitled to general services and support. In Iceland, most adults with intellectual disabilities are in residential care, provided by the municipalities. These are clusters of flats or small group homes where several people share support staff. Some people live on their own or in social housing and receive no or minimal support.

We used two sets of data drawn from a larger research project, *Disability in the Time of Pandemic*, which focuses on the experiences, health, and well-being of disabled people during the COVID-19 pandemic. The first set of data comprises survey data from the Social Science Research Institute of the University of Iceland (SSRI), gathered during the third wave of COVID-19. The second data set consists of information collected in three focus group interviews. This integration of quantitative and qualitative data enabled deeper probing of critical issues arising from the survey results in collaboration with focus group participants to ensure that conclusions drawn were meaningful and relevant to them.

SURVEY DATA

The survey was conducted by the SSRI from the 16th of September to the 8th of December 2021 and was funded by the Ministry of Social Affairs and Labour. A random sample of 809 was chosen from individuals who use services according to the Act on Services for Disabled People with Long-term Support (Ministry of Social Affairs and Labour 2018), and they could choose to receive the questionnaire online or via mail or participate by phone. The survey had a 51% response rate (n = 412). Over half of the participants responded by phone (n = 201; 51%), followed by online (n = 177; 43%) and mail respondents (n = 25; 7%). The sample comprised 46% women (n = 189) and 54% men (n = 223) aged 18 or older. People with intellectual disabilities comprised 38% (n = 144) of the survey respondents; we focus on their experiences in this article.

The questionnaire was based on a health questionnaire from a previous research project focusing on the health of disabled people (Snæfríðar- og Gunnarsdóttir 2017). This version of the questionnaire included questions about COVID-19, and to ensure the inclusion of questions about important pandemic-related issues, it was customized accordingly and amended in collaboration with members of the disability movement in Iceland.

From the survey dataset, four variables were utilized to gather information on: 1) the type of impairments; 2) subjective economic strain; 3) the frequency of communication with friends and family via phone or social media during the pandemic; and 4) living arrangements. The subjective measure of economic strain is a question commonly used in cross-national collaboration surveys. Statistical tests were performed in Jamovi 2.2.5.

Participants could answer the questionnaire online, via mail, or participate by phone. All three methods depend on data-related abilities and specific forms of digital engagement. The survey was made available in an easy-to-read format to facilitate the participation of a broader group. In cases where respondents needed support to participate, assistants and family members were asked to assist them. In 61% of cases, service users answered independently, 17% received support to answer, and in 23% of cases, personal assistants or family members answered on behalf of service users.

The survey has limitations, most notably that the sampling frame only includes people who receive services from the municipalities, excluding those who do not use any services. The reason for this exclusion is the absence of official records for disabled people who do not receive services. The lack of statistical information about disabled people affects policymaking and resource allocation. By prioritizing non-disabled experiences and offering no disability statistics, public institutions responsible for collecting social data contribute to systemic, data-driven discrimination against disabled people in Iceland (Charitsis & Lehtiniemi 2022; D'Ignazio & Klein 2020a).

FOCUS GROUP DATA

Focus groups were used to gather qualitative data as they yield much information in a relatively short time and have the potential to generate diverse and sometimes conflicting information (Creswell & Creswell 2018). The purpose was to create a setting where participants could interact with one another and with the moderator and spark discussions about their experiences during the pandemic. Three focus group interviews were conducted. The first two took place in November 2021, when social restrictions were lifted temporarily. This was followed by a period of stricter restrictions, and therefore, the third and last focus group was carried out in January 2023.

The participants were selected by purposeful sampling (Creswell & Creswell 2018). The selection criteria were as follows: (1) individuals with intellectual disabilities; (2) aged 18 or older; (3) interested in sharing their experiences; and (4) had taken college courses under an inclusive vocational diploma program for students with intellectual disabilities. In addition, some kind of computer training or further education was considered advantageous as it provided possible participants with valuable insights into the specific challenges and barriers they had encountered accessing and using digital technologies. A total of 16 people participated (8 women and 8 men), aged 22–40. Half of the participants had completed their compulsory education in inclusive settings, while others had attended segregated special schools for disabled children. All focus group participants had been in self-contained special education classes in mainstream upper secondary schools. Additionally, they had completed a vocational diploma from the University of Iceland.

The focus group interviews were held at the University of Iceland and were recorded and transcribed by the first author. We encouraged the participants to freely discuss their opinions and experiences during the focus groups, using the survey results as references.

Conscious of the inaccessibility of traditional interview research methods and the need for researchers to respect and recognize alternative modes of communication (Goode 1994), we adapted the length of the interviews to the wishes and needs of the participants, who found it difficult to participate in long sessions. Therefore, one group lasted 20 minutes and two groups a little over 40 minutes. We furthermore engaged in individual meetings with the participants to ensure that our findings accurately reflected their perspectives. This approach, akin to member-checking (Creswell 2012), helped validate the trustworthiness of our findings.

