

Article

# Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing 'a Seat at the Table'

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**Abstract:** The article highlights how the strategic use of the Convention on the Rights of Persons with Disabilities (CRPD) by disabled people's organizations (DPOs) in Iceland has produced a shift in the balance of power with regard to how, and by whom, disability legislation and policy in Iceland is developed. The article draws on a study examining the last stages of a consultative process between representatives of DPOs and policymakers in Iceland leading up to the adoption, in May of 2018, of core disability legislation, Laws pertaining to services for disabled people with long-term support needs (No. 38/2018). It examines the process from the perspective of representatives of DPOs through in-depth interviews and document analysis. This article draws on critical theory and the human rights approach in its analysis, with a particular emphasis on the roadmap to the coproduction of policy provided by the CRPD and the UN CRPD Committee through the issuance of guidance to States Parties to the Convention. It draws attention to the DPOs' ongoing refocusing of their strategies, and their emphasis on harnessing the rights contained in the CRPD to gain recognition of their right to participation in the coproduction of policy and in changing process norms.

**Keywords:** Convention on the Rights of Persons Disabilities (CRPD); disability; disabled people's organizations (DPOs); human rights approach; critical disability studies; co-production of policy

## 1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) ([United Nations 2006](#)) establishes disabled persons as rights-holders and human rights subjects ([Degener 2016](#)). It is broad-ranging, affecting most aspects of life, with the intent to provide a thorough and extensive network of rights to protect and empower disabled people ([Harpur 2012](#); [Quinn 2009](#)). The Convention's incorporation of a civil society mandate has been called unique among international human rights instruments ([Meyers 2016](#)). Just as importantly, it embodies a mandate for disabled people and their representative organizations as full and active participants in the development of law and policy on matters that affect their lives. This mandate, stated in Article 4.3 of the Convention, sets out to create a new politics of disability, calling for changes to the process norms with regard to how policy is made and who is involved ([Quinn 2009](#); [Committee on the Rights of Persons with Disabilities 2018](#)). However, to realize this goal, fundamental changes must be made to existing procedures and processes that reflect the unequal balance of power that has limited the access of disabled people to decision making. These ingrained processes that have become normalized must be critically challenged in order that the new and inclusive dialogue called for by the CRPD can be actualized.

This article draws on an ongoing study aimed at examining how disabled people's organizations (DPOs) in Iceland perceive their access to participation in policy making in affairs that affect them,

as well as the strategies they have adopted to realize the right to effective participation.<sup>1</sup> Iceland shares historical and cultural roots with other Nordic countries, drawing on a legacy of comprehensive welfare policies, including with regard to support and services for disabled citizens. This legacy of providing support based on need, while having been seen as progressive and compassionate, stands in contradiction to the rights-based focus embodied by the CRPD. As [Quinn and Flynn \(2012\)](#) point out, “welfare supports were designed to ‘compensate’ the persons with disabilities for their absence from the life-world. They were not there to question barriers to the life-world—much less contribute to their removal and the empowerment of the person” (p. 30). While Iceland, like the other Nordic countries, has ratified the Convention, the long history of providing welfare rather than rights is at times difficult to overcome, contributing to a roll back of rights, such as with regard to the right to personal assistance in Sweden ([Brennan et al. 2016](#)) and more generally the barriers to implementing the CRPD in Nordic welfare states ([Brennan et al. 2018](#)), as has also been confirmed in Concluding observations by the [Committee on the Rights of Persons with Disabilities \(2014a, 2014b\)](#) on the initial reports of Sweden and Denmark. It is in this light that the right to full and effective participation in all decision making and the development of law and policies pertaining to disabled people has become such a focal point for the Icelandic disability movement.

The study examines the efforts of Icelandic DPOs to increase their access to policy making in the last stages of a legislative drafting process that concluded in May 2018 when Althingi (the Icelandic parliament) passed a core disability legislation, Law pertaining to services for disabled people with long-term support needs (Law No. 38/2018), intended to align Icelandic law with the CRPD ([Althingi 2018](#)).<sup>2</sup> The initial stage of the drafting process, begun in 2014, was criticized both for limited representation of disabled people’s organizations and a lack of inclusion of the lived experience of disability. The draft legislation ([Althingi 2017](#)) was opened for comments in the spring of 2017 and drew strong criticism from DPOs and the research community, inter alia, for the lack of full and effective consultations, as called for by the CRPD ([Löve et al. 2017](#)). The draft legislation was taken up for further review by the Welfare Committee of Althingi, which called for additional comments and suggestions from DPOs and the Center for Disability Studies at the University of Iceland. This article focuses on the last stages of this legislative process, which commenced in January 2018, shortly after a new joint working group representing a united front of disabled people’s organizations and academia came together.<sup>3</sup>

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<sup>1</sup> Representative organizations of disabled people in Iceland consist, on the one hand, of established organizations, which include large umbrella organizations with diverse memberships and, on the other, of activist and grassroots groups and organizations run, directed and led by disabled people. Two umbrella organizations, the Organization of Disabled in Iceland (ODI) and the National Association of Intellectual Disabilities (NAID), have had the right, according to Icelandic law, to be consulted on policy and decision making on issues affecting disabled people. Previous research has found that leaders of both types of DPOs, including those that had a seat at the table, reported having difficulty being heard and perceived consultations often to be more pro forma than truly inclusionary ([Löve et al. 2018](#)).

