Parents with Intellectual Disabilities Negotiating Systemic Challenges through a Rights Based Approach

Sara Stefánsdóttir

Thesis for the degree of PhD
in Disability Studies

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Sara Stefánsdóttir

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Ágrip

Viðhorf til seinfærra foreldra litast enn í dag af hugmyndum fortíðar um mannbætur sem sjúkdómsvæða, stimpla og jaðarsetja þá. Þrátt fyrir að rannsóknir sýni að seinfærir foreldrar geti alið upp og hugsað um börn sín, fái þeir til þess viðeigandi stuðning, standa þeir enn frammi fyrir ýmsum hindrunum, þar á meðal óviðeigandi stuðningi sem stuðlar að háu hlutfalli þeirra sem missa forsjá barna sinna.

Tilgangur þessarar doktorsritgerðar er að kanna á gagnrýninn hátt hvort og hvernig seinfærum foreldrum á Íslandi er veittur stuðningur til að hugsa um börn sín í ljósi þeirrar þróunar sem hefur átt sér stað varðandi réttindi fatlaðs fólks og mannréttindi. Henni er einnig ætlað að greina þær hindranir sem talsmenn og stuðningsfólk seinfærra foreldra mæta er þeir krefjast réttlátrar og sanngjarnar málsmeðferðar, sérstaklega þeirra sem tengjast barnaverndarkerfinu. Að lokum er markmið ritgerðarinnar að koma rödd seinfærra foreldra á framfæri til hagsbóta fyrir aðra foreldra og þá sem koma að þeirra málum.

Rannsóknin sem var framkvæmd byggir á fötlunarfræðum og mannréttindasjónarhorni, sem einkum er undirstrikað í samningi Sameinuðu þjóðanna um réttindi fatlaðs fólks. Þar sem fötlunarfræði er í eðli sínu gagnrýnin er sjónum beint að kúgandi og „gölluðum" ferlum innan þeirra stofnana og kerfa sem gefa sig út fyrir að veita seinfærum foreldrum stuðning við uppeldi barna sinna. Bæði sjónarhorn leggja áherslu á að viðhorf, gildi og stofnanir taki breytingum svo fatlað fólk geti tekið fullan þátt í samfélaginu. Rannsóknin sækir einnig innblástur í gagnrýnar félagskenningar sem beina sjónum frá einstaklingum yfir á samfélagslega þætti með því að skoða félagsmenningarlegar og sögulegar umbreytingar. Að lokum er hugtakið stofnanabundinn réttlætisauður (institutional justice capital) notað til að skilja þau úrræði sem nauðsynleg eru til að rata um kerfið, einkum í tengslum við barnavernd.

Til að svara þeim spurningum sem liggja til grundvallar rannsókninni var eigindleg aðferðafræði valin til að ná fram sem dýpstum skilningi á viðfangsefninu og til að segja sögu þátttakenda. Í þeim tilgangi var grunduð kenning talin henta best sem meginaðferð við greiningu gagna en hún hafði að auki áhrif á aðferðir við gagnaöflun. Til að draga upp heildræna mynd af stuðningi við seinfæra foreldra var notast við mismunandi tegundir gagna sem komu úr ýmsum áttum, þar á meðal viðtöl, fyrirliggjandi skrifleg gögn og athuganir. Viðtöl voru tekin við ýmsa hagsmunaaðila, m.a. seinfær hjón og nokkra af nánustu aðstandendum þeirra; starfsfólk sem veitir stuðning til seinfærra foreldra og starfar á vegum barnaverndar, félagsþjónustu sveitarfélaga og heilsugæslu; og réttindagæslumenn fatlaðs fólks. Alls voru tekin 32 viðtöl við 24 þátttakendur.

Niðurstöður rannsóknarinnar varpa ljósi á hvernig sú þróun sem hefur átt sér stað á undanförnum áratugum á vettvangi mannréttinda er ekki fullnægjandi til þess að ryðja úr vegi samfélagslegum og kerfislægum hindrunum þegar kemur að seinfærum foreldrum. Það gefur til kynna þörf fyrir heildstæða stefnu og aukna vitund og þekkingu innan þeirra kerfa sem þessir foreldrar eiga hlut að. Lögð er áhersla á nálgun sem byggir á samvinnu og réttindamiðaðri nálgun til að tryggja réttláta meðferð og samræmdan og viðeigandi stuðning við seinfæra foreldra. Auk þess er mælt með að stjórnvöld standi að öflugu framtaki í málaflokknum til að bregðast við áðurnefndum hindrunum og að áhersla verði lögð á mikilvægi fjölþætts stuðnings, þar með talið formlegrar þjónustu, fjölskyldustuðnings, og réttindagæslu.

Lykilorð:

Seinfærir foreldrar, stuðningur, barnavernd, réttindi fatlaðs fólks, Ísland

Abstract

Parents with intellectual disabilities continue to be viewed through the lens of the eugenic ideologies of the past which pathologize, stigmatize and marginalize them. Despite research showing that support plays a crucial role in their lives and if appropriate, most of them can successfully parent their children, they continue to face multiple barriers, one being inappropriate support resulting in high rates of child removal.

This dissertation aims to critically explore if, and how, parents with intellectual disabilities in Iceland are supported to raise and take care of their children in light of the developing disability and human rights environment in Iceland. Furthermore, the purpose is to identify barriers advocates and supporters encounter when claiming justice and fair treatment regarding parents with intellectual disabilities, in particular those involved in the child protection system. Finally, its goal is to amplify the voice of parents with intellectual disabilities to inform other parents and those involved in their lives.

The research is grounded in disability studies framework in the context of an evolving human rights environment in Iceland, particularly emphasized through the Convention on the Rights of Persons with Disabilities. As disability studies are critical in nature, focus is on oppressive and problematic processes within the institutions and systems that claim to provide parents with intellectual disabilities support in relation to parenting. The research is furthermore informed by the tenants of critical social theory which shifts the focus from individuals to societal factors and examines sociocultural and historical transformations. Finally, the concept of Institutional Justice Capital is introduced to the analytical framework, centring on the resources essential for navigating the systems that come into play when families are involved with the child protection.

To address the questions at the heart of this research, qualitative methodology was adopted in order to enable deep understanding of the subject and as the best method to relay the narratives of the research participants. For that purpose, grounded theory was chosen as the main method for analysis of the data which also influenced methods for collecting data. With the goal of constructing a holistic picture of support for parents with intellectual disabilities, different types of data from various sources were drawn upon, including interviews, which were the main source of data, analysis of extant documents and observations. Interviews were conducted with various stake holders, which included a couple with intellectual disabilities and some of their closest family members; personnel who support parents with intellectual disabilities working

under child protection, the municipal social services, and health care; and rights protection officers for disabled people. Altogether 32 interviews with 24 participants were carried out.

The findings of the research highlight how recent, positive human rights developments are not effective enough in removing societal and systemic barriers when it comes to parents with intellectual disabilities. That illuminates the need for comprehensive policy and increased awareness and knowledge within the systems these parents are involved with. A shift towards a collaborative, rights-based approach is emphasised to ensure equitable, consistent, and appropriate support for parents with intellectual disabilities. Additionally, strong government-led initiatives and the importance of multifaceted support systems, including formal services, family support, advocacy, and rights protection, is recommended for providing good support.

Keywords:

Parents with intellectual disabilities, support, child protection, disability rights, Iceland

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A heartfelt thanks to my children, Atli, Baldur and Aldís, who are a constant inspiration. For them I strive to do good and be the best person I can be.

Contents

List of Abbreviations

UN CRPD	The United Nations Convention on the Rights of Persons with Disabilities
RPOs	Rights Protection Officers for Disabled People
ID	Intellectual disabilities

List of Figures

List of Tables

List of Original Articles

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I, II, III):

I. Stefánsdóttir, S., Rice, J., Aunos, M., & McConnell, D. (2022). Appropriate measures? Supporting parents with ID in the context of the CRPD. *Scandinavian Journal of Disability Research*, 24(1), p. 29–41. https://doi.org/10.16993/sjdr.820

II. Stefánsdóttir, S., Sigurjónsdóttir, H. B., & Rice, J. (2023). Weapons and tactics: A story of parents with learning disabilities maintaining family integrity. *British Journal of Learning Disabilities, 51*(1), 62-69. https://doi.org/10.1111/bld.12492

III. Stefánsdóttir, S., Rice, J. G., & Sigurjónsdóttir, H. B. (2024). Safeguarding families and rights of parents with intellectual disability involved in child protection: The role of rights protection officers. *International Journal of Disability & Social Justice, 4*(2), 91-110. https://doi.org/10.13169/intljofdissocjus.4.2.0091

Declaration of Contribution

Overall conceptualization and design of the research: SS, JGR, HBS

Data collection: SS

Lead role in data analysis: SS

Analytical direction and theoretical context: SS, JGR, HBS

Assistant with analytical direction and theoretical context: DM, MA

Writing: SS

Editing and supervision of writing: JGR, HBS

In paper I, DM and MA participated in refining the analysis and conceptualization of key areas.

1 Introduction

Families led by parents with intellectual disabilities are some of the most marginalized families. They continue to struggle for acceptance, and the societal barriers they face have contributed to alarmingly high rates of parents having their children removed from their care, despite increased focus on human rights, both nationally and internationally. When introduced with the opportunity to embark on this PhD journey, I felt that it was a chance to have a positive impact, not only by contributing to the ever-growing research base on the subject but also the systems concerned with these families. I have collaborated with researchers and professionals working in this field who are actively aiming towards better support and services that are based on the premises of the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) for the Respect for the home and family. Given that eight years have now passed since the CRPD was ratified in Iceland, the timing of the research provided a valuable opportunity to investigate if the convention's principles had translated into the support and services for parents with intellectual disabilities.

My aspiration for this research is that it will, in some way, have transformative effects on the lives of parents with intellectual disabilities and their children.

1.1 Aims and key questions

The research is within the field of disability studies and has been conducted to investigate support and services for parents with intellectual disabilities. The aim of the dissertation is to critically explore if and how parents with intellectual disabilities in Iceland are supported by the system they live in to raise and take care of their children. Secondly, the study aims to investigate how support is carried out in the evolving disability and human rights environment in Iceland with a specific focus on parents with intellectual disabilities who are involved in the child protection system. The third aim is to identify the barriers and resistance advocates and supporters experience when claiming justice and fair treatment of parents with intellectual disabilities. The fourth aim is to create a platform for parents with intellectual disabilities to tell their story to inform other parents, advocates, and professionals who are involved in the lives of parents with intellectual disabilities.

Five main questions lead the research, each of them addressing different layers of support.

1. Are parents with intellectual disabilities supported in the parenting role to maintain family integrity? If so, what does an examination of these measures reveal about how the support system understands parents with intellectual disabilities and their needs?
2. What characterizes the family support service parents with intellectual disabilities receive?
3. What factors seem to contribute to the divergent outcomes of either unsuccessful or successful support for parents with intellectual disabilities?
4. How do rights protection officers safeguard the rights of parents with intellectual disabilities, and what barriers do they face?
5. In what ways, if any, have the UN Convention principles been translated into the support and services for parents with intellectual disabilities?

To address the question at the heart of this thesis – how parents with intellectual disabilities are supported to take care of and raise their children as stated in the CRPD, and if the signing of CRPD has materialized in the lived reality of parents with intellectual disabilities in Iceland – the study was conducted in three phases, each within qualitative tradition. All phases were grounded in disability human rights approach with an emphasis on the rights of disabled people as enshrined in the CRPD. The concept of institutional Justice Capital by Hamilton and Maslen (2022) was applied in the last phase of the research in order to consider the resources needed to navigate the child protection- and justice system and whether those resources are available at all or form a part of the system itself.

To obtain a thorough understanding of the subject, data was gathered from multiple sources by interviews and an extensive, longitudinal document analysis of extant and secondary documents. Additionally, long-term involvement with participants in phase two, along with observations, produced important data and insights.

From the onset, I realised that achieving the research aims, focusing on individual, institutional/agency, and systemic support, required a multi-faceted view of how parents with intellectual disabilities are supported in Iceland. I set out to interview individuals with experience working with these parents, ensuring that their insights covered the various sites parents engage with, such as social services, family services, child protection, health care, and legal support.

In Article I, I addressed the first and second research aims. I began by interviewing support workers, prompted by recent Icelandic research (Sigurjónsdóttir & Rice, 2017)

suggesting that parental rights of parents with intellectual disabilities were often terminated on the grounds that "all means of support had proven ineffective." I felt it was urgent to investigate how support was provided and whether it aligned with the CRPD's standards and the evolving disability rights environment.

Article II addressed all the research aims, but in particular the second and fourth. This article highlighted the perspective of parents with intellectual disabilities through an intimate and carefully constructed story of a couple involved in child protection for years. To construct this story, I used various methods of inquiry, including interviews, observations, and documents. This approach helped me understand the family's complex situation and how years of child protection interference had shaped their daily lives and responses to support services. This unique case provided a crucial counter-narrative to negative perceptions, emphasising the importance of appropriate support from both immediate and systemic sources. The story also uncovered deep systemic injustices, insightfully expressed by a rights protection officer.

This emergent discovery led to the inclusion of rights protection officers' perspectives in the research. In addressing the second and third aims their insights and experiences proved to be invaluable in uncovering systemic barriers and resistance to supporting parents with intellectual disabilities, which are reported in Article III.

Data collection was undertaken in three intervals, from April 2018-January 2019, April 2021-October 2023 and finally from August 2022-January 2023. The findings have been presented in three peer-reviewed journal articles.

In the first of these articles, I seek to understand the ways in which the values of the CRPD manifest in services and supports for parents with intellectual disabilities. Attention is paid to identifying barriers to the realization of the Convention, as well as any progressive practices that align with these values and may result both in better outcomes for parents and ensuring that Iceland meets its obligations. The title of the article is "Appropriate Measures? Supporting Parents with ID in the Context of the CRPD" and was published in the *Scandinavian Journal of Disability Research* in February 2022.

The second article is titled "Weapons and Tactics: A story of parents with learning disabilities maintaining family integrity" and was published in *British Journal of Learning Disability* in July 2022. In this in-depth case study, my co-authors and I explore the contours of a struggle against deeply entrenched prejudices, as well as social arrangements that often deprive parents with intellectual disabilities of needed resources and supports. We also consider the impacts the developing disability rights environment is having upon these ongoing struggles.

The third article, "Safeguarding families and the rights of parents with intellectual disabilities involved in child protection: The role of rights protection officers," was published in *International Journal of Disability and Social Justice* in September 2024.

The article discusses the role of rights protection officers and primarily focuses on the context of supporting and safeguarding the rights of parents with intellectual disabilities and their encounters with the child protection system.

1.2 My Background and Positionality

My entry into the field of disability studies was not sudden but rather a gradual one. As an occupational therapist, I have a background in a field that rests somewhat between health sciences and social sciences. Occupational therapy puts an emphasis on enablement and participation in a supportive and inclusive environment. However, the focus is most often on the person and their closest environment, and limited attention is paid to how the social and systemic arrangements affect and create barriers in the lives of people, especially marginalized people, such as disabled people. For several years I worked as an occupational therapist with disabled children and their parents and was quite aware of how structural barriers were often the cause of difficulties the families were experiencing. As I continued my education in Health Sciences, I got introduced to disability Studies where I learned about progressive approaches that offered the possibility of understanding disability within cultural and historical contexts. This new understanding of disability made me realize how my own assumptions about disabled people and their position in society were often based on prevailing and deep-seated ideas about what is considered to be the norm. In my MS research, I investigated, from a critical perspective, how professionals such as occupational therapists and physiotherapists work in child and youth rehabilitation and whether their services align with the needs of the families. Later, I began working in academia, and at that time my work still focused on services for families and disabled children.

However, the impetus for me to change course in my research subject and seek a doctoral degree in disability studies was a personal experience. A relative with intellectual disabilities had the heartbreaking experience of losing custody of her children following a child protection intervention. After familiarizing myself with a bulk of case documents attached to her case, I was impelled to investigate how parents with intellectual disabilities were supported to keep their children and take care of them. As I started my research, I was very focused on the role of the support workers (like when investigating rehabilitation), how they performed their job, and what the standards were. However, the more I progressed through the study, the research plan evolved accordingly, and the focus broadened. Instead of emphasizing the performance and role of individuals within the support services I focused on the larger system. My insight does, however, not only come from doing research as in recent years, I have also advocated for the aforementioned family, supported it, and been in a continuous relationship with child protection services by their side and on their behalf. I can thereby honestly say that I have experienced a whole spectrum of attitudes, behaviors, and actions performed by the child protection system in Iceland. From the beginning of this research journey, I realized that my experiences provide me with a unique insight

into the workings of the support system and child protection, but, at the same time, it requires special ethical considerations, which are discussed in Chapter 4.

1.3 The Icelandic Context

It is important to consider and understand where this research comes from and the context of where it was conducted. Iceland is a very small nation with a population of around 390.000 people. It ranks high in evaluations of standards of living, quality of life, and human rights in general, not unlike other Nordic countries that have high national expenditures on welfare services. However, despite, Iceland having many characteristics of Nordic welfare, it has also separated itself, mainly by governance that is marked by increased austerity beyond what is seen in other Nordic countries (Ólafsdóttir & Ólafsson, 2014).

In 2007, Iceland signed the CRPD and ratified it in 2016. By doing so, Icelandic authorities committed to adjusting national laws so that they could be aligned with the Convention, making it possible to translate its principles into disabled people's lives. In the context of this thesis, two Acts of law are of particular importance. The first act is the Act of Services for Disabled People with Long-term Support Needs (Lög um þjónstu við fatlað fólk með langvarandi stuðningsþarfir no. 38/2018), which places responsibility on municipality social service to provide disabled parents with appropriate support to carry out their parenting duties. The second act is the Act on the Protection of the Rights of Disabled Persons (no. 88/2011), passed in the Icelandic parliament in 2011. The act is to ensure that the rights of disabled people are safeguarded and that disabled people have access to proper support when protecting their rights. The CRPD was a guidepost in drafting both acts. There are other acts of law that influence the service and support parents with intellectual disabilities receive. In particular, the Act on Municipal Social Service (Lög um félagsþjónustu sveitafélaga no. 40/1991), and the Child Protection Act (Barnaverndarlög no. 80/2002). While the three first mentioned acts are, according to their purpose, aimed at meeting people's need for support, the Child Protection Act is aimed at preventing harm. It is also important to mention that since this research was performed a new act on the Integration of Services in Favor of Children´s Wellbeing (Lög um samþættingu þjónustu til farsældar barna no. 86/2021) has been passed. That act in particular has not been of attention in this research, and time will have to tell how the act will affect services and support for parents with intellectual disabilities and their children.

The Municipal Social Services Act provides the framework for mainstream social services to work within. Even though the act does not specifically mention disabled parents, the mainstream social service has the obligation to support all families in need. The purpose of the act is to ensure financial and social security and to promote the well-being of its community by improving standards of living for the vulnerable. Additionally, the act ensures a healthy environment for the growth and development of

children and youth, providing assistance to enable people to stay home, work and have a good quality of life and finally to take action to prevent social problems.

The purpose of the Icelandic Child Protection Act is to ensure that children growing up in adverse environments or children that pose a danger to their own health and development receive appropriate assistance, favorably from general family support via the mainstream social service.

Despite some progress in legislation towards ensuring the rights of parents with intellectual disabilities, article 29 of the Child Protection Act goes against article 23 of the CRPD by stating that a child protection committee can request, in a court of law, termination of parental rights on the grounds of child endangerment due to parents' low intelligence. This discrepancy creates tension in the case of parents with intellectual disabilities because it allows for children to be taken from their parents' care specifically because of their disability. It has been eight years since the CRPD was ratified and it is still to be legalized. While disability-specific legislation has incorporated CRPD provisions, due to the dual nature of the Icelandic legal order, the Convention needs to be transposed into Icelandic law to formally gain the status of national law (Gjecaj et al., 2023).

Numerous articles of the convention are important in the case of parents with intellectual disabilities. For the purpose of this dissertation, Article 23, Respect for Home and the Family, along with Article 13, Access to Justice, will be discussed further in Chapter 2.

1.4 The Structure of the Dissertation

This dissertation consists of seven chapters. Chapter two discusses the theoretical background to the dissertation and emphasizes disability studies, and in particular the human rights approach to disability.

In the third chapter, the research literature that informed the study is introduced. It begins with an historical overview that helps to understand the struggle that parents with intellectual disabilities face. This provides an important context for understanding how parents with intellectual disabilities can be supported to take care of their children. Furthermore, the chapter emphasizes literature about appropriate support, how it might be facilitated and the barriers that remains to providing it.

Moving on to the fourth chapter of the dissertation, it offers an in-depth insight into the qualitative approach and methodologies employed throughout this study, along with a rationale for their selection. The chapter discusses the array of data obtained for this dissertation, such as interviews and document analysis. Additionally, it outlines the analytical methodology adopted for the data generation. Finally, ethical considerations are addressed, and an evaluation of the research's strengths and weaknesses is provided.

The fifth chapter comprises a compilation of three journal articles presenting the research findings in an order that represents the research process and time of publication.

Chapter six provides a summary of the research findings presented in the three articles produced for this dissertation. Each article is introduced, and the collective findings of the research are discussed.

Finally, the seventh and concluding chapter, key findings are presented with consideration to the aims and questions that are put forth in the research and the dissertation's contribution to the field of parenting with intellectual disabilities is discussed.

2 Theoretical Background

In this chapter, I will provide a rationale for my theoretical choices and how they are applied to analysing the data acquired from the research on which this dissertation is based; I also provide a brief overview of relevant approaches to disability, giving insights into how disability has been thought of, understood, and acted upon in recent times within the discipline. These perspectives are relevant to explain and understand the subject of this dissertation and their connections to the foundational approaches this research is based on. Though I draw on different theoretical perspectives to make sense of the research data, my approach is also influenced by grounded theory (Charmaz, 2014). There is some debate as to whether grounded theory is a methodological or theoretical approach, and as such, discussion about grounded theory is included in Chapter 3.

I have maintained an open mind to any new theoretical insights acquired during this process that can help to explain the findings. This has led to unexpected avenues being explored, which has, in a sense, led to something of an "organic" development of the process of the analysis. However, despite a reliance upon a grounded approach early in the process, I felt that I still needed theoretical approaches from disability studies and related disciplines to gain deeper insights. As an occupational therapist with background in health sciences, it came natural for me, in the beginning, to pay attention on an individual level to the parents' closest environment and the services they were receiving. However, as this research progressed, I felt that I needed different approaches to help make sense of the larger, structural issues as the parents' environments were much more than their home or local community. I came to understand the systemic issues that also impacted upon parenting with intellectual disabilities. The varied 'models' of disability studies, as discussed below, provided some insights. I found that the human rights perspective, highlighting parents with intellectual disabilities as rights bearing individuals, helpful for the purpose of the analysis of the data. The resources available to the parents extended beyond just services. Additionally, at the later stage of this research, I came across another useful perspective, Institutional Justice Capital, that I felt provided important insights into the systemic injustices that parents with intellectual disabilities involved in the child protection system face and how justice can be accessed as a resource in and of itself. I will now turn to a brief overview of several schools of thought within disability studies and which informed my analysis, to varying degrees.

2.1 Perspectives on Disability

Disability studies in the 1990s and early 2000s were often framed, in theoretical terms, as a series of 'models.' Goodley (2011), for example, frames the disability studies perspective as consisting of the social model, with an emphasis on barriers; the minority model, emerging from the civil rights movement and sharing a common history with the struggle for rights faced by other marginalised populations; a cultural model, with an emphasis upon deconstructing texts to expose their ableist underpinnings; and a relational model, rooted in the principles of normalization in the Nordic countries (Goodley 2011: 10-16). A similar narrative for this theoretical history has also been proposed by other scholars with some variations (see e.g. Shakespeare, 2014; Traustadóttir, 2003). What is common among these narratives is the use of the medical model or the medical perspective as denoting what disability studies are not. As I will discuss, the legacy of the medical approach to disability is very much alive and informs a great deal of the support and the child protection environment concerning parents with intellectual disabilities during the time of this research. All of these models or theoretical perspectives have been influential in the theoretical framing of this dissertation and will be briefly discussed. However, none of these approaches alone has been sufficient for a full picture of the issues at hand. As I will discuss, the social model traditionally lacked attention to the diverse experiences of disabled people, and perhaps in particular people with intellectual disabilities. Issues such as gender, ethnicity and sexuality were not highlighted as well as basic issues pertaining to embodiment in favor of socially constructed barriers (see e.g. Morris, 1991). Yet the idea of barriers to parenting with a disability, or even barriers which prevent maintaining the custody of children, is still a useful framework for analysis. However, more recent developments in disability theory, such as the human rights approach, which has been realized most notably in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), have also played a large role in this thesis, as have some recent additions in the later research process such as Institutional Justice Capital. I will now turn to a brief overview of the theoretical perspectives that have informed my journey in disability studies but with an emphasis on the approaches that I have applied directly to my findings.

2.1.1 The Medical Approach

The medical approach, sometimes called the individual approach, to disability is often presented in disability studies as everything that disability studies are not. The medical perspective on disability views disability as an individual problem or impairment that needs to be fixed or cured. It focuses on identifying and treating the underlying medical condition that is causing the disability, or more accurately the impairment, rather than addressing the social and environmental barriers that people with disabilities face. Disability is seen through this lens as a deviation from the norm, and the responsibility for the disability is placed on the individuals with the impairment

without considering the broader societal factors that may contribute to their disability. Medical interventions are prioritized over support and accommodations as disability is perceived "in terms of medical diagnoses of individual pathology, associated functional limitations and culturally determined deficits" (Oliver & Barnes, 2012:11). Rather than empowering disabled people, this approach situates disability as a "personal tragedy" (Oliver, 1996:32).

Disability studies have long sought to distance itself from the medical approach or else confront it directly. However, it became apparent in this research that the medical approach has not been relegated to a footnote in history but is very much alive, and, I argue, underlies the attitudes toward parenting with a disability, particularly parents with intellectual disabilities. As I will show in the findings section of this dissertation, views based on the medical approach come in the form of the lack of interest in supporting these parents, support approaches aimed at "fixing the problem" and the speed at which these cases are worked, and even the disinterest in acquiring the knowledge and training that can help to support these parents.

The origin of these problematic views are far more than lack of knowledge or poor services but an actual resistance to the idea of these parents as being parents. These attitudes towards people with intellectual disabilities have its roots in the eugenic movement, which as Mitchell and Snyder (2010), among others, situate in the North Atlantic starting in the 18th century. Intertwined with the pseudo 'racial sciences,' the medical establishment of the day grew concerned with certain categories of people having children and passing down what were perceived to be negative hereditary traits. These views extended to concerns about even so-called 'normal' families having to contend with the burden of raising what was referred to as the 'idiot'—to us the language of the period—children and dealing with the effects these children would have upon their siblings. The solution was a mixture of sex-segregated institutions, as well as institutionalization, in order to relieve families of these so-called burdens and to prevent these children from having children of their own in adulthood. This later included non-consensual sterilization. The eugenic approach was widely shared in the 19th and 20th centuries in North America, the Nordic countries, and northern continental Europe (Mitchell & Snyder, 2001; 2006; Snyder & Mitchell, 2006), including Iceland (Stefánsdóttir, 2011; Stefánsdóttir & Hreinsdóttir 2013). The attention to the medical perspective on disability is important, and it should not be seen as an outdated understanding of disability that has been left behind in history. Rather, this history needs to be seen as very much alive in the present as it animates the negative attitudes toward parenting with intellectual disabilities that I have seen and experienced in my research as well in my personal life.

2.1.2 The Social Model

The social model considers disability to be a social construct created by society's

attitudes, practices and structures that fail to accommodate people with impairments, thus preventing them from participating in society. The social model focuses on removing these barriers to allow people with disabilities to have equal access and the same opportunities as others. By viewing disability as a social issue caused by social processes, but not as an individual problem or a medical condition, this approach shifts the focus from the individual to society. In doing so, the perspective has been liberating and empowering for disabled people around the globe (Shakespeare, 2014). However, it has been criticized for oversimplifying disability and not considering the impact of the impairment itself on the lives of many disabled people. Additionally, critics point out the utopian task of building a barrier-free society and how the model primarily addresses people with physical and sensory impairments, with less applicability for people with intellectual disabilities and mental health illnesses (Shakespeare, 2014).

In this dissertation, there is still great value in the social model for its consideration of barriers as rooted in attitudes and prejudice. However, it was the feminist and intersectional critiques of the social model that pushed disability theory forward (Thomas, 2006) and to consider areas that were not as explored previously, such as the gendered dynamics of disability and those pertaining to family life and parenting. The contribution of feminist disability perspectives to the development of disability studies has also been of critical importance for examining power dynamics and the social relations of gendered disability (as a response to the lack of interest and understanding of the realities of disabled women). Those considerations have placed disabled women as holders of their own destiny and directed attention to fundamental human rights issues, such as reproduction, abortion, sterilization, and parenting. This perspective has, in that way, paved the way for an understanding of how the body is more than the physical but embodies oppressive social relations (Flynn, 2022; Lloyd, 2001; Meekosha & Shuttleworth, 2009). However, although disabled people have achieved some success in the struggle for core human rights and social inclusion, there is still a great deal to be done to reach the goals of full inclusion and equality (Thomas, 2006). Lloyd (2001) for example, contended that discrimination in relation to reproductive rights and family life for disabled people is still very much alive, such as when disabled women are denied taking on the highly valued role of motherhood.

2.1.3 The Cultural Model

Instead of focusing on barriers, as the social model does, the focal point of this approach is on how culture shapes, sustains, and supports power relations and the normative idea of the 'able body' through discourse and imagery. Disability is examined in a historical and cultural light to show how people's ideas about disability are created. Culture thus strongly influences how society reacts to disabled people, which in turn affects their lives and circumstances (Meekosha & Shuttleworth, 2009). According to Snyder and Mitchell (2006), the cultural perspective rejects dichotomies

such as disability vs. impairment to argue that while impairment is part of the human experience, it is understood through the lens of cultural knowledge. Disability, as a socio-cultural category, is loaded with meaning that needs to be deconstructed with the tools of literary theory. Goodley contends that this approach can be used to "explore how today's treatment of disabled people reflects the phantoms of the past, including eugenics, institutionalization and science" (Goodley, 2011:15). The implication of this approach for this research is the attention paid to how disabled parents are spoken about in interview material and the assumptions that are apparent in practices as well as legislation and regulations concerning parenting, disability, and child protection.