We used Braun and Clarke's (2022) six stages of reflexive thematic analysis. In the first phase, all three authors familiarized themselves with the datasets and jointly discussed similarities between the two datasets. The second phase consisted of initial coding, primarily done by the first author. Subsequently, in the third phase, initial themes were generated by the first two authors. The fourth phase involved further development and review of the themes that had developed in prior stages. At this point of the analysis, barriers to participants' access to digital technology had become a prominent theme, bringing us to the digital divide concept. In the fifth phase, these themes were refined further collaboratively by the first two authors, guided by the analytical framework provided by CDS (Meekosha & Shuttleworth 2009) and data feminism (D'Ignazio & Klein 2020a). Finally, the findings were written, and the two datasets were interwoven. Direct quotes were translated from Icelandic to English by the first two authors.

ETHICAL CONSIDERATIONS

Importantly, research is not exempted from the broader ableist social context. Indeed, oppressive societal relations can be accentuated and amplified in knowledge creation (disability studies being no exception). It is worth noting that all authors are non-disabled and, therefore, do not share the lived experiences of the oppressive power structures explained by the research participants. Taking a cue from Morris (1992), we turn our spotlight on the ableist structural domain and how power dynamics and prejudices, baked into the social fabric, harm disabled people. With our work, we aim to contribute to both scientific and practical knowledge about structural inequalities encountered by disabled people, which in turn will hopefully benefit their material circumstances.

Throughout the study, we adhered to ethical research practices. The research proposal was reviewed by the Research Ethics Committee for Public Higher Education Institutions (SHV2021-009). Before the focus group sessions, participants were informed of the study's nature and purpose and of their right to withdraw or terminate their participation at any time. Importantly, this information was presented in an accessible format, and care was taken to ensure each participant's opportunities to raise questions and discuss their participation. To protect the participants' anonymity, identifiable background information was omitted, both in the analysis phase and in the published findings. The survey received ethical approval from the National Bioethics Committee (VSN-21-049).

FINDINGS

During the COVID-19 pandemic, the digital divide seemingly intensified, particularly among marginalized groups (Hankerson & Brown 2021; Scanlan 2022; Vargo et al. 2021). As disabled people comprise a heterogeneous group inhabiting diverse social locations, the digital divide is unlikely to have an equal impact on them, and this was evident in the survey findings. Most survey respondents (68%; n = 269) had frequently or very frequently been in contact with family members, friends, or other people via phone or digital technology in the autumn of 2021. To determine whether there was a difference among groups with different impairments, a chi-square test was conducted, which showed that people with intellectual disabilities were less likely to have used a phone or digital technology ($x^2 = 19.5$, $p < 0.001$) than disabled people with other impairments. More specifically, 25.2% of the people with intellectual disabilities never or almost never used a phone or digital technology to contact others, as opposed to 9% of the people with other impairments.

PERCEIVED ECONOMIC STRAIN

Lack of access to digital technology is most often linked to socioeconomic status (Scheerder, van Deursen & van Dijk 2017). In addition to ranking among one of the highest in household Internet access (NORDICOM 2021), Iceland provides a welfare system, potentially decreasing the effects of economic precarity on the disability digital divide among the Icelandic population. When asked about perceived economic strain, around a quarter of the survey participants (n = 93) reported that it was very or rather difficult to make ends meet. Using the same dataset, an SSRI report (Tryggvadóttir, Snæfríðar- og Gunnarsdóttir & Sævarsson 2021) compared these results to those of a general sample of Icelandic citizens and found that disabled people were more likely to report financial hardship and experienced more difficulties in accessing medication and groceries during the pandemic than non-disabled people. This corresponds to international findings that establish disabled people as being more likely to experience economic hardship and poverty than non-disabled people (Friedman 2022). A more exclusive look at participants with intellectual disabilities revealed that approximately 13.8% reported difficulties in making ends meet. However, when examining phone or digital technology use to contact family members, friends, or other people during the pandemic, the chi-square test showed no difference between disabled people who reported financial difficulties and those who did not indicate such problems.

Although socioeconomic status did not seem to be a significant barrier to digital access for people with intellectual disabilities, we identified several intersecting sociocultural barriers that contributed to the participants' digital exclusion during the pandemic in the focus group data. Four main themes regarding barriers to the participants' use of information and communication technology were constructed related to a) non-disabled people's paternalism (staff and family); b) lack of digital training and access to education; c) quality of disability services and support; d) and lack of inclusive technological design and data presentation.

