# Disabled Children, Families and Services in Iceland

Bridging the Gap Between Theory and Practice

**Jóna Guðbjörg Ingólfsdóttir**

Thesis for the degree of PhD
in Disability Studies

September 2023

## School of Social Sciences

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# Ágrip

Þrátt fyrir yfirlýst markmið íslenska velferðarkerfisins um að veita fjölskyldum fatlaðra barna fjölskyldumiðaða þjónustu í samræmi við þarfir þeirra og óskir greina foreldrar oft frá því að þjónustan sé sundurleit, dreifð og fremur veitt á forsendum þjónustuveitenda en þjónustunotenda. Kenningar um fjölskyldumiðaða þjónustu kalla á heildræna nálgun þar sem athyglinni er beint að fjölskyldunni í heild en ekki einungis því barni eða einstaklingi sem í hlut á. Í samræmi við það eru þjónustuveitendur og þjónustunotendur hvattir til samstarfs og sameiginlegrar ákvarðanatöku um framkvæmd þjónustunnar. Heildarmarkmið þessarar doktorsrannsóknar var að öðlast betri skilning á misræminu milli opinberrar stefnu velferðarkerfisins og reynslu fjölskyldna fatlaðra barna af þjónustunni. Megináhersla var lögð á að fanga skoðanir og óskir foreldra fatlaðra barna en einnig var rýnt í hlutverk, viðhorf og starfsumhverfi fagaðila sem veita fötluðum börnum og fjölskyldum þeirra stuðning og þjónustu.

Rannsóknin er á sviði fötlunarfræða og fræðileg nálgun einkennist af samþættingu nokkurra tengdra fræðikenninga. Fyrst ber að nefna félagslegan og mannréttindamiðaðan skilning á fötlun sem hefur þróast innan fötlunarfræða á undanförnum áratugum og er sá skilningur sem samningur Sameinuðu þjóðanna um réttindi fatlaðs fólks byggir á. Félagsfræði barnæskunnar gegnir einnig mikilvægu hlutverki en hún leggur grunninn að barnasáttmála Sameinuðu þjóðanna, fyrstu bindandi alþjóðalögunum sem fjalla ítarlega um mannréttindi barna, þar með talið fatlaðra barna. Aðrar fræðilegar undirstöður rannsóknarinnar eru fjölskyldumiðaðar kenningar sem leggja áherslu á heildræna sýn og samstarf á milli þjónustuaðila og fjölskyldna um sameiginleg markmið og framkvæmd þjónustunnar. Að lokum er stuðst við þriðju kynslóð menningarsögulegrar starfsemiskenningar (CHAT) og starfsþróunaraðferðir sem byggja á samvinnu, sameiginlegum skilningi og námi þvert á faggreinar og skipulagsheildir.

Aðferðafræðin sem valin var fyrir rannsóknina er eigindleg tilviksrannsókn en markmið tilviksrannsókna er að lýsa og veita skilning á afmörkuðum fyrirbærum í lífi fólks. Eitt eða fleiri tilvik eru skoðuð og leitast við að nálgast verkefnið frá mismunandi sjónarhornum til að fá sem gleggsta mynd af tilvikinu. Rannsóknin sem hér um ræðir samanstendur af þremur tilviksrannsóknum sem gerðar voru í þremur ólíkum sveitarfélögum á Íslandi og myndaði hvert sveitarfélag eitt tilvik. Í hverju tilviki voru fötluð börn á leikskólaaldri, fjölskyldur þeirra og þjónustuteymi. Tekin voru ítarleg viðtöl við foreldra níu barna og 11 fagmenn úr mismunandi faggreinum sem störfuðu innan eða í tengslum við leikskóla barnanna. Einnig voru tekin rýnihópaviðtöl í hverju sveitarfélagi við fagfólk sem starfaði utan leikskólanna ásamt því sem opinber

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þjónustugögn voru rýnd og þátttökuathuganir gerðar innan leikskóla barnanna. Þessi fjölbreyttu gögn voru greind og túlkuð með hliðsjón af grunngildum fjölskyldumiðaðrar þjónustu, félagslegri og réttindamiðaðri tengslasýn á fötlun og menningarsögulegri starfsemiskenningu.

Niðurstöður rannsóknarinnar leiddu í ljós mikið samræmi á milli tilvikanna þriggja þar sem breytileiki byggðist fremur á reynslu einstakra fjölskyldna en landfræðilegri staðsetningu eða tegund sveitarfélags. Á heildina litið hrósuðu foreldrarnir leikskóla barna sinna fyrir að taka vel á móti börnunum og fyrir hlýleg og góð samskipti en töldu jafnframt að önnur þjónusta væri sundurleit, ósveigjanleg og íþyngjandi. Þjálfun og meðferð utan leikskólans var álitin óaðgengileg og ótengd daglegu lífi bæði barna og foreldra. Niðurstöðurnar benda jafnframt til að þjónustan stjórnist af ríkjandi læknisfræðilegri sýn á fötlun, þröngum fjárhagslegum ramma og að ýmis hagnýt sjónarmið þjónustuveitenda ráði för fremur en yfirlýst velferðarstefna eða grunngildi fjölskyldumiðaðrar þjónustu. Með hliðsjón af niðurstöðum rannsóknarinnar sem og fræðilegum grunni hennar, lýkur ritgerðinni á því að settar eru fram nokkrar leiðbeinandi hugmyndir um nauðsynlegar umbætur.

# Abstract

Despite the avowed aims of Icelandic welfare policies to provide services in a family-centred manner, parents commonly express their experiences of fragmented services that are offered more on the terms of the service providers than the families. Theories on family-centred approaches call for services to be planned around the whole family, not just an individual child or person, and the family unit is recognised as the service user. Accordingly, the service providers and the family are urged to collaborate when making informed decisions about the support and services needed. The overall aim of this study has been to gain a better understanding of the discrepancies reported in the literature between the welfare policy on providing comprehensive and flexible services and the lived experiences of families raising disabled children. In particular, the dissertation endeavours to capture the views and wishes of families with disabled children while examining the roles, attitudes, and working environments of the professionals who provide services to disabled children and their families.

The study was conducted within the field of disability studies and combines a number of intersecting theoretical approaches. The first is a socio-relational and human rights understanding of disability developed by disability and legal scholars over the past decades, which is at the core of the UN Convention on the Rights of Persons with Disabilities (CRPD). The study is also grounded in social childhood studies emphasising children's rights and the UN Convention on the Rights of the Child (CRC), the first binding international law to comprehensively address the human rights of children, including disabled children. Other central theoretical foundations of the study are family-centred theories, which emphasise collaboration and partnership between the service providers and the family on goals and implementation of services. Finally, the study is informed by the third generation of cultural-historical activity theory (CHAT) and relational practices, which focus on interprofessional and interorganisational collaboration and learning.

A qualitative case study was chosen for this research because it provides an opportunity to contribute to the knowledge and understanding of individual, group, organisational, social, and related matters. The research consisted of three case studies located in three different municipalities in Iceland. Each case included disabled preschool children, their families, and the entire service team for each child. In accordance with the case study approach, a variety of methods were employed to gain a comprehensive view of each case. The data gathering involved in-depth interviews with the families of nine children and with 11 professionals from diverse disciplines who worked within or in relation to the preschools. Focus group interviews with professionals working outside

the preschool were conducted in each municipality along with document review and participant observations. The data were analysed and interpreted using theoretical guidance from family-centred, socio-relational, and rights-based views on disability and cultural-historical activity theory.

The findings reveal a high level of convergence between the cases with variations based on experiences of individual families rather than geographical location or type of municipality. Overall, the parents praised the preschools for welcoming their children and for good interpersonal relationships but reported that other services are fragmented, inflexible, and burdensome. Therapy services were consistently regarded as hardly reachable and disconnected from the daily routine of both children and parents. The findings furthermore indicate services governed by prevailing medical notions of disability, financial restraints, and practical considerations rather than the ideals in welfare policies or family-centred practice. Drawing on the study findings and theoretical foundations, the thesis concludes by proposing some ideas for much needed reforms.

# Acknowledgements

# Contents

# List of Abbreviations

CDC   Counselling and Diagnostic Centre
CHAT  Cultural-Historical Activity Theory
CRC   The UN Convention on the Rights of the Child
CRPD  The UN Convention on the Rights of Persons with Disabilities
EI    Early Intervention
FCEI  Family-Centred Early Intervention
FCS   Family-Centred Services
IHI   Icelandic Health Insurance

# List of Figures

# List of Tables

# List of Original Articles

I.    Ingólfsdóttir, J. G., Traustadóttir, R., Egilson, S. T., & Goodley, D. (2012). Thinking relationally: Disability, families and cultural-historical activity theory. *Barn*, *4*, 13-24. https://doi.org/10.5324/barn.v30i4.4122

II.   Ingólfsdóttir, J. G., Egilson, S. T., & Traustadottir, R. (2017). Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice. *Journal of Intellectual Disabilities*, *22*(4), 361-377. https://doi.org/10.1177/1744629517714644

III.  Ingólfsdóttir, J. G., Jóhannsdóttir, Th., & Traustadóttir, R. (2018). Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland. *Nordisk Välfärdsforskning| Nordic Welfare Research*, *3*(1), 33-46. https://doi.org/10.18261/issn.2464-4161-2018-01-04

IV.   Ingólfsdóttir, J. G., Traustadóttir, R., & Egilson, S. T. (2021). Rethinking practices by rethinking expertise: A relational approach to family-centred inclusive services. *Scandinavian Journal of Disability Research*, *23*(1), 1-13. http://doi.org/10.16993/sjdr.734

# Declaration of Contribution

Overall conceptualisation and design of the research: JGI, RT, SÞE.

Data collection and lead role in data analysis: JGI.

Defining the analytical direction and theoretical context: JGI, RT, SÞE.

Writing JGI.

Editing and supervision of writing: JGI, RT, SÞE.

In paper I, DG took part in conceptualisation and editing.

In paper III, Th J. contributed to theoretical conceptualisation and writing.

# 1  Introduction

Supporting families of young disabled children has been one of my main interests for a long time. When I embarked on my doctoral studies, I had the opportunity to investigate the situation of families with young disabled children and how their needs are being met by the service system. Despite the overall aims of Icelandic welfare and educational legislation to provide flexible, adapted, and inclusive services, families of young disabled children commonly express their experiences of fragmented and hard-to-reach services, provided more on the terms of the system than the families. The mismatch between the policy aims and the lived experiences of the families is the impetus behind this study.

## 1.1  Purpose and Aims

The research on which this thesis is based was conducted within the field of disability studies to explore welfare services aimed at young disabled children and their families in Iceland. The aims were (1) to gain a better understanding of the discrepancies reported in the literature between the welfare policy on providing comprehensive and flexible services and the experiences reported by families of disabled children; (2) to capture the views and experiences of the families of disabled children; (3) to examine the roles, perspectives and working environments of professionals providing services to disabled children and their families; and (4) to put forward ideas for changes in service delivery based on the findings.

To address these aims, a qualitative theory-led multiple case study (Creswell, 2008; Simons, 2009) was undertaken, guided by family-centred theory (Bamm & Rosenbaum, 2008; Dunst, 2002; Espe-Sherwindt, 2008; Rosenbaum et al. 1998). Emphasis was placed on a human rights perspective for disabled children as reflected in the Convention on the Rights of Persons with Disabilities (CRPD) (2007) and the Convention on the Rights of the Child (CRC) (1989). Theoretical approaches included a socio-relational view on disability (Thomas, 2004; Tøssebro, 2004; Shakespeare, 2006, 2013) and Engeström's (2001, 2016) and Edwards' (2017, 2020) cultural-historical approach to expansive learning and relational practices, which guided and informed the development of ideas for change. In accordance with the multi-case study approach (Simons, 2009), a variety of methods were employed to gain a comprehensive view of each case. The data gathering involved in-depth interviews, focus group interviews, document review, and participant observations.

The case studies were carried out in three different municipalities in Iceland where each municipality constituted a case. The participating families, all raising a disabled child or children, were selected by local counsellors in each municipality and were

comprised of families with varying numbers of siblings in the family, the parents' level of education, and socio-economic status. All the children lived with both parents or a parent and a stepparent. The children were three to seven years of age when the study took place, and all had attended preschool from the age of two.

The findings are presented in four published peer-reviewed journal articles. The first of these, entitled Thinking relationally: Disability, families and cultural-historical activity theory, was published in the journal *Barn* [*Child*] in January 2012 by the Norwegian Centre for Child Research. This article presents the study's three main theoretical approaches to disability, services, and organisational and professional development and highlights their interrelated components.

The second article, Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice, was published by *Journal of Intellectual Disabilities* in June 2017. This article outlines the discrepancies between the aims of the welfare services in Iceland and the experiences of parents raising young disabled children. Prevailing views on disability and service delivery are also considered.



**Figure 1:** Overview of the research process

The third article, Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland, was published in *Nordisk Välfärdsforskning| Nordic Welfare Research* in June 2018. This article explores the commonly expressed contradictions between policy ideals and the services as enacted in practice and proposes practical solutions.

The fourth article, Rethinking practices by rethinking expertise: A relational approach to family-centred inclusive services, was published by the *Scandinavian Journal of Disability Research* in January 2021. It introduces the perspectives of in-service professionals and how they view their working conditions. Furthermore, recommendations for service development were made based on Edwards' relational concepts. An overview of the research process is displayed in Figure 1.

## 1.2  Background and Positionality

Throughout the last decades, there has been a growing body of research and writings on the shift in the ideological paradigm around disability. Disability has emerged as a socio-political category through the activism of the international disabled people's movement, which has led to a new understanding of impairment and disability (Barton, 2018; Goodley, 2011; Traustadóttir, 2009; Tregaskis, 2002). The actions of organisations for disabled people, associated scholars, and researchers have influenced policies and legislation, including those aimed at families raising disabled children, to focus on holistic approaches such as family-centred services (Bjarnason, 2010; Ferguson, 2001; Goodley, 2011; Hodge & Runswick-Cole, 2008; Hopwood & Edwards, 2017; Hopwood & Mäkitalo, 2019; McCarthy & Guerin, 2022).

The impetus of my research is rooted in my decades long interest, education, and work experience in social pedagogy, special education, and early childhood services and as a university adjunct lecturer in this field since 2003. Furthermore, my experience as a special education consultant for preschools in one of the local service centres in Reykjavík gave me insight into the services provided in the capital area, which encouraged me to investigate this topic.

Prior to entering academia, I worked for 13 years in a team of professionals as an early childhood interventionist, counsellor, and supporter for disabled children from birth to six and their families. At that time, an increased awareness of the significance of a more holistic approach in services for disabled children and their families was emerging. The close relationship I had with parents during that time, especially with mothers, has been an inspiration to me ever since. Witnessing their resilience in dealing with the system, adapting to ever changing circumstances, and working for the benefit of their children while fulfilling their own duties on the labour market became a source of motivation for embarking on this research journey. There have been major changes in the views and policies regarding disabled children and adults since the beginning of my career. First getting acquainted with the concept of a family-centred

approach (Dunst, 2002; Rosenbaum et al., 1998) and later with the change regarding a new social conception of disability (Traustadóttir 2006, 2009) and the rights-based requirements articulated in the CRPD (2007) had a strong impact on me.

### 1.2.1 Theoretical Perspectives

This research was carried out within disability studies, an academic discipline that emerged in the 1980s and 1990s. It is a multidisciplinary field that has a broad and diverse base in the practical experiences of disabled people and in academic fields such as history, sociology, gender studies, cultural studies, literary theory, law, public policy, and ethics (Ferguson & Nusbaum, 2012; Goodley, 2011; Traustadóttir, 2006, 2009). This broad base enables different disciplines and individual experiences to merge and endeavours to change the understanding of disability and work towards disability rights and justice (Connors & Stalker, 2007; Goodley, 2011; Goodley et al., 2019; Traustadóttir, 2009). A good case in point is Ytterhus et al. (2015, p. 20), where they focus on disability and childhood in the Nordic countries, highlighting how disability studies directs attention to the social, cultural, economic, and political aspects of disability and examines how the social environment and cultural images create and recreate disability instead of understanding disability as an individual problem.

In line with the multidisciplinary approach of disability studies, my research is grounded in interrelated human-rights treaties and theories (Ingólfsdóttir et al. 2012). Firstly, there is the CRPD (2007) and the socio-relational and human rights understanding of disability reflected in the Convention. Secondly, the CRC (1989), the first binding instrument in international law to comprehensively address the human rights of children. The CRC is notable for article 23, which is specifically concerned with the rights of disabled children (Committee on the Rights of the Child, 2006; UNICEF Innocenti Research Centre, 2007).

The theoretical approaches of the research include foundational principles of family-centred services, such as a holistic view of child and family and emphasising partnership and the family's role in decision-making concerning their affairs (Brown & Remine, 2008; Bruder & Dunst, 2014; Dunst & Espe-Sherwindt, 2016; Espe-Sherwindt, 2008; Law et al., 2003; Matthews et al., 2021). Other important approaches informing this study are the third generation of cultural-historical activity theory (CHAT) and relational practices which emphasises interprofessional and interorganisational collaboration and learning as a method to develop services that can incorporate multiple perspectives and voices (Edwards, 2017, 2020; Engeström, 2001, 2016).

These human rights and theoretical approaches will be addressed in more detail in Chapter 2. All the fundamental perspectives that underlie this study share a social-relational and rights-based essence and an emphasis on understanding phenomena in their cultural, historical, social, and political contexts. In line with my theoretical perspectives, the terms disabled children and disabled people are used throughout this

thesis to signify that disability arises in the interaction between persons with impairments and their environments. Children with impairments may indeed have considerable abilities. Although they may be disabled, they do not have disabilities.

## 1.3 The Icelandic Context

To understand the context of the thesis, the characteristics of Icelandic society and the welfare and education systems must be considered. Iceland lies withing the Nordic region and is one of the most sparsely populated countries in Europe, with approximately 385,000 inhabitants (Statistics Iceland, 2022). Two-thirds of the population live in the capital of Reykjavík and the surrounding areas. According to the World Bank, women's participation in the labour force is higher in Iceland than anywhere else in the world (Viðskiptablaðið, 2021). Unlike many other countries, 95-97% of all children, including disabled children, in Iceland attend a full day preschool from an early age, although this is not compulsory (Broström et al., 2018). Despite the uneven distribution of the population in the country, the service and educational role of preschools is considered important in all communities.

The Ministry of Education and Children handles national inclusive school policies and monitors the performance of the education system. Preschools, primary schools, and lower secondary schools are funded and administered by municipalities. High schools are funded and administered by the state. The preschools are defined by law as the first school level, providing education for children up to six years of age, when compulsory education begins (Preschool Act no. 90/2008). Preschool authorities (the municipalities) are obligated to provide special services as needed (Reglugerð um sérfræðiþjónustu sveitarfélaga við leik- og grunnskóla og nemendaverndarráð í grunnskólum [Regulation on municipal school services at pre-schools and compulsory schools and student protection councils in compulsory schools], no. 444/2019). The Ministry of Education and Children formulates the education policy and publishes the Icelandic national curriculum guide for preschools (The Icelandic national curriculum guide for preschools, 2011).

There are no special preschools or segregated units within regular preschools for disabled children. Disabled children also have priority over non-disabled children in being admitted off waiting lists. In the last decades, there has been increasing emphasis on an early intervention approach in preschools in Iceland, highlighting the importance to intervene in a child's developmental process with special education or therapies as soon as learning difficulties or a deviation from the typical development process become apparent (Sérkennslustefna leikskólasviðs Reykjavíkurborgar [Special education policy of the Preschool Division of Reykjavík City], 2009).

The responsibility for most disability services was transferred from the state to the municipalities in 2011 (Velferðarráðuneytið [Ministry of Welfare], 2010). The aim of this decentralisation was to create more cohesive services offered closer to the users

(Lög um breytingu á lögum no. 59/1992, um málefni fatlaðra, með síðari breytingum [Act amending Act no. 59/1992, on disability issues, with subsequent amendments], no. 152/2010). Since then, education and social services are provided at the same level of government, but local health services, including children's therapies, are governed by the state according to laws and regulations thereon. Thus, disabled children who are referred to physio and occupational therapy or speech and language therapy must predominantly rely on services provided at private or semi-private clinics that are detached from the preschools and operate within another administrative system than the school. To be eligible for specialised, or third level, services, children must have an approved diagnosis from authorised organisations (Lög um samþættingu þjónustu í þágu farsældar barna [Act on the integration of services in favour of children's wellbeing], no. 86/2021).

The Counselling and Diagnostic Centre (CDC) plays a significant role in the system described above as a governmental institution serving children and adolescents from birth to 18 years of age and their families from all over the country. A preliminary evaluation is required for admission, and when admitted, each child is evaluated by a multidisciplinary team that works towards a consensus on the child's condition and prognosis (Lög um Ráðgjafar og greiningarstöð [Law on the Counselling and Diagnostic Centre], no. 83/2003). The needs of the child and family for special assistance are defined, counselling is offered, and necessary referrals are made. In the sequel of the evaluation process, the Icelandic Health Insurance (IHI) plays a pivotal role in the lives of many families with disabled children as a governmental organisation which regulates the financing of the services provided by the state (Sjúkratryggingar Íslands [Icelandic Health Insurance], n.d.).

## 1.4  Structure of the Thesis

This thesis consists of six chapters. Following the introduction, Chapter 2 outlines the theoretical foundations for the study. Relevant theories, concepts, and treaties are presented with a particular emphasis on the socio-relational understanding of disability. It also introduces family-centred theory and cultural-historical activity theory. The third chapter contains a review of the research literature that informed the study. The focus is on research addressing services for disabled children and their families and on professional practices. Chapter 4 describes the methodology guiding this study, introduces the qualitative case study approach, and provides detailed information on research methods, participants, data, and analysis. Chapter 5 consists of the four peer-reviewed journal articles presenting the findings of the study. Chapter 6 is the final chapter and provides some recommendations for practices followed by a few concluding remarks.

# 2 Theoretical Foundations

This chapter provides an overview of the theories and concepts that inform the study. It begins with an overview of different views and understandings of disability. The chapter highlights the changes called for in disability studies and the role played by the CRPD and the CRC in creating a human rights approach to disability and childhood. Family-centred theory and cultural-historical activity theory are introduced along with how their principles informed and guided the analysis and interpretation of the data.

## 2.1 Conceptualising Disability

How disabled people are perceived and treated is largely dependent on how disability is understood or interpreted (Altman, 2001; Traustadóttir, 2006; 2009). For the past 40 years or so, diverse models of disability have featured prominently in shaping disability politics, disability studies, and human rights for disabled people. These understandings are still evolving (Dempsey & Nankervis, 2006; Goodley, 2011; Goodley et al., 2019; Lawson & Beckett, 2021; Oliver, 2018; Shakespeare, 2013, Traustadóttir, 2009). An important aspect of my study was to examine which understandings of disability were dominant within the welfare system and how these may inform the design and implementation of services.

### 2.1.1 The Medical Understanding of Disability

The central position of medical knowledge, language, and power in the disability field has been the primary reason for the struggle on how to understand and define disability in new ways, particularly from the 1970s onwards (Grue, 2016; Traustadóttir, 2006, 2009). The way in which disability is understood is important and the language people use to describe disabled individuals influences expectations and interactions with them. According to the medical understanding of disability, managing illness or disability revolves around identifying the illness or disability from an in-depth clinical perspective where the medical profession's responsibility and potential to cure, treat, and care are seen as central (Friedman & Owen, 2017). Because of its focus upon individuals, the medical understanding has led to stereotyping and defining people by a condition or limitations that are often considered to be a personal tragedy (Barnes & Mercer, 2010; Oliver 2018). Gretar L. Marinósson & Kristín Þ. Magnúsdóttir (2016) draw attention to various forms and purposes of child assessment and argue that the aim of making specific diagnosis criteria a precondition for services results in more children getting medical labels than necessary.

This demonstrates how the mechanics of the welfare state are highly dependent on the clinical-medical discourses and ways of thinking that consequently maintain the dominant medical understanding of disability within disability policy, professionalism, and service provision. Many disabled people and researchers within the scope of disability studies are striving to change the rhetoric and the way disability is perceived (Grue, 2011).

### 2.1.2  The Social Understanding of Disability

In an endeavour to move from the narrow, medical view on disability to a wider societal view, a variety of social approaches has been developed. The conceptualisation of disability that evolved in the 1970s in the British disabled people's movement (Barnes et al., 1999; Campbell & Oliver, 2013; UPIAS, 1976) moved the focus from the individual and impairment to the environment and the impact of social, political, and economic arrangements (Campbell, 2009; Ytterhus et al., 2015). This understanding of disability emphasises society's disabling barriers and is often referred to as the British social model of disability or the strong social model (Shakespeare, 2006). However, as the term 'social model' is often used without an accompanying explanation of exactly which social understanding of disability it refers to, there are significant inconsistencies in its articulation and usage (Barnes, 2012; Lawson & Beckett, 2021).

Shakespeare (2006, 2013) argues that the understanding reflected in the strong social model which focuses solely on societal barriers as the cause of disability has become an obstacle to the further development of the disability movement and disability studies and suggests looking at disability as an interaction between the individual and structural factors. This social-relational understanding of disability has been dominant within Nordic disability studies. Tøssebro (2004) emphasises disability as emerging in the interplay between the person and their societal surroundings.

This relational understanding resonates in the preamble of the CRPD (2007), where disability is described as 'the result of the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others' (para e.).

### 2.1.3  The Human Rights Understanding of Disability

The CRPD (2007) was created on the basis of the social-relational understanding of disability with an additional emphasis on equality and human rights principles. (Jackson, 2018; Lawson & Beckett, 2021). It recognises that impairment is a part of human diversity that must be respected and supported in all its forms, stressing that disabled people have the same rights as everyone else in society (Degener, 2016). Degener (2016) emphasises how the human rights understanding of disability embraces impairment as a condition which might reduce the quality of life, but which belongs to humanity and must be valued as part of human variation. Moreover, she draws attention

to how human rights value different layers of identity and acknowledge intersectional discrimination.

The UN Committee on the Rights of Persons with Disabilities (2016) (the CRPD Committee) now refers to the human rights understanding when monitoring the efforts of State parties to implement the CRPD (Lawson & Beckett, 2021). Combined with the social-relational view on disability, the human rights approach is now widely regarded as an improvement and an important asset to support the implementation of the CRPD (Jackson, 2018).

### 2.1.4 The UN Convention on the Rights of Persons with Disabilities

The CRPD is an international human rights treaty that was opened for signature in March 2007 and demands a change in disability policy, based on the notion that persons with disabilities are human rights subjects (Degener, 2016; Lawson & Beckett, 2021). The Convention brings together all basic human rights for disabled people in one place and describes how ratifying governments should implement it. Löve et al. (2018) and Lawson and Beckett (2021) highlight how the processes called for by the CRPD represent a new way of making disability policy and can act as a unifying force if the rights and the power it contains are used in a strategic way in policy making.

In the CRPD, Article 7 is dedicated to disabled children, guides the application of the rights found in that convention, and acts as a bridge between the CRPD and the CRC. Article 7 affirms that 'States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children'. The CRPD was ratified by the Icelandic government in 2016. This is reflected in the 2018 Act on services for disabled people with long term service needs (Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir [Act on services to disabled people with long term service needs], no. 85/2018), which has incorporated the goals and requirements of the CRPD along with the understanding of disability as stated in the Convention.

The right to education addressed in the CRPD's Article 24 includes the right of disabled people to inclusive education and prescribes the steps that must be taken to this end. It states that disabled children should not be discriminated against and that they should be able to participate in the general education system, which has been a statutory right for disabled children in Iceland since the current law on preschools came into force in 2008.

According to the CRPD Committee's General Comment no. 4 on the right to inclusive education (Committee on the Rights of Persons with Disabilities, 2016), inclusion involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches and structures. Furthermore, the CRPD requires strategies in education to overcome barriers with the vision to provide all students of


changed attitude toward children. These principles are *non-discrimination*, *best interest of the child children*, *the right to survival and development* and *the views of the child*. As articulated in the CRC Committee's definition (Committee on the Rights of the Child, 2011), the child rights approach requires a paradigm shift away from approaches in which children are perceived and treated as objects in need of assistance rather than as rights-holders entitled to non-negotiable rights. The four principles mentioned above are based on the notion that children are equal human beings and contribute to a general attitude towards children and their rights. Moreover, they add an ethical and ideological dimension to the convention.

The first principle is that all children should enjoy their rights and should never be subjected to any discrimination. The second is that the best interest of the child shall be a primary consideration in all actions concerning children whether undertaken by public or private social welfare institution, courts of law, administrative authorities, or legislative bodies. The third principle is that state parties shall ensure, as far as possible, the survival and development of the child. The fourth stipulates that state parties shall assure that the child who can form his or her own views the right to express those views freely in all matters affecting the child. The view of the child should be given due weight in accordance with the age and maturity of the child (Committee on the Rights of the Child, 2009).

The CRC was the first human rights convention to contain an article dedicated to disability. Young children, not the least disabled children, are vulnerable and dependent on adults for basic needs such as food, health care and education. The Committee on the Rights of the Child (2006) notes that disabled children still experience serious difficulties and face barriers to the full enjoyment of the rights enshrined in the CRC. The Committee emphasises that the barrier is not the disability itself but a combination of social, cultural, attitudinal, and physical obstacles that disabled children encounter in their daily lives. The strategy for promoting their rights is to take the necessary action to remove those barriers. Article 3 in the CRC (1989) states, as highlighted in the second principle of the CRC, that all official decisions or actions concerning children shall be based on what is in the best interests of the child.

Even though children did not participate in my study, the ideas about children's rights guided the entire research process. The CRPD and CRC have encouraged me and guided my research questions and the focus of the study.

## 2.1.6  The Social Understanding of Childhood

In accordance with the provisions of the CRC, there has been a major development in the sociology of childhood in the past decades (Colver, 2007; James et al., 1998; Wickenden, 2019). These changes involve a movement from perceiving childhood as a transitional state preparing for adulthood to recognising childhood as 'a variable of social analysis, along with other categories such as class, gender, ethnicity and

disability' (Colver, 2007, p. 502). Reconceptualising childhood in this way results in researchers showing increased interest in conducting research with children instead of about them to get insight into their own conceptions of their experiences and opinions (Curran & Runswick-Cole, 2014; Kirk, 2007; Wickenden, 2019).

Although there is an increasing awareness of the right for children to participate in everyday life activities and decision making, there is evidence of a lack of conceptual clarity and operationalisation of the meaning of participation (Egilson et al., 2021; Franklin & Sloper, 2009; Ruiz-Casares et al., 2016). Moreover, disabled children are even less likely to be involved in decision making and participation activities than non-disabled children, and knowledge of the experiences of disabled children of engagement and sense of belonging is still lacking (Egilson & Hemmingson, 2009; Egilson et al., 2021; Fleming et al., 2011; Franklin & Sloper, 2009). However, increased awareness has affected studies exploring the lives of disabled children, resulting in a growing appreciation of their scope to define and articulate who they are, what they value, and who they wish to become (Connors & Stalker, 2007; Curran & Runswick-Cole, 2014; Egilson et al., 2021; Franklin & Sloper, 2009; Goodley & McLaughlin, 2008; Traustadóttir et al., 2015).

The future agenda for disabled children's childhood studies is on listening to disabled children in ways that recognise their hopes and aspirations. Franklin and Sloper (2009) refer to Article 13 of the CRC which grants children the right to receive information and express all kinds of ideas in a variety of forms which is reiterated in Article 21 in the CRPD. In the field of childhood studies, this view has been developed further as reflected when Wickenden (2019) suggests reimagining disabled children within childhood studies by thinking about childhood through relational ontologies. Relational ontologies refer to a particular understanding of ontology which gives primacy to the relations between entities as a constitutive element of their existence (Spyrou, 2019). This recently changed view of childhood is likely to have a major impact on professional service provisions in the future and to affect the balance of power as the professionals will need to develop their working procedures to adapt to the needs and expectations of parents and of the children as expressed by the children themselves.

## 2.2 Family-Centred Theory and Practice

The beginning of family-centred theory can be traced back more than 70 years, to when Carl Rogers began to practice family-centred or client-centred therapy with families of 'problem' children (Law et al., 2003; Law et al., 2005; Rosenbaum et al., 1998). At that time, paradigm changes from an authoritarian practice to a partnership practice were already emerging and reference to this evolution date back to the early 1950s (Bamm & Rosenbaum, 2008; Espe-Sherwindt, 2008).

The transition from medically focused to person and family-centred models of service delivery has its roots in the ecological systems theory of human development outlined

by Bronfenbrenner (1974). He stated that people encounter different environments throughout the lifespan that may influence their development and behaviours which consists of a scientific study of the progressive, mutual interplay with the immediate settings, in which the developing person lives as described by Oliver (2013). This process is affected by the relations between these settings and by the larger contexts in which the settings are embedded (Edwards, 2011, 2017; Engeström, 2001; Hopwood & Mäkitalo, 2019). Another significant element in this theoretical evolvement is the family systems theory (Kerr & Bowen, 1988) that is based on the idea that human beings and families function as one emotional unit which can be better understood when viewed within the context of their family ties and relationships. These theories underpin many models of service delivery which are still being used today. They recognise the interrelatedness of family members and the importance of acknowledging their combined needs, not only the needs of the person with an illness or impairment. This is important to bear in mind when investigating the lives and circumstances of disabled children and their families.

In accordance with what has been said above, family-centred theory is based on the understanding that the family is the fundamental social unit, the main educator, supporter, and shaper of each person and emphasises the importance of the recognition of the uniqueness of each family in terms of lifestyle, experience, and culture (Bamm & Rosenbaum, 2008). All these factors affect the views of disability, parental role, and services (Dempsey & Keen, 2016; Ferguson, 2001; Law et al., 2003; Turnbull, Turbiville & Turnbull, 2000). These views support the relevance of recognising the parents' ideas on their own issues and acknowledging this leads to increasing attention on environmental circumstances in conjunction with disability and how it affects the life of the child and family.

What is fundamental in family-centred theory is turning the focus from the child in isolation to the child as a part of the family system (Bamm & Rosenbaum, 2008; Kerr & Bowen, 1988). Rouse (2012) describes family-centred practice as a model of partnership and argues that the family-centred philosophy has developed from help-giving and empowerment literatures. She outlines (p. 21) four core principles that drive the implementation of family-centred practice, which are the cornerstones of this thesis.

1. Children exist within the context of their families, wider community, and society.
2. What affects one member of the system impacts the other members.
3. All families have strengths.
4. Families are key decision makers in addressing their children's and family's needs.

Dunst and Espe-Sherwindt (2016) and Dunst and Trivette (2014) describe the term family-centred as a particular type of help-giving relational practices that includes treating families with dignity and respect, information sharing, building on family

strengths, and active participation in early childhood intervention. These components of effective strategies, relational and participatory, must be present in order to achieve positive outcomes for both the child and family. Furthermore, family-centred theory confirms the socio-relational and rights-based views of disability and the holistic view of children and families and recognises parents as experts in their own and their child's status and needs (Bamm & Rosenbaum, 2008; Bruder & Dunst, 2014; Dunst et al., 2007; Dunst & Espe-Sherwindt, 2016; Espe-Sherwindt, 2008; Law et al., 2003). Service models based on family-centred theory emphasise the interpersonal relationship between the family and the professionals and feature a dynamic view of the relationship between the family and the community (Dempsey & Keen, 2008; Dunst & Espe-Sherwindt, 2016; Egilson, 2011, 2015). The main premises, principles, and elements of family-centred service were outlined by Rosenbaum (1998) and are presented in the table below.

**Table 1:** Premises, principles, and elements of family-centred service, adapted from Rosenbaum et al. (1998, p.6)

| Premises (basic assumptions) | | |
|---|---|---|
| Parents know their children best and want the best for their children | Families are diverse and unique | Optimal child functioning occurs within a supportive family and community context: The child is affected by the situation and wellbeing of other family members |
| **Guiding principles ('should' statements)** | | |
| Each family should have the opportunity to decide the level of involvement they wish in decision-making for their child. Parents should have ultimate responsibility for the care of their children | Each family and family member should be treated with respect (as individuals) | The needs of all family members should be considered. The involvement of all family members should be supported and encouraged |
| **Elements (key service provider behaviours)** | | |
| **Service provider behaviours** | **Service provider behaviours** | **Service provider behaviours** |
| To encourage parent decision-making<br>To assist in identifying strengths<br>To provide information<br>To assist in identifying needs<br>To collaborate with parents<br>To provide accessible services<br>To share timely and important information about the child | To respect families<br>To support families<br>To listen<br>To provide individualised service<br>To accept diversity<br>To believe and trust parents<br>To communicate clearly<br>To collaborate across professional and organisational boundaries | To consider psychosocial needs of all members<br>To encourage collaboration between all members<br>To respect and accommodate different preferences and coping styles<br>To encourage use of community supports<br>To build strengths |

## 2.3  Cultural-Historical Activity Theory

Cultural-historical activity theory (CHAT) brings together the theory developed by Vygotsky (1980) and the theory developed by Leont'ev (1974), widely considered to be the founder of activity theory. Leont'ev suggested that 'activity' is not a reaction or aggregate of reactions, but a system with its own structure, internal transformations, and development. According to him, the object of activity not only objectifies what is worked on in an activity but also the needs, emotions, and feelings associated with it.

