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The Inclusion of the Lived Experience of Disability in Policymaking

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Abstract: This paper examines the process under way in Iceland to align national law with the UN Convention on the Rights of Persons with Disabilities, focusing on the Convention's call for the active involvement of disabled people and their representative organizations in policy and decision making on matters that affect them. The paper draws on comments submitted by Icelandic DPOs on draft legislation intended to replace the existing law on services for disabled people, focusing on comments relating to their ability to participate in and affect the policymaking process. Furthermore, it draws on interviews with leaders of representative organizations of disabled people that solicited their views on the issue. The findings indicate that there is a reluctance on behalf of Icelandic authorities to make changes to the established process, which limits the active participation of disabled people and their representative organizations. The draft legislation has neither been revised to include provisions for expanding the participation of DPOs in policy and decision making, nor to ensure that disabled people themselves participate in the process.

Keywords: disability; CRPD; inclusion; policymaking

1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) reflects the fundamental principle that those most affected have the right to participate in decisions that impact them, a contribution that has been called “one of the most progressive developments in human rights law provided by the CRPD” (Stein and Lord 2010, p. 698). There is an emphasis on participation that runs throughout the Convention that embeds within it an advocacy role for civil society organizations representing disabled people, which also extends to disabled people themselves (Meyers 2016; Stein and Lord 2010; Sabatello 2014). The preamble sets the stage by proclaiming that “Persons with disabilities should have the opportunity to be actively involved in decision making processes about policies and programs, including those directly concerning them” (United Nations 2007). Further emphasizing this stand in Article 4(3), the Convention demands that State parties “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations when developing and implementing policies and legislation concerning persons with disabilities.” The Convention maintains a focus on the importance of participation in the monitoring processes where it states that civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully (Article 33(3)), requiring states parties to recognize the obligation set out in Article 4(3). Finally,

Article 34(3) encourages states parties to give “due consideration” to representation by persons with disabilities on the monitoring body (Stein and Lord 2010).

The CRPD sets out to create a new politics of disability and calls for changes to the process norms with regard to how disability policy is made. Bearing in mind how the Committee on the Rights of Persons with Disabilities (CRPD Committee), the body of independent experts that monitors implementation of the Convention by the States Parties, defines representative organizations of disabled people, this paper asks the question whether the new draft legislation on disability services currently before the Icelandic parliament, intended to bring national legislation into compliance with the CRPD, sufficiently embodies the Convention’s call for changes to the process norms, particularly the principle that those most affected have to right to participate in decisions that most impact them. This is a question that may have wider relevance to other States Parties in the process of aligning national legislation with the CRPD. To shed light on this, the paper draws attention to the important role of DPOs in the drafting of the Convention and highlights those articles that lay the foundation for the argument that disabled people should be recognized as decision makers in their own affairs. Furthermore, it draws on theories that focus on the active involvement of marginalized groups, including disabled people, as a necessary component of changing their position of oppression. The paper then goes on to address the process underway in Iceland and examines comments submitted by Icelandic DPOs on the draft legislation pertaining to their views on the policymaking process. Furthermore, it draws on interviews with leaders of DPOs about their perceptions of their ability to affect decision making.

The prominent role afforded to civil society, particularly disabled people and their representative organizations, in the implementation and monitoring of the CRPD can be attributed to the unprecedented involvement of non-governmental organizations (NGOs), and in particular disabled persons’ organizations (DPOs), in the drafting process of the Convention (Brennan et al. 2016; Degener 2016; Kanter 2014). Over 400 NGOs were accredited by the Ad Hoc Committee, the body responsible for the drafting of the treaty, which was at the time a historically high number for a UN process (Degener 2016; Kanter 2014). The involvement of civil society extended to a Working Group established by the Ad Hoc Committee to produce the first draft of the Convention. An unusual feature of the Working Group, which met in January 2004, was that it was equally composed of States, NGOs/DPOs and National Human Rights Institutions (NHRIs).¹ The DPOs were mostly led by and composed of disabled people themselves and much of the language of the Convention, when it was finally adopted, reflected their inputs during the Working Group. Further, many State delegations included disabled people who also helped shape the dialogue. This unique way of working—affording equal status to civil society in a treaty drafting process—gave the Convention an edge it would otherwise have lacked. It built relationships of trust with States and demonstrated how the lived experience of disabled people could enrich the process of developing norms and international standards.

An emphasis on the lived experience of disability was high on the agendas of many of the DPOs. The International Disability Caucus (IDC), a coalition of over 70 world-wide, regional and national DPOs that worked together to coordinate their efforts during the Ad Hoc Committee, put forth a suggestion that the Monitoring Committee be composed entirely or of a majority of disabled people (Stein and Lord 2010; Kumpuvuori and Virtanen 2017). The suggestion was rejected by the Ad Hoc Committee, as was the proposal that the Chair of the CRPD Committee be a disabled person

¹ Membership of the Working Group included 27 States from every region of the world and six global NGOs/DPOs who had equal standing with the States in the Working Group’s deliberations. NHRIs were represented by one person nominated by the International Coordination Committee (ICC) of NHRIs; there were three in all throughout the entirety of the process (Anuradha Mohit from the Indian National Human Rights Commission, Charlotte McLain-Nhlapo of the South African Human Rights Commission and, in the latter stages, Gerard Quinn of the Irish Human Rights Commission). The NGOs/DPOs included the World Blind Union, the World Federation of the Deaf, Inclusion International, and Rehabilitation International. They were mostly led by and composed of disabled people themselves.

(Stein and Lord 2010). However, it is worth noting that the call for disabled people themselves to have significant representation and a leading role in the Convention's monitoring body has materialized. As Degener (2016) points out, in 2016 the CRPD Committee consisted of 18 independent experts who were all disabled people except for one.