<sup>2</sup> The first Icelandic disability legislation, dating back to 1979, focused on assistance for people with intellectual disabilities (Law on assistance to the intellectually disabled, Law No. 47/1979) ([Althingi 1979](#)). The law called for equality, normalization and the right of people with intellectual disabilities to participation and to be included in society ([Traustadóttir 2003](#)). The law was replaced in 1983 when the first comprehensive disability legislation aimed at reaching all disabled people (Act on the Affairs of Disabled People, Law No. 41/1983) was passed by Althingi in 1983 ([Althingi 1983](#)). A decade later, new core disability legislation also entitled Act on the Affairs of Disabled People (No. 59/1992) ([Althingi 1992](#)) took effect. Several amendments have been made to the law, with the most significant amendment adopted in 2010 instituting major changes to service structures with the responsibility for disability services being decentralized to the municipalities. This amendment included a reference to Iceland’s international obligations, particularly the CRPD ([Löve et al. 2017](#)). Following ratification of the CRPD in 2016, new legislation aimed at aligning Icelandic law with the CRPD were adopted by Althingi, including Law No. 83/2018, now the central disability legislation in Iceland and the focus of this study. The participation of DPOs in the process is detailed and analyzed, with reference to the aim of the CRPD, in an article published by *Laws* in 2017 entitled *The Inclusion of the Lived Experience of Disability in Policymaking* ([Löve et al. 2017](#)).

<sup>3</sup> The joint working group was composed of representatives of the Organization of Disabled in Iceland (ODI); the National Association of Intellectual Disabilities (NAID); Tabu, a feminist grass roots and activist group; the Center for User-led Personal Assistance (CUPA); and the Center for Disability Studies at the University of Iceland.

This study draws on qualitative data consisting of in-depth interviews with representatives of Icelandic DPOs who were part of a joint working group formed in the final stages of consultations. In addition, the research data consists of written memoranda, letters and other communications with the authorities that were provided by members of the joint working group. Furthermore, the findings presented in this article draw on both critical theory and the human rights approach to provide a theoretical foundation and to highlight key elements of the roadmap provided by the UN CRPD Committee in its General Comment No. 7.

## 2. Theoretical Approaches

Critical theory questions the taken for granted assumptions that people make about society's structures and norms, which it maintains are a reflection of a particular power structure that serves to maintain the status quo and, therefore, also the marginalization of groups such as disabled people (Agger 1991). Critical theory claims that only by revealing the underlying power dynamics that maintain and benefit from the status quo, can change take place (Kellner 1993; Meekosha and Shuttleworth 2009).

An important part of critical theory is its emancipatory agenda and its emphasis on the role of lived experience, which stems from its assertion that any understanding of society must be historically specific and contextualized, and that the questioning of a particular social situation should always be rooted in experience gained from that very setting (Kellner 1993; Young 1990). A similar understanding is reflected in the social model on disability and in disability studies, which call for changes to society to address the uneven balance of power that has led to the exclusion and marginalization of disabled people (Barnes 1991; Campbell and Oliver 1996; Shakespeare 1993). There is, moreover, a shared emphasis on the need to recognize the voices of disabled people and their authority in the process. The critical theory perspective is particularly relevant in the context of this study as it focuses on the need to reevaluate accepted and normalized structures and systems within society and asks what can be changed from the perspective of disabled people.

The human rights approach to disability takes a similar stance by adopting the social model's call for changes to society and its emphasis on questioning the status quo, but it goes further by providing a road map for change, based on securing disabled people's human rights. The human rights approach is both driven and supported by the CRPD, as Quinn and O'Mahony (2017) point out. It recognizes disabled people as rights-holders who are more often disabled by barriers created by society than by their impairments (Kanter 2015). The perceived problem is, therefore, located outside the disabled person, requiring a change to structural, economic and social processes to accommodate difference (Degener 2016; Kanter 2007; Quinn and O'Mahony 2017). As Kanter points out, the CRPD identifies the limitations that are placed on disabled people as violations of their human rights and calls for change (Kanter 2015). The strength of the human rights approach as reflected in the Convention is that it obligates society to provide the needed mechanisms and support to realize disabled people's rights (Stein and Stein 2007). These theoretical approaches share a critical view of existing norms and structures for the purpose of delivering change that can shift the underlying power balances that have created and maintained the observed inequality of marginalized groups, such as disabled people.