Since 1979, the Finnish scholar Yrjö Engeström has been working on a conceptual model of an activity system based on CHAT that can help to describe the relation between individuals and community in workplace activity (Engeström, 1987). His formulation of the structure of human activity systems is depicted in a triangular diagram (Figure 2).

**Figure 2:** The general model of an activity system (Engeström, 1987, p. 78)

In the context of welfare and school services, the subject refers to the individual or a group of individuals whose agency is chosen as the point of view for the analyses. The object is the target of the activity within the system. The mediation between the subject and the object can occur by using many types of tools, material tools as well as mental tools, including culture, ways of thinking, and language, which is highly relevant concerning the research topic under discussion.

The conceptual tools in this case are the service ideology applied by the service providers based, for example, on the requirements of the CRPD, family-centred theory and inclusive schooling. The rules refer to the set of norms and conventions which, in

the context of this thesis, are the international treaties, national laws and policies regarding school practices, disabled children, and families that regulate the relationships between community and object. Division of labour mediates the relation between the community and the object, reflecting on the forces within the community, the hierarchy of labour, and division of tasks between its members. CHAT explains how the division of labour within the organisation, workplace, or system and the culture within it, the official and work-related operating rules and objective and subjective tools interact and cause tension or contradictions which often become obstacles in the practice but can, with a changed mindset be regarded as opportunities for service development. The model of an activity system provides a tool for analysis where it is possible to focus on individual and institutional factors at the same time and examine the interrelationships among several interacting systems, as is done in this study. Engeström (2001) suggested at least two interacting activity systems as the minimum unit of analysis.



**Figure 3:** A model of three interacting activity systems, adapted from Engeström, 2001

The unit of analysis in this thesis consists of three interacting activity systems (Figure 3) central to disabled children's lives. These are the family, the preschool, and external services such as physio and speech and language therapies, all working towards the common goal of supporting the development and wellbeing of the child and family. For example, schools or in-service professionals may engage in collaborative interaction with families or between themselves, where everyone will learn something from each other (Woods et al., 2011). According to family systems theory (Kerr & Bowen, 1988 Lang 2020), the family is best understood by examining the structure of the family unit and the processes that occur within that unit. It is from that viewpoint that I see the

family as an activity system interacting with other related activity systems. Because of the dynamic nature of activity systems, the transfer that takes place is called developmental transfer (Tuomi-Grön, 2007) and is at the core of Edwards' relational concepts described in the section below.

### 2.3.1  Edwards' Relational Concepts

Edwards (2011, p. 35) draws on Christensen and Lægreid who suggest that successful interagency work requires performing 'more as a gardener than an architect'. Edwards (2011) takes this metaphor further by introducing three gardening tools to cultivate relational practices: common knowledge, relational expertise, and relational agency. Edwards (2011) describes relational expertise as a form of expertise that adds to existing knowledge. Professionals recognise each other's point of view and strive to adjust their expertise to other people's strengths and needs.

Common knowledge is about transfer, translation, and transformation of knowledge across boundaries. It relates back to the concept of relational expertise and the importance of professionals to be able to identify their own expertise, with an eye on differences across professions. Common knowledge is made up of what matters to each profession, the motives that shape and move professional practice forward and can become a resource that mediates responsive collaborations on complex problems. Common knowledge does not arise spontaneously but is created over time by recognising shared goals for the benefit of children, revealing specific professional values and motives (Edwards 2017, p. 10).

Relational agency is Edwards' final tool. It is about identifying a shared goal and matters to the group composed of child and family and related professionals, all with diverse expertise, viewpoints, and roles. A basic premise of relational agency is that professionals exercise both a core and a relational expertise when they work with others which fits well with the requirements that inclusive practices make for professionals.

### 2.4  Summary

This chapter has described the key concepts and theories that are at the core of my study. Emphasis has been on discussing different understandings of disability and the development of a human rights approach to disability and childhood and their manifestation in international law. The core principles of family-centred services and CHAT were described with a focus on the relational features which they have in common and which they also have in common with the social-relational understanding of disability. The following chapter reviews the literature relevant to this thesis.

# 3 Research on Family-Centred Approaches

This chapter provides a review of the research literature that informed and helped shape my study and emphasises literature focusing on everyday services for disabled children and their families. The term family-centred services (FCS), which is at the heart of this thesis, is commonly used interchangeably with other terms such as family-centred practice, family-centred care, and a family-centred approach. Despite a long-standing worldwide acknowledgement of family-centred principles in services, conceptual definitions and implementation strategies are still somewhat unclear (Bamm & Rosenbaum, 2008; McCarthy & Guerin, 2022; King et al., 2017; Rosenbaum et al., 1998). Authors writing from different professional and policy perspectives refer to different and sometimes overlapping definitions and use diverse literature to underpin their research (McCarthy & Guerin, 2022). These various, and often unclear, explanations increase the complexity when conducting a systematic overview of previous research, but they also give an idea of how family-centred principles in child and family services have been widely accepted for a while.

The chapter is divided into two main sections, each addressing significant topics that have enriched my understanding of my research subject. The first section reviews literature on family-centred services and early childhood intervention. The later examines the effect, or lack thereof, of prevailing paradigms on professional practices and services to disabled children and their families.

## 3.1 Family-centred services

During the past decades, the idea of family-centred services (FCS) has gained currency in child and family services worldwide (Espe-Sherwindt, 2008; Dunst, 2002; Dunst et al., 2007; Dunst & Espe-Sherwindt, 2016; Fordham et al., 2011; Mas et al., 2019; Rosenbaum et al., 1998; Stefánsdóttir & Egilson, 2016), and the importance of FCS has been stated across services and programs such as hospitals, mental health settings, early childhood services, rehabilitation and schools (Ahl et al., 2005; Egilson, 2011; Espe-Sherwindt, 2008; Guralnick, 2011; King & Chiarello, 2014; Kokorealias et al., 2019; Darrah et al. 2012; Stefánsdóttir & Egilson, 2016). MacKean et al. (2005) conducted a comprehensive literature review to condense the main concepts of FCS. They describe how the concept emerged from a strong advocacy movement in the 1960s in North America on behalf of disabled persons in general, and particularly parents of children with additional healthcare needs. In the early stages of this movement, parallel movements were emerging elsewhere, including in the UK, which were predominantly led by parents of children with chronic illnesses and/or disabilities

advocating against the dominant expert model and demanding more involvement in their child's health and related care. MacKean et al. (2005, p.75) identified the following six key features most frequently used in the literature to describe FCS up to and including 2000.

1. Recognising the family as central to and/or the constant in the [child's] life, and the [child's] primary source of strength and support.
2. Acknowledging the uniqueness and diversity of [children] and families.
3. Acknowledging that [parents] bring expertise to both the individual care-giving level and the systems level.
4. Recognising that family-centred care is competency enhancing rather than weakness focused.
5. Encouraging the development of true collaborative relation between families and health-care providers, and partnership.
6. Facilitating family-to-family support and networking and providing services that provide emotional and financial support to meet the needs of families.

This list highlights the main principles that were, and are still, considered to be the main characteristics of FCS.

Espe-Sherwindt (2008) refers to Dunst et al. (2007) when she outlines how family-centred practice in services is a systematic way of creating partnership with families that treats them with dignity and respect, honours their values and choices, and provides supports that strengthen and enhance their functioning as a family. Moreover, the core principles of FCS stipulate that services should be enacted by relationships and interactions that are characterised as being culturally sensitive, inclusive, and reciprocal while recognising and respecting one another's knowledge and expertise (Airoldi et al., 2021; Bailey et al., 2012; Bamm & Rosenbaum, 2008; Dunst, Dunst & Espe-Sherwindt, 2016; Trivette & Hamby, 2007; Espe-Sherwindt, 2008; Rosenbaum, 1998).

Recent studies (García-Grau et al., 2021) claim that a paradigm shift from a professional-directed, child-focused approach to a holistic and family-centred approach is growing in Europe as is reflected in both awareness and practice. This complies with the rights-based and relational ways of thinking about disability and childhood as set out in the CRPD and the CRC (Committee on the Rights of Persons with Disabilities, 2016; Traustadóttir, 2009; United Nations, Human Rights Treaty Bodies, 2022). However, research is also somewhat conflicted, as can be seen in many studies focusing on collaboration and partnership in services for disabled children and their families which have commonly found a lack of communication and coordination among professionals, resulting in parents feeling isolated from decision-making and not being heard or taken seriously (Arfa et al., 2022; Bruder & Dunst, 2014; Egilson, 2011, 2015; Matthews et al. 2020; Tøssebro & Wendelborg, 2015).

Furthermore, research findings focusing on welfare and educational services for families of disabled children often report a lack of relevant resources and difficulties in

accessing recommended services as their main concerns (Edwards et al., 2009; Egilson & Stefánsdóttir, 2014; Egilson, 2015; Greve, 2007). This calls for overall changes in welfare and educational practices aimed at increased collaboration and knowledge transfer across boundaries (Edwards, 2017, 2020; Edwards et al., 2009; Goodley, 2011; Sigurðardóttir et al., 2022).

In their extensive review of the literature, Kokorealias et al. (2019) emphasise how the literature calls for a move to family-centred care to improve the wellbeing of those with illness and/or disability and their family caregivers. This is in accordance with the stance of families with disabled children worldwide, who predominantly claim to be more satisfied and find FCS to be more helpful than other models of practice (Bruder & Dunst, 2014; Dempsey & Keen, 2008; Dunst, 2002; Egilson & Stefánsdóttir, 2014; Egilson, 2015; Espe-Sherwindt, 2008; Hanna & Rodger, 2002; García-Ventura et al., 2021; King et al., 2017; McCarthy & Guerin, 2022; Trivette et al. 2010). Moreover, recent evidence (McCarthy & Guerin, 2021) suggests that FCS can be seen as a reciprocal model whereby the facilitation of family education and skills-development has direct implications for positive outcomes, such as, the carry-over of therapeutic goals, family engagement with services, and the ability for parents to advocate for their child and family. There is also evidence that families' self-reported experience of FCS is positively associated with their feeling of well-being and lower stress in dealing with the system (Egilson, 2015; Kokorealias et al., 2019). It must be noted, however, that parents of younger children commonly consider services that they receive as more family-centred than parents of older children (Egilson, 2011; Stefánsdóttir & Egilson, 2016).

FCS has been widely adopted as a best practice in a variety of disciplines and settings over a long period of time. However, many studies show how the relationship between family-centred principles, provision of services, and the achievement of positive outcomes for children and their parents still needs better clarification (Bailey et al., 2012; Bruder & Dunst, 2014; García-Grau et al., 2019; McCarthy & Guerin, 2022; Shields 2015). This can be seen in Espe-Sherwindt and Serrano (2016) and King et al., (2017), who argue that, although FCS is valued in all disciplines involved in support and services to families of disabled children, the concept is often misunderstood, for example, in terms of understanding what constitutes a holistic approach, parent-professional collaboration, and adapted and flexible services. These inconsistencies contribute to and sustain the persistent gap between the recommended and actual use of family-centred principles. This is in line with evidence indicating that practitioners and program directors often claim that their programs are guided by family-centred principles, when  further scrutiny reveals that they are, in fact, professionally centred and the needs of parents are overshadowed by an emphasis on direct services to the child (Bamm & Rosenbaum, 2008; Dodd et al., 2009; García-Ventura et al., 2021; King et al., 2017; McCarthy & Guerin, 2021).

Although issues of cultural diversity were not part of my research, this is an area of importance considering the rapid cultural changes currently taking place in Iceland, which are reflected in a growing body of research on the diverse and interrelated factors rooted in a complex web of discrimination caused by negative social attitudes and cultural assumptions (Charmaz, 2020; Egilson et al., 2020; Gunnþórsdóttir et al., 2019). Additionally, it has been pointed out that environmental barriers, such as policies, law and services result in economic marginalisation and social exclusion of disabled children and that professionals must acknowledge these realities by supporting parents in their struggles (Arfa et al. 2022; Charmaz, 2020; Egilson et al., 2019, 2020; Williams and Porter, 2017; Ytterhus et al. 2015). The recognition of these disabling barriers highlights the interplay of additional factors that affect the relational aspects of disability, which is the foundation of the human rights perspective on childhood and disability and needs to be high on the agenda of those who work with disabled children and families.

Despite the ambitious and often progressive policies of providing family-centred inclusive services, more research is needed on this matter as pointed out by Foster et al. (2020). Researchers such as Dodd et al. (2009) highlight how family-centred practice has been provided by allied health professionals in a way that incorporates ideas of individual responsibility and how ideal families live their lives. In Iceland, Einarsdóttir and Jónsdóttir (2017) conducted a study in five Icelandic preschools concerning the collaboration between preschools and families. Their findings, along with findings from Gunnþórsdóttir et al. (2019), indicate that educators in Iceland are unsure about how to communicate with and accommodate families from cultures different from their own. These notions are in line with the findings from Egilson et al. (2019, 2020) and Arfa et al. (2022) regarding migrant parents of disabled children, when they claim that therapists are more likely to take the needs and goals of children and their families into account if they are similar to their own culture.

In addition to the plethora of research that deals with content, principles, and practices in FCS, numerous studies have identified barriers that limit its implementation. According to King et al. (2000), examples of such barriers include limited time, scant human and financial resources, and the lack of skills needed to put family-centred principles into practice. These are all familiar elements within the Icelandic research literature (Bjarnason, 2010; Egilson, 2011, 2015; Egilson et al., 2021; Ingólfsdóttir et al., 2021; Marinósson & Bjarnason, 2014; Sigurðardóttir et al., 2022).

The research presented above indicates that implementation of FCS, rather than the ideology, is the main barrier to successful practice. This highlights the significance of knowledge transfer, flexibility, collaboration, and building of common knowledge at the boundaries between professions and organisations (Edwards, 2011). A recurrent theme within the FCS literature is that, besides professional expertise, certain skills such as

empathy, good listening skills along with good collaboration and mediating skills are also imperative for providing FCS (Lundeby & Tøssebro, 2008).

### 3.1.1 Early Intervention and Family-centred Services

The rich history of early intervention (EI) spans many disciplines and fields of study, including health, psychology, early childhood education, and special education (Bruder & Dunst, 2014; Guralnick, 2008; Leiter. 2004). Foster et al. (2020) describe how early intervention aims to produce optimal health and developmental outcomes for children who have or are at risk of impairment. Many traditional approaches in EI have been based on what can be identified as the medical model where practitioners have worked one-on-one with the child to 'fix' what is seen as lacking in the child's development or moderating effect of a specific aetiology with respect to developmental influences (McWilliam, 2010). Guralnick (2017) argues that early intervention for all children remains a prevention or resolution process but emphasises how intervention strategies must additionally include the family, the intervention team and other supports within the community.

According to Foster et al. (2020), EI practitioners view FCS as a distinct approach to the provision of EI services, one that is comprised of specific practices and practitioner qualities. However, their findings point to a broadening definition of what family-centred practice means in the field of EI and how this wider definition incorporates the now much desired holistic approach in services. This evolvement is in line with the wishes of parents as articulated by King et al. (2017), Egilson (2011, 2015); Egilson et al. (2019, 2020) and Stefánsdóttir and Egilson (2016) when they point to the fact that research consistently indicates that parents not only expect services for their child but additionally express a need for emotional support, advice, navigation of the service system and relevant and timely information. The term family-centred early intervention (FCEI) is evidence of this development as it encompasses an ecological view on both early intervention and preschool special education as outlined by Fordham et al. (2011) and Carpenter (2007). This broad definition of EI emphasises a shift in focus from a child-centred to an inclusive and family-centred approach in working with parents, their disabled children and other family members (Espe-Sherwindt, 2008; Foster et al., 2020; Guralnick, 2017; Runswick-Cole & Hodge, 2009; Odom & Wolery, 2003). This is reflected in research which has highlighted that the most successful interventions are the ones that are woven into the daily child and family routine (Brown & Remine, 2008; Cameron, 2018; Dunst & Espe-Sherwindt, 2016; Elvarsdóttir & Gunnþórsdóttir, 2014; Mas et al., 2019; McWilliam, 2010, 2016; Reindal, 2008; Woods et al., 2011). Moreover, the interplay between the family, professionals and other actors within the service sphere plays a significant role as parents repeatedly highlight that effective service delivery requires coordinators with interpersonal practice skills who work within an adequately resourced service system.

Recent research by Foster et al. (2020), García-Ventura et al. (2021) and Mas et al. (2022) describe diverse views on service provisions in relation to recommended practices. According to their findings some practitioners focus on direct work with the children, while others support the idea of coaching or mentoring primary caregivers to help the child. Their mutual conclusion is that although practitioners are willing to develop their early intervention practices towards a more family-centred approach, they still have difficulties in actively involving families by using participatory practices and sharing responsibility. These arguments appear recurrently and direct the attention to vocational training and occupational culture within the respective professions, which will be discussed later.

Research on the features of CHAT would be beneficial to better adapt family-centred services to the specific conditions prevailing in Iceland, as they take advantage of the historical and cultural context in relation to personal needs and organisational practice (Blackler, 2009). Edwards (2004) and Nummijoki and Engeström's (2010) presentation of the hallmarks of improving organisational work, makes these ideas relevant in a family-centred context as they emphasise the importance of the client's active and continuous contribution to the evolution and shaping of the system. The expansive learning theory as introduced by Engeström (2001, 2016) puts primacy on the collective community-learning for the creation of a new culture which is an essential source for system development and has created the ground on which I base my perspectives on the service reform needed in Iceland. All the research highlighted above supported the focus of my study which was examining the everyday practices in family-centred services for families of young disabled children and encouraged me to explore professional practices in more detail, where both relational and participatory components of services are seen as equally important.

## 3.2  Paradigm Changes and Professional Practices

In the early 1980s Oliver (1983) drew attention to how the individual (medical) model was aimed largely at professionals. He suggested that those working with disabled people had until then operated largely within a framework based on the individual model and to make their practice more relevant, they needed to re-orient their work to a framework based upon the social model. Despite the overall efforts to move from a narrow personal defect view on disability to a wider rights-based, socio-relational, and participatory perspective in welfare services for disabled children, it has been argued that, instead of altering or developing professional practices, parents have been given more responsibilities for treating or training their children at home. In addition, parents have been expected to assume more responsibility in their child's treatment or care, service management, and advocacy (Bamm & Rosenbaum, 2008; Dodd et al., 2009; Hiebert-Murphy et al., 2011; King et al., 2017; MacKean et al., 2005; Runswick-Cole et al., 2016; Swain & French, 2001). This has happened without acknowledging that families and individual family members may be limited in their ability, time, or energy

to take on these roles (Dodd et al., 2019; Hiebert-Murphy et al., 2011; Runswick-Cole et al., 2016; Swain & French, 2001).

According to Icelandic research, most parents of young disabled children want to take an active part in decision-making concerning the services provided to them and their children (Arnadottir & Egilson, 2012; Egilson, 2011; Ólafsdóttir et al., 2019). What they do not want, however, is having to 'pull the wagon' and have the main responsibility for services or be team coordinators or be responsible for the sharing of information between services. This complies with the findings from Bamm and Rosenbaum (2008), Cameron (2018) and McWilliam (2010) who draw attention to the fact that parents frequently report having to navigate the system on their own as if they were the first to follow this path and even more remarkably, having to guide and coordinate the work of the professionals involved in supporting them. Thus, professionals must be able to identify and adapt to the different views, needs and wishes as articulated by different families, also by parents who express a desire to be allowed to be 'just parent', without adding extra responsibilities, such as treatments or training duties (Bamm & Rosenbaum, 2008; Cameron, 2018; Hodge & Runswick-Cole, 2008; McLaughlin et al., 2008; Runswick-Cole et al., 2016). This highlights the importance of flexibility in order to respect and accommodate the needs of different families at different times and in the Icelandic context, to take into account mothers' general participation in the labour market.

Evetts (2011) and Huijts et al. (2011) demonstrate how professional views and attitudes often include group notions on values, norms and virtues concerning an occupation which sheds light on how professional theories have developed, and deal with different interpretations between individuals within an occupational field. Moreover, they explain professionalism as an occupational value and indicate both the changes and continuities in professionalism in these organisational contexts which point to the fact that professional attitudes vary less within the same occupational field than across occupations. An influential factor in this regard could be, as Hermansen (2020) suggests, that these group notions about values may relate to differences in the education and training of professions and the prevailing traditions within each occupational field. Hence, professional development is a key element for the shift to family-centred inclusive mechanisms within the entire service system (Garzón Diaz & Goodley, 2021; Goodley, 2011). In the efforts to promote and achieve knowledge translation in practitioners' actions, many challenges are reported such as the political managerialism to strict coordination through hierarchical and productivity-related control, organisational authority, and organisational values (Airoldi et al., 2021). These primarily encompass efficiency and profitability with contradictory professional and managerial principles (Garzón Diaz & Goodley, 2021; Noordegraaf, 2015). The strict guidelines, often set for service coordination and improvement and the lack of human resources, may provide little space for the flexibility needed in the provision of FCS. Moreover, the lack of consistency among researchers and policymakers has been

considered an obstacle so that research questions and methods fail to meet the needs of the community for the transfer of knowledge to practice (McCarthy & Guerin, 2022). When considering these barriers, it is evident that implementation of FCS is a complex process which needs to be confronted.

The premise for developing the ideas of relational expertise, relational agency and the production of common knowledge (Edwards, 2004; 2009; 2011; 2017; 2020) in the context of family-centred inclusive practices, can be regarded as a benefit derived from the collaboration of diverse professions across practice boundaries (García Grau et al., 2022). Edwards et al. (2009), Hopwood and Edwards (2017) and Cameron (2018) examined the joint professional-parent work to explore the role of parents in multidisciplinary collaboration. Edwards (2009) distinguishes between distributed expertise and relational agency and explains how distributed expertise on the one hand, recognises that expertise is scattered across local systems and that practitioners need to become adept at recognising, drawing on and contributing to it. Furthermore, Edwards (2017) emphasises how common knowledge acts as a mediator of relational agency as it consists of what matters for each collaborating person when they interpret a problem. It comprises their motives in relation to the object of activity, the problem space they are working in. It is through common knowledge that practice can be oriented towards shared goals of interacting activities which is a core value when aiming to provide coordinated services. Relational agency on the other hand, offers a more precise analysis of what is involved in working in systems of distributed expertise. According to this ideology, distributed expertise demands professionals to develop relational agency as an extra feature of expertise alongside their core professional expertise looking at children and their families as 'people to be worked with relationally rather than clients to be worked on' (Edwards, 2009 p., 33). I build on these ideas in the implications for practices presented in the final chapter of this thesis.

Apart from the concerns highlighted above, Kogan (2005) attracts attention to the idea that language can act as a powerful means of constructing, regulating or disciplining people and places or how distinct discourses can be an obstacle to progress within the affairs of marginalised groups. Similar considerations have been raised by other researchers (Goodley & Runswick-Cole, 2011; Hanna & Rodger, 2002; Runswick-Cole & Hodge, 2009). Therefore, professionals need to be aware of the profound change in terminology following the development of the social and rights-based views on disability and accordingly they must pay special attention to their way of expressing themselves orally and in writing so that the rights based social-relational and family-centred focus is clear.

### 3.2.1 Knowledge-to-Practice

Despite accepted ideologies and stated policies, the literature repeatedly points to profound difficulties in transferring knowledge into practice as illuminated above.

Bruce et al. (2002), Espe-Sherwindth (2008) and Rouse (2012) point to the fact that many service providers find it difficult to be family-centred in their practices because they were trained and expected to work in line with the medical model in which the service provider is seen as the expert and the service receiver as the client. It is in the context of this complexity that professionals still take on the role of the expert when the features of family-centred services are meant to be applied as previously discussed in relation to EI services.

Whether professionals are allied to the community or the profession to which they belong can be used as an approach to better comprehend the findings of this thesis in connection with disability studies views on human rights and inclusive practices. In this sense professionals can be categorised as allied to profession(als) (PAP) or to the community (PAC) (Goodley, 2011). Goodley (2011) refers to Finkelstein when he describes how 'PAPs' have the key role in relation to disabled people and their work in cure- care- or social services and are dominated by a culture of welfare provision for the 'vulnerable' which is in line with the medical or individual view on disability. Contrary to this, 'PACs' refer to services and professionals who respond to and are led by aspirations of disabled people and their representative organisations. This demands that professionals must invest less time in pathological views of impairment and more in challenging the social situation and context of disabled people (see examples in table 2). This distinction presents a simplified picture of a complex situation but is displayed here for clarification. It presents a simple idea of the terms on which the system operates which in turn affects the way in which the professionals act, speak, and experience their work, which is highly important in relation to my study.

**Table 2:** Professionals categorised as allied to profession(als) (PAP) or to the community (PAC), adapted from Goodley (2011, p. 174)

| PAP<br>Professionals allied to profession(als) | PAC<br>Professionals allied to the community |
|---|---|
| • Individual and medical models<br>• Impairment<br>• Individual adjustment and repair<br>• Care and cure<br>• Expertise<br>• Services culture<br>• Diagnoses | • Social, minority, cultural and relational models<br>• Intersections<br>• Systemic change and community cohesion<br>• Support and hope<br>• Emancipation<br>• Collective empowerment<br>• Community culture |

Edwards (2004, 2017), Edwards et al. (2009), and Egilson (2011, 2015) point to the fact that the conception of interorganisational working rests upon 'relational' models of collaboration and how utterly important this is in the provision of FCS as parents commonly report having to provide the same information repeatedly whenever they contact a new agency and how they even must bring information between professionals and institutions. In accordance with this, Hodge, and Runswick-Cole (2008) propose that welfare services should shift power from allied health professionals 'directing' and families 'doing'. They furthermore emphasise the importance of good listening skills among professionals, bearing in mind that the parents' views and theirs can differ in important aspects as has been discussed before.

There are other significant barriers to change defined in literature apart from those mentioned above. An example is Evetts' (2011) conceptualisation of the 'new professionalism' where she illustrates common work conditions as organisational in contrast to occupational professionalism. This description implies some regression in professional practice-development, reflected in the shift from notions of partnership, collegiality, discretion and trust, towards increasing levels of managerialism, bureaucracy, standardisation, assessment and performance reviews, which involves a challenge to the occupational work control. In this light, Evetts (2011) views professionalism as increasingly organisationally defined which made me pay special attention to the question whether this has been a tendency in Iceland.

The trend articulated above, indicating that professionals tend to be allied more towards traditional individualised one-to-one practices than practices in the child's natural learning environments, raises a question about the working conditions of professionals in societies where emphasis is on productivity beyond less measurable content, such as better performance in authentic situations and less troubled families (Charmaz, 2020). Therefore, current governance may prevent professionals from transforming prevailing streamlined practices toward family-centred services. My study is designed to elucidate the current services provided to young disabled children and their families and create knowledge that can be used to design and provide more flexible, accessible, inclusive and seamless services.

## 3.3  Summary

This chapter has provided an overview of the literature which has informed this thesis, provided context to my research, and helped develop its arguments. It has highlighted that although the ideology of FCS has been highly regarded for a long time, research shows a lack of understanding and criteria for what is meant by the term along with inevitable consequences in the implementation, evaluation of services and performance measures. The chapter also discusses the literature on professional practice and work conditions which research shows has often created barriers to implementing FCS. Although extensive, this literature also demonstrates the necessity to continue research

in this important area in order to clarify whether services that claim to be family-centred are so in reality and figure out possible reasons for the persistent difficulties in the implementation of FCS. The next chapter will describe the methodology and methods employed in conducting the study this thesis presents.

# 4 The Study

The research was performed in three phases lasting from 2011-2020 (see Figure 1). In the first phase from 2011-2013, the theoretical framework was created, taking into account the relational views reflected in the CRPD. The second phase from 2013-2018 consisted of in-depth interviews with parents and preschool professionals in all three cases along with document review and participant observations. In the third phase from 2018-2020, three focus group interviews with professionals who worked outside the preschools were conducted, one interview in each case together with additional document review. Each phase closed with the submission of one or two publications. This chapter presents an overview of the research methodology, methods, and procedures. It begins with a presentation of the research aims and research questions, followed by a description of the methodology and methods employed. I also provide an overview of the study sample, data sources, data collection, and data analysis. The chapter concludes with a discussion of ethical issues, the relevance of the study, and a reflection on its strengths and weaknesses.

## 4.1 Aims and Research Questions

The four main aims of the study were to explore the gap between Icelandic welfare policies and the every-day experiences of families of disabled children (1) with a primary focus on capturing the families' views and experiences (2), but also on the roles, attitudes and working environments of professionals providing services to disabled children and their families (3). Based on the overall findings, the study put forward suggestions for changes in service delivery (4).

Four research questions were developed, each addressing a specific area within the broader themes and aims of the study.

1. What views prevail among families of disabled children of preschool age on their experiences of the services provided to them?
2. How do professionals and authorities see their responsibilities and obligations regarding services for young disabled children and their families?
3. How has the service system managed to keep up with new paradigms and societal changes that call for innovative approaches in service provision?
4. How can cultural-historical activity theory (CHAT) and Edwards' three relational concepts be utilised to develop services according to the needs and wishes of families of young disabled children?

## 4.2  Study Design and Methodology

A qualitative case study methodology was chosen for this research to provide an opportunity to contribute to the knowledge and understanding of individual, group, organisational, social, and related matters (O'Leary, 2010; Yin, 2009). At the same time, the case study methodology seeks to understand and interpret social phenomena from the participants' perspectives and how people perceive their experiences (Taylor et al., 2015). Qualitative case studies usually focus on one case or a small number of related cases from which the researcher seeks detailed information (O'Leary, 2010; Yin, 2009). In this study, three cases were under scrutiny. By investigating the situation at three different sites, which each formed one case, I gained a deeper comprehension and overview of the research subject and its complexity in its unique context. In line with the relational theoretical approach, I found CHAT (Engeström, 2001) to be a helpful framework to conceptualise the relations within and among different parts of the interacting activity systems and to better understand the contradicting forces that are at play within and between those systems. The importance of these relations was found within the relevant activity systems, such as, the family, the preschool and the external specialists, and in the cultural-historical relations that connect the activities and their participants with a wider social context. The relational theoretical approach and transformative character of CHAT resonated well with the qualitative approach to the study.

In line with the above, the multi case study approach was designed to gain in-depth knowledge of the research topic from diverse perspectives. A variety of qualitative methods were applied for data gathering (Audet & d'Amboise, 2001; O'Leary, 2010; Yin, 2009), which consisted of interviews, document review and participant observations. These methods were used to generate and reflect on the research topic from various sources. In accordance with the case study approach, the research process was flexible and evolved during the research period.

## 4.3  The Study Sample

Each of the three case studies included two to four children, their families (eight families in all), and the service team for each child. The service teams were composed of the preschool professionals, related specialists (speech and language therapists, physiotherapists, and occupational therapists) and the service coordinators (see Table 3). Case study A was carried out in the capital area. Case study B was conducted in a rural municipality with a total of 8,000 inhabitants which is composed of several small communities. Case study C was undertaken in a municipality with 18,000 inhabitants at the time of the study. This municipality was previously regarded as a model in integrated welfare services and had been involved in a state-led development project beginning in 1994 where the transfer of disability services from the state to the municipality was tested before nationwide decentralisation took place in 2011. These

three different municipalities were selected because they provided an opportunity to reflect on services in locations of varying population, geographical region, type of municipality, and experiences of service provisions to disabled people.

The participating families were selected by the local social service or educational counsellors. The families represent diverse educational backgrounds, socio-economic statuses, and number of children. All were of native Icelandic origin. The disabled children had various intellectual, psychosocial, and physical impairments. They all lived with both parents or a parent and a stepparent, and all the parents worked full-time or part-time outside the home except one father who received disability benefits and a mother who was a university student.

The children were between three and seven years of age when the study took place and had all attended preschool from approximately two years of age. Although two of the children had recently been transferred to elementary school at the time of the data collection, the research focused on the parents' experiences of their child's preschool years. All the children had some form of special support within the preschool, and all had been provided with additional services outside the preschool from an early age. The study sample also included a group of preschool teachers, administrators, and professionals providing services to the families and children. The professionals working within the preschools took part in individual in-depth interviews. In addition, three focus group interviews were conducted, one for each case study, with specialists working outside the preschools (see Figure 1 and Table 3).

**Table 3:** Overview of participants and data sources in the case studies.

| | Case (a) Reykjavik, the capital | | Case (b) Rural municipality | | | | Case (c) Municipality in North Iceland | | The study as a whole (across cases) |
|---|---|---|---|---|---|---|---|---|---|
| | Child one and two | Child three | Child four | Child five | Child six | Child seven | Child eight | Child nine | |
| **Child details** | Twin boys; Four years; Intellectual impairment and ADHD | Boy; Two years; Intellectual impairment (Downs syndrome) | Girl; Three years; Intellectual impairment (Downs syndrome) | Girl; Five years; Physical- and intellectual impairment | Boy; Five years; Mild intellectual- physical- and speech impairment | Boy; Seven years; Autism spectrum disorder | Boy; Four years; Severe intellectual, physical and speech impairment | Boy; Five years; Mild intellectual physical- and speech impairment; ADD | |
| **Family and community details** | Live with father and stepmother; One older sister. Both parents work outside the home; Attend local preschool | Lives with both parents and two older brothers; Both parents work outside the home; Attends a local preschool | Lives with both parents. Both parents work outside the home; Attends local preschool | Lives with both parents and two older sisters; Father receives disability benefits; Mother works outside the home; Attends a local preschool | Lives with mother & stepfather. Both parents work outside the home. Attends local preschool | Lives with both parents and three siblings. Both parents work outside the home; Attends local preschool | Lives with both parents and younger sister; Father works outside the home, mother a university student; Attends preschool nearby a rehabilitation centre | Lives with both parents. Half-brother stays with the family every second weekend; Both parents work outside the home. Attends a local preschool | |
| **Specific data sources** | Interviews: Father; Father & stepmother; Observation: Team meeting (parents, teachers and service coordinator from the local service centre) | Interview: x2 with both parents | Interview: Both parents | Interviews: Mother; Preschool social pedagogue; Head of preschool; Observations: Story time at preschool; Home | Interview: Mother; Service coordinator, Observation: Team meeting | Interviews: Mother; Preschool teacher Observation: Home Review: Individual education plan | Interviews: Mother; Father; Special education teacher; Head of preschool; Speech therapist Observations: Preschool playtime and mealtime; Team meeting Review: Assessment report; Individual education plan | Interviews: Mother x2; Special education teacher; Head of preschool Observations: Preschool playtime and mealtime, Language training session, Team meeting Review: Individual education plan | |
| **Focus group interviews** | Participants: Two language and speech therapists, one occupational therapist, one physiotherapist, one social pedagogue | | Participants: Three language and speech therapists, one social pedagogue | | | | Participants: Two language and speech therapists, one preschool special educator, one social pedagogue | | |
| **Generic data sources for municipality** | Interviews: City special education project leader; Head of advisory preschool(*); Advisory preschool special education coordinator; Speech pathologist Presentation of services: Advisory preschool Observation: Arrangements of disabled children's services within advisory preschool Documents from city's official website: Information on family- and educational services; reports and official rules | | Interview: Municipality service consultant Review of local guiding rules Review of documents from municipality's official website: information on family- and educational services; reports and official rules | | | | Interviews: Municipality preschool special education counselor; Municipality family service manager Review of documents from municipality's official website: information on family- and educational services; reports and official rules | | Interview: Parent-counsellor operating nationwide Documents: Icelandic laws and regulations on social and educational services for disabled children and families; UN-CRPD |

*A preschool that specialises in serving disabled children and provides advice to other preschools in Reykjavik

## 4.4  Data Collection

Before the in-depth interviews with parents and professionals, a small pilot study (Yin, 2009) was performed, composed of qualitative interviews with the parents of four disabled children aged five to seven in Reykjavík and an interview with an experienced parent counsellor who worked nationwide (Ingólfsdóttir & Traustadóttir, 2010). The pilot study gave insight into the situation in family services in most parts of the country. The interviews from the pilot study were not included directly in the case study but provided valuable insights, information, and knowledge that served to prepare the thesis research presented here.

A semi structured interview guide was developed for both parents and professionals with the key issues to be discussed (see Appendices A and B). The themes included (a) the participants' experiences, perspectives and understanding of the welfare services offered to the children in the study; (b) co-operation and consistency within the service system; and (c) the participants' views on what worked well and what did not work so well. The interviews allowed for an in-depth exploration of the key areas identified by the participants while exploring specific areas of interest to the research. In addition to the interviews and participant observations, a review of official and local documents was carried out.

### 4.4.1  In-Depth Interviews

In-depth interviews are a qualitative data collection method that involves direct, one-on-one engagement with individual participants to explore their perspectives and experiences regarding a particular concept, place, activity, or situation (Taylor et al., 2015). To gain an insight and grasp the views of the parents, 12 semi-structured in-depth interviews were carried out (6 with mothers alone, 2 with fathers alone and 4 with the parents together) to elicit their views and experiences of the services they had received. The interview guide was designed with reference to the core principles of FCS and rights-based inclusive practices as stipulated in the CRPD (see Appendix A). The intention was to get the parents to talk on their own terms, hence questions were not too specific allowing for a range of responses (Creswell, 2008). Additionally, 11 in-depth interviews with professionals working within or in relation to the preschools were undertaken. Most of them held managerial positions or played a specific role towards the children, such as preschool principals, social pedagogues, early childhood special educators or consultants from the municipalities. These interviews took place either in the special education rooms in the preschools or in the homes of the participating families if they preferred so. Each interview lasted between one and two hours. All the interviews were recorded and transcribed verbatim.