BARRIERS TO DIGITAL ACCESS – PATERNALISM

According to the survey results, a substantial portion of people with intellectual disabilities rarely or never used a phone or digital technology during the pandemic to contact others, raising concerns about the social structures that may hinder digital access and use. While most (73%) of the focus group participants used technology daily, they were aware of negative or paternalistic attitudes toward their Internet use and highlighted them as significant barriers for people with intellectual disabilities. Four focus group participants stood out in terms of Internet access. They had limited social media presence and restricted Internet use, as their parents or support staff were 'in charge' of their social media use. Two of these were in their late twenties and lived at home with their parents and explained that they were not 'allowed' to own computers or use the Internet. The other two participants were in residential care and had access to computers and digital devices but rarely logged on, even during the pandemic. These participants had been told by non-disabled staff and family members that the Internet was 'not for them', that it was too complicated and risky to navigate. One explained, 'My mom takes care of this completely. She manages Facebook'. Although these four participants were in the minority, their experiences correspond to previous research reporting caregivers' negative perspectives about the Internet usage of people with intellectual disabilities (Heitplatz, Bühler & Hastall 2021; Löfgren-Mårtenson 2008). Prohibiting people with intellectual disabilities from using the Internet is commonly done under the guise of preventive and safeguarding measures as a way to shield them from online scams, cyberbullying, harassment, and grooming by predators (Chadwick, Quinn & Fullwood 2017).

The focus group participants discussed these paternalistic attitudes or fears and unanimously agreed that digital citizenship training would be a more feasible way to protect people from possible harm. Such dialogue would make them more capable of navigating the negative aspects of the Internet and aid them in actively participating in making the Internet a safer space for everyone. A man in his early twenties explained, 'Everyone needs to know about digital citizenship and the risks of the Internet like addiction and bullying…You have to be responsible and report any type of bullying you see on the Internet'. Another young man added, 'Maybe the [support] staff needs to be educated about the Internet and that we have the right [to use it]'.

For participants, their lack of access to the Internet and technological use was not due to lack of availability of devices or socio-economic status, as suggested by first-level digital divide research. Rather, their access was hindered by ableist power dynamics, namely the assumption that non-disabled people were better equipped to determine what was in the participants' best interest. These results echo previous findings and the fact that people with intellectual disabilities are often perceived as vulnerable and needing care and oversight (Björnsdóttir, Stefánsdóttir & Stefánsdóttir 2015). Furthermore, such attitudes tend to prioritize the needs and preferences of parents and support staff over those of people with intellectual disabilities (Carlson 2001).

BARRIERS TO DIGITAL ACCESS – DIGITAL TRAINING AND EDUCATION

The focus group participants agreed that lack of access to digital training and education was a significant barrier for people with intellectual disabilities. Those who had attended a segregated special school reported minimal computer education prior to college. Their education had mainly focused on life skills, with little emphasis on digital literacy. This corresponds to previous research, which shows that students in segregated special education settings often face low expectations and are excluded from educational activities such as Internet training. At the upper secondary level, emphasis is placed on life skills and vocational training over digital literacy (Björnsdóttir 2014; Sigurðardóttir 2013).

A similar disregard for people with intellectual disabilities' need for digital technology was apparent in the daily press briefings broadcast on TV and radio during the pandemic. During periods of social restrictions, the Directorate of Health and the Chief Epidemiologist held press briefings where they frequently addressed the circumstances of older people and encouraged caregivers to teach seniors digital technology so they could maintain their social connections. A woman in her late twenties from a focus group criticized that similar needs of disabled people were overlooked, explaining, 'It is not very good when they [disabled people] do not know how to use Zoom. People will simply isolate themselves if they do not know how to use the computer or anything [social media]'.

Focus group participants claimed that in their limited digital education, there had been no introduction of assistive technology that could help them to navigate the Internet or facilitate their technology use, and none of the focus group participants had access to any such assistive digital devices during the pandemic. This is in line with research that shows that people with intellectual disabilities are less likely to use assistive technology than other disabled people (Boot et al. 2018). The availability of such technology seems dependent on various factors and often comes down to individual educators' or staff's interests, knowledge, and attitudes towards people with intellectual disabilities, as well as policies stating who is eligible to apply for it. Technoableism, the prevalent notion that technology can 'fix' the problem of disability, is embedded in the development of assistive technologies. Furthermore, despite being the intended beneficiaries, disabled people are often excluded from the development process of such technology (Shew 2023). However, when it comes to people with intellectual disabilities and their access to assistive technology, technoableism seems intertwined with cognitive ableism—the ubiquitous belief that people with intellectual disabilities think and process information at a level that is inferior to that of people who do not have intellectual disabilities (Carlson 2001)—resulting in digital exclusion.

Despite these barriers, participants had found various methods to assist their Internet and social media access. They primarily learned from peers, classmates, and friends to use applications such as text-to-speech applications, word prediction software, speech-to-text add-ons, and grammar checks. Notably, Icelandic language support in information communication technology has improved, benefiting people with intellectual disabilities during the pandemic by making the Internet more accessible.

BARRIERS TO DIGITAL ACCESS – QUALITY OF SERVICES AND SUPPORT

Digital use is often defined in ways that prioritize non-disabled engagement, overlooking the diverse intersections disabled people have with technology (Jaeger 2012; Shew 2023). Many participants in the focus group demonstrated digital use that differed from typical definitions of digital access and use, reflecting broader, more relational digital engagements. An example of diverse technological engagement is the case of the four participants who had restricted computer access. Despite not using computers, they owned smartphones and used several different applications, such as a digital bus pass, a clock, and a text/audio message application. They furthermore watched content through streaming services and used the devices as phones. Their way of using technology aided them in everyday life and helped them become more independent. Research that focused solely on acts such as retrieving information from the Internet or posting on social media would easily have overlooked the diverse digital technology uses of participants. Relational use of technology, with the assistance of support staff, family, and friends, was common among participants. A man in his thirties who is physically unable to use digital technology but has learned how to navigate the Internet and use digital devices through his personal assistants, explained his digital use thus, 'I use technology through my assistants. It is never a problem except when the technology does not work. That happens a lot. All my assistants know how to use digital technology, and if they don't, I teach them. It works well for me'.