## 3. The Right to Full and Effective Participation

The CRPD maintains a clear focus on disabled people's right to participation in both its implementation and monitoring processes, an emphasis that is both implicitly and explicitly woven throughout the text (Stein and Lord 2010). In particular, the Convention takes a firm and progressive stance by obligating States Parties to "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations," in the development and implementation of legislation and policies that relate to them (Article 4.3), a position that "reflects the fundamental principle that the persons most affected have the right to participate in decisions that impact them" (Stein and Lord 2010, p. 698). Furthermore, it opposes the position of marginalization and lack of voice in decision making processes that so often has been the lived reality of disabled people.

As part of the CRPD monitoring mechanism, the Convention establishes a Committee on the Rights of Persons with Disabilities (the UN CRPD Committee).<sup>4</sup> In keeping with the practice of other human rights treaty bodies, the Committee issues General Comments intended to clarify the rights and legal obligations of States Parties and provide guidance, suggestions and recommendations in an effort to foster effective implementation of the Convention. Thus far, the Committee has issued seven General Comments, including on Articles 4.3 and 33, which focus on the participation of persons with disabilities in the implementation and monitoring of the Convention and, thus, have a particular relevance to the theme of this study. Despite the establishment of these mechanisms, “there is no guarantee that the new values that are embedded in the text of the Convention will be internalized and then operationalized,” as (Quinn 2009, p. 216) points out. There is often a significant gap between rights as stated by law and what actually materializes on the ground, a concern voiced by many, including the UN CRPD Committee (Committee on the Rights of Persons with Disabilities 2018, p. 8). Studies that have focused on the implementation of the rights contained in Article 4.3 have found that DPOs often encounter obstacles to their full and effective participation. Examining the state of affairs in France, (Sherlaw and Hudebine 2015) point out that despite policy mechanisms that enable DPOs to provide input into legislative and policy making processes, there are no assurances that the voices of disabled people will be taken into account. Similar results were found in a study of nine European countries—the Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the United Kingdom (Waldschmidt et al. 2017), as well as in a comparative study of DPOs in Canada, the U.S. and the U.K. (Levesque and Langford 2016). Research focusing on countries in Africa observed that a lack of support, including support from independent national human rights institutions, and funding for capacity building had played a significant role in hindering the full and effective participation of DPOs (Birtha 2013; Lang et al. 2011).

The right to participation in decision making on all matters, policies and laws that affect one’s life is central to the role of the CRPD as a tool for the empowerment of disabled people. Furthermore, it is fundamental to bringing about necessary changes to society and a shift in the uneven power balances that are at the root of the marginalization of disabled people. The CRPD and the General Comments of the UN CRPD Committee work hand in glove to deliver these changes. The CRPD states the necessary legal obligation and the Committee’s General Comments provide analysis and guidance on how to arrive at a new approach to law and policy making that delivers a change to established processes and norms in a culture where “persons with disabilities still face significant attitudinal, physical, legal, economic, social and communication barriers to participate in public life,” as stated in General Comment No. 7 (Committee on the Rights of Persons with Disabilities 2018, p. 5).

An important part of the road-map provided by General Comment No. 7 concerns the range and immediacy of the obligation to consultation contained in Article 4.3. The UN CRPD Committee clarifies that these obligations should be broadly interpreted to include “the full range of legislative, administrative and other measures that may directly or indirectly impact the rights of persons with disabilities” (Committee on the Rights of Persons with Disabilities 2018, para. 18), including general laws, the public budget as well as disability-specific laws. Additionally, this obligation covers “legal and regulatory frameworks and procedures across all levels and branches of Government” (Committee on the Rights of Persons with Disabilities 2018, para. 15). Furthermore, the General Comment provides clarification on the development of new process norms by emphasizing that they include the contribution of disabled people’s knowledge and lived experience. In this context, it is particularly important to clarify that while Article 4.3 calls for the participation of disabled people through their representative organizations, it is not the Convention’s intent to distance

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<sup>4</sup> The Committee is comprised of 18 members nominated by States Parties who serve in their individual capacity. Following ratification of the Convention, States Parties submit regular reports to the Committee, which addresses concerns and makes recommendations. The aim of this process is to review progress made by States Parties in bringing national law and policy in line with the provisions of the Convention (Office of the High Commissioner for Human Rights 2006).

disabled people themselves from participation in decision making processes. The Committee defines organizations of persons with disabilities as those that “are led, directed and governed by persons with disabilities” ([Committee on the Rights of Persons with Disabilities 2018](#), para. 11) and are made up of a clear majority of persons with disabilities themselves. This clarification is of prime importance as it leaves no doubt that the intent of the CRPD is to ensure that disabled people are recognized as an important source of knowledge in decision making on matters that affect their lives. To this end, the Committee calls on States to recognize the “positive impact on decision-making processes” that ensuring the participation of persons with disabilities through their representative organizations brings, “because of their lived experiences and knowledge of the rights to be implemented” ([Committee on the Rights of Persons with Disabilities 2018](#), para. 9). These clarifications by the Committee underline its position that disabled people’s lived experience of disability makes them uniquely capable of reflecting their own needs. It also represents a fundamental change to process norms by incorporating recognition of disabled people as fully capable and entitled as citizens to participation in the co-production of policies that affect them.