### 4.4.2 Focus Group Interviews

In addition to the individual in-depth interviews outlined above, focus group interviews with professionals were conducted. Focus group-interview is a form of group-interview that capitalises on communication between research participants to generate data (Creswell, 2008; Fern, 2001; Krueger & Casey, 2009). The idea behind the focus group method is that group processes can help people to explore and clarify their views in ways that would be difficult in a one-on-one interview. The interview guide for the focus group interviews (Appendix B) was constructed to help guide the conversations and keep focus on issues regarding their views and opinions on professional priorities, guiding ideologies and working situations. The focus group discussions encouraged the participants to reflect on and agree or disagree regarding specific issues and helped explore the opinions, ideas, and values of the informants. Basnet (2018) describes how focus-groups are useful in bridging research and policy as they provide insight into different opinions and situations as was the case in my focus group interviews.

Altogether, 13 professionals from six disciplines holding divergent positions took part in three interviews, four people in two groups and five in one group. The participants, 12 females and one male, had diverse educational backgrounds in areas such as speech and language therapy, occupational therapy, physiotherapy, preschool special education, and social pedagogy. Their work experience ranged from six years to about four decades. All had direct or indirect relations with the children and families involved. Each focus group lasted one-and-a-half to two hours. Prior to each focus group, an interview protocol was developed with the key issues to be discussed, including the participants' experiences, perspectives and understanding of the services offered to the children and families in the study (see Appendix B). The participants were encouraged to discuss, ask questions, exchange stories and examples and comment on each other's experiences and opinions. The focus groups were recorded and transcribed.

### 4.4.3 Participant Observations

Participant observation also often referred to as 'naturalistic observation' (Adler & Adler 1998, p. 79), constituted a part of the methods used in the data gathering. Participant observers usually enter the field in an unobtrusive manner in order to experience first-hand the realities of the people under study (Taylor et al., 2015). This was how I approached the observations in the preschool settings. I tried to blend in without disturbing or interfering. When observing the daily practices, the spotlight was on the interaction between the child and her/his peers, and how and where the support and/or special services were provided. At the team meetings the focus was on who were present, on the power balance and collaborative actions, and if or how the parent

was urged to participate in the decision-making procedures about their own affairs as well as their child's.

A total of nine participant observations were conducted in the preschools. Six of them took place at the children's immediate surroundings, each lasting for between two and three hours and three observations took place at team-meetings with the preschool staff, a counsellor from the school office and a parent, each session lasting for about an hour. None of the specialists that served the children outside the preschool attended the team meetings.

These on-site observations were an important source and a context for the information and data obtained in the interviews as they gave an opportunity for me to get acquainted with the children involved in the study, also to observe the interactions and circumstances they experienced in their day-to-day realities. During the observations I jotted down notes. After each observation, detailed descriptions and reflections were documented in the form of fieldnotes.

### 4.4.4  Document Review

In case study research, researchers use documents as a source of contextual information on matters that cannot be directly observed; documents are also used by researchers to confirm or question information from other sources (Stake, 1995). Documents provide important background information and broaden the coverage of data and are therefore helpful in contextualising the research (Bowen, 2009). In this study a review of both official and practice-based documents was carried out. These documents were international human-rights treaties, domestic laws, regulations, reports, curricula, and other managerial and working documents from the preschools. The documents provided additional research data and formed an important context for the interviews and participant observations that supported and strengthened the research and its findings.

### 4.4.5  Data Analysis

Data analysis was conducted during and after the data collection took place. This included the transcripts from the individual and focus group interviews, fieldnotes from the participant observations and the documents obtained. The data were analysed both inductively and deductively. Braun and Clarke (2013) describe how thematic analysis can be used for both inductive and deductive analyses, and to capture explicit and underlying meaning. These methods were relevant in the data analysis, bearing in mind the diverse nature of the data in my study.

In the beginning, an inductive procedure was followed, based on familiarisation with the data. Each transcribed interview was reviewed and read repeatedly to determine the main messages (Creswell 2008; Simons 2009). At this stage I made notes on the

margins of the transcripts before I began coding. Then an inductive open line-by-line coding was performed, and the themes and codes were derived from the content of the data themselves. During the analysis, some themes were merged and formed new ones. Others were divided into new themes and subthemes, theme names were changed, and new themes were identified (Braun and Clarke, 2013). The analysis procedure was flexible, and a thematic theory-based coding method was followed in the later stages when deductive analysis was carried out to detect and identify categories and themes that were in line with, or contradicted, the core principles and values in inclusive family-centred services. The relational and rights-based views on disability that were the basis for the theoretical frameworks and research questions were also important tools during the final phase of the theory-based deductive data analysis (Braun & Clarke, 2013).

Analytic memo writing was an important part of the process of analysing the data. In the last round of analysis, main themes were formulated by combining initial sub-themes. Final conceptualisations were generated through parallel investigation and comparison of the main themes within case and cross-cases. During the entire process of analysis an effort was made to focus on the quality and meanings of the statements made by participants rather than the quantity of ideas presented (Patton, 2002).

The analysis of the focus groups interviews followed basically the same process as the analyses of the in-depth interviews described above (Taylor et al., 2015). I combined and compared themes within and across the three focus-groups and examined how these related to the themes from the in-depth individual interviews. Examples of common themes that reoccurred repeatedly within and across cases in the diverse sets of data (such as dealing with long waiting lists, heavy workload and struggles with the IHI) were compared with the individual interviews. The analysis also included a focus on the common themes between municipalities as expressed by the parents and professionals. The focus group interviews with the professionals which were performed later in the research procedure were a valuable data source as they gave an opportunity to better understand their role and work situation in addition to obtaining their experiences and points of view. Their input was also important for cross-checking information for the validation of the data.

Analysis of documents is a part of the qualitative research approach (Braun & Clarke, 2013; Patton, 2002; Taylor et al., 2015). It calls for documents to be examined and interpreted to gain an understanding of their content. Document analysis aims to inspect the text and its content to reveal their significance and how they relate to the wider context (Braun & Clarke, 2013). In this study, analysis of the core ideas and key concepts in the CRPD and the CRC along with national policy documents such as the Icelandic national curriculum guide for preschools (2012) and other regulations and procedures for services to disabled children and families, provided the wider context of the research. Analysis of the working documents from the preschools created an

opportunity to learn about the practitioners' day-to-day work and the activities and routines of the children within the preschools and at home to some extent. This process of analysis of the diverse datasets led to the identification of key findings regarding services for young disabled children and their families in the three Icelandic municipalities which are presented in four journal articles, each with a different focus on special aspects of the findings.

The research data were collected and analysed in Icelandic. Thus, the research process involved the translation of the findings from Icelandic into English as they were presented in English in the international journal articles and in this thesis. All recorded material, transcripts of interviews and field notes have been kept confidential and to ensure the anonymity of the participants, no names identifying individual persons are used.

## 4.5  Ethical Issues

The study focuses on the lives of families with young disabled children which is a sensitive research topic. In addition, Iceland's small population and short social distances require specific consideration in terms of confidentiality and anonymity. Thus, care has been taken in presenting the study to protect the identity of all participants. The families were proposed by the local counsellors in each municipality, none of whom I knew beforehand. All potentially recognisable characteristics of persons have been avoided in order to protect the privacy of participants.

At the outset of the study, a detailed research plan was constructed in collaboration with a committee member and my supervisor. This plan was accepted by my doctoral committee and the Scientific Committee of the Faculty of Social and Human Sciences at the University of Iceland. Before any data was collected, an application, based on the research plan, was submitted to the Icelandic National Bioethics Committee accompanied with an introductory letter, a declaration for consent for the participants and a thematic framework for the interviews enclosed. The study was approved by the National Bioethics Committee (11-100-S1).

My prior knowledge and experiences regarding the research topic were particularly helpful at the outset of the research procedure and made access to the study field smooth and easy. Familiarity with the field also helped throughout the study process with regard to the comprehension of various complex situations within the service systems. However, in light of my former experience of clinical work with families of disabled children, I constantly and consciously had to be on guard throughout the research process not to be influenced by my preconceived clinical opinions. One way to avoid this during the data analysis process was to adopt a theory-based framework for the analysis of the data. Thus, to a large extent, data were analysed on the basis of the core themes and principles in family-centred services, along with the rights-based

views on disability, children, families and services that form the theoretical background of the study.

Even though the disabled children were not interviewed in this study, their interests were in the foreground through the entire research process and considered in all aspects of the research. Care has been taken to protect their integrity and images throughout the research process.

## 4.5.1 Strengths and Weaknesses

The main contribution of this thesis to the field of disability studies is to shed light on what characterises the gap between Icelandic welfare policies and the experiences of families with disabled children of the services provided. Moreover, to analyse, by combining complex theories, which elements are most important in daily services to the children and their families, how these elements are interrelated and the contradicting forces that are involved. Three predominant discursive elements were revealed: fragmentation, incompatibility and inflexibility, which all relate to the services and the system. Furthermore, it is an important contribution to detect how these tensions can be turned into opportunities for change. With that mindset, the thesis introduces the human rights treaties of the CRC and CRPD and social-relational theories on disabilities and professional practices in order to influence and develop new inclusive and relational trends in service provisions for families of disabled children. The trends proposed are based on Edwards' three relational concepts presented in the thesis and further described and emphasised in section 6.1, Implications for Practice, as highly relevant and useful instruments for service reform called for in Iceland and elsewhere. However, the limited number of cases must be considered when drawing conclusions from the study and the fact that the participants were nominated by the local counsellors in each municipality. This method of recruiting participants might have increased the probability that the parents chosen were parents who they expected, due to previous experience, to be willing to take part. This limited the study to families the local authorities identified as "good" participants for the study. To compensate for these limitations emphasis was on diversity within and across the cases as well as on obtaining data from a variety of sources and reflecting diverse perspectives. The absence of migrant families is regrettable as it is a research area of increased importance in line with the rapid (multi)cultural changes currently taking place in Iceland. However, at the outset of the study, there was limited attention to cultural diversity among preschool children and this was not in the spotlight of my research project. Since previous Icelandic research has focused mostly on children and families in urban and suburban areas, emphasis was on including families from a rural municipality in this study.

## 4.6  Summary

This chapter has given a detailed description of the methodology and methods employed in the research which is at the core of this thesis. I have also provided reasons for selecting the case-study approach within the broader qualitative methodology. This approach has served the intended aim to gain a holistic knowledge and understanding of the complicated phenomena under scrutiny. The chapter concluded by discussing ethical issues and the significance of the study including reflections on its strengths and weaknesses.

# References (Chapters 1-4)

Adler, P. A., & Adler, P. (1998). Observational techniques. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 79–109). Sage.

Ahl, L. E., Johansson, E., Granat, T., & Carlberg, E. B. (2005). Functional therapy for children with cerebral palsy: An ecological approach. *Developmental Medicine and Child Neurology*, *47*(9), 613–619. https://doi.org/10.1017/S0012162205001210

Airoldi, M. J., Vieira, B. S., Teplicky, R., Chalfun, D., Bonfim, R. G. A. S., Mancini, M. C., Rosenbaum, P., & Brandão, M. B. (2021). Information and empowerment of families of Children with cerebral palsy in Brazil: The knowledge translation role of Nossa Casa Institute. *Frontiers in Rehabilitation*, *2*, 709983. https://doi.org/10.3389/fresc.2021.709983

Altman, B. M. (2001). Disability definitions, models, classification schemes, and applications. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies*. Sage.

Arfa, S., Koren Solvang, P., Berg, B., & Jahnsen, R. (2022) Challenges and facilitators in supporting sustainable participation after rehabilitation: Experiences of immigrant parents and their children with disabilities. *Scandinavian Journal of Occupational Therapy*, *29*(8), 631–644. https://doi.org/10.1080/11038128.2020.1856183

Arnadottir, U., & Egilson, S. T. (2012). Evaluation of therapy services with the Measure of Processes of Care (MPOC-20): The perspectives of Icelandic parents of children with physical disability. *Journal of Child Health Care*, *16*(1), 62–74. https://doi.org/10.1177/1367493511423769

Audet, J., & D'Amboise, G. (2001). The multi-site study: An innovative research methodology. *The Qualitative Report*, *6*(2), 1–18. https://doi.org/10.46743/2160-3715/2001.2001

Bailey, D. B., Raspa, M., & Fox, L. C. (2012). What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education*, *31*(4), 216–223. https://doi.org/10.1177/0271121411427077

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, *89*(8), 1618–1624. https://doi.org/10.1016/j.apmr.2007.12.034

Barnes, C. (2012). The social model of disability: Valuable or irrelevant? In N. Watson, A. Roulstone, & C. Thomas (Eds.), *The Routledge handbook of disability studies* (pp. 12–29). Routledge.

Barnes, C., & Mercer, G. (2010). *Exploring disability* (2nd ed.). Polity Press.

Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: A sociological introduction*. Polity Press.

Barton, L. (2018). *Disability and society: Emerging issues and insights*. Routledge.

Basnet, H. B. (2018). Focus group discussion: A tool for qualitative inquiry. *Researcher: A Research Journal of Culture and Society*, *3*(3), 81–88. https://doi.org/10.3126/researcher.v3i3.21553

Bjarnason, D. S. (2010). *Social policy and social capital: Parents and exceptionality, 1974–2007*. Nova Science Publishers.

Blackler, F. (2009). Cultural-historical activity theory and organization studies. In A. Sannino, H. Daniels, & K. D. Gutiérrez (Eds.), *Learning and expanding with activity theory* (pp. 19–39). Cambridge University Press.

Bowen, G. A. (2009). Document analysis as a qualitative research method. *Qualitative Research Journal*, *9*(2), 27–40. https://doi.org/10.3316/qrj0902027

Braun, V., & Clarke, V. (2013). *Successful qualitative research*: A practical guide for beginners. Sage.

Bronfenbrenner, U. (1974). *Developmental research, public policy, and the ecology of the child. Child Development*, *45*(1), 1–5. https://doi.org/10.2307/1127743

Broström, S., Einarsdottir, J., & Samuelsson, I. P. (2018). The Nordic perspective on early childhood education and care. In M. Fleer, & B. van Oers (Eds.), *International handbook of early childhood education*. *Springer international handbooks of education*. Springer. https://doi.org/10.1007/978-94-024-0927-7_45

Brown, P. M., & Remine, M. D. (2008). Flexibility of programme delivery in providing effective family-centred intervention for remote families. *Deafness and Education International*, *10*(4), 213–225. https://doi.org/10.1179/146431508790559742

Bruce, A., Quinn, G., Degener, T., Burke, C., Quinlivan, S., Castellino, J., Kenna, P., & Kilkelly, U. (2002). *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability*. United Nations Press. https://www.ohchr.org/sites/default/files/Documents/Publications/HRDisabilityen.pdf

Bruder, M. B., & Dunst, C. J. (2014). Parental judgements of early childhood intervention personnel practices. *Topics in Early Childhood Special Education*, *34*(4), 200–210. https://doi.org/10.1177/0271121414522527

Cameron, D. L. (2018). Barriers to parental empowerment in the context of multidisciplinary collaboration on behalf of preschool children with disabilities. *Scandinavian Journal of Disability Research*, *20*(1), 277–285. https://doi.org/10.16993/sjdr.65

Campbell, F. (2009). *Contours of ableism: The production of disability and abledness*. Springer.

Campbell, J., & Oliver, M. (2013). *Disability politics: Understanding our past, changing our future*. Routledge. https://doi.org/10.4324/9780203410639

Carpenter, B. (2007). The impetus for family-centred early childhood intervention. *Child: Care, Health and Development*, *33*(6), 664–669. https://doi.org/10.1111/j.1365-2214.2007.00727.x

Charmaz, K. (2020). Experiencing stigma and exclusion: The influence of neoliberal perspectives, practices, and policies on living with chronic illness and disability. *Symbolic Interaction*, *43*(1), 21—45. https://doi.org/10.1002/SYMB.432

Colver, A. (2007). A shared framework and language for childhood disability. *Developmental Medicine and Child Neurology*, *47*(11), 780—784. https://doi.org/10.1111/j.1469-8749.2005.tb01078.x

Committee on the Rights of Persons with Disabilities. (2016). General comment no. 4. Article 24: Right to inclusive education (CRPD/C/GC/4). https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-4-article-24-right-inclusive

Committee on the Rights of the Child. (2006). General comment no. 9: The rights of children with disabilities (CRC/C/GC/9). https://www.refworld.org/docid/461b93f72.html

Committee on the Rights of the Child. (2009). General comment no. 12: The right of the child to be heard (CRC/C/GC/12). https://www.refworld.org/docid/4ae562c52.html

Committee on the Rights of the Child. (2011). General comment no. 13: The right of the child to freedom from all forms of violence (CRC/C/GC/13). https://www2.ohchr.org/english/bodies/crc/docs/crc.c.gc.13_en.pdf

Connors, C., & Stalker, K. (2007). Children's experiences of disability: Pointers to a social model of childhood disability. *Disability and Society*, *22*(1), 19—33. https://doi.org/10.1080/09687590601056162

Convention on the Rights of Persons with Disabilities (CRPD). (2007). https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

Convention on the Rights of the Child (CRC). (1989). https://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx

Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating: Quantitative and qualitative research*. Prentice Hall.

Curran, T., & Runswick-Cole, K. (2014). Disabled children's childhood studies: A distinct approach? *Disability & Society*, *29*(10), 1617—1630. https://doi.org/10.1080/09687599.2014.966187

Darrah, J., Wiart, L., Magill-Evans, J., Ray, L., & Andersen, J. (2012). Are family-centred principles, functional goal setting and transition planning evident in therapy services for children with cerebral palsy? *Child: Care, Health and Development*, *38*(1), 41—47. https://doi.org/10.1111/j.1365-2214.2010.01160.x

Degener, T. (2016). Disability in a human rights context. *Laws*, *5*(3), 35. https://doi.org/10.3390/laws5030035

Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhood Special Education*, *28*(1), 42–52. https://doi.org/10.1177/0271121408316699

Dempsey, I., & Keen, D. (2016). Desirable outcomes associated with family-centred practices for young children with a disability. In H. Sukkar, C. Dunst, & J. Kirkby, (Eds.), *Early childhood intervention: Working with families of young children with special needs* (pp. 75–88). Routledge.

Dempsey, I., & Nankervis, K. (2006). Conceptions of disability. In I. Dempsey, & K. Nankervis (Eds.), *Community disability services: An evidence-based approach to practice* (pp. 3–26). UNSW Press.

Dodd, J., Saggers, S., & Wildy, H. (2009). Constructing the 'ideal' family for family-centred practice: Challenges for delivery. *Disability and Society*, *24*(2), 173–186, https://doi.org/10.1080/09687590802652447

Dunst, C. J., & Espe-Sherwindt, M. (2016). Family-centered practices in early intervention. In B. Reichow, B. A. Boyd, E. E. Barton, & S. L. Odom (Eds.), *Handbook of early childhood special education* (pp. 37–55). Springer.

Dunst, C. J. (2000). Revisiting "Rethinking early intervention". *Topics in Early Childhood Special Education*, *20*(2), 95–104. https://doi.org/10.1177/027112140002000205

Dunst, C. J. (2002). Family-centered practices: Birth through high school. *The Journal of Special Education*, *36*(3), 141–149. https://doi.org/10.1177/00224669020360030401

Dunst, C. J., & Trivette, C. M. (2014). Capacity-building family-systems intervention practices. In G. Singer, D. Biegel, & P. Conway (Eds.), *Family support and family caregiving across disabilities* (pp. 39–63). Routledge.

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(4), 370–378. https://doi.org/10.1002/mrdd.20176

Edwards, A. (2004). The new multi-agency working: Collaborating to prevent the social exclusion of children and families. *International Journal of Integrated Care*, *12*(5), 39. https://doi.org/10.1108/14769018200400033

Edwards, A. (2011). Building common knowledge at boundaries between professional practices. *International Journal of Educational Research*, *50*(1), 33–39. https://doi.org/10.1016/j.ijer.2011.04.007

Edwards, A. (2017). *Working relationally in and across practices: A cultural-historical approach to collaboration*. Cambridge University Press.

Edwards, A. (2020). Agency, common knowledge, and motive orientation: Working with insights from Hedegaard in research on provision for vulnerable children and

young people. *Learning, Culture and Social Interaction*, *26*, 100224. https://doi.org/10.1016/j.lcsi.2018.04.004

Edwards, A., Daniels, H., Gallagher, T., Leadbetter, J., & Warmington, P. (2009). *Improving inter-professional collaborations: Multi-agency working for children's wellbeing*. Routledge.

Egilson, S. T. (2011). Parent perspectives of therapy services for their children with physical disabilities. *Scandinavian Journal of Caring Sciences*, *25*(2), 277–284. https://doi.org/10.1111/j.1471-6712.2010.00823.x

Egilson, S. T. (2015). User perspectives on support services to disabled children and their families. *Childhood and disability in the Nordic countries*, 231–245. https://doi.org/10.1057/9781137032645_15

Egilson, S. T., & Hemmingsson, H. (2009). School participation of students with physical and psychosocial limitations: A comparison. *British Journal of Occupational Therapy*, *72*(4), 144–52. https://doi.org/10.1177/030802260907200402

Egilson, S. T., Ólafsdóttir, L. B., Ingimarsdóttir, A. S., Haraldsdóttir, F., Jóhannsdóttir, Á., Gibson, B. E., & Hardonk, S. (2021). Life quality and participation of disabled children and young people: Design and methods of a transformative study. *International Journal of Qualitative Methods*, *20*. https://doi.org/10.1177/16094069211016713

Egilson, S. Þ., & Stefánsdóttir, S. (2014). Velferðarþjónusta og fötluð börn: Reynsla foreldra af starfi Fjölskyldudeildar Akureyrarbæjar [Welfare services and disabled children: Perspectives from parents in the municipality of Akureyri]. *Stjórnmál og stjórnsýsla* [*Icelandic Review of Politics and Administration*], *10*(2), 589. https://doi.org/10.13177/irpa.a.2014.10.2.19

Egilson, S. Þ., Ottósdóttir, G., & Skaptadóttir, U. D. (2020). The intersection of childhood disability and migration in family lives. *Scandinavian Journal of Disability Research*, *22*(1). https://doi.org/10.16993/sjdr.689

Egilson, S. Þ., Skaptadóttir, U. D., & Ottósdóttir, G. (2019). Innflytjendafjölskyldur með fötluð börn: Reynsla foreldra [Immigrant families with disabled children: Parents' experiences]. *Tímarit um uppeldi og menntun* [*Icelandic Journal of Education*], *28*(1). https://doi.org/10.24270/tuuom.2019.28.1

Einarsdóttir, J., & Jónsdóttir, A. H. (2019). Parent-preschool partnership: Any levels of power. *Early Years*, *39*(2), 175–189. https://doi.org/10.1080/09575146.2017.1358700

Elvarsdóttir, S. A. & Gunnþórsdóttir, H. (2014). Sérkennsla í nýju ljósi: Frá aðgreiningu til samvinnu [Special education in a new light: From segregation to collaboration] *Glæður: Fagtímarit íslenskra sérkennara* [*Embers: Journal of the association of Icelandic special educators*], *24*, 51–60

Engeström, Y. (1987). *Learning by expanding: An activity-theoretical approach to developmental research*. Orienta-Kosultit.

Engeström, Y. (2001). Expansive learning at work: Toward an activity theoretical reconceptualization. *Journal of Education and Work*, *14*(1), 133–156. https://doi.org/10.1080/13639080123238

Engeström, Y. (2016). *Studies in expansive learning*. University Press.

Espe-Sherwindt, M. (2008). Family-centred practice: Collaboration, competency, and evidence. *Support for Learning*, *23*(3), 136–143. https://doi.org/10.1111/j.1467-9604.2008.00384.x

Espe-Sherwindt, M., & Serrano, A. M. (2016). It takes two: The role of family-centered practices in communication intervention. *Revista de Logopedia, Foniatría y Audiología*, *36*(4), 162–169.

European Agency for Special Needs and Inclusive Education. (2017). *Education for all in Iceland – External audit of the Icelandic system for inclusive education*. https://www.stjornarradid.is/media/menntamalaraduneyti-media/media/frettatengt2016/Final-report_External-Audit-of-the-Icelandic-System-for-Inclusive-Education.pdf

Evetts, J. (2011). A new professionalism? Challenges and opportunities. *Current Sociology*, *59*(4), 406–422. https://doi.org/10.1177/0011392111402585

Ferguson P. M., & Nusbaum E. (2012). Disability studies: What is it and what difference does it make? *Research and Practice for Persons with Severe Disabilities*, *37*(2), 70–80. https://doi.org/10.1177/154079691203700202

Ferguson, P. (2001). Mapping the family. Disability studies and the exploration of parental responses to disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 373–395). Sage.

Fern, E. F. (2001). *Advanced focus group research*. Sage.

Fleming, J. L., Sawyer, L. B., & Campbell, P. H. (2011). Early intervention providers' perspectives about implementing participation-based practices. *Topics in Early Childhood Special Education*, *30*(4), 233–244. https://doi.org/10.1177/0271121410371986

Fordham, L., Gibson, F., & Bowes J. (2011). Information and professional support: Key factors in the provision of family-centred early childhood intervention services. *Child: Care, Health and Development*, *38*(5), 647–653. https://doi.org/10.1111/j.1365-2214.2011.01324.x

Foster, T. D., Decker, K. B., Vaterlaus, J. M., & Belleville, A. (2020). How early intervention practitioners describe family-centred practice: A collective broadening of the definition. *Child: Care, Health and Development*, *46*(3), 268–274. https://doi.org/10.1111/cch.12749

Franklin, A., & Sloper, P. (2009). Supporting the participation of disabled children and young people in decision-making. *Children & Society*, *23*(1), 3–15. https://doi.org/10.1111/j.1099-0860.2007.00131.x

Friedman, C., & Owen, A. L. (2017). Defining disability: Understandings of and attitudes towards ableism and disability. *Disability Studies Quarterly*, *37*(1). https://dsqsds.org/article/view/5061/4545

García-Grau, P., Martínez-Rico, G., McWilliam, R. A., & Grau, D. (2021). Early intervention and family-centeredness in Spain: Description and profile of professional practices. *Topics in Early Childhood Special Education*, *41*(2), 160–172. https://doi.org/10.1177/0271121419846332

García-Grau, P., McWilliam, R. A., Bull, K., & Foster, J. (2022). Good goals matter: Functional child goals, family goals, and parent perceptions of difference in performance. *Infants & Young Children*, *35*(2), 106–119. https://doi.org/10.1097/IYC.0000000000000215

García-Grau, P., McWilliam, R. A., Martínez-Rico, G., & Morales-Murillo, C. P. (2019). Child, family, and early intervention characteristics related to family quality of life in Spain. *Journal of Early Intervention*, *41*(1), 44–61. https://doi.org/10.1177/1053815118803772

Garzón Díaz, K. D. R., & Goodley, D. (2021). Teaching disability: Strategies for the reconstitution of disability knowledge. *International Journal of Inclusive Education*, *25*(14), 1577–1596. https://doi.org/10.1080/13603116.2019.1640292

Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. Sage.

Goodley, D., & McLaughlin, J. (2008). Theorising parents, professionals, and disabled babies. In J. McLaughlin, D. Goodley, E. Clavering, & P. Fisher (Eds.), *Families raising disabled children: Enabling care and social justice*. Springer.

Goodley, D., & Runswick-Cole, K. (2011). Problematising policy: Conceptions of 'child', 'disabled' and 'parents' in social policy in England. *International Journal of Inclusive Education*, *15*(1), 71–85. https://doi.org/10.1080/13603116.2010.496197

Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, *34*(6), 972–997. https://doi.org/10.1080/09687599.2019.1566889

Gretar L. Marinósson, & Kristín Þ. Magnúsdóttir. (2016). Greiningarheiti grunnskólanema. Til íhugunar [Diagnostic classification of elementary school students. For consideration]. In Dóra S. Bjarnason, Hermína Gunnþórsdóttir, & Ólafur Páll Jónsson (Eds.), *Skóli margbreytileikans. Menntun og manngildi í kjölfar Salamanca* [*School for all. Education and human values following Salamanca*] (pp. 137–155). Háskólaútgáfan.

Greve, B. (2007). What characterise the Nordic welfare state model. *Journal of Social Sciences*, *3*(2), 43–51. https://www.academia.edu/671692/What_Characterise_the_Nordic_Welfare_State_Model

Grue, J. (2011). Discourse analysis and disability: Some topics and issues. *Discourse & Society*, *22*(5), 532–546. https://doi.org/10.1177/0957926511405572

Grue, J. (2016). The social meaning of disability: A reflection on categorisation, stigma and identity. *Sociology of Health & Illness*, *38*(6), 957–964. https://doi.org/10.1111/1467-9566.12417

Gunnþórsdóttir, H., Barillé, S., & Meckl, M. (2019). The education of students with immigrant background in Iceland: Parents' and teachers' voices. *Scandinavian Journal of Educational Research*, *63*(4), 605–616. https://doi.org/10.1080/00313831.2017.1415966

Guralnick, M. J. (2008). International perspectives on early intervention. *Journal of Early Intervention, 30*(2), 90–101. https://doi.org/10.1177/1053815107313483

Guralnick, M. J. (2011). Why early intervention works: A systems perspective. *Infants and Young Children*, *24*(1), 6. https://doi: 10.1097/IYC.0b013e3182002cfe

Guralnick, M. J. (2017). Early intervention for children with intellectual disabilities: An update. *Journal of Applied Research in Intellectual Disabilities*, *30*(2), 211–229. https://doi.org/10.1111/jar.12233

Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration. *Australian Occupational Therapy Journal*, *49*(1), 14–24. https://doi.org/10.1046/j.0045-0766.2001.00273.x

Haug, P. (2016). Understanding inclusive education: Ideals and reality. *Scandinavian Journal of Disability Research*, *19*(3), 206–217. https://doi.org/10.1080/15017419.2016.1224778

Hermansen, H. (2020). Knowledge discourses & coherence in professional education. *Professions and Professionalism*, *10*(3). https://doi.org/10.7577/pp.3713

Hiebert-Murphy, D., Trute, B., & Wright, A. (2011). Parents' definition of effective child disability support services: Implications for implementing family-centered practice. *Journal of Family Social Work*, *14*(2), 144–158. https://doi.org/10.1080/10522158.2011.552404

Hodge, N., & Runswick-Cole, K. (2008). Problematising parent–professional partnerships in education. *Disability and Society*, *23*(6), 637–647. https://doi.org/10.1080/09687590802328543

Hopwood, N., & Edwards, A. (2017). How common knowledge is constructed and why it matters in collaboration between professionals and clients. *International Journal of Educational Research*, *83*, 107–119. https://doi.org/10.1016/j.ijer.2017.02.007

Hopwood, N., & Mäkitalo, Å. (2019). Learning and expertise in support for parents of children at risk: A cultural-historical analysis of partnership practices. *Oxford Review of Education*, *45*(5), 587–604. https://doi.org/10.1080/03054985.2018.1553776

Huijts, P. M., De Bruijn, E., & Schaap, H. (2011). Revealing personal professional theories. *Quality & Quantity*, *45*(4), 783–800. https://doi.org/10.1007/s11135-010-9322-z

Ingólfsdóttir, J. G., Traustadóttir, R., & Egilson, S., T. (2021). Rethinking practices by rethinking expertise: A relational approach to family-centred inclusive services. *Scandinavian Journal of Disability Research*, *23*(1), 1–13. https://doi.org/10.16993/sjdr.734

Ingólfsdóttir, J., G. & Traustadóttir, R. (2010). Þjónusta og þarfir: Hvernig mætir velferðarkerfið þörfum fatlaðra barna og fjölskyldna þeirra? [Services and needs: How does the welfare system meet the needs of disabled children and their families?]. In *Rannsóknir í félagsvísindum XI* [*Research in the social sciences XI*]. Félagsvísindastofnun Háskóla Íslands. https://skemman.is/handle/1946/6839

Jackson, M. A. (2018). Models of disability and human rights: Informing the improvement of built environment accessibility for people with disability at neighbourhood scale? *Laws*, *7*(1). http://dx.doi.org/10.3390/laws7010010

James, A., Jenks, C., & Prout, A. (1998). *Theorizing childhood*. Polity Press.

Kerr, M. E., & Bowen, M. (1988). *Family evaluation: An approach based on Bowen therapy*. W. W. Norton and Company.

King, G., & Chiarello, L. (2014). Family-centered care for children with cerebral palsy: conceptual and practical considerations to advance care and practice. *Journal of Child Neurology*, *29*(8), 1046–1054. https://doi.org/10.1177/0883073814533009

King, G., Williams L., & Goldberg, S. Hahn. (2017). Family-oriented services in paediatric rehabilitation: A scoping review and framework to promote parent and family wellness. *Child: Care, health and development*, *43*(3), 334–347. https://doi.org/10.1111/cch.12435

Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies*, *44*(7), 1250–1260. https://doi.org/10.1016/j.ijnurstu.2006.08.015

Kogan, M. (2005). Modes of knowledge and patterns of power. *Higher Education*, *49*(1), 9–30. https://www.jstor.org/stable/25068056

Kokorealias, K. M., Gignac, M. A. M., Naglie G., & Cameron J. I. (2019). Towards a universal model of family centered care: A scoping review. *BMC Health Services Research*, *19*(1), 564. https://doi.org/10.1186/s12913-019-4394-5

Krueger, R. A., & Casey, M. A. (2009). *Focus groups: A practical guide for applied research*. Sage.

Lang, D. (2020). *Parenting and family diversity issues*. Ames, IA: Iowa State University Digital Press. https://doi.org/10.31274/isudp.8

Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health, and Development*, *29*(5), 357–366. https://doi.org/10.1046/j.1365-2214.2003.00351.x

Law, M., Teplicky, R., King, S., King, G., Kertoy, M., Moning, T., Rosenbaum, P., & Burke-Gaffney, J. (2005). Family-centred service: Moving ideas into practice. *Child: Care, Health, and Development*, *31*(6), 633—642. https://doi.org/10.1111/j.1365-2214.2005.00568.x

Lawson, A., & Beckett, A. E. (2021). The social and human rights models of disability: towards a complementarity thesis. *The International Journal of Human Rights*, *25*(2), 348—379. https://doi.org/10.1080/13642987.2020.1783533

Leiter, V. (2004). Dilemmas in sharing care: Maternal provision of professionally driven therapy for children with disabilities. *Social Science & Medicine*, *58*(4), 837—849. https://doi.org/10.1016/s0277-9536(03)00258-2

Leont'ev, A. N. (1974). The problem of activity in psychology. *Soviet Psychology*, *13*(2), 4—33. https://doi.org/10.2753/rpo1061-040513024

Lög um breytingu á lögum no. 59/1992, ummálefni fatlaðra, með síðari breytingum [Act amending Act No. 59/1992, on disability issues, with subsequent amendments] no. 152/2010. https://www.althingi.is/altext/stjt/2010.152.html

Lög um Ráðgjafar- og Greiningarstöð [Law on the Counselling and Diagnostic Centre] no. 83/2003. https://www.althingi.is/lagas/nuna/2003083.html

Lög um samþættingu þjónustu í þágu farsældar barna [Act on the integration of services in favour of children's wellbeing] no. 86/2021. https://www.althingi.is/altext/151/s/1723.html

Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir [Act on services to disabled people with long term service needs] no. 85/2018. https://www.althingi.is/lagas/nuna/2018038.html

Löve, L., Traustadóttir, R., & Rice, J. G. (2018). Trading autonomy for services: Perceptions of users and providers of services for disabled people in Iceland. *Alter*, *12*(4), 193—207. https://doi.org/10.1016/j.alter.2018.04.008

Lundeby, H., & Tøssebro, J. (2008). Exploring the experiences of "not being listened to" from the perspective of parents with disabled children. *Scandinavian Journal of Disability Research*, *10*(4), 258—274. https://doi.org/10.1080/15017410802469700

MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations*, *8*(1), 74—85. https://doi.org/10.1111/j.1369-7625.2005.00319.x.

Marinósson, G. L., & Bjarnason, D. S. (2014). Special education today in Iceland. In A. F. Rotatori, J. P. Bakken, S. Burkhardt, F. E. Obiakor, & U. Sharma (Eds.), *Special education international perspectives: Practices across the globe* (Part of *Advances in special education*) (pp. 271—309), *28*, Emerald Group Publishing.

Mas, J. M., Dunst, C. J., Balcells-Balcells, A., Garcia-Ventura, S., Giné, C., & Cañadas, M. (2019). Family-centered practices and the parental well-being of young children with disabilities and developmental delay. *Research in Developmental Disabilities*, *94*, 103495. https://doi.org/10.1016/j.ridd.2019.103495

Mas, J. M., Dunst, C. J., Hamby, D. W., Balcells-Balcells, A., García-Ventura, S., Baqués, N., & Giné, C. (2022). Relationships between family-centred practices and parent involvement in early childhood intervention. *European Journal of Special Needs Education*, *37*(1), 1–13. https://doi.org/10.1080/08856257.2020.1823165

Matthews, E. J., Gelech, J., Graumans, R., Desjardins, M., & Gélinas, I. (2021). Mediating a fragmented system: Partnership experiences of parents of children with neurodevelopmental and neuromuscular disabilities. *Journal of Developmental and Physical Disabilities*, *33*(2), 311–330. https://doi.org/10.1007/s10882-020-09750-0

McCarthy, E., & Guerin, S. (2022). Family-centred care in early intervention: A systematic review of the processes and outcomes of family-centred care and impacting factors. *Child: Care, Health and Development*, *48*(1), 1–32. https://doi.org/10.1111/cch.12901

McLaughlin, J., Goodley, D., Clavering, E., & Fisher, P. (2008). *Families raising disabled children: Enabling care and social justice*. Springer.