2.1.4 The Human Rights Approach

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the legal framework under which child protection in Iceland is supposed to operate when it comes to parents with disabilities. It is also the background of this research, but it also has various important theoretical implications. The CRPD is a good representation of the human rights approach to disability, but the development of this approach has continued beyond the CRPDs early years of existence.

The human rights perspective considers disability as a human rights issue, with disabled people having the same inherent rights and dignity as all other human beings. The perspective emphasizes the importance of ensuring that disabled people have equal access to education, employment, healthcare, and other human rights. In the context of policy making and human rights law, the human rights perspective is considered to be the most important of the social models and is regarded as essential for the implementation of the CRPD (Degener, 2016; Lawson & Beckett, 2021). Quinn and Degener (2002: 14) explain that the human rights model "focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual center stage in all decisions affecting him/her and, most importantly, locates the main 'problem´ outside the person and in society."

From the early 21st century onwards, the disability human rights perspective has enacted a paradigm shift in how disabled people are viewed. It highlights disabled people as right holders and human rights subjects instead of objects of charity. It questions the notion that disabled people are problematic and asserts, instead, that prevailing social arrangements and environments play a pivotal role in creating the many barriers disabled people face in their everyday lives. This shift has not happened swiftly but rather slowly and unevenly throughout economic and social systems (Quinn & Degener, 2002). It took decades to prepare the legal and political grounds for one of the major instruments in pushing this shift through: the UN Convention on the Rights of Persons with Disabilities (CRPD) (Begg & Degener, 2017; Degener, 2016; O´Mahony & Quinn, 2017).

Parents with intellectual disabilities is a group that warrants special attention in relation to parental rights and their protection. From the 19th century onwards, particularly in North America and Northern Europe, people with intellectual disabilities have been denied the right to have children of their own or to raise them. Laws concerned with restricting marriage and sex, institutionalization and sterilization were all methods used to prevent people with intellectual disabilities from having children. Today, these methods have largely been substituted for other, less obvious methods (Powell et.al., 2024). Of special concern here is the absence of or lack of proper support and problematic child protection (CP) interventions resulting in high rates of termination of parental rights (Powell, 2022; McConnell et al., 2021, Rice & Sigurjonsdottir, 2018; Tarleton, 2015; Tøssebro et al. 2017). In Iceland, this understanding is reflected in the Child Protection Act which still allows for children to be removed from the care of their parents because of their disability status, if there is deemed to be a risk to the child's health and safety.

Distinct from conventional non-discrimination treaties, the CRPD innovatively integrates principles of non-discrimination with the right to equality, interconnecting them with a spectrum of comprehensive rights. These encompass not only civil and political rights, such as the right to liberty and political participation, but also substantive rights like access to education, health, and engagement in cultural and recreational activities (Stein & Stein, 2007; Waddington, 2009). Through this inclusive approach, the Convention encapsulates a human rights perspective on disability, uniquely melding it with a social perspective. Notably, it consciously strives to align civil and political rights with a strong emphasis on social justice, extending its focus to encompass economic, social, and cultural rights (Quinn & Flynn, 2012).

The CRPD (United Nations, 2006) is the first treaty that specifically aims at protecting the rights of all disabled people and acknowledges that impairment is not to be used for denial or restrictions of human rights (Degener, 2016). Its uniqueness lies in the fact that it places positive duties on the part of the convention parties instead of stating only the general rights of disabled people. It should also be noted that, according to Goldschmidt (2017: 11), the convention reflects the following four dimensions of substantive equality; redressing disadvantage (the redistributive dimension); addressing stigma, stereotyping, prejudice, and violence (the recognition dimension); facilitating voice and participation (the participative dimension) and accommodating difference, including through structural change (the transformative dimension).

The right to appropriate support in the performance of the parenting role was a guiding light in all phases of the study. To sensitize what such support constitutes, the four dimensions (redistribution, recognition, participation, transformation) of substantive equality (Goldschmidt, 2017: 11) served as a lens for understanding whether support was in line with the goals of the CRPD. It helped to draw attention to the barriers that inhibit successful or appropriate support as stated in article 23, but also to define ways

to provide good support that enables parents with intellectual disabilities to take care of and raise their children. In this research, attention is paid to whether supportive measures reflect the goals of the CRPD and to the role of rights protection officers in attempting to support just treatment of parents with intellectual disabilities, in particular those involved in the child protection system.

The disability human rights perspective provides the legal and regulatory framework in which social services and child protection in Iceland should work. For the purpose of this research and in regard to parents with intellectual disabilities article 13 (Access to Justice), and article 23 of the CRPD (Respect for Home and the Family) are discussed in specific.

2.1.4.1 Access to Justice – Convention on the Rights of Persons with Disabilities, Article 13

Lord et al. (2007: 137) define access to justice as "encompassing people's effective access to the systems, procedures, information, and locations used in the administration of justice". Until the CRPD, access to justice was not specifically stated in other UN human rights treaties. However, and particularly for marginalized groups, such access has been highlighted as fundamental to realizing human rights (Flynn, 2017). The intention with the making of the CRPD was not to create new rights but to reiterate existing human rights norms for disabled people. However, during the convention's drafting, it became evident that additional provisions were necessary to ensure effective access to justice for disabled people. These encompassed the recognition of the need for legal aid, the need for flexibility and accommodation, and the reaffirmation of a positive obligation to enforce such remedies (Flynn, 2017). In the final CRPD draft, Article 13, Access to justice, stipulates that parties must "ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages." (United Nations, 2006). Additionally, the article emphasizes that "States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff" (United Nations, 2006).

A comprehensive report on parents with disabilities and their children conducted by the US National Council on Disability reveals that bias against parents with intellectual disabilities within the child protection system is systemic, enduring, and pervasive (National Council on Disability, 2012). In the context of Icelandic child protection and parents with intellectual disabilities, research consistently indicates multiple violations on behalf of the child protection system towards parents with intellectual disabilities and their families. These violations encompass discriminatory practices, failure to accommodate needs, and inaccessible information and services (Sigurjónsdóttir & Rice, 2018; Sigurjónsdóttir et al., 2019; Rice et al., 2021; Sigurjónsdóttir & Rice, 2023; Leifsson et al., 2024). Despite the increased awareness of these injustices, no specific

procedures have been issued concerning protection, legal aid, or accommodations for disabled parents to access justice involved in the Icelandic child protection process. Accommodations, such as granting additional time, ensuring comprehension of information, and conducting parenting assessments that consider the unique needs of parents with intellectual disabilities can contribute to a more just process for parents involved in child protection.

2.1.4.2 Respect for Home and the Family- Convention on the Rights of Persons with Disabilities, Article 23

Article 23 of CRPD (United Nations, 2006) enshrines the right of all disabled people to establish a family and become parents. For people with intellectual disabilities, this article is of particular importance as it addresses their right to form and maintain family relationships on an equal basis with others—opportunities they have historically been denied. Article 23 recognizes the right of disabled people, including those with intellectual disabilities, to retain their fertility on an equal basis with others, ensuring that people with intellectual disabilities have the right to make decisions about family planning and reproduction without facing discriminatory practices. The article confirms that a child should never be separated from its parents based on disability of one or both parents or the disability of the child. This is reiterated as well in the United Nations Convention on the Rights of the Child (CDC) (United Nations, 1989). Furthermore, the article emphasizes the principle of equality and non-discrimination and calls for the prevention of discrimination against disabled people in matters related to marriage, family, parenthood, and relationships. For parents with intellectual disabilities, this means that they should be treated fairly and without prejudice in family-related matters, such as when in need of support.

To enable disabled people to truly exercise their right to parent, positive duties are declared in section 2 of the article, stating that parties are obligated to provide appropriate assistance to disabled people to enable them to exercise their rights to family life, such as in the performance of their childrearing responsibilities (United Nations, 2006). For parents with intellectual disabilities, this support may include accommodations such as accessible information, parenting training, and assistance in navigating challenges associated with parenting. Finally, the article promotes the inclusion of people with disabilities in family-related decision-making processes, which are essential for ensuring that their perspectives are considered and that they have a say in matters that affect their family life. This is of particular importance in the context of child protection interventions.

2.2 Institutional Justice Capital

Toward the end stages of the research process, particularly while writing the third article, the concept of Institutional Justice Capital proved to be a valuable, albeit late, edition to the analytical framework of this research. Hamilton and Maslen (2022: 539)

define institutional justice capital as the focus on "the capacity and resources to understand, navigate, and communicate fairly and equitably in all aspects of the criminal justice process". While not stated by Hamilton and Maslen, their work is likely inspired by the sociologist Pierre Bourdieu's well-known forms of capital thesis, which extends the Marxist economic form of capital to include cultural and social forms of capital as well (Bourdieu, 1986). Bourdieu's framework is rather broad and considers the resources that an individual, or groups of people, can accumulate as primarily concerning their position within class relations or social status. In contrast, Hamilton and Maslen focus more specifically on the resources, or forms of capital, needed to navigate the justice system; however, they also argue that the absence or presence of these forms of capital on the part of the individual is only a partial analysis. For example, attention needs to be paid to whether these resources are available and form part of the justice system itself; for instance, CRPD's Article 13 demands the inclusion of procedural and age-appropriate accommodations.

Hamilton and Maslen extended the work of Cloud and Granfield (2009) to apply their perspective to marginalized parents involved in the child protection system in Australia. They considered factors within institutional justice capital such as 'recovery capital' ("personal resilience skills and resources"); 'social capital' ("family, peers, networks"); and 'community capital' ("access to training and education to reduce stigma"). Furthermore, Hamilton and Maslen consider the family dynamics and generation regarding access to these forms of capital: "Families involved in child protection now more commonly experience child removal across generations, and distrust of the system presents barriers to accessing and utilizing resources in the community" (Hamilton and Maslen, 2022: 539). The authors are writing primarily here about aboriginal families and other marginalized parents in Australia, but there are parallels that can be drawn with the international literature pertaining to families of people with intellectual disabilities. For example, some qualitative research (e.g. Sigurjónsdóttir & Rice, 2020) has shown that children who have been removed from disabled parents have similar inter-generational negative feelings about the child protection system, as articulated by Hamilton and Maslen.

Feelings of anger, distrust toward the system, or shame resulting from being the subject of a child protection investigation can prevent parents from accessing the capital or resources crucial for their case. The institutional justice capital framework is also helpful as it pays attention to whether these resources are available at all and the numerous barriers that may impede access to them. In this study, the application of the framework sets focus on the mechanisms used by child protection and whether parents with intellectual disabilities can access necessary resources to ensure fair treatment.

2.3 Summary

I have discussed in this chapter the theoretical underpinnings of the dissertation. It outlines theoretical choices and provides an overview of various disability perspectives, including the social model, cultural model, and human rights approach to disability. The enduring influence of the medical model is discussed along with the limitations and contributions of the social model and feminist and intersectional critiques. Additionally, the human rights perspective, specifically the UN Convention on the Rights of Persons with Disabilities (CRPD), is highlighted as a crucial framework for analysing and understanding the challenges faced by parents with intellectual disabilities. The concept of Institutional Justice Capital was introduced as a valuable late addition to the analytical framework, focusing on the resources needed to navigate the justice system, especially within the context of child protection. The chapter concludes by underscoring the importance of addressing systemic issues and providing appropriate support for parents with intellectual disabilities to fulfil their parenting roles in accordance with human rights principles.

3 Parenting with Intellectual disabilities in Light of History, Modern Welfare and Disability Rights

This chapter provides the background material and context needed to expand upon the three articles that form this dissertation's findings. It explains how parents with intellectual disabilities became perceived the way that they are by the social service system, and how this perception impacts the provision of services and the treatment of these families; but the resistance toward recognizing these parents' capabilities and the lack of support for their rights for family life has its roots in this history. As discussed in previous chapter Mitchell and Snyder (2010) trace the roots of the eugenics movement to the 18th-century North Atlantic, where pseudo 'racial sciences' influenced efforts to prevent certain groups from reproducing. By the late 19th and early 20th centuries, this ideology led to the institutionalization and sterilization of people with intellectual disabilities in the global north, including North America and Europe (Mitchell & Snyder, 2001, 2006; Snyder & Mitchell, 2006; Sigurjónsdóttir & Rice, 2020; Stefánsdóttir, 2011; Stefánsdóttir & Hreinsdóttir, 2013). Iceland, however, did not embrace these practices until the mid-20th century (Margeirsdóttir, 2001). Although eugenics fell out of favor after World War II, its practices and the underlying ideology have not disappeared but have become more covert and embedded within everyday social practices. The focus has shifted from sterilization and sex-segregation in order to prevent pregnancy toward increased child protection involvement and child removal (McConnell & Phelan, 2022; Sigurjónsdóttir & Rice, 2016).

In the late 1960s, a new ideology began to emerge that came to be known as normalization. This new thinking held that conditions in institutions needed to be created that would enable disabled people (at the time this was focused on people with intellectual disabilities) to live as normal life as possible—one which was patterned upon what was typical in mainstream society (Kugel & Wolfensberger, 1969; Nirje, 1969, 1980; Bank-Mikkelsen, 1980; Wolfensberger, 1972). In the wake of normalization, reform initiatives began in the US and Europe which influenced residential services and led to the later process of de-institutionalization. That development, however, did not lessen these older eugenic fears that this population would begin to have children once they were no longer under the governance of the older system, resulting in measures such as surveillance in smaller group home settings. In the latter part of the 20th century, influenced by the independent living and disability rights movement, this population did start to live independently and become parents. Following the deinstitutionalization movement and banning of nonconsensual

sterilization, the number of parents with intellectual disabilities grew. As a result, most local services began experiencing a growing number of these families on their service rolls (Tymchuk & Feldman, 1991; Ray et al., 1994; McGaw, 1997). This caused difficulties due to the system being generally ill prepared and resourced to deal with the multiple needs of this expanding population (Tymchuk, 1992; Llewellyn, Bye & McConnell, 1997). Older stigmatic views and prejudice toward these parents still informed the service practices, along with a lack of knowledge as to how to support these parents. However, these views have had to contend in recent decades with disability-related discourses that are grounded in the framework of human rights. Signs of this new approach were seen in the 1990s, as reflected in the United Nations Standard Rules on the Equalization of Opportunities for Disabled Persons, article 9 (United Nations, 1994), which stipulated that member states should work against negative attitudes towards disabled people and parenting and promote the availability of appropriate counselling for expecting parents. In recent years, systems that disabled people are involved with have had to encounter an increasing emphasis upon human rights, as reflected in the UN Convention on the Rights of Persons with Disabilities. This shift is further supported by strengthened activism and policy measures that incorporate this new human rights approach, such as with the disability rights protection officers in Iceland (Lög um réttindagæslu fyrir fatlað fólk no. 88/2011) which is the focus of article III.

The research for this dissertation was conducted in Iceland; as such, the literature review that follows will mainly be focused on work done in the global north – primarily the Nordic countries, northern Europe, North America and other "Western" nations, such as Australia as these regions share to an extent similarities in culture, ideologies and practices pertaining to the issues at hand. However, despite the similarities, there are variations in the terminology pertaining to parents with intellectual disabilities and their inclusion criteria. In some countries, such as the United States and Australia, the term "intellectual disabilities" is commonly used. In contrast, the United Kingdom prefers the terms "learning disability" or "learning difficulties." Determining who has a learning disability is challenging, as definitions vary across different times and places, so prevalence is at best unclear. Additionally, we need to consider that some individuals have no formal diagnosis or have not received any formal services until they become parents. This is the experience in my own research journey, and it is difficult to gauge the extent of this population. However, it is generally agreed that these parents typically have mild or borderline intellectual disabilities (Llewellyn et al., 2010; Tøssebro et al., 2017; Working Together with Parents Network, 2021). Finally, the literature often refers to mothers with intellectual disabilities, as the focus of service provision and child protection has largely been mothers, though in recent years fathers with intellectual disabilities have also been gaining some attention. I will now turn to outline some of the scholarly developments in research with parents with intellectual disabilities.

3.1 Research on Parenting with Intellectual disabilities

Research on parenting with intellectual disabilities as a field of study is rather new and most research that has been done was undertaken in the final decades of the 20th century. There are, however, some earlier cases of research done in this field. For example, an investigation into the care and outcomes for children of "feeble-minded" parents in the US published in 1947 was one of the first studies in the field (Mickelson, 1947). Other earlier research dates from the sixties and the seventies, e.g., in work done by Edgerton (1967) and de la Cruz and La Veck, (1973) which investigated various aspects of the lives of parents with intellectual disabilities, such as stigma, the unique challenges they face and support needs. However, a significant milestone in the field was the first international conference on parenting with intellectual disabilities which was held in Denmark in September of 1996 (Danish Ministry of Social Affairs, 1996). The papers that were presented at this conference were the collective work of the key scholars active in the field at the time and represented some of the pressing research and advocacy-based issues. These scholars included the experiences and perspectives of the parents at the forefront of their research, which was a novel development (Booth & Booth, 1994; Llewellyn, 1994, 1995). At this conference, these scholars engaged with the core debates facing the field, such as whether adults with intellectual disabilities should even have the right to marry and have children (Llewellyn et al., 2010), and, among others, understanding who the population consisted of, how they parented, the challenges they faced, and their support and service needs. Since this time, an international group of researchers, scholars, and advocates have, individually and collectively, focused their attention on the topic of parenting with intellectual disabilities. The knowledge base of the field has expanded, and the focus of research has evolved. One critical development in research on parenting with intellectual disabilities is that families led by parents with intellectual disabilities cannot be understood without careful consideration and attention to each family contextual situation (McConnell et al., 2017), while also turning the lens of inquiry to the service system itself.

The field of study of intellectual disabilities and parenting is expansive, and below I have highlighted the major works that pertain to the focus of this study with an emphasis upon the last two to three decades. In the UK, Tim and Wendy Booth (2003) were the first to highlight the importance of advocacy and peer support, after having received attention for their work on the experiences and outcomes of children growing up in families headed by parents with intellectual disabilities in the 1990s (e.g. Booth & Booth, 1998). The work of the Booth's was paralleled in the US, for example as found in Taylor's focus on families and support networks (2000). Since that time, research has continued to focus on the experiences of families and parents sharing their stories (e.g. Collings et al., 2018; Höglund et al., 2013; Mayes & Llewellyn, 2012). These narratives remain crucial as parents still face persistent negative attitudes (Mayes et al., 2006; Pacheco et al., 2024) and poor services in recent years (see e.g. Spencer et al., 2024)

as they have in the past. Other bodies of work have looked at the material circumstances of these parents, such as difficulties in accessing suitable, safe housing and financial hardship or even poverty (Hindmarsh et al., 2015; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008).

An important focus has also been the service provision system itself. Alexander Tymchuk and Maurice Feldman (1991) pioneered research on evidence-based practice in support work with parents with intellectual disabilities. Investigating the support needs of these parents has since continued to be a major focus (e.g. Lightfoot et al. 2018), as well as a number of specific research areas such as what constitutes successful practices in this area (Tarleton et al. 2006); the collaborative and accessible assessment process for shared decision-making between support workers and parents about parenting supports (Spencer & Llewellyn, 2005); the effects of specific interventions (Hodes et al., 2018; Starke et al., 2013); system abuse (Booth & Booth, 1994, 1995); gender-based violence (Granqvist et al., 2014; McConnell et al., 2022; Rice et al., 2021); and the parental experiences of trauma (Hammarlund et al., 2023); the training and education of child welfare workers (Laliberte et al., 2013) as well as their attitudes and experiences (Strnadová et al., 2017); and a consideration of the use of parenting assessments with this population (Aunos & Pacheco, 2021). These selected mentions are only a small example of the growing field of research on parenting with intellectual disabilities and are intended to portray the expanding field of research on parenting with intellectual disabilities. While the focus here is work done in the global north, it is important to note that despite some differences in terms of culture, legal and service provision systems, outcomes and the experiences of these parents demonstrate significant similarities.

Scholars strongly agree that the challenges parents with intellectual disabilities experience are to a large part due to systemic failures, such as the lack of knowledge, insufficient or inappropriate support rather than the parents' innate limitations (Booth & Booth, 2003; Emerson et al. 2015; Feldman & Aunos, 2020; Llewellyn & Hindmarsh, 2015; Strnadová et al., 2017). Within the child protection systems in particular, parents with intellectual disabilities continue to be viewed through the lens of the eugenic ideologies of the past, which continue to pathologize, stigmatize and marginalize these parents (McConnell & Phelan, 2022), despite collective findings that have documented that support plays a crucial role in the lives of parents with intellectual disabilities. If they are provided with appropriate support, most of them can successfully parent their children (Booth & Booth, 1993; Feldman, 1994; Feldman et al., 2012; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008; McConnell et al., 2021; Wade et al., 2008; Tymchuk & Feldman, 1991). The common approach used by child protection systems seems deeply flawed, leading to harmful practices against these parents. These practices include assuming, from the outset, incompetence in parenting roles and organizing evidence to support claims of the unfit parent (Powell, 2022; Cox et al., 2015). Research has demonstrated that parents with

intellectual disabilities are not being treated fairly in court proceedings (see e.g. Granqvist et al. 2014; Forslund et al. 2021). This unfair treatment includes an over-reliance on parenting assessments based on measures such as attachment theory, which Forslund et al. (2021) argue are unfortunately too often misapplied, especially in the case of neuro-diverse populations.

The consequences of unjust treatment are well documented, as scholars and researchers have paid attention to such practices and the staggering rate of parents with intellectual disabilities involved in the child protection system. In an Australian study (Man et al., 2017), the prevalence of parents with intellectual disabilities was estimated to be less than 1% of all Australian parents. Despite this low prevalence, a study by Llewellyn et al. (2003) found that 9% of child maltreatment court cases in Australia involved parents with intellectual disabilities. This disproportionate involvement is also evident in other jurisdictions; in Canada, this figure is as high as 27% (McConnell et al, 2011) and in the US, Laliberte et al. (2017) estimated that parents with intellectual disabilities were twice as likely to be involved in child protection interventions than parents without disabilities. These numbers are reinforced in the study by Laliberte et al. (2024), which determined that parents with intellectual disabilities are disproportionately overrepresented in the child protection system, especially when it comes to terminating parental rights. DeZelar and Lightfoot (2018) have found that 19% of children in the US foster care system have been placed there due to their parents' disability. Similarly, studies from Canada and Norway show that an estimate of 20-25% of all children in foster care are removed from parents with intellectual disabilities (McConnell et al., 2021; Tøssebro et al., 2017). In the UK, Booth et al. (2005) documented that only 13% of children of parents with intellectual disabilities who were in foster care were re-unified with their family, compared with 31% of children who did not have a parent with intellectual disabilities. In these countries disability alone is often sufficient grounds for terminating parental rights, without considering available supports (Lightfoot et al., 2010; Powell, 2023). In Iceland, Sigurjónsdóttir and Rice (2017; 2018) have highlighted that the Icelandic Child Protection Act (Barnaverndarlög no. 80/2002) allows for the removal of children based on parental intellectual disabilities. Despite strong agreement across countries about what kind of services and support can help mitigate risks and are likely to be beneficial for these parents and their children (which will be discussed later in the chapter), known barriers continue to contribute to disproportionate involvement in child protection and to high rates of child removal in these families (Booth & Booth, 2005; DeZelar & Lightfoot, 2018; Lightfoot et al., 2017). It has been argued that there has been a failure or even reluctance to translate findings from research to practice (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008; Laliberte et al., 2024; Spencer er al., 2024). Therefore, appropriate support and services to parents with intellectual disabilities continue to be lacking (Koolen et al., 2020; Laliberte, 2013; MacIntyre et al., 2019), and, instead of scrutinizing or

questioning the available support, the lack of progress following an intervention is used to confirm the system's views of parents with intellectual disabilities as incompetent (Lightfoot et al., 2010; Starke et al. 2013; Strnadová et al., 2017; Sigurjónsdóttir & Rice, 2017).

As this research was conducted in Iceland, the local scholarship will receive specific attention. In Iceland, the topic of parenting with intellectual disabilities was first researched over twenty years ago by Hanna Björg Sigurjónsdóttir and Rannveig Traustadóttir (Sigurjónsdóttir & Traustadóttir, 1998; 2001; Traustadóttir & Sigurjónsdóttir, 2008; 2010). Their research focused on motherhood and intellectual disabilities, the support these mothers were provided and the resistance they showed to services that viewed them in a stereotypical way. Their study revealed support services that were incidental and often provided by workers with no or little knowledge about parenting with intellectual disabilities. The findings also highlighted the importance of support from the extended family, particularly a female relative, which was considered especially important whereas the Icelandic legislation did not, at that time, recognize these parents' need for service and support. Individuals with intellectual disabilities, especially women, are still pressured into using birth control and undergoing abortions in Iceland (Björnsdóttir et al., 2017), which demonstrates that the eugenic ideologies of the past are still present. A body of work in Iceland has focused specifically on child protection and parents with intellectual disabilities. Research by Hanna Björg Sigurjónsdóttir, along with James Rice, have for example, investigated court cases concerning parents with intellectual disabilities involved in child protection cases. In their research they have analyzed the term "neglect" (Sigurjónsdóttir & Rice, 2018) and how it has been used in the case of parents with intellectual disabilities. Some of their research explores how evidence of neglect is generated by stigma and prejudices surrounding intellectual disabilities, which are also rooted in the historical context of eugenics (Sigurjónsdóttir & Rice, 2016). They have also investigated how notifications of neglect made to child protection authorities have been used by their workers to produce narratives that serve to undermine the parents (Rice & Sigurjónsdóttir, 2018). Their studies suggest that parents with intellectual disabilities are subjected to prejudice and problematic work procedures within the child protection system, which has been described as systemic violence and plays a vital role in custody deprivation cases of parents with intellectual disabilities. Recent work by Leifsson et al. (2024) has been collaborative in nature and co-authored with a parent who was at the center of one of these cases.

The plethora of international collective research has established a solid knowledge base about parenting with intellectual disabilities and has revealed common themes indicating that these parents are dealing with similar issues despite differences in policy and service provision between countries.

3.2 Addressing the Support Needs of Parents with Intellectual disabilities

Support needs of parents with intellectual disabilities can be complex and difficult to describe as they are diverse and ever changing (Tarleton et al., 2006). Because of this diversity, research stresses the importance of tailor-made support so individual needs of parents, and their families, are met (Collings et al., 2017; Sigurjónsdóttir & Rice, 2017; Wade et al., 2008). However, helpful support has been characterized throughout the literature by several key attributes at the same time as it needs to be tailored to meet each family and the individuals within that family. In 1996, Tim Booth and Wendy Booth published a paper featuring an approach for supported parenting for parents with intellectual disabilities which other researchers have since confirmed. This early contribution is still of great relevance and features needed qualities of support along with laying out many of the common support needs of parents with intellectual disabilities.

3.2.1 Principles of Good Support

According to the Booths (1996), respect for the parents and their relationship with their child is at the core of good support. Such approaches should prioritize the family as a unit instead of focusing on individuals, which often results in attention being given primarily to the child, while neglecting the parents' needs (Booth & Booth, 1996; Llewellyn & McConnell, 2002, Wade et al., 2008). Such support is also less likely to be seen as threatening by the parents and often addresses difficulties that, if not attended to, may present barriers to parenting (poverty, inadequate housing, isolation) (Booth & Booth, 1996).

Research consistently indicates that support for parents with intellectual disabilities is most effective when provided on a long-term basis, as this approach facilitates the development of trust and respect between parents and service providers (Booth & Booth, 1996). The timing of such support is also crucial; whenever possible, it should be proactive rather than crisis-driven (Stewart et al., 2016). Equally important is the way support is delivered. It must be non-intrusive and non-threatening, given that many parents live in constant fear of losing custody of their children (McConnell et al., 2011). This is particularly significant because many parents with intellectual disabilities have had negative experiences with services in the past, leading to feelings of fear, suspicion, and resistance towards new interventions (Traustadóttir & Sigurjónsdóttir, 2010). Consequently, establishing positive relationships with these parents often requires time and a willingness to engage meaningfully in their family lives. Moreover, long-term support not only allows for the development of these crucial relationships but also provides opportunities for preventive measures and the identification of support methods that align with the parents' unique learning styles (Booth & Booth, 1996).

A fundamental aspect of effective support is a focus on the strengths of the parents, viewing them as valuable resources and giving due attention to their abilities and preferences (Aunos & Pacheco, 2013; Collings et al., 2017). By adopting this perspective and involving parents as equal partners in service planning and decision-making, there is a greater likelihood that they will be more motivated and perceive the support as relevant to successful parenting. Such an approach is seen as empowering, fostering a sense of control and competence, which in turn encourages families to remain engaged and invested in the support process (Booth & Booth, 1996; Spencer & Llewellyn, 2007; Tucker & Johnson, 1998). Moreover, support is most effectively received when delivered in the home environment, ideally within the context of the parents' extended families and communities, in a manner that is both comprehensible and consistent (Atkin & Stenfert Kroese, 2022; Aunos & Pacheco, 2021; Booth & Booth, 1996, 2005). Providing support in this context enhances the potential to leverage the strengths within the parents' environment, translating more effectively into the family's daily life compared to support offered in settings disconnected from the family's lived experience (Booth & Booth, 1996; Feldman & Case, 1999).

More than twenty years ago, Strike and McConnell (2002) described an approach to working with parents with intellectual disabilities to address the parents' frequent experiences of being under surveillance, having limited opportunities for learning, and small support networks. At the core of this approach are six main principles that emphasize a supportive, flexible, and collaborative framework that focuses on the needs and strengths of parents with intellectual disabilities. These principles are still relevant and are highlighted in the Good Practice Guidance on Working with Parents with a Learning Disability (2021). The principles are founded on the conviction that the parents have the potential to thrive and succeed, emphasizing personal development over just acquiring skills. The approach prioritizes learning from the parents' experiences and adhere to a tailor-made support design that enable parents to participate in shaping the agenda. The approach stresses support that is adaptable and responsive, permitting parents to engage in practices in their own way and at their own speed. Additionally, it highlights the importance of peer mentoring and learning through shared narratives (Strike & McConnell, 2002). The approach laid out by Strike and McConnell have much in common with the approach by Booth and Booth (1996) by emphasizing respect, partnership and context.