The Committee stresses the need to ensure that consultations are initiated in a timely manner and that access is provided to all relevant information in accessible form, with reasonable accommodation when needed, such as Easy Read text, Braille and sign language interpretation. The obligation to closely consult and actively involve DPOs also includes informing them of the outcome of consultation processes and to provide explanations, including “considerations and reasoning of decisions, on how their views were considered and why” ([Committee on the Rights of Persons with Disabilities 2018](#), para. 23). This obligation is of particular importance as it invites reflection by decision makers on the contribution of DPOs, encourages accountability and can serve as the basis for further meaningful dialogue between parties.

The General Comment lays out a process for the co-production of policy that is characterized by a spirit of collaboration, respect and a desire to reach collective agreement ([Committee on the Rights of Persons with Disabilities 2018](#), para. 47). In addition, it calls for checks to be built into the process, calling on States Parties to “undertake periodic evaluation of the functioning of their participation and consultation mechanisms, with the active involvement of organizations of persons with disabilities” ([Committee on the Rights of Persons with Disabilities 2018](#), para. 47). Finally, the Committee encourages remedies to enforce compliance, including “quashing, totally or partially, the decision, based on non-compliance with articles 4.3 or 33.3” ([Committee on the Rights of Persons with Disabilities 2018](#), para. 66). These measures have the potential to introduce accountability that can help to build trust between parties, as well as provide firm checks and guidance on the new structure being developed.

These guidelines provide a new path to developing inclusive and co-produced laws and policies that affect disabled people. They represent a radical change to established norms and processes, where disabled people, through their representative organizations, are recognized as capable and entitled participants who can demand and expect their contributions to be both welcomed and facilitated through reasonable accommodations and support. The call for full and effective participation of disabled people “brings them into the democratic process as contributing participants in the development of solutions to policy issues that take into account different perspectives and needs, in addition to their own” ([Löve et al. 2017](#)).

A road map to achieving these goals is provided by the General Comments of the UN CRPD Committee ([Arstein-Kerslake and Flynn 2016](#); [Degener 2016](#)). However, as the Committee states, there is still a significant gap between the goals set by the CRPD and their implementation on the ground ([Committee on the Rights of Persons with Disabilities 2018](#), para. 8), a gap that has also been recognized in academic research that highlights the need to examine how the rights stated in the CRPD are experienced in the lived reality of disabled people. Among the scholars who have called for a stronger connection between disability law and disability studies to address this discrepancy are [Kanter \(2011\)](#); [Mor \(2013\)](#); [Arnardóttir and Quinn \(2009\)](#); [Traustadóttir \(2009\)](#). This study contributes



to bridging this gap by employing empirical data to shed light on how the rights to participation in law and policy making stated by the CRPD are materializing on the ground. It does so by highlighting the perspectives of leaders of DPOs with regard to their effectiveness in impacting policy making as participants in a consultative process aimed at bringing Icelandic law in line with the CRPD. It draws attention to the potential shift in power relations from the perspective of critical theory and the human rights approach, with reference to the changes to process norms called for by the UN CRPD Committee in its General Comments.

#### 4. Methods

This paper focuses on the strategies and emphasis adopted by the key DPOs that joined forces and formed a joint working group, which also included representation from the research community, to present a united front in the final stretch of consultations with the Icelandic authorities on the new draft disability legislation. An examination of the DPOs' strategies at this stage of the process was considered pertinent as a study of earlier stages of the process had revealed a lack of political interest on the part of the authorities, including in changing established process norms to ensure the full and effective participation of DPOs in law and policy making, as called for by Article 4.3 of the CRPD (Löve et al. 2017; Löve et al. 2018).

This research draws on qualitative data gathered through in-depth interviews with seven members of the joint working group, composed of representatives and leaders of disability groups and organizations and academia. About ten people took part in the group, whose members were leaders from a range of disabled people's organizations, including umbrella associations and activist groups. There was a diversity of impairment groups presented, it included both men and women, and several members had a background in human rights law and disability studies. The research also draws on written memoranda, letters and other communications with the authorities that were provided by members of the joint working group. The aim of the research was to gain an understanding of the access that the Icelandic DPOs had to full and effective participation in policy making and their call for changes to the process norms, in line with Article 4.3 and the UN CRPD Committee's General Comments, in the final stages of consultations before the adoption of core disability legislation in May 2018 (law No. 38/2018) intended to bring Icelandic law in line with the CRPD. The data was collected from August to November 2018.