McWilliam, R. A. (2010). *Routines-based early intervention. Supporting young children and their families*. Brookes.

McWilliam, R. A. (2016). Birth to three: Early intervention. In B. Reichow, B. A. Boyd, E. E. Barton, & S. L. Odom (Eds.), *Handbook of early childhood special education* (pp. 75–88). Springer.

Messiou, K. (2016). Research in the field of inclusive education: Time for a rethink? *International Journal of Inclusive Education*, *21*(2), 146–159. https://doi.org/10.1080/13603116.2016.1223184

Noordegraaf, M. (2015). Hybrid professionalism and beyond: (New) Forms of public professionalism in changing organizational and societal contexts. *Journal of Professions and Organization*, *2*(2), 187–206. https://doi.org/10.1093/jpo/jov002

O'Leary, Z. (2010). *The essential guide to doing your research project* (2nd ed.). Sage.

Odom, S. L., & Wolery, M. (2003). A unified theory of practice in early intervention/early childhood special education: Evidence-based practices. *The Journal of Special Education*, *37*(3), 164–173. https://doi.org/10.1177/00224669030370030601

Ólafsdóttir, L. B., Egilson, S. T., Árnadóttir, U., & Hardonk, S. C. (2019). Child and parent perspectives of life quality of children with physical impairments compared with non-disabled peers. *Scandinavian journal of occupational therapy*, *26*(7), 496–504. https://doi.org/10.1080/11038128.2018.1509371

Oliver, M. (1983). *Social work with disabled people*. Macmillan.

Oliver, M. (2013) The social model of disability: Thirty years on. *Disability and Society*, *28*(7), 1024–1026. https://doi.org/10.1080/09687599.2013.818773

Oliver, M. (2018). *Understanding disability: From theory to practice*. Macmillan International Higher Education.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Sage.

Preschool Act [Lög um leikskóla] no. 90/2008. https://www.government.is/media/menntamalaraduneyti-media/media/frettatengt2016/Preschool-Act-No-90-2008.pdf

Reglugerð um sérfræðiþjónustu sveitarfélaga við leik- og grunnskóla og nemendaverndarráð í grunnskólum no. 444/2019. [Regulation on municipal school services at pre-schools and compulsory schools and student protection councils in compulsory schools]. https://www.reglugerd.is/reglugerdir/eftir-raduneytum/menntamalaraduneyti/nr/16592

Reindal, S. M. (2008). A social-relational model of disability: A theoretical framework for special needs education. *European Journal of Special Needs Education*, *23*(2), 135–146. https://doi.org/10.1080/08856250801947812

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical and Occupational Therapy in Paediatrics*, *18*(1), 1–20. https://doi.org/10.1080/J006v18n01_01

Rouse, L. (2012). Family-centred practice: Empowerment, self-efficacy, and challenges for practitioners in early childhood education and care. *Contemporary Issues in Early Childhood*, *13*(1), 17–26. https://doi.org/10.2304/ciec.2012.13.1.17

Ruiz-Casares, M., Collins, T. M., Tisdall, E. K., & Grover, S. (2016). Children's rights to participation and protection in international development and humanitarian interventions: Nurturing a dialogue. *The International Journal of Human Rights*, *21*(1), 1–13. https://doi.org/10.1080/13642987.2016.1262520

Runswick-Cole, K., & Hodge, N. (2009). Needs or rights? A challenge to the discourse of special education. *British Journal of Special Education*, *36*(4), 198–203. https://doi.org/10.1111/j.1467-8578.2009.00438.x

Runswick-Cole, K., Lawthom, R., & Goodley, D. (2016). The trouble with 'hard working families.' *Community, Work and Family*, *19*(2), 257–260. https://doi.org/10.1080/13668803.2016.1134153

Sérkennslustefna Leikskólasviðs Reykjavíkurborgar [Special education policy of the Preschool Division of Reykjavík City]. (2009). Reykjavíkurborg: Leikskólasvið. https://reykjavik.is/sites/default/files/skjol_thjonustulysingar/Serkennslustefna_-_lokaeintak.pdf

Shakespeare, T. (2006). The social model of disability. In L. J. Davis (Ed.), *The disability studies reader* (2nd ed.) (pp. 197–204). Routledge.

Shakespeare, T. (2013). *Disability rights and wrongs revisited*. Routledge.

Shields, L. (2015). What is 'Family-centred care'? *European Journal for Person Centered Health Care*, *3*(2), 139–144. http://dx.doi.org/10.5750/ejpch.v3i2.993

Sigurðardóttir, S. M., Sigurðardóttir, A. K., Hansen, B., Ólafsson, K., & Sigþórsson, R. (2022). Educational leadership regarding municipal school support services in Iceland. *Educational Management Administration and Leadership*, *0*(0). https://doi.org/10.1177/17411432221076251

Simons, H. (2009). *Case study research in practice*. Sage.

Sjúkratryggingar Íslands [Icelandic Health Insurance]. (n.d.) https://www.sjukra.is/english/social-insurance-in-iceland/

Spyrou, S. (2019). An Ontological Turn for Childhood Studies? *Children & Society*, *33*, 316-323. https://doi.org/10.1111/chso.12292

Stake, R. E. (1995). *The art of case study research*. Sage.

Statistics Iceland. (2022). https://www.statice.is/publications/news-archive/inhabitants/population-in-the-3rd-quarter-2022/

Stefánsdóttir, S., & Egilson, S. T. (2016). Diverging perspectives on children's rehabilitation services: A mixed-methods study. *Scandinavian Journal of Occupational Therapy*, *23*(5), 374−382. https://doi.org/10.3109/11038128.2015.1105292

Swain, J., & French, S. (2001). The relationship between disabled people and health and welfare professionals. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 734−753). Sage.

Taylor, S. J., Bogdan, R., & DeVault, M. (2015). *Introduction to qualitative research methods*: *A guidebook and resource* (4th ed.). John Wiley & Sons.

The Icelandic national curriculum guide for preschools. (2011). https://www.government.is/publications/reports/report/2012/01/22/The-Icelandic-national-curriculum-guide-for-preschools-2012-/

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability and Society*, *19*(6), 569−583. https://doi.org/10.1080/0968759042000252506

Traustadóttir, R. (2006). *Fötlun*: *Hugmyndir og aðferðir á nýju fræðasviði* [*Disability*: *Ideas and methods in a new field of study*]. Háskólaútgáfan.

Traustadóttir, R. (2009). Disability studies, the social model and legal developments. In O. M. Arnardottir, & G. Quinn (Eds.), *The UN convention on the rights of persons with disabilities: European and Scandinavian perspectives* (pp. 3−16). Brill.

Traustadóttir, R., Ytterhus, B., Egilson, S. Th., & Berg, B. (Eds). (2015). *Childhood and disability in the Nordic countries: Being, becoming, belonging*. Palgrave Macmillan.

Tregaskis, C. (2002). Social model theory: The story so far. *Disability & Society*, *17*(4), 457−470. https://doi.org/10.1080/09687590220140377

Trivette, C. M., Dunst, C. J., & Hamby, D. W. (2010). Influences of family-systems intervention practices on parent-child interactions and child development. *Topics in*

*Early Childhood Special Education*, *30*(1), 3—19.
https://doi.org/10.1177/0271121410364250

Tuomi-Grön, T. (2007). Developmental transfer as a goal of collaboration between school and work: A case study in the training of day care interns. *An International Journal of Human Activity Theory*, *1*, 41—67.
https://core.ac.uk/download/pdf/228665672.pdf

Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of family—professional partnerships: Collective empowerment as the model for the early twenty-first century. In J. P. Shonkoff, & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (pp. 630—650). University Press.
https://doi.org/10.1017/CBO9780511529320.029

Tøssebro, J. (2004). Introduction to the special issue: Understanding disability. *Scandinavian Journal of Disability Research*, *6*(1), 3—7.
https://doi.org/10.1080/15017410409512635

Tøssebro, J., & Wendelborg, C. (2015). Ordinary or not? Families of children growing up with disabilities. In R. Traustadóttir, B. Ytterhus, S. T. Egilson, & B. Berg (Eds.), *Childhood and disability in the Nordic countries: Being, becoming, belonging* (pp. 199—213). Palgrave Macmillan. https://doi.org/10.1057/9781137032645_13

UNICEF Innocenti Research Centre. (2007). *Promoting the rights of children with disabilities* (Innocenti digest no. 13). United Nations Publications.
https://www.un.org/esa/socdev/unyin/documents/children_disability_rights.pdf

United Nations, Human Rights Treaty Bodies. (2022). Joint Statement: The rights of children with disabilities. *Committee on the rights of the child and committee on the rights of children with disabiliti*es. https://eurochild.org/uploads/2022/04/CRC-CRPD-joint-statement_18March2022.pdf

UPIAS. (1976*). Fundamental principles of disability: Being a summary of the discussion held on 22nd November 1975 and containing commentaries from each organisation*. UPIAS/Disability Alliance, 1976. https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf

Velferðarráðuneytið [Ministry of Welfare]. (2010). *Samkomulag ríkis og sveitarfélaga um tilfærslu þjónustu við fatlaða [Agreement between the state and municipalities on the transfer of services for the disabled]*.
https://www.stjornarradid.is/media/velferdarraduneyti-media/media/utgafa2010/SamkomulagTilfaerslaThjonustuFatladra.pdf

Viðskiptablaðið [Icelandic Financial News]. (2021, May 6). *Há atvinnuþátttaka kvenna skilar góðum lífskjörum [High participation rate of women in the labour force results in a good standard of living]*. Viðskiptablaðið. https://www.vb.is/frettir/god-lifskjor-islenskum-konum-ad-thakka/105724/?q=UN%20women

Vygotsky, L. (1980). *Mind in society: The development of higher psychological processes*. Harvard University Press.

Wickenden, M. (2019). Reimagining disabled children with childhood studies: The challenge of difference. In S. Spyrou, R. Rosen, & D. T. Cook (Eds.), *Reimagining childhood studies* (pp. 183—199). Bloomsbury

Williams, V., & Porter, S. (2017). The meaning of 'choice and control' for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities*, *30*(1), 97—108. https://doi.org/10.1111/jar.12222

Woods, J. J., Wilcox, M. J., Friedman, M., & Murch, T. (2011). Collaborative consultation in natural environments: Strategies to enhance family-services. *Language, Speech and Hearing Services in Schools*, *42*(3) 379—392. https://doi.org/10.1044/0161-1461(2011/10-0016)

Yin, R. K. (2009). *Case study research: Design and methods*. Sage.

Ytterhus, B., Egilson, S. T., Traustadóttir, R., & Berg, B. (2015). Perspectives on Childhood and Disability. In R. Traustadóttir, B. Ytterhus, S. T. Egilson, & B. Berg (Eds.), *Childhood and disability in the Nordic countries: Being, becoming, belonging* (pp. 15—33). Palgrave Macmillan

Ytterhus, B., Wendelborg, C., & Lundeby, H. (2008). Managing turning points and transitions in childhood and parenthood — insights from families with disabled children in Norway. *Disability and Society*, *23*(6), 625—636. https://doi.org/10.1080/09687590802328535

# 5 Collection of Articles

## 5.1 Introduction

The four peer reviewed articles contained in this chapter reflect the progress of the research and present the findings. Each article adopts a specific and targeted perspective for the purpose of contributing to understanding the mismatch between the official aims of services to families of young disabled children and the actual services provided to them. Furthermore, the professional views and attitudes of the participants serving the families are examined along with their working conditions. Each article also contributes innovative recommendations for service development.

Family-centred theory and cultural-historical activity theory informed the arguments and recommendations made, since these allow for a critical examination of the similarities and differences of the interacting activity systems. These theories are practical instruments to detect the contradictions within and between the main activity systems in the lives of disabled children and their families and provide an opportunity for both the system and practice to develop.

The first of the four articles presented in this chapter, titled Thinking relationally: Disability, families and cultural-historical activity theory, was published in January 2012 in the journal *Barn* [*Child*], published by the Norwegian Centre for Child Research. In this article, three theoretical approaches were presented to views on disability, services, and organisational and professional development. It argues that these three theoretical approaches could, in concert, create the basis for changes in the implementation of welfare services for many families of disabled children in Iceland. The three approaches are the socio-relational understanding of disability, family-centred theory, and cultural-historical activity theory (CHAT).

The second article, titled Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice, was published by the *Journal of Intellectual Disabilities* in June 2017. This paper examines the reported discrepancies between the aims of welfare services in Iceland and the experiences of parents raising young disabled children. It reports that all the parents in the study were pleased with their children's preschools but found it onerous to seek specialised services elsewhere at inconvenient hours. Prevailing views on disability and service delivery were also considered and cultural-historical activity theory (CHAT) was introduced as a beneficial framework for further improvements to the system.

The third article, Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland was published in *Nordisk Välfärdsforskning|Nordic Welfare Research* in June 2018. The article explores contradictions within the service system and suggests corresponding learning actions

according to Engeström's expansive learning theory. It argues that changes in services influenced by a recent emphasis on disability and children's rights call for systemic changes in professional thinking and provision of services. Based on the characteristics of the contradictions within the service system, suggestions are made for changes in resource allocation to support a relational turn in professional practices.

The fourth article, titled Rethinking practices by rethinking expertise: A relational approach to family-centred inclusive services, was published in the *Scandinavian Journal of Disability Research* in January 2021. In this article, the focus shifted from the service users to the service providers as it examines the perspectives and working conditions of professionals who provide specialised services. The findings indicate that old service traditions are still prevalent despite changes in professional criteria and the declared policy of the welfare system. Based on the findings, suggestions for changes grounded in relational approaches in professional practice were put forward to demand rethinking and developing expertise and professional work. It argues that such changes involve the adaption of socio-relational and rights-based understandings of disability and childhood as articulated in the CRPD and the CRC and highlights how conventional thinking about professionalism, professional practices, and administrative arrangements need to be challenged. Three relational concepts, referred to as gardening tools, are described as compelling instruments to develop overlooked possibilities for such changes and move practice forward.

## 5.2  The Articles

I.      Ingólfsdóttir, J. G., Traustadóttir, R., Egilson, S. T., and Goodley, D. (2012). Thinking relationally: Disability, families and cultural-historical activity theory. *Barn*, *4*, 13-24. https://doi.org/10.5324/barn.v30i4.4122

II.     Ingólfsdóttir, J. G., Egilson, S. T., and Traustadottir, R. (2017). Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice. *Journal of Intellectual Disabilities*, *22*(4), 361-377. https://doi.org/10.1177/1744629517714644

III.    Ingólfsdóttir, J. G., Jóhannsdóttir, T., and Traustadóttir, R. (2018). Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland. *Nordisk Välfärdsforskning| Nordic Welfare Research*, *3*(1), 33-46. https://doi.org/10.18261/issn.2464-4161-2018-01-04

IV.     Ingólfsdóttir, J. G., Traustadóttir, R., and Egilson, S. T. (2021). Rethinking practices by rethinking expertise: A relational approach to family-centred inclusive services. *Scandinavian Journal of Disability Research*, *23*(1), 1-13. http://doi.org/10.16993/sjdr.734

# Article I

R

# Thinking relationally: Disability, families and cultural-historical activity theory

**Jóna G. Ingólfsdóttir, Rannveig Traustadóttir, Snæfríður Thóra Egilson and Dan Goodley**

Abstract

It is commonly expressed by parents of disabled children within the Nordic region that there is a mismatch between the official aims of the welfare state and the services provided. In an attempt to explore ways to improve welfare services for disabled children and their families this article proposes three social-relational approaches to disability, family, and service systems which combined may create a basis for new and dynamic ways of working with families. The first approach is a relational understanding of disability, the second a family-centred theory characterized by partnerships with parents, and the third a cultural-historical activity theory emphasizing inter-organizational learning as a method to develop services. Developing ways to fulfil the welfare states' promise of equality and human rights for all is particularly relevant now when all the Nordic countries are currently striving to meet the demands of the new UN Convention on the Rights of Persons with Disabilities.

## Introduction

Modern trends in welfare services are characterized by ideas about freedom, equality and solidarity, aiming at equal opportunities for each member of society. These principles are also clearly outlined in the new UN Convention on the Rights of Persons with Disabilities (UN CRPD) (United Nations 2007), signed by 154 nations including all the Nordic countries (as of September 2012). The welfare state plays a key role in achieving such civil liberties. As the Nordic countries have a long tradition of community focus in welfare services, these human rights perspectives regarding disabled people have been found for several decades in welfare policies and

legislation in those countries (Abrahamson, Boje and Greve 2005, Greve 2007, Ólafsson 2005). Nevertheless, it is commonly expressed by parents of disabled children within the Nordic region that there is a mismatch between the goals of the services and the service provision (Jónsdóttir 2003, Tössebro and Lundeby 2002). Furthermore they find services to be incidental, incompatible and uncompromising (Bjarnason 2010, Egilson 2011, Lundeby and Tøssebro 2008, Ytterhus, Wendelborg and Lundeby 2008). Additionally, many parents complain about not being listened to and having to fight for their statutory rights (Bjarnason 2010, Jónsdóttir 2003, Lundeby and Tøssebro, 2008). This seems to be the case despite the clear intentions of the welfare

state to provide individual support and modified solutions. Given the above findings of the research literature on services for disabled children and their families there is an obvious need for new approaches if the promises of the welfare services are to be fulfilled.

In this article we present three theoretical approaches to disability, family and service systems, and argue that these can, in concert, create the basis for new forms of welfare services for families of disabled children. The three approaches are: First, a social-relational understanding of disability which has been developed during the past few decades where, instead of viewing disability as a medical condition, it has emerged as a socio-political category (Goodley 2011, Traustadóttir 2003, Tregaskis 2002). The second is a family-centred theory which highlights partnership with parents and focuses on the family's role in decision-making about their child's needs (Bruder 2000, Dunst and Trivette 1996, 2005, Espe-Sherwindt 2008, Law et al. 2003). And thirdly a cultural-historical activity theory (CHAT) which emphasizes inter-organizational learning as a method to develop services that can incorporate multiple perspectives and voices, and meet new interactive demands, trends and official goals (Engeström 2001). Here below we explore these approaches in-depth in an attempt to analyse how, if combined, these social-relational and dynamic approaches can advance our understanding of disability, family and welfare services. This is particularly relevant when all the Nordic countries are currently working towards meeting the demands of the new UN Convention on the Rights of Persons with Disabilities for equality, solidarity, participation, dignity and autonomy.

# Social-relational views on disability

Within the field of disability research the conceptualisation of disability is widely debated and one can find a plethora of definitions. In the minds of many the concept "disability" has changed from being a medically-defined classificatory concept, signifying an abnormality or malfunctions of the body or mind, to being seen as a socially produced phenomenon (Altman 2001, Thomas 2004) or as a relative construct emerging out of interaction between impairment and societal surroundings (Shakespeare 2006, Tøssebro 2004). Since the 1970s, the disability movement has aimed at moving the gaze from the impaired body to the important role of the surroundings, and the fact that societal barriers restrict the participation of people with impairments (Oliver 1990, Barnes, Mercer and Shakespeare 1999). This has succeeded in shifting debates about disability from bio-medically dominated agendas to discourses about politics, citizenship and accessibility (Gustavsson, Tøssebro and Traustadóttir 2005). These definitions presume that disability may be defined either in a person-oriented or in a situation-oriented way where the individual or personal "tragedy" understanding of disability is often referred to as the medical model opposed to the social-relational understanding of disability typically referred to as the social model.

Shakespeare (2006) argues that an understanding of the social model which focuses solely on societal barriers has become an obstacle to the further development of the disability movement and disability studies and suggests to always look upon disability as an interaction between

the individual and structural factors. This view accords with the main idea behind one of the definitions now commonly accepted, the so called Nordic relational view on disability as articulated by the Norwegian scholar Jan Tøssebro (2004). He describes disability from the viewpoint of the deepset notion of social equality and human rights within the Nordic societies, resulting in three main assumptions. (1) Disability is a person-environment mismatch that occurs because the environment is not adapted to accommodate the whole range of people, (2) disability is situational or contextual, meaning that specific individual limitations can become disabling or not due to concrete situations and (3) disability is relative, as the cut-off point in impairment-based disability definitions is to some extent arbitrary. Tøssebro (2004) further combines this relational view on disability to the interplay between the person and the societal surroundings and to the notion of equal rights and opportunities which are at the core of the Nordic welfare states. This environmentally relative definition views disability as constituted both by impairments and the disabling environment in which the person lives, and acknowledges that disability is physically based but socially produced. In practice this means that segregated, standardized solutions are not acceptable, and efforts should be made to allocate integrated and individualized services. This understanding also helps determine people's real needs and how these can be met. However, despite widespread acceptance of the social-relational understanding of disability in Nordic scholarship and policy, it has served primarily as a guiding philosophy rather than a basis to develop service practice (Gustavsson, Tøssebro and Traustadóttir 2005). We argue

for the importance of better integrating the social-relational and dynamic understanding of disability into services and suggest the benefits of combining this approach with other social theories, in particular family-centred theory, in order to contribute to improved services for children with disabilities and their families.

## Family-centred theory

The transition from medically focused to person- and family-centred models of service delivery has its roots in the ecological systems theory of human development outlined originally by Bronfenbrenner (1979). Although this is a generally accepted approach, services seem to have tendencies to be more child-focused, taking the form of a specialist concentrating on the child alone. This professional work is typically controlled by the processes of diagnosis as is often the case in educational and therapeutic circumstances. In this context scholars have drawn attention to how parents of disabled children have been affected by research that pathologises their children's condition instead of acknowledging disability as constantly shifting, always moveable and social in character (Goodley and McLaughlin 2008). Recognising the socially constructed nature of parenting explains why parents of disabled children resist normative modes of feeling about their kids or dealing with everyday life as they seek out productive alternatives according to their needs and lived experiences. It is evident that a child focused approach alone does not lead to a constructive change if the parents' views and needs for support and information are overlooked (Turnbull, Turbiville and Turnbull 2000).

Consequently, it seems essential to search for empirically useful strategies for conceptualization and characterisation of the complex social processes in serving families raising a disabled child.

## Family-centred services

Currently there is an overall agreement in welfare policies and legislations that the family is the most desirable place for disabled children to grow up in, and disabled children are entitled to attend mainstream schools and leisure activities with their nondisabled peers. This is in line with the UN Convention on the Rights of the Child (United Nations 1989), the Salamanca Statement and Framework for Action on Special Needs Education (United Nations 1994) and the UN CRPD (United Nations 2007). Furthermore it is an expressed goal within the Nordic welfare state that families with disabled children shall have access to coordinated and flexible services, adapted to their needs as interpreted by the parents and where parents are met as partners by the professionals (Arbeids- og sosialdepartementet 200, Félagsmálaráðuneytið 2006).

Family-centred theory is a philosophy and method of service delivery for children and parents that emphasizes partnership between the parents and service providers. It focuses on the family's role in decision-making concerning their child and recognizes parents as experts on their child's status and needs (Bruder 200, Dunst and Trivette 1996, 2005, Espe-Sherwindt 2008, Bamm and Rosenbaum 2008, Law et al. 2003*)*. Here the terms "parents" or/and "family" refer to all the important adults in a child's life. Furthermore family-centred theory takes the interplay between the person and the immediate surroundings into consideration. This process is affected by the relations between these settings and by the larger contexts (Turnbull and Turnbull 2001). The family is regarded as the basic social unit, the main educator, supporter and shaper of each person. Family-centred services also *emphasize* the recognition of the uniqueness of each family in terms of lifestyle, experience and culture which affects its view on disability, parental role and services (Law et al. 2003, Turnbull, Turbiville and Turnbull 2000*)*.

Thus, the basic principles of family-centred theory support the relevance of making every effort to recognize the parents' views on their own affairs. Acknowledging this leads to increased attention to environmental circumstances in conjunction with disability and how it affects the life of the child and its family. These family-centred values in service delivery are highly regarded by parents of disabled children but are yet to be fully understood and developed in practice (Bamm and Rosenbaum 2008, Egilson 2011). Bruder (2000) argues that research in early childhood practices during the past decades has provided a foundation for the growth and development of interventions aimed at minimizing the impact of a child's delay or impairment and promoting his or her competence which should be the main focus within services. Bruder also refers to Dunst, Trivette and Jodry (1997) when she argues that the processes that influence early learning and development are produced by the interaction of the environments experienced by a child and the characteristics of the people within these environments.

## Family-centred early intervention

During the last decade there have been increased arguments for an early interven-

tional approach in children's services in Nordic policymaking in pre-school education (Lov om barnehager 2005, Rammeplan for barnehagens innhold og oppgaver 2006, Sérkennlustefna leikskólasviðs Reykjavíkurborgar 2009). Dunst (2000) claims that the field of early intervention adopted family-centred theory as its philosophical foundation in the 1990s. Accordingly the "third generation model" of early intervention takes into account knowledge about environmental factors when conceptualizing and structuring intervention and family support as can be noted in Nordic strategy plans for services (Arbeids- og sosialdepartementet 2005, Félagsmálaráðuneytið 2006). The conceptualization of family-centred early intervention framework is based on an ecological model of human learning and development along with family systems theory (Turnbull and Turnbull 1990) arguing that individuals cannot be understood in isolation, but rather as a part of their family as the family is the emotional unit. Families are seen as systems of interconnected and interdependent individuals, none of whom can be understood in separation from each other, and therefore the child, parent, and family function as a complex social unit (Bowen 1978). This approach to early intervention has a close resemblance to the relational view on disability in that it acknowledges the relevance of the interplay between the individual and the societal surroundings that may need to be changed, instead of emphasizing solely on the cure or adjustment of the child.

The term "parent-professional partnership" is at the core of family-centred theory and has therefore become a widespread term within service policy and early intervention (Dunst and Trivette 1996, Turnbull, Turbiville and Turnbull 2000).

Working in partnership means that there is a close cooperation between two or more parties having specified and joint rights and responsibilities which is often contractual (Kagan 1991). According to Armstrong (2005) partnership implies mutual respect, complementary expertise, and a willingness to learn from each other. However, recent Nordic research indicates that although "partnership" is a commonly used term in legislations and policy guidelines, it is generally loosely defined, if at all (Sæmundsdóttir and Karvelsdóttir 2008, Christiansen 2010). Therefore limited guidance is given to the interlocutors within services regarding the motives and preferred methods in practice (Árnadóttir and Egilson 2012). Thus, it can be asserted that despite the overall calls and agreement for parent-professional partnership within welfare policies, it seems like there is little awareness or understanding about what it means in real situations and how it should be performed.

As parents often hesitate to carry forward their wishes, and professionals overlook to ask both parties, parents and professionals are confused about how to handle their cooperating roles. To avoid discrepancies between the expectations of the partners, services need to be performed in a co-configured manner. Nummijoki and Engeström (2010) present the hallmarks of co-configuration work according to the Cultural-Historical Activity Theory, CHAT,

*Traditionally, learning is understood as changes in the subject, for example in the behaviour and cognition of the learners.*

when they emphasize "the client's active and continuous contribution to the shaping of the product service" (p. 49). Further they describe how co-configuration requires new kinds of agency from both the client and the service provider who must be willing to change the shape of the service and experiment with new patterns of provisions when a need arises. Traditionally, learning is understood as changes in the subject, for example in the behaviour and cognition of the learners. Contrary to this, CHAT regards expansive learning as manifested primarily in changes in the object of the collective activity. This is explained below where we turn to CHAT as a relational and dynamic utility which is suitable for applying the system's approach in services to families of disabled children.

## The Cultural-Historical Activity Theory (CHAT)

Activity theory has a long history within Soviet psychology, drawing on Vygotskian notions of tool mediation and socio cultural-historical theories of learning (Engeström 2001). Vygotsky's followers identified the *activity* as the fundamental unit of analysis. Leont'ev (1981) also indicated that *activity* is a system with its own structure, its own internal transformations, and its own development. An activity has a motive and refers to a goal-oriented hierarchical system of actions and operations, mediated by cultural artefacts or tools. A fundamental assumption of CHAT is, therefore, that activities cannot be analysed meaningfully in isolation from their social contexts (Sannino 2008).

Since 1987, Yrjö Engeström has been working on a conceptual model of an activ-

ity system which can serve as an analytical tool to explore the relations between individual and community in any kind of human activity. His formulation of the structure of human activity system is discribed in a triangular diagram (Figure 1).



Figure 1. The meditational structure of an activity system (Engeström 1987: 78).

The *subject* refers to the individual or a group of individuals whose agency is chosen as the point of view in the analysis. The *object* refers to the ends towards which activity is directed. The object is the target of the activity within the system. The subjects act on the object by tools, giving the activity a specific direction. The mediation occurs through the use of many different types of tools, material tools as well as mental tools, including culture, ways of thinking and language. The *instruments (tools)* mediate relationships between the subject and the object. The *rules* refer to the set of norms and conventions that regulate the relationships between community and object, and *division of labour* mediates the hierarchy of labour and division of tasks between its members. In this context, the child and family can be seen as the subject of an activity and their welfare as the object. To be able to analyse such complex interactions and relationships, a theoretical account of the constructive elements of the system under investigation is needed. As

cultural-historical activity theory has evolved through three generations of research, it is seen as a feasible theoretical framework for such a unit of analysing. Within activity theory conceptual tools have been developed to better understand dialogue, multiple perspectives and voices, and networks of interacting activity systems (Engeström 2001). To be able to analyze such complex interactions and rela-

tionships as between families of disabled children and the educational system a theoretical account of the constitutive elements of the system under consideration is needed. In analysing those, the basic model described above is expanded to include minimally two interacting activity systems with a collective meaningful object jointly shared or constructed by the activity systems (Figure 2).



Figure 2. The school and family; two interacting activity systems.

From this standpoint meaningful transfer only takes place through interaction between two or more collective activity systems. For example, the school engages in collaborative interaction with the family, resulting in both parties learning from each other. Transfer is not based on the transition of knowledge only, but is rather a culmination of collaboration capable of producing new theoretical concepts and solutions to problems or tasks that lack ready-made answers (Engeström 2001). As stated by Tuomi-Gröhn (2007) such a process is multidirectional and multifaceted and has a dynamic nature. It can give an applicable approach to explain how new knowledge, activities, and practices are created collaboratively and facilitate moving towards an identified goal. These ideas provide a

ground for a rich belief in parent-professional partnership within welfare services.

*To be able to analyze such complex interactions and relationships as between families of disabled children and the educational system a theoretical account of the constitutive elements of the system under consideration is needed.*

The contradictions that emerge may be created by different views on disability, unbalanced power-relations or misleading views on the shared objects resulting in the manifestation of tertiary contradictions between the central form of the activity and

a new version of it. Tertiary contradictions appear when a culturally more advanced object and motive is introduced into the activity. Such a contradiction can arise when practitioners within welfare-services are to adopt new ideas such as regarding disability as a relational construct or incorporating a family-centred approach without believing in them. Therefore, the new ideas might be formally implemented by the authorities, but internally resisted by the vestiges of the old activity. By recognizing this and working collaboratively with the internal forces, the activity system gradually transforms into a more advanced form. As a result, the tensions are likely to prompt the creation of new approaches in services as to make them function more cohesively in favour of all the participants. Human activity is also affected by the communicative use of language and the production of activity is a key determining factor of human mind and action. In other words, discursive exchanges do not only stem from activity but also generate and regenerate activities through the agentive initiatives of those involved. Sannino (2008) argues that the relationship between the activity and the communicative sign system may be grasped by focusing on the way interlocutors experience talk in a conversation. In her view the gap between conversation and activity is intimately connected to the structure-agency problem.

CHAT is not a predictive theory but a conceptual framework within which different theoretical perspectives may be employed. Thus, linking the Nordic relational view on disability to family-centred theory and further describing welfare services as interacting activity systems makes it possible to utilize the activity theory model as an analytical tool to explore and analyse its intra related elements. Activity theory describes the activity systems as constantly working through tensions within and between its elements, and this can shed a light on the believed mismatch between the aims and the implementation of welfare services. Potentially it can also support moving the tenets within the Nordic relational understanding of disability from the theoretical level to a practical guiding ideology in accordance with the aims and demands of the UN CRPD. As activity systems take shape and get transformed over lengthy periods of time, their problems and potentials can only be understood against their own history. Furthermore history itself needs to be studied as local history of the activity, its objects and the theoretical ideas and tools that have shaped the activity. Thus, welfare services aiming at being family-centred need to be analyzed in connection with the history of their local situation in relation with the global history in order to better understand the views and concepts related to human rights, ideas about equality, disability, procedures and tools employed and accumulated in the local activity. Therefore the features of CHAT can draw the attention of researchers and professionals to the complex context of disability, families and services that otherwise might be missed.

## Conclusion

The promise of the Nordic welfare state about freedom, equality and equal opportunities for all its citizens has been difficult to fulfil when it comes to disabled children and their families. This calls for new efforts on behalf of the welfare states to develop new initiatives in services for this group.

This is particularly relevant at current times when all the Nordic countries are working towards meeting the demands of the new UN Convention on the Rights of Persons with Disabilities which calls for the fulfilment of all human rights for all disabled people. This new human rights treaty highlights a particular need for the protection and advancement of human rights for two groups: Disabled women and disabled children. In this article we have suggested three theoretical approaches to disability, family and service systems, and argued that these, if employed in concert, have the potential to create new forms of welfare services for families of disabled children. The move towards a more family-centred approach in services is already evolving in the Nordic countries through new trends in understanding disability and more dynamic ways of working with parents. In keeping with CHAT, welfare services aiming at enhancing their practices need to take history and the external reality into account along with up to date theories. Organisational changes geared towards parent-professional partnership require new forms of negotiated professional practice which is argued for in this article. Without a substantive understanding of societal surroundings and the historically changing character of the work performed in a given organisation, theories of organisational and professional learning are likely to remain too general and abstract to capture the emerging possibilities and new forms of learning.

Combining the social-relational view on disability, family-centred theory and CHAT is an attempt to deconstruct objects such as "parent", "disability", "professional" and "services" and their interrelations and connections with the external environments. It is argued that utilising these three relational, dynamic, discursive and inter-dependent approaches can create a much needed fruitful and dynamic ways in working with families.

## References

Abrahamson, P., Boje, T. & Greve, B. 2005. *Welfare and Families in Europe.* Aldershot: Ashgate.

Altman, B. M. 2001. Disability definitions, models, classification schemes, and applications. In: G. L. Albrecht, K. D. Seelman &. M. Bury, eds. *Handbook of Disability Studies*: 97–122. Thousand Oakes: Sage.

Armstrong, D. 2005. Reinventing "inclusion": New labour and the cultural politics of special education. *Oxford Review of Education* 31(1): 135–151.

Arbeids- og sosial departementet. 2005. Strategiplan for familier med barn som har nedsatt funksjonsevne. Retrieved from http://www.regjeringen.no/upload/kilde/asd/bro/2005/0003/ddd/pdfv/247788-strategiplan_for_familier_med_barn_med_nedsatt_funksjonsevne.pdf

Árnadóttir, U. & Egilson, S. 2012. Evaluation of therapy services with the Measure of Processes of Care (MPOC-20): the perspectives of Icelandic parents of children with physical disability. *Journal of Child Health Care* 16(1): 62–74.

Bamm, E. L. & Rosenbaum, P. 2008. Family-centred theory: Origins, development, barriers, and support to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation* 89(8): 1618–1624.

Barnes, C., Mercer, G. & Shakespeare, T. 1999. *Exploring Disability: A Sociological Introduction.* Cambridge: Polity.

Beresford, P. 2005. "Service user": regressive or libratory terminology? *Disability and Society* 204: 469–477.

Bengtsson, S. & Greve, J. 2004. Defining disability in applied social research. In: J. Tøssebro, & A. Kittelsaa, eds. *Exploring the Living Conditions of Disabled People.* Lund: Studentlitteratur.

Bjarnason, D. S. 2010. *Social Policy and Social Capital. Parents and Exceptionality 1974-2007*. New York: Nova Science Publishers.

Bowen, M. 1978. *Family Therapy in Clinical Practice*. New York: Aronson.

Bronfenbrenner, U. 1979. *The Ecology of Human Development.* Cambridge: Harvard University Press.

Bruder, M. B. 2000. Family-centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education* 20(2): 105–115.

Christiansen, N. K. 2010. *Skóli og skólaforeldrar: Ný sýn á samstarfið um nemandann [School and parents of schoolchildren: New perspective on collaboration around pupils].* Reykjavík: Höfundur.

Dunst, C. J. 2000. Revisiting "rethinking early intervention". *Topics in Early Childhood Special Education* 20: 95–104.

Dunst, C. J. & Trivette, C. M. 1996. Empowerment, effective helpgiving practices and family-centered care. *Pediatric Nursing* 22: 334–337.

Dunst, C. J. & Trivette, C. M. 2005. *Characteristics and Consequences of Family-centered Helpgiving Practices*. Retrieved 29. 08. 2011 from http://www.fipp.org/Collateral/casemakers/casemakers_vol1_no6.pdf

Dunst, C. J., Trivette, C. M. & Jodry, W. 1997. Influences of social support on children with disabilities and their families. In: M. Guralnick, ed. *The Effectiveness of Early Intervention*: 499–522. Baltimore, Maryland: Paul H. Brookes.