3.2.2 Types of Preferred Support

It is important to explore what kind of support the parents themselves consider to be helpful and needed (Llewellyn, 1995). In an extensive systematic review on support needs of parents with intellectual disabilities done by Koolen et al. (2020), parents described activities they wanted support with. The findings, along with other research, suggest that parents often prefer hands-on assistance with childcare and housekeeping activities, such as feeding, bathing, dressing, cooking, doing homework and playing

(Koolen et al., 2020; Stenfert Kroese et al., 2002; Wilson et al., 2013). Findings also suggests that parents with intellectual disabilities often need support in navigating the service system and dealing with the various service providers involved in their life (Koolen et al., 2020). Such support involves activities such as filling out forms, accompanying the parents to meetings or court and help with understanding professional language, such as when communicating with doctors or lawyers (Stenfert Kroese et al., 2002; Tarleton & Ward, 2007). Parents have expressed that practical support is especially valued when coming from close family members or other parents with intellectual disabilities (Llewellyn, 2005; Tarleton & Ward, 2007; Traustadóttir & Sigurjónsdóttir, 2008).

Parents have also emphasized the significance of emotional support. They have expressed the need for someone who is willing to listen, is available when needed, and shows genuine interest in their children (Booth and Booth, 2004). Such support is particularly valued when it comes from a family member or partner (Wilson et al., 2013). In Llewellyn's (2005) research, parents described how they would typically prefer to first turn to their partner and then to extended family members before reaching out to professionals. However, other research has also highlighted that support workers and healthcare staff frequently provide crucial emotional support as well (Booth & Booth, 2004; Strike & McConnell, 2002; Wilson et al., 2013).

Advocacy for parents with intellectual disabilities is receiving more attention as an essential part of creating a more equitable environment for parents with intellectual disabilities, who often face discrimination from a system that fails to recognize their unique needs (Albert & Powell, 2019; MacIntyre & Stewart, 2012). According to the systematic review done by Koolen et al. (2020), parents regard advocates to be crucial for their voices to be heard and to help in their struggle in maintaining custody of their children or continued contact with their children if placed in foster care. Parents have also recommended that they need to have access to good advocacy when navigating the child welfare system in order to provide a needed power balance (Albert & Powell, 2019). MacIntyre and Stewart (2012) investigated the lived experiences of parents with intellectual disabilities. The parents stressed the crucial role of advocacy in ensuring that their voices and perspectives were considered in formal proceedings. Furthermore, advocates were instrumental not only in facilitating communication but also in addressing the psychological, social, and emotional challenges of parenting. The parents interviewed reported feelings of empowerment, improved understanding of child protection processes, and enhanced support in daily life after being involved with an advocate. MacIntyre and Stewart (2012) conclude that if not for the advocates these parents would continue to be marginalized, particularly within the child protection system. Authors such as Hamilton and Maslen (2022) have proposed that access to such practical resources are made available to parents and professionals as soon as parents with intellectual disabilities are involved in the welfare system.

3.2.3 Parenting Programs

International research has highlighted the need for institutions and agencies to emphasize and invest in the training of their workers in evidence-based services and interventions specifically tailored for parents with intellectual disabilities (Clayton et al., 2008; Laliberte, 2013). Most interventions focus on training or teaching skills needed for successful parenting (Feldman, 1994; Starke et al., 2013) and/or creating environments that mitigate risk and foster parenting success, such as by strengthening social relations (Feldman, 1994; McConnell et al., 2008; Tarleton & Turner, 2015).

There is now a growing body of literature that demonstrates the effectiveness of parenting intervention for parents with intellectual disabilities, affirming that they can learn the skills needed for taking care of their child (Feldman, 1994; Hodes et al., 2018; Tarleton & Heslop, 2021; Tymchuk & Feldman, 1991). However, more research is needed to develop the interventions further and establish a stronger evidence base. Wilson et al. (2013) concluded in their systematic review of intervention programs for parents with intellectual disabilities that, although studies on interventions are promising and support their effectiveness to some extent, those studies have limitations due to their design, such as small groups of participants. Despite these limitations there are programs that are considered to be promising and facilitate positive effects. These programs are both group-based (McConnell et al., 2014; McConnell et al., 2009; Tarleton & Turner, 2015) and home-based (Feldman et al., 1992; Hodes et al., 2018; Starke et al., 2013) in design. However, intervention programs for parents with intellectual disabilities are not widely known or accessible (Laliberte, 2013). In the field of parenting with intellectual disabilities, Step by Step (Feldman, 1994) is probably the most researched and well-known of such parenting programs. Another parenting program, sharing components of the Step-by-Step program, is Parenting Young Children (Mildon et al., 2008; Starke et al., 2013). Both programs are home-based interventions intended for parents with intellectual disabilities at risk of neglecting their children of 0-3 years. The program is based on behavioral and adult learning approaches and is contextual- and strengths based. The benefits for institutions implementing such parenting programs are that these programs are not only about parenting-training but equally important also about training the professionals as it demands reflexivity on the part of the practitioner to be aware of his or her own feelings, biases and attitudes, societal stereotypes and prejudices (Rice & Sigurjónsdóttir, 2022). These programs also emphasize the critical importance of time to establish trust and that the parent must set the aims for collaboration to be possible. Research conducted on the usefulness of such programs for increasing childcare skills has shown positive gains across a range of parenting skills such as child-parent relations, feeding, bathing and diapering (e.g., Feldman et al., 1992; Feldman & Case, 1999; Feldman et al., 1999; Starke et al., 2013). Other parenting skills-training programs have shown promising results, e.g. Parenting Young Children (Starke et al., 2013), Home Learning Program (Llewellyn, 2003), and Video-feedback intervention to

promote positive parenting for parents with learning difficulties (VIPP-LD) (Hodes et al., 2018).

Social relationships of parents with intellectual disabilities have also been the focus of some programs. In England, Booth and Booth (2003) studied the effects of a group-based program, Supported Learning Project, aimed at strengthening the support networks and advocacy skills of mothers with learning difficulties. The results were encouraging and supported the use of the program. Research on the Australian version of the Supported Learning Program – Me and My Community (McConnell et al., 2009) – also showed positive gains in mothers' relationships and psychological wellbeing, along with goal attainment. Another program, Mellow Futures (Tarleton & Turner, 2015), is both home-based and group intervention for mothers to enhance attachments and relationships. Both mothers and professionals recognized gains in maternal confidence, parenting skills and social relationships (Tarleton & Heslop, 2020; Tarleton & Turner, 2015). Intervention for parents with intellectual disabilities is more likely to be successful if it is implemented in the place where the skills are to be used and when based on the parent's learning needs, strengths and interests (Feldman & Case, 1999, Spencer & Llewellyn, 2005).

3.2.4 Individual Factors that Influence Support Needs and Support Provision

Individual-level factors of parents with intellectual disabilities, along with characteristics of their family, are related to involvement with the child protection system. According to Powell et al. (2024) these factors directly influence inequities in the system. Spencer and Llewellyn (2007) also note the significance of interpersonal relationships between system workers and the parents in determining whether the outcomes are positive or negative. As stressed earlier, parents with intellectual disabilities are far from being a homogeneous group and their support needs vary significantly. Each family is influenced by different factors that must be taken into account and considered when planning and implementing support services. These are, for example, the presentation of the impairment, learning styles, and different contextual and positional factors (e.g. family ties, income, housing, health) that intersect with the disability (McConnell & Llewellyn, 2002; Tarleton & Turney, 2020).

It is known that parents with intellectual disabilities often have small or even non-existent social networks, leaving many socially isolated, especially from their local communities (Llewellyn, 1995; Llewellyn & McConnell, 2002). Small or no social networks can result not only in loneliness but also limited opportunities for support and access to suitable role models (Lightfoot et al., 2018; Llewellyn & McConnell, 2002). At the same time, research has also highlighted the importance of informal support provided by the social network of the parents, demonstrating that the support from e.g. family, friends and neighbours is preferred by parents, and such support relates to both families' wellbeing

and developmental outcome of their children (Darbyshire & Stenfert Kroese, 2012; Lightfoot et al., 2018; Llewellyn and Hindmarsh, 2015). According to Llewellyn and McConnell (2002) it is critical that mothers with intellectual disabilities take part in their community and that service providers are responsive to their support networks. They suggest that professionals and support personnel work actively with parents with intellectual disabilities towards strengthening the social network of parents and increase their community involvement. The role of the service provider can involve fostering existing relationships, finding friends or companionship through participation in activities in their local community.

The characteristics of the parents are not only of importance but also those of the support worker. Research has found that parents consider the most helpful support coming from individual support workers who are willing to listen and hear what they have to say, give repeated step by step guidance, and provide hands-on assistance with practical matters instead of only focusing on theirs or the child's behaviours (Booth & Booth, 2004; Tarleton & Turner, 2020; Tarleton et al., 2018). Tarleton & Turner (2020) found by interviewing professionals who were considered to provide successful support to parents with intellectual disabilities that they shared similar views and understandings. They understood in similar ways the struggle and the many barriers these parents are up against and the belief that neglect could be avoided with the provision of proper support. Relationships-based practice has been highlighted in the literature (Ruch, 2005; Tarleton & Turner, 2020). The importance of the support worker getting to know the parent has been stressed, and they are encouraged to be sensitive to their individual- and disability-related needs and to be aware of the parent's contextual characteristics and pressures, such as social isolation and financial hardships. Furthermore, it is also important that the support worker knows the parent's history and former interaction with the child welfare system and understand the parent's fears (Traustadóttir & Sigurjónsdóttir, 2010).

3.3 Barriers to Support

After introducing the research on parenting with intellectual disabilities (3.1.) and the kind of support needs these parents require or want (3.2.), I will now turn to a discussion in the research of some of the barriers and hindrances to providing appropriate and meaningful support for these parents that have been observed. Scholars in the field widely concur that the struggles faced by many parents with intellectual disabilities, such as the difficulties maintaining custody of their children, are largely caused by environmental and systemic barriers and failures rather than inherent parental limitations (Emerson et al., 2015; McConnell et al., 2021; Pacheco et al., 2022; Rice & Sigurjónsdóttir, 2018). The barriers encountered can vary significantly depending on a range of contextual factors, including societal attitudes, policy frameworks, the legal and administrative landscape, prevailing political ideologies, available funding, and requirements for professional development, as well as the personal characteristics of both service providers and the families they serve (Powell et al., 2022).

3.3.1 Discrimination, Stigma and Prejudice

As discussed above, scholars have long pointed out the inequities parents with intellectual disabilities are subjected to and which often appear in the form of discrimination, stigma and prejudice; these factors reside at the core of the struggles these parents face. These inequities are multifaceted and come in the form of, among other things, the reluctance to provide appropriate and meaningful support for parents with intellectual disabilities, inaccessible services or even processes that undermine their rights to keep and take care of their children (Laliberte et al., 2024; Powell et al., 2024). Research has highlighted that inequities parents with intellectual disabilities experience in the welfare system are not only affected by factors on institutional and individual levels but are also very much influenced by laws and policies put in place on the governmental level (Powell et al., 2024; Laliberte et al., 2024, Lightfoot et al., 2018). The way child welfare is carried out is largely determined by policy and laws as it provides the frame for workers to implement their work (Laliberte, 2013). An examination of such legal framework suggests they have been constructed in reference to the history of eugenics outlined earlier in this chapter and which, in turn, guides practice. For instance, there are laws that continue to permit the termination of parental rights based on disability (Powell, 2023). The Icelandic child protection laws, article 29 (80/2002), is an example of such legislation: it states that a termination of parental rights should be performed in the case of endangerment of the child's health or development because of the parents' low intelligence or mental health challenges. Furthermore, legislation related to child welfare has, for the most part, failed to recognize families led by parents with intellectual disabilities and their need for specific services (Laliberte, 2013). Additionally, needed or available services are not necessarily accessible or open to parents with intellectual disabilities. Slayter and Jensen (2019) found that parents with intellectual disabilities are far less likely than parents without intellectual disabilities to be given access to general services such as case management or support aimed at family preservation. Alarmingly, parents with intellectual disabilities face difficulties accessing legal aid, and they encounter evidence used against them that parents without intellectual disabilities do not (Hamilton & Maslen, 2022; Sigurjónsdóttir & Rice, 2017). McConnell et al. (2023: 116) suggest that such failures may stem from "pervasive and prejudicial assumption of inherent and intractable parental incompetence."

It is alarming that the courts and judicial system seems as biased as other systems parents with intellectual disabilities encounter (Hamilton & Maslen, 2022; Powell, 2023; Powell et al., 2024). For example, within the judicial system where decisions are made whether a parent will lose or maintain their parental status, the courts continue to use parenting assessments that do not consider the disability, over-rely on parental IQ and show limited knowledge about disability, disability rights and of those specific measures that are needed in order to meet the needs of disabled people stated in laws and conventions (Callow et.al., 2017; Pacheco et al., 2024; Powell, 2023; Powell et

al., 2024). Powell (2016) even states that "some judges appear more inclined to base decisions on 'intuition' rather than scientific fact". This deficiency perpetuates negative and stereotypical views (Jones, 2013; Laliberte et al., 2024; McConnell et al., 2021; Strnadová et al., 2017), and such biases and discrimination lead to practices that further marginalize parents with intellectual disabilities (Laliberte et al., 2024). To fight these discriminative practices researchers in the field have repeatedly called for a shift in policy, from emphasizing the pathologizing medical model towards the social- and human rights understanding of disability with the potentials to foster and support all families and to help institutions and their workers to implement services and supports where all people have the same opportunity to form and maintain a family (Laliberte et al., 2024; Powell et al., 2024).

3.3.2 Nature of Support Agencies

Despite the vast available research on support strategies for parents with intellectual disabilities, the support provided is often inappropriate and discriminatory, a concern highlighted by scholars for decades (Hayman, 1990). The persistence of inappropriate measures in services and support for these parents can in part be attributed, as discussed above, to discrimination, stigma and prejudges but also to the lack of training and education within the service system (Laliberte et al., 2024). Practitioners have described their lack of knowledge and experience, self-doubt, and little confidence in their ability to meet the specific needs of parents with intellectual disabilities (Clayton et al., 2008; Pacheco et al., 2022). Lightfoot et al. (2017) reported on the experiences of disabled parents and attorneys of the child protection system where findings indicated an overwhelming lack of knowledge and expertise among child protection workers about disability and disability rights. However, barriers to appropriate support are not confined to insufficient professional training. The lack of access to needed services has been reported in research. This inaccessibility often exists because service providers are unequipped to offer evidence-based services to parents with intellectual disabilities, resulting in ineffective support (International Association for the Scientific Study of Intellectual and Developmental Disabilities Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). Furthermore, provided support services often contrast with research evidence on what constitutes appropriate and useful support for parents with intellectual disabilities. These inappropriate measures, which include practices such as providing crisis-driven, short-term support, have been reported in research (Booth & Booth, 2003; McConnell et al., 2002). Providing short-term support in isolation can lead to a cycle of recurring crises. When a specific issue or concern is alleviated, the reduction or withdrawal of support often results in the re-emergence of those same concerns or problems (Tarleton et al., 2006). Another inappropriate measure is support focusing separately on either the child or the parent rather than the family as a unit, risking fragmented services and overlooking the holistic needs of the family unit (Sigurjónsdóttir et al., 2019, Wade et al., 2007). Child-centric practice, which

dominates much of child protection work, has been criticized for its dogmatic focus on the child with the exclusion of other family members, including the parents (Featherstone et al., 2014). While child protection work rightly emphasizes the child's rights, safety, and well-being, these objectives can also be achieved by providing timely, appropriate and tailor-made support to the parents and thereby fostering family unity (Hamilton et al., 2020; Maylea et al., 2023; Powell, 2023).

Another well-known barrier, due to how the support agencies operate, in particular the child protection, is that the services are most often only available for short periods. However, parents with intellectual disabilities typically need long-term support, though it can vary in intensity depending on circumstances at every given time (Collings et al., 2017; Strnadová, 2017). One explanation for this is a lack of understanding of the nature of the needs of parents with intellectual disabilities. Another explanation is how the system is designed (Powell, 2022; Pacheco et al., 2022). For extended periods of time, high caseloads have been reported in child welfare, resulting in time pressure on service providers (Llewellyn et al., 1997; Pacheco et al., 2022). These pressures make it hard to provide services that are responsive to the individual needs of families led by parents with intellectual disabilities, and which can only be achieved by having time to develop relationships that are built on mutual trust and respect (Pacheco et al., 2022). Spencer et al. (2024) argues that the resistance to providing long-term support can partly be explained by a reluctance to recognize the interdependent nature of parenting for parents with intellectual disabilities, unlike the recognition given to parents without such disabilities. Instead, parents with intellectual disabilities are required to be able to perform independently and without assistance or support (Leifsson et al., 2024).

As parents with intellectual disabilities are often involved with many agencies, a lack of interagency collaboration can result in confusion and failure for both parents and service providers. Parents with intellectual disabilities who are involved with different agencies are at risk of not receiving coordinated services, and therefore they either get "lost" in the system and do not receive sufficient support, get services that are in discrepancy with each other, or they are consequently overwhelmed and burdened (Aunos & Pacheco, 2013; Lightfoot et al., 2018). Pacheco et al. (2022) contend that without proper collaboration and communication between agencies and professionals, support risks becoming service-centered, only addressing needs through the agency's specialty instead of meeting the support needs holistically. Continuity and consistency in support is furthermore often lost with the revolving door of new workers in the service and support system causing the parents stress and anxiety as important knowledge can be lost at the same time as the parents have to form relationships and build trust with yet a new support worker (Albert & Powell, 2020).

Another factor that presents a barrier to successful or appropriate services for parents with intellectual disabilities are the uneven power dynamics that are skewed toward child protection. Tarleton (2008) has used the term "institutional abuse" to describe

how parents with intellectual disabilities are systematically discriminated against in child protection work, leaving the parents feeling powerless and overwhelmed by child protection authorities (Booth et al., 2005; Collings et al., 2018; McConnell et al., 2002; McConnell & Sigurjónsdóttir, 2010). Research has also suggested that parents with intellectual disabilities are held to higher standards than other parents (Cox et al., 2015), and they have described feeling unheard and disrespected by service providers while they are caught in a system where they have difficulties understanding the processes that are being undertaken (Collings et al., 2018; McConnell & Sigurjónsdóttir, 2010).

3.4 Actions towards Appropriate Support

Having introduced some of the barriers that impede the provision of appropriate support, I will now focus on literature that suggest ways to move support and services towards more just and equitable support and services for parents with intellectual disabilities. In doing so, attention must be paid to research, policy, and practice (Laliberte et al. 2024).

3.4.1 Human Rights into Policy

According to Powell et al. (2024), laws and policies are tools that contain the possibility to ensure that parents with intellectual disabilities receive equal treatment to others and are given the possibility to parent their children supported by needed services. Legislation that allows disability as grounds for termination of parental rights can, for example, be amended and thereby used to counter-act discriminatory practices we continue to see around the globe, as well as in Iceland. One of the biggest developments in pushing for the protection of the human rights of disabled people is the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). In the case of parents with intellectual disabilities, The CRPD has the potential to be a valuable tool to confront discrimination. Signatory states that have ratified the convention are to adjust their legislation in accordance with it or, if needed, put in place new legislation to fulfil the requirements put forth by the convention (Ministry of welfare, 2013). Such legislative actions should ensure that laws and policies that touch upon parenting and disability are in line with the convention and, at the very least, do not work against its aims.

Emphasizing the importance of legislative actions as an act of change, The National Research Center for Parents with Disabilities (Powell & Rubinstein, 2020) has outlined strategies for creating effective legislation that supports the rights of disabled parents (Powell & Rubinstein, 2020). The strategies are informed by interviews with advocates and legislators, highlighting key principles for developing legislation that unequivocally protects and supports the rights of disabled parents. These principles are intended to leave little room for misinterpretation of key terms such as "reasonable

accommodations" and "support services". Moreover, they stress the importance of actively involving disabled parents in training and education of child welfare workers, drawing on their lived experiences of parenting and support services, to better address their needs (Powell & Rubinstein, 2020). However, there is an enduring lack of knowledge about the rights of disabled people within the governmental system (Laliberte et al., 2024; Lightfoot et al., 2018, National Council on Disability, 2012). This lack underscores the necessity for education and awareness raising initiatives that are focused on disability and disability rights that are crucial for building rights-based policies and combating negative societal attitudes against parents with intellectual disabilities (Powell et al., 2024).

In Iceland, the Act on Rights Protection for disabled people is an example of how the CRPD has pressed for new legislation to meet the state obligations declared in Article 12, 13 and 33 of the convention (Ministry of Welfare, 2013). The effects of the CRPD can also be seen in the act about services for disabled people with long-term support needs (38/2018) and thereby meeting obligations under article 23 of the CRPD. These laws are fundamental for disabled parents as they were mentioned for the first time in an Icelandic act of law as being rightsholders of support and should be able to access specialized justice mechanisms in case of violation of their rights.

3.4.2 Research into Practice

Providing parents with intellectual disabilities with the support and services they need for their families to thrive is a task that continuously needs to be under investigation. Despite the ongoing research that has mostly agreed on the kinds of support parents want and need, there seems to be profound difficulties in putting evidence into practice. Goodley (2011) suggests that such difficulties may stem from the expert role professionals occupy in health and social services where the medical view on disability is still dominant, causing nuanced issues, such as parenting with intellectual disabilities, being addressed without sufficient consideration of contextual factors. Others have suggested that the reasons for these difficulties can first and foremost be traced to tenacious assumptions about the (in)ability of parents with intellectual disabilities, the nature of parenting as an independent act and ideologies that are in favor of individualism at the expense of social welfare (Spencer et al., 2024).

Different suggestions have been put forth to close this gap and overcome barriers for appropriate support and achieving services that are in line with suggestions from parents and researchers. IASSIDD, Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008) and Laliberte et al. (2024) have suggested that services need to move away from the "deficiencies" mindset and towards services that are characterized by holistic, reflexive, strength-based, and tailored support with flexibility in intensity and duration. Education is a must for this to be possible. Educational initiative on institutional and agency level, aimed at educating and training child protection staff and other professionals involved in services, has been highlighted

as one of the most powerful ways of fighting injustices and providing evidence-based, appropriate support for parents with intellectual disabilities (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008; Powell et al., 2024). This point is supported by research that indicates that knowledge and expertise about disability within child welfare staff is inadequate, and some research suggest that the education of future child welfare workers does not prepare them well enough to become professionals who can work well and effectively with parents with disabilities (Cleaver & Nicholson, 2007; Laliberte, 2013; Tarleton & Turner, 2020). Furthermore, Pacheco et al. (2022) have highlighted that entry-to-practice and continuing education serve an important role in building systems' capacity to support parents with intellectual disabilities and address institutionalized discrimination. Laliberte et al (2017) and Powell et al. (2024) have highlighted not only the urgent need for more education about disability and parenting within institutions but also on accommodative methods, specific needs related to disability and about disability rights.

Other institutional and agency characteristics are also vital to be able to bring research and practice together. The literature indicates that workers within child welfare often work under significant time and resource constraints (Proctor & Azar, 2013), making it challenging to stay updated with the latest research or to apply research findings. It is therefore important to properly manage caseloads both to create space for knowledge building and to provide sufficient time to establish trusting relationship with the parents and collaborate with them in a respectful way that considers relevant contextual factors (Booth & Booth, 2003; Feldman, 2002; Pacheco et al., 2022). Furthermore, multi-agency collaboration has also been reported as a crucial element of successful practices. Support workers must be encouraged to collaborate and foster partnerships with other services involved, such as health care, child protection, social services, and disability services to provide preventative services instead of crisis-driven (Aunos & Pacheco, 2013; McConnell et al., 2008; Pacheco et al., 2022; Tarleton & Turney, 2020).

In order to ensure that services, including child protection services, are of high quality and in line with latest knowledge, Pacheco et al. (2022) suggest a strong common governmental-led framework of child, parent, and family support. Unfortunately, there are not many national-led programs or strategies that have been put in place that focus on successful parenting by people with intellectual disabilities. However, there are examples of such initiatives worth mentioning. In 2004, Australia became the first nation to introduce a strategy for building a national agenda for early childhood (McConnell et al., 2008). The aim of the agenda was to get an all-around governmental approach to invest in the early years of childhood development. Under this framework, the Australian government allocated considerable resources for the agenda, enabling the implementation of the Healthy Start project for over three years. The project successfully continues today in Australia, though it is no longer supported by governmental funding. The aim of the Healthy Start initiative was to build system capacity to reduce risk for families led by parents with intellectual disabilities. The initiative built a bridge between research, policy and practice, and resulted successfully in networks of practitioners across and within disciplines, where knowledge,

innovation, and information are shared through online platforms, courses, workshops, and leadership support (McConnell et al., 2008). Today, the aim of the Healthy Start initiative remains the same as when it was originally implemented (Parenting Research Center, n.d.). Another governmental-led initiative based in the UK is The Good Practice Guidance on Working with Parents with a Learning Disability (Department for Education and Skills and Department of Health, 2007). The guidance is an outcome of the collaboration of parents with learning disability, children of parents with intellectual disabilities, scholars in the field, professionals in the field, NGOs, and advocacy groups. The Good Practice Guidance is intended for adult and children's services and is concerned with multi-agency collaboration along with the role of statutory and private sector services. The aim is to improve support and services for parents with intellectual disabilities and their children to increase the chances of children being cared for in a supportive environment. The guidance material developed by this initiative is updated on a regular basis by the 'Working together with Parents Network' to ensure that the guidance is relevant and based on current knowledge, law, policies and practices (Working Together with Parents Network, 2021). These governmental-led projects show that policy that properly funds and supports such initiatives has the potentials to reach the institutional and agency level and actually be implemented in real life.

3.5 Summary

In this chapter I have provided a foundation of research that informs this dissertation. The chapter starts with an introduction to how parents with intellectual disabilities have been viewed and treated in the past and through to the present. Key academic advancements and developments in the study of parents with intellectual disabilities are reviewed with a focus on studies conducted in the global north, particularly within the Nordic countries, northern Europe, North America, and other European-influenced regions like Australia, as these areas share common cultural, ideological, and practical aspects relevant to the topic.

The chapter also delves into the specific support needs of parents with intellectual disabilities and addresses the various barriers, both systemic and societal, that hinder the realization of comprehensive support mechanisms aligned with international human rights frameworks. By exploring these challenges, the chapter underscores the complexity of developing support services that are not only accessible but also equitable and tailored to the unique circumstances of parents with intellectual disabilities. Finally, the chapter explores scholarly literature that proposes pathways towards more just and appropriate support systems and how it is possible to address the seemingly persistent research-practice gap. By doing so, the chapter aims to contribute to the ongoing discourse on how to better align support services with the principles of justice, inclusion, and human rights, ultimately advocating for a paradigm shift in how support for parents with intellectual disabilities is conceptualized and delivered.

4 The Study

This chapter provides an overview and rationale for the aims of the research, the research questions and methodology. I will explain the research process and how and why I began this journey. The research, which can be described as hybrid qualitative approach with elements of ethnography and grounded theory, was performed in three different phases, which resulted in one publication for each stage. A detailed description of the overall study is provided, including an overview of the participants, the research design choices and the data collection, and followed by an explanation of the data analysis process. The chapter will conclude with a discussion about the ethical considerations and practices, along with strengths and limitations of the research.

4.1 The Research Process

In 2015 I received a telephone call that could be said to have been the inspiration and beginning of this research. The call was from a relative who has intellectual disabilities and was going through a crisis in the form of an intensive child protection intervention. As I became involved in the case as an advocate on her behalf, the mother provided me with the case documentation. As I familiarized myself with the ongoing case, I also actively engaged in communication with the child protection workers and advocated on behalf of the mother. I also became aware of how I was treated by the child protection system as an advocate, even with a professional degree in occupational therapy and as an academic and wondered about the experiences of those in similar situations who are socially marginalised or lack strong support networks. Through this experience, I began to form grave concerns about the support this family had been provided during the time of the intervention. I also wanted to know what kind of experiences other families in similar situations had and became interested in pursuing this subject in academic research. I applied to the doctoral program in disability studies at the University of Iceland. I wrote a research proposal that concluded in acceptance into the program in 2017. The formal data gathering spanned five years in total and was conducted in three phases, starting in April 2018 and ending in January 2023. In early 2020, the Covid pandemic hit worldwide, making in-person interviewing and observations impossible. This delayed the data collection of the research and explains in large the gap in the research process seen in figure 1.

During the time of the research, I had the opportunity to use the knowledge and experience that I acquired related to the research subject. I have continued to support and advocate for the beforementioned family and stayed in contact with and followed regularly up on another couple who participated in and played a large role in this research. I also had the opportunity to collaborate, educate and work with professionals within the social services, health care and child protection agencies that work with

parents with intellectual disabilities. Both the advocacy and the collaborative work I have done during the course of this research provided me with important insights and understandings of the situation of parents who are involved with the child protection services.

As parents with intellectual disabilities struggle in society generally, poorly equipped support services often seem to contribute to and exacerbate that struggle (Strnadová et al., 2017). In Iceland, parental rights can be terminated based on claims that all support measures have proven to be ineffective, often without much in the way of critical examinations of the supports that have been provided and the knowledge-base of the providers (Sigurjónsdóttir & Rice, 2017). Difficulties, when they do arise, are often attributed to the disability without the support itself being scrutinized (Strnadová et al., 2017), resulting in lost opportunities to improve the support system to better fit the needs of parents with intellectual disabilities. With that in mind, I began interviewing support workers to investigate how the support was carried out and if disability rights, as highlighted in the CRPD, had been translated into the service. The next phase of the research involved talking to parents with intellectual disabilities and to hear their stories of their experiences of support. However, after doing only two interviews, I met a mother who shared her family's narrative with me, and I realized that it was important to take a deep dive into her story and investigate how she and her partner had managed to keep custody of their children despite years of struggle. I felt it was important to highlight the success of parents with intellectual disabilities as a counter-narrative to that of parents with intellectual disabilities as helpless and incapable of taking care of their children. Exploring these stories of resilience can also shed light upon what works as well as what does not. The analysis in this specific case involved data obtained from interviews with the parents and their supporters and various documents extending over a decade of child protection involvement.

While doing this research, I became aware of the important role played by disability rights protection officers for disabled people and that the project should also include a consideration of their work in this process. The final and third phase of the research involved conducting interviews with rights protection officers about the work they do for and with parents with intellectual disabilities and their experiences of safeguarding their rights. As such, the research project evolved from its beginnings to have a tripartite focus: the understanding of the support measures from those in the system who provide it; the experiences of the parents of these measures; and the role of disability rights protection officers who work to ensure that the rights of the parents in this process are respected. I will now provide an explanation of the project in terms of its academic underpinnings, starting with the research questions.