In-depth interview was the method chosen as it allows the researcher to gain a subjective understanding of the perspectives and meanings that participants attach to the issues under discussion. Furthermore, they allow the interviewees to direct the discussion to issues that they perceive to be important and that they choose to focus on, while at the same time allowing the interviewer to direct the discussion to the themes that are in keeping with the topic of the research (Esterberg 2002; Taylor et al. 2016). The decision to focus on the experience and perceptions of representatives of disabled people's organizations in the legislative process is derived from the belief that disabled people themselves are best positioned to judge whether policies aimed at delivering disability equality have been successful or not, a position taken by Sherlaw and Hudebine (2015), among others, as well as Disability Rights Promotion International (Samson 2015). It is in line with the emphasis adopted by disability studies to afford disabled people and their representative organizations a voice and to recognize their lived experience of disability as knowledge of importance to all research and decision making in matters concerning their affairs.

Purposeful sampling was used to identify and recruit interviewees as it allows the researcher to select individuals who have experience of or particular insight and knowledge into the concepts being explored (Creswell and Clark 2017). In this instance, because the intent of the research was to focus on participants in a particular process, the selection of interviewees was limited to those who had participated. However, in the selection of interviewees, an attempt was made to provide a broad representation of the working group membership.

The analysis of the data was directed by the grounded theory method, which reflects the premise that theory can be developed from rigorous analysis of empirical data (Charmaz 2014). The constant comparative method that is a part of the grounded theory approach was used to collect and analyze data. This method calls for data gathering to be continued while data is simultaneously coded and analyzed and analytical memos developed. The goal of this process is to identify central themes from the data as they merge to help direct further data collection and theory building (Charmaz 2014). In keeping with this approach, the interviews were conducted in three stages, in August, October and November 2018. At the beginning of the interview process, broad questions were posed regarding the DPOs' participation in the consultation process and the approaches and strategies they had adopted. As the data analysis progressed, the questions were narrowed in focus as themes began to develop based on the ongoing analysis of the data. The interviews were recorded, transcribed and coded. Coding consisted of a detailed reading of the transcripts, followed by sorting and organization of the codes, which revealed patterns in the data that helped develop a deeper understanding of the issues at hand (Creswell 2009). All participants gave informed consent and agreed to have the interviews recorded. All interviews were conducted in Icelandic and direct quotations were translated by the first author of this paper. Keeping in mind the small size of the Icelandic population, both names and identifying details have been omitted to the extent possible to ensure confidentiality.

## 5. Findings

The findings of the study draw attention to the DPOs' focus on harnessing the power of the CRPD to strengthen their ability to affect policy and decision making with regard to the drafting of core disability legislation intended to align Icelandic law with the CRPD. In addition, they draw attention to how the DPOs' forward-looking strategies emphasize their intent to continue and to expand on this strategy.

### 5.1. *The Lead Up to the Final Consultations*

The initial stages of the drafting process leading up to the adoption of the new Laws pertaining to services for disabled people with long-term support needs (Law No. 38/2018), as part of the process intended to bring Icelandic law in line with the CRPD, were marked by a lack of participation of disabled people's organizations and of representation of the lived experience of disability. A working group appointed in 2014 by the Minister of Social and Housing Affairs to produce an initial draft of the legislation was composed of 12 representatives, of which only two were designated by disabled people's organizations. In addition to the limited representation of DPOs (16%), only one member of the working group was a disabled person. After the resignation of the disabled representative half way through the process, there was no disabled person in the working group for the remainder of its work, which concluded in October 2016. A study conducted in 2016 and 2017 that examined this process from the perspective of the leaders of disabled people's groups and organizations in Iceland, found a lack of meaningful involvement of DPOs and of political interest in disability affairs, resulting in stagnation in the implementation of disability rights (Löve et al. 2018). Despite this reluctance, DPOs continued to maintain pressure on the authorities to include the voices of disabled people and to comply with the CRPD. The methods they employed varied, with the more established organizations emphasizing engagement through dialogue, mostly through established channels, while activist groups focused predominantly on advocating for greater representation of the lived experience of disability. While the DPOs reported citing the rights stated by the CRPD in their interactions with the authorities, there was, nevertheless, a hesitation, particularly among the established organizations, to adopt a forceful stance in this regard by demanding the rights enshrined in the CRPD.

Following the initial drafting stage, the draft legislation was opened for comments in the spring of 2017, drawing strong criticism from DPOs and the research community, among other things for the lack of full and effective consultations, as called for by the CRPD (Löve et al. 2017). A total of 36 comments on the draft legislation were submitted, with 12 from disability groups and organizations

(Althingi, Welfare Committee 2017). The focus and scope of these comments differed considerably as many of the disabled people's organizations focused on issues specific to the interests and needs of their membership, resulting in diverse and at times conflicting comments. A study that analyzed the commenting process and Althingi's response to it revealed very limited reaction from the Welfare Committee, the parliamentary body that makes suggestions on changes to draft legislation that falls under its mandate before it goes to a vote. This inaction resulted in deferred decision making and a virtual stalemate (Löve et al. 2017).