Egilson, S. T. 2011. Parent perspectives of therapy services for their children with physical disabilities. *Scandinavian Journal of Caring Sciences* 25: 277–284.

Engeström, Y. 1987. *Learning by Expanding: An Activity-theoretical Approach to Developmental Research*. Helsinki: Orienta-Konsultit.

Engeström, Y. 2001. Expansive learning at work: toward an activity theoretical reconceptualization. *Journal of Education and Work* 14(1): 133–156.

Espe-Sherwindt. 2008. Family-centred practice: collaboration, competency and evidence. *Support for Learning* 23(3): 136–143. Francisco: Berrett-Koehler.

Félagsmálaráðuneytið [Ministry of Social Affairs] (2006) *Mótum framtíð: Þjónusta við fötluð börn og fullorðna 2007-2016; traust, sveigjanleiki, þróun: Samantekt og helstu niðurstöður* [Designing the future: Services to disabled children and adults]. Retrieved from:
http://felagsmalaraduneyti.is/media/thjonusta_f/framtidarsyn_stefna_samantekt.pdf.

Goodley, D. 2011. *Disability Studies: An Interdisciplinary Introduction*. London: Sage Publications.

Goodley, D. & McLaughlin, J. 2008. Theorising parents, professionals and disabled babies. In: J. McLaughlin, D. Goodley, E. Cavering & P. Fisher, eds. *Families Raising Disabled Children: Enabling Care and Social Justice.* United Kingdom: Palgrave Macmillan.

Greve, B. 2007. What characterises the Nordic welfare state model. *Journal of Social Sciences* 3(2): 43–51.

Gustavsson, A., Tøssebro, J. & Traustadóttir, R. 2005. Introduction: Approaches and perspectives in Nordic disability research. In: A. Gustavsson, J. Sandvin, R. Traustadóttir & J. Tøssebro, eds. *Resistance, Reflection and Change: Nordic Disability Research* : 23–44. Lund: Studentlitteratur.

Hodge, N. & Runswick-Cole, K. 2008. Problematising parent-professional partnerships in education. *Disability and Society* 23(6): 637–647.

Jónsdóttir, E. S. 2003. Milli vonar og ótta: Sjónarmið foreldra fatlaðra leikskólabarna [Fear and hope: Perspectitves of parents of disabled preschool children]. In: R. Traustadóttir, ed. *Fötlunarfræði: nýjar íslenskar rannsóknir* [Disability studies: New Icelandic research]: 55–71). Reykjavík: Háskólaútgáfan.

Kagan, S. K. 1991. United we stand: *Collaboration for Child Care and Early Education Services.* New York: Teachers College Press.

Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M. & Rosenbaum P. 2003. Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health & Development* 29(5): 357–366.

Leont´ev, A. N. 1981. The problem of activity in psychology. In: J.V. Wersch, ed. *The Concept of Activity in Soviet Psychology.* New York: M. E. Sharp.

*Lov om barnehager (Act on day care centres).* 2005. Kunnskapsdepartementet. Sist endret i 2012.

Lundeby, H. & Tøssebro, J. 2008. Exploring the experiences of "not being listened to" from the perspective of parents with disabled children. *Scandinavian Journal of Disability Research* 10(4): 258–274.

Nummijoki, J. & Engeström, Y. 2010. Towards co-configuration in home care of elderly: Cultivating agency by designing and implementing the mobility agreement. In: H. Daniels, A. Edwards, Y. Engeström, T. Gallanger & Ludigsen S. R., eds. *Activity Theory in Practice: Promoting Learning Across Boundaries and Agencies.* USA: Routledge.

Oliver, M. (990. *The Politics of Disablement.* Basingstoke: Macmillan.

Ólafsson, S. 2005. *Disability and Welfare in Iceland in an International Comparison.* University of Iceland: Social Science Research Institute.

*Rammeplan for barnehagens innhold og oppgaver (The framework on day care centres' content and tasks).* 2006. Kunnskapsdepartementet.

Sannino, A. 2008. Experiencing conversations: Bridging the gap between discourse and activity. *Journal for the Theory of Behaviour* 38(3): 267–291.

Sérkennlustefna leikskólasviðs Reykjavíkurborgar [The special-education policy for preschools in Reykjavík]. 2009. Reykjavíkurborg, Leikskólasvið.

Shakespeare, T. 2006. *Disability Rights and Wrongs*. Oxford: Routledge.

Sæmundsdóttir, J. & Karvelsdóttir, S. 2008. Þáttur ráðgjafar í samstarfi leikskólakennara og foreldra (The role of consultants in the collaboration between pre-school teachers and parents). *Tímarit um menntarannsóknir* 5: 77–91.

Thomas, C. 2004. How is disability understood? *Disability and Society* 19(6): 563–568.

Tregaskis, C. 2002. Social model theory: The story so far. *Disability & Society* 17(4): 457–470.

Traustadóttir, R. 2003). Fötlunarfræði: Sjónarhorn, áherslur og aðferðir á nýju fræðasviði [Disability studies: Perspectives, emphasis and methods in a new field of study]. In: R. Traustadóttir, ed. *Fötlunarfræði: Nýjar íslenskar rannsóknir* [Disability studies: New Icelandic research]: 17–47). Reykjavík: Háskólaútgáfan.

Tuomi-Grön, T. 2007. Developmental transfer as a goal of collaboration between school and work. A case study in the training of day care interns. *An International Journal of Human Activity Theory* 1: 41–67.

Turnbull, A. & Turnbull, H. 1990. *Families, Professionals, and Exceptionality: A Special Partnership* (2nd Edition). New York: Merrill.

Turnbull, A. P. & Turnbull, H. R. 2001. *Families, Professionals and Exceptionally: Collaborating for Empowerment* (4th Edition). New Jersey: Prentice Hall, Inc.

Turnbull, A. P., Turbiville, V. & Turnbull, H. R. 2000. Evaluation of family-professional partnerships: Collective empowerment as the model for the early twenty-first century. In: J. P. Shonkoff & S. J. Meisels, eds. *Handbook of Early Childhood Intervention* (2nd edition): 630–647. USA: Cambridge University Press.

Tøssebro, J. 2004. Understanding disability: Introduction to the special issues of SJDR. *Scandinavian Journal of Disability Research* 6(1): 3–7.

Tøssebro, J. & Lundeby, H. 2002. *Å vokse opp med funksjonshemming – de første årene*. Oslo: Gyldendal Norsk Forlag.

United Nations.1989. *The UN Convention on the Rights of the Child.* Retrieved from http://www2.ohchr.org/english/law/crc.htm

United Nations. 1994. The Salamanca statement and framework for action on special needs education: Adopted by the world conference on special needs education: Access and quality, Salamanca Spain, 7-10 June 1994. Paris: UNESCO.

United Nations. 2007. *The UN convention on the rights of persons with disabilities.* Retrieved 22. 09. 2012 from http://www.un.org/disabilities/convention/conventionfull.shtml

Ytterhus, B. Wendelborg, C. & Lundeby, H. 2008. Managing turning points and transitions in childhood and parenthood: insights from families with disabled children in Norway. *Disability & Society* 23(6): 625–636.

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# Article II

# Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice

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## Abstract

This paper outlines the reported discrepancies between the aims of the welfare services in Iceland and the experiences of parents raising young children with intellectual disabilities. Prevailing views on disability and service delivery were also considered. A multi case study design was employed to reflect the situation in different parts of the country. Families of eight children with intellectual disabilities and professionals in three different municipalities formed the cases. The findings reveal a high convergence between the three cases with variations based on individual experiences rather than geographical location. Overall, parents praised the preschools but experienced support services often as fragmented and uncompromising. Particular components of the services were consistently regarded as hard to reach and not in accordance with the needs of the family. Cultural-historical activity theory is introduced as a beneficial framework for further study and system improvement.

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## Introduction

As a response to social change, service developments and new research-based knowledge, the field of services for people with intellectual disabilities has evolved rapidly during the last decades (e.g. Björnsdóttir et al., 2015; De Chenu et al., 2016). The traditional clinical approach is being replaced by several conceptualizations of intellectual disability, in terms not only of mental ability but also adaptive functioning and learning that is age-appropriate and meets the standards of culture-appropriate demands of daily life (Carulla et al., 2011). Consequently, there is an increased call for holistic integrated services to families raising children with intellectual disabilities (Case, 2010; McLaughlin et al., 2008) besides inclusive schooling and identical learning environments for all children (Bruder and Dunst, 2014; Moore, 2008; Ytterhus et al., 2015). A family-centred approach (Espe-Sherwindt, 2008) has become a visible trend in service policies worldwide and has had an impact on legal provisions and practice in Iceland (Arnadottir and Egilson, 2012; Egilson, 2011). Despite this, parents of children with intellectual disabilities in Iceland and elsewhere commonly express that there is a mismatch between the aims of the welfare legislations and the service provision in practice. Services are found to be incidental, incompatible and uncompromising (Bjarnason, 2010; Lundeby and Tøssebro, 2008; Ytterhus et al., 2008). Moreover, many parents complain about having to fight for their statutory rights (Bjarnason, 2009; Egilson, 2011).

This article is based on a qualitative multi case study (Creswell, 2008) conducted in three different municipalities in Iceland. It is a theory-led research (Simons, 2009) based on family-centred theory (Bamm and Rosenbaum, 2008; Dunst, 2002) and the Nordic relational view on disability (Tøssebro, 2004). These social relational and dynamic theories draw attention to the significance of the interplay between the individual and his or her societal surroundings (Ingólfsdóttir et al., 2012). This is highly relevant as focussing on interactive relations is an emerging trend in legislation and policies regarding welfare services and is reflected in the UN Convention on the rights of persons with disabilities (CRPDs) (United Nations, 2007).

The aims of the study are (1) to gain a better understanding of the discrepancies reported in the literature between the welfare policy, provision of services and the experiences of parents of young children with intellectual disabilities in Iceland; (2) to investigate the existence of relational views on disability within services and (3) to explore the actual provision of family-centred services.

We conclude by elaborating on the findings with emphasis on the parents' views and propose cultural-historical activity theory (CHAT) as a framework for further study of the complexities of the service system and as a tool to improve practices to better comply with its objectives.

## Theoretical frameworks

There is a growing awareness of the importance of systemic ecological models in services directed at young children with intellectual disabilities (Case, 2010; Emerson, 2003), shifting from a child-focussed to a family-focussed approach. Guralnick (2005) points out the increasing understanding of how family functioning depends on the immediate community and wider social environments which consequently calls for the need to provide services that take these wider social aspects into account. For several decades, international research within the field of disability has focussed on families (Dempsey and Keen, 2008; Ferguson, 2001; Lundeby and Tøssebro, 2008) and on family-centred services (Dunst and Trivette, 1987; Espe-Sherwindt, 2008; Rosenbaum et al., 1998). This is also a growing emphasis within Icelandic disability research (Bjarnason, 2009; Egilson, 2011;

Egilson and Stefánsdóttir, 2014). Bailey et al. (2011) highlight the essentials in a family-centred approach and explain how families should not be seen as clients receiving services but as partners in making decisions about goals and activities as does Tøssebro (2015). These changes in professional roles and views influence the power relations within the service system and recent Icelandic scholarship indicates the importance of further research, particularly on the parents' perspectives and their experiences of the services (Bjarnason, 2010; Egilson, 2011; Egilson and Stefánsdóttir, 2014).

Since the 1970s, the disability movement has aimed at moving the gaze from the impaired body to the important role of the surroundings, and the fact that societal barriers restrict the participation of people with impairments (Barnes et al., 1999; Goodley, 2001; Oliver, 1990). This has succeeded in shifting scholarship and debates about disability from biomedically dominated agendas to discourses about politics, citizenship, accessibility and social participation (Gustavsson et al., 2005; Traustadóttir, 2009).

A number of 'models' of disability have been articulated over recent decades. The two most frequently mentioned are the 'social' and the 'medical' models of disability. The social model has its roots in the disabled people's movement and views disability as socially created primarily by the barriers erected by society that hinder disabled persons from participating in the community and living independently, and thus identifies the difficulties faced by disabled children and adults as a consequence of external factors.

In contrast to the social model, the medical model views disability as a 'problem' or 'deficiency' that resides within the disabled individual and identifies the person's impairment as the cause for being unable to access what society has to offer. It is this medical understanding that has mainly informed the development and structure of legislation, policies and practices and is reflected in people's attitudes and discourse.

In recent years, disabled people and disability scholars (Barnes, 2012; Traustadóttir, 2009) have developed a social relational understanding of disability. One of these approaches is the Nordic relational view on disability as described by Tøssebro (2004) and later in more details by Gustavsson et al. (2005) and Ytterhus et al. (2015). This social relational approach is in accordance with the basic understanding of disability in the CRPD (United Nations, 2007), which states in its Preamble (e), that 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'. This relative understanding of disability is also in line with that of Shakespeare (2014: 75) when he proposes that 'disability is always an interaction between individual and structural factors'.

The theoretical framework for the research presented in this article is based on relational understandings, combining the family-centred approach outlined above and the social relational view on disability (Ingólfsdóttir et al., 2012). This is also in line with the current definition of intellectual disabilities which no longer is solely based on an IQ score below 70 but also on the individual's functional skills in his or her environments (Schalock et al., 2010).

## The Icelandic context

Iceland is one of the five Nordic countries and one of the most sparsely populated countries in Europe with approximately 335,000 inhabitants (Statistics Iceland, 2016). Two-thirds of the population lives in Reykjavík, the capital and the surrounding areas. The Ministry of Education, Science and Culture is responsible for the national school policies and monitors the performance of

the education system. Preschools, primary schools and lower secondary schools are funded and administered by the municipalities. The preschool is governed by the Preschool Act 90/2008 (Ministry of Education, Science and Culture, 2008) as the first school level for children 2–6 years of age and provides non-compulsory education for all children below the compulsory school age of 6–16 years. Nevertheless, a full-time attendance in the preschool is the norm for all young children in Iceland, including children with intellectual disabilities. All preschools in Iceland are integrated and there are no special schools or segregated units within the regular preschools.

School authorities are obliged to provide 'special services' as needed according to regulation nr. 584/2010 (Ministry of Education, Science and Culture, 2012). Parents of children with intellectual disabilities must also rely on services from professionals outside the preschool, working within diverse settings and with different preconditions such as views on disability, work arrangements and systematic and professional opinions on how services should be implemented.

In order to be eligible for specialized services, the child has to have a diagnosis from authorized organizations. The State Diagnostic and Counselling Centre (SDCC) is the main evaluation centre for children and adolescents in Iceland. Each child is evaluated by an interdisciplinary team which works towards a consensus on the child's condition and prognosis (Ministry of Welfare, 2003). The needs of the child and family for special services are defined, counselling offered and necessary referrals made. For many families of children with intellectual disabilities, the National Social Insurance Administration (NSIA) plays a pivotal role as a governmental service organization in regard to social assistance and the payment of pension insurance.

The responsibility for disability services in Iceland was transferred from the state to the municipalities in 2011. The aim of this decentralization was to create a better cohesion in services offered in close proximity to the users. Since then, education and social services are provided at the same level of governance.

## The study

This article is a part of an ongoing research focussing on services for young children with intellectual disabilities and their families in Iceland (Ingólfsdóttir et al., 2012). This part of the research project consists of three case studies carried out in different municipalities and focusses mainly on the families' perspectives and experiences. The intention was to explore the manifestation of inconsistencies between official aims of welfare policies and the services provided as repeatedly presented in the Icelandic research literature (Bjarnason, 2009; Egilson, 2011; Egilson and Stefánsdóttir, 2014).

### The case studies

The research consists of three case studies. Each case included two to four children with intellectual disabilities, their families (eight families in all) and the service team for each child including the preschool professionals (teachers, special teachers and a social educator) and the service coordinators from the municipalities (see Table 1). Case study A was carried out in Reykjavík, the capital of Iceland. Case study B was conducted in a rural municipality which is composed of several small communities with aggregated 8000 inhabitants. Case study C was undertaken in a municipality in North Iceland with 18,000 inhabitants, and which has been widely regarded as a model in integrated welfare services. This municipality had been involved in a state-led experimental project since 1994 where the transfer of disability services from state to the

**Table 1.** Overview of participants and data sources in the case studies.

| | Case (a): Reykjavík, the capital | | | Case (b): Rural municipality | | | Case (c): Municipality in North Iceland | | The study as a whole (across cases) |
|---|---|---|---|---|---|---|---|---|---|
| | Child 1 and 2 | Child 3 | Child 4 | Child 5 | Child 6 | Child 7 | Child 8 | Child 9 | |
| Child details Family and community details | Twin boys; 4 years; Live with father and stepmother; one older sister; both parents work outside the home; attend local preschool | Boy; 2 years; Lives with both parents and two older brothers; both parents work outside the home; attends a local preschool | Girl; 3 years; Lives with both parents; both parents work outside the home; attends local preschool | Girl; 5 years; Lives with both parents and two older sisters; father receives disability benefits; mother works outside the home; attends a local preschool | Boy; 5 years; Lives with mother and stepfather; both parents work outside the home; attends local preschool | Boy; 7 years; Lives with both parents and three siblings; both parents work outside the home; attends local preschool | Boy; 4 years; Lives with both parents and younger sister; father works outside the home, mother a university student; attends preschool nearby a rehabilitation centre | Boy; 5 years; Lives with both parents; half-brother stays with the family every second weekend; both parents work outside the home; attends a local preschool | |
| Specific data sources | Interviews: father and stepmother; Observation: team meeting (parents, teachers and service coordinator from the local service centre) | Interview: ×2 with both parents | Interview: both parents | Interviews: mother; preschool social pedagogue; head of preschool; Observations: story time at preschool | Interview: mother; service coordinator; Observation: team meeting (mother, teachers and service coordinator from the local service centre) | Interviews: mother; preschool teacher; Review: individual education plan | Interviews: mother; father; special education teacher; head of preschool; speech therapist; Observations: preschool playtime and mealtime; team meeting (mother, teachers and service coordinator from the local service centre); Review: assessment report; individual education plan | Interviews: mother ×2; special education teacher; head of preschool; Observations: preschool playtime and mealtime, language training session, team meeting (parents, teachers and service coordinator from the local service centre); Review: individual education plan | |

*(continued)*

**Table 1. (continued)**

| | Case (a): Reykjavík, the capital | | Case (b): Rural municipality | | | | Case (c): Municipality in North Iceland | | The study as a whole (across cases) |
|---|---|---|---|---|---|---|---|---|---|
| | Child 1 and 2 | Child 3 | Child 4 | Child 5 | Child 6 | Child 7 | Child 8 | Child 9 | |
| Generic data sources for municipality | Interviews: city special education project leader; head of advisory preschool*; advisory preschool special education coordinator; speech pathologist; Presentation of services: advisory preschool; Observation: arrangements of disabled children's services within advisory preschool; Documents from city's official website: information on family and educational services, reports and official rules | | Interview: municipality service consultant; review of local guiding rules; Review of documents from municipality's official website: information on family and educational services, reports and official rules | | | | Interviews: municipality preschool special education counsellor; municipality family service manager; Review of documents from municipality's official website: information on family and educational services, reports and official rules | | Interview: parent–counsellor operating nationwide; Documents: Icelandic laws and regulations on social and educational services for disabled children and families; UN-CRPD |

*A preschool that specializes in serving disabled children and provides advice to other preschools in Reykjavík.

municipality was tried out before the nationwide decentralization took place in 2011. These three different municipalities were selected because they provided the opportunity to reflect on services in diverse locations with respect to population, geographical region, type of municipality and varied experiences of service provision.

The participating families, all of whom were raising a child or children with intellectual disabilities, were selected by the local councillors and reflected diversity with regard to the number of siblings in the family and the parents' level of education. All the children lived with both parents or a parent and a step-parent. The children were 3–7 years of age when the study took place and all had attended preschool from when they were about 2 years old. All the parents worked full-time or part-time outside the home except one father who received disability benefits and a mother who was a university student.

Although two of the children had recently been transferred to elementary school at the time of the data collection, the research focussed on the parent's experiences of their child's preschool years. All the children had some kind of special support within the preschool and all received additional therapeutic services outside the school such as speech- or/and physiotherapy.

The limited number of cases has to be considered when drawing conclusions from this study and also the fact that the participants were proposed by the local counsellors in each municipality. To compensate for these limitations, emphasis was on diversity within the cases as well as on obtaining data from multiple sources. Since previous Icelandic research has focussed mostly on children and families in urban and suburban areas (Bjarnason, 2009; Egilson, 2011; Egilson and Stefánsdóttir, 2014), more families were selected from the rural municipality than from the other two municipalities.

The study was approved by the Icelandic Bioethical Committee (11-100).

## Data collection and analysis

In line with the case study approach, we drew on multiple sources of information including in-depth interviews, participant observations and document analysis (Creswell, 2008). A review of policy documents was carried out, including laws and regulations regarding the education of children with intellectual disabilities and related welfare services. Curricula and other working documents from each preschool were examined as well as individual plans for each child.

Before embarking on in-depth interviews with parents and professionals, an expert interview was conducted with a highly experienced parent-counsellor. This interview provided an insight and overview of the state of the art in family services in the whole country. Following this, 12 semi-structured in-depth interviews with parents were conducted (6 with mothers alone, 2 with fathers alone and 4 with the parents together) in order to elicit their views and experiences of the services they had received. Furthermore, 11 interviews were carried out with professionals from diverse disciplines who worked within or in relation with the preschools. Most were preschool teachers who were either in managerial positions or worked in direct contact with the children.

The interview data were analysed by theoretical propositions (Creswell, 2008; Simons, 2009) of family-centred theory and relational view on disability. An interview protocol was developed for both parents and professionals with the key issues to be discussed. The themes included (a) the participants' experiences, perspectives and understanding of the welfare services offered to the children in the study; (b) co-operation and consistency within the service system and (c) the participants' views on what worked well and what did not work so well. However, the interview format remained open, flexible and adaptable to encourage in-depth responsive descriptions of participants.

In addition to the interviews, nine participant observations were conducted in order to gain a comprehensive overview and insights which cannot be obtained solely by speaking with people (Simons, 2009). Six observations focussed on school practices, the children's participation and interactions with adults. Three observations took place at team meetings with the individual teams (see Table 1). The observations created an important opportunity for comparing and contrasting information with data obtained in the interviews.

The interviews were recorded, transcribed and analysed according to deductive within-case and cross-case analysis (Creswell, 2008; Simons, 2009) with the prior described features of family-centred services and the social relational view on disability as a framework. During the entire process of analysis, an effort was made to focus on the quality of the statements made by participants rather than the quantity of ideas presented (Patton, 2002). Initial categories and themes were identified by reading the transcribed data and selecting expressions that manifested family-centred services. In the second round of analysis, main categories were formulated by combining initial subcategories. Final conceptualizations were generated through parallel investigation and comparison of the main categories. During this phase, the main topics, as expressed by the parents and professionals, were compared internally and between municipalities in order to detect similarities and differences between the three cases. This comparison process of analysis led to the identification of key findings regarding services for young children with intellectual disabilities and their families in the three municipalities.

## Findings

There was a high convergence between all the three cases on what worked well for the children and their families and what did not. The differences obtained were rather based on individual experiences than geographical location. The key findings are presented in accordance with the underlying theories and the main themes: gaining access to services; systems within the system and prevailing inconsistencies.

### Gaining access to services

Despite the official objectives stated in the welfare legislation to deliver services according to individual needs, the statutory guidance in decision-making relies first and foremost on the psycho-medical diagnosis of the child. When it came to entitlement to services, the diagnosis and nature of the child's impairment was of much greater importance than the substantiated need for assistance as an experienced parent counsellor argued:

> Concerning for instance . . . if we take the ADHD kids as an example, with these related disorders and mental disorders, then there is obviously no legal definition as to what rights these children have. And then it is actually down to each counsellor or each school how they engage with these children and this often turns into quite a struggle for the parents and it is only the toughest parents who can tackle this all by themselves . . . that is a fact.

In all three municipalities, the rules for allocation of support hours in the preschools were based on the IQ classification and other impairment-related facts such as if the child had autism spectrum disorder, intellectual and/or physical impairment. Thus, both parents and professionals emphasized having the child diagnosed in order to gain access to assistance and support. One of the mothers said:

> I am pretty certain that he will need some form of assistance. That is why it feels so good to have . . . that is why I am still calm, because I know he will be accepted at the Diagnostic Centre this winter. Just so that this issue is clear before he begins elementary school.

A local psychologist had previously assessed her son but she found the results inaccurate and was hoping for a more reliable assessment at the SDCC which also would give access to appropriate assistance.

In fact, almost all the parents requested to be referred to the SDCC as they knew that a diagnosis on their behalf was the premise for services. Moreover, they regarded SDCC as a respectable authoritative organization providing careful multidisciplinary assessments which also helped eliminate uncertainties. Due to this requirement of psycho-medical diagnosis, things could become really difficult when assessors were hard to reach or if the results did not provide access to the support and help obviously needed.

In previous research, Icelandic parents of disabled children have complained about limited access to information (Egilson, 2011; Egilson and Stefánsdóttir, 2014). That was not the unanimous view in this study, especially when parents referred to their first encounters with the service system. In fact, parents from all the municipalities had expected more efforts and problems in obtaining information about services from the local community when they first entered the service system. One mother said:

> She [the counsellor] said she called everyone that had had some kind of a diagnosis. So now he's got this preliminary diagnosis, then she said she just called everyone, invited everyone to a meeting, help them fill it out [the form], and sent it for them and then you would simply get an answer. It was really great. I was just, yes, yes . . . I was just like a fool when I answered the phone. I had no idea about this. I thought it was really great.

A mother in another municipality expressed the same experience by saying: ' . . . and this has, in fact, all been pushed at you'. On the other hand, the parents described their struggle to get in touch with the specialists they had been referred to and how they needed to be 'pushy' in order to get a quicker processing through the system. Furthermore, as the child grew older and new needs arose, the terms 'coincidence' and 'unreliability' came to the scene, as parents in all three municipalities had discovered some valuable entitlements from their interaction with other parents in a similar situation. One mother described that she had been informed far too late about their rights for free diapers: ' . . . [I heard of it] just before he was six years old, so I really missed out almost three years . . . ', besides the convenience of having the diapers delivered at the doorstep.

It is noteworthy that many of the negative examples mentioned involved rights or services provided by the NSIA but not the municipal services. Parents from all three municipalities complained about the lack of 'service-motivated persons' giving information at the NSIA and described the lack of knowledge and coordinated information as a part of the problem. Therefore, parents were sceptical about whether or not they were receiving what they were entitled to. A comment from one father reflects this view:

> There is one thing in all of this that is missing, it is actually from the Social Insurance Administration and that whole mechanism . . . is deficient in most ways. For example, it was approved . . . you know the device . . . the gastric feeding tube and we were actually given a tube and things to connect to it. Nobody told us that the syringes were included. So for over a year we bought the syringes ourselves.

This point was not primarily about rights or money, but rather the need for trustworthy information and a sense of coherent and holistic services. There was a common call for ongoing disclosure in order for the parents to be confident that they were receiving what they needed and were entitled to by law without having to struggle or verify periodically that the 'child still has Down's syndrome' as pointed out by a mother.

## Systems within the system

The parents in all three municipalities valued their child's preschool and praised the preschool staff for good interaction and support as stated by a mother who said: 'All the people [at the preschool] are really nice talking to and willing to do anything for you'. This statement was in line with the overall positive attitude observed in the interviews with the preschool professionals. However, the parents found other parts of the services detached from this main service unit such as physio-, occupational- and speech-therapy services, which were mostly provided at the specialists' venue without any connections, neither to the preschool nor to other professionals involved with the child. This is in contrast with the official school policy (Ministry of Education, Science and Culture, 2008) and the spirit of the prevailing 'Regulation on expert advisory service for municipalities' preschools and compulsory schools [ . . . ]' (Ministry of Education, Science and Culture, 2008) which prioritizes the provision of essential services within the schools. It was also observed that those specialists did not participate in the 'team' meetings. Their absence resulted in the parents (mostly mothers) acting as messengers between service programmes and professionals. In one of the meetings observed, the mother brought a written note from the physiotherapist 'to be able to be precise in describing the current status' as she said.

The parents also spoke about how time-consuming, costly and complicated it was to bring the child to, and sometimes between different therapists during their working day and the child's school hours. The parents were also unanimous about the difficulties they encountered when striving for an appointment with fully booked specialists such as speech therapists and had to accept any appointment-time offered. Usually, it was the mother's role to take the child to therapy, and consequently all the mothers in the study had been compelled to reduce their working hours or change their occupations to be able to transport their children to and from various specialists. One mother described it this way:

> Because he [the son] has been going there every day and it is difficult to find time with the specialists after school [ . . . ], so I had to reduce my working hours, and I only work from 8-12 now. [ . . . ] It was either that I would decrease my work or he wouldn't get an appointment.

Another example which points in the same direction came from the mother who was a university student and had altered to a less challenging subject for the same reason. These arrangements prevented the full-time participation of the mothers in the labour market (which is the main rule for women in Iceland) and brought a major disruption in their personal- and family circumstances in terms of both career and financial income. This shows that the service system and the practitioners' needs dominate rather than the needs of the families which contradict the main objectives of family-centred services.

The mothers also spoke about the consequences for their children to be taken out of school for therapy in front of their schoolmates at any time of the day. One mother declared how disruptive it felt when she came to the preschool to take her son to the physiotherapist when he was playing

outside with his peers. She felt this was illogical and had a negative effect on their otherwise good relationship as he often got annoyed and even refused to join her.

One child with significant mobility impairment had been directed to a preschool located near a rehabilitation centre but outside his own neighbourhood. On the one hand, this arrangement facilitated flexibility in the implementation of the services due to an easy access to therapy without the parents acting as intermediaries. On the other hand, it meant that the child did not attend the same preschool as his neighbour peers, which is contrary to inclusive schooling, the official national school policy in Iceland (Ministry of Education, Science and Culture, 2008).

The preschool administrators in all three municipalities were open to the idea of providing therapy within school premises in accordance with the legal provisions, but barriers seemed to be dependent on the therapists' working conditions and sometimes also on their personal preferences as a mother who had been trying to influence the working arrangements experienced. She said:

> She [the physiotherapist] understood me perfectly and I spoke with the preschool and we booked a time in the common playroom, so that he could have his physiotherapy in the preschool, and it was great. But then she [the physiotherapist] went on maternity leave and the new physiotherapist [says he] can't do this.

The service system did not require collaboration between service providers nor were official guidelines about individualized services to follow. As a result, it was up to individual therapists or their agencies where and how services were provided.

## Prevailing inconsistencies

In this study, a noticeable mismatch was evident between the avowed aims of the service system to provide flexible and adjusted services and the implementation, which relied on psycho-medical diagnosis. A social relational understanding of disability is reflected in all the policy documents as the basic principle for service provision. However, in their practices, the service providers and professionals took the conventional biomedical and individualistic approach. The main reason was the fact that eligibility for specialized services was primarily decided on the basis of child's impairment but not the actual need for support or the situation of the family as a whole. Also, instead of removing barriers and adjusting the environment according to the needs of the child and family, the emphasis was mainly on making the child fit in. The therapeutic services were not adapted to the daily routines of each child and family and various specialists operated in a different manner, all of which caused negative experiences of the parents who consequently perceived the services as fragmented and incompatible to their needs.

To seek necessary assistance based on the 'malfunctions' of the child could be exhausting and was likely to evoke a sense of inadequate services. A father of disabled twins reported how his family was directed to different institutions, both with long waiting lists, for further diagnoses due to slightly different IQ outcomes in the primary assessments. He said:

> We are trying to get into the Diagnostic Centre [with one son] because he was classified under 70 and . . . then the other boy [is not eligible because his IQ is over 70]. We have visited the Centre for Child Development and Behaviour [which has obligations to children with IQ over 70] . . . trying to get in for the assessment . . . I have been dealing with this for over two years . . . all these things . . . it is all very difficult.

The family's complex situation and instant need for support was ignored. This is an example of the prevailing inconsistency within the system and the lack of operating within the stated aims of services based on the social relational view on disability and the needs and preferences of the family. Although a more relational and flexible view on disability could be identified as emerging within the preschools, inconsistent and different understandings of key concepts such as 'disability', 'parent-professional collaboration' and 'family-centred services' were apparent. Another inconsistency was identified in the fact that the child and the family frequently had to adapt to the services, which is not in line with the family-centred approach articulated in policy documents.

## Discussion and future developments

Interestingly, the findings of this study revealed high consistencies between the three cases as to what worked well and what did not. In all three municipalities, the preschools had a good reputation among the parents due to flexibility and a welcoming and supportive attitude, while the other parts of the service system were seen as fragmented and complicated to deal with. These unanimous findings were somewhat unexpected as the cases were diverse in respect to characteristics of participants, type and size of municipalities and the fact that the welfare services in Iceland are not centralized.

Although policy documents at the national and community levels reflect a social relational understanding of disability, the conventional biomedical and individualistic approach was the most prominent in practice. Since the child's diagnosis was the key to accessing support and services, emerging relational views on disability were neither formalized nor implemented in everyday service delivery. Different understandings of key concepts such as disability and family-centred services also appeared to play a role in this mismatch between policy and practice. Most parents and professionals seemed to adhere to the conventional notion of normality where the emphasis is rather on fixing the individual than on adjusting environmental factors in order to promote the child's and family's participation and well-being. The unilateral vision on disability and service provision – which sees children with intellectual disabilities and their families more as clients receiving services than partners in making decisions – characterized the arrangements under study. This may have contributed to the fact that, overall, parents were more concerned about the organization of services than the content. They valued the warmth and respect they and their children encountered on behalf of most professionals and appreciated being informed about the school activities and did not question or see a reason for being too involved in decisions on what was being done.

Lack of services was not as much of an issue for parents as the long waiting lists, incompatibility and detachment from the daily routine of the child and family. Consistent with recent findings (Egilson, 2015; Tøssebro and Wendelborg, 2015), parents' critical views about fragmented and poorly coordinated services were not only related to services being carried out in diverse settings but also due to the arbitrariness based on each professional's views and working arrangements. While some professionals outside the preschool focussed their efforts to serve the child and family in a manner that would cause the least possible disruption to their daily routine, more commonly the services were provided according to the professionals' preferences and the service system's rules and routine practices.

Previous research reveals how important it is that schools and therapy services delineate strategies and coordinate work procedures to promote and formally establish family-professional collaboration in practice (Kruijsen-Terpstra et al., 2016; Nachshen, 2015; Stefánsdóttir and Egilson, 2016). By relieving parents from the stress, resulting from the transport and associated interference into the daily lives of the child and family, several objectives of family-centred

approach would be attained. Providing therapy services at the child's preschool venue would create an opportunity for collaboration, promote distribution of expertise among professionals and be more easily integrated to daily life situations within the preschool and at home. Adaptations of activities and environments that facilitate the child's active participation and peer relations are among core values of inclusive schooling. Such arrangements are also in line with the relational views on disability which are at the heart of the rights outlined the CRPD. Moreover, parents would gain more control over their own time, giving them a better scope for participating more actively in decision-making about the content and focus of preschool and support services on an ongoing basis.

If services for young children with intellectual disabilities and their families are to comply with the merits of family-centred services and the relational approach to disability, an increased emphasis and space for partnership with parents needs to be developed and incorporated into professional practices as well as acknowledged within the institutional contexts of professional activity both within and outside the preschool. For that purpose, and in order to better comprehend and act upon the complexities of the service system for children with intellectual disabilities and their families, we propose CHAT (Engeström, 1987, 2008) as a potential framework for further study and system development. According to CHAT, the family and the main elements of the service system can be seen as interactive activity systems, which may generate tensions or contradictions that appear on the surface as disturbances or problems (Engeström, 2001). It is important to identify these contradictions and consider how they can become a source of new ideas and solutions rather than a cause of fragmentation. Nummijoki and Engeström's (2010) presentation of the hallmarks of improving organizational work makes these ideas relevant in a family-centred context as they emphasize the importance of the client's active and continuous contribution to the evolution and shaping of the system. Furthermore, CHAT both reflects and reveals the complexity of human activity and strives for understanding the cultural specifics and the historically changing character of the organization or system under consideration. The amendments within welfare services are a continuous task taking into account the culture, scientific knowledge, ethos and ever-changing nature of society.

The features of CHAT, to take advantage of the historical and cultural context in relation to personal needs and organizational practice (Blackler, 2009), fit well to better adapt family-centred theory to the specific conditions prevailing in Iceland such as the extensive role of the preschool, general female employment and diverse cultures and working conditions among poorly interconnected professionals. In order to improve services aimed at young children with intellectual disabilities and their families in Iceland, we argue for translating the social relational and dynamic understanding of disability into practice by attending simultaneously to the child and his or her social environment (Egilson, 2015; Ingólfsdóttir et al., 2012). The findings of this study clearly call for more in-depth analysis of the many conflicts and inconsistencies within the services. There is an even greater need for a tool to address how to integrate the different aspects and tensions of the service system. For this purpose, we highlight the advantage of CHAT as a practical tool in the study of complex service systems as well as an approach to the development of a more coordinated, flexible and users based welfare service system.

