



 **Opin vísindi**

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Author(s)/Höf.:

**Jóna G Ingólfssdóttir  
Snæfríður Þóra Egilson  
Rannveig Traustadóttir**

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**Jóna G Ingólfssdóttir  
Snæfríður Þóra Egilson  
Rannveig Traustadóttir**

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

**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 under consideration. 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 (CHAT) is introduced as a beneficial framework for further study and system improvement.

**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 conceptualisations 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, 2001; 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 (Arnadóttir 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 paper 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 (Ingólfssdóttir et al., 2012). This is highly relevant as focusing 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 (CRPD) (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 (Emerson, 2003; Case, 2010), shifting from a child-focused to a family-focused 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 focused on families (Dempsey and Keen, 2008; Ferguson, 2001; Lundeby and Tøssebro, 2008) and on family-centred services (Dunst and Trivette, 1987; Dunst et al., 1997; 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 (Oliver, 1990; Barnes et al., 1999; Goodley, 2001). This has succeeded in shifting scholarship and debates about disability from

bio-medically 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 the last 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 paper is based on relational understandings, combining the family-centred approach outlined above and the social-

relational view on disability (Ingólfssdóttir 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, 2011). 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 specialised services the child has to have a diagnosis from authorised organisations. 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 organisation 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 decentralisation 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 paper is a part of an on-going research focusing on services for young children with intellectual disabilities and their families in Iceland (Ingólfssdóttir et al., 2012). This part of the research project consists of three case studies carried out in different municipalities and focuses 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 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 8.000 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 municipality was tried out before the nationwide decentralisation 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.

**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	
<b>Child details</b>	<i>Twin boys; Four years</i>	<i>Boy; Two years</i>	Girl; Three years	Girl; Five years	Boy; Five years	Boy; Seven years	Boy; Four years	Boy; Five years	
<b>Family and community details</b>	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	
<b>Specific data sources</b>	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	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 x2; 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	

<b>Generic data sources for municipality</b>	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-counselor operating nationwide Documents: Icelandic laws and regulations on social and educational services for disabled children and families; UN-CRPD
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\*A preschool that specialises in serving disabled children and provides advice to other preschools in Reykjavik

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 number of siblings in the family and the parents' level of education. All the children lived with both parents or a parent and a stepparent. The children were 3 -7 years of age when the study took place and all had attended preschool from when they were about two 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 focused 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 focused 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, twelve semi-structured in-depth interviews with parents were conducted (six with mothers alone, two with fathers alone and four with the parents together) in order to elicit their views and experiences of the services they had received. Furthermore, eleven 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 focused 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 sub-categories. Final conceptualisations 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 emphasised 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 State Diagnostic and Counselling Centre (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 organisation 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 National Social Insurance Administration (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, 2010) which prioritises 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 programs 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 both in terms of 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 intermediate. 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 individualised 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 bio-medical and individualistic approach. The main reason was the fact that eligibility for specialised 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 amongst 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 bio-medical 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 formalised 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 – characterised the arrangements under study. This may have contributed to the fact that, overall, parents were more concerned about the organisation 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 focused 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 (Kruijssen-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 amongst 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 cultural-historical activity theory (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 organisational work make 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 organisation 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 organisational 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 amongst 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; Ingólfssdóttir 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 cultural-historical activity theory (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 emphasised 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 characterised by bio-medical understanding of disability. The number of cases our findings are based on are 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; Ingólfssdóttir 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.

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