As a human rights convention, the CRPD aims not only to ensure disabled people their full human rights; it also recognizes that a part of having full human rights is the right to participate in decision making with regard to one's own affairs. In fact, as Gerard Quinn (Quinn 2009) points out, one of the key changes that the CRPD brings with it is that it treats disabled people as subjects capable of making decisions regarding their own lives and not as objects to be managed or cared for. The recognition of the right to be in charge of one's own life and affairs draws on Articles 12 and 19 of the CRPD, which lay the foundation for actualizing the right to make decisions regarding one's own life and to effective inclusion in society. Article 12 emphasizes the right to legal capacity for people with disabilities "on an equal basis with others and in all areas of life." As Quinn (2010) argues, legal capacity is instrumental to the recognition of a person as a human being and of full personhood. Having legal capacity provides recognition of the right to make decisions for oneself and to enter into contracts (O'Donnell and O'Mahony 2017; Quinn 2010). Article 19 provides further support for the right to personal autonomy by recognizing the right to independent living and community inclusion as a human rights issue (Brennan et al. 2016). While the Article does not include a definition of the term "independent" (O'Donnell and O'Mahony 2017), it reflects the principles of autonomy and choice, which align with the key principles outlined in Article 3 of the Convention. These include "independence of persons", "freedom of choice", and "full and effective participation in society". In addition, the two Articles, 12 and 19, are interdependent (Committee on the Rights of Persons with Disabilities 2014a; Keys 2017; O'Donnell and O'Mahony 2017). In order to live independently, it is necessary to have the legal capacity to make decisions and enter into agreements. In turn, the right to live independently and in accordance with one's own choices provides a platform to exercise the right to legal capacity and individual autonomy. Furthermore, the rights stated in Articles 12 and 19 are fundamental for the active participation of disabled people in policy and decision making that affects them, as stated in Article 4(3). As Mary Keys points out, it is necessary to have the right to choose to be able to actualize the right to participate actively in political life at all levels, including in policymaking (Keys 2017).

The importance of full and active participation by marginalized groups in the policymaking process has been recognized by many, including Young (1990), Oliver (1990), Charlton (2000), Guldvik et al. (2013), Keys (2017) and Priestley et al. (2016). Young argues that society's structures and norms are a reflection of existing power relations, created and defined by dominant groups to maintain the status quo (Young 1990). To change their position of oppression, marginalized groups must be a part of the political structure, engage in setting the agenda and defining the issues, and redefining the concepts that relate to their lives. Without their active involvement, their position of marginalization and oppression will be maintained (Young 1990). Keys adopts a similar focus and points out that to be able to leave behind the paternalistic approach that has created and maintained the historic disadvantages that disabled people have experienced, it is necessary that they themselves participate in policymaking to change laws and policies that do not reflect their experiences (Keys 2017). This focus draws attention to Dorothy Smith's argument that recognizing lived experience as knowledge is pivotal to the ability of marginalized groups to assert themselves. Smith maintains that all knowledge is socially constructed and that people's understanding of the world is derived from how they are differently socially located (Smith 1990). However, "privileged forms of discourse [are] claimed by master narratives", meaning that the knowledge produced by some people and groups are given greater acceptance (Mann and Kelley 1997, p. 395). Smith points out that, traditionally, everyday life experiences have been undervalued as the basis for knowledge, weakening the position of marginalized groups. Recognizing knowledge that emerges from lived actualities will strengthen the knowledge claims of marginalized and oppressed people (Smith 1990). Smith's focus on the need to value

the knowledge provided by everyday lived experiences reflects the emphasis of the DPOs during the drafting of the CRPD, as well as the subsequent focus of the Convention on ensuring the full participation of both disabled people and their representative organizations in policy and lawmaking in all matters affecting them.

It is important that the participatory focus is maintained as states parties assume the task of aligning national laws with the CRPD, particularly as it pertains to the lived experience of disability. A state commits to develop and reform national laws and bring them in line with the CRPD when ratifying the Convention (Stein and Lord 2009). As of 30 September 2017, 175 countries have ratified the CRPD and are in various stages of fulfilling this obligation. This includes Iceland, which ratified the CRPD in 2016 and is in the process of finalizing draft legislation that has as its stated goal to bring Icelandic law into alignment with the Convention. This draft legislation, entitled “Laws pertaining to services for disabled people with significant support needs” (Althingi 2016–2017), is the central legislation concerned with disability issues in Iceland. In combination with other draft legislation on social services provided by local authorities in general (i.e., not specific to disabled people), it is intended to replace the existing Icelandic law on services for disabled people from 1992, the Act on the Affairs of Disabled People (No. 59/1992) (Althingi 1992). (Amendment 1055/2010 was passed in 2010, reiterating the obligation to uphold the aims of the CRPD.) The draft legislation states that the authorities shall ensure that disabled people and their representative organizations have the ability to influence policy and decision making in matters that pertain to their affairs (Article 1 of the draft legislation). This point is further reiterated in Article 4 of the draft legislation, which states that disabled people shall have the opportunity for active participation in policymaking in matters that concern them.

It is important to recognize, as Quinn points out, that adopting a legal text will not automatically translate into changes on the ground. “There is no guarantee that the new values that are embedded in the text of the Convention will be internalized and then operationalized” (Quinn 2009, p. 216). There are indeed hurdles to be cleared. As Arstein-Kerslake points out with regard to legal capacity and Article 12, not only does it require states parties to make changes to their existing legal systems; it also tests people’s ability and willingness to change their often ingrained perceptions of disabled people as lacking in decision making skills (Arstein-Kerslake 2017). Furthermore, it is important to recognize that the full and active participation of disabled people does not mean that their opinions, suggestions and comments will translate directly into law and policy outcomes. The final decision making remains in the hands of democratically elected representatives.

2. Methods

This paper draws on qualitative data from two sources: transcripts of interviews with leaders of Icelandic disabled people’s representative organizations; and comments submitted by representative organizations on the draft legislation “Laws pertaining to services for disabled people with significant support needs” (Althingi 2016–2017).

2.1. The Interviews

Eleven semi-structured in-depth interviews were conducted with leaders of nine disability groups and organizations in Iceland in 2016 and 2017. The focus of the interviews was to obtain the leaders’ perceptions and experiences of their ability to affect the changes underway aimed at implementing the CRPD in Iceland. This focus is derived from the belief that disabled people themselves are best positioned to judge whether policies aimed at delivering equality have been successful or not, a perspective adopted by Sherlaw and Hudebine (2015), as well as Disability Rights Promotion International (Samson 2015). To this end, semi-structured interviews were chosen as a method of inquiry to gain knowledge of the subjective understanding, perspectives and meaning that participants attach to the issues. They enable the interviewees to direct the discussion to what they find to be of importance and to express the meaning they attach to concepts, while at the same time allowing

the discussion to be directed toward predetermined topics in keeping with the theme of the research (Esterberg 2002; Taylor et al. 2016).

Purposeful sampling was used to identify and recruit participants as it allows researchers to select participants who have experience or particular insight and knowledge into the concepts being explored (Creswell and Plano Clark 2017). The leaders selected were of both genders. Six of the 11 leaders were women and five were men. Their ages and educational background varied. While the participants differed as to how long they had served as leaders of their organizations, they all had considerable experience in promoting disabled people's rights in various capacities, and all had spoken in public on the issue.