## Conclusion

The point of departure in this study was the reported discrepancy between the stated goals of welfare policies and the actual service delivery. What we found was a service system in

transition. On the one hand, official policies emphasized holistic and integrated services and a social relational understanding of disability, in line with the international human rights development (United Nations, 2007) and key characteristics of family-centred services (Bruder and Dunst, 2014; Espe-Sherwindt, 2008). On the other hand, we found service delivery heavily characterized by biomedical understanding of disability. The number of cases our findings are based on is limited. We believe, however, that the inconsistencies and conflicts identified in our study need to be addressed.

In order to improve and develop the welfare services as indicated in our findings, we argue for translating the social relational and dynamic understanding of disability into practice by looking simultaneously at the child and his or her social environment (Egilson, 2015; Ingólfsdóttir et al., 2012). For this purpose, we highlight the advantage of CHAT as a practical tool in the development of a more coordinated and flexible welfare service system in Iceland and elsewhere where the disadvantages within the welfare services are of a similar nature.

## References

Arnadottir U and Egilson ST (2012) Evaluation of therapy services with the measure of processes of care (MPOC-20): the perspectives of Icelandic parents of children with physical disability. *Journal of Child Health Care* 16(1): 62–74. DOI: 10.1177/1367493511423769.

Bailey DB, Raspa M and Fox LC (2011) What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education* 31(4): 216–223. DOI: 10.1177/0271121411427077.

Bamm EL and Rosenbaum P (2008) Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation* 89(8): 1618–1624. DOI: 10.1016/j.apmr. 12.034.

Barnes C (2012) The social model of disability: valuable or irrelevant? In: Watson N, Roulstone A and and Thomas C (eds) *Routledge Handbook of Disability Studies*. London: Routledge, pp. 12–29.

Barnes C, Mercer G and Shakespeare T (1999) *Exploring Disability: A Sociological Introduction*. Malden: Polity Press.

Bjarnason DS (2009) Parents and professionals: an uneasy partnership? In: Allan J, Ozga J and Smyth G (eds) *Social Capital, Professionalism and Diversity*. Rotterdam: Sense, pp. 123–139.

Bjarnason DS (2010) *Social Policy and Social Capital: Parents and Exceptionality, 1974–2007*. New York: Nova Science.

Björnsdóttir K, Stefánsdóttir GV and Stefánsdóttir A (2015) 'It's my life' Autonomy and people with intellectual disabilities. *Journal of Intellectual Disabilities* 19(1): 5–21.

Blackler F (2009) Cultural-historical activity theory and organisational studies. In: Sannino A, Daniels H and andGutierrez KD (eds) *Learning and Expanding with Activity Theory*. New York: Cambridge University Press, pp. 19–40.

Bruder MB and Dunst CJ (2014) Parental judgments of early childhood intervention personnel practices: applying a consumer science perspective. *Topics in Early Childhood Special Education* 34(4): 200–210. DOI: 10.1177/0271121414522527.

Carulla LS, Reed GM and Vaez-Azizi LM (2011) Intellectual developmental disorders: towards a new name, definition and framework for mental retardation/intellectual disability in ICD-11. *World Psychiatry* 10(3): 175–180.

Case S (2010) Learning to partner, disabling conflict: early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities. *Disability and Society* 16(6): 837–854. DOI: 10.1080/09687590120083985.

Creswell JW (2008) *Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research*. Upper Saddle River: Pearson/Merrill Prentice Hall.

De Chenu L, Dæhlen D and Tah J (2016) A critical comparison of welfare states and their relevance to people with an intellectual disability. *Journal of Intellectual Disabilities* 20(4): 397–415. DOI: 10.1177/1744629515624613.

Dempsey I and Keen D (2008) A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhood Special Education* 28(1): 42–52. DOI: 10.1177/0271121408316699.

Dunst CJ (2002) Family-centered practices: birth through high school. *The Journal of Special Education* 36(3): 141–149. DOI: 10.1177/00224669020360030401.

Dunst CJ and Trivette CM (1987) Enabling and empowering families: conceptual and intervention issues. *School Psychology Review* 16(4): 443–456.

Egilson ST (2011) Parent perspectives of therapy services for their children with physical disabilities. *Scandinavian Journal of Caring Sciences* 25(2): 277–284. DOI: 10.1111/j.1471-6712.2010.00823.x.

Egilson ST (2015) User perspectives on support services to disabled children and their families. In: Traustadóttir R, Ytterhus B and Egilson ST, et al. (eds) *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging*. UK: Palgrave Macmillan, pp. 231–247.

Egilson ST and Stefánsdóttir S (2014) Velferðarþjónusta og fötluð börn: Reynsla foreldra af starfi fjölskyldudeildar Akureyrarbæjar [Welfare services and disabled children: Perspectives from parents in the municipality of Akureyri]. *Stjórnmál og Stjórnsýsla [Icelandic Review of Politics and Administration]* 10(2): 589–612.

Emerson E (2003) Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research* 47: 385–399.

Engeström Y (1987) *Learning by Expanding: An Activity-theoretical Approach to Developmental Research*. Helsinki: Orienta-Konsultit.

Engeström Y (2001) Expansive learning at work: toward an activity theoretical reconceptualization. *Journal of Education and Work* 14(1): 133–156. DOI: 10.1080/13639080123238.

Engeström Y (2008) *From Teams to Knots: Activity-theoretical Studies of Collaboration and Learning at Work*. Cambridge: Cambridge University Press.

Espe-Sherwindt M (2008) Family-centred practice: collaboration, competency and evidence. *Support for Learning* 23(3): 136–143. DOI: 10.1111/j.1467-9604.2008.00384.x.

Ferguson PM (2001) Mapping the family. Disability studies and the exploration of parental responses to disability. In: Albrecht GL, Seelman KD and Bury M (eds) *Handbook of Disability Studies*. Thousand Oaks: SAGE, pp. 373–396.

Goodley D (2001) 'Learning difficulties', the social model of disability and impairment: challenging epistemologies. *Disability & Society* 16(2): 207–231.

Guralnick MJ (2005) An overview of the developmental systems model for early intervention. In: Guralnick MJ (ed) *The Developmental Systems Approach to Early Intervention*. Baltimore: Paul H. Brookes, pp. 1–23.

Gustavsson A, Tøssebro J and Traustadóttir R (2005) Introduction: approaches and perspectives in nordic disability research. In: Gustavsson A, Tøssebro J and Traustadóttir R et al. (eds) *Resistance, Reflection and Change: Nordic Disability Research*. Lund: Studentlitteratur, pp. 23–45.

Ingólfsdóttir JG, Traustadóttir R, Egilson ST, et al. (2012) Thinking relationally: disability, families and cultural-historical activity theory. *Barn* 4(4): 13–24.

Kruijsen-Terpstra AJ, Verschuren O, Ketelaar M, et al. (2016) Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. *Research in Developmental Disabilities* 53–54: 314–322. DOI: 10.1016/j.ridd.2016.02.012.

Lundeby H and Tøssebro J (2008) Exploring the experiences of "not being listened to" from the perspective of parents with disabled children. *Scandinavian Journal of Disability Research* 10(4): 258–274. DOI: 10.1080/15017410802469700.

McLauchlin J, Goodley D, Clavering E, et al. (2008) *Families Raising Disabled Children*: *Enabling Care and Social Justice.* London: Palgrave Macmillan.

Ministry of Education, Science and Culture (2008) *The Preschool Act, No. 90/2008. Ministry of Education, Science and Culture Regulation on Expert Advisory Service for Municipalities' Preschools and Compulsory Schools and Pupil Welfare Committees in Compulsory Schools, No. 584/2010*. Ministry of Education, Science and Culture.

Ministry of Education, Science and Culture (2012) *The Icelandic National Curriculum Guide for Preschools*. Ministry of Education, Science and Culture.

Ministry of Welfare (2003) *Lög um Greiningar- og ráðgjafarstöð ríkisins* [Law on the State Diagnostic- and Counselling Centre] *No. 80/2003*.

Moore T (2008) Early childhood intervention: core knowledge and skills. CCCH working paper 3. Centre for Community Child Health. Available at: http://apo.org.au/files/resource/eci_skills_and_knowledge.pdf (accessed 22 February 2017).

Nachshen JS (2015) Empowerment and families: building bridges between parents and professionals, theory and research. *Journal on Developmental Disabilites* 11(1): 67–76.

Nummijoki J and Engeström Y (2010) Towards co-configuration in home care of elderly: cultivating agency by designing and implementing the mobility agreement. In: Daniels H, Edwards A and Engeström Y et al. (eds) *Activity Theory in Practice: Promoting Learning Across Boundaries and Agencies*. London: Routledge, pp. 49–72.

Oliver M (1990) *The Politics of Disablement*. London: Macmillan Education.

Patton MQ (2002) *Qualitative Research and Evaluation Methods*, 3rd ed. Thousand Oaks: SAGE.

Rosenbaum P, King S, Law M, et al. (1998) Family-centred service: a conceptual framework and research review. *Physical and Occupational Therapy in Paediatrics* 18(1): 1–20. DOI: 10.1080/j006v18n01_01.

Schalock RL, Sharon A and Borthwick-Duffy S (2010) *Intellectual Disability: Definition, Classification, and Systems of Supports*, 11th ed. Washington: American Association on Intellectual and Developmental Disabilities (AAIDD).

Shakespeare T (2014) *Disability Rights and Wrongs Revisited*, 2nd ed. London: Routledge.

Simons H (2009) *Case Study Research in Practice*, 3rd ed. Los Angeles: SAGE.

Statistics Iceland (2016). Availible at: http://www.statice.is/Statistics/Population (accessed 21 February 2017).

Stefánsdóttir S and Egilson ST (2016) Diverging on Children's rehabilitation services: a mixed-methods study. *Scandinavian Journal of Occupational Therapy* 23(5): 374–382. DOI 10.3109/11038128.2015.1105292

Tøssebro J (2004) Introduction to the special issue: understanding disability. *Scandinavian Journal of Disability Research* 6(1): 3–7. DOI: 10.1080/15017410409512635.

Tøssebro J (2015) Disabled children and welfare policy in the Nordic countries. In: Traustadóttir R, Ytterhus B and Egilson ST et al. (eds) *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging*. UK: Palgrave Macmillan, pp. 35–50.

Tøssebro J and Wendelborg C (2015) Ordinary or not? Families of children growing up with disabilities. In: Traustadóttir R, Ytterhus B and Egilson ST et al. (eds) *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging*. UK: Palgrave Macmillan, pp. 199–214.

Traustadóttir R (2009) Disability studies, the social model and legal developments. In: Arnardottir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*. Leiden: Martinus Nijhoff, pp. 3–16.

United Nations (2007) The UN convention on the rights of persons with disabilities. Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (accessed 21 February 2017).

Ytterhus B, Egilson ST, Traustadóttir R, et al. (2015) Perspectives on childhood and disability. In: Traustadóttir R, Ytterhus B and andEgilson ST (eds) *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging*. UK: Palgrave Macmillan, pp. 15–33.

Ytterhus B, Wendelborg C and Lundeby H (2008) Managing turning points and transitions in childhood and parenthood – insights from families with disabled children in Norway. *Disability and Society* 23(6): 625–636. DOI: 10.1080/09687590802328535.

# Article III

# Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland

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## ABSTRACT

Despite the avowed aims of the Icelandic legislation to provide family-centred and inclusive services, families raising disabled children commonly express their experiences of fragmented services provided more on the terms of the service providers than the users. This article is based on data derived from an on-going qualitative multi case-research in three municipalities in Iceland. The aims of the paper are 1) to identify the main contradictions that explain tensions and dilemmas within the service system as experienced by the parents, and 2) to suggest potential solutions for improving practices in accordance with family-centred inclusive policy and enhanced user participation. The cultural-historical activity theory was applied as an analytical framework. Three activities central to the wellbeing of the children and their families were identified as the unit of analysis, and contradictions within the activities were located and classified by following the expansive learning theory. Based on our findings we propose Edwards's three 'gardening tools' of relational practices as innovative and appropriate concepts for the necessary changes needed. By utilising these tools, the disabled children and their families are brought to the forefront and the professionals enhance their expertise in partnership with all stakeholders.

### Keywords

disabled children, family-centred services, preschools, relational practices, service development, cultural-historical activity theory

## INTRODUCTION

During recent decades a family-centred approach has become prominent in welfare service policy worldwide (Espe-Sherwindt, 2008) and has consequently had an impact on legal provisions and practice in Iceland (Arnadottir & Egilson, 2012; Egilson, 2010). However, it is commonly expressed by parents of disabled children that there is a mismatch between the aims of the welfare legislations and the service provision that appears in practice i.e. in service-based solutions lacking collaborative efforts between service providers and service users (Lundeby & Tøssebro, 2008; Ytterhus, Wendelborg & Lundeby, 2008; Egilson, 2015). Bailey, Raspa & Fox (2011) highlight the essentials in a family-centred approach and draw particular attention to how families should be seen as partners in making decisions about goals and activities in matters affecting them and their children. Although not compulsory in Iceland, the vast majority of all children at 2–6 years of age (disabled or not) attend preschool full time. This is both an educational issue for the child and a practical issue for the families, as it enables both parents to work outside the home, as is customary in Iceland. Inclusive schooling, also referred to as 'education for all', is the prevailing school policy. Preschools are funded and administrated by the municipalities and governed by the Preschool Act no 90/2008 (Lög um leikskóla [The Preschool Act], 2008) and school authorities are obliged to provide special services as needed. The amount of time for special education in the preschools is allocated on the grounds of 'type' and 'severity' of impairments according to psycho-medical diagnosis. Additional services are provided by specialists, either employed by the municipalities or self-employed. Those working privately get paid from the national health insurance according to rules based on the number of clients served. A recent external audit of the Icelandic system on inclusive education (European Agency for Special Needs and Inclusive Education, 2017) reveals the need for guidance for all stakeholders on how inclusive practices should be monitored and evaluated in line with national legislation and policy.

This article is based on data derived from on-going multi-case research on services for young disabled children (2–6 years) and their families in Iceland (Ingólfsdóttir, Egilson & Traustadóttir, 2017). The aim of this part of the project is 1) to identify the main contradictions that explain tensions and dilemmas within the service system as experienced by the parents, and 2) to suggest potential solutions for improving practices in accordance to family-centred inclusive policy and enhanced user-participation.

## CULTURAL-HISTORICAL ACTIVITY THEORY AS AN ANALYTICAL FRAMEWORK

Historically it is well known that taking new ideas or theories into practices can be complicated. New paradigms call for changes when implementing new forms of practice that may cause discrepancies and tensions hindering the development of the relevant practices. Cultural-historical activity theory is a theoretical framework that helps to understand and analyse human activities in their social contexts (Engeström, 1987; 1999; 2001; 2016). Based on Vygotskty (1978), who suggested mediated activity for researching individual-societal interaction in context, Engeström (1987) put forward a model of an activity system for use as an analytical tool to explore the relations between individual

and community in human activity. The model describes the structure of an activity system in a triangular diagram (Figure 1).



**Figure 1.** The structure of a human activity system (Engeström, 1987, p. 78)

The *subject* refers to an individual or a group whose agency is chosen as the point of view in the analysis. The *object i*s the target of the activity system and the *outcome* is the goal or the ends towards which activity is directed. The subject's relationship with the object is mediated by use of different types of *tools* afforded by the culture, which can be both material and conceptual. The *rules* refer to the set of norms and conventions that regulate the activity, the *community* consists of the people involved in the activity who share the same object, and the *division of labour* mediates the hierarchy of labour and division of tasks between its members. Since activities are always related to other activities, Engeström (2001) suggested two interacting activity systems to be the minimum unit of analysis.

According to this theory, contradictions are present in every collective activity system, causing tensions, problems and dilemmas that disrupt the activity. Contradictions are understood as challenges that practitioners need to deal with, and identifying these contradictions may open up opportunities for the development of practices. To clarify the way in which practitioners collaborate to overcome contradictions, Engeström (2001) developed the 'expansive learning theory' and presented a model of the *expansive learning cycle* (Figure 3) for analysing and supporting development. The expansive learning cycle directs analysis of step-by-step evolution of activities (Engeström 2016).

## THE RESEARCH

This paper is part of an on-going qualitative multi-case research (Creswell, 2008) focusing on services for young disabled children (2–6 years of age) and their families in Iceland (Ingólfsdóttir et al., 2017). It is a theory-led research (Simons, 2009) based on family-centred theory (Bamm and Rosenbaum, 2008; Dunst, 2002) and the Nordic relational view on disability (Tøssebro, 2004). The research was conducted in three different municipalities in Iceland. Each case included two to four children, their families (eight families in all) preschool professionals, service counsellors and external experts (see table 1). Case study A was carried out in Reykjavík, by far the largest municipality in Iceland. Case study B was conducted in a rural municipality that is composed of several small communities with aggregated 8,000 inhabitants. *Case study C* was undertaken in a municipality in North Iceland with 18,000 inhabitants that has been widely regarded as a model in integrated welfare services. These three different municipalities were selected because they provided the opportunity to reflect on services in diverse locations with respect to population and geographical region, since preschools and the affairs of disabled children are run by the municipalities. Since previous Icelandic research has focused mostly on children and families in urban and suburban areas (Bjarnason, 2009; Arnadottir & Egilson, 2012), more families were selected from the rural municipality than from the other two municipalities.

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**Table 1:** Overview of participants and data sources in the case studies

| | Case (a) Reykjavik, the capital | | Case (b) Rural municipality | | | | Case (c) Municipality in North Iceland | | The study as a whole (across cases) |
|---|---|---|---|---|---|---|---|---|---|
| | Child one and two | Child three | Child four | Child five | Child six | Child seven | Child eight | Child nine | |
| **Child details** | Twin boys; Four years; Intellectual impairment and ADHD | Boy; Two years; Intellectual impairment (Downs syndrome) | Girl; Three years; Intellectual impairment (Downs syndrome) | Girl; Five years; Physical- and intellectual impairment | Boy; Five years; Mild intellectual-physical- and speech impairment | Boy; Seven years; Autism spectrum disorder | Boy; Four years; Severe intellectual, physical and speech impairment | Boy; Five years; Mild intellectual physical- and speech impairment; ADD | |
| **Family and community details** | Live with father and stepmother; One older sister; Both parents work outside the home; Attend local preschool. | Lives with both parents and two older brothers; Both parents work outside the home; Attends a local preschool. | Lives with both parents. Both parents work outside the home; Attends local preschool. | Lives with both parents and two older sisters; Father receives disability benefits; Mother works outside the home; Attends a local preschool. | Lives with mother & stepfather; Both parents work outside the home; Attends local preschool. | Lives with both parents and three siblings; Both parents work outside the home; Attends local preschool. | Lives with both parents and younger sister; Father works outside the home, mother a university student; Attends preschool nearby a rehabilitation centre. | Lives with both parents. Half-brother stays with the family every second weekend; Both parents work outside the home; Attends a local preschool. | |
| **Specific data sources** | Interviews: Father; Father & stepmother; Observation: Team meeting (parents, teachers and service coordinator from the local service centre). | Interview: x2 with both parents. | Interview: Both parents. | Interviews: Mother; Preschool social pedagogue; Head of preschool; Observations: Story time at preschool; Home. | Interview: Mother, Service coordinator, Observation: Team meeting. | Interviews: Mother; Preschool teacher; Observation: Home; Review: Individual education plan. | Interviews: Mother; Father; Special education teacher; Head of preschool; Speech therapist; Observations: Preschool playtime and mealtime; Team meeting; Review: Assessment report; Individual education plan. | Interviews: Mother x2; Special education teacher; Head of preschool; Observations: Preschool playtime and mealtime, Language training session, Team meeting; Review: Individual education plan | |
| **Generic data sources for municipality** | *Interviews: City special education project leader; Head of advisory preschool\*; Advisory preschool special education coordinator; Speech pathologist Presentation of services: Advisory preschool Observation: Arrangements of disabled children's services within advisory preschool Documents from city´s official website: Information on family- and educational services, reports and official rules* | | *Interview: Municipality service consultant Review of local guiding rules Review of documents from municipality's official website: Information on family- and educational services, reports and official rules* | | | | *Interviews: Municipality preschool special education counselor; Municipality family service manager Review of documents from municipality's official website: Information on family- and educational services, reports and official rules* | | *Interview: Parent-counsellor operating nationwide Documents: Icelandic laws and regulations on social and educational services for disabled children and families; UN-CRPD* |

\*A preschool that specialises in serving disabled children and provides advice to other preschools in Reykjavik

The participating families were selected by the local special education counsellors aiming at diversity with regard to intellectual and/or physical impairment, number of siblings in the family and societal circumstances. The children were 3–7 years of age when the research took place and all had attended preschool from when they were about two years old. All the children received special education within the preschools according to the prevailing rules for allocation, and all received additional specialised services outside the school such as speech therapy or/and physiotherapy. The authors were in no previous contact with the children or their families. The limited number of cases has to be considered when drawing conclusions from this study, as well as the fact that the participants were proposed by the local counsellors in each municipality.

### Data collection and analysis

In line with the case-study approach, we drew on multiple sources of information including in-depth interviews, participant observations and document analysis (Creswell, 2008). A review of policy documents was carried out, including laws and regulations regarding disabled children and families. Data also consisted of documents published on the local government websites and websites of individual preschools, which provided rich information related to policy and preschool services. Twelve semi-structured in-depth interviews with parents were conducted (six with mothers alone, two with fathers alone and four with the parents together) and twelve interviews were carried out with professionals from diverse disciplines. In addition to the interviews, nine participant observations were conducted: six participant observations in the preschools, and three at meetings concerning the children, in order to gain a comprehensive overview and insights that cannot be obtained solely by speaking with people (Simons, 2009). The observations created an important opportunity for comparing and contrasting information with data obtained in the interviews**.**

The interviews were recorded, transcribed and analysed according to deductive within-case and cross-case analysis (Creswell, 2008; Simons, 2009), with the prior described features of family-centred services and the social-relational view on disability as a framework. During the entire process of analysis an effort was made to focus on the quality of the statements made by participants rather than the quantity of ideas presented (Patton, 2014). Initial categories and themes were identified by reading the transcribed data and selecting expressions that manifested family-centred services. In the second round of analysis, main categories were formulated by combining initial sub-categories. Final conceptualisations were generated through parallel investigation and comparison of the main categories. During this phase the main topics were compared within and between municipalities in order to detect similarities and differences between the three cases, as expressed by the parents and professionals. Unexpectedly, there was a high convergence between all the three cases on what worked well for the children and their families and what did not. The differences obtained were based on individual experiences rather than geographical location. The parents in all three municipalities valued their child's preschool and praised the preschool staff for good interaction and support. However, the parents found other parts of the services detached from this main service unit, such as physical and speech therapy services, which were mostly provided at the specialists' venue.

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## THE UNIT OF ANALYSIS IN THE LIGHT OF THE EXPANSIVE LEARNING THEORY

In analysing the services for disabled children with regard to family-centeredness and inclusive practices, we identified three activity systems central to the children's wellbeing: the family, the preschool and the external services of specialised experts as the unit of analysis (Figure 2).



**Figure 2.** Three interacting activity systems as the unit of analysis (Adapted from Engeström, 2001)

The family is seen as an activity with parents being the subject, the upbringing of their child the object, and the long-term welfare of the child as the outcome. In the preschool's activity system, the preschool practitioners are the subject and the children's education and development the object. In both activities, the desired outcome of the activity, i.e. the goal, is children's wellbeing. The family and the preschool clearly share a common object, being the upbringing of the children with the common goal to support their wellbeing. Most children participate in these two activity systems. However, in the case of disabled children there is often an additional activity involved consisting of the therapies and treatments they receive from external experts. According to our data, this activity calls for most attention since the way this activity system and its practices causes disruptions in the lives of the families, especially the children's and the mothers'. Our data suggests, however, that chan-

ges within these practices (the activities of the external experts) are emerging as some therapists/experts have developed their occupational practices in line with new ideologies and are now seeking opportunities to work more inclusively in collaboration with the other two activities. This situation – when some practitioners start to doubt the old model and find the need for changing their practice – is identified as the *needs state* in the expansive learning theory, and the first step of contradictions that need to be attended to and worked with for the expansion of organisational learning (Figure 3).



**Figure 3.** The expansive learning cycle (Adapted from Engeström, 2001)

Following the theory, expansive learning is predicated upon a progression from individuals questioning the state of the art in current practice through the modelling of new forms of practice (see Table 2). The theory of expansive learning puts the primacy on the collective community learning for the creation of new culture (Engeström, 2016, p. 36). In the case of our research, the service users (the children and their families) and the professionals construct a new co-owned object, (children's upbringing) with the shared goal of the welfare of the children and families according to new policy ideals. This implies that the contradictions identified in our research can, if addressed, become a source of change in the services in Iceland. In order to better understand how, when and why interacting activity systems develop, close attention to the four levels of contradictions, identified in Table 2, is essential (Engeström, 1999).

## LEVELS OF CONTRADICTIONS AND CORRESPONDING LEARNING ACTIONS

### Primary contradictions: tension between the old and the new

Despite the avowed aims of the Icelandic legislation to provide family-centred and inclusive services, the data from all the three cases demonstrated fragmented services being provided more on the terms of the service providers than the users. This is due to the mismatch between the policy ideals, representing family-centeredness and inclusion on the one hand, and the rules for the allocation of services based on the psycho-medical diagnosis of impairments on the other. In the research, a father of prematurely born twins reported how his family was directed to two different institutions for further diagnoses due to their slightly different IQ outcomes in the primary assessments of his sons. The reason was the different roles of the institutions according to the severity of impairments. This is an example of how the fact that eligibility for specialised services is primarily decided on the basis of child's diagnosis rather than the actual need for support. The paradigm change described before requires services to better align with the needs and wishes of the service users.

The previously mentioned discrepancy between policy and service actions is caused by the primary contradiction, which is the fundamental contradiction that keeps the activity system in constant tension. It surfaces in everyday contexts, in various forms and in other levels of contradictions.

Table 2. Levels of contradictions and corresponding learning actions (adapted from Foot, 2014)

| Levels of contradictions | Characteristics of contradictions | Corresponding learning action |
|---|---|---|
| **Primary** | Mismatch between policy and practice. New visions on disability and human rights vs. old forms of practices based on medical views. | Questioning – Needs state. New ideas call for new forms of practices. Services need to move from provision on the terms of the specialists or the system to being on the terms of the service user. |
| **Secondary double bind** | Psycho-medical diagnosis as the main predictor for the allocation of services vs. the rights for family-centred services according to needs. Fragmented services reducing quality of life for disabled children and families. | 2A Historical analysis – The paradigm shift from medical view on disability to social-relational views. 2B Empirical analysis The paradigm change calls for new solutions. Develop new forms of family-centred practices in accordance with new views on disability, official aims of services, inclusive schooling, regulations and the emerging implementation of the CRPD. |
| **Tertiary** | Arises when a more developed activity is introduced into the central activity system such as: A new model is emerging, characterized by relational professionalism aiming at monitoring and controlling professional work according to the needs and wishes of the service users vs. professionalism led by the professions according to the old model based on the medical view. | Modeling the new solution. Rethinking practices by rethinking expertise and multi-agency practices. Relational expertise, common knowledge and relational agency being the central concepts in a new model. Examining the model. Implementing the model on a systemic level requires change of rules; regulations on a systemic level in accordance to new policy and law. Evaluating process. |
| **Quaternary** | Occurs between central activity and neighbouring activities, triggered by tertiary contradiction. | Consolidating new practice. Questioning – the spiral goes on. |

According to Foot (2014) the primary contradiction is not only continually present, but also serves as a foundation for other levels of contradictions. Furthermore, she claims that even if attempts to resolve the other levels of contradictions are temporarily successful, the primary contradiction remains. The levels of contradictions and corresponding actions are outlined in Table 2.

### Secondary contradictions: tensions between rules for expert practice and ordinary life of children and families

The parents we interviewed were unanimous about the difficulties they encountered when striving for an appointment with fully booked specialists, which forced them to accept any appointment slot offered. Usually it was the mother's role to take the child to the therapists and, consequently, all the mothers taking part in the research had been compelled to reduce their working hours or change their occupations to be able to bring their children to the specialists. Thus, the service arrangements disrupted their personal and family circumstances both in terms of career and financial income, quite apart from disturbing the children's routines. This indicates that services are provided on the specialists' terms – the old policy contradicting the new, which presumes that needs of children and the families are at the forefront. The allocation of funds for specialised services is primarily decided on the basis of the 'severity' of the child's diagnosis, running in opposition to the new policy, which declares that the services should be provided on the bases of the actual need for support expressed by the families. However, the data reveal an emerging trend of both diagnostic measures and services in accordance with the new family-centred and inclusive policy.

A mother of a young girl with Down's syndrome felt 'lucky' as the impairment her daughter has is well known. She added that they [the family] were guided along a prepared path designed for families with children with Down's syndrome. Furthermore, parents of children diagnosed with autism reported how they were offered a choice of highly structured behaviour therapy provided individually within the preschool by specially trained (para-) professionals. Since the rules for the allocation of services are based on diagnosis, parents and preschools tend to strive for psycho-medical diagnosis of children (often against their own better judgment and conviction) as it gives access to financial resources. This is against the spirit of the prevailing law favouring family-centred services, where the will and preference of the service-users and their individual needs for assistance are supposed to be at the forefront.

### Tertiary contradictions: new forms of practices cause fragmentation in services where some practitioners have changed their practice while others fall behind

An example of an emerging new model of practice in the specialists' services was reported by one of the participating mothers. She explained how she had managed to influence her son's services when a physical therapist accepted to alter her usual service to accommodate the mother's wishes. Instead of bringing the boy to the therapist's premises, the therapist went to the preschool to work with the boy. In the mother's opinion this was the ideal

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arrangement as it had a minimal effect on her son's school routine and she herself did not have to break up her workday to drive her son to the session with the therapist. Additionally, it gave the preschool staff an opportunity to extend their knowledge. Unfortunately, this therapist went on a maternity leave and the new therapist did not accept to continue this arrangement. This can be identified as a tertiary contradiction between developed practices in accordance to new views versus traditional modes of practice that does not take new understandings and policy into account.

In all three municipalities the preschool administrators were open to the idea of providing specialised services at the school premises in accordance with the spirit of the law, but evidently the lack of official rules, relevant guidelines and supervision prevented this. Furthermore, the specialists' working conditions and even professional preferences appeared to stand in the way at times. An experienced speech therapist expressed her views on this by saying: 'Professionals need to look into and reconsider their own practices and stop just acting according to their own convenience'. A special education consultant was unequivocal when she said she envisioned that the specialist services would be transferred into the preschools and included in everyday activities. She continued, however, by describing the obstacles, such as the limited number of specialists working within the school system and increased emphasis on individual behaviour therapy. These are signs of tertiary contradictions motivating new dynamics for developing family-centred services in an inclusive way.

## IMPLICATIONS FOR SERVICES

Based on our analyses directed by Engeström's theory of expansive learning, we are able to suggest which changes need to be implemented in order to develop inclusive family-centred welfare services for disabled children and their families. *Firstly,* we refer to the problems and dilemmas faced by the families, especially mothers, when policy ideals on the one hand and the provision of services on the other do not combine to provide services in a family-centred inclusive manner. Our analyses suggest a need to change the rules for the allocation of financial resources for specialised services, and to adopt official guidelines for new approaches in professional practices in accordance with family-centred inclusive services. *Secondly,* we refer to the importance of pursuing relational practices between all inter-related activity systems. This is the key change needed to overcome the current contradictions within the welfare services, especially when striving for family-centeredness and inclusive practices. Inclusive practice in preschool education requires making adjustments, modifications and individualised accommodations in instructional methods so the disabled child can fully participate in play and everyday learning activities with their peers (Grisham-Brown, Hemmeter & Pretti-Frontczak, 2017). Hence, inclusive practices call for professional collaboration and transfer of knowledge across professional boundaries. In this context, we find the cultural-historical approach to collaboration within and across practices as introduced by Edwards (2017) well suited to promote the development of welfare services, better to comply with the merits of family-centred theory and inclusive practices. The three fundamental concepts in her theoretical contribution are: *relational expertise* (including the parents as experts*), common knowledge* and *relational agency* to

support both professional and organisational development (see Figure 3). These concepts are labels Edwards has given to the aspects of the expertise exercised by professionals who accomplish effective inter-professional work to bolster children and families (pp. 7–12). She refers to those three concepts as *gardening tools* that have been used to build, nurture and sustain the expertise needed for collaborations across professional boundaries. The first and overarching concept is *relational expertise*, which is the capacity to work with others on complex tasks, involving a joint interpretation of the work ahead as well as a joint response. Relational expertise is therefore an additional form of expertise that augments specialist expertise and makes fluid and responsive collaborations possible. The second concept, *common knowledge*, acts as a mediator of relational agency in the sense that through common knowledge, practice can be oriented towards coherent goals of interacting activities. Professionals learn from one another and therefore common knowledge is created in interactions in sites of intersecting practices (Edwards, 2017, p. 10). Lastly, the third gardening tool, *relational agency*, is the capacity of professionals from different practices to align with the thoughts and action of one another, in this case the families, preschool professionals and external experts all drawing on the resources they offer to strengthen their purposeful responses in order to act in line with the objectives of family-centred services and inclusion.

## CONCLUSION

The high convergence between all three cases on what worked well for the children and their families, and on what caused tensions and dilemmas, draws attention to the commonly expressed contradictions between policy ideals and the services as enacted in practice. The emerging paradigm change followed by changes in the views on disability calls for systemic development in professional thinking and provision of services. The necessary changes require official guidelines from the authorities about the working arrangements that conform to the ideology, within existing laws and conventions. In our view this demands new solutions and the will and capacity of service providers to interact intensively across professional boundaries with the families of disabled children. The existing rules for the allocation of resources and the working conditions of external experts motivate them to follow a process of identifying the impairment and its limitations, aiming at taking the necessary action to improve the position of the individual disabled child, often without looking at the wider context. This has produced a service system in which an authoritarian service provider prescribes and acts for a 'passive client' irrespective of his or her actual needs and wishes. In order to develop new ways of practices for better complying with the aims of family-centred services, inclusion and other human rights perspectives, we suggest changes in rules on how the welfare authorities allocate resources in order to support a relational turn in expert practices. Our proposition is that by utilising the *gardening tools* of relational practices, the disabled children and their families will be brought to the forefront and professionals will be able to enhance their own expertise in partnership with all stakeholders. According to the expansive learning theory, the next step in the learning cycle would be to develop a new service model by rethinking practices and expertise. Based on the characteristics of the contradictions identified in this research and the sug-

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gested learning actions to develop the services, multi-agency practices with relational expertise, common knowledge and relational agency will be central concepts in our future work aiming at the enhanced participation of disabled children and their parents.

## REFERENCES

Arnadottir, U., & Egilson, S. T. (2012). Evaluation of therapy services with the Measure of Processes of Care (MPOC-20): The perspectives of parents of children with physical disability. *Journal of Child Health Care, 16*(1), 62-74. DOI: https://doi.org/10.1177/1367493511423769.

Bailey, D. B., Raspa, M., & Fox, L. C. (2011). What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education, 31*(4), 216-223. DOI: http://dx.doi.org/10.1177/0271121411427077

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation, 89*(8), 1618-1624. DOI: http://10.1016/j.apmr.2007.12.034.

Bjarnason, D. S. (2009). Parents and professionals: A uneasy partnership. In J. Allan, J. Ozga, & G. Smyth (Eds.), *Social capital, professionalism and diversity* (pp. 123-139). Rotterdam: Sense.

Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research.* Upper Saddle River, NJ: Pearson/Merrill Prentice Hall.

Dunst, C. J. (2002). Family-centered practices: Birth through high school. *The Journal of Special Education, 36*(3), 141-149. DOI: http://journals.sagepub.com/doi/abs/10.1177/00224669020360030401.

Edwards, A. (2017). *Working relationally in and across practices: A cultural-historical approach to collaboration.* Cambridge, UK: Cambridge University Press. DOI: https://doi.org/10.1017/9781316275184.

Egilson, S. T. (2010). Parent perspectives of therapy services for their children with physical disabilities. *Scandinavian Journal of Caring Sciences, 25*(2), 277-284. DOI: https://doi.org/10.1111/j.1471-6712.2010.00823.x.

Egilson, S. T. (2015). User perspectives on support services to disabled children and their families. In R. Traustadóttir, B. Ytterhus, S. T. Egilson, & B. Berg (Eds.), *Childhood and disability in the Nordic countries: Being, becoming, belonging* (pp. 231-247). London: Palgrave Macmillan UK.

Engeström, Y. (1987). *Learning by expanding: an activity-theoretical approach to developmental research.* Helsinki, Finland: Orienta-Konsultit.

Engeström, Y. (1999). Activity theory and individual and social transformations. In *Perspectives on activity theory* (pp. 19-38). Cambridge: University Press.

Engeström, Y. (2001). Expansive Learning at Work: Toward an activity theoretical reconceptualization. *Journal of Education and Work, 14*(1), 133-156. DOI: https://www.tandfonline.com/doi/abs/10.1080/13639080020028747.

Engeström, Y. (2016). *Studies in expansive learning: Learning what is not yet there.* New York, NY: Cambridge University Press.

Espe-Sherwindt, M. (2008). Family-centred practice: collaboration, competency and evidence. *Support for Learning, 23*(3), 136-143. DOI: http://dx.doi.org/10.1111/j.1467-9604.2008.00384.x.

European Agency for Special Needs and Inclusive Education. (2017). *Education for all in Iceland – External audit of the Icelandic system for inclusive education.* Odence, Denmark: European Agency for Special Needs and Inclusive Education. Retrieved from: https://www.stjornarradid.is/media/menntamalaraduneyti-media/media/frettatengt2016/Final-report_External-Audit-of-the-Icelandic-System-for-Inclusive-Education.pdf.