Following general elections that resulted in the formation of a new Government, the draft legislation was taken up for further review by a newly appointed Welfare Committee of Althingi, which called for additional comments and suggestions from DPOs and the Center for Disability Studies at the University of Iceland. The study this article draws on focuses on the subsequent final stages of the drafting process, which commenced in January 2018 and saw the development of a new approach to consultations by the DPOs.

### *5.2. A New Strategy Is Developed*

Responding to what leaders of DPOs perceived to be frustration among politicians, blaming division among the DPOs for their reluctance to take action, a number of representatives and leaders of disabled people's groups and organizations, and the research community, formed a joint working group. Seizing on the changes to the political leadership of the Welfare Committee, which the members perceived to be more open to an inclusive and co-operative policy making process, the joint working group initiated a strategy focused on presenting a united front by focusing exclusively on core issues where the positions of the DPOs were aligned, leaving other matters to the side to be pursued separately. The new approach was intended to give the DPOs a greater presence and strength in numbers, as well as an accumulation of knowledge that would be harder for the authorities to overlook.

### *5.3. Changes Achieved*

The establishment of the joint working group was perceived to have been effective in influencing the policy outcome, with a significant number of changes to the draft legislation reflecting the group's emphasis. Among the key changes to the draft that the members of the group attributed to their participation in the consultation process concerned changes to articles that instituted personal assistance as a legally mandated service form. As DPOs pointed out, the draft legislation had initially included contingencies that enabled the authorities to limit access to the right to personal assistance, raising the DPOs' concerns, particularly with regard to the access of children and people with intellectual disabilities. "We pushed for personal assistance for everyone, not just some groups. In the draft legislation, it was up to local authorities to decide whether they would provide personal assistance to children or not" (member of the joint working group). Reflecting on the process, the members of the joint working group perceived that referring to the CRPD and its intent in support of their arguments had been an effective way to call for changes to the draft legislation, with the adopted law now containing the right to personal assistance for all disabled people, regardless of type of impairment or age.

Another critical change to the draft legislation achieved through the DPOs' participation was an addition to article 36 of the law, which now states that the membership of a consultative body to the Minister is to be composed of a majority of disabled people (Law No. 38/2018). This change was brought about by the DPOs' continued emphasis on the right to full and effective participation in the development of law and policy being recognized. This change was perceived by the members of the working group to be ground breaking. "In the beginning, there wasn't even any mention of disabled representatives on the committee," stated a member, with another emphasizing "I don't think people have fully realized what we achieved by getting this through... If the consultative committee is led by disabled people, then I'm confident we can do what we set out to do." Additionally, the emphasis of the DPOs on the right to participation in law and policy making resulted in changes throughout the



legislation on consultative processes. Previously, the draft legislation had only called for consultations on a number of issues with local governments, as the providers of services, whereas now the law also calls for consultations with DPOs in these instances.

Leaders of DPOs also pointed out that their persistent emphasis on the obligations contained in Article 4.3 of the Convention has resulted in a significant increase in consultations by the Ministry with DPOs on the development of regulations. “The authorities have become conscious of the obligation to consult and we have made it very clear to them that these consultations must be real, not tokenistic” (member of the joint working group). “We have been very vocal in calling for consultations and we have probably never received as many requests to active participation as we have this winter and I hope that continues” (member of the joint working group).

Furthermore, the members of the group emphasized their successful efforts to change the name of the law. Originally, it was slated to be named “Laws regarding services for disabled people with significant support needs” but was changed at the suggestion of the DPOs to “Laws regarding services for disabled people with long term support needs.” The change in name was considered significant because, as members of the joint working group argued, by attaching support services to a set number of needed service hours, there was a risk that the law would exclude, for example, people with limited but nevertheless long-term service needs from being able to obtain the assistance necessary for them to live independently. “We were concerned that it was being left too much in the hands of the local governments to determine how much support you need and therefore whether the law applies to you or not . . . They also have a financial interest at stake when making these decisions” (member of the joint working group).

In addition, members of the joint working group reported taking the lead in the translation of key definitions, based on their expert knowledge and understanding of the CRPD, its underlying intentions, and the concepts it embodies. DPOs and working group members also reported that the authorities had expressed a willingness to incorporate other important changes to the legislation emphasized by DPOs, which ultimately did not materialize due to time constraints and a lack of viable replacement options.

#### *5.4. The Key Contributing Factors*

The DPOs’ approach, to present a united front, was regarded as an important contribution to the success of the consultations. “It’s hard to ignore us when so many of us are there all saying the same thing” (member of the joint working group). Furthermore, a change in political leadership was seen as having facilitated the DPOs’ influence on the final draft legislation. Members reported greater interest and a genuine willingness among the politicians on the Althingi’s Welfare Committee to listen to the DPOs and to incorporate their suggestions in the final draft. For example, participants recounted the Committee requesting direct guidance via phone calls and written communications during the final stages of the drafting process, including on the wording of definitions. These exchanges were perceived by working group members to indicate a willingness to reflect both the emphasis and experiences of the DPOs, as well as recognition of the knowledge that the research community brought to bear concerning definitions and interpretations of the Convention. Moreover, members pointed out that the working group had been given repeated opportunities to comment on the document during the final stages of the process.

The working group members’ in-depth knowledge of the CRPD was reported to have been of key importance to the progress made. This was exemplified by the strategic use of articles of the CRPD to support arguments for the need for changes to the draft legislation. For example, one member of the working group recalled another reading out loud from the General Comments before the Welfare Committee of Althingi in support of arguments concerning the appropriate interpretation of the right to personal assistance. A similar prior instance was reported by a member of the working group who had requested a meeting with the Minister of Welfare, insisting on his signature to certify that the Minister had been made aware of the obligations under article 4.3 to full and effective consultation.

The meeting occurred after the DPO leader had learned that the Ministry had initiated the drafting of several regulations of concern to disabled people without calling disabled people or their representative organizations to the table. “I handed him [the Minister] a document to sign, stating our protest . . . pointing out that this was in violation of the CRPD. Two weeks later, we were called to the table” (member of the joint working group). Being able to state a right and an obligation by the State, as called for by the CRPD, was seen to have been of pivotal importance, especially when coupled with the threat of potential political fallout if the Ministry were to be accused of violating disabled people’s rights while being fully aware of the obligations prescribed by the CRPD.

Other factors that were perceived to have contributed to the success of the working group included strategies such as making sure to leave a paper and electronic trail of all suggestions, comments and memoranda submitted to preclude any claims of a lack of clarity concerning the DPOs’ intent. Members also pointed out that being part of a group created synergy, mutual support and shared enthusiasm for the work. In addition, it made it possible to divide up the workload, which proved to be useful as meetings were often convened at short notice and DPO representatives participated predominantly on a voluntary basis.

While members of the group emphasized the strategic advantage brought about by presenting a united front on the basis of shared concerns, they were also aware of the group’s inability to pursue issues that were, in some cases, of primary importance to individual organizations or groups, but not others. However, there was a general consensus that while not perfect, this approach had been effective. In the words of one member, “it is good to be able to both work together on some issues and separately on others” (member of the joint working group). The members expressed a desire to continue to build on this collaborative process.

#### 5.5. Next Steps

Reflecting on their plans for the work ahead, members of the joint working group emphasized the continued strategic use of the CRPD to pressure the authorities to live up to their obligations and their intent to maintain the initiative in their continued pursuit of greater access to law and policymaking. A member of the group described his thoughts about the process ahead thus: “There is a lot more power to it when we can claim a right instead of relying on the willingness of others.” A similar sentiment was expressed by another member: “What I say to people is, just to be clear, this is no longer a question of choice because when Iceland ratified the Convention, it accepted its obligation to consult and ensure participation. If it’s not done, then you are in breach of it” (member of the joint working group).

As part of the DPOs’ plans for the work ahead, the leaders discussed initiating a push to ensure that the authorities recognized the CRPD as a broad ranging human rights convention, affecting all aspects of life, with implications beyond and not limited to service provisions. Furthermore, they pointed to the need to ensure that the authorities fully grasped the Convention’s reach, affecting all layers of government, requiring, for example, local authorities to ensure the full and effective participation of disabled people, through their representative organizations, in the development of all policies and programs. Envisioning a challenge ahead, a leader stated “[i]t’s going to be very important to ensure the legislation’s implementation in the seventy-something municipalities. I don’t think they [the local governments] fully grasp this yet. All of these regulations all over the country, and there needs to be consultations on them all. This is no small task” (a member of the joint working group).

The strategic use of the CRPD has empowered DPOs to take a more assertive stance toward the authorities. Iceland’s ratification of the CRPD has initiated a shift in the balance of power between the authorities and DPOs as it relates to the latter’s ability to claim rights, including the right to full and effective participation in the development and implementation of laws and policies that affect them. This shift, even if only a slight one, is recognized by the DPOs who report a growing responsiveness on the part of the authorities and an awareness of the obligation to ensure the active involvement of DPOs. They do, however, continue to express a need for vigilance, particularly with regard to legislation and

policies that do not directly concern services for disabled people but that, nevertheless, clearly affect their lives and well-being, which is an obligation that falls within the parameters of Article 4.3.

## 6. Discussion

The changes to the process norms that General Comment No. 7 calls for represent a fundamental realignment of the accepted and ingrained norms and procedures that have dictated how disability policy is made and who gets to participate in that process. They call for full and effective inclusion, where consultations are truly collaborative and broad-ranging, on all legislations affecting disabled people and at all levels of government. As critical theory maintains, such a realignment is key to changing existing power structures, which should be regarded, first and foremost, as the product of particular historical circumstance that should, like other human constructs, be questioned and challenged (Agger 1991). The changes advocated by the CRPD are aimed at bringing disabled people to the table through their representative organizations, thus inviting the contribution of lived experience in the development of law and policy, as clarified by the General Comment. Recognition of the lived experience of disability as valuable knowledge that can strengthen the policy making process is a fundamental change that shifts the balance of power in the direction of disabled people. The changes to process norms called for by the General Comment—such as making relevant information available in accessible formats, providing accommodations to ensure that the process is open to people with a broad range of impairments, and allocating funding to support DPO participation—all represent a shift in the balance of power and a challenge to existing norms. Moreover, they are likely to require additional steps to work protocols and may require the allotment of additional resources to ensure the needed support and availability of all relevant information in a timely manner.

In addition to serving as an empowerment tool by stating the rights of disabled people and the obligations of the authorities to make changes to established norms and structures to actualize these rights, the CRPD also empowers by embodying a common core of interests and values around which DPOs can unite. This was the case with the otherwise diverse group of Icelandic DPOs in the last stretch of negotiations, before the final draft of the new disability legislation was adopted by Althingi. Prior to the formation of the joint working group, the Icelandic DPOs had primarily engaged with the authorities separately, more often than not focusing on issues of particular relevance to their respective memberships. The diversity of DPOs and their tendency to work separately was evident when the draft legislation was initially opened for comments in the spring of 2017 and the DPOs and the activist groups submitted separate comments, some both extensive and very critical (Löve et al. 2017). The diversity of DPOs is not unique to Iceland (Sherlaw and Hudebine 2015). Disability is in its nature a diverse phenomenon (Erevelles 2011; Goodley 2013, 2016) and there is often little that unites disabled people other than the call for disability equality. While diversity continues to be duly reflected in the broad range of disability organizations and activist groups in Iceland, they all emphasize and refer to the rights and core values embodied in the CRPD in their mandates and strategies. This shared emphasis helped to bring key DPOs and activist groups together, with the support of the research community, to form a working group to present a united front in the negotiations with the authorities. This initiative was perceived to have enabled the DPOs to more confidently argue their case based on a broad representation of the lived experience of disability and with strategic reference to rights contained within the CRPD. The strategy proved effective as a significant number of the DPOs' comments and suggestions were adopted in the final document. The process also served to empower the DPOs through the development of new work strategies, such as the sharing of the workload among the DPOs and research community, which also allowed for greater specialization on issues. Pooled resources also represented pooled knowledge, both of the rights stated in the CRPD and their interpretation based on the UN CRPD Committee's General Comments, which served the DPOs well throughout their dialogue with the authorities. Furthermore, the process created synergies and greater camaraderie among the members.

The empowerment of the DPOs through their strategic use of the CRPD and the General Comments can also be observed in their formulation of forward-looking strategies to ensure that the authorities act on and recognize the reach of the obligations to consult with DPOs, not only with regard to all laws and policies that affect disabled people, i.e. not just disability specific laws, but also throughout the political system and at all levels of government that affect disabled people. In the work that lies ahead in this regard, the Icelandic DPOs have expressed their intention to seize upon the obligations set out in the CRPD, supported by the guidance provided in General Comment No. 7, which they have already drawn on in communications with the authorities.

The DPOs' strategic reference to the rights stated by the CRPD into their work processes and their interactions with the authorities have produced tangible results and served to empower DPOs and encourage them to take a more assertive stance toward the authorities. Their strategies align with the human rights approach, which maintains that a focus on rights provides the road map for change. Much like critical theory and the social model on disability, the human rights approach recognizes the necessity to change the underlying power structures that marginalize disabled people. Unlike the other schools of thought, however, the human rights approach places primary importance on viewing disabled people as rights-holders and on identifying any restrictions on these rights as human rights violations, a stance that fundamentally changes the position of disabled people (Degener 2016; Kanter 2015). The forward-looking strategies of the Icelandic DPOs follow the trail blazed by the human rights approach of stating rights and supporting their claims with interpretations derived from the UN CRPD Committee's General Comments. This approach is also reflected in the DPOs' comments about the steps that will be required to ensure that the right to consultation and participation is actualized at all levels of government and with regard to all policies that affect disabled people, not just disability-specific legislation.

## 7. Conclusions

The established balance of power with regard to how and by whom disability legislation and policy in Iceland is developed has shifted in the direction of disabled people and their representative organizations. This shift has been enabled by the Icelandic DPOs' strategic use of the rights contained in the CRPD and the Convention's power as a unifying force. At the heart of this strategy is the DPOs' in-depth knowledge of the CRPD, which has given them the confidence to cite the Convention in support of their arguments in their interactions with the authorities. The DPOs' use of the Convention reflects the position of the human rights approach, that the CRPD provides a road map forward, as well as critical theory's emphasis on the need for changes to norms and structures in order to shift the balance of power. The changes to process norms called for by the CRPD represent a new way of making disability policy. The Icelandic DPOs have been able to seize upon the potential for this change in the way that disability-related law and policies are made in Iceland. It remains to be seen, however, whether the shift in power is permanent and whether DPOs will be able to maintain their leverage to broaden the scope of the obligation to consult beyond disability-specific legislation and policies.

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