4.2 Aims and Research Questions

The aim of the research was firstly to critically explore if, and how, parents with intellectual disabilities in Iceland are supported to raise and take care of their children. A second aim was to investigate how support is carried out in the evolving disability

and human rights environment with a specific focus on parents with intellectual disabilities who are involved in the child protection system. Thirdly, I wanted to understand how rights protection officers carry out their work and what kind of barriers and resistance advocates and supporters experience in their attempt to claim justice and fair treatment of parents with intellectual disabilities. The fourth aim of the study was to assist in providing parents with intellectual disabilities a platform to tell their story in order to inform other parents, advocates, and professionals who are involved in the lives of families led by parents with intellectual disabilities.

Five main questions lead the research. Each of them addresses different layers of support as reflected in the aims. The five research questions are as follows:

1. Are parents with intellectual disabilities supported in the parenting role to maintain family integrity? If so, what does an examination of these measures reveal about how the support system understands parents with intellectual disabilities and their needs?
2. What characterizes the family support service parents with intellectual disabilities receive?
3. What factors seem to contribute to the divergent outcomes of either unsuccessful or successful support for parents with intellectual disabilities?
4. How do rights protection officers safeguard the rights of parents with intellectual disabilities, and what barriers do they face?
5. In what ways, if any, have the UN Convention principles been translated into the support and services for parents with intellectual disabilities?

4.3 Study Design and Methodology

This research was conducted within a disability studies framework in the context of an evolving human rights environment in Iceland. As disability studies are critical in nature, I take efforts to expose oppressive and problematic processes within the institutions and systems that claim to provide parents with intellectual disabilities support in relation to parenting. The research is informed by the tenants of critical social theory which shifts the focus from individuals to societal factors and examines sociocultural and historical transformations that will not be explained by quantitative approaches alone but require qualitative methods that capture social relations and subtle nuances of culture (Meekosha & Shuttleworth, 2009). Burghardt (2011:13) further contends that for work to be transformative an "in-depth analysis of the structural and as-yet incompletely understood psychic underpinnings of oppression" must be undertaken.

The concept of intellectual disabilities is at the foreground of this research. However, it is important to be mindful and acknowledge how disability intersects with other positions the parents hold, such as gender and class among others (Goodley et al., 2019). When conducting interviews with service providers, it was often not clear how strong their knowledge was of support provision for parents with intellectual disabilities,

or even what they understood intellectual disabilities to mean; the latter had to be analyzed from their responses. It is also important to understand that it is known through previous research done in Iceland (e.g. Sigurjónsdóttir & Rice 2017, 2018) that child protection will respond in certain ways to parents being labelled as having intellectual disabilities, or suspected to have such a label, whether such a diagnosis existed as would be understood in a diagnostic context. In this research, the specific diagnostic attributes of parents in terms of impairment level or degree are not the focus; rather, the focus is on how the system responded to parents labelled as such.

To address the questions at the heart of this research, a hybrid qualitative methodology with elements of ethnography and grounded theory was adopted. This approach enabled a deep exploration and understanding of the subject, and it was the most effective method for conveying the narratives of the research participants. An inductive approach was chosen as it allows for new inquiries to emerge and the emergent research to align to new findings (Creswell, 2013). Each phase of the research led to the next in an attempt to fill in knowledge gaps that were exposed in the previous phase of the research. For that reason, the research process could be described as organic or emergent, without losing focus on the aims of the research. An image of the research process can be seen in Figure 1.

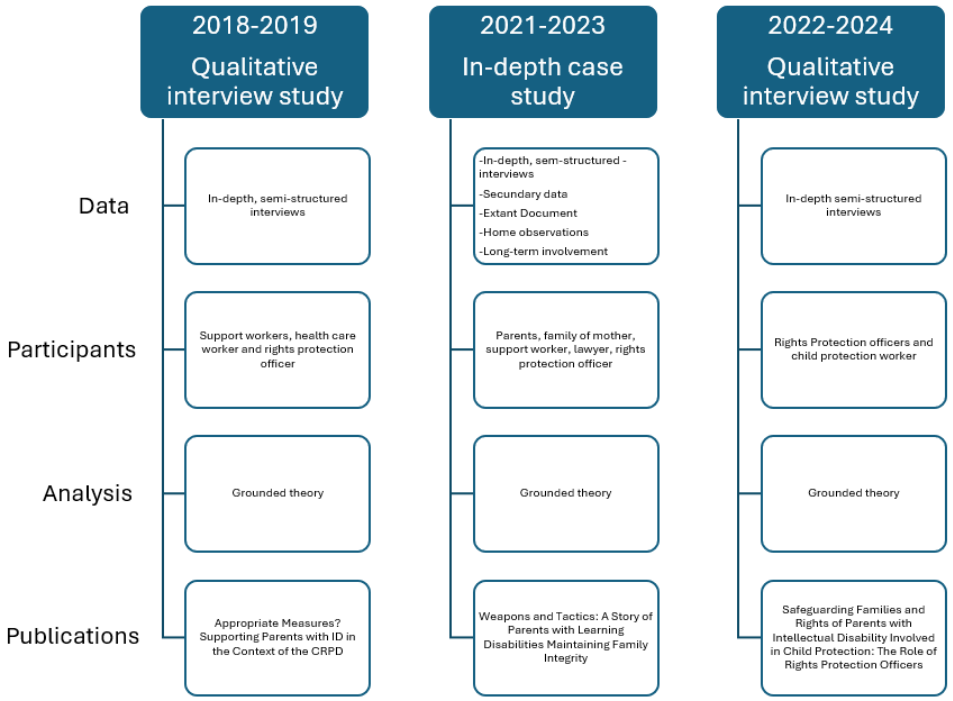

Figure 1. The research process.

For the purpose of this research, grounded theory was chosen as the main method for the analysis of the data, which also influenced the choice of data collection methods. Originally Glaser and Strauss developed and introduced this approach in their book *The Discovery of Grounded Theory* (1967). They introduced a systematic approach to qualitative research practice, providing some answers to the criticisms that qualitative research was subjected to at the time. In these earlier versions grounded theory was considered to be a method of discovery where the analysis 'emerged' from the data itself rather than applied in a top-down fashion, as is typical of traditional social theory. Grounded theory, as seen in the classic work of Glaser and Strauss (1967), has evolved and has since been taken into different directions by various researchers. Strauss and Corbin (1990) later described grounded theory as a method of verification. The emphasis is a turn from positivism toward a constructivist direction but still offering a framework for qualitative inquiry and practical guidelines (Charmaz, 2014). In my research constructivist grounded theory as prescribed by Charmaz (2014) guided all the data collection and analysis. One of the main reasons for choosing Charmaz's approach instead of traditional grounded theory was the acknowledgment of the researcher's involvement in the construction of the research and in particular the data analysis.

> Researchers and research participants' make assumptions about what is real, possess stocks of knowledge, occupy social statuses, and pursue purposes that influences their perspective views and actions in the presence of each other. Nevertheless, researchers, not participants, are obligated to be reflexive about what we bring to the scene, what we see, and how we see it (Charmaz, 2014: 27).

By accepting the subjectivity of the researcher, an opportunity for engaging in reflexivity is created, which encourages the researcher to reflect upon how one's experiences, views and visions have influenced the research.

With the goal of constructing a holistic picture of support for parents with intellectual disabilities, different types of data from various sources (see section 4.5.) were drawn upon. For the second phase of the study, a case study methodology was applied. The case study approach enabled a rich and detailed description of a single case (Yin, 2009). According to Yin and Davis (2007), case study method is ideal for understanding a real-world case in depth, within its real-world context. The method is also useful when it is assumed that an understanding is most likely going to involve important contextual conditions relevant to the case. The method requires an exploration over time through in-depth data collection using various sources of information, such as interviews, documents, reports, and observations (Creswell, 2013). Case study method is also useful in research to understand the complexities of the relevant relations, processes, practices, and institutions (Harrison et al., 2017).

The case that is the focus of this research concerned a couple with intellectual

disabilities parenting two children (and later three children), their closest family, and their involvement with the child protection services in their hometown. The data included interviews, observations in their home, documents of various sources, such as child protection intervention plans, case files, parenting assessments, and letters written by health professionals, child protection employees, advocates, and family. This also included casual conversations and social media materials. The richness and the variety of the data proved to be important in contextualizing and understanding the parents' stories, lived experiences and reactions to the interference of the child protection system. This particular case is useful as it illustrates how these parents have overcome significant barriers and maintained their family by having access to and utilizing certain resources in their environment, some of them which are specific for Iceland and relate to legislation and the CRPD.

4.4 Description of Participants

To get a holistic picture of how parents with intellectual disabilities are supported and the processes involved, interviews were conducted with a range of relevant stakeholders. This included a couple with intellectual disabilities and some of their closest family members; personnel who support parents with intellectual disabilities working under child protection, the municipal social services, and health care; and rights protection officers who support parents with intellectual disabilities in a number of areas, including when they are subjected to child protection investigations.

The first phase of the study focused on how support from social services and child protection workers was conducted. As there are not many professionals or support workers practicing in Iceland who are known to be experienced in supporting parents with intellectual disabilities, purposeful sampling (Creswell, 2013) was used to recruit participants with relevant experience and to gather data from different municipalities across the country. Agencies known to employ these support workers were selected for invitation to participate in the research. Six municipal agencies from four municipalities were invited to participate in the study. The population of the municipalities in question ranged from 9000 to 130000 inhabitants, two belonging to the Reykjavík capital area and the two smaller ones belonging to areas outside the capital area. From those six agencies, 15 prospective participants were sent an invitation letter. Eleven workers from five agencies agreed to take part in the research, which mainly involved interviews exploring how they supported parents with intellectual disabilities in their parenting role. All participants had some experience of supporting parents with intellectual disabilities, though it varied from a few months up to 30 years. The education and training of the participants also varied. All of them held one or two university degrees in such fields as education, psychology, social work or health care. Four participants worked within teams that provide special family support, from which two also worked part-time in child protection. Five participants worked in the mainstream social service and one in health care. During a later stage of the data analysis, one additional

participant was recruited for the purpose of reflecting on and refining ideas and categories that had developed during the data analysis process. That participant worked as a rights protection officer and had extensive experience of advocating for parents with intellectual disabilities involved in the welfare system and could therefore cast a light on some of the processes and working methods involved when supporting these parents.

In phase two of the study, the original plan was to interview parents with intellectual disabilities about their experience of support. Access to those parents was gained through the long-established connections of one of my supervisors who has worked and done research with this group of parents for years. After initially interviewing two parents, I met a couple whose case forced me to reassess my approach of this second phase of the study. Originally, the couple was invited to participate in the study to tell their stories of support. Due to their long-term involvement and extensive experience of the welfare system they were invited to take part in the study as an example of parents with intellectual disabilities who have kept their children and made use of certain support and strategies. The parents were also eager to participate as they stressed the importance of telling their story so others could learn from their tactics and their experiences. They accepted the invitation, and, in the following months, they were interviewed several times (see section 4.5.1.). However, these interviews with the couple also extended to their closest supporters, including the mother's sister, the mother's mother, their closest support worker, their rights protection officer, and their former lawyer. The contributions of all these participants enabled the construction of a holistic picture of their success but also their struggles. The couple were raising two children. By the time I completed my research, they had another child, with a fourth on the way.

As a result of the initial findings, I found it important to evaluate whether and how the CRPD, along with domestic legislation inspired by it, had any bearings on the situation of parents with intellectual disabilities involved in the child protection system in Iceland. To expand on that topic, rights protection officers for disabled people were recruited to participate in the third phase of the study. Altogether eight such officers held positions in all four regions of Iceland at the time of the research. All of them received an invitation letter sent by email. Initially, five officers accepted to take part in the research and three declined. In addition, one former rights protection officer, known to have an extensive experience of working with parents with intellectual disabilities, was contacted via email and offered to participate in the research, which he accepted. In the later stages of the analysis, an experienced, information-rich former child protection worker was contacted and invited to participate in the study, which he accepted. The seven participants all had university-level education from various fields including law, administration, pedagogy and sociology, health, and disability studies.

4.5 Data Collection

Interviews were main data collection method, but data was also collected from observations, and from extant documents some, of which were secondary data sources provided by a supervisor of this dissertation. The data collection was done in three different phases: a) interviews with workers who provide support for parents with intellectual disabilities in different regions of Iceland; b) interviews with a couple with intellectual disabilities and their family and supporters, the knowledge of which was supplemented by the analysis of relevant documents associated with the case as well as observations conducted in the parent's home; and c) interviews with rights protection officers and child protection worker.

4.5.1 Interviews

In qualitative interviewing, the approach used in this research, the emphasis was placed upon the creation of knowledge produced through social interaction and communication of the interviewer and the interviewee (Brinkmann & Kvale, 2015). An understanding was sought through the in-depth exploration of the participants' experience (Charmaz, 2014). Semi-structured interviews, or intensive interviewing, as prescribed by Charmaz, can be described as gently guided, mostly one-sided conversations used to explore in-depth the interviewee's perspective on their experience in relation to the subject of the research.

Altogether 32 interviews were carried out with 24 participants (some participants were interviewed more than once) to gain insight and knowledge of the perspectives and experiences of supporting parents with intellectual disabilities, or of receiving support as a parent. Four main interview guides were developed to manage the flow of the interviews and elaborate on the interviewee's responses. Each interview guide contained 10-15 core questions that were intended to reflect rights-based services and support as highlighted in the CRPD (Appendixes A-D). As the understanding of the subject started to develop and initial themes were constructed, questions were added or removed from the guide. The guide was mainly used to maintain a comfortable flow in each interview but was not followed in a precise or consistent manner. This allowed the participants to express views on their own terms and describe their unique experiences that explored issues that went beyond the content of the guide. In total, 13 interviews with support workers were conducted, each of which took place at the interviewee's workplace and generally lasted around 60 minutes. Additionally, ten interviews, 70 minutes on average, were taken with a couple with intellectual disabilities and their closest supporters at different locations depending on the preference of the interviewee. Finally, nine interviews were conducted with rights protection officers as well as a child protection worker, averaging 60 minutes in length. Seven of the interviews in the last phase of the research took place via computer-based applications and two were conducted at the researcher's office. All interviews were originally

conducted in Icelandic, but for the purpose of international publication, all quotations that appeared in the articles included as part of this dissertation were translated to English by the authors. All 32 interviews were administered, recorded, and transcribed verbatim by me. I agree with Brinkmann and Kvale (2015) in that by doing so I not only learned more about my interview style, allowing me to develop it further, but it also enabled me to revisit the interview and contribute further to the analysis.

4.5.2 Documents

Information sought in documents can provide rich contextual data. They can also be helpful for confirming or contesting information provided by different sources (Stake, 1995). Prior (2008) advocated the importance of not only focusing on what is 'in' the documents, as in documents merely seen as containers for words and information, but rather to think about what documents 'do' as in how they can influence social interaction and social organization. In this research, documents of various kinds were used to construct a holistic thick-description of how a family led by parents with intellectual disabilities, with years of child protection involvement, managed to keep custody of their children. The case examines in detail the tactics drawn upon by the parents and how their support network has provided them with important resources. All documents used in the research were provided voluntarily by the couple participating in the study. They owned and had in their possession all files and documents that had relevance to their former and ongoing case in child protection. However, in this sense the data collection did not start in 2020 but in 2010 when the couple took part in a study that resulted from the advocacy work of one of my supervisors, Hanna Björg Sigurjónsdóttir. The bulk of the documents (secondary data) belong to that period and were accessed through my supervisor with the parents' permission. The research then continued again in 2020, reaching until the year 2022. This prolonged period of data collection, extending over a decade provided rich longitudinal data on the experiences of this couple. The documents used in this research were mostly from the birth of their first child, at the time ten years earlier, until the conclusion of the research. They included child protection case files and plans, communication and reports from hired experts, such as from psychologists, letters from midwives, doctors and nurses and old letters and case files since the couple were children and involved in child protection and placed in foster care. All these documents provided important data which enabled me to contextualise the lives of the parents, understand their reactions and actions and explore the intergenerational effects of child protection intervention. These documents also provided me with an understanding how such documents can be used consistently as a form of power, both in the interests of the system but also for the parents when put to work as research and advocacy.

4.5.3 Observations

In qualitative research, observations are one of the main data collection methods and is defined by Angrosino (2007) as the act of observing and noting a phenomenon in a certain setting, through the senses of the observer. It is research that requires joint effort from both the researcher and the participant and is based on mutual trust, respect and honesty (Tierney, 2007). In ethnographic research, the emphasis of intensive participant-observation is placed on long-term engagements in the everyday lives of research participants (see. e.g. Moeran, 2009). In the case of this study, the focus was on shorter periods of observations while I interacted with research participants in their home. I observed the couple, in total three times, both without and with their children at their home. During the observations I took part in everyday activities at the home, but at times I changed roles and observed more than I participated. It is expected in this form of research that the role of the researcher will shift depending upon circumstances (see e.g. Hammersley & Atkinson, 2019). Being engaged while observing helped with establishing rapport in the beginning. But as trust developed, I withdrew more from participating and observed instead. During and after the sessions of observation, notes were written that included not only details of what was observed but also my reflections. The observations were always meant to be used as a method to gain insight into the family life and their day-to-day realities but not as a main data collection method. Nonetheless they provided important insights that proved to be useful when constructing a holistic picture of the case in question.

4.6 Data Analysis

All data analysis was performed in line with the principles of Constructivist grounded theory prescribed by Charmaz (2014), which is a critical inquiry rooted in social constructionism and focuses on social justice. The approach is inductive in nature and certain flexibility is allowed in the process. By applying grounded theory, core constructs are identified within the data which guides further data gathering while also noting contrasts across and within data sets. The analysis included all obtained documents, notes from observations and transcripts from the interviews. The approach is appropriate when the research involves multiple forms of data, such as the case in this research (Charmaz, 2014, Creswell, 2013). While conducting this research the approach was primarily used for data gathering and analysis but not for theory building.

The process of the analysis was similar for all data sets. It went back and forth from data gathering and data analysing, making constant and iterative comparisons to allow for new information to be investigated as the study proceeded and further avenues of inquiry opened. The data analysis for each set was completed in a few phases. The first phase was based on familiarisation of the data as I read through interview transcripts, fieldnotes and documents multiple times to get a feeling of what it contained. Next,

initial coding was performed where I stayed close to the data and mostly explored instance by instance with focus on events, actions and descriptions that contributed to the increased understanding of the support system in place for parents with intellectual disabilities. Analytical ideas and first thoughts were noted down. Initial coding was followed by focused coding where the emphasis was placed on codes that stood out in the initial coding. I worked with those codes as the main themes of the developing analysis until I could develop further categories. When main- and or sub-categories had developed, additional participants were contacted and asked to reflect on the constructed categories, lending me the opportunity to further develop them if needed. None of the additional interviews, however, led to major changes in the outcome. Research meetings were conducted with my supervisors in which the findings were discussed, and the analysis refined. Table 1 provides examples of initial and focused coding done on two interviews that preceded the findings and which were published in the third article of this dissertation.

Table 1: Example of coding

Quote from interview	Initial coding	Focused coding	Main Category
We [RPOs] are securing that the voice of disabled people is heard within the governmental system (stjórnkerfisins)...the group is marginalized and at times holds little power (Regn)	-Creating a space in the system for people with less power	Amplifying voices of the marginalized	
As soon as we step inside, the power structure changes drastically. We ask questions, ones that the parents have asked but have gotten no answers to... 'How does that work? And who is supposed to do that? Who's responsible for that to happen? Are you doing counselling? Support? or is this surveillance? and what are the differences? (Rökkur)	-Changing power structures -Asking questions -Demanding answers	Being an agent of change	
How big do I need to be at today's meeting? Should I be the good Rökkur who gets people to play in my team, or do I need to be the tough Rökkur with all the rules and regulations laid out on the table? I really need to prepare for how I will appear at the meeting. (Rökkur)	-Deciding how to play -predeterminate cooperation -Predeterminate toughness -Being prepared	Wearing a Cloak of power	Altering power relations
We try to make sure that the parents have a path in the system, and they have someone that fights for them and with them. (Regn)	-Securing a pathway in the system -Advocating for parents	Being a resource for justice	

4.7 Ethical Considerations

This research is focused on parents with intellectual disabilities and the support they are provided with in taking care of their children. The research was also meant to cast a light on the many barriers these parents face in the form of oppressive practices, systemic injustice, and violations of their human rights. There are number of ethical issues that need attention due to the sensitive nature of the subject and because of the small population of Iceland. With a greater emphasis on disability rights in the government and society in general, people with intellectual disabilities are now increasingly participating in all aspects of society. This includes research, where their voices can be heard and the knowledge and experience, they have acquired can be used to lobby for change. However, doing research with people with intellectual disabilities requires special considerations to ethical matters which will be discussed in the following section (Stefánsdóttir et al., 2022).

Informed consent and protection from harm are the core principles when conducting research involving people, as is the tenet of the Nuremberg Code, widely recognized

as one of the foremost ethical codes, set by judges at the conclusion of the Nuremberg Trials in 1946. These principles are also integral to the Declaration of Helsinki, established by the World Medical Association in 1964 and consistently revised (Boulton & Parker 2007). Informed consent and protection from harm are the most prominent issues in research guidelines when doing research with people. These guidelines are meant to ensure that participants in research enter it voluntarily, understand the nature of the research and what it entails. It is also meant to ensure that participants are not subjected to risk or harm that is greater than possible gains (Bogdan & Biklen, 1997). When doing research that involves marginalized people, such as in this research, special considerations must be taken to ensure that participants take part of their own free will and without any pressure to do so (Sigurjónsdóttir, 2006). Special accommodations were made to try to ensure that the principles of informed consent and protection from harm were followed to the utmost. Information about the research was provided in an easy-to-read format information letter but also by reading the letter to the parents in person, offering explanations and making sure that they understood what the participation involved, including risks of triggering past trauma or the risk of being recognised. All participants provided informed consent before entering the research process. For all other participants to be able to provide informed consent, they received an information letter prior to the interview stating the aim of the research, an explanation of the research process, and what would be required of participants. Another issue important to consider is the relationship that is being established with participants, and when professional distance is not appropriate. The researcher needs to be able and willing to contribute time and effort that can go beyond when doing research with other groups of people (Sigurjónsdóttir, 2006).

To protect the participants' confidentiality, all were given pseudonyms and localities were kept ambiguous. Furthermore, because of the small population of Iceland, and hence the small group of both parents with intellectual disabilities and people who work within the field, it was further decided to only provide minimum descriptions of participants, such as using non gendered pseudonyms in phase three and not disclosing certain characteristics such as age or gender. This was particularly important in phase three as rights protection officers are very few in number, their position is public, and they need to be able to maintain good communication and cooperation with professionals when safeguarding the rights of parents.

In this research, I delve into the intricate and personal narrative of Anna and Tómas. Given the intimate nature and complexity of their story, ethical considerations warrant special attention. Thackray (2018) raises the question of ownership of a narrative and the right to tell it. With this in mind, it is important to consider the purpose of storytelling and whether it holds the potential for societal change (Runswick-Cole & Ryan, 2019). In this study, the parents expressed a desire to share their story openly, with the hope that it might contribute to systemic changes for parents with intellectual disabilities in Iceland. Sharing one's story can empower individuals and raise

awareness about their experiences. The aim of the "narrative-construction" in this study was to authentically represent the data provided by the parents. Recognizing the importance of reflecting Anna and Tómas's reality, they, along with key participants, reviewed the narrative I and my co-authors in article II constructed. Anna and Tómas received an easy-to-read summary, it was read aloud to them, with opportunities to suggest changes. Other participants concurred with the published narrative, which underwent minor edits. I feel it is also important to note that Anna, the mother, actively participated in all interviews during phase two and engaged in discussions between myself and other participants. This involvement granted her the opportunity to contribute to and elaborate on events and descriptions related to her family's case.

Phase one and three of the study, which involved interviewing people supporting or safeguarding parents, was approved by the National Bioethics Committee. Phase two, the case study, was approved by the Scientific Ethics Committee of the University of Iceland (VSH202-009).

4.8 Strengths and Limitations

This study is subject to the same limitations as other qualitative research according to Queirós et al. (2017). These limitations are inherent to research that investigates the socially constructed reality of people and the ever-developing interactions of people and their environment, bounded by time and place. With in-depth exploration on selected people, institutions or municipalities, such as done in this research, it is impossible to generalize from the findings from one study, but the practices and patterned behaviors that are revealed are analyzed in conjunction with similar published studies from Iceland and abroad. Studies, such as this one, can be a thread, reflected in a larger pattern seen in other studies and in that way contribute to an important developing knowledge base.

I would like to highlight the richness of the research data, in particular the case study data, and the multiple actors, situated in various contexts, who participated in the study and provided the interview material that contained multi-faceted knowledge about how people with intellectual disabilities are supported when it comes to family life and parenting. Furthermore, I consider the organic design of this research as one of its main strengths. The developing findings steered the data collection process, allowing me to follow up on emergent and interesting themes relevant for parents with intellectual disabilities involved in the welfare system.

From the outset of this research the aim was to find ways to help to improve the situation of parents with intellectual disabilities and their families. For research intended to be transformative and have beneficial effects for the population in question, it is vital to identify barriers and problems within societies and systematic practices people are subjected to, particularly those belonging to marginalized and disadvantage groups, such as parents with intellectual disabilities. This research casts a light on some of the

problematic issues and processes in the institutions that support services operates within but also on more systemic levels, such as on governmental and juridical levels. Regarding practice, this research has led to communications and relations between me and professionals involved in the support and services for parents with intellectual disabilities. Those relations have enabled collaborative work aimed towards improving the support of parents with intellectual disabilities and their families. In that process the knowledge and expertise I have acquired by doing this research has proven invaluable.

4.9 Summary

In this chapter, I have provided a comprehensive description of the methodology and research methods used in this dissertation. I have explained the rationale behind choosing qualitative methodology and the selection of methods considered most appropriate for achieving the study's objectives. After a thorough overview of the chosen research methods, the chapter concludes with a discussion on the ethical considerations relevant to this research, as well as its strengths and limitations.

5 Collection of Articles

I. Stefánsdóttir, S., Rice, J., Aunos, M., & McConnell, D. (2022). Appropriate measures? Supporting parents with ID in the context of the CRPD. *Scandinavian Journal of Disability Research, 24*(1), 29-41. https://doi.org/10.16993/sjdr.820

II. Stefánsdóttir, S., Sigurjónsdóttir, H. B., & Rice, J. (2023). Weapons and tactics: A story of parents with learning disabilities maintaining family integrity. *British Journal of Learning Disabilities, 51*, 62–69. https://doi.org/10.1111/bld.12492

III. Stefánsdóttir, S., Rice, J., & Sigurjónsdóttir, H. B. (2024). Safeguarding families and rights of parents with intellectual disability involved in child protection: The role of rights protection officers. *International Journal of Disability & Social Justice 4*(2), 91-110. https://doi.org/10.13169/intljofdissocjus.4.2.0091

Article I

SJDR Scandinavian Journal of Disability Research
Established by the Nordic Network on Disability Research

Appropriate Measures? Supporting Parents with ID in the Context of the CRPD

RESEARCH

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ABSTRACT

The international literature continues to show that parents with intellectual disabilities (ID) do not receive proper support and face disproportionate rates of custody deprivation. Despite the efforts of activists, critical scholars and some progressive support workers, it seems that the situation of parents with ID have not improved much. Iceland ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2016. This contribution is one part of a larger project that aims to explore the impact of the ratification of the CRPD on service responses to parents with ascribed ID. Thirteen in-depth interviews were conducted with staff supporting these parents. The findings indicated attitudinal and organizational barriers to realizing the goals of the CRPD in this area. However, the findings also indicated a number of pathways forward upon which to build and which may help to produce better outcomes for parents with ID.

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INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006) represents a paradigm shift in disability policy and rights (Degener 2016; Goldschmidt 2017). Previously, the rights of disabled people were largely excluded in practice throughout several human rights treaties. The resulting Convention is the first international disability rights treaty that touches on a wide range of topics relevant to achieving and maintaining the human rights and dignity of disabled people. As Quinn contends: 'The real value of the Convention therefore will be revealed in how government, human rights organisations, services and organisations of and for people with disabilities internalise their values, principles and rules' (Quinn 2009: 245). This contribution, and the larger research project underlying it, seeks to understand the ways in which the values of the Convention are manifest in services and supports for parents with intellectual disabilities (ID). Attention is paid to identifying barriers to the realisation of the Convention, as well as any progressive practices that align with these values and may result both in better outcomes for parents and ensuring that Iceland meets its obligations. Through the process of ratification, Iceland made a commitment to ensure that disabled people are treated as equal to other citizens, including equal rights to family life and parenthood. It has been noted that the CRPD reflects four dimensions of substantive equality. These include

> redressing disadvantage (the redistributive dimension); addressing stigma, stereotyping, prejudice and violence (the recognition dimension); facilitating voice and participation (the participative dimension) and accommodating difference, including through structural change (the transformative dimension) (Goldschmidt, 2017: 11).

We contend that these dimensions of equality are necessary components of support services in order to help to ensure that parents with ID are able to exercise their rights as parents. As such, these dimensions can serve as the basis for critique when analysing support practices as well as hopefully acting as sensitizing concepts for service personnel in the goal of transforming the values of the Convention into practice.

Despite Iceland's ratification of the CRPD in 2016, after signing in 2007, questions remain as to whether the principles of the CRPD have been internalised in the child protection and family support systems. There is precedent for this line of questioning as Iceland is also a State Party to the earlier UN Convention on the Rights of the Child (1989). However, the non-discrimination article (Article 2) of the CRC, as it pertains to discrimination against both children and their parents on the basis of disability, to our knowledge is rarely invoked in Iceland in contrast to Article 9, which justifies custody deprivation in the best interests of the child on the grounds of abuse or neglect.

There are a number of articles of the Convention that are relevant for the study at hand. This includes, among others, Article 12 (Equal recognition before the law) and in particular Article 23 (Respect for home and the family), which declares in Section 2, 'State Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities' (CRPD 2006: Art. 23(2)), with the overarching goal that parties 'shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships' (CRPD 2006: Art. 23(1)). We recognise that other articles of the Convention are also relevant to issues of parenting, but we leave this discussion aside for the moment.

This particular contribution draws upon an analysis of interview data provided by support workers and will focus on the characteristics of support services for families headed by parents with ID in Iceland. The purpose of the study was to perform a critical analysis of the social support services available for parents with ID to shed light on factors in the service provision that potentially play a role both in outcomes leading to custody deprivation or else outcomes that lead to maintaining family unity. The interviews were based upon a set of core research questions: What characterizes the family support service parents with ID receive? What factors contribute to the divergent outcomes of either unsuccessful or successful support for parents with ID? The results can be used to improve family support services and to ensure that the rights of parents with ID and their children are not violated in the process.

