



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

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RESEARCH



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ABSTRACT

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

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

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

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

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

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

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

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

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

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

METHODOLOGY

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

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

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

FINDINGS

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

BARRIERS

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

Focus on child, rather than family

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

Inappropriate measures

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

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

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

Another worker said,

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

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

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

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

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

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

Organizational collaboration and culture

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

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

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

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

Emphasis on the quick fix

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

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

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

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

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

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

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

PATHWAYS FORWARD

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

A holistic approach

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

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

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

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

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

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

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

The need for long-term, appropriate measures

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

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

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

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

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

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

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

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

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

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

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

Acting as navigators and fostering good collaboration

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

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

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

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

DISCUSSION

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

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

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

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

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

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

STUDY LIMITATIONS AND FUTURE RESEARCH

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

CONCLUSION

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

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

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

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