The success of relational use hinged on the quality of support that the participants received. Several participants discussed being in college during the pandemic and the shifting requirements that arose due to remote learning. The available support to enable them to adapt to these changes differed substantially among the participants. A woman in her early twenties said:

> It was obvious that some students needed more help, but nobody at home—their parents or siblings—knew how to do this [use communication platforms]. And for the people living in group homes, it was obvious that they did not get any help. They often missed classes. Nobody at home told them when to log on, or nobody helped them log on.

It may seem counterintuitive that people living in group homes with 24-hour support receive less assistance with technological issues than those who have less support in daily life. However, research before the pandemic has demonstrated that the quality of the services provided in residential care has not been in line with policy goals (Jónsdóttir and Egilson 2013). To compare the use of phone or digital technology between people with intellectual disabilities living independently and those in residential care in the survey data, we performed a chi-square test. The majority (73.4%) of survey participants living independently reported using a phone or digital technology frequently or very frequently to contact their family members, friends, or other people during the pandemic. Those who resided in assisted living settings were less likely to use a phone or digital technology ($x^2 = 24.2$, $p < 0.001$) compared to other disabled people. More specifically, 27.1% of those in residential care never or almost never used a phone or digital technology to contact other people, as opposed to 9.7% of those who lived independently. These findings indicate that social interactions, such as through digital devices, are not prioritized within service entities struggling to provide essential support.

The option of using technology during the pandemic was important to most of the participants. An example of online opportunities was described by a man in his early thirties who was in residential care. He was independent in technology use and had remained active during the first wave of the pandemic through various online engagements: 'Zoom saved us. My theatre and music groups met on Zoom. There were even Zumba classes on Zoom, which was very nice'. Other focus group participants, especially those who required more support, claimed, however, that they had missed many online opportunities during social restrictions as they did not know where to look for them. A young man who was housebound during most of the pandemic because he needed to shield explained the importance of digital technology to him:

> I could use technology during COVID. I was lucky in a way. I had quit my job, so I was not doing anything anyway during COVID. I could talk to people on Messenger, but I was not going out meeting people. I used Facetime or the phone and stuff. My personal assistants assisted me [in accessing technology], but they had to wear protective gear when I was in quarantine. They were like aliens [laughs]. This was boring, but you just must go through this; [there is] nothing you can do about it…I was in contact with my mum and nan and my family and watched Netflix… Technology helped me a lot during the pandemic. I used the technology to access TV; otherwise, I would not have anything to watch except the ceiling in my room.

His use of technology and the Internet had clear offline benefits, as emphasized in third-level digital divide conceptualizations, keeping in touch with his family during the pandemic and for entertainment purposes.

BARRIERS TO DIGITAL ACCESS – DIGITAL DESIGN AND DATA PRESENTATION

Focus group participants had all encountered significant challenges with digital technology, particularly navigating websites and using communication platforms during the pandemic. One focus group participant described the difficulty of learning to join an online activity, initially feeling overwhelmed because he did not have much faith in his own digital abilities: 'I thought to myself that I could not learn this', and then a relief when he figured it out. Participants had struggled to retrieve pandemic-related information from the official COVID-19 website. Although the United Nations (n.d.) urged governments to provide reliable information about global and national COVID-19 developments digitally, the Icelandic COVID-19 website lacked accessible information or easy-to-read alternatives and proved inaccessible to participants. To demonstrate this to us, four focus group participants scrolled through the website, explaining the accessibility barriers they encountered. The official information website clearly did not meet accessibility standards, which is of great concern. The website's design and content privilege non-disabled experiences and information processes, emblematic of data ableism (Charitsis & Lehtiniemi 2022; D'Ignazio and Klein 2020a), and, as a result, participants could not use the information on it to their benefit. Some focus group participants had accessed information provided on the National Association for People with Intellectual Disabilities website but were disappointed that it mainly provided information about personal hygiene and social distancing rules, with no details about the pandemic's development. Other participants relied on family members and support staff for pandemic-related information.

