

## RESEARCH

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

Jóna G. Ingólfssdóttir, Rannveig Traustadóttir and Snæfríður Þóra Egilson

University of Iceland, School of Social Sciences, IS

Corresponding author: Jóna G. Ingólfssdóttir ([jonaingo@hi.is](mailto:jonaingo@hi.is))

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, Sagers & Wildy 2009; Egilson 2011; Egilson & Stefánsdóttir 2014; Ingólfssdóttir, 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 (Ingólfssdóttir, 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; Ingólfssdóttir, 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
<b>1. Common knowledge</b> <ul style="list-style-type: none"> <li>Transfer, translation, and transformation of expert knowledge.</li> <li>Professionals being able to identify and integrate one's own expertise with what others know and do.</li> </ul>	<ul style="list-style-type: none"> <li>What affects one member of the system impacts on the other members.</li> <li>Equal power relations.</li> <li>Parent/professional partnership.</li> <li>Recognising and respecting one another's knowledge and expertise.</li> </ul>	<ul style="list-style-type: none"> <li>Parents are seen as experts in their own matters.</li> <li>Meaningful parent involvement.</li> <li>Stakeholders have a clear and shared understanding of their roles and responsibilities and know that they are expected to collaborate with partner organisations.</li> </ul>
<b>2. Relational expertise</b> <ul style="list-style-type: none"> <li>To be explicit about what matters for you.</li> <li>To recognise what matters for others.</li> <li>Joint interpretation of the problem.</li> <li>To attune ones actions with those of others.</li> <li>Adds to existing knowledge.</li> </ul>	<ul style="list-style-type: none"> <li>An ecosystems relational thinking.</li> <li>The children exist within the context of their families, wider community, and society.</li> <li>Take advantage of both core expertise and additional capabilities.</li> <li>Augments specialist expertise and enables fluid responsive collaborations.</li> </ul>	<ul style="list-style-type: none"> <li>A curriculum which requires staff to collaborate with children, colleagues, and parents and to reflect on their own practice.</li> <li>Individualised, flexible, coordinated, and responsive services.</li> <li>Monitoring and evaluation which is in the best interest of the child.</li> </ul>
<b>3. Relational agency</b> <ul style="list-style-type: none"> <li>Collaboration within and between activity systems.</li> <li>Professionals can, and need to, draw on and contribute to systems of distributed expertise.</li> </ul>	<ul style="list-style-type: none"> <li>Experts build links and try to integrate what they know with what others want to, or should, know and do.</li> <li>All entities are working towards a common goal.</li> </ul>	<ul style="list-style-type: none"> <li>Families are key decisionmakers in addressing their children's and families' needs.</li> <li>Parents are seen as equal partners in decision making and goal setting.</li> </ul>

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.

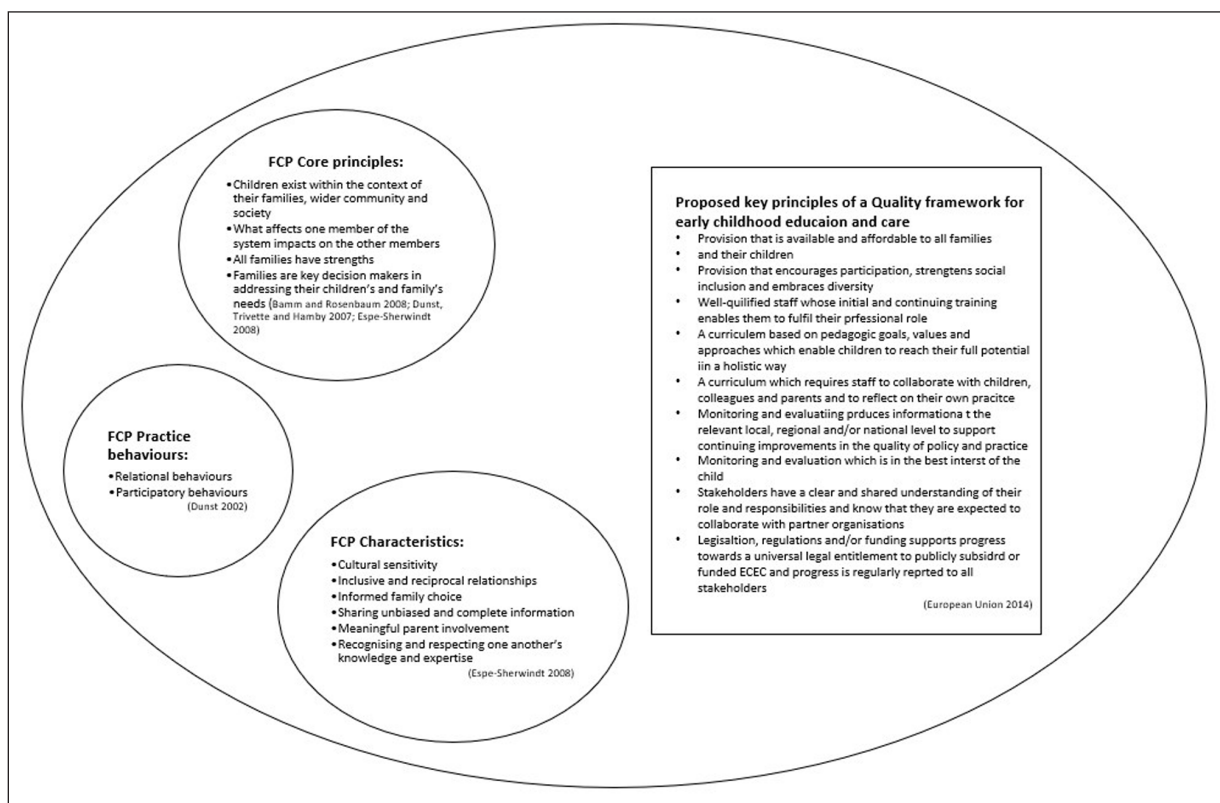
Research findings focusing on welfare services for disabled children and their families commonly report poor coordination, the lack of relevant resources, and difficult access to recommended services as the main concerns of families raising disabled children (Egilson & Stefánsdóttir 2014; Egilson 2015; Goodley & McLaughlin 2008; Ingólfssdóttir, Egilson & Traustadóttir 2017; Ingólfssdóttir, Jóhannsdóttir & Traustadóttir 2018; Tøssebro & 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 & Læg Reid (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 (Ingólfssdóttir, Egilson & Traustadóttir, 2017; Ingólfssdóttir, 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 (Ingólfssdóttir, 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 (Ingólfssdóttir, 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 (Ingólfssdóttir, Egilson & Traustadóttir 2017; Ingólfssdóttir, 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 (Ingólfssdóttir, 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 (Ingólfssdóttir, 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 (Ingólfssdóttir, 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 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

The authors have no competing interests to declare.

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