SUPPORT SERVICES FOR PARENTS WITH ID

Studies show that parents with ID are struggling as they often encounter a system not equipped to assist them (Strnadová et al. 2017). Intersecting factors, such as social isolation, poverty, stigma and lack of formal and informal support, are prominent features in these parents' lives, which contribute to their struggles (Llewellyn & Hindmarch 2015; McConnell, Feldman & Aunos 2017; McConnell et al. 2011). Studies from the Czech Republic, Sweden and Iceland show that the parents' challenges to meet social expectations and norms are commonly attributed to the parents' disabilities, while the lack of proper support, both formal and informal, is overlooked (Sigurjónsdóttir & Rice 2017; Starke et al. 2013; Stmadová et al. 2017). As a consequence, studies from the US reveal that parents with ID are over-represented in the child protection system and even more so in custody-deprivation cases (DeZelar & Lightfoot 2018; Feldman et al. 2012; Francis 2019). In Iceland, IQ measures continue to figure prominently in custody deprivation decisions (Rice & Sigurjónsdóttir 2018) though research has consistently argued that IQ alone is a poor predictor of parenting ability and that parents with ID can successfully take care of their children given appropriate support (Feldman et al. 2012; McConnell & Llewellyn 2002; Tymchuk & Feldman 1991).

Parents with ID are a diverse group in terms of their levels of impairments, numerous intersecting environmental factors and varied support needs, among other positional factors. Because of this diversity, studies from Australia and Iceland have highlighted the importance of customized support for parents with ID and their families (Collings et al. 2017; Sigurjónsdóttir & Rice 2016; Wade, Llewellyn & Matthews 2008). Booth and Booth (2004) did an extensive study on the views of parents with ID navigating their way through the British child protection and legal systems. Findings showed that effective support is based on support workers who are willing to listen rather than talk, are able to advise as opposed to instruct and are ready to help with broader, practical needs instead of focusing only on those narrowly defined as relating to child rearing. The importance of support based on a family-centred view is furthermore supported by Collings et al. (2017).

In Iceland, the child-focused approach appears to remain dominant. In the case of families headed by parents with ID, support services have not evolved the same way as human right agreements and legislation focused on appropriate support for disabled parents (Sigurjónsdóttir & Rice 2017). Thus, families headed by parents with ID are at risk of receiving family support that has not been shown to be effective for this population. The Icelandic service system available for parents with ID in need of support is mainly threefold: (a) the mainstream social services, which, among other things, offers financial assistance, social home service, housing, and service for disabled people, also, it can provide personal counselling to parents and home-based service; (b) special family support service is a resource used by mainstream social services or by child protection or sometimes both, and it most often provides home-based, short-term service for parents who are experiencing difficulties with their children's upbringing; and (c) child protection services.

METHODOLOGY

The study took place across four different municipalities in Iceland, with populations ranging from approximately 9000 to 130,000 inhabitants. The implementation and structure of the support services, and to some level the organizational structure, differed between the municipalities. Two larger and two smaller municipalities were chosen from the study for comparative purposes. Semi-structured interviews were the principal method chosen with the aim of encouraging the research participants to articulate in their own words their perspectives, views and experiences (Kvale 1996). An invitation letter was sent to 15 support workers in 6 different municipal agencies known to provide services to parents with ID. Altogether, 11 professionals from 5 agencies accepted the invitation and participated in the research. The primary criterion for participation in the research was that the support workers were involved in supporting families headed by parents with ID. The participants had a range of experience in this area, from a few months up to 30 years. They also had varied levels of education, though all of them had one or two degrees in the areas of education, psychology, social work or health care. Out of the four interviewees who worked in special family support services, two also worked in the child protection system, six worked in the mainstream social

services or health care services and one interviewee worked as a rights protection officer for disabled people. The interviews lasted 60 minutes on average and were all recorded and transcribed verbatim. All interviews were conducted in Icelandic and translated by the first author. The data analysis was inspired by Charmaz's (2014) constructivist grounded theory approach. Constructivist grounded theory is a critical inquiry rooted in social constructionism and focuses on social justice. The approach is inductive and allows certain flexibility for data gathering and analysing. In this research it was mainly used for data gathering and analysis and not for theory building.

The study was approved by the Icelandic Bioethics Committee and the Data Protection Authority (no. 14-062/-V1). All participants received an introduction letter explaining the study. Informed consent of the participants was obtained before the interview took place and documented. Due to the small size of the Icelandic population, efforts were made to minimize the possibility that the identities of the research participants could be compromised. All participants were given pseudonyms and certain details omitted or altered in order to protect their privacy.

FINDINGS

The findings are presented as two main categories, each comprised of a number of related sub-categories: the first, *Barriers*, identified a number of views and practices that would be considered unhelpful and appeared to play a role in negative outcomes for parents and family unity, and at its worst contribute to custody deprivation. The second, *Pathways Forward*, identified a number of positive practices categories, which demonstrates that there is some measure of knowledge and interest upon which to build a base to further the incorporation of the goals of the CRPD into supporting parents with ID.

BARRIERS

Barriers that seem to contribute to the difficulties parents with ID have in maintaining family unity were found to be in the form of practices and attitudes held by staff and embedded within agencies' organizational cultures. These barriers appear to impede the incorporation or translation of the CRPD into practice. Specific examples of barriers include an exclusive focus on the child rather than family, inappropriate measures, poor collaboration between supporting agencies and an emphasis on a 'quick fix.'

Focus on child, rather than family

The Icelandic Child Protection Act, which is the dominant legislation under which the child protection authorities operate, understandably takes a child first focus, and this is reflected in the data. In the responses of the interview participants there was a marked emphasis on disability, or 'individual deficiency,' at the expense of contextual or environmental factors, such as community involvement, employment or social status. This strong focus on the child was much more evident in the child protection services and the special family support services than when support was implemented from the mainstream social services. For example, a worker in special family support said, 'We of course go in because of the children, we don't go in because the parents have intellectual disability…we go in because there is something regarding the child…the support should be aimed at the child.' Even where supports aimed directly at parents are referenced in the interview data, such as Parent Management Training-Oregon method (PMTO), the outcome appears to be oriented towards helping the child, rather than the family as a unit. As one worker commented, 'Our help is to help people help themselves, so we basically just come up with advice on how you can get your child, for example, out of bed, we have a reward system or you know this PMTO.' For many workers the support had a strong focus on building a routine for the child, accompanied with education about behavioural techniques. Although this may be considered an important measure, it overlooks intersecting factors that influence the family and the parenting.

Inappropriate measures

Article 23 of the CRPD states that measures put into place to support disabled parents are to be 'effective' and 'appropriate' so that disabled parents may adequately perform their parenting role. In consideration of the interview data, it often seemed that measures were implemented

without considering contributing factors, such as poverty or loneliness, leading to the difficulties the family was experiencing. The measures implemented positioned disability status as the principal problem and were not necessarily supported by research as being effective with this population. Some support workers indicated that they used programs that they considered to work well for the child but not so well for the parents. As an example, PMTO was widely used even though some of the support workers indicated that they felt it would not be suitable for parents with ID. In fact, one third of the support workers said that in many cases their support methods did not work very well for parents with ID, yet these continued to be used despite evidence of their inappropriateness for this population. Sometimes the blame was placed upon the parents for the failure of these methods. One worker stated,

> We use PMTO a lot…we try to teach them, give them some tools they can use, but like I said about them transferring knowledge…you know, I feel like sometimes that's the problem for them…it's like they don't get it". (Ester, Special family support and child protection worker).

Another worker said,

> She got different types of assistance, she got special family support, she got PMTO, she got MST (Multisystem Therapy) and it seems to work when someone is constantly helping her to use it, so she can have a routine for the kid, but as soon as that stops everything goes back being a mess (Rut, Special family support worker).

In the interview with the rights protection officer, the ability of the support services to even implement appropriate measures was raised. This officer questioned the confusion over what was defined as 'support' as well as the basic training of workers:

> Sometimes it's surveillance, sometimes it's support, sometimes it's advice…I have even been in the position of asking a child protection worker how he intends to carry out what is stated in the treatment plan, and then he does not know himself what is expected of him as an employee (Lára, Rights protection officer).

She pointed out that it makes her role very difficult as she is supposed to evaluate the measures implemented to support the parents, yet the measures themselves are ill-defined. She continued, 'I know a lot of these people are social educators and have experience working with children with disabilities…but it does not mean that they have what they need to assist parents with ID.' A worker in special family support did not criticise the training the parents received in PMTO and argued that it was good that they learned these skills. But at the same time, she admitted that it was not very suitable for parents with ID because in practice it basically amounted to general counselling aimed at raising children rather than specialised support aimed at the parents.

An interviewee stated how a parent's experiences with inappropriate measures could result in a spiralling effect, leading to mistrust and resulting in ineffective support outcomes that tend to be blamed on the parents. She worried that some support workers did not have that intersectional view required to understand the complicating underlying factors that need to be taken into account when assessing whether or not a support measure is working.

> It's like they [support workers] don't have their [parents] whole situation in mind. Many of these women have a history of abuse, they are poor, or they come from extremely complicated social situations…that needs to be recognised. Were the parents themselves in the child protection system?; what experiences do they have?; That has a huge effect on their position and their will to accept these systems into their lives…some of those parents lived in institutions where they experienced violence…and then they start to have children and it is very understandable that they don't trust what is said and done because their experience of professionals is very broken (Lára, Rights protection officer).

Organizational collaboration and culture

A number of interviewees pointed to some issues with regard to how closely the mainstream social services collaborated with the child protection authorities. In smaller municipalities, this closeness was fostered by their proximity within a single building; in larger municipalities, they were distinct entities and seemingly with their own organizational culture. The children's

protective services were described as 'a very isolated phenomenon in an ivory tower' leading to an over-reliance upon the knowledge within child protection to the exclusion of others:

> I'm trying to say this in a polite way, but it looks like when certain people get a power in a case they don't take advantage of the knowledge that exists out there…you can't work a case like that. Child protection is not taking advantage of what already exists, like trust between parents and counsellors [in social service]… I know cases where a counsellor who has the trust of parents, is the key to introducing other professionals and other staff to them (Lára, Rights protection officer).

The workers with the mainstream social services generally saw this organisational distance as a problem and also saw the distance between parents and workers as an issue, which led them to take efforts to mitigate this. In two out of four municipalities, the key worker in mainstream social services stayed in contact and kept on following the issues even if child protection was also involved. A worker from the mainstream social services was aware of the importance of maintaining this contact: 'There is certain input that we have and we provide guidance [to the special family support]…we just know better how to talk to people with ID, they often don't.'

Emphasis on the quick fix

Perhaps related to organisational culture, as well as the specific function of these different agencies, it was evident that child protection worked cases differently than the mainstream social services. Child protection typically becomes involved with the family in response to notifications made, generally about abuse or neglect. Child protection will rapidly gather evidence, complete assessments and place an emphasis upon closing the case. The mainstream social services, in contrast, operated within a longer timeframe and were prepared to offer support and services for the long term. Mentioned as well was the additional strain of operating within a child protection context with parents who needed longer term support. A worker described supporting parents with ID compared to families that have children experiencing difficulties in school:

> It's [supporting parents with ID] really exhausting for us … to experience that everything happens so slowly or even just nothing, you're just stuck. Then we get a case from the school and it's totally different, just awesome, it's really good to feel that everything is just going really well and everybody [the parents without ID] are learning our stuff and then we can just close the case (Ester, Special family support and child protection worker).

The pressure of closing cases was still evident despite the support worker's knowledge that positive outcomes for parenting with ID often demands longer-term support.

Cases were perceived as having a logical and clearly defined process: '[the service] is something that has a beginning, a middle and an end, and it will be over and then these parents can come back in a year' (Rósa, Mainstream social services worker). The tendency to want to 'close the case' resulted in support aimed at 'fixing and patching.' Complicated matters that would require long-term support, such as social isolation, were not often addressed. Some support workers understood the need for long-term support when working with parents with ID but admitted that the system they worked for simply did not offer that kind of flexibility: 'Look, these cases, of course they aren't finished, we know that…but we won't keep a case open forever' (Ólivía, Special family support and child protection worker). Workers in the mainstream social services were aware of the different expectations of child protection regarding long-term support.

> The nature of their [child protection] work is that they open a case, they investigate, they work on it and then they close it. We never close a case involving disabled people because they need life-time service or at least have open access to it. The ideology we use in service for people with intellectual disability is different from the ideology the child protection service works by (Hanna, Mainstream social services worker).

A mainstream social services worker described the child protection approach as temporary, as they are acting upon notifications pertaining to childcare concerns that have to be investigated and assessed: 'The home support is intended as temporary counselling and visits to parents because of child rearing, which is usually intended for 6–8 weeks, then it is in-home surveillance.'

It should be noted that in-home surveillance in Iceland is often described by child protection as a form of support. However, in practice its role is primarily to observe and gather information in the home, and it is primarily conducted by people specifically hired by child protection for this task but who often have no specialised training in child protection matters, let alone parenting with ID (More 2015).

PATHWAYS FORWARD

It would be unfair, or inaccurate, to disregard or downplay the evidence that attests to progressive practices, thinking and ideologies aimed at supporting parents with ID. It is also important to focus on some of the pathways forward to implementing the goals of the CRPD through a consideration of what positive groundwork there is to build upon. Here we have defined categories from the interview material that attest to this: a holistic approach to treating the family as a unit; the need for long-term measures to counter-act the rapid, quick-fix approach; acting as navigators for parents through a complex support system and fostering good collaboration between child protection and the mainstream social services.

A holistic approach

Progressive workers recognised that supporting the parents meant offering specific support for parents and for children and it also meant treating the family as a unit in a holistic way. Some of the measures they addressed went beyond parent 'training,' narrowly understood to include support for a broad variety of measures intended to aid the parents and stabilise the family environment.

> It's like, put the oxygen mask on yourself and then on the child, so they [the mothers] can stay strong, they need to be supported, get stronger for the child's sake, for example I try to provide them with a respite service once a month so they can do things for themselves, that also helps them becoming better mothers (Selma, Mainstream social services worker).

Such workers were aware that addressing a need in one area could help the family overall:

> I have this one family…the mother has a driver's license but he [the father] does not, and I wanted to support him so he can get his license; it would help her so much because they have four children and she's working but he's not, and just help his social position I've already explained to him how much assistance he can get to make it happen (Astrid, Mainstream Social Services worker).

For others, a holistic approach meant recognising and taking into consideration inter-personal and intra-personal dynamics within the family and how, in turn, these factors intersected with support measures. A common complaint from the child protection services is that parents are not 'cooperating' with them. The progressive support workers realized that the parents' perceived resistance often had an underlying cause that better explained the strained relationships between parents and workers. This understanding made them better able to adjust their support to fit the family's needs and reduce parental fears.

> Because these mothers, sometimes they don't want anybody in their home and I know why, it's because the home is cluttered. They're maybe working full time and then they come home and they can't do more… and I say 'no problem, we just apply for home service, someone that comes and helps you to take care of the home' and instantly you can tell that they feel better… because there is always this fear that the baby will be taken, it's always this fear! (Selma, Mainstream social services worker).

One interviewee described her working methods as part of a 'much bigger package.' As an example, she mentioned financial aid and the problems of attempting meaningful support measures without addressing these needs: 'we also go into financial aid because sometimes people are just in debt everywhere… people somehow just got into a complete [financial] mess and then you just have to start by addressing this' (Sara, Special family support worker).

The need for long-term, appropriate measures

The workers that appreciated the need for a holistic approach to supporting parents with ID also recognised that the 'quick-fix/close the case' model common in child protection would not

be very effective for these parents. They recognised that once a measure was put in place, and was initially successful, it did not mean it would stay that way, especially without a long-term commitment to seeing the process through by workers. These workers also spoke about other factors like building trust, addressing the day-to-day needs of running a household and the importance of not overreacting to situations.

> Now there is trust, she [the mother] has started to unpack all those boxes that have been in the corridor all those months and we have also managed to guide her a little bit with cleaning, but the goal is to guide her regarding the child... we don't evaluate the situation like it's neglect, like [makes a siren sound], so we are able to approach it like this, and we just assume that this case will take time and I think it's a privilege to be able to do it like this (Ólivía, Special family service and child protection worker).

These support workers, generally with years of experience and working within the mainstream social services, considered their time well spent solving urgent matters with the parents, as well as the mundane, or simply just being there for them when they needed someone to talk to: 'She often sends me messages or emails asking if I can call her... and I try to call her as soon as possible so she knows that I'm in no way bored with her or agitated' (Soffía, Community health care worker).

What was also prominent in the interview data was the importance for workers to recognise when a support measure was inappropriate or not working and to look beyond the typical practices to think creatively and assist with daily matters:

> I have such a strange job...you are enabling the parents, you know, maybe it's someone who is socially isolated...I went with one [mother] to an NGO the other day, you know just going with her for the first time because she felt she couldn´t go by herself, and just going to the bank to apply for a payment service...it's all kinds of everything (Rut, Special family support worker).

Part of the successful formula, argued by a worker, is patience and the recognition that some parents need a longer or repeated trial for a support measure to be effective:

> Sometimes I think 'oh this is not working, what can I do?' When I have already talked about the problem [to the mother] again and again, discussed why things need to change, and then maybe when I visit for the fourth, fifth and the sixth time, I go like 'YESSS! It's happening'... she just needed more time, she needed to hear it six times... and the baby is still developing normally, and I can't ask for more... so then I walk out and just 'YESSS! It worked!' (Emma, Mainstream social services worker).

It was pointed out that with some parents certain tasks or duties may never adequately be addressed by the parents. This does not mean they are incapable parents overall, but that they may always need help with certain responsibilities over an unspecified duration:

> Her [the mother's] school experience was very difficult, so she won't read to her child, and I thought, 'ok, this is just a task we need to take on,' the boy is still young and we have YEARS to work with this (Emma, Mainstream social services worker).

Not everyone within the services shared these workers' knowledge or patience. This required that some of their energies be focused not only on helping the parents and the family but also on running a form of interference with other workers who did not share their views or practices and who could interfere with a worker's support plan. An interviewee explained how she would sometimes negotiate more time when workers from the Special family support did not have faith in the parents' competence: ' I've been like "let her, let them try, wait a little," not everybody needs to raise their children like you and I and everybody else, and now I have one teaming up with me at the healthcare centre' (Selma, Mainstream social services worker).

Acting as navigators and fostering good collaboration

Some of the workers played an informal role as a sort of navigator to help guide families through a complex multi-agency support system that also intersected with other agencies beyond their direct scope, such as the education and healthcare systems. For the parents this may be a daunting prospect to face alone, especially if they considered the system to be hostile toward them and complex and opaque at the best of times. These workers attempted to steer

the family the best or safest way through the service system, drawing upon their experience and contacts. One of them said: 'We need to think about what preschool do we want the child to attend, where do we get good collaboration? … sometimes we say "no, not this one, we should rather apply for this school," even though it is much further away' (Emma, Mainstream social services worker). Another described how she would try to ensure a good fit between the parent and the support workers in the special family support and child protection by facilitating a non-threatening environment for the family so the parents were more comfortable and felt safe having a support worker in their home.

> I selected [the special family support worker], I said 'I want this one on the case' because I knew that they had already tried but failed…also if a case turns into a child protection case I often try to get a certain case worker on it…you know people have different strengths and they don't all have the understanding they need to have to work with parents with ID (Astrid, Mainstream social services worker).

The ability for progressive workers to facilitate the implementation of appropriate measures and to act as effective navigators also depended upon creating or preserving a good collaboration between social services and child protection. Close physical proximity and short social and organisational distances between agencies were important, as knowing each other's names and easy access played a role in two municipalities where the child protection services were described as having good collaboration with the mainstream social services. 'I mean, a child protection worker just walked downstairs and took a seat in my office and said "look, we have two notifications, so we somehow really need to sharpen the support you are providing"' (Selma, Mainstream social services worker). Another worker in the social services maintained that close collaboration is also a necessity, as each agency can bring their strengths into a case while making up for their weaknesses. She pointed out that in her capacity she has no authority to access a client's financial information, even if this information may be helpful in planning and implementing support. In contrast, child protection has this authority but may not have the proper skillset in working with parents with ID. It was also mentioned that the additional surveillance provided by child protection can sometimes bring peace of mind to ensure that everyone is safe while support measures are being implemented: 'I feel very good that there is such a good collaboration, I mean if you're worried, you can always check with child protection' (Sara, Special family support worker).

DISCUSSION

This contribution identified numerous impediments for providing proper parenting support for parents with ID while drawing attention toward to some of the barriers in place that work against realising the goals of the CRPD, in particular Article 23 (Respect for home and the family). But we also suggest some pathways forward in providing for families headed by parents with ID, pathways that can contribute to strengthening family unity, protecting the right to parent and helping meet Iceland's obligations as a state party to the Convention.

The support for parents with ID, as described by support workers in the interview data, seems to be incidental, depending on the vagaries of the system, and without much consideration paid toward the principles of equality and non-discrimination as found in the CRPD. Some interviewees describe their work as reflecting a strong relationship and collaboration with the parents. Others are primarily focused on the child and consumed with assessing risk, resulting in work aimed at preventing harm rather than addressing needs, which are likely to be more intimidating than helpful. These divergent, incidental practices ultimately are likely to lead to unequal opportunities for parents with ID to take care of their children and to maintain family unity, leading to inconsistent outcomes within and between municipalities in Iceland. The Government Agency for Child Protection (which serves as an advisory institution for all municipal child protection committees) has not, yet, published guidelines about working with disabled parents, and no information about the CRPD is to be found on its webpage at the time of writing. At best this indicates a lack of awareness regarding the general situation of parents with disabilities and little understanding about the government's duty to protect the equal rights for all to have a family, to raise children and, when needed, to get proper support to do so.

This shortage of policy and guidelines are certain to be reflected in the work of the support workers. As described earlier, there was a noticeable difference in how the support workers thought about or conveyed their work with parents with ID, often depending on if they were working in the mainstream social service, working in a specialised support service or child protection. Support workers from child protection and special family service were more likely to be focused on the child, without taking into account the social milieu of the family. Furthermore, they seemed to be pressured to end the support within a delimited time. However, support workers in mainstream social services had more experience working with people with ID and understood their needs differently from support workers coming from other agencies. They described their work in line with holistic practises for the long haul, with emphasis on good collaboration with parents and also other agencies. These findings are supported by Booth and Booth (2004) who have pointed out that parents with ID are more likely to criticise support workers coming from specialised children and family services than support workers coming from adult and disability teams. That indicates that effective partnership between parents and support workers can be related to professional status and certain culture and attitudes within different service fields.

The type and quality of support received by families varies, and although support workers and practitioners are eager to do well, many are inexperienced, lack knowledge and feel insecure in the performance of their duties (Sigurjónsdóttir 2005; Sigurjónsdóttir & Traustadóttir 2001). In line with findings from Sigurjónsdóttir, Harwick and Rice (2019), too often the support focuses on the child or the parent but not on the family as a unit. The primary emphasis on the rights, safety and well-being of the child is at the heart of child protection work, and there are often good reasons for this emphasis. However, these goals can also be met through supporting parents and promoting family unity.

Findings also reveal that, for a large part, the family's social environment is overlooked in the context of the child protection focus on the child. Unless the child protection legislation is brought up to date to take into consideration the CRPD, the emphasis will continue to be on the protection of the child over the support of the family system. Factors like employment status, social network, sense of belonging and participation in meaningful activities are all known to contribute to the family's well-being (Aunos, Feldman & Goupil 2008; Feldman et al. 2002). Therefore, support needs to be holistic, based on multi agency collaboration, sensitive to the family's social environment and provided in the context that the parenting is fostered in, tackling complex social issues just as the parent's or child's individual traits or impairment (Aunos & Pacheco 2013). DeZelar and Lightfoot (2019) stress that effective support does not have to be directly related to parenting, but nevertheless, it can improve the overall family situation, for example by helping parents connect with different services that could have indirect effects on their parenting role.

Parents with ID are a varied group with diverse support needs that coincide with a number of intersecting factors, including temporal dimensions. A template with a pre-determined timeframe is unlikely to produce the desired outcomes. Parents with ID need time to learn new skills, to evaluate new information and to build trust with those who are involved in their lives. It is essential that support for an extended period of time is available and is seen as normal for parents with ID and not seen as a failure. It is also crucial that parents have the opportunity to seek repeated support without being seen as a parent that is unable to learn or is a difficult case. A change in attitude towards parents with intellectual disability, their families and their needs is critical so they have equal opportunity as others to parent their children. The lack of consistency in support practices must be addressed, as does the lack of a human rights framework in child protection work that emphasizes respect for the integrity of the home and family and the principles of equality and non-discrimination. That needs to be done by implementing a CRPD-based policy and work practices, developing guidelines for agencies working with parents with ID that are sensitized toward the four dimensions of substantive equality (Goldschmidt 2017), facilitating cooperation between different fields and agencies and providing support workers with education about parenting with ID. The CRPD can only define the goals and the desired outcomes; it is up to policy makers and support staff to see these goals realised in practice.

STUDY LIMITATIONS AND FUTURE RESEARCH

It should be noted that there are a number of limitations to the study. The voices of the parents are absent here, but they will be featured in future publications linked to the larger research project. It is also not known how many support workers in Iceland have direct experience working with parents with ID. Even though contact was made with support workers known to work with parents with ID, it is likely that other workers were not contacted. However, due to the small population of Iceland, the overall potential pool of research participants is not large. Therefore, it is not known how representative these research participants are of support services in Iceland, though the findings coincide with other Icelandic researches. Further, due to the fact that ID is often poorly defined and understood among the support staff, it was not always clear if they were referring to parents with clearly diagnosed ID or were referring broadly to other groups, such as people with psycho-social difficulties. We also acknowledge that further research is needed to understand how experiences of parents with ID may vary in regard to intersectional influences, such as racial and class backgrounds, marital status and family forms.

CONCLUSION

There are signs that disabled people are influencing how disability legislation and policy develops in Iceland in line with article 4.3 of the CRPD (Löve, Traustadóttir & Rice 2019). However, these policy developments do not seem to reach support services for parents with ID. The support remains incidental and inconsistent, with outcomes dependent upon the factors outlined in this article. Even though Iceland ratified the CRPD in 2016, the effects upon policymaking or practices appears meagre so far. Though not mentioned in the findings, only a single interviewee, a disabled person's rights protection officer, explicitly referred to the CRPD, and only one support worker talked about parents with disabilities as rights holders. This research has shown that there is still a great deal of work to be done in mainstreaming the CRPD into child protection and support services in Iceland. The continuing lack of understanding of ID and what it entails for parenting, as well as the persistence of negative discourses and stigmas towards people with ID, seems difficult to dislodge. Positive or progressive findings in this area in Iceland appear to exist despite, not because of, the CRPD. Positive outcomes, where they do appear, are the result of acquired knowledge, experience or dispositions of select support workers. This, in and by itself, will not result in sustained and widespread change. By viewing parents as rights holders, we contribute to the possibility of developing services that take necessary steps to protect these families' rights in a broad and consistent manner.

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

Sara Stefánsdóttir and James Rice drafted the first outline of the manuscript. Marjorie Aunos and David McConnell contributed to the second draft through refining some of the analysis and argumentation, revising the focus in key areas and providing substantial assistance with addressing the comments from the reviewers. All authors have read and approved the final manuscript.

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WILEY

Weapons and tactics: A story of parents with learning disabilities maintaining family integrity

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Abstract

Background: Many parents with learning disabilities find themselves locked in a struggle with child protection authorities to retain custody of their children. This struggle is one against deeply entrenched prejudices as well as social arrangements that often deprive parents of needed resources. This in-depth case study explores the contours of such a struggle, and the 'tools' deployed by one couple to keep child protection at bay. The goal is first to give the parents a platform to tell their stories. The second is to help inform the knowledge base of parents, advocates and allied professionals. The third is to consider the impacts the developing disability rights environment is having upon these ongoing struggles.

Method: This is a qualitative case study based on interview and document analysis and long-term involvement with a couple with learning disabilities. The material was coded according to the principles of grounded theory.

Findings: Three key categories were identified. The first is 'Lessons learned', referring to the knowledge and experience that the parents collected over a lifetime. The second is 'Allies: The family', highlighting the importance of a strong family network. The third is 'Secret weapons', a phrase used by the parents to denote a collection of advocates and professional supporters they strategically surrounded themselves with when needed.

Conclusion: This story illustrates the parents' tactical skill and resourcefulness to retain custody of their children. We also document the addition of new tools the parents are able to make use of such as domestic disability and human rights protections that are in turn supported by international conventions such as the United Nations Convention on the Rights of Persons with Disabilities. However, we also contend that families like theirs live in a state of fragility, and disruptions to their support can result in further child protection interventions.

KEYWORDS

parents with learning (intellectual) disabilities, family integrity, support, child protection, United Nations Convention on the Rights of Persons with Disabilities (CRPD)

Accessible summary

- Parents with learning disabilities can take care of their children but often need support.
- It is important to share stories about parents with learning disabilities who have raised their children and what helped them deal with child protection.
- This is a story about a resourceful couple who raised three children with the help of family, supportive service people and lawyers.

1 | INTRODUCTION

The focus of this contribution is to explore the story of a family headed by parents with learning disabilities in Iceland to understand how they cope in the face of child protection interventions. Their story illustrates their skill and resourcefulness in drawing upon several tactics and utilising a number of 'weapons' to retain custody of their children. The adversities faced by parents with learning disabilities in dealings with child protection are well-documented, in particular in work done in North America, Western Europe, the Nordic countries and Australia as discussed further. The historical arc common to these parts of the globe has shown that the processes of deinstitutionalization, independent living, the banning of nonconsensual sterilisation and the growth of international human rights agreements have contributed to people with learning disabilities living independently and establishing their own families (Man et al., 2017). As positive as these developments are, this has also brought families headed by these parents to the attention of children's protective services.

The aforementioned regions also share a history of eugenic ideologies and practices which acted to prevent procreation among the so-called 'undesirable' groups through sex-segregated institutionalisation, restrictive marriage laws and nonconsensual sterilisation (Mitchell & Snyder, 2003). Eugenics increasingly fell out of favour after the Second World War. However eugenic practices have not vanished but have become more covert and embedded within everyday social practices such as those concerned with child welfare (McConnell & Phelan, 2022). The emphasis shifted from birth prevention to child removal, though in Iceland people with learning disabilities, particularly women, are still pressured into using birth control and having abortions (Björnsdóttir et al., 2017). Several international studies show that these parents still face significant barriers in keeping and raising their children. Poverty, social isolation, stigma and loneliness, as well as inappropriate or counter-productive support measures, are common in families headed by parents with learning disabilities (Llewellyn & Hindmarsh, 2015; McConnell et al., 2017; Stefánsdóttir et al., 2022; Strnadová et al., 2017). These barriers have been recognised as contributing to disproportionate child protection involvement and child removal in the lives of these families (Booth & Booth, 2005; DeZelar & Lightfoot, 2018; Lightfoot et al., 2017).