During the pandemic, a digital acceleration took place in different spheres of public administration, which affected the focus group participants in various ways. For example, municipalities stopped accepting hard-copy applications for support and services and instead made forms available online. Applicants needed an Internet connection, devices, digital skills (or assistance), and electronic identification to access the forms. The electronic ID is saved to the SIM card of a mobile phone, and the user selects a PIN that they type in each time they use their electronic ID. According to the Digital Iceland webpage, electronic IDs are supposed to 'make our lives easier and are simple to use' (Digital Iceland n.d.). However, regulations pertaining to the identifications excluded many people with intellectual disabilities from obtaining them, as the process requires individuals to choose a PIN and enter it into the phone without assistance. Consequently, many people could not communicate with healthcare service providers, get results from COVID screenings, obtain information about vaccine appointments, obtain prescription drugs, or give others power of attorney. This hastened development of digital government caused a great deal of stress and hassle for the participants. A couple of focus group participants were not approved for electronic IDs, and none were able to navigate and use the service platform without support. A man in his thirties who resided in assistive living settings described the difficulties some of his housemates encountered during the pandemic as they did not have electronic identifications:

> It was a hassle for these people. They could not even get their medication or access online banking. One guy who used a ventilator had to go in an ambulance to the electronic identification service provider to apply for his identification. There is this rule that you must physically show up at this office.

The adoption and uptake of digital public services breaches the Convention on the Rights of Persons with Disabilities, which clearly states that disabled people should be allowed support in exercising their legal capacity (United Nations 2007, Article 13). It furthermore perpetuates a system that disregards people with intellectual disabilities, reinforcing their societal marginalization.

DISCUSSION AND CONCLUDING REMARKS

The aim of this article is to explore people with intellectual disabilities' technology use during the COVID-19 pandemic. Using a combination of survey data and qualitative data, we explored the disparate use of technology in the pandemic, how it relates to social inequalities, and to what extent it aligns with common conceptions of the digital divide. In short, our findings show that people with intellectual disabilities' lack of access to information and communications technology does not reflect their abilities or limitations but results from systemic barriers preventing them from accessing and using digital technology.

Although socioeconomic status did not appear to be a significant barrier to digital access for people with intellectual disabilities in Iceland, we identified several intersecting sociocultural barriers that contributed to digital exclusion during the pandemic. These findings highlight how power relations are deeply embedded in societal institutions and everyday experiences (D'Ignazio & Klein 2020a). Our research indicates that people with intellectual disabilities experience discrimination within the structural and disciplinary domains of power (D'Ignazio & Klein 2020a), leading to digital exclusion, a situation exacerbated in the pandemic. Consistent with previous research (Chadwick, Wesson & Fullwood 2013), we attribute the first-level divide, the lack of digital access (Lutz 2019), to the quality of support and societal attitudes that can hinder people with intellectual disabilities' use of and access to the Internet. People with intellectual disabilities often face paternalism and belittling attitudes, and their perceived vulnerability is used to justify blocking their access to digital technology (Löfgren-Mårtenson 2008). This paternalism stems from ableism, which circulates through society as part of the hegemonic power domain, enabling discriminatory policies and practices. It shapes and reinforces notions about who holds power and who does not (D'Ignazio & Klein 2020a; Goodley 2013).

Our findings further indicate that people with intellectual disabilities lack access to quality education and computer training opportunities. Some of the research participants lacked digital skills and were not able to access the Internet independently, which reflects the second-level digital divide (Lutz 2019). It is crucial to recognize that these educational disparities stem from ableist beliefs about the learning abilities and societal roles of people with intellectual disabilities. Our findings support previous findings that digital education is not prioritized for people with intellectual disabilities (Sigurðardóttir 2013) and suggest that they are perceived as unable to acquire such skills or that digital access is not important for their social participation. Deficit-based digital divide models (Brock 2016) that view people's impairments or limitations as the main barriers to digital access perpetuate cognitive ableism (Carlson 2001). Instead of focusing on people with intellectual disabilities as lacking the technological know-how, we argue that attention should be paid to the discriminative structures that create barriers to accessing technology, requiring digital skills.

Our findings demonstrate that people with intellectual disabilities can be digital users, though some may require support to access successfully technological devices and software. They, however, experience discrimination within multiple and intersecting domains of power. During the pandemic, their lack of access to technology was in great part due to belittling attitudes, as well as understaffed homes, untrained support staff, and a strained social service system. Research has highlighted the various factors that have negatively affected services and hindered disabled residents' agency and decision-making, such as lack of resources, training, and support. Although this strain had been reported before the pandemic (Jónsdóttir & Egilson 2013), it worsened during it.

It is important to acknowledge that most people with intellectual disabilities do not have jobs that require them to access or use the Internet. We believe that previous digital divide research has a too narrow focus, privileging Internet use for learning and work purposes. In contrast, people with intellectual disabilities might use it for leisure (online games) or use digital devices for purposes such as bus passes or Netflix. This type of engagement had been positive for the participants before and during the pandemic, fostering their independence and social participation and improving their digital skills. We suspect that researchers and policymakers may dismiss this type of technological engagement, along with relational access to the Internet through support, as non-use of digital technology.

When exploring the disability digital divide, it is also important to critically examine the technological developments and designs shaped by the current configurations of structural privilege and structural oppression (D'Ignazio & Klein 2020b). Over 20 years ago, Gorski and Clark (2002) asked why technologies were not designed in such a way that assured equitable access. In turn, we ask why technological advancements seemingly continue to be designed in a way that works to increase the disability digital divide. It is alarming that the Department of Civil Protection and Emergency Management decided to forgo inclusivity in their provisions of important pandemic-related information to its citizens. Furthermore, the government did not collect disability-related statistics during the pandemic, which raises concerns regarding future policymaking and resource allocation. The accelerated digitalization that took place during the pandemic served to exclude groups of people, such as those with intellectual disabilities. This reiterates how privilege is embedded in technological development, benefiting non-disabled experiences and centring on non-disabled bodies (Charitsis & Lehtiniemi 2022) and is a form of technoableism (Shew 2023).

In terms of the third-level divide and the offline benefits of online participation (Lutz 2019), our findings demonstrate that those who had access to the Internet had positive outcomes, such as staying in touch with friends and passing the time during social restrictions by playing online games. However, the criteria for measuring the third-level divide are ableist or ability-oriented and assume certain type of social participation in which people with intellectual disabilities are generally excluded from (Björnsdóttir, Stefánsdóttir & Stefánsdóttir 2015).

We conclude by calling for a more critical discussion on digital access and use that highlights the barriers derived from ableism. Importantly, concepts that aspire to explain social behaviors cannot be conceptualized in a social vacuum, devoid of structural injustices and power relations that restrict the choices, opportunities, and resources available to specific groups. Otherwise, we risk drawing from widespread stereotypes and inaccurately portraying the lived realities of people with intellectual disabilities, stigmatizing them and others who encounter similar barriers to technology access and use. The pandemic provided us with an opportunity to examine the disability digital divide. We should use this knowledge to intentionally design inclusive technology that advances equity and eliminates the digital divide.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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Appendix A – Icelandic introductory letter to disabled people and parents of disabled children

Aðstæður fatlaðs fólks í COVID-19

Kæri viðtakandi

Þér er boðið að taka þátt í rannsókn þar sem sjónum er beint að reynslu fatlaðs fólks og fjölskyldna þeirra í COVID-19. Rannsóknin er unnin á Menntavísindasviði Háskóla Íslands og er fjármögnuð af Rannís. Vinsamlega íhugaðu neðangreindar upplýsingar vandlega áður en þú ákveður hvort þú viljir taka þátt í rannsókninni.

Markmið rannsóknarinnar er að kanna hvort og hvernig COVID-19 og þær samfélagslegu aðstæður sem hafa skapast vegna faraldursins, hafi haft áhrif á aðstæður og líf fatlaðs fólks og fjölskyldna þeirra.

Þátttaka felur í sér viðtal þar sem rætt verður um reynslu þína í faraldrinum, og sér í lagi því sem viðkemur þjónustuna sem þú eða fjölskyldan notar. Viðtalið tekur um það bil klukkustund og fer fram ýmist í gegnum fjarfundabúnað eða á þeim stað og tíma sem þér hentar. Óskað er eftir því að viðtalið verði tekið upp í því skyni að auðvelda úrvinnslu.

Fyllsta trúnaðar er gætt á öllum stigum rannsóknarinnar. Við skrif upp úr viðtölunum verður þess gætt að svör þín verði ekki persónugreinanleg. Lista yfir þátttakendur verður eytt að loknum viðtölum og öllum hljóðupptökum eytt strax að afritun lokinni.

Mikilvægt er að þú vitir að þó að þú ákveðir að taka þátt er þér ekki skylt að svara spurningunum sem bornar eru upp í viðtalinu. Einnig getur þú hætt þátttöku hvenær sem er og án útskýringa.

Ábyrgðarmenn rannsóknarinnar eru Dr. Ásta Jóhannsdóttir og Dr. Kristín Björnsdóttir. Rannsakandi í verkefninu er Hrafnhildur Snæfríðardóttir Gunnarsdóttir og mun hún taka viðtalið ákveðir þú að taka þátt.

Hafir þú spurningar eða vilt fá frekari upplýsingar er þér velkomið að hafa samband við Hrafnhildi í síma 6…… eða senda vefpóst: hsg@hi.is

Appendix A – English introductory letter to disabled people and parents of disabled children

Experiences of disabled people during COVID-19

Dear recipient,

You are invited to participate in a study focusing on the experiences of disabled people and their families during COVID-19. The research is carried out at the University of Iceland's Faculty of Education and is funded by Rannís. Please consider the information below carefully before deciding whether to participate in the study.

The study aims to investigate whether and how COVID-19 and the social conditions that have arisen as a result of the pandemic, have affected disabled people and their families.

Participation entails an interview to discuss your experiences during the outbreak, particularly as it relates to the services you use. The interview takes about an hour and takes place either through teleconferencing equipment or at a place and time of your choosing. We will kindly request permission to record the interview in order to facilitate the analysis.

Complete confidentiality is maintained at all stages of the research. When transcribing the interviews, care will be taken to ensure that your answers are not personally identifiable. Identifiable information about participants will be deleted after the interviews, as will all audio recordings be deleted immediately after their transcription.