Idunn
Nordiske tidsskrifter på nett

Foot, K. A. (2014). Cultural-Historical Activity Theory: Exploring a Theory to Inform Practice and Research. *Journal of Human Behavior in the Social Environment, 24*(3), 329-347. DOI: https://www.tandfonline.com/doi/abs/10.1080/10911359.2013.831011.

Grisham-Brown, J., Hemmeter, M. L., & Pretti-Frontczak, K. (2017). *Blended practices for teaching young children in inclusive settings* (2nd ed.). Baltimore, MD: Paul H. Brooks Publishing Co.

Ingólfsdóttir, J. G., Egilson, S. T., & Traustadóttir, R. (2017). Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice. *Journal of Intellectual Disabilities.* DOI: http://journals.sagepub.com/doi/10.1177/1744629517714644.

Lundeby, H., & Tøssebro, J. (2008). Exploring the Experiences of "Not Being Listened To" from the Perspective of Parents with Disabled Children. *Scandinavian Journal of Disability Research, 10*(4), 258-274. DOI: https://www.sjdr.se/articles/10.1080/15017410802469700/.

Lög um leiksóla [The preschool act]. (2008). *90/2008: Lög um leikskóla.* Retrieved from https://www.althingi.is/lagas/nuna/2008090.html.

Patton, M. Q. (2014). *Qualitative research & evaluation methods: Integrating theory and practice: the definitive text of qualitative inquiry frameworks and options.* Thousand Oaks, CA: SAGE Publications, Inc.

Tøssebro, J. (2004). Introduction to the special issue: Understanding disability. *Scandinavian Journal of Disability Research, 6*(1), 3-7. DOI: http://dx.doi.org/10.1080/15017410409512635.

Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes.* Cambridge, Ma: Harvard University Press.

Ytterhus, B., Wendelborg, C., & Lundeby, H. (2008). Managing turning points and transitions in childhood and parenthood – insights from families with disabled children in Norway. *Disability & Society, 23*(6), 625-636. DOI: http://dx.doi.org/10.1080/09687590802328535.

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Nordiske tidsskrifter på nett

# Article IV

SJDR

## RESEARCH

# Rethinking Practices by Rethinking Expertise: A Relational Approach to Family-Centred Inclusive Services

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This article focuses on the views and experiences of professionals providing specialised services to disabled children and their families. It is part of a larger research project that investigates the gap between policy ideals and service provision for young disabled children and their families in Iceland. Contrary to official policies, earlier findings based on the families' perspectives reported strain and stress from fragmented and inflexible services. The findings presented here are based on three focus-group interviews, conducted with 13 professionals from six disciplines. The aim was to capture their views on their roles, responsibilities, and working conditions. A number of organisational and professional barriers were exposed along with an overall lack of awareness of the basic principles of family-centred services and the human rights relational approach to disability. Recommendations for service development are inspired by Edwards' relational theory about building inter-professional and inter-organisational links to create high quality practices.

**Keywords:** Family-centred services; disabled children; professionals; preschools; activity theory; relational practices

## Introduction

A family-centred approach in services is a way of working in partnership with families to better understand their unique circumstances and to help parents decide what strategies will best suit their families (Dunst & Espe-Sherwindt 2016). Despite ambitious and often progressive policies about providing family-centred inclusive services for disabled children and their families, more research is needed in this field on what this really means for service providers (Foster et al. 2020) as numerous studies show persistent difficulties in translating these policies into practice (Dodd, Saggers & Wildy 2009; Egilson 2011; Egilson & Stefánsdóttir 2014; Ingólfsdóttir, Egilson & Traustadóttir 2017). The study presented in this article is part of a larger qualitative multi-case research project that investigates the mismatch between policy ideals and the provision of services aimed at disabled children of preschool age and their families in Iceland (Ingólfsdóttir, Egilson & Traustadóttir 2017). Furthermore, the project aims are to develop recommendations based on the findings on how services can be arranged in order to better align with current rights-based family-centred welfare policies.

During the first stages of the research project, the focus was mainly on the families and their views and experiences of the services provided to them. In this article, however, we present data about specialised services from professionals' points of view. Professionals such as physiotherapists, occupational therapists, and speech and language therapists play a pivotal role in the services for disabled children and their families. Consequently, their views on their professional roles, priorities, and working conditions provide important understanding on why the implementation of progressive policies has proven to be problematic, which, in turn, can assist in bringing about improvements in service organisation and delivery. As pointed out by Bamm & Rosenbaum (2008), information about the roles of specialised professionals within the service system is an important aspect of developing new ideas and ways for service provisions that better comply with the needs and wishes of families raising disabled children. In developing our recommendations for service improvements, we employ the cultural-historical account of expertise (Engeström 2001; Engeström 2016; Edwards 2017; Edwards 2020; Hopwood 2017; Ingólfsdóttir, Jóhannsdóttir & Traustadóttir 2018). To guide our way, we utilise Edwards' (2017; 2020) concepts of common knowledge, relational expertise, and relational agency together with the official policy aims of family-centred inclusive services (**Table 1**). This relational turn in expertise encompasses many of the characteristics and principles of family-centred practice that characterise official policies in welfare and educational services in Iceland (Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir nr. 85/2018; The Ministry of Education, Science and Culture 2011).

**Table 1:** Edwards' three 'gardening tools' in relation to family-centred inclusive practices.

| The gardening tools | Common characteristics and principles | FCIP core values |
| --- | --- | --- |
| **1. Common knowledge**<br>· Transfer, translation, and transformation of expert knowledge.<br>· Professionals being able to identify and integrate one's own expertise with what others know and do. | · What affects one member of the system impacts on the other members.<br>· Equal power relations.<br>· Parent/professional partnership.<br>· Recognising and respecting one another's knowledge and expertise. | · Parents are seen as experts in their own matters.<br>· Meaningful parent involvement.<br>· Stakeholders have a clear and shared understanding of their roles and responsibilities and know that they are expected to collaborate with partner organisations. |
| **2. Relational expertise**<br>· To be explicit about what matters for you.<br>· To recognise what matters for others.<br>· Joint interpretation of the problem.<br>· To attune ones actions with those of others.<br>· Adds to existing knowledge. | · An ecosystems relational thinking.<br>· The children exist within the context of their families, wider community, and society.<br>· Take advantage of both core expertise and additional capabilities.<br>· Augments specialist expertise and enables fluid responsive collaborations. | · A curriculum which requires staff to collaborate with children, colleagues, and parents and to reflect on their own practice.<br>· Individualised, flexible, coordinated, and responsive services.<br>· Monitoring and evaluation which is in the best interest of the child. |
| **3. Relational agency**<br>· Collaboration within and between activity systems.<br>· Professionals can, and need to, draw on and contribute to systems of distributed expertise. | · Experts build links and try to integrate what they know with what others want to, or should, know and do.<br>· All entities are working towards a common goal. | · Families are key decisionmakers in addressing their children's and families' needs.<br>· Parents are seen as equal partners in decision making and goal setting. |

In the following we give information about the context of the study and the theoretical background and frameworks. The description of the research, including the research questions, data collection, participants, and methods of analysis, is also provided. Findings are then presented, followed by discussion and implications for services. Last, there are some concluding remarks.

## The Icelandic Context

Altogether, 95–97% of all children in Iceland (including disabled children) attend preschool from an early age (Statistics Iceland 2018). Preschools are defined by law as the first school level, providing education for children up to six, when compulsory education begins (Lög um leikskóla nr. 90/2008), and preschool authorities are obliged to provide special services as needed (Reglugerð um sérfræðiþjónustu sveitarfélaga við leik- og grunnskóla og nemendaverndarráð í grunnskólum no. 584/2010). However, disabled children who are referred to physiotherapy, occupational therapy, or speech and language therapy must predominantly rely on services provided by specialists working at clinics outside the preschool.

According to a recent legislation, services shall be based on individual needs, circumstances, wishes and other relevant matters of the person concerned (Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir nr. 85/2018). This law is based on, and intended to comply with, requirements in the United Nations Convention on the rights of persons with disabilities (CRPD) (United Nations 2006), ratified by the Icelandic government in 2016. Furthermore, the aims of these services are in line with the core values of a family-centred ideology (Bamm & Rosenbaum 2008; Dunst 2002; Espe-Sherwindt 2008; Dunst & Espe-Sherwindt 2016) and inclusive school policies (Ainscow 2005; Haug 2017), which are the prevailing ideologies in Iceland regarding young disabled children and their families (Lög um leikskóla nr. 90/2008; Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir nr. 85/2018). In line with these ideologies, recent official documents reflect the will to increase collaboration between relevant ministries 'with the aim of breaking down barriers between systems in an endeavour to guarantee comprehensive and coordinated service in accordance with children's needs' (Samband íslenskra sveitarfélaga 2018). Although these values have been at the forefront in official welfare and educational policies in Iceland for a long time, they appear to be difficult to implement and maintain (Egilson 2011; Egilson 2015).

## Theoretical Background and Frameworks

Since the ratification of the CRPD in 2016, the Icelandic government has been committed to ensuring that disabled people enjoy all rights in the convention and to making the necessary changes to guarantee its provisions to be fulfilled (Alþingi 2018–2019). Thus, official service providers and professionals are obliged to abolish practices that do not comply with its requirements and promote appropriate professional and institutional development.
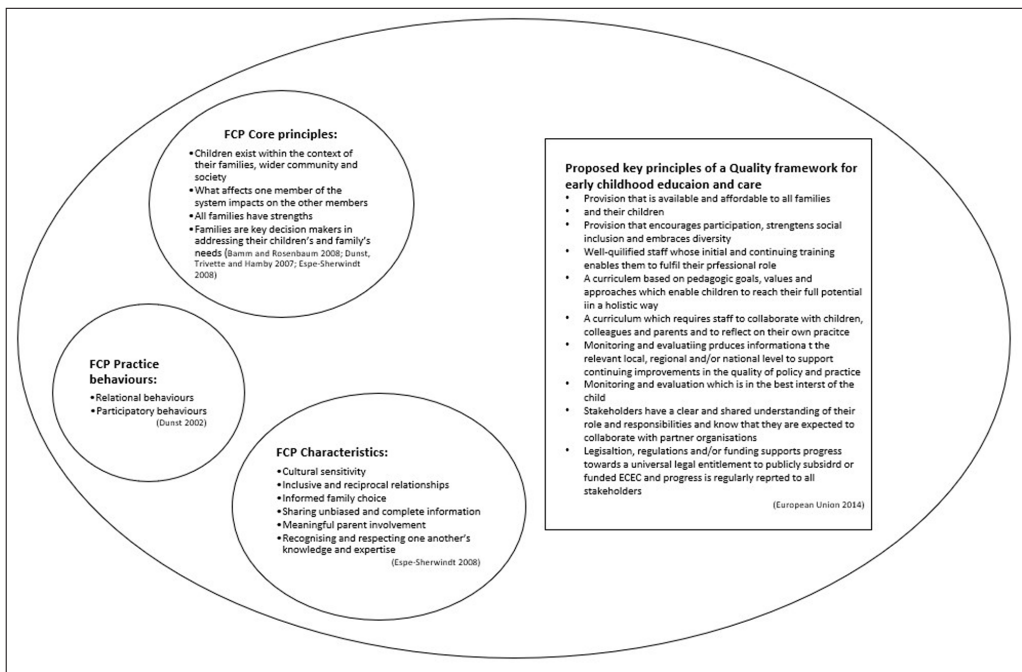
Research findings focusing on welfare services for disabled children and their families commonly report poor coordination, the lack of relevant resources, and difficult access to recommended services as the main concerns of families raising disabled children (Egilson & Stefánsdóttir 2014; Egilson 2015; Goodley & McLaughlin 2008; Ingólfsdóttir, Egilson & Traustadóttir 2017; Ingólfsdóttir, Jóhannsdóttir & Traustadóttir 2018; Tossebro & Wendelborg 2015). Along with the paradigm change from a medically and impairment-focused focus to a rights-based and relational way of thinking about disability as required by the CRPD (Traustadóttir 2009), there is an overall call for changes in welfare and educational practices (Dunst, Trivette & Hamby 2007; Edwards et al. 2009; Goodley 2011; Edwards 2017; Edwards 2020).

There is a common view, though, that organisational theories and professional development have not moved towards knowledge creation and innovation accordingly (Edwards et al. 2009). This is particularly true concerning the increased requirement on extensive collaboration within welfare and educational services (Edwards et al. 2009; Espe-Sherwindt 2008; Haug 2017). Hence, the focus in this article is on the benefit inherent in the collaboration of diverse professionals across practice boundaries and how it can be the premise for developing the idea of relational expertise in the context of family-centred inclusive practice.

### Family-centred inclusive practice

Family-centred inclusive practice (**Figure 1**) is the theoretical foundation of this research. It is an officially agreed upon policy reflected in *The Icelandic National Curriculum Guide for Preschools* (The Ministry of Education, Science and Culture 2011: 33), which states that 'the wellbeing of a child in preschool is interconnected with the welfare of the child's family and home'. Moreover, Article 24 of the CRPD (United Nations 2006) calls for inclusive education, which has been the declared school policy in Iceland since 2008 (Lög um leikskóla nr. 90/2008).

Family-centred practice is a set of values, skills, behaviours, and knowledge that recognises the centrality of families in the lives of children. It is grounded in respect for the uniqueness of every child and family and a commitment to partnering with families and children to learn, grow, and thrive. It puts family life and the needs and choices of the children and their families at the centre. The core principles of family-centred services (see **Figure 1**) stipulate that services should be enacted by relationships and interactions that are characterised as being culturally sensitive, inclusive, and reciprocal while recognising and respecting one another's knowledge and expertise (Bamm & Rosenbaum 2008; Dunst, Trivette & Hamby 2007; Espe-Sherwindt 2008; Dunst & Espe-Sherwindt 2016). Since the 1990s the developing international field of early intervention with young disabled children and their families has increasingly adopted family-centred practice as its philosophical foundation (Bruder 2000; Flemming, Sawyer & Campbell 2011). However, Campbell & Sawyer (2007) demonstrate that early intervention services often remain child-oriented, inconsistent with



**Figure 1:** A model of family-centred inclusive practices.

the core principles of family-centred practice. Within the evolving field of early intervention practices, Foster et al. (2020) highlight how the definition of family-centred practice continues to grow and change, reflective of the dynamic interaction between all stakeholders.

### Relational practices

Edwards (2009; 2011; 2017; 2020) has offered a cultural-historical account of expertise in her analysis of inter-professional work. She refers to a relational turn in expertise with emphasis on the understanding of professional practice and the negotiations that occur between professionals. Her findings in the field of education and social care indicate a need to build relational links between different services in order to create high quality services for children and their families (Edwards 2011). However, she underlines how knowledge accrues, identities are formed, and values and priorities are shared within the professions which can make it difficult to move knowledge across practice boundaries (Edwards 2020).

Edwards (2011: 35) draws on suggestions by Christensen & Lægreid (2007) that successful inter-agency work requires performing 'more as a gardener than an architect'. Applying their metaphor of gardening, she introduces three relational concepts as the 'gardening tools' to cultivate relational practices: *common knowledge*, *relational expertise,* and *relational agency*. According to Edwards (**Table 1**) the first tool, *common knowledge*, is about transfer, translation, and transformation of knowledges across boundaries. It is made up of what matters to each profession, the motives that shape and take forward professional practice (Edwards 2017: 9). Therefore, *common knowledge* can become a resource that mediates responsive collaborations on complex problems. *Common knowledge* does not arise spontaneously but is created over time by recognising shared goals for the benefit of children, revealing specific professional values and motives (Edwards 2017: 10). The second tool, *relational expertise*, is a form of expertise that adds to existing knowledge. Professionals recognise each other's points of view and strive to adjust their expertise to other people's strengths and needs. *Relational expertise* therefore involves the importance of professionals to be able to identify their own expertise, with an eye on differences across professions. It is therefore an additional form of expertise that augments specialist expertise and makes fluid and responsive collaborations possible. *Relational agency* is Edwards' final tool. It is about identifying shared goals and matters to the group composed of child and family and related professionals, all with diverse expertise, viewpoints, and roles. A basic premise of relational agency is that professionals exercise both a core and a relational expertise when they work with others (Edwards 2017: 9). These relational concepts are the inspiration for how expertise is reviewed for the development of practices in this article and are reflected in the research questions presented below.

### The Study

This study is part of a larger qualitative multi-case and theory-led research project (Creswell 2008; Simons 2009) focusing on services for young disabled children (2–6 years of age) and their families in three different municipalities in Iceland. Each case included two to four children, their families (eight families in all), preschool professionals, service counsellors, and other related professionals (Ingólfsdóttir, Egilson & Traustadóttir, 2017; Ingólfsdóttir, Jóhannsdóttir & Traustadóttir, 2018). As stated at the outset, this article focuses on specialised services in the municipalities that took part in this research. In order to gain a better understanding of the service policies and service, a qualitative focus-group design was applied (Creswell 2008; Krueger & Casey 2009) to obtain the professionals' views on their practices and work circumstances. Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data (Krueger & Casey 2009). The idea behind the focus-group method is that group processes can help people to explore and clarify their views in ways that would be difficult in a one-on-one interview. Everyday conversations in a group discussion give insight into personal and professional knowledge, views, and day-to-day situations, which is of great value in this research.

The study was guided by the following three research questions:

(1) What views prevail among professionals working outside the preschools about their practices?
(2) How do professionals and authorities understand their responsibilities and obligations regarding the service development needed to comply with the paradigm changes and policy ideals provided in laws and regulations?
(3) How can Edwards' 'three relational concepts' be utilised to improve family-centred inclusive practices within services in Iceland?

### Participants and procedures

Altogether, 13 professionals from six disciplines holding divergent positions took part in three focus-group interviews, four people in two groups and five in one group. The participants, 12 females and one male, had backgrounds in areas such as language and speech therapy, occupational therapy, physiotherapy, preschool special education, and social pedagogy. Their work experience ranged from six years to about 40. All had direct or indirect relations with the children and families involved in the larger research project. The focus-group interviews were conducted in May and June 2018. Each session lasted approximately one-and-a-half to two hours. Prior to the interviews, an interview protocol was developed with the key issues to be discussed, including (a) the participants' experiences, perspectives,

and understanding of the services offered to the children and families in the study; (b) how they perceive their role and obligations in enforcing predominant policies and their knowledge of family-centred values in services; and (c) the participants' views on what works well and what does not work so well regarding their services.

However, the interview format remained open, flexible, and adaptable to encourage in-depth responsive descriptions of the participants. The participants were encouraged to talk together, ask questions, exchange anecdotes, and comment on each other's experiences and points of view. All the focus-group sessions were recorded and transcribed verbatim. Each transcribed interview was reviewed and read iteratively to determine its accuracy (Creswell 2008; Simons 2009). Additional data consisted of field notes from visits to the relevant preschools and official public policy documents regarding education and specialised services for preschool children and their families.

The data from the focus-group interviews were analysed with the hallmarks of family-centred inclusive practices (**Figure 1**) in mind. An inductive approach to qualitative content analyses was chosen as an analytic procedure where coding rules and definitions of category development were derived from the theoretical background and research questions (Mayring 2019). First, the interview transcripts, field notes, and official documents regarding specialised services were carefully read and reread in order to identify categories and themes expressed in this data. In the second round of analysis, the main categories and sub-categories were analysed, compared, and contrasted. During this phase, the main topics expressed by the professionals were analysed within and across cases (municipalities) in order to detect similarities and differences between the three cases. This led to the identification of key findings regarding services and service arrangements for young disabled children and their families in the three Icelandic municipalities. The findings section presents the three main themes, each in a section.

## Findings

The findings show that the traditional medical view on disability is still prevalent both within authoritative organisations and among the professions providing services to families of disabled children. The consistent point of view expressed by the professionals was their motivation to enhance the children's performance. Their conversations also reflected how the services they provide are governed by a focus on developmental milestones and underlying impairments which, in turn, strongly affects their professional practices. Diagnostic outcomes are an important prerequisite for the eligibility of specialised interventions and the professionals are expected to utilise their expertise to treat or remediate the defined impairments at their clinics without complying to stated official common policy or practice goals.

### *My children or your children: Who is to serve whom?*

A prevailing theme was the authoritative requirement for diagnoses as a precondition for services. Decisions on who is to pay, the National Health Insurance (NHI) or the family's municipality, are based on diagnostic outcomes. According to *Reglugerð um greiðsluþátttöku sjúkratryggðra í kostnaði vegna heilbrigðisþjónustu* nr. 225/2018, the NHI covers the cost 'if the health insured has significantly impaired skills with ongoing intervention being indispensable' (Article 20). Thus, the main rule is that the state covers the cost of speech and language intervention services for those expected to have long-term needs, and the local authorities are responsible for those with milder or short-term conditions (Samband íslenskra sveitarfélaga 2014). In practice, this prerequisite often entails diagnostic evaluations before any intervention begins. These requirements, along with an overall shortage of speech and language therapists, cause long waiting lists. Similar issues were raised among other professionals.

The following focus-group conversation demonstrates how the rules function.

Speech and language therapist:
I am, of course, mainly working under a contract between the NHI and the local authorities, but also directly for municipalities, and there is a clear-cut division between the groups of children that are entitled [to services] through the NHI and the children who are the responsibility of the municipalities […]

Researcher:
But you mean, you also serve the children who are not covered by the NHI criteria?

Speech and language therapist:
Yeah. We who are hired by the municipalities are meant to serve the children at the limits of the official diagnostic criteria for receiving services provided by the state. This is a large group, so it's a major task.

Researcher:
You mean the children who do not have a diagnosis, or [...]?

Speech and language therapist:
Yes, they may not have enough pronunciation flaws, but they meet the theoretical standards for language development deviation. Although they are not low enough, they still have difficulties that cause them trouble. And they need help.

Occupational therapist:
It is the same for us. I mean, physiotherapists and occupational therapists get orders about the children having to score so and so. We have a lot of children who are exactly at the margins.

This clear-cut distinction based on the diagnostic outcomes and classification causes tensions among the professionals, who often come across children who do not meet the diagnostic criteria but, in their professional opinion, still need intervention. Although some municipalities have employed full-time or part-time professionals who can better adapt to the individual needs of children, most professionals work as contractors for the local authorities but receive payment through the NHI and are restricted by its criteria for services. The significant shortage of professionals also complicates the situation and causes additional tensions.

   In all three municipalities, the participants who worked as contractors claimed that, because of the long waiting lists, a tendency arises to prioritise the children who have minor impairments and only need short term interventions and put the children with the more complex intervention needs aside to wait. One professional explained: 'Children with the most complex impairments await the longest', and another argued that, when there is a lot to do, there is a tendency to postpone the 'long-term' children because 'if you start working with them, you are giving them a subscription to your services for the next 20 years. It is impossible to say to them, "you are all done now"'. This reflects the ethical dilemma professionals face as it is in their hands to prioritise and decide what criteria to follow as a part of their time management. One professional said that:

We are trying to set up some framework to be fair somehow, so that long-term children can get in without taking up all the time, so new children get a chance. We're working on this right now, but it is such a puzzle.

For outsiders, this situation can be hard to understand and is complicated by the fact that some professionals are self-employed and working as contractors simultaneously for the municipalities and the NHI or are hired at clinics that operate according to a contract with the NHI. Hence, the NHI has great power and influence over the service provisions and affects decisions on the allocations of finances without regard to the laws and policies that demand flexible and inclusive services in accordance with the needs and wishes of the service users.

### Service arrangements: Impact on families and professionals
The interviews revealed how the organisation of services, funding and administration influenced both families and professionals.

#### Families
A recurring theme across municipalities was the transport of children to receive treatment during their preschool hours and the associated disruption for the children and the parents, especially the mothers who are usually doing the transportation. A speech and language therapist elaborated on this.

I'm experiencing the fact that parents need to decrease their working hours and only work part-time to be able to take their children to therapy. This is because we usually work from eight to four and these are also the traditional working hours [of the parents]. And then one can ask: 'What does it cost for the society when parents are always taking a break from work or dropping out of work because of their children's frequent visits to therapists?'

A physiotherapist in another municipality described the situation in a similar way.

We often sense that it is difficult for parents to bring their child to us. This is not easy, of course. Some parents simply cannot get away from their job so […] the attendance is sometimes poor […]. But […], we must keep going somehow, and we simply have to ask for the children to come to us.

These narratives about the consequences of scattered service arrangements on the lives of families with disabled children are in accordance with the parents' complaints previously reported in our research (Ingólfsdóttir, Egilson & Traustadóttir 2017) about how time-consuming and complicated it is to bring the child to and sometimes between different professionals during their working hours and in the middle of the child's school hours.

   This dilemma is also reflected in other research (e.g. Stefánsdóttir & Egilson 2016) and in a report from the city of Reykjavík (Reykjavíkurborg 2016) which says that 'the responsibility is placed on parents who are made to leave work to bring their child to the speech and language therapist' (p.6). Moreover, it is argued that many parents are not able to fulfil these obligations with unforeseen consequences. This topic is of utter relevance in the Icelandic context as both parents commonly work full-time outside the home and children attend full-day preschools from an early age. Therefore, it is logical that the preschool should act as a platform for specialised interventions in an inclusive manner. There is a legal basis for such arrangements (Reglugerð um sérfræðiþjónustu sveitarfélaga við leik- og grunnskóla og nemendaverndarráð í grunnskólum nr. 584/2010). The current situation is far from being

culturally sensitive to individual families and their social environment, which is one of the main characteristics of family-centred practice.

**Professionals**
Most of the professionals were obliged to treat as many children as possible every day to meet demands for efficiency and their own efforts to shorten waiting lists. Such requirements add to their workload and limit their opportunities to work flexibly in collaboration with the parents and other professionals – in line with the core values of family-centred services. A physiotherapist at one clinic spoke about a former development project to make services more family-centred. This project was discontinued due to new funding regulations. Some professionals tried to 'stretch the frame' to better meet the needs and wishes of the children and their families and provide inclusive services in the child's natural environment, but were obliged to work centre-based and get everyone to come to their clinic. An occupational therapist provided such an example.

> I have always been an advocate for providing services in the children's environment, whether it's preschools, schools or their homes, and I try to do it whenever possible […]. If you can practice within the preschool, I prefer to do so […], but there are some new obstacles in the way, such as, for example, the new contract with the NHI that was made with my clinic. It means that we are entering a more restrictive system that requires accurate counting of the units processed. […] I think we are going backward.

The professionals who are hired directly by the municipalities are on monthly wages and experience diverse work conditions. They usually have more autonomy over their working arrangements and are trusted to organise their own work. Moreover, many have no official guidelines, follow-up or performance indicators to comply with. 'Nobody knows more about my work than myself', one professional said and sounded happy with this arrangement. The following interview excerpt sheds light on the work condition in a rural municipality where the professionals are employed by the municipality.

> A speech and language therapist:
> I'm always just in the schools […] in the special education spaces […] which are usually good facilities. I try to get parents to come occasionally; they do not need to come every time. I just arrive at the school and see who of 'my children' are there […] I am not saying that Joe, for example, is booked at nine o'clock if he is playing outside at that time. This is how flexible it is. I have learned by experience that it is not worth planning too much in advance. It is easiest to find out who is present when I arrive in the morning and then plan the order somehow.

> Researcher:
> So, you are not under time pressure?

> Professional:
> No, no, no there is no pressure on me. I just manage everything myself. I am my own boss.

This example shows how different the working conditions can be depending on who is administratively responsible. The trend, however, is that the number of professionals who work directly for the municipalities is decreasing. As one of the professionals reported, 'there are always fewer and fewer speech and language therapists who seek to work for the municipalities. There are hardly any left there. And now, when we, the old ones, are slowly dropping out, there are no replacements'.

***Policy ideals versus political priorities***
There were discussions about how various circumstances often make the work situations of professionals unpredictable and unstable. In this context, the size, population, and finances of the municipalities were considered important along with the division of responsibility between the state and local authorities.

Prior to the decentralisation of disability services in 2011, when local authorities in Iceland became responsible for the vast majority of disability service provision, one of the research sites was developing and coordinating their services to become a model municipality for services for disabled children and families. An integrated service system was developed resulting in social, school, specialist, and local health services being under one administration umbrella in the municipal family division. This arrangement was meant to make services more family-centred and minimise the strain and stress caused by fragmented and uncompromising services. The service system that was established during that period was a source of satisfaction by parents of disabled children and was generally considered to be an exemplary service model nationwide. The participating professionals from this municipality were unanimous when they expressed their regrets over how the accomplishments were erased in 2014 when these core units of welfare services were separated again due to a new health minister coming into power with new goals and new plans. Below is an excerpt from the focus-group conversation.

An administrator at the Family Division:
[…] the school special services were taken out of the family division and moved to the education division and the local health service was moved back to the state. There was no justification for it. The best reason I heard was 'because we could do it'. We were never asked, never any service evaluation or anything. It was discussed, of course, and we came up with various ideas, but none of them were better.

Researcher:
Are you saying that there is a relapse to the former service arrangement?

Head of the Family division:
Without a doubt. I will always disagree with this. This has been like it is now for some time now, and we still do not see [the benefit of this change] […] Of course, there are a few advantages, but it is still […] I mean, although we [the school and the family divisions] are in the same building, we are far apart.

Researcher:
But, why were these changes made?

Head of the Family division:
One of the reasons for the change was that our service arrangements were different from other municipalities of similar population size that we were compared with. And I asked in all innocence: 'Now, is this too good here?' And there was no answer.

This conversation shows how powerful politicians can make decisions against the will and wishes of the professionals who were then forced to move back to old service forms.

A physiotherapist said: 'There are some new obstacles in the way […]. Now, we need to have all the listings very accurate and all treatments are defined and have certain codes with certain units behind each of them.' What she found especially odd and paradoxical, however, was that 'now the NHI pays more for centre-based treatments than out of centre [community-based] treatments'. These arrangements make it difficult for professionals to provide services according to a public policy that calls for them to adapt services to the needs and wishes of the service users, which is at the core of family-centred policies. Moreover, it is likely that these strict funding regulations reduce inter-professional collaboration as there is little space given to work across organisational and/or professional boundaries. Thus, the political decisions at the ministry level regarding the organisation of local services appear to contradict the policy ideals held up by national and local governments.

## Discussion: Impediments and Opportunities in Service Development
The findings presented in this article cast light on the situation regarding specialised services aimed at disabled children's families in Iceland from the viewpoint of the professionals providing these services. Their stories are consistent with the main findings from the previous stages of our research project focusing on families of disabled children about the discrepancies between the policy aims and the conditions for service provision. These inconsistencies affect the work situation of the professionals, who are not encouraged by their employers to work in a family-centred inclusive manner. Instead, they meet various obstacles if they strive to adapt to the wishes and needs of the families to provide services at the child's preschool or home.

### Systems impediments
The findings reflect a welfare system governed by health and medical notions dominated by financial considerations despite the official paradigm shift following a new social-relational understanding of disability and increased emphasis on human rights, parent-professional partnership, and collaboration in family-centred inclusive services (Ingólfsdóttir, Egilson & Traustadóttir 2017; Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir nr. 85/2018). The children are classified by psycho-medical categories, which decides which administrative system is responsible for their services. Recently, the authorities have increased their demands for diagnosis and classification as a prerequisite for specialised services, also requiring professionals to provide intervention at their places of work. More emphasis is on counting processed units at the same time as new law enters into force (Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir nr. 85/2018) stipulating that 'public service providers must ensure that the services offered are compatible and integrated for the benefit of individual users' (Art 1).

This development contradicts the rights-based views and wishes of the parents that are inherent in family-centred practice (Bamm & Rosenbaum 2008; Dunst, Trivette & Hamby 2007; Espe-Sherwindt 2008; Dunst & Espe-Sherwindt 2016). There are obvious inconsistencies between such arrangements and providing adapted, coordinated, and responsive services that are the core of family-centred practice (Ingólfsdóttir, Egilson & Traustadóttir 2017; Ingólfsdóttir, Jóhannsdóttir & Traustadóttir 2018). Current organisations and most professionals seem to work in isolation, governed by traditions and ideas about best practice within their field of expertise as well as by regulations. This prevents them

from building *common knowledge* as they are deprived of identifying one's own expertise in relation to what others know and do. Moreover, the shared goals of 'what matters, that give shape to and are shaped in institutional practices' (Edwards 2017; Edwards 2020) is out of their sight. They may either be unaware of the tenets of family-centred practices or simply choose to disregard their obligations to provide adapted, coordinated, and responsive services (Ingólfsdóttir, Jóhannsdóttir & Traustadóttir 2018; Stefánsdóttir & Egilson 2016). Those, however, who strive to do so have difficulties in developing and maintaining their service arrangements. Even a well-recognised initiative in a large municipality to work in a holistic and integrative way was discontinued, although it was against the will and wishes of both the service users and providers.

It is also noteworthy that the few professionals who were employed directly by the municipalities enjoyed more freedom in organising their work. Nevertheless, working for the municipalities does not seem particularly attractive, for reasons such as being obliged to provide services according to the personal sentiments of their administrators or the financial and political situation at any given time, which can be difficult.

### Professional impediments

Influenced by situational conditions, the participating professionals worried mainly about their heavy workload, how to tackle long waiting lists, and the stress it causes parents to have to transport their children to and from services. Besides these worries, some described how the scope of their work conditions are constantly made more restrictive and less and less time is given for teamwork and collaboration which are the hallmarks of family-centred services. However, most of the professionals chose to work independently as contractors rather than in permanent positions in, for example, municipal services.

This trend is in line with Evetts' (2011) conceptualisation of the new professionalism, where she illustrates such work conditions as organisational in contrast to occupational professionalism. She describes this change as a shift from notions of partnership, collegiality, discretion, and trust, towards increasing levels of managerialism, bureaucracy, standardisation, assessment, and performance reviews which involves a challenge to the occupational control of work. Accordingly, she views professionalism as increasingly being organisationally defined, including the logics of the organisations and the managerialism and commercialism of the market. This propensity is also reflected in the situation of the professionals who took part in this study, and it is noteworthy how their concerns were mainly about various practical aspects of their work arrangements. In fact, only a few were well informed about the principles of family-centred practice, and a small number mentioned the CRPD and the values and rights it entails for disabled people, including disabled children. Moreover, little desire was uttered about working relationally on a peer-to-peer bases with parents and other professions, so one may ask whether these professionals couldn't envision that things could be otherwise.

Professionals are entitled to continuing education and training to update their professional knowledge and working methods. In light of this, it is important to note how little significance the principles and practices of the family-centred approach had for the professionals in child and family services. Admittedly, these professionals have difficult work situations, but they still have professional and ethical responsibilities to act according to the best theoretical and professional knowledge at any given time. The silence and lack of critical thinking and dialogue about these matters were striking.

The preschools in Iceland play an important role in the lives of all families raising young children, not the least disabled children. The learning opportunities that exist in the child's immediate surroundings within the preschool seem to be an undervalued resource in the service arrangements. Like other studies of disabled children have demonstrated (Stefánsdóttir & Egilson 2016), the interventions primarily emphasise enhancing the child's functioning outside their everyday surroundings and activities. Earlier findings from this research project show that parents trust the preschools and appreciate the collaborative atmosphere created by preschool staff (Ingólfsdóttir, Egilson & Traustadóttir 2017).

Thus, the preschool seems an ideal place to coordinate and integrate the various services for disabled children. In developing specialised practices within preschools, it is relevant to highlight the statutory authority for such arrangements (Reglugerð um sérfræðiþjónustu sveitarfélaga við leik- og grunnskóla og nemendaverndarráð í grunnskólum nr. 584/2010). The knowledge about individual children within the preschool is of great importance in this context, and the preschool facilities and resources can be utilised more effectively for the benefit of the children and their families. The increased emphasis on professional productivity and bureaucracy reflected in our findings does not seem to be a good strategy if the services are to be developed in accordance with the prevailing family-centred policy ideals.

### Opportunities

The findings presented here indicate a great need for new and innovative professional practices. It is necessary to translate policies more effectively into practice in order to overcome the current mismatch between the two. There is a need for more cultural sensitivity and parent-professional collaboration, as these are the hallmarks of family-centred practice. In this regard, the societal characteristics of Iceland must be taken into account when services are organised, such as high female employment and children's general daylong attendance in preschools from an early age.

Moreover, families need to be listened to and their role and importance recognised. The essential interconnections between the core principles and characteristics of family-centred inclusive practice are needed at all levels. If these relations are not at the forefront in administrative decision making, the practices will remain uncompromising and maladapted to the families. For the necessary changes to happen, we suggest shifting the focus from looking at disability through the narrow developmental and impairment-focused lens with centre-based service provision to making every effort to provide inclusive services within the child's and/or families' immediate surroundings. By viewing the situation from a cultural-historical perspective, we recognise the extensive role of preschools as an important factor in developing services for young disabled children and their families.

Icelandic preschools have a legal obligation to provide facilities for external services if needed, but more importantly, preschool administrators are commonly open to the idea of providing therapies within school premises (Ingólfsdóttir, Egilson & Traustadóttir 2017). Thus, preschools can serve as a platform for developing services where professionals share their expertise systematically in order to develop *relational expertise* within in the child's natural day-to-day environment. Such arrangements would also reduce the strain on parents that inevitably follows distributed services. Changes in this direction call for new views about professionalism among the professionals and their employers, with an emphasis on collaboration across organisational and professional boundaries.

These are the core values of Edwards' three gardening tools for building *common knowledge*, *relational expertise,* and *relational agency* (**Table 1**). Such requirements add to individual professional knowledge by producing additional *common knowledge*, which is of great value when moving from centre-based impairment-focused services to a relational service arrangement in line with the existing policy ideals. Developing new *relational expertise* is, therefore, not only beneficial for the individual child but also for the parents and school practice in general and lays the foundation for family-centred inclusive and flexible practices. In order to be able to provide coordinated services in a family-oriented and inclusive way, the third tool of *relational agency* is the basic premise meaning that all entities envision and agree upon a shared goal with a well thought-out and interactive approach.

This is how family-centred inclusive practices involve transforming the service system. The financing, administration, design, delivery, and monitoring of services, and the ways services are organised, must be rethought in favour of disabled children and their families. The theoretical values of family-centred and inclusive practices cannot be enacted if the underlying ideologies are neither acknowledged nor accepted by those in power. In this regard service premises and conditions for the professionals play a pivotal role.

The restrictive service arrangements reflect an ongoing development in the value aspects of professionalism as described by Evetts (2011). These must be turned around. Such change calls for a transformation in one's professional self, as described by Egilson (2015). Moreover, the responsibility borne by the leaders to change institutional cultures in line with the prevailing policies inherent in the CRPD (United Nations 2006) and the needs and wishes of the families is indisputable. In this transformation, there is great need to move from the increasing authoritative demand for organisational professionalism towards a more occupational and relational professionalism.

## Conclusion
In the earlier stages of our research project on the service provisions for families with disabled children in Iceland, the parents shared their difficulties resulting from distributed and fragmented services. In this article, however, we examined the perspectives of service professionals and information about their working conditions. Our findings show both scant knowledge and understanding within the service system of what it means to provide family-centred inclusive services. Also, due to current policies, heavy workloads, and professional traditions, service providers seemed to have difficulties with moving from traditional views and ways of working to a rights-based inclusive practice based on social-relational view of disability.

There is an obvious need for radical changes at all levels including the administrative level of the overall service organisation, the education of future professionals, and the continuing education and training of practicing professionals, in order to be able to implement the paradigm change contained in the CRPD and family-centred service. Rethinking expertise and professional work is an important aspect of making this possible and involves redefining conventional thinking about professionalism in accordance with internationally recognised visions and values. The three gardening tools that have been presented and discussed above, are put forward as compelling instruments to develop overlooked possibilities and move practices forward. These call for new work priorities and processes from both the authorities and the relevant professions. In a system of distributed expertise, we see relational expertise as a feasible achievement for developing services in line with new rights-based relational views on disability and family services which should be reflected in service provisions.

## Competing Interests

## References
Ainscow, Mel. 2005. "Developing inclusive education systems." *Journal of Educational Change* 6: 109–124. Accessed April 22, 2020. DOI: https://doi.org/10.1007/s10833-005-1298-4

Alþingi [The Parliament of Iceland]. 2018–2019. "Tillaga til þingsályktunar um lögfestingu samnings Sameinuðu þjóðanna um réttindi fatlaðs fólks [Proposal for a parliamentary resolution on the legalisation of United Nations convention on the rights of persons with disabilities]." Accessed April 22, 2020. https://www.althingi.is/altext/149/s/0021.html.

Bamm, Elena L., and Peter Rosenbaum. 2008. "Family-centered theory: Origins, early childhood special education." *Archives of Physical Medicine and Rehabilitation* 89(8): 1618–1624. Accessed April 15, 2020. DOI: https://doi.org/10.1016/j.apmr.2007.12.034

Bruder, Mary B. 2000. "Family-centered early intervention: Clarifying our values for the new millennium." *Topics in Early Childhood Special Education* 20(2): 105–115. Accessed April 22, 2020. DOI: https://doi.org/10.1177/027112140002000206

Campbell Philippa, H., and L. Brook Sawyer. 2007. "Supporting learning opportunities in natural settings through participation-based services." *Journal of Early Intervention* 29(4): 287–305. Accessed November 15, 2020. DOI: https://doi.org/10.1177/105381510702900402

Christensen, Tom, and Per Lægreid. 2007. "The whole-of-government approach to public sector reform." *Public Administration Review* 67(6): 1059–1066. Accessed April 15, 2020. DOI: https://doi.org/10.1111/j.1540-6210.2007.00797.x

Creswell, John W. 2008. *Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research.* Upper Saddle River: Prentice Hall.

Dodd, Jenny, Sherry Saggers, and Helen Wildy. 2009. "Constructing the 'ideal' family for family-centred practice: Challenges for delivery." *Disability & Society* 24(2): 173–186. Accessed April 22, 2020. DOI: https://doi.org/10.1080/09687590802652447

Dunst, Carl J. 2002. "Family-centered practices: Birth through high school." *The Journal of Special Education* 36(3): 141–149. Accessed March 30, 2020. DOI: https://doi.org/10.1177/00224669020360030401

Dunst, Carl J., Carol M. Trivette, and Deborah W. Hamby. 2007. "Meta-analysis of family-centered help giving practices research." *Mental Retardation and Developmental Disabilities Research Reviews* 13(4): 370–378. Accessed April 22, 2020. DOI: https://doi.org/10.1002/mrdd.20176

Dunst, Carl J., and Marilyn Espe-Sherwindt. 2016. "Family-Centered Practices in Early Intervention." In *Handbook of Early Childhood Special Education*, edited by Brian Reichow, Brian A. Boyd, Erin A. Barton, and Samuel L. Odom, 37–55. Switzerland: Springer International Publishing. DOI: https://doi.org/10.1007/978-3-319-28492-7_3

Edwards, Anne. 2011. "Building common knowledge at the boundaries between professional practices." International *Journal of Educational Research* 50(1): 33–39. Accessed March 30, 2020. DOI: https://doi.org/10.1016/j.ijer.2011.04.007

Edwards, Anne. 2017. *Working Relationally in and Across Practices: A Cultural-Historical Approach to Collaboration.* Cambridge: Cambridge University Press. DOI: https://doi.org/10.1017/9781316275184

Edwards, Anne. 2020. "Agency, common knowledge and motive orientation: Working with insights from Hedegaard in research on provision for vulnerable children and young people." *Learning, Culture and Social Interaction* 26(2020): 100224. Accessed November 15, 2020. DOI: https://doi.org/10.1016/j.lcsi.2018.04.004

Edwards, Anne, Harry Daniels, Tony Gallagher, Jane Leadbetter, and Paul Warmington. 2009. *Improving Inter-Professional Collaborations: Multi-Agency Working for Children's Wellbeing.* London: Routledge. DOI: https://doi.org/10.4324/9780203884058

Egilson, Snaefridur T. 2011. "Parent perspectives of therapy services for their children with physical disabilities." *Scandinavian Journal of Caring Sciences* 25(2): 277–284. Accessed April 22, 2020. DOI: https://doi.org/10.1111/j.1471-6712.2010.00823.x

Egilson, Snæfríður T. 2015. "User Perspectives on Support Services to Disabled Children and Their Families." In *Childhood and Disability in the Nordic countries*, edited by Rannveig Traustadóttir, Borgunn Ytterhus, Snæfríður Thóra Egilson, and Berit Berg, 231–245. London: Palgrave Macmillan. DOI: https://doi.org/10.1057/9781137032645_15

Egilson, Snæfríður Þ., and Sara Stefánsdóttir. 2014. "Welfare services and disabled children: Perspectives from parents in the municipality of Akureyri." *Stjórnmál og stjórnsýsla* 10(2): 587–610. Accessed March 30, 2020. DOI: https://doi.org/10.13177/irpa.a.2014.10.2.19

Engeström, Yrjö. 2001. "Expansive learning at work: Toward an activity theoretical reconceptualization." *Journal of Education and Work* 14(1): 133–156. Accessed March 30, 2020. DOI: https://doi.org/10.1080/13639080123238

Engeström, Yrjö. 2016. Studies in Expansive Learning. Cambridge: Cambridge University Press. DOI: https://doi.org/10.1017/CBO9781316225363

Espe-Sherwindt, Marilyn. 2008. "Family-centred practice: Collaboration, competency and evidence." *Support for Learning* 23(3): 136–143. Accessed March 15, 2020. DOI: https://doi.org/10.1111/j.1467-9604.2008.00384.x

Evetts, Julia. 2011. "A new professionalism? Challenges and opportunities." *Current Sociology* 59(4):406–422. Accessed April 22, 2020. DOI: https://doi.org/10.1177/0011392111402585

Foster, Tricia D., Kalli B. Decker, J. Mitchell Vaterlaus, and Amanda Belleville. 2020. "How early intervention practitioners describe family-centred practice: A collective broadening of the definition." *Child: Care, Health and Development* 246(3): 268–274. Accessed November 15, 2020. DOI: https://doi.org/10.1111/cch.12749

Goodley, Dan, and Janice McLaughlin. 2008. "Theorising Parents, Professionals and Disabled Babies." In *Families Raising Disabled Children,* edited by Janice McLaughlin, Dan Goodley, Emma Clavering, and Pamela Fisher, 1–20. London: Palgrave Macmillan. DOI: https://doi.org/10.1057/9780230583511_1

Goodley, Dan. 2011. *Disability Studies: An Interdisciplinary Introduction.* Thousand Oaks: SAGE.

Haug, Peder. 2017. "Understanding inclusive education: Ideals and reality." *Scandinavian Journal of Disability Research* 19(3): 206–217. Accessed March 15, 2020. DOI: https://doi.org/10.1080/15017419.2016.1224778

Ingólfsdóttir, Jóna G., Snæfrídur T. Egilson, and Rannveig Traustadóttir. 2017. "Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice." *Journal of Intellectual Disabilities* 22(4): 361–377. Accessed March 5, 2020. DOI: https://doi.org/10.1177/1744629517714644

Ingólfsdóttir, Jóna G., Thurídur Jóhannsdóttir, and Rannveig Traustadóttir. 2018. "Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland." *Nordisk välfärdsforskning | Nordic welfare research* 3(1): 33–46. Accessed March 15, 2020. DOI: https://doi.org/10.18261/issn.2464-4161-2018-01-04

Krueger, Richard A., and Mary A. Casey. 2009. *Focus Groups: A Practical Guide for Applied Research.* Thousand Oaks: SAGE.

Lög um leikskóla [Preschool Act] nr. 90/2008.

Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir [Act on services to disabled people with long-term service needs] nr. 85/2018.

Mayring, Philipp. 2019. "Qualitative content analysis: Demarcation, varieties, developments." *Forum: Qualitative Social Research* 20(3). Accessed February 5, 2020. DOI: https://doi.org/10.17169/fqs-20.3.3343

Reglugerð um greiðsluþátttöku sjúkratryggðra í kostnaði vegna heilbrigðisþjónustu [Regulation on the participation of the health insured in health care costs], nr. 225/2018.

Reglugerð um sérfræðiþjónustu sveitarfélaga við leik- og grunnskóla og nemendaverndarráð í grunnskólum [Regulation on municipal specialist services at preschools and compulsory schools and student protection councils in compulsory schools] nr. 584/2010.

Reykjavíkurborg [City of Reykjavík]. 2016. "Talþjálfun barna í leik- og grunnskólum: Ábyrgð Reykjavíkurborgar [Speech training for children in pre- and primary schools: Responsibility of the City of Reykjavík]." Accessed February 15, 2020. https://reykjavik.is/sites/default/files/skyrsla_talthjalfun_barna_i_leik-_og_grunnskolum_0.pdf.

Samband íslenskra sveitarfélaga [Icelandic Assosiation of Local Authorities]. 2014. Samkomulag um talmeinaþjónustu [Agreement on speech and language services]. Accessed February 15, 2020. https://www.samband.is/media/skolamal/Samkomulag-talmeinathjonusta.pdf.

Samband íslenskra sveitarfélaga [Icelandic Assosiation of Local Authorities]. 2018. Viljayfirlýsing um aukið samstarf í þágu barna [Statement of intent on enhanced partnership for the benefit of children]. Accessed February 10, 2020 https://www.samband.is/frettir/aukid-samstarf-i-thagu-barna.

Simons, Helen. 2009. *Case Study Research in Practice*. London: SAGE Publications Ltd. DOI: https://doi.org/10.4135/9781446268322

Statistics Iceland. 2018. "Almost Half of One Year Old Children Attend Pre-Primary Schools." Accessed February 15, 2020. https://www.statice.is/publications/news-archive/education/pre-primary-schools-2017/.

Stefánsdóttir, Sara, and Snæfrídur Thóra Egilson. 2016. "Diverging perspectives on children's rehabilitation services: A mixed-methods study." *Scandinavian Journal of Occupational Therapy* 23(5): 374–382. Accessed February 5, 2020. DOI: https://doi.org/10.3109/11038128.2015.1105292

The Ministry of Education, Science and Culture. 2011. "The Icelandic national curriculum guide for preschools." Accessed March 15, 2020. https://www.government.is/lisalib/getfile.aspx?itemid=3e4939f4-cb84-11e7-9421-005056bc530c.

Tøssebro, Jan, and Christian Wendelborg. 2015. "Ordinary or Not? Families of Children Growing Up with Disabilities." In *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging*, edited by Rannveig Traustadóttir, Borgunn Ytterhus, Snæfríður Thóra Egilson, and Berit Berg, 199–213. Basingstoke: Palgrave. DOI: https://doi.org/10.1057/9781137032645_13

Traustadóttir, Rannveig. 2009. "Disability Studies, the Social Model and Legal Developments." In *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, edited by Oddný Mjöll Arnardóttir and Gerard Quinn. Leiden: BRILL.

United Nations. 2006. Convention on the Rights of Persons with Disabilities (CRPD). Accessed March 15, 2020. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.

## 5.3 Summary of Findings

The findings presented in the four journal articles reveal a high convergence among all three case studies with regard to what worked well for the children and their families and what did not. Overall, the parents valued the preschools for welcoming their children and the supportive atmosphere and the preschool professionals' expressed interest and willingness to provide the children with the support they needed. All the children, however, had to attend specialised services outside the preschool and the parents were unanimous on the fragmentation, incompatibility, and inflexibility of these services. However, these complaints were directed more towards the system than the professionals or the content of services.

A social-relational and rights-based understanding of disability and childhood is reflected in internationally binding treaties, welfare legislation, and policy documents as the basic principle for service provision. However, traditional medical views are still prevalent within authoritative organisations and among the professions providing services to the families of disabled children. The eligibility for specialised services is primarily based on a formal diagnosis of the child's impairment, which is constantly being contested, and there are no guidelines about working arrangements that conform to the ideology and aims of existing laws and international treaties.

Most of the participating professionals were therapists who worked outside the preschool under the rules of the Icelandic Health Insurance (IHI) and were restricted by the criteria for services determined by the IHI. Some described the changes in their working environment following new and stricter rules as back sliding. Despite this, the consistent point of view expressed by the professionals was their motivation to enhance the children's performance, and some expressed worries related to the long waiting lists for their services. Many argued the waiting lists affected priorities in such a way that the children with minor impairments would be offered services ahead of the ones who needed more time. It is also notable that most of the professionals in the study were unfamiliar with the content and requirements of the CRPD and thus not aware of the radical changes it entails regarding views on disability, the rights of disabled children, and the provision of professional services.

The lack of coordination and adapted and inclusive services had a great impact on the lives of the children and their families, both personally and financially. This relates to a large degree to the fact that the services are provided within three different systems: the social service system, the educational system, and the health system. Each system has different and sometimes contradicting external legal frameworks, attitudes, traditions, and working methods. Additionally, the miscellaneous professionals have been educated and trained within these diverse systems, each with an ingrained professional culture. Consequently, some professionals explained the changes in their working environment following new and stricter rules for productivity as a step backwards,

others mentioned a poorly based administrative decision that reversed a valuable achievement within one of the municipalities. In this municipality, the main components of the family service system, the health care system, the education system and the social service system, had been joined administratively for experimental purposes to the great satisfaction of all involved.

The findings also reflect how long it has taken for the rights-based and inclusion notions inherent in the CRPD and the CRC to reach and influence policy makers, financing authorities, and professionals to look holistically at the child and family and adapt their services accordingly. There is still little incentive on behalf of the authorities to establish and/or support innovative service models that comply with the requirements inherent in these binding treaties.

The situation that appears in the findings above is both confusing and contradictory. This is mostly because different rules apply to the service provisions of local authorities and the state and service providers have no official guidelines to follow. Moreover, it is commonly argued that the strict requirements for a medical diagnostic as a prerequisite for services is too extensive and sometimes intensifies unnecessary medicalisation of human diversity, which is contradictory to the core values of binding international treaties and corresponding legislative frameworks.

# 6 Conclusion

In this final chapter, I discuss the contribution of the thesis to the implementation of relational practices in services to families with young disabled children with reference to its main findings. This is followed by concluding remarks.

## 6.1 Implications for Practice

As previously stated, the four main aims of the study were to explore the gap between Icelandic welfare policies and the every-day experiences of families of disabled children (1). The primary focus was on capturing the families' views and experiences (2), but also on the roles, attitudes, and working environments of professionals providing services to disabled children and their families (3). The final aim was to put forward ideas for changes to service delivery (4).

Based on these aims and the findings presented in the four research publications, this thesis provides insight into the much-discussed theory-practice gap and presents some innovative ideas for necessary service reform (Papers III and IV). In the first phase of the study, three social-relational theories on disability, family, and services were chosen as the theoretical framework. The first approach presented was a socio-relational understanding of disability (Tøssebro, 2004), the second was family-centred theory (Rosenbaum et al. 1998, Dunst, 2002), and the third was cultural-historical activity theory (Engesström, 1987) which emphases interorganisational learning as a method to develop services. Later in the research procedure Edwards' concepts for relational practices (Edwards, 2017) entered the scene.

In the second phase, the prevailing views on disability and services from the parents and preschool professionals within the three selected municipalities were investigated, which revealed consistent findings between the three cases on what worked well and what caused difficulties with regard to the daily services for the disabled children and their families. The parents in the study were unanimous in their satisfaction with their children's preschools, an opinion which was mainly based on feelings of security and positive attitudes towards the children. The preschool administrators demonstrated flexibility and open mindedness regarding the use of the preschool premises and collaboration with external experts.

However, the arrangements of the recommended therapies outside the preschools were regarded as stressful and hard to fit into the families' schedules. These services were mainly administered and provided according to the terms of the medical notion of disability, and most of the specialists were unfamiliar with the content and requirements

of the CRPD. These findings were presented in the second paper and gave a reason for further scrutiny.

For that, CHAT was applied as an analytical tool. Three interacting activities (Engesström, 2001) central to the wellbeing of the children and their families were identified and introduced as the unit of analysis and the contradictions within and between the activities considered. The three activities, the family, the preschool and the external experts, were located and classified with the help of CHAT and the expansive learning theory (Engeström, 2001; 2016). Accordingly, some ideas for changed service arrangements were presented and argued for with reference to Engeström (2001) and Edwards (2004). In a nutshell, these arrangements are characterised by transdisciplinary collaboration to create common knowledge which comprises the motives of each profession in relation to the shared object of the interacting activity systems to build relational inclusive working procedures within the preschools.

In the study's third and last phase, the views and working conditions of professionals providing specialised services to disabled children and their families in Iceland were investigated. A number of organisational and professional barriers, such as, inconsistent administrative policies, lack of professional resources, strict time limits, productivity requirements, and different professional views and traditions, were exposed from the specialists working outside the preschools. Furthermore, persistent unawareness about the basic principles of family-centred services and the core content of the CRPD, currently being legalised in Iceland, was revealed. Recommendations for service development presented in Paper III and Paper IV were made based on Engeström's expansive learning theory (Engeström, 2001, 2016) and Edwards' theory on relational practices with emphasis on her relational concepts of the gardening tools (Edwards, 2011; 2017). The gardening tools were proposed in Paper IV as innovative and appropriate concepts for the identified service reform.

Developing practices based on these concepts adds something new to individual professional knowledge and practices, which is of great value when moving from one-to-one centre-based services to a relational service arrangement in line with existing rights-based inclusive policy ideals. It is about professionals working together purposefully towards goals that reflect the motives that shape the specialist expertise of each participant, and using the resources that each specialism can bring to bear. Working towards the production of common knowledge, one of the gardening tools, is not only beneficial for individual children but also for the parents, the school, and welfare practices in general. It is claimed that the relational turn in professional practice offers the opportunity for an enhanced form of practice. As previously described, practice reform on these terms is what the parents in the study call for and comply with the core values of the CRPD and intended service implementation.

## 6.2 Concluding Remarks

The subject of this thesis fits into the widespread debate currently going on in Iceland about the need to improve services and support for children and families in order to enhance their wellbeing. This need was manifested in new legislation in 2021 (Lög um samþættingu þjónustu í þágu farsældar barna [Act on the integration of services in favour of children's wellbeing], no. 86/2021). At the same time, there is a common worry about the increased lack of professional resources and increasingly long waiting lists for psycho-medical diagnoses, which are important prerequisites for specialist services. This thesis clearly shows that efforts to address the needs of disabled children and their families require significant improvements. The current situation causes increased marginalisation of the disabled children and adds extra strain and stress on their parents, particularly mothers.

As reflected in this thesis, I have witnessed many years of development and changes in the service system. While notable progress has been made in welfare services in the past, both at the state and municipality levels, a sense of instability persists. This is reflected in administrative decisions that have caused both short and long-term highly regarded innovative developmental endeavours to be abandoned along with unstable financial support and a lack of encouraging professionals to develop innovative services. These fluctuations have been attributed to various factors, such as administrative changes, shifting political priorities, or even the departure of key professionals. Additionally, recent research (Snæfríðar-Gunnarsdóttir et al., 2023) indicates that, during the COVID-19 pandemic, the gaps in the already fragmented services widened and families were left to navigate this new reality on their own. This occurred at the same time as research showing evidence of a fast-growing need for increased psycho-social services for children and youth following the pandemic.

Based on my observations, I draw attention to the importance of learning from history to avoid recurring mistakes. This is especially urgent now that the implementation of the previously mentioned 2021 law is currently under way (Lög um samþættingu þjónustu í þágu farsældar barna [Act on the integration of services in favour of children's wellbeing], no. 86/2021). An important lesson of this thesis highlights the need for radical changes in the service system in Iceland aiming to provide rights-based inclusive services. For this to happen a platform for developing services must be created where professionals are urged to share their expertise systematically in order to develop relational expertise and practices in the child's day-to-day environment. Such arrangements would also reduce the parental strain that inevitably follows distributed services. The responsibility borne by the leaders to change institutional cultures in line with the prevailing policies inherent in the CRPD is indisputable. However, the theoretical values of family-centred and inclusive practices cannot be embodied if the underlying ideologies are neither acknowledged nor accepted by those in power.

# References (Chapter 6)

Dunst, C. J. (2002). Family-centered practices: Birth through high school. *The Journal of Special Education*, *36*(3), 141–149. https://doi.org/10.1177/00224669020360030401

Edwards, A. (2004). The new multi-agency working: Collaborating to prevent the social exclusion of children and families. *International Journal of Integrated Care*, *12*(5), 39. https://doi.org/10.1108/14769018200400033

Edwards, A. (2011). Building common knowledge at boundaries between professional practices. *International Journal of Educational Research*, *50*(1), 33–39. https://doi.org/10.1016/j.ijer.2011.04.007

Edwards, A. (2017). *Working relationally in and across practices: A cultural-historical approach to collaboration*. Cambridge University Press.

Engeström, Y. (1987). *Learning by expanding: An activity-theoretical approach to developmental research*. Orienta-Kosultit.

Engeström, Y. (2001). Expansive learning at work: Toward an activity theoretical reconceptualization. *Journal of Education and Work*, *14*(1), 133–156. https://doi.org/10.1080/13639080123238

Engeström, Y. (2016). *Studies in expansive learning*. University Press.

Lög um samþættingu þjónustu í þágu farsældar barna [Act on the integration of services in favour of children's wellbeing] no. 86/2021. https://www.althingi.is/altext/151/s/1723.html

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical and Occupational Therapy in Paediatrics*, *18*(1), 1–20. https://doi.org/10.1080/J006v18n01_01

Snæfríðar-Gunnarsdóttir, H., Ólafsdóttir, T., & Björnsdóttir, K. (2023). Risky Obliviousness Within Fragmented Services: Experiences of Families With Disabled Children During the Covid-19 Pandemic. *Social Inclusion*, *11*(1), 5-15. https://doi.org/10.17645/si.v11i1.5642

Tøssebro, J. (2004). Introduction to the special issue: Understanding disability. *Scandinavian Journal of Disability Research*, *6*(1), 3–7. https://doi.org/10.1080/15017410409512635

# Appendix A – Icelandic

## Viðtalsrammi vegna viðtala við foreldra

**Inngangur – upphaf viðtals**

Rannsakandi og viðmælendur kynna sig, markmið rannsóknarinnar rifjað upp, ítrekað að trúnaði og nafnleynd verði gætt í hvívetna, tímalengd viðtals tilgreind, upplýsingablað afhent og leyfis aflað fyrir upptöku viðtalsins.

**1. Núverandi aðstæður**

Farið yfir grunnupplýsingar í stuttu máli til að fá stutt yfirlit yfir núverandi aðstæður fjölskyldunnar og koma viðtalinu af stað.

- Aldur barns og kyn
- Fjölskylduaðstæður (foreldrar og systkin)
- Búseta
- Staða foreldra
- Leikskóli
- Fötlun (skerðing) barns og greining
- Hvernig tjáir barnið sig
- Heilsufar barnsins

**2. Fjölskyldubakgrunnur**

Nánari lýsing á lykilatburðum/tímabilum, samskiptum og tengslum, merkingu, o.fl.

- Hvar og hvenær er barnið fætt
- Samsetning fjölskyldunnar
- Fjölskylduaðstæður (efnahagslegar, flutningar, félagsleg tengsl og tilfinningatengsl)
- Stórfjölskyldan
- Stuðningur/umönnun frá fjölskyldunni (hverjum)
- Hvenær fékk barnið greiningu og hvar – áhrif greiningarinnar
- Áhrif skerðingar-fötlunar á uppeldi barnsins, systkini þess og fjölskyldulíf
- Áhrif skerðingar-fötlunar á daglegt líf og þátttöku fjölskyldunnar t.d. í tengslum við áhugamál og frístundir

**1. Leikskólinn**

Um leikskólagöngu barnsins og samskipti foreldranna við leikskólann og tengda aðila vegna hennar.

- Leikskóli (segja frá leikskólanum)
- Samskipti við starfsfólk
- Samskipti við aðra foreldra
- Samskipti við ráðgefandi sérfræðinga
- Sérstuðningur innan leikskólans (hvernig er fyrirkomulagið, hver sinnir sérstuðningi, samvinna við foreldra, val námsmarkmiða o.fl.)
- Þátttaka og félagstengsl barnsins í leikskólanum - utan leikskólans
- Áhrif skerðingar - fötlunar á leikskólagöngu

- Þættir í umhverfinu sem hafa áhrif á leikskóladvöl barnsins
- Upplýsingagjöf/fræðsla/samstarf við foreldrana
- Almennt um reynsluna af leikskólanum
  - hvað gengur/gekk vel
  - hvað er/var erfiðast
  - hvað þarf að bæta

**2. Skólaþjónusta sveitarfélagsins**

Um þjónustu skólaþjónustunnar.

- Þjónusta Fjölskyldudeildar við barnið og fjölskylduna
- Viðmót, viðhorf og almenn samskipti
- Sveigjanleiki þjónustunnar
- Eitthvað sem vantar eða gæti verið betra
- Hjálpartæki ef þarf — hvernig gengur að fá þau, hvernig nýtast þau
- Hvað hjálpar og hvað hindrar
- Aðgengi að þjónustunni
- Upplýsingar um réttindi
- Eftirfylgni
- Samhæfing þjónustunnar
- Tenging á milli þjónustuveitenda
- Yfirsýn
- Beinist þjónustan að barninu, að fjölskyldunni, að barninu og fjölskyldunni saman
- Beinist þjónustan að því að hafa áhrif á- eða leita lausna í umhverfinu
- Upplýsingagjöf/fræðsla/samstarf við foreldrana
- Almenn upplifun af samskiptum við fjölskyldudeild
  - hvað gengur/gekk vel
  - hvað er/var erfiðast
  - hvað þarf að bæta

**5. Aðstoð/þjónusta/stuðningur/fræðsla aðila utan opinbera kerfisins**
- Hverra?
- Hvernig?
- Hvers vegna?
- Reynslan af þeirri aðstoð/þjónustu/fræðslu

**6. Félagsleg tengsl foreldra við aðra sem tengjast skerðingu/fötlun barnsins**
- Tengsl við aðra foreldra
- Starf innan hagsmunasamtaka
- Tengsl við aðstoðarfólk, stuðningsfulltrúa, aðstoðarfólk, kennara, stuðningsfjölskyldu og/eða annað launað aðstoðarfólk og stuðningsaðila
- Tengsl við fagfólk af ýmsum toga

**Lok viðtals**
- Eitthvað sem foreldrarnir vilja bæta við
- Spurning um annað viðtal ef þarf, eða biðja um leyfi til að hafa samband aftur ef þörf krefur

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# Appendix A – English

## Interview framework for interviews with parents

**Introduction – the beginning of the interview**

The researcher and interviewees introduce themselves; the aim of the research is recalled, confidentiality and anonymity reiterated, the duration of the interview is specified, an information sheet is handed out and permission is obtained for the recording of the interview.

1. **Current situation**

A brief review of basic information to get a quick overview of the current situation and get the interview started.

- Child's age and gender
- Family situation (parents and siblings)
- Residence
- Occupation and/or employment status of parents
- Preschool
- Description of the child's impairment
- How does the child express him/herself?
- The child's health

2. **Family background**

A more detailed description of key events/periods, interactions, relationships, meaning, etc.

- Where and when was the child born?
- Family structure
- Family situation (financial, transport, social network and family ties)
- The size of the extended family
- Support/care from family (from whom and how much)
- Where and at what age was the child diagnosed, and what was the impact of the diagnosis for the child and family
- The impact of impairment-disability on the upbringing of the child, siblings and family life
- The impact of the child's impairment-disability on daily life and family participation, e.g. in relation to free time activities and hobbies

3. **The preschool**

About the child's preschool attendance and the parents' relationship with the preschool and related professionals.

- The preschool (tell me about the preschool)
- Communication/Collaboration with the preschool staff

- Communication/Collaboration with parents of other children
- Communication/Collaboration with consulting specialists
- Special support within the preschool (what is the arrangement like, who provides special support, collaboration with parents, choice of learning goals, etc.)
- The child's participation in activities and social relations in the preschool - outside the preschool
- Impact of impairment/disability on preschool attendance
- Environmental factors that affect the child's presence in the preschool
- Information/education/cooperation (collaboration) for the parents
- The experience of the child's preschool attendance
- What is going/went well?
- what are/were the hindrances?
- what needs to be improved?

4. **The municipal school services**

About the school services.

- Services from the Family Department for the child and the family
- Attitude, and general communication
- Flexibility of the service
- Something missing or could be better
- Assistive devices if needed – how are they provided, how do they fulfil the needs
- What helps and what hinders in the system?
- Availability of the service
- Information about rights
- Follow-up
- Coordination within the service system
- Connection/collaboration between service providers
- Overview
- Is the service focused on the child, on the family, on the child and the family together?
- Is the service focused on adaption or looking for solutions within the environment?
- Provision of information/education/cooperation with the parents
- General experience of communication with the Family Department
  - What is going/went well?
  - what are/were the most difficult hindrances?
  - what needs to be improved?

5. **Assistance/services/support/education of parties outside the public system**
- From whom?
- How?
- Why?
- The experience of that assistance/service/education

6. **Parents' social relationships with others which relates to the child's impairment/disability**

- Relationships with other parents
- Work within an interest group
- Relationships with assistants, support staff, teachers, support family and/or other paid assistants and support staff
- Relationships with professionals of various kinds

**End of interview**

- Something the parents want to add
- Ask for another interview if needed, or ask for permission to contact again if needed

# Appendix B – Icelandic

## Viðtalsrammi vegna rýnihópaviðtala við fagfólk

**Inngangur – upphaf viðtals**

Rannsakandi og viðmælendur kynna sig með nafni, starfsheiti og vinnustað, markmið rannsóknarinnar rifjað upp, ítrekað að trúnaði og nafnleynd verði gætt í hvívetna, tímalengd viðtals tilgreind, upplýsingablað afhent og leyfis aflað um upptöku viðtalsins.

**1. hluti**

| Vinnuaðstæður, fagleg sýn og foreldrasamvinna |
| --- |

- Getið þið lýst vinnuumhverfi ykkar, starfsfyrirkomulagi og starfsskilyrðum?
- Getið þið lýst þeirri faglegu sýn sem þið hafið að leiðarljósi í störfum ykkar?
- Hvernig gengur að samræma persónulega/faglega sýn á hvernig gæðavinna á ykkar sviði er framkvæmd við þau starfsskilyrði sem þið búið við?
- Hvað styður við að ykkar mati og hvað hamlar?
- Ríkir sameiginlegur skilningur allra sem koma að vinnu með börnunum og fjölskyldum þeirra um lykilhugtök s.s.
    - Skóli án aðgreiningar (inclusion)
    - Þátttaka
    - Foreldrasamvinna

**2. hluti**

| Fagleg stefna og starfshættir, áhrif laga og alþjóðlegra samninga á starfið, starfslýsing/leiðbeiningar |
| --- |

- Hefur vinnuveitandi ykkar gert ykkur grein fyrir breytingum á faglegri nálgun í kjölfar nýrra laga og alþjóðlegra samþykkta?
- Er til starfslýsing um þitt starf?
- Hvað ræður hvaða börnum þú sinnir?
- Eru til einhverjar leiðbeiningar um framkvæmd/fyrirkomulag starfsins?
- Er hvatt til samvinnu og sameiginlegrar ákvarðanatöku?
    - Við börnin
    - Við foreldra
    - Við annað fagfólk

**3. hluti**

| Nánar um fyrirkomulag starfsins, starfsþróun og faglegt samstarf |
| --- |

- Vinnið þið mikið ein með einu barni eða...?

- Hvar fer vinnan ykkar fram?
- Hvernig eru tengslin við foreldrana?
- Hvernig gengur að forgangsraða og framkvæma allt það sem ætlast er til af ykkur?
- Hvað hefur helst haft áhrif á ykkar fagvitund og þróun
    - Námið
    - Reynsla í starfi
    - Samstarf við annað fagfólk með sömu eða aðra menntun
    - Endurmenntun
    - Breyttar faglegar forsendur vegna breytinga í viðhorfum til barna og einnig til fatlaðs fólks (að börn hafi meira um sín mál að segja og breyting í viðhorfum til fötlunar frá læknisfræðilegri sýn til félagslegrar tengslasýnar með mannréttindi og félagslegt réttlæti að leiðarljósi)

**4. hluti**

| Sýn þátttakenda á starf sitt og æskilegar breytingar |
| --- |

- Ef þú mættir ráða hvernig þú framkvæmdir þína vinnu hvaða breytingar myndir þú þá gera ef einhverjar?
- Hver er þín sýn á þær kröfur sem gerðar eru til fagfólks og þá þróun sem er að eiga sér stað?
- Ef þú mættir ráða þínu starfsfyrirkomulagi – hverju myndir þú breyta?

# Appendix B — English

## Framework for focus group interviews with professionals

**Introduction — the beginning of the interview**

The researcher and interviewees introduce themselves by name, job title and place of work, the aim of the research is recalled and reiterated that confidentiality and anonymity will be respected in all aspects. The duration of the interview is specified, an information sheet is handed out and permission is obtained to record the interview.

**Part 1**

| Working conditions, professional vision, and parental cooperation. |
| --- |

- Can you describe your work environment, work arrangements and working conditions?
- Can you describe the professional vision that guides you in your work?
- How do you reconcile your personal/professional view of how quality work in your field is carried out with your working conditions?
- What supports and what hinders?
- Is there is a common understanding of all involved in working with the children and their families about key concepts, e.g.
    o   Inclusion
    o   Participation
    o   Parent-professional collaboration

**Part 2**

| Professional policy and practices, the impact of laws and international conventions on the work arrangements, job description/instructions. |
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- Has your employer made you aware of changes in the professional approach following new laws and international conventions?
- Is there a job description for your job?
- What determines which children you serve?
- Are there any job instructions or guidelines for the services you provide?
- Are you encouraged to collaborate with parents and other professionals and to take part in joint decision-making?
    o   With the children
    o   With parents
    o   With other professionals

**Part 3**

More about the organisation/arrangement of the work, professional development, and professional collaboration.

- Do you mostly work alone with one child at a time...?
- Where does your work take place?
- How is the relationship with the parents?
- How do you prioritise and make sure that you accomplish all that is expected of you?
- What has had the strongest impact on your professional awareness and development?
    - Your professional education
    - Clinical experience
    - Collaboration with other professionals within the same or diverse disciplines
    - Continuing education
    - Changed professional beliefs due to changes in attitudes towards children and also towards disabled people (that they have their own say and a change in attitudes towards disability from a medical view to a social relationship view with human rights and social justice as a guide)

**Part 4**

Participants' view of their work and desired changes if any.

- If you were in charge, how would you manage your job, what changes would you make, if any?
- What is your view on the requirements for new approaches among professionals and the changes within the work environments that are taking place?
- If you could arrange your work according to your own views and wishes - what changes would you make?

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