A review of the literature suggests that one of the most crucial factors for parents with learning disabilities to be successful in taking care of their children is the support, when available, from the extended family (Llewellyn, 1995) and in particular someone that represents a mother figure (Traustadóttir & Sigurjónsdóttir, 2008). The resourcefulness of parents and their agency in seeking support has also been noted (Aunos et al., 2003; Mayes et al., 2008; Traustadóttir & Sigurjonsdottir, 2010).

This contribution will examine in detail some of the specific tactics drawn upon by parents with learning disabilities to keep child protection at bay by way of a case study example of Anna and Tómas (pseudonyms) in Iceland. The material that comprises the bulk of this case study extends over a decade from the time of the birth of their first child to the recent pregnancy, at the time of writing, of what will be their fourth. To understand the interactions of the parents with child protection, and how child protection perceives their behaviours, it is important to contextualise the lives of these parents and to explore the intergenerational effects of child protection interventions in specific families. In conjunction with the histories of the parents, it is also critically important to assess newly emergent factors, such as the changing legal and human rights environment coming with instruments such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006). To illustrate this, we have compiled a narrative story about Anna and Tómas drawn from numerous sources and over an extended timeframe which highlights the words and experiences of the couple from interview data but also includes interview and case file data drawing on the views of key actors in their lives, such as close family members, support personnel, advocates and legal professionals. The data collection began in 2010 when the couple participated in research as the result of the advocacy work of the second author which continued into the present. Formal research was, again, conducted by the first author from 2020 to 2022 in the form of interview and document analysis, and in the latter stage some participant observation in the home along with telephone, texting and video call exchanges. Earlier childhood experiences of Anna and Tómas were collected through interviews and some archival sources. This included child protection case files and intervention plans provided by the parents. These data were especially important to deepen the understanding of the parents' stories, lived experiences and reactions to the interference of the child protection system.

The data analysis was performed in line with the principles of grounded theory described by Charmaz (2014). The approach is inductive and certain flexibility is allowed in the process. Interviews and case documents were coded using constant and iterative comparison of 'events' resulting in a number of categories that were used to build the analysis. Research meetings were conducted among

all three authors in which the findings were discussed, and the analysis refined. The idea for framing the analysis in terms of 'weapons' was suggested to an extent by the parents who, several times in an interview, referred to disability rights protection officers, legal professionals and advocates they surrounded themselves with as their 'secret weapons.'

Telling people's intimate stories is complex and requires special attention to ethical matters. The question of who owns the story and who has the right to tell it must be raised (Thackray, 2018). It is also important to ask if the storytelling has a purpose and even contains within it the possibility of social change (Runswick-Cole & Ryan, 2019). In this study, the parents were eager to share their experiences in the hope that it would lead to some systemic changes in Iceland. Telling one's story is also empowering for the individuals but also in a practical sense of drawing more attention to their situation and increasing the number of allies, or 'weapons', at their disposal. Anna, the mother, was present during all the interviews and participated in the discussions that took place. It is extremely important that the story told reflects Anna and Tómas's reality. We asked them, along with other key participants, to read the narrative we had created. Anna and Tómas received an easy-to-read summary, which was read aloud for them, and opportunities were created for them to make changes. All the participants agreed with the narrative presented here. To protect the participants' privacy, pseudonyms have been used throughout and some details have been changed. The study was approved by the Scientific Ethics Committee of the University of Iceland (VSH202-009).

What follows will first be a presentation of the story of Anna and Tómas. But this curated version is intended as the necessary background material for the analysis and discussion. One category we have identified is referred to as 'Lessons learned'. This refers to the knowledge and experience that the parents collected over a lifetime from their dealings with child protection extending back to their own childhoods. This will be followed by 'Allies: The family', as the parents know full well from experience that isolated parents are also vulnerable parents, and that their chances of maintaining custody of their children are highly dependent upon demonstrating to child protection the existence of a strong family network for support. The final category before the concluding remarks is that of 'Secret weapons', used to counter the threat of child removal and mobilise for support when needed. The partial story of Anna and Tómas presented next provides some of their backgrounds and early encounters with child protection associated with the birth of their first child, concluding with a recent look at the fracturing of their support and its effects during the COVID-19 pandemic.

2 | ANNA AND TÓMAS

Anna and Tómas are both in their thirties at the time of writing. They got to know each other in a school they attended for children with special needs and then were reacquainted in their early twenties and fell in love. Anna had, as long as she remembered, been determined to be a mother, and 4 years after getting married the couple decided it was the right time to establish a family and have children. Three months into her pregnancy Anna was notified to a 'Precaution and treatment team' by a concerned midwife who worried because Anna was, as she phrased it, 'a lot behind' and would need considerable support taking care of the baby. Another notification to child protection, classified as neglect concerning care and supervision, was made when Anna was 28 weeks into the pregnancy. This notification triggered strong emotions within Anna and Tómas who became terrified as a result. When Anna was a young girl her two older sisters were removed from the home and she herself was removed at the age of 10 and remained in foster care until the age of 16. Tómas also grew up in foster care for most of his childhood and youth. Their experiences in foster care were not positive. They were both treated harshly, especially Tómas who is still coping with the consequences of the sexual abuse he experienced as a young teenager. At the time of the abuse, Tómas wrote letters to his child protection officer asking for help but he never received a reply. Anna asked repeatedly to be reunited with her family, which also resulted in silence from the child protection authorities. These experiences cultivated a deep-seated distrust and fear toward the social welfare system on the part of both Anna and Tómas. Perhaps in reaction to this level of mistrust they sensed, the midwives emphasised talking to Anna during pregnancy about the role of social services and child protection to change her 'misconceptions' about the system.

Following this notification, child protection decided that both parents should undergo a parenting assessment which should be finished at least one week before the baby was due. In the request, made by child protection workers, it was stated that the aim of it was to 'assess their parenting competence and their will and ability to cooperate with child protection'. The assessment made Anna and Tómas even more worried as they did not understand what it was and were afraid that this might be a tactic of child protection to have their baby removed from their care. While Anna and Tómas were fearful of having their baby taken from them, the workers in the child protection system also had fears about the couple's ability to raise a child. To get a sense of the couple's caring ability before the baby was born, Anna and Tómas were given two RealCare baby infant simulators, one for each. Out of fear the couple did not object, even though they were only expecting one child. When Anna thinks back to these times, she shakes her head and says, 'this was a big, big mess'. Normally these dolls are used with teenagers to teach them the realities of infant care with the goal of preventing early pregnancy. The recommended duration is 72 hours of caretaking.[1] However, for Anna and Tómas, the aim was to ensure that both parents would be doing caretaking and to keep track of their performance. The two dolls had to be taken care of around the clock. Knowing that the dolls obtained and stored information about their

[1]Realityworks. 2020. 'RealCare Baby® Implementation Guide.' https://www.realityworks.com/wp-content/uploads/2020/10/09282020_AJ-RealCare-Baby-Implementation-Guide-Brochure-WEB.pdf. Accessed 24.03.2022.

parenting performance, it terrified them that the doll Tómas was given cried constantly and nothing seemed to soothe it. At this stage, Anna was starting to have complications with her pregnancy and had been ordered by her medical doctor to rest and avoid all stress. Frightened that the information obtained through Tómas' doll would work against them and determined to prove that they could take good care of a baby, Anna and her mother took shifts helping Tómas to care for the crying doll. Two and a half days later Anna returned it and informed the professionals that it was broken. Child protection decided not to replace the doll. She however continued to take care of the other doll for four more days; in sum, this doll was cared for over six days or 144 hours. At the conclusion of this process, Anna scored 9.8 out of 10 in caretaking and Tómas scored 8.0.

Anna's pregnancy and the first weeks after delivery were coloured by extreme anxiety about not being allowed to take their baby, Klara (pseudonym), home from the hospital. The parents were notified to child protection by staff from the National Hospital the same day she was born. The notification indicated that both parents had learning disabilities and deep concerns were raised if the parents would be able to take care of her and ensure her safety when back home. As Klara was born five weeks premature, Anna stayed at the hospital during the first week. During this time everything went well, and it was decided that Anna and Klara were ready to transition to the local hospital where the parenting assessment, which had already started, would continue. In letters to the local hospital and child protection, written by nurses and physicians from the National Hospital, it was stated that the parents took good care of the baby, and she was thriving. The parenting assessment continued at the local hospital where Anna was observed while caring for Klara and there the two parents were interviewed. One observer reported in this assessment:

> She has a quite good understanding of the baby's basic needs and she's taking good care of it. She follows guidance and asks for advice. She has, however, great difficulties in talking about the baby's long-term needs and therefore we can assume her abilities are lacking in that area.

The observer concluded that 'Anna was a good mother but would need support in the parenting role'. Anna, who had difficulties understanding the process behind the parenting assessment, described how she was once observed making her bed. When talking about this Anna expressed her frustration and surprise: 'I mean, is that what is normally done when you just had your baby? Do people normally make their beds when they are at the hospital?' Despite only good reports from doctors, midwives, nurses and an excellent 'doll score', child protection was still hesitant about sending the parents and their child home. A letter was written three days after the transition to the local hospital demonstrating these concerns:

> If the baby will go home with its parents, it is clear we need to build extensive support for the family, e.g., in-home surveillance (Is. *tilsjón*)[2], in-home services (Is. *félagsleg heimaþjónusta*), *liðveisla*[3] and *frekari liðveisla*[4]. We estimate that they will have to have in-home surveillance for four hours, seven days of the week and in addition to irregular surveillance.

As much as Anna and Tómas wanted to make child protection 'disappear' from their life, they knew from their own experience that it was unlikely to happen. Cooperation became the tactic they adopted; they did as they were told and showed no resistance toward the child protection interventions due to fear of retaliation.

However, the family was not permitted to return home as child protection insisted that the parenting capacity assessment needed to be completed. After three weeks at the local hospital, not knowing if and when they could go home with Klara, they realised that it did not matter how well they did; it looked like cooperation and positive remarks were not going to be enough to maintain custody of Klara. Some of the professionals around the parents were also growing concerned about the length of time the process was taking and about the ethical and legal problems that were emerging. It was at this point in time in the process that frustrated healthcare staff contacted the second author, who is a scholar in Iceland in the field of families headed by parents with learning disabilities. They claimed that Anna and Tómas were doing everything that was needed for caring for their baby as could be expected of first-time parents. They felt the parents' rights were being violated by child protection who did not permit the hospital to discharge the family, arguing '...it must be illegal to keep them here against their will, hospitals are not prisons'. The staff asked if the second author could visit the parents at the hospital. She agreed and took a student along who, at that time, was studying disability studies and held a law degree. Anna had to fight to be discharged from the hospital and began to draw upon members of her social network who might be able to help. Anna contacted her aunt, an attorney, and asked her to protect their interests. At the same time, Anna's sister wrote a letter in her support to child protection where she stated: 'I write this letter to ensure that my words will not be twisted or misunderstood'. In the letter, she continued that Anna and Tómas could take care of Klara if they would get the space they needed; that she would be ready to live with them if needed and if they would not be trusted with the baby that she would be ready to adopt. The grave situation made Anna and Tómas realise that the cooperation and positive reports on their parenting they were receiving were not enough. They began to gather allies around them, starting with family members, and this is a strategy they have used ever since.

[2]Tilsjón in English translates as 'supervision' or 'guidance'. However, we have opted to translate the term as 'in-home surveillance' to better reflect, in our experience, what is actually done in the home.
[3]A municipal social service support intended to enhance community participation.
[4]An extension of *liðveisla*, this is also a support intended to enhance community participation, but which takes into account the increased support for services due to disability and to prevent the need for institutional living arrangements.

The parenting assessment was finally finished 27 days after Anna delivered Klara. In it, the psychologist argues that two main viewpoints intersect: the best interests of the child to ensure its safety and good upbringing conditions, and the rights of people with disabilities to live independent lives and which includes the right to form and have families. He determined: 'Their capacity to take care of a child is insufficient but not to the extent that it justifies custody deprivation'. The report concludes to say that Anna and Tómas will need a lot of positive support, up to 2-4 hours, daily. A dozen years have elapsed since and during that time Anna and Tómas have added two more children to their family and at the time of writing have maintained custody of their children throughout.

3 | LESSONS LEARNED

The couple's initial encounters with child protection were informed by their own experiences of the system as children. These were lessons learned, as Anna and Tómas knew well enough how child protection in Iceland operated. They were aware that their measures could be harsh and most significantly that 'the system' was not to be trusted. Tómas in particular has never forgotten how his pleas for assistance from child protection when he was abused in foster care were never answered. This was seemingly overlooked by the system when they encountered Anna and Tómas as first-time parents. As mentioned in their story, a midwife, in response to Anna's fears and distrust, wanted to correct Anna about her 'misconceptions' about the child welfare system. We contend that these were not misconceptions at all, but logical and rational points of view formed as the result of bitter experiences. This knowledge extended to other family members, such as Anna's sister, who prefaced her letter to child protection with the statement that she was doing so in writing to ensure that her words 'will not be twisted or misunderstood'. In our collective research, we have also learned that the words of parents and innocent actions were commonly twisted, misinterpreted, or blown out of proportion, with isolated, specific incidents serving as exemplars of patterns.

Anna and Tómas reacted with fear when notifications were made about their parenting, and this too is an understandable reaction. Notifications initiate child protection interventions, but they can also be misused as evidence to support custody deprivation cases (see e.g., Rice & Sigurjónsdóttir, 2018). In their case, the notifications were generally categorised under 'neglect.' As the classification options are limited, neglect is a common choice and in certain ways acts as a catchall classification when the intent of the notification does not fit the available choices. This practice extended as well to other documents, such as treatment plans. The parents, aware of the seriousness of accusations of neglect, managed to change the standard neglect denotation on the first child protection plan. For the parents, this was and still is important. 'I refuse to have neglect written on the plan, I would never neglect my child' (Anna). Demanding that the language used reflects what the case is about —'need for support' rather than 'neglect'—is crucial, as the parents know from their experiences that once a case is stamped with the neglect label that the system will react accordingly. The couple has become so adroit in their management of notifications that at times they have taken pre-emptive actions. They insist upon records of goings-on around them to be made which, if necessary, could be later compared with the content of notifications, as Tómas explains:

> We were scared because our neighbor always calls the police if a baby cries …but now the plan is that the support workers will come in, check to see if everything is okay, write down if the baby is crying, for example, if it is getting teeth and cries a lot because of it… so if the neighbor notifies us to the child protection, everything is written down by them.

As a result of lessons learned, Anna and Tómas knew that they had to develop and maintain good relations with the workers within the system. However, they knew that this was not always possible and poor relations with a specific worker could create problems for them. The couple is therefore tactical in their dealings with the system, and they are aware of the power imbalances. There is one key practitioner in particular who understands the family's situation and how vulnerable they are. In a respectful way, she has created a platform for the parents to be active participants in organising the support, choosing or even refusing to have some workers in their home. Anna gave an example: 'I didn't like Eva (in-home surveillance), she didn't help me, so I got rid of her'. Despite all the good, and tactical, relationships Anna has nurtured throughout the years, the situation nevertheless remains fragile.

4 | ALLIES: THE FAMILY

Anna and Tómas early on recognised the importance of surrounding themselves with family members who held powerful positions in the larger society, such as an aunt who was a lawyer, as well as those who offered practical support to the couple, such as Anna's sister. Family support also included other benefits. The staff hired by child protection had a high turnover rate, which meant that Anna and Tómas were forced to renegotiate their relationship with another stranger in their home each time this occurred, and which added to their stress and anxiety. To their credit, the child protection workers were aware of the strain of having this heavy in-home surveillance and did what they could do to soften this for the family. In contrast with the revolving door of surveillance and support workers, Anna's sisters and mother have been the constant in Anna and Tómas's life, and the ones they trust the most and turn to when they need help. For the parents that meant that they have received the critical support needed to create the environment that allows them to raise their children and even distribute some childcare duties.

> It's better to turn to the ones who are close [family]… of course there is our support worker…but Anna's

> sister is the rock, and she helps us raising them [the children] … the older ones stay one week with her and one week with us (Tómas).

Even though the parents seem happy with the formal support system in place, as of the time of writing their family is still the constant in their life, the 'rock'. However, there are very few mentions of the extended family in older reports, and they did not appear to be considered as a source of support, most likely the result of their history with child protection. Anna's sister has always played a significant role in the children's lives, but it was only when their (at the time) two children were three and five years of age that Anna's sister's importance was recognised by the system. The sister then received a formal support role which meant that she was now paid by child protection for providing respite care to the family. This recognition became particularly important after Anna and Tómas had their third child in the middle of the Covid-19 pandemic. Child protection worried about how Anna and Tómas would manage with a new baby in an environment of unreliable services, and with schools and leisure activities closing down. To ease the stress of taking care of three children during these times of uncertainty, child protection made an agreement with Anna and Tómas that the two older children would live with their aunt every other week for some time. This 'suggestion' made Anna and Tómas uneasy, but they saw no other way but to agree as a tactic of cooperation. However, what happened is that the arrangement came to be seen as favourable for them and they have deep trust in Anna's sister. They also feel that the arrangement does not diminish their abilities but rather allows them to demonstrate their strengths while addressing their limitations, as Tómas phrased it: 'She [the sister] helps us teach them… we can teach them how to read and write, but she helps with the math'. The 'shared parenting' has been a highly effective tactic to build an environment that promotes better child and parental health by reducing stress, allowing the parents to take care of their own relationship, and recharge for the coming week with three children. Anna says: 'I feel like we just have these kids together, me and she [the sister] …I always say "they are our kids"'.

5 | SECRET WEAPONS

The couple drew a distinction between their family members, who they relied upon as allies by virtue of kinship, with a collection of advocates, rights protection officers, legal professionals and supportive professionals, their 'weapons', who they could turn to and wield in times of crises. Anna and Tómas knew that when certain issues arose that it was best to have one of their weapons at their disposal. During a meeting when the parents were being held in the hospital after the birth of their first child, the pattern of the involvement of both system representatives as well as professional allies began to take shape. By way of example, attending this particular meeting included:

- the parents, Anna and Tómas.
- the child protection case manager.
- the head of child protection.
- an infant nurse.
- a psychologist.
- a support worker (who performed the in-home surveillance).
- Anna's aunt (noted lawyer).
- the second author (disability studies scholar).
- Dóra (pseudonym), the second author's student (future lawyer and disability rights protection officer).

At this meeting, it became obvious that the system did not listen to the young parents, but the others were more difficult to ignore. Following the meeting, it was decided that Anna and Tómas would get a new case manager, as was their desire. Reflecting on this meeting, Dóra said:

> It was extremely important for this family that we could step in and reference human rights and explain to them [child protection] how this was a violation. Anna cried because of her case manager, and child protection refused to change managers, but then we could step in and claim that it was a violation of her rights. I referenced a verdict from the European Court of Human Rights.

It was quite clear that having 'weapons' of this sort from the very beginning had a significant impact on the overall process. Dóra explained that the mere presence of professionals acting as advocates helps to address the power imbalance, but their role is also to 'slow' the process down so the parents have the time and chance to demonstrate their abilities and strengths.

Not all of these 'weapons' were available to parents in the past. In 2007, Iceland became a signatory to the CRPD. In 2011, the position of the national rights protection officers for people with disabilities in Iceland was established. The office is tasked with overseeing the rights of people with disabilities and assisting them in rights protection matters. Following the ratification of the CRPD in 2016, in 2018 new disability rights legislation was enacted in Iceland which incorporated elements of the CRPD. Of particular relevance here is the 'Law on services to disabled people with long-term support needs 38/2018' (Lög um Þjónustu við fatlað fólk með langvarandi stuðningsþarfir nr. 38/2018), in which it states that supports for people with disabilities are essential to the goal of an inclusive society, especially mentioning the needs of parents with disabilities in the care and upbringing of their children.

Anna and Tómas have kept up with the development of disability rights in Iceland and used their knowledge when working with child protection and the support services. It is also important to note how the creation of disability rights protection officers and the codification of these rights into Icelandic law shifts the power relationship in another way. Anna and Tómas no longer needed to rely on what were essentially favours from their 'weapons' but were now legally entitled to support and protections. Anna and Tómas are now assisted by their rights protection officer, which includes reading over every child

protection intervention plan to tackling more serious matters like notifications. The couple knew about the power of these notifications, but they could not find out information like their source. With the authority wielded by the rights protection officer, they were able to find out that all the notifications at one point came from the same person, a neighbour who notified them for various reasons, usually related to noise coming from their apartment. Not only were the details of the notifications helpful but finding their source enabled the couple and their advocate to take action and illustrate to child protection that the parents were being bullied. Child protection realised that they were being harassed by their neighbour and accepted the notifications but with precaution. After tolerating this harassment for years, the couple managed to stop the notifications by using one of their 'weapons'. In a letter written by their lawyer, the neighbour was told that the notifications had created emotional harm for the family and, if not stopped, he would be sued.

Anna and Tómas have used their so-called 'weapons' in situations where the couple are scared or feel their rights are being violated. Tómas sometimes uses militaristic terms when he speaks about these issues: 'If we're scared or there is trouble then we see her sister or her mom, that team… and of course, we use the armory, we get the weapons'. In the past few years, this kind of protection was less needed but nonetheless, Anna and Tómas continue to seek this kind of support frequently, for different reasons and situations. The relationship with child protection and social services remains fragile and past experiences continue to affect Anna and Tómas, often making them scared or insecure. For Anna, the importance of having those allies is highlighted in her many remarks, about her weapons: 'I have to attend this darn meeting again… a big one, team meeting… I will try to have Katrín [advocate] and Dóra [lawyer], and my rights protection officer with me'.

6 | CONCLUDING REMARKS

The framework of this contribution is built upon the analysis of the tactics that Anna and Tómas need to employ over the years to maintain the integrity of their family. This also includes a consideration of the 'weapons', as they put it, that they must wield from time to time. Unfortunately, there is a militaristic and arguably violent subtext to the language in what is essentially a positive narrative. This is unfortunate, but also accurate; the relationship between the parents and the child protection system is sometimes adversarial. The couple are aware that the child protection authorities engage in their own tactics when it comes to marginalised parents, so they respond in kind. This is not ideal, but the reality is that the relationship between the couple and the child protection system was in a sense established before the birth of their first child as the result of the poor practices of child protection in the past. Despite the positive narrative arc of their story concerning their successes, it must be remembered that it has come at a cost. Their story is filled with examples of specific battles that have been won, but the campaign is characterised by long-term worries, stress and fears. The fracturing of the support services could result in a cold war between the family and child protection turning hot. For example, their support became fragmented due to the Covid-19 pandemic. During a visit to their home, it was obvious that this lack of support had resulted in a less than ideal home environment. The family's key support worker realised how this fragmented service has affected the family and, at the time of writing, child protection was planning to increase support in the form of, among others, more frequent cleaning of the home and respite services. Anna was afraid but accepted the support, partly because she missed the company of one of the in-home surveillance persons but also because she knew the consequences of resistance.

The hybrid mix of formal, family and advocate supports, in this case, appeared to be successful. But it is important to remember that each part plays a vital role. This story should not be read as in support of privatisation and retrenchment of the state in the area of social services, but quite the opposite. Family is the vital, and constant, support for Anna and Tómas. However, it may be unreasonable to expect family members to take up this support role to the degree of Anna's sister. Though governmental funding for her work helps with this considerably, the fragility of families where families alone are helping has been recognised (Llewellyn & McConnell, 2002). In contrast, the state (if supports and funding remain in place) can be somewhat more constant in that governmental systems and programs can persist despite changing personnel. But it is the revolving door of new faces in the support and surveillance system that also caused the parents a great deal of stress and anxiety. Neither source of support is ideal on its own, but this hybrid model contains within it plenty of possibilities.

The story of Anna and Tómas owes much to their own skills and resourcefulness, how they wield their weapons and engage in their tactics. In the later years of their story, the inclusion of a supportive worker within the child protection system helped a great deal. We wish to stress that the parent–child protection relationship need not be adversarial, though it often is. The signing and later ratification of the CRPD, and the creation of the office for disability rights protection, transformed what were essentially favours performed by family members and advocates into rights codified into law with positive duties placed upon the part of the state. Another critical factor that has made the case of Anna and Tómas so far successful is early intervention. Anna and Tómas did not make the mistakes that other parents do who may have little or no experience of child protection, such as refusing to co-operate and assuming, or hoping, that everything will turn out all right. The lessons they learned and the tactics they engaged in during the birth of their first child critically prevented this intervention from turning into a custody deprivation case in the first place. Had they waited longer, had they not recognised the significance of the increasing numbers of notifications, had they not built a familial support network or called upon the assistance of professional advocates, we contend that this contribution would not be an accounting of how a family headed by parents with learning disabilities can maintain family integrity; rather, this contribution

would be another story of where things have gone wrong. Anna and Tómas have shown us how there are other possibilities for the lives of families in their situation.

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Article III

Safeguarding Families and Rights of Parents with Intellectual Disability Involved in Child Protection

The Role of Rights Protection Officers

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ABSTRACT

The focus of this contribution is on how rights protection officers (RPOs) experience supporting parents with intellectual disabilities involved in child protection investigations. We situate the role of the RPOs within disability human rights framework as well as the institutional justice capital perspective to comprehend how RPOs function as a resource for parents and professionals. We identified four overlapping themes: *Altering power relations*, *Lack of knowledge*, *Systemic apathy*, and *Challenging the informal*. We argue that pervasive discrimination towards parents with intellectual disability, from the highest levels of government to interactions between parents and the child protection system, inform these interactions and influence outcomes. The work performed by the RPOs in supporting marginalised parents, raising awareness of disability rights,

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and countering prejudice is of critical importance. We emphasise the role of RPOs within the justice system and recommend the strengthening of such mechanisms to meet international human rights obligations.

KEYWORDS
Rights protection, parents with intellectual disability, Iceland, child protection, institutional justice capital, Convention on the rights of persons with disabilities

Introduction

International research has found that parents with intellectual disability are over-represented in child protection cases (Lightfoot & DeZelar, 2016; Slayter & Jensen, 2019). Contextual factors such as poverty, social isolation, and lack of social support are known to be prominent features in these parents' lives (Powell et al., 2017; MacIntyre et al., 2019). Presumptions about child neglect, mistreatment, and not being able to attain new skills or benefit from support are among the biases held by professionals and child protection workers (McConnell & Llewellyn, 2002; Laliberte & Lightfoot, 2013; Rice & Sigurjónsdóttir, 2018; Albert & Powell, 2021; Sigurjónsdóttir & Rice, 2023). It is also well documented that parents with intellectual disability can be effective parents if meaningful and appropriate supports are put into place, their social supports are strengthened, and negative views and expectations from the system are countered (see e.g. Llewellyn, 1995; Aunos et al., 2003; Booth & Booth, 2005; Mayes et al., 2008; Traustadóttir & Sigurjónsdóttir, 2008; Feldman et al., 2012).

Our analysis places the work of the rights protection officers for disabled persons (RPOs) in Iceland into the framework of critical disability studies, human rights and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) as the scholarly, legal and ethical underpinnings of how parents with intellectual disability should be respected and supported in the parenting role. We also apply the perspective of institutional justice capital, as suggested by Hamilton and Maslen (2022), to understand how the RPOs serve as a resource not only for parents with intellectual disability but also for the workers in the system.

1. Recent Developments in Rights Protection for Disabled People in Iceland

Legislation concerning disabled people in Iceland that explicitly referenced the notion of rights has existed in different forms since 1992. The *Act on the Affairs of Disabled People 59/1992* (1992), Articles 36 and 37 are of specific importance here. The main purpose of those articles was to safeguard the rights of disabled people living in small-scale institutions and group homes. In 2010, following Iceland's signing of the United Nations CRPD 2007, changes were made to the act which signalled a shift toward a greater emphasis upon disability rights in light of the provisions of

the Convention. Representatives (*trúnaðarmenn*) were then appointed to safeguard the rights of disabled people. Iceland's signing of the CRPD, followed by formal ratification in 2016, continued to have an impact upon disability rights in the country as disability legislation was revised considering the anticipated ratification process. One such example is the 2011 *Act on the Protection of the Rights of Disabled Persons 88/2011*. With the act, the position of rights protection officers for disabled people (formerly named representatives) was created. Rights protection was expanded from being primarily concerned with safeguarding the rights of disabled people living in small-scale institutions to safeguarding the rights of all people who self-identify as disabled persons in all aspects of life (Ministry of Welfare, 2013). The main aim of the act is to ensure that disabled people are provided with appropriate support in safeguarding their rights, ensure that their right to self-determination is respected, and that their legal rights are protected when urgent interventions in their life are required. The act states that rights protection for disabled people should be threefold. First, the act includes the implementation of the Ministry's[1] rights monitoring unit, which is responsible for collecting information about rights-related matters for disabled people and providing relevant education and information to various stakeholders, including disabled people themselves, their spokespersons, and service providers. Second, an important inclusion is a provision for a personal spokesperson for disabled people (*persónulegir talsmenn fatlaðs fólks*), if so required. The spokesmen provide the disabled person with support in safeguarding their rights and taking care of their personal affairs, such as decision-making in their personal lives or assisting with their finances. The personal spokesman is, when possible, chosen by the disabled person.