Importantly, participation in the interview is voluntary. You are not required to answer the questions, and you can opt out of the research at any time without providing a reason.

The study is led by Dr Ásta Jóhannsdóttir and Dr Kristin Björnsdóttir, with researcher Hrafnhildur Snæfríðardóttir Gunnarsdóttir conducting the interviews for those who decide to participate.

If you have questions or would like more information, you are welcome to contact Hrafnhildur via phone 6…… or by sending an email to: hsg@hi.is

Appendix B – Icelandic introductory letter to representatives of DPOs

Reynsla félagasamtaka fatlaðs fólks í COVID

Kæri viðtakandi

Þér er boðið að taka þátt í rannsókn þar sem sjónum er beint að reynslu fatlaðs fólks í COVID-19. Rannsóknin er unnin á Menntavísindasviði Háskóla Íslands. Vinsamlega íhugaðu neðangreindar upplýsingar vandlega áður en þú ákveður hvort þú viljir taka þátt í rannsókninni.

Markmið rannsóknarinnar er að kanna hvort og hvernig COVID-19 og þær samfélagslegu aðstæður sem hafa skapast vegna faraldursins, hafi haft áhrif á aðstæður og líf fatlaðs fólks og fjölskyldna þeirra. Í því skyni er mikilvægt að fá innsýn í reynslu félagasamtaka fatlaðs fólks.

Þátttaka felur í sér viðtal þar sem rætt verður um reynslu þína í starfi félagasamtaka þinna í COVID. Viðtalið tekur um það bil klukkustund og fer fram ýmist í gegnum fjarfundabúnað eða á þeim stað og tíma sem þér hentar. Óskað er eftir því að viðtalið verði tekið upp í því skyni að auðvelda úrvinnslu. Fyllsta trúnaðar er gætt á öllum stigum rannsóknarinnar. Við skrif upp úr viðtölunum verður þess gætt að svör þín verði ekki persónugreinanleg. Lista yfir þátttakendur verður eytt að loknum viðtölum og öllum hljóðupptökum eytt strax að afritun lokinni.

Mikilvægt er að þú vitir að þó að þú ákveðir að taka þátt er þér ekki skylt að svara spurningunum sem bornar eru upp í viðtalinu. Einnig getur þú hætt þátttöku hvenær sem er og án útskýringa.

Rannsóknin er unnin af Dr. Laufeyju Löve og Hrafnhildi Snæfríðar- og Gunnarsdóttur á Menntavísindasviði Háskóla Íslands. Hún er ennfremur hluti af stærra rannsóknarverkefni, sem er fjármagnað af Rannís og miðar að því að fá fram hagnýtar upplýsingar til að unnt sé að draga lærdóm af faraldrinum.

Ef þú vilt frekari upplýsingar eða ert með spurningar er þér velkomið að hringja í Hrafnhildi í síma 6…... eða senda vefpóst: hsg@hi.is.

Appendix B – English introductory letter to representatives of DPOs

Experiences of DPOs during COVID

Dear recipient

You are invited to participate in a study focusing on the experiences of disabled people during COVID-19. The research is conducted at the Faculty of Education at the University of Iceland. Please consider the information below carefully before deciding whether to participate in the study.

The study aims to investigate whether and how COVID-19 and the resulting social conditions impacted the lives of disabled people and their families. To that end, it is important to gain insight into the experiences of organizations representing disabled people.

Participation entails an interview discussing your experience in your DPO's work during the pandemic. The interview takes about an hour and takes place either through teleconferencing equipment or at a place and time of your choosing. We request that the interview be recorded in order to facilitate analysis. Complete confidentiality is maintained at all stages of the research. When transcribing the interviews, care will be taken to ensure that your answers are not personally identifiable. The list of participants will be deleted after the interviews, and all audio recordings deleted immediately after transcription.

It is important that you know that even if you decide to participate, you are not obliged to answer the questions raised in the interview. You can also opt out of the study at any time and without providing an explanation.

The study is done by Dr. Laufey Löve and Hrafnhildur Snæfríðar- and Gunnarsdóttir at the Faculty of Education, University of Iceland. It is also part of a larger research project, which is funded by Rannís and aims to obtain practical information so that lessons can be learned from the epidemic.

If you want more information or have questions, you are welcome to call Hrafnhildur on phone 6...... or send an e-mail: hsg@hi.is.

Appendix C – Interview guide 1

Mutual introduction. Revising information in the introduction letter and the aim of the research. Discussing confidentiality, obtaining permission for recording. Any questions?

Introduction to family, family members and family life and the child

- Family size, age of family members
- Living arrangements
- Employment status of parents
- Age, gender of child
- Child´s school and hobbies
- Services to the family and the child
- Child´s impairment and health

Probes:
Can you tell me a little about the family?
Can you tell me about a typical day in your life?
What is it that [child] loves to do?