An effort was made to provide a balanced representation of leaders of both established disability organizations and grassroots and activist groups. The five established organizations that were a part of this study, including three large umbrella organizations, are comprised of both disabled people and non-disabled people. Their rules vary with regard to whether or not non-disabled members can serve in leadership positions or on their boards. Some of these organizations own and operate services for disabled people and are thus in some cases employers of staff and specialists, as well as being interest organizations. Six interviews were conducted with leaders of established organizations. Of these six leaders, three were disabled and three non-disabled. In addition, five interviews were conducted with leaders of activist groups; in the case of a horizontally organized group, a representative was interviewed. The activist groups referred to in this paper are all comprised of, run and directed by disabled people. All five leaders interviewed were disabled. The groups and organizations represented varied considerably with regard to how long they had been operational, ranging from less than five years to more than fifty. Membership also varied greatly, with one of the three established umbrella organizations claiming approximately 30 thousand members, with some of the activist groups having fewer than 50. This fact was not considered to be of concern as the focus of the study was predominantly on their views and experiences with regard to the ability of disability groups and organizations to participate in policy and decision making on matters of concern to disabled people.

All the interviews were conducted in Icelandic and direct quotations were translated by the first author of this paper. In addition, 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. All participants gave informed consent and agreed to have the interviews recorded. In one instance, a list of topics to be discussed was provided in advance to give room for preparations.

2.2. Comments on the Draft Legislation

Following the initial discussion by Althingi (the Icelandic Parliament) during its 146th session (2016–2017) of the draft legislation on “Laws pertaining to services for disabled people with significant support needs”, it was sent to the Althingi's Welfare Committee, which opened it for public comment. A total of 36 comments on the draft legislation were submitted by public, private and academic institutions, as well as groups, organizations, associations, local authorities and individuals. Of these, 12 were submitted by 10 different disability groups and organizations (Althingi 2017a). (Two organizations submitted two comments).

The comments submitted by disability groups and organizations differed in scope. A number of the organizations submitted comments that were primarily focused on areas specific to the interests and needs of their membership. This includes the Communication Center for the Deaf and Hearing-Impaired (Samskiptamidstöð heyrnarlausra og heyrnarskertra), which primarily focused on the draft's omission of reference to disabled deaf citizens, as Icelandic sign language is now recognized as an official language in Iceland (Althingi 2011). In the same manner, the Center for User-led Personal Assistance (CUPA) (NPA Midstöðin) focused predominantly on the need to secure the right to personal assistance, as did the Icelandic Federation of Physically Disabled People (Sjálfsbjörg) and the Association of Rehabilitated People with Spinal Cord Injuries (Samtök endurhæfðra mænuskaddadra),

for the most part. These and other comments that do not relate to the focus of the paper are not addressed in the findings.

Four of the 10 disability organizations that submitted comments on the draft legislation addressed the issue that is the focus of this paper—the active participation of disabled people and their representative organizations in policy and decision making processes on issues that concern them—but to varying degrees. The paper examines predominantly the comments of two of the organizations, the umbrella organization the Organisation of Disabled in Iceland (ODI) (Öryrkjabandalag Íslands) and the activist feminist disability group Tabu, as these two organizations made the most extensive comments relating directly to the subject of the paper. The two other organizations that touch on the issue, the umbrella organization the National Association of Intellectual Disabilities (NAID) (Landssamtökin Throskahjálp) and CUPA, did so without making it a focus area of their comments in the same manner that ODI and Tabu did.

The analysis of the data, as it pertains to the interviews and the comments submitted by the representative organizations was based on an inductive process (Creswell 2009). To analyze the data, the grounded theory method was employed. This method reflects the premise that theory can be developed from rigorous analysis of empirical data (Charmaz 2014). In keeping with this approach, the collection and analysis of data was directed by the constant comparative method of grounded theory. This method calls for data gathering to be continued while data is simultaneously coded and analyzed, and analytical memos developed, with the goal of identifying central themes to help direct further data collection and theory building (Charmaz 2014). The goal of this approach is to identify central themes while the process is ongoing to help direct further data collection and theory building (Charmaz 2014). To this end, interviews were conducted in three intervals, in December 2016, April 2017 and July 2017, until it was concluded that new information obtained had ceased to provide further insight. Initially, broad questions were posed to leaders of the representative organizations about their approaches to advancing the rights of disabled people. As the research progressed and themes began to emerge from the analysis of the interviews, the questions were narrowed. The interviews were recorded, transcribed and coded. Coding consisted of detailed reading of the transcripts followed by sorting and organization of the codes, revealing patterns in the data that helped develop a deeper understanding of the issues at hand (Creswell 2009). Based on the findings, the information relating to the theme of this study was selected and further analyzed.

3. Findings

On 17 February 2014, the Icelandic Minister of Social and Housing Affairs established a working group tasked with drafting the new legislation on services for disabled people; it completed its work in October 2016. The draft legislation (Althingi 2016–2017) opened for comments toward the end of Althingi's 146th session in the spring of 2017, was based on the group's proposal. The working group was initially comprised of 12 persons, who included the appointed representatives of Althingi, government ministries, local authorities, and several interest groups and NGOs, including two umbrella organizations representing disabled people, ODI and NAID.² Representatives of organizations representing disabled people thus made up only one-sixth of the working group, or 17%. In addition, only one of the two representatives designated by these organizations was a disabled person. This person resigned in March 2015 and was replaced by a non-disabled person. As a result, for 19 months no disabled person served on the working group.

The two umbrella organizations representing disabled people on the working group are also the two representative organizations of disabled people that have the right, according to Icelandic law, to be consulted on policy and decision making on issues affecting disabled people. It is important to note here that neither fulfills the criteria established by the CRPD Committee in its Guidelines on the

² An additional representative of the Ministry of Welfare was added at a later date.

Participation of Disabled Persons' Organizations (DPOs) and Civil Society Organizations in the work of the Committee ([Committee on the Rights of Persons with Disabilities 2014b](#)). DPOs, according to the Guidelines, are organizations that are "comprised by a majority of persons with disabilities—at least half of its membership—governed, led and directed by persons with disabilities ([Committee on the Rights of Persons with Disabilities 2014b](#)). Following the example of [Sturm et al. \(2017\)](#), this paper will henceforth use "disability organizations" (DO) as a general term when both organizations that do and do not fulfill the criteria are concerned.

The comments submitted by ODI and Tabu on the draft legislation stand out as both the most comprehensive and critical in nature. They are also the most relevant to this discussion as they make the issue that is the subject of this paper—ensuring the active involvement of disabled people and their representative organizations in policy and decision making processes on matters that concern them—a special focus of attention. Their comments provide valuable insight into how they perceive their ability to be heard by the authorities and to affect the policymaking process.

The two other representative organizations that address to some extent the issue of active involvement are NAID and CUPA. In the case of NAID, which like ODI, was part of the working group tasked with drafting the new legislation, it expresses frustration in one instance about not being heard on its objection to the omission of a requirement for a minimum number of residents living in a service area. In addition, NAID emphasizes the importance of ensuring active consultation with disabled people and their representative organizations with regard to future regulations to be set by the Ministry on the basis of the draft legislation. In a second comment, NAID stresses the need to ratify the Optional Protocol to the Convention to strengthen the ability of disabled people to pursue their rights in their interactions with the authorities. As for CUPA, it had been granted observer status in a project group established in 2011 by the Ministry of Social and Housing Affairs to lay the groundwork for the introduction of personal assistance as a legally mandated service option in the draft legislation. In its comments on the draft legislation, CUPA states that comments received from DPOs had been taken into account in the proposal submitted by the project group to the working group, which then incorporated them into the draft legislation. In other regards, the comments submitted by NAID and CUPA do not focus on the subject of this paper.

Pointing to the obligations stated in the CRPD, both ODI and Tabu strongly criticize the very limited amount of time granted to civil society for the submission of comments on the draft legislation ([Althingi 2017a](#)). "It is important to note that this way of working is very inaccessible and unprofessional, and contradicts the objectives and principles of the CRPD," states ODI. When the legislation was initially opened for comments, only 10 days were allocated to the process. The perceived rush led the DOs to comment that the lack of time devoted to the process was in contravention of the CRPD, which places an obligation on states to ensure the active participation of disabled people and their representative organizations. The Welfare Committee of Althingi, which was responsible for reviewing the draft legislation before submission for further parliamentary action, responded to the criticism at its meeting of 29 May 2017 ([Althingi 2017b](#)). It recognized its obligation pursuant to Article 4(3) of the CRPD and suggested that further parliamentary action on the draft legislation be postponed so that additional time could be given, until 7 September 2017, for comments to be submitted.

3.1. Organisation of Disabled in Iceland (ODI)—The Ability to Affect Outcomes

One of the concerns expressed by ODI is that the draft legislation does not sufficiently reflect the need to ensure the full participation of disabled people through their representative organizations in policymaking in matters pertaining to them, as stated in Article 4(3) of the CRPD. "The authorities have failed greatly in its compliance with this Article," ODI states in its comment ([Althingi 2017a](#)). Furthermore, ODI emphasizes the need to clarify that wherever the draft refers to "participation", the wording "active participation" should be used, and suggests that the law specify in certain articles collaboration with umbrella organizations. ODI cites [Kumpuvuori and Virtanen's \(2017\)](#) analysis of what constitutes full DPO participation, according to which two conditions must be met, the first being

that the participation of DPOs extend from the very beginning of the policy formulation process to the very end, and, secondly, that the opinions, perspectives and suggestions presented by DPOs are taken into account and not ignored. Keeping in mind that ODI is one of two DOs appointed to the working group that drafted the legislation and that it participated from when it was first convened until the conclusion of its work, ODI's criticism seems to be directed more toward the second point, that is a lack of meaningful participation, where the perspectives and suggestions made by the DOs are not taken into account in the policy outcome. ODI's comments on the draft legislation, which are both extensive and critical, seem to bear this out.

Among the issues raised by ODI are the need to review and rewrite a number of articles of the draft legislation to sufficiently reflect the intent of the CRPD. Furthermore, it points to the need to redefine the definition of disability contained in the draft legislation's first Article on Objectives to sufficiently reflect the CRPD's understanding of the interplay between society and impairment. "ODI respectfully suggests that a real collaboration with disabled people, their representative organizations and academic institutions take place in order to avoid inconsistency" in how disability is defined (Althingi 2017a). ODI points out that the draft neglects to sufficiently state the right of disabled parents to assistance, as stipulated in the CRPD, Article 23(2), and to a lack of understanding of the independent living ideology behind personal assistance. All in all, ODI proposes changes in one form or another to about half of the 42 articles of the draft legislation, suggesting that despite having participated in the work of the committee, its perception is that it was not sufficiently able to affect the policy outcome. ODI's overall position is summed up with the comment that if the proposed legislation becomes law, it is clear that the Icelandic state still has a considerable distance to go to achieve compliance with the CRPD (Althingi 2017a).

3.2. *Tabu—Giving a Voice to Disabled People Themselves*

In its comments, Tabu also criticizes what it maintains is a lack of meaningful involvement by disabled people and their representative organizations in the drafting of the proposed legislation. Unlike ODI's criticism, which seems to be predominantly concerned with not being able to affect policy outcomes, Tabu focuses on disabled people themselves being given a proper voice and recognized as having valuable expertise to offer.

Tabu's criticism is two-pronged. First, it criticizes the inadequate representation of disabled people and their representative organizations in the working group preparing the draft legislation, which amounted to 17% of the membership (Althingi 2017a). To rectify the problem, Tabu suggests increasing the number of representatives of disabled people. Secondly, Tabu criticizes the fact that the participation of disabled people themselves is not ensured and points out: "According to the current law on the affairs of disabled people, ODI and NAID are the only ones with the legal right to be consulted on matters pertaining to disabled people. It's clear that times have changed and it is appropriate to increase the number of seats for disabled people at the table where decisions are made," Tabu further states in its comments on the draft legislation. "ODI and NAID have made important contributions in the past decades in the fight for disabled people's rights but it is clear that it is very problematic that more often than not they send non-disabled people to the table. This is in contradiction with the CRPD." (Althingi 2017a). Tabu draws attention to the need to make a clear distinction between the two types of disabled people's organizations, those that are led by disabled people and those that are led by non-disabled people representing disabled people's interests. Or, put another way, organizations of disabled people and organizations for disabled people. This echoes the importance that the CRPD Committee attaches to this distinction, as evidenced by its Guidelines on the Participation of DPOs (Committee on the Rights of Persons with Disabilities 2014b).

In its comments, Tabu emphasizes that the expertise of disabled people when it comes to their needs and lives, based on their own lived experience, must be effectively harnessed in policy and decision making. To this end, Tabu offers its expertise, in addition to identifying two other activist groups comprised of and led by disabled people themselves, CUPA and the Self-Advocacy Group

of People with Intellectual Disabilities (Átak—Félag fólks med throskahömlun), and calls for all three to be given consultative status on issues pertaining to disabled people's affairs on an equal footing with the two umbrella organizations stating that, "All these groups are led by disabled people and our contribution, knowledge and experience are a necessary addition to working groups, committees and other policymaking that concerns disabled people." (Althingi 2017a). In addition, Tabu emphasizes the CRPD's call to also include the participation of disabled children and youth. The increase in representation suggested by Tabu would have raised the percentage of disabled people and their representatives to about 30% of the working group's membership, which, for the purposes of comparison, is closer to what Sherlaw and Hudebine (2015) report being the case in France, for example. Furthermore, it would have ensured the inclusion of at least three disabled people. Tabu maintains that such a change would not only lead to a better work product, drawing on the expertise and lived reality of disabled people themselves, but also serve to empower disabled people by giving them an opportunity to serve in such a capacity. Tabu points out how challenging it is for a single disabled person to be put in a position of having to face a committee comprised almost exclusively of non-disabled people, many of whom represent the interests of the authorities.

3.3. Interviews with Leaders—Pro Forma Consultations

The experience of not being "heard" by the authorities and not being able to affect policy outcomes, is supported by the findings of the in-depth interviews that this paper draws on. While the leaders of the established organizations focus primarily on advancing the rights of disabled people through collaboration with authorities, they shared with the activist groups interviewed the experience of having difficulty at times being heard by the authorities in the sense that their comments and suggestions were either not taken into account in the formulation of policy or in other ways acted upon. A lack of funds was frequently cited as a reason for inaction. "You experience an incredible reluctance," said a leader of an established organization. Another commented: "And of course, we always get the same answer. It doesn't matter what issue category you ask about, it's always just money." Reflecting on the collaboration with the authorities, one of the leaders stated "sometimes it feels to me as if it's pro forma. They have to include us. And then it's like decisions have already been made at some kind of pre-meeting, where you have the feeling that all the decisions have been made in advance." A leader also mentioned having to remain vigilant about ensuring that the comments made by DO representatives were included in minutes of the meetings. A leader of an activist group recounted similar experiences and reported feeling that other meeting participants were sometimes either not interested in what he had to say or just ignored his comments.

The issues highlighted by Tabu also find support in the in-depth interviews with leaders of other activist groups. They reveal feelings of frustration over not being given due access to decision making bodies. "We are the ones who have experienced disability on our own skin. Without this experience, it is really impossible for people to fully understand," stated a leader of an activist group. Another leader expressed a similar sentiment, "If you're not disabled, you don't have the experience to draw from. You can't imagine what being disabled is like, no matter how hard you try." A third said "Nobody can properly see things with our eyes." All the leaders expressed the importance of ensuring that disabled people themselves have a leading voice in matters that concern them. Similar to Tabu's comment on the draft legislation, the activist leaders also pointed to the need for the authorities to make more of a distinction between DPOs for disabled people and DPOs of disabled people. "These old organizations have been around for so long," said one leader. "Sometimes you get the feeling that they're protecting the rights of their staff or the interests of some system. Maybe it's a bit difficult to sit on both sides of the negotiating table," said one leader referring to the fact that some of the established organizations own and operate services for disabled people.

The activist leaders also reported a lack of responsiveness on the part of the authorities and a feeling of being ignored at times when trying to speak up for disabled people's interests. "Sometimes we feel that because we are critical of the system, we are not popular with the authorities and they want

to minimize their engagement with us,” stated a leader of an activist group. The leaders described how they sought to counter this apathy and to gain recognition of disabled people as experts in their own affairs and as leaders in the fight to secure full rights, a role that has traditionally been occupied exclusively by others. The means they employed were intended to establish disabled people themselves as the ones on the front lines, speaking up, taking to the streets in demonstration, delivering declarations to the authorities, taking the initiative of drafting proposed legislation for submission to the authorities, and writing and publishing first-person accounts of the lived realities of disabled people (Löve et al. 2017).

3.4. *The Active Participation of Disabled People*

The data gathered indicates that there is less focus on ensuring the participation of disabled people, and thereby the lived experience of disability, among both the established DOs and the authorities, compared to activist groups made up of and run by disabled people themselves.

The draft legislation under consideration in Iceland does not include a reference to the criteria contained in the guidelines issued by the CRPD Committee on what constitutes a DPO, and therefore seems to lack the emphasis embodied in the CRPD on ensuring the inclusion of the lived experience of disability in decision making. While the draft legislation stipulates, in Chapter 1 on Objectives and Definitions (Article 1) and Chapter 2 on Governance and Organization (Article 4), that disabled people shall have the opportunity to actively participate in policy and decision making that relate to their affairs, other articles refer to consultations with representative organizations without specifying how such organizations should be defined (Althingi 2016–2017). In Althingi’s first discussion (and only one to date) of the draft legislation, on 2 May 2017, one member of Althingi raised the need to clarify how disabled people and service users would be able to convey their views on matters that affect them. “This whole regulatory framework is rather confusing,” she noted, “and points to a lack of a coordinated strategy as to how consultations with users, representative organizations and others will be managed”. Changes to the decision making process were otherwise not mentioned and there was no discussion of the need to increase DPO representation, as defined by the CRPD Committee. Nor did the Minister address the issue in his response to questions.

While being critical of the process, ODI does not raise the need to increase the number of DOs with the right to participation on matters pertaining to disability issues, nor does it mention the need to ensure the inclusion of disabled representatives. ODI does suggest the addition of a sentence to a number of articles of the draft legislation stating the obligation to engage in active collaboration with umbrella organizations, thereby excluding the grassroots and activist groups. There is only one reference to the need to include disabled people themselves, in ODI’s comments on Article 9 on housing where it suggests adding a reference to active collaboration with disabled people and their umbrella organizations, while again excluding reference to other types of organizations (Althingi 2017a).

Finally, as stated earlier, the Welfare Committee of Althingi, in its meeting of 29 May 2017, responded to the comments it had received at that time. While suggesting an extension of the time provided for submission of comments and that consideration of the draft legislation be delayed until Althingi’s fall session of 2017, the Committee did not suggest accommodating changes that would either increase DOs representation in general or ensure the participation of disabled people themselves. Furthermore, nor did it in general respond to other comments and criticism concerning the need to ensure the active participation of disabled people and their representative organizations.

4. Discussion

The drafting process initiated by the Icelandic authorities, intended to align Icelandic disability law with the CRPD, was criticized by both ODI and Tabu as inadequate in terms of ensuring the full participation of disabled people and their representative organizations in setting laws and policies pertaining to their rights and matters that concern them. Referring to Article 4(3), ODI stated that “[t]he authorities have failed greatly in its compliance with this article” (Althingi 2017a). However, the two

DOs criticize the process from different perspectives. ODI, which was involved in the drafting process from start to finish, is critical of the policy outcome and submits extensive and critical comments on the draft legislation. In its comments, ODI calls attention to the fact that having representation doesn't ensure a DO's ability to impact outcomes if its suggestions and opinions are ignored. The experience of not being able to affect decision making, even when participating in the decision making process, is not unique to ODI or the leaders of the Icelandic DOs interviewed. A study carried out in nine European countries on the ability of organizations representing disabled persons to affect the implementation of the CRPD on a national level found mixed results, with some organizations reporting having difficulty affecting policy outcomes despite being represented in the process (Waldschmidt et al. 2017). Other international research—including in Italy (Biggeri et al. 2011); Bulgaria (Mladenov 2009); Canada, the U.S. and the U.K. (Levesque and Langford 2016); and Africa (Lang et al. 2011)—has also pointed to mixed results with regard to the ability of DOs to affect policy and have concluded that both structural and attitude changes are needed, as well as ensuring sufficient resources and capacity building among disabled people and DOs, to effectively participate in policymaking processes. There is, however, as stated earlier, a need to differentiate between, on the one hand, the right to full and active participation in the policymaking process on equal footing with others, and, on the other, the demand that one's opinions, perceptions and suggestions be included in the policy outcome. Such a demand, which this paper does not make, can be seen as running counter to the principles of representative democracy, which allocate the ultimate policymaking power to elected representatives.

While ODI focuses on its impact on the policy outcome, Tabu and the other activist groups focus predominantly on the lack of recognition of the need for disabled people themselves to be a part of the policymaking process. As the composition of the working group bears out, DOs had very limited representation during the drafting of the legislation. In addition, for more than a year-and-a-half (19 months), the working group did not have any disabled persons among its members. Moreover, no representative organizations made up of, run and directed by disabled people—the criteria established by the CRPD Committee—were represented in the working group. This lack of significant participation is in stark contrast to the prominent focus on the participation of DPOs and disabled people themselves during the drafting of the CRPD, an emphasis that became embedded into the Convention, and is reflected in its recognition of the lived experience of disability and that the persons most affected have the right to participate in decisions that impact them (Stein and Lord 2010).

The two other DOs that comment on participation in decision making, NAID and CUPA, are less critical in their comments, with CUPA expressing a positive experience in the project group that worked on articles of the draft legislation pertaining to personal assistance. Like ODI, NAID has a seat at the table in the established policymaking process and may, therefore, have less of a reason than those not included to suggest changes to it. Moreover, as the interviews reveal, the leaders of the established organizations express a commitment to working within the established process. This may also apply to the other established organizations that did not address the issue of participation in their comments on the draft legislation. CUPA, for its part, has succeeded in gaining partial access to the process on the one issue that dominates its agenda, personal assistance, and that may explain why—when it comes to this matter—it does not specifically address the need for change. As for the activist groups, which do not have access to the process as it is currently constructed, one can speculate that they may feel that the process is so closed and the barriers to entry so high that they do not feel sufficiently empowered to demand access. As Sherlaw and Hudebine point out, all participatory processes involve tension. “Participation of the vulnerable and needy often involves institutions and persons giving up a degree of power, which is no easy option, and is often unwelcome and strenuously resisted” (Sherlaw and Hudebine 2015, p. 15). Changing the status quo requires a radical approach. Tabu has challenged the status quo by demanding entrance, possibly leading the way for others.

The importance of the participation of disabled people in policy and decision making is emphasized by Young and Keys, who point out that without disabled people's active contribution and involvement in setting the political agenda, defining the issues that relate to their lives from their

own perspectives and needs, their marginalization will be maintained, leaving in place laws that have created and maintain their historical disadvantage (Keys 2017; Young 1990). The work of the Icelandic activist groups, and Tabu's comments on the draft legislation, reflect Young's and Keys's positions. Furthermore, they embrace Smith's position on the validation of everyday lived experience as knowledge. This understanding is also echoed in the responses by the leaders of the activist groups interviewed; they assert that only with the lived experience of disability can one fully comprehend "what it is really like", underlining the importance of disabled people themselves having a leading voice in matters that concern them.

The Icelandic activist groups have set out to change the perception of disabled people as lacking the capacity to be in charge of their own affairs, and to introduce and gain recognition of this position in the political arena. However, as the draft legislation and the response of the Welfare Committee to the comments received show, their efforts seem to have made limited inroads with the authorities and the established disability organizations.

The draft legislation makes no reference to establishing the participation of DPOs as defined by the CRPD Committee in its guideline for DPOs, which would ensure recognition of the lived experience of disability and pave the way for changes to the process norms with regard to how disability policy is made. This is of particular concern as ODI and NAID, the two representative organizations that have the right to consultative status on disability issues according to Icelandic law, and which therefore represent the interests of disabled people in shaping policy and legislation, fail to meet the CRPD Committee's criteria for DPOs (Committee on the Rights of Persons with Disabilities 2014b).

Furthermore, it is of interest that while ODI, for its part, emphasizes the need to ensure full and effective participation, it does not suggest increasing the number of representative organizations that have consultative status in order to strengthen and embolden the voice of the disability community, nor does it suggest that disabled people themselves be ensured representation. Further, ODI appears to actively distance itself from organizations by disabled people by stating in its comments on the draft legislation that "consultation with umbrella organizations for disabled people", to the exclusion of other types of disability organizations, should be specified in three articles of the draft legislation (Althingi 2017a).

The Welfare Committee, which makes suggestions on changes to draft legislation during the legislative process, before Althingi votes on it, did not in its meeting of 29 May 2017 address Tabu's request to increase the overall representation of DOs on matters pertaining to disability, or the request to ensure the participation of disabled representatives. To date, the Committee appears to have paid little attention to calls for increased and effective participation by disabled people and their representative organizations, apart from its decision to extend the time for submitting comments from the initial ten days to over three months. In that instance, the Committee stated that its decision to do so was in recognition of its obligations under Article 4(3) of the CRPD (Althingi 2017b).

As far as the process of aligning Icelandic disability law with the CRPD is concerned, there seems to be a reluctance to fully embrace the fundamental principle reflected in the CRPD, that the persons most affected have the right to participate in decisions that impact them (Stein and Lord 2010). The CRPD's call for new process norms with regard to how disability policy is made seems to require more changes to the current consultation process than the Icelandic authorities are prepared to initiate. This is particularly the case with regard to making a distinction between the two types of representative organizations, ensuring the participation of disabled people themselves, and recognizing the value of their contribution and their expertise based on their everyday lived experience of disability.

This draws attention to Quinn's point that there is no guarantee that by setting laws, new values will be internalized (Quinn 2009, p. 216). The lack of confidence in the ability of disabled people to be in charge of their own affairs is deeply rooted. Throughout history, disabled people have been identified as different, kept at the margins of society and perceived as having little to contribute (Braddock and Parish 2001). Their status as non-producers and dependents led, in great part, to their

segregation and marginalization, and robbed them of the opportunity to participate as citizens and exercise full civic and political rights (Snyder and Mitchell 2006).

Article 4(3) sets out to create a new politics of disability. It calls for changes to the process norms with regard to how disability policy is made. In the past, disabled people were commonly excluded from the process of policymaking on matters that pertained to them, reflecting the position of the medical model on disability, which views disabled people as having to be taken care of and managed by others. The result has been laws that have mostly fallen short by curbing the rights of disabled people and their quality of life. By expanding the policymaking process as Article 4(3) of the CRPD does, to include disabled people through their representative organizations, it enables a new politics of disability to emerge. The laws and policies produced as a result are likely to better serve and reflect the needs and perspectives of disabled people themselves. However, in order to live fully up to the intent of the CRPD and its emphasis on incorporating the lived experience of disability, it is important that States Parties adopt the CRPD Committee's criteria as to what constitutes a disabled people's representative organization, namely that they are governed, led and directed by persons with disabilities.

It is important to recall that the full and active participation of disabled people should not be taken to mean that their opinions, suggestions and comments will automatically translate into law and policy outcomes. Rather, the new politics of disability bring disabled people and their representative organizations 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. Thus, Article 4(3) should be seen to describe a process whereby social policy is co-produced.

5. Conclusions

The findings indicate that the new draft legislation on disability services in Iceland does not sufficiently embody the Convention's call for changes to the process norms with regard to how disability policy is made. The new process calls for the active involvement of disabled people through their representative organizations, as defined by the CRPD Committee in its guidelines on DPOs, that are led and directed by disabled people. The criteria established by the Committee are aimed at ensuring that the lived experience of disability is incorporated into the policymaking process. It seems that this priority is not given due attention in the draft legislation, which makes no reference to the need for changes to the current process to ensure that the lived experience of disability is brought to bear in policy and decision making. The limited representation of DPOs, and the fact that those represented do not meet the CRPD Committee's criteria for what constitutes a DPO, is a cause for concern. It seems to contradict the fundamental principle embodied in the CRPD that those most affected have the right to participate in decisions that impact them. Accepting disabled people as full participants with valuable knowledge and expertise means letting go of ingrained perceptions of disabled people as lacking in capacity for decision making and management of their own affairs. With this in mind, it is important to recognize that the call for a new politics of disability embodied in Article 4(3) of the CRPD provides a path forward toward the co-production of social policy with the active and effective contribution of civil society. The need to fully take into consideration the CRPD Committee's criteria for how to define DPOs in the context of the CRPD may be of relevance to other States Parties as they align their national legislation with the Convention as part of the ratification process. Furthermore, the co-production of social policy described above may have a wider application, not exclusive to the case of disability policy but to social policy making in general.

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References

- Althingi. 1992. *Lög um Málefni Fatlads Fólks (The Act on the Affairs of Disabled People)*. Law No. 59/1992; Reykjavik: Althingi.
- Althingi. 2011. *Lög um Stöðu Íslenskrar Tungu og Íslensks Táknmáls (Law on the Status of the Icelandic Language and Icelandic Sign Language)*. Law No. 61/2011; Reykjavik: Althingi, Available online: <https://www.althingi.is/lagas/nuna/2011061.html> (accessed on 18 September 2017).
- Althingi. 2016–2017. *Frumvarp til Laga um Thjónustu við Fatlad Fólk Med Miklar Studningstharfir (Draft Legislation Pertaining to Services for Disabled People with Significant Support Needs)*. Parliamentary Document No. 571-438; Reykjavik: Althingi.
- Althingi. 2017a. Welfare Committee: Comments by Representative Organizations of Disabled People on Draft Legislation Pertaining to Services for Disabled People with Significant Support Needs. Available online: http://www.althingi.is/pdf/erindi_mals/?lthing=146&malnr=438 (accessed on 6 October 2017).
- Althingi. 2017b. Summary of the 42, Meeting of The Welfare Committee Held on 29 May 2017. Available online: <https://www.althingi.is/thingnefndir/fastanefndir/velferdarnefnd/fundargerdir/faerslunr=8925> (accessed on 8 August 2017).
- Arstein-Kerslake, Anna. 2017. Legal Capacity and Supported Decision-Making: Respecting Rights and Empowering People. In *Disability Law and Policy: An Analysis of the UN Convention*. Edited by Charles O'Mahony and Gerard Quinn. Dublin: Clarus Press.
- Biggeri, Mario, Nicolò Bellanca, Sara Bonfanti, and Lapo Tanzj. 2011. Rethinking policies for persons with disabilities through the capability approach: The case of the Tuscany Region. *Alter, European Journal of Disability Research* 5: 177–91. [CrossRef]
- Braddock, David L., and Susan L. Parish. 2001. An Institutional History of Disability. In *Handbook of Disability Studies*. Edited by Gary L. Albrecht, Katherine D. Seelman and Michael Bury. Thousand Oaks: Sage Publications.
- Brennan, Ciara, Rannveig Traustadóttir, Peter Anderberg, and James Rice. 2016. Are Cutbacks to Personal Assistance Violating Sweden's Obligations under the UN Convention on the Rights of Persons with Disabilities? *Laws* 5: 23. [CrossRef]
- Charlton, James I. 2000. *Nothing about Us without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.
- Charmaz, Kathy. 2014. *Constructing Grounded Theory*, 2nd ed. Los Angeles: Sage.
- Committee on the Rights of Persons with Disabilities. 2014a. *General Comment No. 1 (2014). Article 12: Equal Recognition before the Law*. CRPD/C/GC/1; Geneva: CRPD.
- Committee on the Rights of Persons with Disabilities. 2014b. *Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the Work of the Committee*. CRPD/C/11/2, Annex II; Available online: <https://goo.gl/7bqnCW> (accessed on 5 August 2017).
- Creswell, John W. 2009. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, 3rd ed. Thousand Oaks: Sage.
- Creswell, John W., and Vicki L. Plano Clark. 2017. *Designing and Conducting Mixed Methods Research*, 3rd ed. New York: SAGE Publications.
- Degener, Theresia. 2016. Disability in a Human Rights Context. *Laws* 5: 35. [CrossRef]
- Esterberg, Kristin G. 2002. *Qualitative Methods in Social Research*. Boston: McGraw Hill.
- Guldvik, Ingrid, Ole P. Askheim, and Vegard Johansen. 2013. Political citizenship and local political participation for disabled people. *Citizenship Studies* 17: 76–91. [CrossRef]
- Kanter, Arlene S. 2014. *The Development of Disability Rights Under International Law: From Charity to Human Rights*. New York: Routledge Press.
- Keys, Mary. 2017. Article 12 of the UN Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights. In *Disability Law and Policy: An Analysis of the UN Convention*. Edited by Charles O'Mahony and Gerard Quinn. Dublin: Clarus Press.
- Kumpuvuori, Jukka, and Riku Virtanen. 2017. Are we right or are we right?: 'Right approach' in the advocacy work of organization of persons with disabilities. In *Disability Law and Policy: An Analysis of the UN Convention*. Edited by Charles O'Mahony and Gerard Quinn. Dublin: Clarus Press.

- Lang, Raymond, Maria Kett, Nora Groce, and Jean-Francois Trani. 2011. Implementing the United Nations Convention on the rights of persons with disabilities: Principles, implications, practice and limitations. *Alter, European Journal of Disability Research* 5: 206–20. [\[CrossRef\]](#)
- Levesque, Mario, and Brynne Langford. 2016. The role of disability groups in the development and implementation of the UN Convention on the Rights of Persons with Disabilities. *Canadian Journal of Disability Studies* 5: 62–102. [\[CrossRef\]](#)
- Löve, Laufey, Rannveig Traustadóttir, and James Rice. 2017. Achieving Disability Equality: Empowering Disabled People to Take the Lead (under review). *Social Inclusion, Special Issue on Disability Equality*. Forthcoming.
- Mann, Susan A., and Lori R. Kelley. 1997. Standing at the Crossroads of Modernist Thought: Collins, Smith, and the New Feminist Epistemologies. *Gender and Society* 11: 391–408. [\[CrossRef\]](#)
- Meyers, Stephen. 2016. NGO-Ization and Human Rights Law: The CRPD's Civil Society Mandate. *Laws* 5: 21. [\[CrossRef\]](#)
- Mladenov, Teodor. 2009. Institutional woes of participation: Bulgarian disabled people's organisations and policy-making. *Disability & Society* 24: 33–45.
- O'Donnell, Sinead, and Charles O'Mahony. 2017. The UN Convention on the Rights of Persons with Disabilities: Exploring the synergy between Article 12 and Article 19. In *Disability Law and Policy: An Analysis of the UN Convention*. Edited by Charles O'Mahony and Gerard Quinn. Dublin: Clarus Press.
- Oliver, Michael. 1990. *The Politics of Disablement: Critical Texts in Social Work and the Welfare State*. London: Macmillan.
- Priestley, Mark, Martha Stickings, Ema Loja, Stefanos Grammeons, Anna Lawson, Lisa Waddington, and Bjarney Fridriksdóttir. 2016. The political participation of disabled people in Europe: Rights, accessibility and activism. *Electoral Studies* 42: 1–9. [\[CrossRef\]](#)
- Quinn, Gerard. 2009. Resisting the 'Temptation of Elegance': Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour? In *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*. Edited by Oddný Mjöll Arnardóttir and Gerard Quinn. Leiden: Martinus Nijhoff Publishers.
- Quinn, Gerard. 2010. Personhood & legal capacity: Perspectives on the paradigm shift of Article 12 CRPD. Paper presented at the HPOD Conference, Harvard Law School, Boston, MA, USA, February 20.
- Sabatello, Maya. 2014. A short history of the international disability rights movement. In *Human Rights & Disability Advocacy*. Edited by Maya Sabatello and Marianne Schulze. Philadelphia: University of Pennsylvania Press.
- Samson, R. M. 2015. Securing the full participation of persons with disabilities and their representative organizations in disability rights monitoring. In *Rights Monitoring, and Social Change: Building Power out of Evidence*. Edited by Marcia H. Rioux, Paula C. Pinto and Gillian Parech. Toronto: Canadian Scholars' Press.
- Sherlaw, William, and Hervé Hudebine. 2015. The United Nations Convention on the Rights of Persons with Disabilities: Opportunities and tensions within the social inclusion and participation of persons with disabilities. *ALTER, European Journal of Disability Research* 9: 9–21. [\[CrossRef\]](#)
- Smith, Dorothy E. 1990. *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. Boston: Northeastern University Press.
- Snyder, Sharon L., and David T. Mitchell. 2006. *Cultural Locations of Disability*. Chicago: The University of Chicago Press.
- Stein, Michael A., and Janet E. Lord. 2009. Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities. In *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*. Edited by Oddný Mjöll Arnardóttir and Gerard Quinn. Leiden: Martinus Nijhoff Publisher.
- Stein, Michael A., and Janet E. Lord. 2010. Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, lost opportunities, and future potential. *Human Rights Quarterly* 32: 689–728. [\[CrossRef\]](#)
- Sturm, Andreas, Anne Waldschmidt, Anemari Karacic, and Timo Dins. 2017. Exercising influence at the European level: Political opportunity structures for disability rights advocacy and the impact of the UN CRPD. In *The Changing Disability Policy System: Active Citizenship and Disability in Europe Volume 1*. Edited by Rune Halvorsen, Bjorn Hvinden, Jerome Bickenback, Delia Ferri and Ana Marti Guillén Rodriquez. New York: Routledge.
- Taylor, Steven J., Robert Bogdan, and Marjorie L. DeVault. 2016. *Introduction to Qualitative Research Methods: A Guidebook and Resource*, 4th ed. New York: John Wiley & Sons.

- United Nations. 2007. *The Convention on the Rights of Persons with Disabilities and Optional Protocol*. New York: United Nations.
- Waldschmidt, Anne, Andreas Sturm, Anemari Karacic, and Timo Dins. 2017. Implementing the UN CRPD in European countries: A comparative study on the involvement of organisations representing persons with disabilities. In *The Changing Disability Policy System: Active Citizenship and Disability in Europe Volume 1*. Edited by Rune Halvorsen, Bjorn Hvinden, Jerome Bickenback, Delia Ferri and Ana Marti Guillén Rodriquez. New York: Routledge.
- Young, Iris M. 1990. *Justice and the Politics of Difference*. Princeton: Princeton University Press.



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