Thirdly and of most importance for this contribution, a key development in the above-mentioned legislation is the creation of a special Office of Rights Protection for disabled people funded by the Icelandic government. The rights protection officers for disabled persons, hereafter referred to as RPOs or officers, are responsible for monitoring the circumstances of disabled persons and are available to assist them in securing their rights. According to the *Rights Protection Act*, there should be eight officers serving seven different regions of the country, which includes approximately 380,000 inhabitants (Statistics Iceland, 2024). The officers are hired by the Minister of Social Affairs and Labor after receiving a comment about potential applicants from the Icelandic Disability Alliance. RPOs are not required to have a specific educational background but to be knowledgeable and experienced in the affairs and rights of disabled people. Anyone may notify and is, in fact, required to notify the office if they are concerned that the rights of a disabled person may have been violated. RPOs can also initiate a case by their own initiative. RPOs, in conjunction with the disabled individual in question, may assist in investigating the claim and support the individual in pursuing a remedy. Such remedies can, for example, be

1. At the time the responsible ministry was known as the Ministry of Welfare. As of the time of writing, the responsible ministry is the Ministry of Social Affairs and Labour.

actions to initiate a formal process for claiming improvements in services or, if necessary, send a formal complaint to either of the two governmental bodies that oversee surveillance in the matters on the rights of disabled people. What seems to set this safeguarding mechanism apart from many other countries is that the Office of Rights Protection and the officers working within it are able to assist in cases on an individual level, whereas it seems more common that safeguarding mechanism elsewhere involves primary an emphasis on education and awareness-raising about the rights of disabled people (similar to the purpose of the rights monitoring unit described earlier) (Ministry on Welfare, 2013). In recent years there has been an increase in cases that are reported to the office. In 2021, the office received 4028 notifications about possible human rights violations, which is an increase of 1725 notifications from the year 2020. The reason for this increase is unknown. In general, the notifications most often come from disabled persons (32%), their closest relatives (27%), or service workers (26%). In most cases, the notifications are about insufficient services (24%,) the need for support in an ongoing case (19%), lack of services (12%) and violence (10%) (Rights Protection for Disabled People, 2021). It is not known how many cases are pertaining to parents with ID.

2. Theoretical Context

The analysis presented here on the role of rights protection officers regarding supporting parents with intellectual disability and their encounters with child protection services draws upon two key perspectives. The first is the disability human rights perspective, largely inspired by the CRPD and disability studies scholars working in this area. The Convention provides the legal (and arguably also moral and ethical) framework in which child protection in Iceland should work within when a case involves disabled parents. Our analysis draws attention to how this regularly falls short and the vital role that RPOs play in attempting to rectify these injustices. The second draws inspiration from the concept of "institutional justice capital" as outlined by Hamilton and Maslen (2022). While Hamilton and Maslen focus on marginalised families in Australia that come into contact with child protection, there is enough overlap with the situations faced by parents with intellectual disabilities in Iceland to adapt their work for our purposes. The institutional justice capital perspective suggests that the RPOs could be seen as a vital resource for the parents to ensure that the child protection process is transparent, respective to the human rights of disabled people, and which results in just outcomes for families.

2.1 The Human Rights Perspective and Parents with ID

Disability studies emerged from the disability rights movement which, in turn, grew out of a larger push for various civil rights that occurred in the global north in the 1960s and 1970s. Intellectual and political agitations against varied forms of oppression, discrimination and socio-economic segregation have been at the forefront of the disability rights movement since its earliest days (Oliver, 1990; Traustadóttir, 2006; Shakespeare, 2014). However, the CRPD has been referred to as a "paradigm

shift" in the area of disability human rights (Degener, 2016) in how disabled people are highlighted as rights holders and human rights subjects. This perspective challenges the view in which disabled people are seen as problematic and instead claims that social arrangements and environments are the major contributors to the many barriers disabled people face in their everyday lives. For the purpose of this article, and with regard to disabled parents specifically, Article 23 of the CRPD (Respect for Home and Family) and Article 13 (Access to Justice) are particularly significant. For marginalised groups, such as parents with intellectual disability, access to justice has been highlighted as fundamental to realising human rights in general. The ratification of the CRPD has arguably influenced Icelandic legislation in relation to parenting. In late 2018, disabled parents were, for the first time, mentioned in an Icelandic act of law in relation to services and support (*Act on Services for Disabled People with Long-Term Support Needs*, 2018, 38/2018). The act places responsibility on municipal social services to provide disabled parents with appropriate support to fulfil their parenting duties.

One key issue with the CRPD is its applicability to child protection interventions concerning families headed by parents with intellectual disabilities. The international literature (e.g. Collins et al., 2018; MacIntyre et al., 2019; McConnell et al., 2021; Powell, 2022) and the Icelandic literature (e.g. Sigurjónsdóttir & Rice, 2018; Sigurjónsdóttir et al., 2019; Sigurjónsdóttir & Rice, 2020; Rice et al., 2021; Stefánsdóttir et al., 2022; Stefánsdóttir et al., 2023) have highlighted several issues, such as difficulties by parents in understanding the complexities of the child protection and legal systems, poor working practices on the part of the child protection system, inappropriate or inflexible supports, and that the justice systems are inherently ableist. These studies also highlight the importance of early interventions to prevent later harsh measures, such as custody deprivation, and the critical importance of advocates on behalf of the parents whose views are listened to and respected. In the absence of demonstrable child abuse or neglect, custody deprivation is still possible if the child protection authorities present an argument based upon the risk to the child's future well-being or development under the continued custody of the birth parents. It is in such cases where the parent's disability status figures prominently and where the need for knowledgeable advocates, supporters and counter-experts is urgently required.

2.2 Institutional Justice Capital

Hamilton and Maslen (2022, 539) define institutional justice capital broadly as the focus on "the capacity and resources to understand, navigate, and communicate fairly and equitably in all aspects of the criminal justice process". Extending the work of Cloud and Granfield (2009), Hamilton and Maslen (2022, 538) apply this to the child protection system in Australia to consider factors included within institutional justice capital such as "recovery capital" ("personal resilience skills and resources"); "social capital" ("family, peers, networks"); and "community capital" ("access to training and education to reduce stigma"). However, attention needs to be paid to

whether these resources are available and form part of the justice system itself, as for example, CRPD's Article 13 that demands the inclusion of procedural and age-appropriate accommodations. Furthermore, Hamilton and Maslen consider the dynamics of family and generation regarding access to these forms of capital. They write: "Families involved in child protection now more commonly experience child removal across generations, and distrust of the system presents barriers to accessing and utilising resources in the community" (Hamilton & Maslen, 2022, 539). The authors are writing primarily here of Australia in the context of aboriginal families, but there are some parallels that can be drawn with the international literature pertaining to families of people with intellectual disability. While some research has shown that children who have been removed from disabled parents can demonstrate resilience and may do well (e.g. Collings & Llewellyn, 2012; Lightfoot & DeZelar, 2016), some qualitative work (e.g. Sigurjónsdóttir & Rice, 2020) points to similar inter-generational negative feelings about the system by parents and children as articulated by Hamilton and Maslen. Feelings of anger or mistrust toward the system, or shame for being the focus of a child protection investigation, can prevent parents from accessing the capital that can help them with their case. Another appealing facet of the institutional justice capital framework is that attention must be paid to whether these resources exist at all and the numerous barriers that can block access to these necessary resources. Our application of the framework is meant to support the position of rights protection officers as a critically important form of capital in helping disabled parents navigate the child protection system and the courts.

3. Methods

This contribution draws upon data collected from interviews with rights protection officers for disabled persons (RPOs) in Iceland. Their experiences were explored in order to understand their role and the challenges of their work. The specific focus of this contribution is how RPOs support parents with intellectual disability and safeguard their rights when they have become the focus of a child protection investigation. The data gathering and analysis was inspired by Charmaz's (2014) grounded theory approach, which is rooted in social constructionism. The approach is inductive and allows certain flexibility for data gathering and analysing. The analysis itself was conducted using such an inductive approach that focused on patterned meanings that emerged from the data. This allowed for exploring the rights protection officers' perspectives and understandings of their work through their own words, as well as to solicit their views as to whether, and to what extent, their efforts impacted on their cases. The study took part in Iceland and all eight RPOs who held either part-time or full-time positions at the time of the study were contacted by email and asked to participate. Altogether five of them accepted the invitation and three declined. In addition, one former RPO and one child protection worker participated. The former RPO was invited to take part as he was known by the researchers to have a great deal of experience working with parents with intellectual disabilities.

At the end stage of the data analysis, the child protection worker was recruited. All seven participants in the research had some experience in supporting parents with intellectual disability in relation to child protection interventions. It is worth mentioning, that despite this small sample size, that the entire population of RPOs at the time of the research were only eight officers in total and therefore, it could be said that the sample is quite representative of RPOs in Iceland.

Data were obtained through nine semi-structured interviews. All interviewees participated in one interview except for two officers who participated in two interviews each. This format was chosen with the aim to encourage the participants to articulate in their own words their experiences and perspectives (Kvale, 1996). An interview guide was developed to determine/articulate the domains of inquiry and acquire the core dataset from all participants. As the understanding of the subject matter started to develop, questions were added or removed from the guide. Participants were asked to describe their work with parents with intellectual disability with an emphasis on parents who were involved in the child protection system. Some examples of questions that were asked included: "Can you tell me about your work with parents with intellectual disability?"; "Can you describe the process you go through with parents with intellectual disability who are involved with child protection?"; "Who contacts you when there is a possible violation on the rights of parents with intellectual disability?" As proposed by Charmaz (2014), additional data collection was performed at the end of the first stage of the process, and participants were asked if they were willing to take part in the research again at a later stage of the analysis to elaborate and refine the categories identified from the data. For that purpose, an information-rich former employee of child protection was also contacted via email and offered to participate in the study. This helped to enhance the analysis, allowing us to compare the views of the RPOs on the decision-making process with the views of a child protection worker.

The first phase of the analysis included familiarisation with the interview data by repeatedly reading through the transcripts. Analytical ideas and first thoughts were noted down, followed by initial coding in which many of the key analytical themes emerged. The final coding process was performed to develop the final themes presented in this article. Seven interviews took place via computer-based applications and two were conducted at the researcher's office. The interviews lasted 60 minutes on average. They were all recorded and transcribed verbatim. To protect the privacy of participants, and due to the small population of rights protection officers in Iceland, a decision was made to not describe participants in detail. Furthermore, all participants were given non-gendered pseudonyms. The overall study, of which this contribution is part of, was approved by the Icelandic Bioethics Committee and the Data Protection Authority (no. 14-062/-V1).

4. Findings

In the process of the data analysis, multiple themes emerged. After discussion among the authors, the decision was made to present four overlapping core

themes. The first is *Altering power relations*. In this section, we explore what RPOs do for parents in a practical sense to illustrate the role they play in enabling parents to exercise their rights, and the forms of institutional capital they provide. Sometimes this means altering the power dynamics of the situation through the RPOs amplifying and supporting the voices of the parents. The final three themes draw the attention away from the parents and look specifically at the issues and barriers that confront the officers in their work. The first of these we call *Lack of knowledge*. While the lack of knowledge on the part of the child protection system in how to appropriately support parents with intellectual disability is well-known in the literature, the lack of knowledge we refer to here extends into the judicial system. Judges, not being well-informed about disability rights or what constitutes appropriate and meaningful support for those parents, as a result tend to defer to the authority of child protection and their hired experts. This dynamic is challenging for RPOs to counter. Another role of the RPOs seems to involve educating the workers in the system that what is at stake is more than about "service provision" but human rights. Iceland arguably enjoys an international reputation for gender and LGBT+ equality, yet according to our data, it seems that this thinking about equality often does not extend into the disability area. Some officers have commented that this association of Iceland with "equality", while simultaneously not extending this to disability, poses some issues for their work. The next theme is *Systemic apathy*. RPOs articulated their frustration with the general lack of interest in disability rights, which extends to apathy as seen in poor attendance at meetings concerning disability rights by service workers, and which presents a serious barrier to the effectiveness of their office. The last theme we call *Challenging the informal*. While some of the key statements in the social sciences on bureaucracy and governance (e.g. Weber, 1922 [1978]; Herzfeld, 1992; Scott, 1998), as well as those in philosophy on governmentality and governmental rationality in the tradition of Michel Foucault (e.g. Burchell et al., 1991), tend to situate documents, dossiers, and the knowledge making activities of state agencies as oppressive, our argument here in this context is somewhat different. RPOs commented that one of their challenges in their work is fighting to ensure transparency in the process, so that the assessments and decision-making activities about parents are rendered even more visible. To do so, they have repeatedly insisted that the minutes of meetings need to be taken and disseminated and the decision-making process needs to be documented and made available to parents and their supporters in an attempt to safeguard their rights.

4.1 Altering Power Relations

As expressed by the rights protection officers most cases in which they are involved are about lack of or inappropriate services, support for visitation when a child is in foster care, objecting to or disputing out-of-home placements of children, support in dealing with and communicating with child protection workers and, in some instances, the judicial system in cases pertaining to custody deprivation. One key role the RPOs play is to simply

to be present when parents interact with child protection authorities and the courts. In addition to making parents aware of their rights, they use their presence to "force" the system to take the parents seriously, to ensure that they are listened to and respected. The RPOs articulated that, in their experiences, the power dynamics in the child welfare context are skewed toward child protection workers, often leaving the parents powerless and vulnerable to unjust interventions. With marginalised parents, such as those with intellectual disability, power imbalance is an issue that needs to be addressed. In the interviews conducted with rights protection officers, mixed feelings were expressed about how effective they considered their contribution to be for cases involving parents with intellectual disability and child protection. However, most of them agreed that the involvement of an advocate with the expertise and disability-related knowledge influenced the process of how cases are worked in the system. The officers' presence gave little room for the exclusion of the parents' voices as the RPOs supported them in raising their concerns and gave them more leverage over the proceedings, as summarised by Norður:

> *The case is, unfortunately, that we are often escorting the parents to meetings, and we are there because, otherwise, they are not taken seriously. That's really sad because we don't have any formal power […] but the reality is that meetings that we attend end differently than meetings where parents attend without us; they end differently and usually not well […] the parents just don't get the chance to express their point of view, and there are instances where something is decided in a meeting with a parent and later when we ask for the minutes, the already made decisions have been altered.*

The powerlessness of parents with intellectual disability in their dealings with the system and the need for a strong advocate was evident in the responses from the RPOs. The power imbalance reached outside meetings and into venues supposedly designed to support and teach the parents. Logn described an instance where a mother had been placed at a residential parenting unit to observe her when taking care of her child and to teach proper childcare skills:

> *The workers were supposed to be the professionals […] and there she was [a mother with ID] asking for painkillers for her baby, who cried and cried because of an ear infection. They didn't believe her when she asked for medicine for an ear infection. They just said "No" and refused to give the baby something for the pain. It wasn't until I called them and said: "Listen! Now you're going to give her paracetamol". It really needed the third party to call right before midnight and tell them. They didn't believe the mother, even though the baby was crying with a high fever. Being far away, I had no idea if the baby had this infection, but I believed the mother. And as it turned out, she was right. This is happening in the year 2022!* [emphasis added].

Getting results in an environment imbued with such power imbalances, as the RPO experienced, sometimes required them to be very strategic in how they approached each case and, at times, put on a tactically changing "cloak of power". Rökkur said:

> *How big do I need to be at today's meeting? Should I be the good Rökkur who gets people to play in my team, or do I need to be the tough Rökkur with all the rules and regulations laid out on the table? I really need to prepare for how I will appear at the meeting.*

All the RPOs talked, in one way or another, about the importance of "taking space" in meetings that involved child protection and support services. That simply meant that they were not afraid of being critical of the services that were being implemented or work that had taken place in each case. That included, for example, asking critical questions and investigating if all appropriate support had been tried.

> *As soon as we step inside, the power structure changes drastically. We ask questions, ones that the parents have asked but have gotten no answers to […] "How does that work? And who is supposed to do that? Who's responsible for that to happen? Are you doing counselling? Support? or is this surveillance? and what are the differences?"* (Rökkur).

The RPOs felt that by showing presence and asking demanding or critical questions had multiple effects on the work that was being done by the workers, one of which was to create more time. Slowing down the process not only gave the parents more time to act but seemingly also gave the child protection workers the opportunity to reflect on their own work and identify other service options.

> *It is all too common in child protection cases that for the sake of the child's interests it is necessary to intervene quickly, but action is taken without particularly thinking it through, without demonstrating proportionality, but when there is pressure [from the RPOs] to perform of high quality and justify actions, more space for the process is created* (Ariel).

Logn had a similar experience:

> *When I ask challenging questions, it makes way for different views of the case and new ideas to come forward, and it also changes how fast the child protection workers are able to work their cases.*

By questioning the system instead of only the parents, the focus sometimes shifted, and the responsibility for the welfare of the family was not placed solely upon the parents but upon the system as well.

4.2 Lack of Knowledge

One role of the rights protection officers is to educate the parents on what their rights are and what kinds of support they are entitled to, but another appears to be educating workers within the system itself. It is difficult to understand how the rights of disabled parents can be respected within the child protection system if this knowledge is not in place, which was one issue that was repeatedly raised by the RPOs. Júlí, a former child protection committee member, spoke to this:

> *The committee is supposed to ensure that the work in a case was done properly. But the reality is that there was no expertise within the committee, the members just said "yes" to what the child protection workers proposed. When I was appointed to the committee, there were no requirements for knowing human rights or disability rights […] I got no information or education when I started. The people who also sat on the committee had no specialized knowledge or knowledge of trauma or anything similar […] and we got no education about the CRPD […] so there was no factual discussion there. So it's very easy for child protection to drive their decisions forward when parents have little or no support.*

An RPO, Regn, felt that this knowledge was not entirely absent, but certainly lacking:

> *Knowledge about the rights of disabled people, the CRPD, or laws like 38/2018 within child protection just isn't there. Sure, there are workers here and there who have the knowledge, and I've met those workers, and I just love them, and I really push to get them involved on the case [. . .] but knowledge in general, no! [emphasis added].*

The RPOs interviewed also felt that the protections afforded to disabled parents in the Convention and the domestic legislation are "weak" due to the lack of knowledge and understanding of those documents in the judicial system, leaving judges in custody deprivation cases pertaining to disabled parents "insecure". The judges' insecurities and lack of knowledge of disability rights were argued by some of the RPOs to be the reason why they rely so heavily on the information provided by child protection and their paid experts (e.g. psychologists) when they make their decisions. Ariel stated: "There is little awareness about human rights and certainly not disability rights and what they entail in the judicial and child protection system". This lack of knowledge was considered to have an impact on the process of each case and works against the possibility for parents with intellectual disability to be treated fairly by the system. Ariel continued:

> *Parents [with intellectual disability] who go to court with their case don't stand a chance [. . .] There is a tremendous lack of knowledge within the judicial system on the Convention, on law 38/2018, and a lack of understanding about basic concepts like "disability", "parenting capacity", they don't have a clue about what "reasonable accommodation" entails, there is lack of understanding on how psychological assessments are done so these psychologists can do what they want without any rationale [. . .] judges seem to believe that disabled people all live in institutions and are not people that can run a home and have a family [. . .] it can be extremely difficult to fight this.*

As Ariel suggested, sometimes the issue is not a lack of knowledge, as in knowledge that is not acquired, but countering the "knowledge" that is already held in place, such as prejudice and stigma toward disabled people and their capabilities. Another related theme that emerged from the data is the tendency, as some officers noticed, for workers within the social services system to equate "equality" solely with gender or LGBT+ issues, while overlooking disability. Alex interpreted this as linked to Iceland's reputation for equality in this area, and which is officially embraced by the state, yet which often overshadows issues connected to disability and which makes it difficult for their work to be recognised or valued in the same way:

> *Heaps of people within the government ministries attend seminars about the rights of gay people, LGBTQ people, women's rights; they go to the women's conferences and support international policy pertaining to equality strategies and gender equality in Iceland, but that is not the case when it comes to the rights of disabled people, there is absolutely no [emphasis added] interest! There is no interest within the government to secure that training in this area that is in accordance with international policy-making [. . .] and we can also talk about the Office of Equality, they have no knowledge about the affairs of disabled people, or due process or reasonable accommodation. Nonetheless that's the institution that oversees all equality affairs in Iceland, but the focus is all on gender equality.*

The lack of knowledge also appears to result in deference to the experts hired by child protection, such as psychologists who conduct parenting capacity or custody assessments. The RPOs indicated that the assessments produced by these hired experts appear to be accepted by the courts without question and which play a significant role in custody deprivation cases. Some of the RPOs expressed how the opinions of psychologists become almost incontestable in a courtroom setting, especially if their opinions align with the desired outcome on behalf of child protection. The view of how the courts "rubber stamp" the narrative put forward by child protection workers was expressed and Rökkur's comments reveal how parents with intellectual disability have indeed very little access to justice when it comes to disputing the claims of child protection authorities:

> *We have taken a case to the court where a specialist in disability (on our client's behalf) testified, saying that proper support was not provided and that did not change anything [. . .] because in my experience it is very rare for judges to be critical about the treatment of a case in child protection or go against what child protection is proposing.*

The RPOs have also stressed that the views of the psychologists working on behalf of child protection, and the child protection staff themselves, are trusted and respected by the judges while in the process downplaying the views of the parents and their lawyers. This creates a mutually reinforcing and legitimising triumvirate between the psychologists, child protection staff, and judges, which makes it very difficult for counter-arguments to be heard and considered. While we do not dispute the RPOs' experiences and contentions, which we have experienced elsewhere and noted in the literature, this must be tempered by the indications, as offered in Section 4.1, that the very presence of RPOs can alter the power relations of the situation. Whether their presence is powerful enough to alter the outcomes is a question for further research, though the authors have experience with cases where the early intervention of advocates has done so (see, e.g. Rice et al., 2021; Stefánsdóttir et al., 2023). However, the crucial point here is how this lack of knowledge would be even more profound if not for the presence of rights protection officers who act as a critically important counter-balance of support in these cases.

4.3 Systemic Apathy

The finding framed as *Systemic apathy* runs the risk of appearing overly dramatic or possibly being misunderstood, but this is what emerged from the analysis of the interview data even though the RPOs did not use this term specifically. "Apathy" appears to be a fitting description for some of the findings from the data, as will be discussed. However, we are extending the term apathy slightly in order to avoid the simplistic assumption that child protection workers or judges are uninterested in their work or that they intentionally act in unprofessional ways. Rather this form of apathy, we suggest, can be linked to factors as discussed in the previous section in which "equality" is associated only with gender issues, or the societal-level assumptions about disability or disabled parents result in little interest or energy to think

critically about equality work in the disability arena. According to the interview data, some of the RPOs perceived this apathy in the system as rooted in the larger society and culture, a further analysis of which is beyond the scope of this contribution. But for the purposes here, the officers note that these forms of apathy appear to stretch from higher governing systems, such as state ministries, which distribute funding and draft and enact laws and regulations affecting disabled people's lives, down to managers and then workers in the service systems, such as child protection and social services. The RPOs, when talking about basic requirements on the governmental level, argued that knowing about and understanding the CRPD ought to be a must. Yet a significant amount of work on the part of the officers involves fighting this apathy, such as through attempts at awareness-raising about these issues or simply getting officials to listen. Alex heatedly explained:

> *Since the Convention was signed in 2007 and ratified in 2016, no one [emphasis added] from the Ministry, no one, [emphasis added] except us, the rights protection officers, and people from NGOs, have attended special seminars about the rights of disabled people and the Convention.*

The lack of interest in disability justice often complicated the work of the RPOs and essential time and efforts were spent in the basic education of people in the government about how the Convention needed to be translated into support and services. One RPO, Regn, interpreted this apathy as rooted in the misconception that the issue is merely about service provision:

> *The trouble with the government is that they don't know if the Act [38/2018] is service-based or rights-based [. . .] knowledge about the Convention, and how it should be used, implemented and translated into Icelandic laws, is very limited, and we spend time educating about that.*

Alex admitted that this becomes tiring, and which introduces a form of apathy into their own work:

> *When I started, I used to write letters that were like these big reports because I was trying to educate the Parliamentary Ombudsman about the Convention and what it meant, and where they could find supplementary material and such things, but with time I don't do it as much. Now I just refer to previous writings.*

According to the data, the disability apathy noted in the systems described above also appeared to seep into the systems of workers who directly work with those parents and even those whose role is to support the parents. Some of the interviewees described mixed feelings about their work that involved being in a relationship or contact with child protection workers, mostly because of the general lack of understanding of the needs of parents with intellectual disability and their resulting frustrations.

4.4 Challenging the Informal

The last theme speaks to an issue raised by the rights protection officers that another challenge they faced was that the system was too informal in how it operated. The demand that a governmental agency function in a more "bureaucratic" way was not

expected by us. The RPOs framed the issue as one of "transparency" and which spoke to their frustrations that the decision-making process by child protection was opaque to both them and the parents, and which made it difficult to critique and challenge. This also extended to a demand by the RPOs to make the process understandable to the parents they supported, such as insisting that accommodations were made to fit the parent's needs in the form of written documents such as Easy-to-read documents, having all decisions documented, and having no documents signed without proper explanations about the consequences of doing so.

From the point of view of the interviewees, in these kinds of child protection cases the goalposts, in a manner of speaking, often appeared unclear and shifting, and it was uncertain to them how decisions were made, by whom, and when. This was interpreted by some interviewees not as a lack of professionalism, but by design. For example, some of the RPOs speculated that minutes of meetings are often not taken for purposeful reasons; that is to say, properly recorded meeting minutes would reveal a process that child protection may not want to be held up for inspection. The importance of formality came up in the interviews repeatedly. One of the key roles of the RPOs is to ensure that parents with intellectual disability receive fair treatment in the process. Alex described a common issue they face with their clients, including parents with intellectual disability, when asking for appropriate support as stated in the CRPD and Icelandic laws such as 38/2018:

> *It is very common that people just get a no [emphasis added] when applying for a service, but there is no formal procedure, there is no inquiry that takes place, there is no evaluation that takes place, there is no formal conclusion; this is somehow taken care of verbally with a no, [emphasis added] so we are asking for it to be formal, so there is a least some rationale behind the rejection, not just "there is no money available".*

In safeguarding the parents' rights, most of the RPOs favoured a formal process in order to get results. And even though their job required them, for the most part, to use formal pathways to achieve their objectives, some said there was a "push" in the system to use informal ways. However, despite sometimes trying the informal method, it usually did not produce results and being formal was considered to be far more successful than an "office chat" with the people working in the system. For the RPOs, formalities were seen as a reassurance that every case had a defined pathway to justice and would not be forgotten about or put in a drawer somewhere.

> *Being formal, for example, in writing letters secures a certain pathway […] It's always popular to solve things in a conversation or through a phone call […] but we have found out that it's more beneficial to have everything formal and direct each case down this formal pathway, even if it takes longer and we are drowning the Ombudsman and social services complaints board in work* (Norður).

Some of the RPOs' reluctance to be informal and instead opting for formality seemed to reflect mistrust towards the service system, especially child protection, as they wanted every meeting and decision noted and written down in case they would need to refer to it later:

> *Many of our cases are about getting support needs evaluated and putting things in a formal pathway [. . .] It can't be some chit-chat at the office or a chat with the parents; we want cases put in formal pathways so we can then support the parents if there is a need to send in a formal complaint or a charge* (Logn).

One would assume that a certain degree of formality is demanded in child protection work for their working methods and decisions to be trusted, so it was initially a surprise to some RPOs to encounter resistance to formal documentation of the process. Demanding that meeting minutes would be recorded for all meetings, and conclusions and decisions be formalised, was seen as essential to better inform the parents of the process that was being undertaken and what could be expected. Some of the RPOs experienced that the formality they brought with their presence and demands was, in some instances, unpopular and even seen as intimidating by some of the child protection workers who seemed to have difficulties with having their meetings and conclusions written up and available for parents and their rights protection officers to read.

> *Fortunately, things are changing, but the way it has been is that as soon as we arrive at the meeting, we are the most disliked people in that room [. . .] we always demand that meeting minutes are written up [. . .] child protection thinks that's uncomfortable because they want to discuss something that they don't want to be written down. They don't want to stand by the decisions they are about to make. It's very different when there is a rights protection officers in the case, then it becomes formal; when the parent is there on their own, people talk differently* (Norður).

Based on their experiences, the RPOs argued that to ensure that the parents' rights are respected the system needs to be as fair and open as possible through a rigorous documentation of the process.

5. Discussion

This contribution has explored the role of Icelandic RPOs for disabled persons primarily focusing on the context of supporting and safeguarding the rights of parents with intellectual disability in their encounters with the child protection system. We have argued that the creation of this office is linked to a paradigm shift (Degener, 2016) in how disabled people are viewed and treated by the social services as well as the larger society, from being perceived as patients or the objects of charity to equal members of society and rights-bearing individuals who should enjoy the same human rights as others. However, as argued earlier, the ideology contained within the United Nations Convention on the Rights of Persons with Disabilities, and which has influenced domestic Icelandic legislation, needs to transition into practice. One role of the RPOs is to do just that. We have adapted the institutional justice capital framework from Hamilton and Maslen (2022) to analyse the interview data to explore how the RPOs serve as a resource or form of capital for disabled parents who have found themselves the focus of a child protection investigation.

Acting as a form of capital in terms of personal resilience and skills, the RPOs have articulated how they help to educate parents about their rights and entitlements, and

help them to navigate a complex, and often hostile, system. They provide knowledge about how the system works, and what to expect, and which is particularly important in the context of marginalised populations who may have limited access to the forms of capital that more powerful and privileged sectors of society can draw upon. As a resource, the RPOs do more than just provide information. As discussed earlier, their mere presence can alter the power relations in the setting of meetings in which the views and voices of the parents are amplified and taken more seriously than would otherwise be the case.

Of equal significance, the work of the rights protection officers is not just directed to the parents, but at the system itself. Alerting power relations means affecting the working methods of the child protection system, such as through demanding formalism in the process in which meetings and decisions are documented and justified to ensure the parents are treated fairly and their rights are respected. The work of the RPOs also seems to extend educating the workers in the system and even members of the judiciary in what disability rights means, as well as more technical concepts such as reasonable accommodation. The interview data also reveals the resistance that RPOs encounter in their work, from workers being displeased at having to document the process in a more extensive way to the general apathy they encounter from child protection workers and judges who are disinterested or unwilling to educate themselves about disability rights, the CRPD, and in specific what appropriate and meaningful supports mean for parents with intellectual disability. It appears from the data that rights protection officers wear many hats, in a manner of speaking than just acting as a support or advocate for these parents.

5.1. Limitations

In this research, the experiences of parents with intellectual disability regarding the work of the RPOs were not sought as the focus of this specific arc of a larger research project was on the experiences of the RPOs. In continuing research, it will be important to investigate the experiences of parents of the support the RPOs provide and whether they consider it to be helpful or not. If such is the case, and some preliminary indications suggest this is so, this can be used to strengthen the argument about the importance of this office and the need to strengthen their role and resources.