Services to the family

- What type of services does the family receive
- Municipal services
- Support in school
- Support from other entities
- Health professionals
- Experiences of services
- Sufficient, inadequate? „How does it suit your needs?"
- Collaboration
- Information
- What is going well?
- What can be improved?
- Who is the family's main support

Probes:
Can you tell me about the services you receive?
How has the collaboration been with professional / staff within the services?
Is there a particular person you reach out to when you have questions?
Are there any other services you have experience of / that you know of?
Do you feel like everyone working towards a mutual goal?

Life in the pandemic

- Changes to daily life in the pandemic
- Shielding
- Infections/quarantine
- Decisions regarding measures to take for safety of the child/family
- Access to meaningful information
- Support provided by/ collaboration with service entities
- Health professionals
- Municipal services
- Services in school
- Other service entities
- Service cancelations
- Vaccination
- Communication with family and friends

Probes:
What were your main worries/ first thoughts when you first heard of the virus outbreak?
Can you tell me about a memorable day in the pandemic? / How did your life change?
Was there anyone that assisted you in making decisions that regarded the safety of child / decisions to shield / decisions to quarantine?
Did someone contact the family from the municipality of other service entities / health professionals?
What kind of support would you have wished for?

Concluding discussion

- Other important issues
- Lessons learned
- Something the participant wants to add

Probes:
Are there any important issues you feel I have forgotten to ask about or have overlooked that you believe are important to the topic? Or regarding the pandemic?
What lessons can we draw from all this?
Looking back – is there something you feel could have been done better?

Appendix D – Interview guide 2

Mutual introduction. Revising information in the introduction letter and the aim of the research. Discussing confidentiality, obtaining permission for recording. Any questions?

Introduction to organization

- Size
- Aims, objectives, advocacy focus
- Work, projects
- Collaboration with public institutions
- Consultation

Probes:
Can you tell me a little about what goes on in the office on a daily basis?
What are the most current issues you pursue in your advocacy?
What determines the focus of your advocacy?
Can you tell me about consultation / collaborative projects that you felt were noteworthy/ important?

Pandemic

- Work and advocacy in the pandemic
- Well-being of grassroot in the pandemic and how they were addressed by official entities
- Issues/problems emerging
- Infections
- Shielding/quarantine/isolation
- Service cancellations
- Vaccinations
- Information
- Access to meaningful information – retrieval and dissemination
- Consultation with public entities in the pandemic
- Scope of collaboration
- What issues – who determined
- Who´s initiative
- Factors that hinder/facilitate
- Collaboration with other DPOs

Probes:
What were your main worries/ first thoughts when you first heard of the virus outbreak?
In which ways was your grassroot most affected?
What were the main issues you advocated in the pandemic and why?
I am very interested in consultation practices during the pandemic, can you tell me about your experiences of them.
Was there something that you felt had been successful or done particularly well?
Were there any issues that were overlooked?

Concluding discussion

- Other important issues
- Lessons learned
- Something the participant wants to add

Probes:
Are there any important issues you feel I have forgotten to ask about or have overlooked that you believe are important to the topic? Or regarding the pandemic?
What lessons can we draw from this?
Looking back – what is it in particular that could have been done better?

Appendix E – Interview guide 3

Mutual introduction. Revising information in the introduction letter and the aim of the research. Discussing confidentiality, obtaining permission for recording. Any questions?

Introduction

- Age
- Employment status
- Family size
- Living arrangements
- Hobbies

Probes:
Can you tell me a little about yourself?
Can you tell me about a typical day in your life?

Services

- PA services
- Sufficient, inadequate? „How does it suit your needs? "
- Collaboration
- Information
- What is going well?
- What can be improved?
- Experiences of prior services
- Collaboration with municipality
- Main consultant?
- Other service entities?

Probes:
Can you tell me about the services you receive?
How did your PA services come about?
How has the collaboration been with municipal staff?
Is there a particular person you reach out to when you have questions?
Do you feel like everyone working towards a mutual goal?

Life in the pandemic

- Changes to daily life in the pandemic
- Decisions regarding measures to take for safety
- Shielding
- Infections/quarantine
- Access to meaningful information
- Sickness/health of p. or family
- Vaccination
- Communication with family and friends

Probes:
What were your main worries/ first thoughts when you first heard of the virus outbreak?
How did your life change? / Can you tell me about a memorable day in the pandemic?

PA services in the pandemic

- Changes to the services received
- Changes to manager role
- Social distancing rules
- Acquiring protective equipment
- Service cancelations
- Challenges encountered?
- Solutions to them
- Support provided by/ collaboration with municipalities or other service entities

Probes:
Was there anyone who assisted you in making decisions regarding your services and how they could be amended to comply with rules of social distancing?
Could you find information that was helpful meaningful for you? - provided by whom?

Concluding discussion

- Other important issues
- Lessons learned
- Something the participant wants to add

Probes:
Are there any important issues you feel I have forgotten to ask about or have overlooked that you believe are important to the topic/ regarding the pandemic?
In hindsight – is there anything you would have done differently – and why?
Looking back – is there something you feel could have been done better by officials / municipalities?
What lessons can we draw from all this?

Neoliberal,
and ableist clusterfuck
Let’s choose kinder ways
(a haiku)