6. Conclusion

The themes we have presented here overlap in many ways. There is a notable trickle-down or cascade effect in which prejudicial or stigmatic views of disabled people in general, and parents with intellectual disability in specific, in the larger society influences the upper reaches of government at the policy and funding level, down to the judiciary, to the social services and into the meetings between parents with intellectual disability, child protection and the rights protection officers. The officers have articulated how these views explain some of the systemic apathy they encounter in their work, which in turn plays a role in the lack of knowledge as judges and workers in the system have little interest in acquiring the knowledge they need. Parents with

intellectual disability are perceived in the system as incompetent and even harmful parents from the outset, and which influences how cases are treated and evidence is collected and analysed. Judges, as members of the larger society, in turn defer to child protection and the knowledge of their hired experts. Article 8 of the CRPD (Awareness-raising) places a demand upon State Parties to combat stereotypes and prejudice. However, while the RPOs do indeed engage in this kind of work, and which clearly needs to be done, their limited numbers and resources and large caseloads suggest that this role needs to be taken up to a greater extent by the state and municipalities so RPOs can better support the disabled people with whom they work. Supporting parents and their families, educating themselves about disability law and human rights, educating the social services system and the judiciary and in addition to dealing with the resistance they encounter is in sum an unreasonable burden upon the exiting officers unless their numbers and resources are increased.

Further, the theme of resistance on the part of the system needs additional consideration. The RPOs appear to have at times been placed into an adversarial position contra the child protection system. All three authors have experienced similarities in different ways. This needs not to be the case. All parties involved want the same or similar outcomes – strengthened families and happy and safe environments for children. The interview data suggests that the core issue is the divide between those who do not believe that parents with intellectual disability can be suitable parents, and those who believe they can, with the proper support in place. This fundamental divide appears to drive the outcomes of cases in varied ways. A careful consideration of the interview data reveals numerous other issues at work – for example the resistance RPOs encountered to formalising the process. However, if early in the case, it is decided that parents are "unsuitable" based on disability, then it makes sense to resist demands to make the process transparent. Again, we return to the issue of societal-level prejudice which also speaks to the other issues raised by the RPOs, from a lack of interest in knowledge about disability rights, what reasonable accommodations means and demands as well as appropriate and meaningful support, to the judicial deference to child protection and their hired experts, among others. However, to expect the RPOs to continually engage in challenging societal-level views about parents with intellectual disability or disabled people in general is a significant expenditure of time and resources.

The human rights protections contained within the CRPD, and which have undoubtedly influenced legislation in different ways within its member states, are simply not enough. We argue for the importance of specialised rights protection mechanisms for disabled people as an accessible part of the justice system. Parents with intellectual disability are at a particular risk for unjust processes once involved in the child protection system, and therefore it should be a standardised practice to make the support of rights protection officers available as soon as involvement is initiated.

Gerard Quinn (2009, 256) has claimed that the CRPD has the potential to be used as a powerful tool to persuade and socialise states to "transform the political process to the point that justice and rights for persons with disabilities is seen as the

primary departure point and not as an annoying distraction". Though we are not there yet, rights protection officers are important actors in changing how the government and institutions think about and respond to disabled people and their rights. The RPOs are, in a sense, activists and collectively act as change agents in the interplay between the disabled people they support and the service system in which they engage. The Office of Rights Protection gives them an additional layer of influence within the system for acting upon violations of the rights of disabled people. It is vital that such mechanism functions as an independent agency and is supported on the governmental level to ensure that the rights of disabled people will eventually be seen as a primary departure point in the process.

Competing Interests

The authors have no competing interests to declare.

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6 Summary of Findings and Discussion

In this chapter the findings reported in three peer reviewed articles will be presented and discussed. The three articles are focused on support and services for parents with intellectual disabilities in the context of human rights of disabled people. In each article, a specific view is offered to contribute to a holistic insight into how parents with intellectual disabilities are supported in Iceland and the pathways for just and appropriate support according to the human rights agreements Iceland are part of. Together, the insights derived from the articles provide a more expansive and nuanced understanding of the research questions than each article would individually. Furthermore, the research explores the broader implications for human rights, support services, policy and access to justice.

Article I seeks to understand if and how the values of the CRPD have translated into services and supports for parents with intellectual disabilities. The findings delineate two primary categories: barriers that hinder the integration of CRPD values into practice, and practices that represent positive steps towards aligning with the goals of the CRPD. Practices that were identified as barriers to the translation of the CRPD were linked to neglect of the family context, inappropriate measures, organizational collaboration issues and culture and emphasis on short term support. The other main category identified pathways forward. Positive practices reflected holistic approach, long term support and help to navigate the system and collaborate within it. The findings suggest that practices that align with the goals of the CRPD does so not because of the convention but rather because of progressive workers illuminating the need for policy making in Iceland in the field of parenting with intellectual disabilities.

Article II is a detailed case study that delves into the struggles faced by a couple with intellectual disabilities and the 'tools' they utilize to keep child protection at a distance while examining the influence of the evolving disability rights landscape on these persistent conflicts. The article reports on the three key categories identified. The first is "Lessons learned", which pertains to the insights and understanding the parents have gained throughout their lives. The second category, "Allies: The family", underscores the critical role played by a solid family support system in the couple's life. The third category is "Secret weapons", a term the couple used to describe a network of advocates and professionals they strategically engaged as necessary. The adoption of new tools available to the couple are noted, such as human rights protections, reinforced by the CRPD, in the form of rights protection officers for disabled people. The study emphasizes the importance of a hybrid support system that includes formal

services, family involvement, and advocacy, cautioning against the privatization of social services and highlighting the need for sustained government support.

In article III the focus shifts from parenting support primarily on an institutional and individual level to a focus on support in the form of rights protection on systemic level. The article reports on the experiences of rights protection officers for disabled people (RPOs) in Iceland, as they support parents with intellectual disabilities who are involved in child protection. The role of RPOs is analyzed within the context of a disability human rights framework and the institutional justice capital perspective to understand how they serve as a valuable resource for parents. Four key themes were identified. The first, "Altering power relations", focus directly on how the RPOs support the parents in exercising their rights and on the form of justice capital they provide. The remaining themes, "Lack of knowledge", "Systemic apathy" and "Challenging the informal" explore the systemic barriers the RPOs experience when performing their work. Based on the findings it is contended that widespread discrimination against parents with intellectual disabilities, spanning from governmental policies to everyday interactions within the child protection system, shapes these dynamics and impacts outcomes. The efforts of RPOs in supporting marginalized parents, promoting awareness of disability rights, and combating prejudice are crucial. The article stresses the importance of RPOs within the justice system and recommendation for enhancing mechanisms to uphold international human rights are made.

Collectively, the findings presented in these articles highlight some of the barriers people with intellectual disabilities face as parents, such as inappropriate support services, prejudges, and limited knowledge about their rights within the systems they are, indirectly or directly, involved with. The findings also illuminate how positive developments in the Icelandic human rights landscape, such as in the form of the CRPD and new domestic laws, are still not effective enough to provide these families with appropriate support and protection of their rights for family life. Other Icelandic studies on services for disabled people show similar results (Löve et al., 2018; Rice at al., 2015). Löve et al. (2018) concludes that there is still a long way to go before the goals of the CRPD will be met in Iceland. They argue that if services are to be reflected in the goals enshrined in the CRPD the concept of service need to be redefined and include full inclusion and participation of disabled people. Additionally, it should aim to end unequal power relations and paternalistic attitudes which encompasses services for disabled people.

Furthermore, the findings suggest a necessity for a development of comprehensive policies and guidelines at both systemic and organizational level. According to Powell et al. (2024) the way parents with intellectual disabilities can access appropriate support is largely dependent on the characteristics of the agency providing the support. These characteristics influence what kind, along with the quality and scale, of services are available, which in turn are likely to affect case outcomes. However, agency

characteristics do not just emerge but are inevitably affected by policy (Staub-Bernasconi, 2016). Subsequently, without a clear policy regarding services for parents with intellectual disabilities in family and child welfare work, there is considerable risk of practice that is arbitrary, performed in an inconsistent manner, lacking evidence-based foundation and focused on deficiencies (Laliberte, 2013, Laliberte et al., 2024). Disinterest in and limited knowledge about disability and disability rights exacerbates the lack of policy. There is a critical need to address this deficiency across all systems to ensure that parents with intellectual disabilities receive equitable and consistent support that respects their rights and family integrity.

Overall, the research contributes to a better understanding of the complex challenges faced by parents with intellectual disabilities in Iceland, highlighting the critical role of support networks, advocates, rights protection and policy and legal frameworks in promoting parental rights and family unity.

7 Conclusion

In this last chapter, I will discuss the dissertation's contribution to the field of parenting with intellectual disabilities considering its main aims and the question it was set out to answer. As previously introduced, the overall aims of the research were to explore and understand the support and services available to parents with intellectual disabilities in Iceland in the developing disability and human rights context. Furthermore, the aim is to understand what kind of barriers and resistance advocates and supporters experience in their attempt to claim justice and fair treatment of parents with intellectual disabilities. The study also set out to provide parents with intellectual disabilities a space to tell their story to inform other parents, advocates, and professionals involved in their lives. Based on the research it is evident that there are significant challenges faced by parents with intellectual disabilities in Iceland in terms of receiving appropriate support in the performance of the parenting role.

In my study I have sought to illuminate specific features of support and services parents with intellectual disabilities in Iceland receive. I have also tried to identify service gaps and opportunities for improvement in the support systems to uphold the rights of these parents to lead family lives. Such opportunities have been identified in the hybrid support provided by family, progressive workers and advocates. Furthermore, this study has brought to attention the role of rights protection officers for disabled people (RPOs) who play a crucial role in transforming how governments and institutions perceive, learn about and respond to the rights of disabled individuals. Acting as both advocates and change agents, RPOs engage with the disabled community they support while navigating the service systems that support them. This dual role positions them uniquely to influence both policy and practice. There is some uncertainty, as of the time of writing, as to the future of this office given the numerous challenges they face, such as underfunding and employee burnout. It is crucial that this office and their mission be supported and strengthened if Iceland has any chance of meeting the obligations of the CRPD in this area.

Despite the fact that CRPD has undoubtedly influenced Icelandic legislation, such as with the creation of the Office of rights protection for disabled people, it has not yet led to anticipated paradigm shift within the society so that disabled parents are viewed and treated as rightsholders and human rights subjects. Iceland is still to legalize the convention and only time can tell how such actions can further contribute to developments that support parents with intellectual disabilities. Rather, it seems that the disinterest and lack of knowledge about disability and disability rights encompass much of governance and extend through institutions and support systems. Such apathy allows

old prejudicial or stigmatic attitudes toward parents with intellectual disabilities to thrive which permeate society, influencing government policies and funding decisions, judicial proceedings, social services, and interactions between parents with intellectual disabilities, social services, and child protection. Empowering parents through advocacy, altering power relations, and enhancing mechanisms to uphold human rights are crucial steps in addressing the systemic challenges identified in the research. Parents should be listened to, and their needs respected, but it is also crucial that they are included in the development and implementation of support services for parents with intellectual disabilities.

Finally, the adversarial nature of the relationship between parents with intellectual disabilities and child protection authorities suggest a need for a more collaborative and rights-based approach. The importance of a robust, multifaceted support system is underscored, highlighting the important role of formal services, family support, advocacy and rights protection in maintaining family unity. This research stresses the need for appropriate and effective support that is tailored, long-term and holistic. Furthermore, the support needs to be informed by a nuanced understanding of systemic challenges, personal experiences, and strategic advocacy within the child protection system.

7.1 Concluding Remarks

The research calls for policy changes to ensure that parents with intellectual disabilities are supported in a manner that respects their rights and promotes the well-being of their families. There is an obvious need for a paradigm shift from a deficiency and charity approach to the adoption of a rights-based approach that acknowledges the role of parents with intellectual disabilities and seeks to support, rather than undermine, family integrity. For these changes to occur there is simultaneously an urgency to address systemic issues, such as lack of knowledge and systemic apathy, regarding disability, within the system. Based on current knowledge, access to justice is pivotal for parents with intellectual disabilities and the need for enhancing the capacity and authority of RPOs to effectively advocate for the parents and ensuring that child protection and judicial systems are informed about disability rights and appropriate support mechanisms is crucial for ensuring their rights as stated in the CRPD and domestic law. Strengthening support systems on all levels is possible by including parents in service development, ensuring continued governmental support and funding of mechanisms that enable equitable treatment of parents with intellectual disabilities, such as training, education, and accessible support.

By addressing the identified issues and implementing recommendations, there is potential to improve outcomes for families led by parents with intellectual disabilities in Iceland.

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Appendix A - Icelandic

Viðtalsrammi vegna viðtala við starfsfólk stuðningsþjónustu

(Gera grein fyrir tilgangi rannsóknar, fara yfir upplýst samþykki, ítreka nafnleynd og trúnað)

Almennar spurningar - bakgrunnur

- Getur þú byrjað á því að segja mér frá þér, s.s. aldri, menntun?
- Getur þú sagt mér frá þínu starfi eða þínu hlutverki hér innanhúss?

Starf með seinfærum foreldrum

- Segðu mér frá reynslu þinni af því að starfa með seinfærum foreldrum?
- Getur þú sagt mér hvað þér finnst mikilvægast í starfi þínu með seinfærum foreldrum?
- Hvernig er best hægt að styðja seinfæra foreldra?
- Ef þú hugsar um eina fjölskyldu þar sem foreldrar eru seinfærir, getur þú sagt mér frá hvernig vinnur?
- Getur þú sagt mér hvernig stuðningsþarfir eru metnar?
- Getur þú sagt mér frá samvinnu þinni og foreldranna?
    - Hvað finnst þér ganga vel?
    - Hvað finnst þér ekki ganga nógu vel?
- Segðu mér frá hvernig þú teljir að þjónusta þín hafi áhrif á fjölskylduna
    - Jákvæð áhrif
    - Neikvæð áhrif
- Geturðu sagt mér frá ef það er ákveðin hugmyndafræði sem stýrir starfinu þínu með seinfærum foreldrum?

Samstarf innan og utan húss

- Getur þú sagt mér frá samvinnunni hér innan húss og við aðra í sambandi við þessa foreldra?
- Barnavernd
- Félagsþjónusta
- Heilsugæslu
- Skólakerfið
- Annað

- Er eitthvað sem þú vilt koma á framfæri að lokum?

Athugasemdir:

Appendix A - English

Interview framework for interviews with support workers

(Explain the purpose of the study, review informed consent, and reiterate anonymity and confidentiality)

General questions

- Can you start by telling me about yourself, e.g. age, education…?
- Can you tell me about your job or your role in the agency?

Work with parents with intellectual disability

- Can you tell me about your experience working with parents with ID?
- Can you tell me what you find most important in your work with parents with ID?
- How can parents with ID be best supported?
- If you can think of one family led by parents with ID, can you tell me how you carry out your work?
- Can you tell me how support needs are assessed?
- Can you tell me about your cooperation with the parents?
    - what's going well?
    - what is not going well enough?
- Can you think about how the service you provide impacts the family?
    - Positive influence
    - Negative effects
- Can you tell me if there is a particular theoretical approach that guides your work with parents with ID?

Cooperation within institution and outside

- Can you tell me about the cooperation, both within the agency and outside it, in relation to these parents?
- Child protection
- Social services
- Healthcare
- The school system
- Other agencies or systems
- Is there anything you would like to conclude with?

Comments/Notes:

Appendix B - Icelandic

Viðtalsrammi vegna viðtala við foreldra

(Kynna mig, segja frá tilgangi rannsóknarinnar, fara yfir upplýst samþykki, ítreka nafnleynd og trúnað og fá leyfi til að taka viðtal upp.)

Bakgrunnur viðmælanda

- Getur þú sagt mér aðeins frá sjálfri þér, t.d.
    - Hvað ertu gömul/gamall?
    - Hvar áttu heima?
    - Ertu að vinna eða í námi?
- Getur þú sagt mér svolítið frá fjölskyldunni þinni?
    - Hvað þú átt mörg börn og hvað eru þau gömul?
    - Ertu í sambandi eða ertu einstæð?
    - Systkini eða foreldrar, amma eða afi?

Daglegt líf og stuðningur

- Getur þú sagt mér frá venjulegum degi hjá þér og börnunum?
- Hvernig er venjulegur morgunn hjá þér?
- Ef þú ferð út, hvert ferðu til dæmis?
- Hittir þú annað fólk? Geturðu nefnt dæmi?
- Getur þú t.d. lýst gærdeginum?
- Hvað finnst þér mikilvægast í lífinu?
- Getur þú sagt mér frá hvernig það er að vera mamma/pabbi?
- Er eitthvað sérstakt sem þú þarf hjálp við?
- Finnst þér þú hafa fengið þá hjálp sem þú hefur þurft á að halda til að hugsa um börnin þín?
- Geturðu gefið mér dæmi um slíka hjálp?
- Getur þú sagt mér hvað eða hver hefur hjálpað þér mest í móðurhlutverkinu/ föðurhlutverkinu?
    - T.d. fjölskylda, vinir, félagsþjónustan, barnavernd, nágrannar, aðrar mömmur...
- Hvaða hefur þér fundist erfiðast við að vera foreldri?

Reynsla af stuðningi

- Er einhver sérlega góð reynsla sem tengist þínum fjölskyldustuðningi sem þú vilt segja frá?
- Er einhver slæm reynsla sem tengist þínum fjölskyldustuðningi sem þú vilt segja frá? (T.d. einhverntímann á síðustu árum komið illa fram við þig eða skilið þig útundan vegna þinnar fötlunar? t.d. þú ekki fengið að vera á mikilvægum fundi eða tekið þátt í mikilvægum ákvörðunum?)
- Gerist þetta oft eða gerðist þetta bara einu sinni?
- Er eitthvað fleira sem þú vilt segja mér varðandi þetta atvik?

Reisn / Dignity (Að vera kurteis, að hlusta, að gefa tíma, að þekka foreldrið, huga að tilfinningum, virða einkalíf/svæði/tilfinningar)

- Finnst þér að þeir sem styðja ykkur gefa ykkur nægan tíma? Dæmi?
- Finnst þér þeir sem styðja ykkur hlusta á ykkur?
- Finnst þér stuðningsaðilar virða heimilið ykkar og einkalíf?

Sjálfræði / Autonomy

- Finnst þér þú geta stjórnað hvernig stuðning þú færð sem móðir/faðir?
    - Getur þú sagt hvernig þú hefur stjórn/eða ekki? (hver kemur, hversu lengi, hversu oft, á hvaða tíma, hvað er aðstoðað við?)
    - Hefur þú verið spurð hvernig stuðning þið viljið?
- Hefur verið tekið mark á ykkar vilja og stuðningur aðlagaður að ykkar vilja?
    - Hvernig þá?
- Hefur þú fengið nógu góðar upplýsingar til að geta tekið ákvörðun um hvernig þjónustu þið viljið?
    - Ef Já, hvernig upplýsingar fékkstu?
    - Ef ekki, veistu af hverju?
- Hefur þú verið þvinguð/þvingaður til að þiggja þjónustu/stuðning?
    - Ef já, geturðu sagt mér frá því? (t.d. hvernig leið þér?)

Þátttaka, aðild og aðgengi / Participation, Inclusion & Accessibility

- Hefur þú fengið hjálp/stuðning frá einhverjum í bænum? (vinum, nágrönnum, fólki sem býr í bænum)
    - Getur þú sagt mér hvernig þá? Hvað gerðu þeir?
- Hefur þú verið skilin útundan eða útilokuð þegar það er verið að ákveða stuðning/þjónustu fyrir þig og fjölskylduna?
    - Hvernig þá?
- Finnst þér þú þurfa stuðning til þess að geta tekið þátt með öðrum foreldrum í viðburðum/ athöfnum sem tengjast foreldrahlutverkinu?
    - Geturðu sagt mér frá því?

Jafnræði og jafnrétti

- Heldur þú að það sé komið fram við þig á sama hátt og ófatlaða foreldra sem þurfa stuðning við að hugsa um börn sín?
- Heldur þú að fólk komi örðuvísi fram við þig en aðra af því að þú ert seinfær?
    - Hvernig þá?

- Finnst þér stuðningurinn hafa breyst á síðustu árum?
    - Hvernig þá?
- Hvernig væri hægt að bæta stuðning við seinfæra foreldra?
- Er eitthvað fleira sem þú vilt segja frá?

Athugasemdir:

Appendix B - English

Interview guide for interviews with parents

(Introduce myself, state the purpose of the study, review informed consent, reiterate anonymity and confidentiality, and obtain permission to record the interview).

Background questions

- Can you tell me a little bit about yourself?
    - How old are you?
    - Where do you live?
    - Are you working or studying?
- Can you tell me about your family?
    - How many children do you have and how old are they?
    - Are you in a relationship or are you single?
    - Siblings or parents, grandparents?

Daily life and support

- Can you tell me about a normal day for you and your kids?
    - How's your typical morning?
    - If you go outside, where do you go as an example?
    - Do you meet other people? Can you give an example?
    - Can you describe yesterday?
- What do you think is most important in life?
- Can you tell me what it's like to be a mom?
- Is there anything in particular you need help with?
- Do you feel like you've had the help you've needed to take care of your children?
    - Can you give me an example of that kind of help?
- Can you tell me what or who has helped you the most in motherhood/fatherhood?
    - e.g. family, friends, social services, child welfare, neighbors, other moms...
- What have you found most difficult to deal with as a parent?

Support experience

- Are there any particularly good experiences related to your family support that you would like to share?
- Are there any bad experiences related to your family support that you would like to share? (Have you been treated badly or left out because of your disability? e.g. you didn't get to attend an important meeting or participate in important decisions?)
    - Does this happen often, or did it only happen once?
    - Is there anything else you want to tell me about this incident?

Dignity (Being polite, listening, giving enough time, knowing the parent, mindful of feelings, respecting privacy/area/feelings)

- Do you think those who support you are giving you enough time? Example?
    - Can you tell me about that?
- Do you feel that those who support you are listening to you?
    - Can you tell me about that?
- Do you think sponsors respect your home and privacy?
    - Can you tell me about that?

Autonomy

- Do you feel you can have influence/control of what kind of support you receive as a mother/father?
- Can you tell me how you are in control or not? (Who comes, for how long, how often, at what time, what is assisted with?)
    - Have you been asked what kind of support you want?
- Are your needs respected and support adapted to your preferences?
    - Can you tell me how?
- Have you been given good enough information to be able to make a decision about what kind of service you want?
    - If Yes, what kind of information did you get?
    - If not, you know why?
- Have you been coerced into accepting services/support?
    - If yes, can you tell me about it? (e.g. how did you feel?)

Participation, Inclusion & Accessibility

- Have you had any help/support from anyone in town? (friends, neighbors, people who live in town)
    - Can you tell me how? What did they do?
- Have you been left out or excluded when deciding about support/service for you and your family?
    - How's that?
- Do you feel that you need support to participate with other parents in events/activities related to parenting?
    - Can you tell me about that?

Non-Discrimination & Equality

- Do you think you are treated the same way as non-disabled parents who need support with taking care of their children?
    - If so, who do think that is?
- Do you think people treat you differently than others because of the intellectual disability?
    - How's that?

- Do you think your support has changed in the last few years?
    - How's that?
- How could support for parents with intellectual disability be improved?

- Is there anything else you want to share?

Comments/Notes:

Appendix C - Icelandic

Viðtalsrammi vegna viðtala við stuðningsaðila Önnu og Tómasar

(Kynna mig, tilgang rannsóknar, fara yfir upplýst samþykki, ítreka nafnleynd og trúnað, leyfi til að taka viðtal upp).

- Getur þú sagt mér aðeins frá sjálfri þér (aldur, fyrri störf, reynslu, tengslum við Önnu og Tómas)
- Geturðu sagt mér hvert þitt helsta hlutverk er gagnvart fjölskyldunni?
- Hvað heldur þú að sé mikilvægast varðandi stuðning fyrir fjölskylduna?
- Hvað telur þú að hafi verið hjálplegast eða gagnast best fyrir fjölskylduna?
- Getur þú sagt mér frá því sem þú telur að hafi verið óhjálplegt eða skaðlegt fyrir fjölskylduna?
- Geturðu sagt mér frá helstu styrkleikum eða bjargráðum Önnu og Tómasar?
    - Persónulegir styrkleikar
    - Styrkleikar í umhverfinu (fjölskylda, þjónusta, vinir, réttindi)

- Hvað finnst þér hafa heppnast sérstaklega vel varðandi þann stuðning sem þau fá frá þér eða ykkur?
    - Hvað finnst þér ekki hafa heppnast eins vel?
- Er eitthvað að lokum sem þú vilt að komi fram?

Athugasemdir:

Appendix C - English

Interview guide for interviews with Anna and Tómas's supporters

(Introduce myself, describe the purpose of the study, review informed consent, reiterate anonymity and confidentiality, and obtain permission to record the interview).

- Can you tell me about yourself (age, work, former work experience, relationship with Anna and Tómas)
- Can you tell me what your main role is in relation to the family?
- What do you think is most important in relation to support for the family?
- Can you tell me what you consider to be most helpful or useful for the family?
- Can you tell me about what you think was unhelpful or harmful to the family?
- Can you tell me about Anna and Tómas' main strengths or coping strategies?
    - Personal strengths
    - Strengths in the environment (family, services, friends, rights)
- Can you tell me about what you consider particularly successful regarding the support they receive from you?
- Can you tell me about what you consider unsuccessful in relation to the support you have provided?
- Is there anything you would like to say in conclusion?

Comments/Notes:

Appendix D - Icelandic

Viðtalsrammi vegna viðtala við réttindagæslumenn fyrir fatlað fólk

(Kynna mig, tilgang rannsóknar, fara yfir upplýst samþykki, ítreka nafnleynd og trúnað, fá leyfi til að taka viðtal upp).

Almennt

- Hvað hefurðu starfað lengi sem réttindagæslumaður f. fatlað fólk?
- Geturðu sagt mér í hverju starfið þitt felst?
- Er samstarf milli ykkar sem starfið í réttindagæslu?
- Finnst þér þú geta verið óháður/sjálfstæður í störfum þínum sem réttindagæslumaður?
- Er einhver sérstakur hópur sem leitar til þín umfram aðra?

Réttindi foreldra (málsvari/talsmaður/lagalegur stuðningur)

- Geturðu sagt mér frá þinni reynslu af því að vinna með seinfærum foreldrum?
- Þegar þú vinnur með seinfærum foreldrum um hvað snýst það oftast (t.d. stuðning, vanrækslu, ofbeldi)?
- Hvernig kemur þú inn í slík mál, hver kallar þig til, og á hvaða stigi?
- Telur þú að seinfærir foreldra hafi aðgengi að réttlæti til jafns á við aðra foreldra?
    - Hvernig þá?
- Telur þú að seinfærir foreldrar njóti réttinda sinna þegar mál eru komin til barnaverndar? Er t.d. farið eftir verklagsreglum varðandi seinfæra foreldra?
- Telurðu að Sáttmáli sameinuðu þjóðanna um réttindi fatlaðs fólks hafi áhrif á stuðning eða málsmeðferð seinfærra foreldra innan barnaverndar?
    - Hefur þú beitt honum í máli?
- Telur þú að lög um þjónustu við fólk með langvarandi stuðningsþarfir frá 2018 hafi breytt einhverju fyrir þennan hóp foreldra?
    - Hefur þú beitt þeim í máli?
- Hefur þú fengið einhverja þjálfun í að styðja við foreldra sem eiga í tengslum við barnavernd?
    - Er þörf á slíkri þjálfun?

Virðingarík tengsl (Samvinna, samráð)

- Hvernig finnst þér komið fram við seinfæra foreldra innan barnaverndarkerfisins eða annara kerfa sem koma að börnum þeirra?
- Hvernig myndir þú lýsa samstarfi þessara kerfa við seinfæra foreldra?
- Hver er þín reynsla að samstarfi milli kerfa í málum er varða seinfæra foreldra?

Samskipti án ofbeldis (Traustleiki og gegnsæi)

- Hver er reynsla þín af gegnsæi hjá barnavernd? (ákvarðanataka varðandi t.d. stuðning, eftirlit, fóstrun, réttur til að hitta börn (ef börn eru í fóstri)

- Hver er þín reynsla af upplýsingagjöf til foreldra eða til þín frá barnavernd, t.d. sem snerta ákvarðanatöku eða ferlis sem framundan er?
- Er eitthvað ákveðið ferli sem þú ferð eftir þegar þú vinnur mál sem eru í barnavernd?
- Hefur þú tekið þátt í að andmæla ákvörðunum eða tillögum sem barnavernd setur fram í máli seinfærra foreldra? Nánar
- Hverjar telur þú helstu hindranir sem seinfærir foreldrar mæta varðandi tækifæri til að hugsa um börn sín?
- Er eitthvað að lokum sem þú vilt segja frá?

Athugasemdir:

Appendix D - English

Interview guide for interviews with rights protection officers for disabled people

(Introduce myself, the purpose of the study, review informed consent, reiterate anonymity and confidentiality, and obtain permission to record the interview).

General

- How long have you worked as a rights protection officer for disabled people?
- Can you tell me what your job entails?
- Is there a partnership between rights protection officers?
- Do you feel you can be independent in your work as a rights protection officer?
- Is there a particular group that seeks your support more than anyone else?

Parental rights (legal representation, advocacy)

- Can you tell me about your experience working with parents with intellectual disability?
- When you work with parents with intellectual disability, what is it most often about (e.g. support, neglect, violence)?
- How do you get involved, who notifies you, and at what point?
- Do you believe that parents with intellectual disability have access to justice equal to other parents?
    - Can you tell me more?
- Do you believe that parents with intellectual disability enjoy their rights when cases have reached child protection? For example, are there any special procedures for parents with intellectual disability?
- Do you believe that the United Nations Convention on the Rights of Persons with Disabilities (CRPD) affects support or procedures for parents with intellectual disability involved in child protection?
    - Have you applied CRPD in a case?
- Do you think the Services for People with Long-Term Support Needs Act of 2018 has changed anything for this group of parents?
    - Have you applied the act in a case?
- Have you received any training for supporting parents who are involved with child protection?
    - Is such training required?

Respectful relationships (collaboration, consultation)

- In your experience, how are parents with intellectual disability treated within the child protection system or other systems involved in their children's lives?
- How would you describe the partnership between these systems and parents with intellectual disability?
- What is your experience of collaboration between systems in cases pertaining to parents with intellectual disability?

Non-violence (Accountability, transparency)

- What is your experience of transparency at Child Protection? (decision-making on e.g. support, supervision, fostering, right to see children (if children are in foster care)
- What is your experience of information provision from child protection to parents or you, e.g. concerning decision-making or the process ahead?
- Is there a specific process you follow when you work on cases that are in child protection?
- Have you participated in objecting to decisions or proposals put forward by the Child Protection Authority in the case of parents with intellectual disability? Details?
- What do you consider the main obstacles parents with intellectual disability face regarding opportunities to take care of their children?
- Finally, is there anything you want to share in the end?

Comments/Notes: