

Article

Exclusion to Inclusion: Lived Experience of Intellectual Disabilities in National Reporting on the CRPD

Laufey Elísabet Löve

Department of Education and Diversity, University of Iceland, Iceland; lel@hi.is

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Abstract

This article critically examines the application of an innovative project aimed at developing a mechanism for people with intellectual disabilities to provide input to the Icelandic government's report on its implementation of the Convention on the Rights of Persons With Disabilities (CRPD). The project was undertaken to comply with the CRPD's obligation to ensure the participation of disabled people in the review process and to respond to the recognized need for changes to consultation processes to accommodate the needs of people with intellectual disabilities. The project was successful in producing its intended outcome, to facilitate meaningful input by people with intellectual disabilities to the national review process. However, the research reveals that effective use of the outcome report by the authorities, which had both funded the project and praised its work, was lacking. These findings draw attention to the need to address unspoken norms and biases, and to take assertive steps to institutionalize a more structured and transparent process of co-creation to ensure that the voices of marginalized groups are in fact heard and effectively taken into account in outcome processes. The research this article draws on is qualitative, comprised of data gathered through document analysis, as well as in-depth interviews with representatives of disabled people's organizations and the authorities.

Keywords

Convention on the Rights of Persons With Disabilities; effective participation; inclusion; intellectual disabilities; marginalization

Issue

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1. Introduction

The right to make decisions in one's own life is regarded as an inherent human right and is perceived by most people as so self-evident that the fact that it is not stated as such by the Universal Declaration of Human Rights (1948) rarely draws much concern. It is, therefore, eye-opening to realize that this right is truly at the heart of the Convention on the Rights of Persons With Disabilities (CRPD; United Nations, 2006) and its aim to uproot what has been the accepted and mostly unquestioned norm, that decisions be taken on behalf of disabled people by third parties (Quinn, 2010). It is a practice that has served to disempower and marginalize disabled people and that the CRPD aims to reverse.

The CRPD approaches the right to decision-making regarding one's own affairs from different angles. It establishes the right to legal capacity in article 12 and the right to independent living as a human right in Article 19 (Brennan et al., 2016). In article 4.3, it obligates States Parties to the Convention to ensure the participation of disabled people, including children with disabilities, through their representative organizations, in the development of laws and policies that affect them. Finally, article 33.3 states the right of disabled people and disabled people's organizations (DPOs) to take part in the CRPD's monitoring process as States Parties report to the Committee on the Rights of Persons With Disabilities (also referred to here as the CRPD Committee or simply the Committee) on measures taken and progress made in

its implementation. States Parties are required to submit an initial report to this committee two years after ratification and then every four years (article 35). Considering the focus of this article, it is important to note that the participation process called for in articles 4.3 and 33.3 should be broadly interpreted and calls for the representation of the great diversity that exists among disabled people as a group, including the diverse forms of impairment (Committee on the Rights of Persons With Disabilities, 2018; Löve et al., 2019).

While the right to participate in public and political life is firmly rooted in human rights law and international agreements, disabled people and DPOs have traditionally been excluded from decision-making mechanisms and are rarely consulted concerning the development and implementation of decisions that affect their lives (Committee on the Rights of Persons With Disabilities, 2018; McVeigh et al., 2021). Even when States Parties to the CRPD have incorporated obligatory consultations with DPOs, it often remains unclear whether such measures do, in fact, enable them to affect policy outcomes as intended (Löve et al., 2018; Sherlaw & Hudebine, 2015). Research shows that DPOs continue to report experiencing difficulties in being heard and resistance to their efforts to affect policy (Committee on the Rights of Persons With Disabilities, 2018; Kumpuvuori & Virtanen, 2017; Löve et al., 2017; Waldschmidt et al., 2017). In this regard, the Committee draws attention to the need to bridge the observed gap between the “goals and the spirit of articles 4(3) and 33(3) and the degree to which they have been implemented” (Committee on the Rights of Persons With Disabilities, 2018, para. 8), pointing out that this gap is in part due to the lack of meaningful consultation and co-production with disabled people, drawing on their lived experience and knowledge of the rights to be implemented. To this end, the Committee emphasizes the need to ensure that the views of persons with disabilities be given due weight in the process and “not only heard as a mere formality or as a tokenistic approach to consultation” (Committee on the Rights of Persons With Disabilities, 2018, para. 48). It calls for the results of consultations to be taken into account and reflected in the decisions adopted. What is being called for is not only that States Parties make changes to their existing legal systems but also recognition of the fact that effecting change will test people’s ability and willingness to change their often ingrained perceptions of disabled people as lacking in decision-making skills (Arstein-Kerslake, 2017). This is particularly relevant in the case of people with intellectual disabilities, who as a group are rarely viewed as fully valued contributors and whose incompetence to participate in decision-making is often assumed (Petri et al., 2017).

When claiming the right to effective participation in the decision-making of people with disabilities through their DPOs, it is important to recognize that hierarchies exist within disability movements themselves (Piepzna-Samarasinha, 2019), where ranking is often

based on the type or circumstance of impairment. People with intellectual or psychosocial disabilities are often the ones on the lowest rungs of the hierarchy and, thus, in a marginalized position within these movements (Deal, 2003; Szmukler et al., 2014). People with intellectual disabilities, therefore, often wield little power within DPOs and their voices are overlooked. Stratification within DPOs can thus further exacerbate the exclusion of people with intellectual disabilities from participation. As Petri et al. (2017) point out in their research on the CRPD review process:

While implementation reports are usually developed by disabled people’s organisations (DPOs) or human rights groups or state bodies, people with intellectual disabilities and autistic people almost never take a leading role in drafting such reports, let alone participate in drafting them.

The result is diminished opportunity to effectively express concerns and interests specific to their lives and circumstances. This is particularly concerning considering that people with intellectual disabilities are frequent users of services and support systems and have experienced disproportional rights abuses, and therefore have a significant stake in the matter.

These factors highlight the need to embed specific strategies and accommodations to ensure that people with intellectual disabilities are able to fully participate and that their lived experience is recognized and incorporated as knowledge in policy making. It is, therefore, of interest to examine, as this research does, to what extent the outcome of a project funded by the Icelandic Ministry of Social Affairs, to ensure that the views of people with intellectual disabilities were included in Iceland’s first national report to the CRPD Committee in 2021, following the country’s ratification of the CRPD in 2016, succeeded in its intended purpose. Or, are further changes in line with the guidance provided by the CRPD Committee needed to uproot ingrown biases that prevent the contributions of people with intellectual disabilities from being effectively incorporated into the monitoring process? The monitoring process aims to bring national law and policy in line with the CRPD through an open and inclusive dialogue where the views of all parties are heard and taken into consideration (Office of the High Commissioner for Human Rights, 2006; Quinn, 2009).

A body of research exists that has focused on the right of participation in policymaking and implementation from the perspective of DPOs, including Kumpuvuori and Virtanen (2017), who provide an analysis of what constitutes full and effective consultations, as called for by the CRPD; Sherlaw and Hudebine (2015), who focus on the issue from the French perspective, drawing attention to the lack of assurances that the voices of disabled people will be heard and taken into account; Levesque and Langford (2016), Lang et al. (2011), and McVeigh et al. (2021), who all focus on the issue from different

national perspectives. However, to date, there is limited research that focuses specifically on the active participation of people with intellectual disabilities in consultation processes concerning implementation and policy development, as called for by the CRPD in articles 4.3 and 33.3 (Petri et al., 2017). Studies focusing on people with intellectual disabilities and implementation of the CRPD have instead primarily focused on specific rights, drawing on quality of life indicators (Gómez et al., 2020). These include Verdugo et al. (2012), Houseworth et al. (2019), Lombardi et al. (2019), Fisher et al. (2015), and Sheridan et al. (2019).

The aim of the project funded by the Icelandic Ministry of Social Affairs (hereafter referred to as the Fjölmennt project) was to support the participation of people with intellectual disabilities as part of the CRPD national reporting mechanism. The project was to deliver an outcome document that would reflect the voices and suggestions of people with intellectual disabilities on the implementation of the CRPD for inclusion in the national report.

The project represented the first time Iceland had taken direct steps to embed the voices of people with intellectual disabilities in a national implementation report to a human rights monitoring body. Furthermore, the project was innovative as its design was directed by the participants themselves and they also had final approval of the drafting of the outcome report. This approach differs from most inclusive research aimed at engaging the views and opinions of people with intellectual disabilities on particular issues and rights contained within the CRPD, which have primarily drawn on the use of focus groups, structured interviews and workshops (Garcia et al., 2014; Salmon et al., 2019).

Funding for the project was directed to NAPID—Iceland's National Association of People With Intellectual Disabilities (Proskahjálpi), the DPO that proposed the project to the Ministry of Social Affairs and contracted Fjölmennt adult education center to assist in developing the project design and overseeing its implementation. The project produced an outcome report entitled *What is the Experience of Disabled People? A Collaborative Project by Effort and The Ambassadors; Report on the Implementation of the Convention on the Rights of Persons With Disabilities by Iceland* (Fjölmennt, 2019).

This article commences by introducing the research's theoretical foundations, which focus on the need to question taken-for-granted norms, structures, processes, and ingrained biases in order to change power relations regarding decision-making. Furthermore, the article draws attention to the concept of accommodations to support the effective participation of marginalized groups and, thus, their access to the means to change existing norms. The article continues by discussing the methodology used in the research, including a description of Fjölmennt's project design. The findings present the outcomes of the document analysis and in-depth interviews, followed by a discussion and analysis of

the findings in the context of the research's theoretical approach and other research in this area.

2. Theoretical Approach

Critical theory and the critical theory approach—the origins of which can be traced to the work of a group of radical philosophers, economists, and sociologists better known as the Frankfurt School, which included Adorno, Horkheimer, and Marcuse (Kellner, 1989, 1993; Meekosha & Shuttleworth, 2009)—emphasizes that accepting existing norms, structures, and procedures serves to reinforce established power relations and, thus, also the marginalization of those deemed different and falling outside of the accepted norm. The dominance of the accepted norm also helps explain how procedures and practices throughout modern institutions have limited the autonomy of some groups more than others and their questioning of the status quo (Foucault, 2000). Fundamental to critical theory is the questioning of existing power dynamics and the need to expose and unveil them (Kellner, 1993; Meekosha & Shuttleworth, 2009). Furthermore, critical theory identifies where change to dominant power balances will come from, arguing that it is dependent on those who are perceived as falling outside the norm obtaining the power and position to restate the underlying and often unquestioned norms (Minow, 1990; Young, 1990). To initiate change, it is, therefore, necessary to secure the actual and effective participation of marginalized groups within the democratic decision-making process as active participants in setting the agenda, defining the issues, and redefining the concepts that relate to their lives (Young, 1990). The focus on the importance of full and active participation by marginalized groups in the policymaking process has been emphasized by scholars that include Charlton (1998), Keys (2017), Oliver (1990), and Priestley et al. (2016).

The principle laid out by the CRPD in article 4.3., stating the right of disabled people to participate through their representative DPOs in decision-making in matters that concern them, reflects critical theory's emphasis on the need to secure the right of marginalized groups to participate in political decision-making processes. It recognizes that change must come from the participation of those who have been marginalized by the existing status quo. The CRPD refuses to accept what has been the unquestioned norm of who is involved in making disability policy, a stance further clarified by the CRPD Committee, which has emphasized that this right needs to reflect the great diversity of impairments and circumstances of disabled people (Committee on the Rights of Persons With Disabilities, 2018). This position can in great part be attributed to the active participation of DPOs and international human rights organizations in the drafting of the CRPD, a document that changed the established norm of how and by whom disability policy is made (Löve et al., 2017).

3. Methods

The research this article draws on is qualitative, consisting of research data that includes document analysis and in-depth interviews. Document analysis was conducted of the outcome report developed by participants in the Fjölmennt project (Fjölmennt, 2019), and of Iceland's national report on the implementation of the CRPD, the *Initial Report Submitted by Iceland Under Article 35 of the CRPD*, submitted to the CRPD Committee (Committee on the Rights of Persons With Disabilities, 2021). Analysis of documents also included related materials provided by the DPOs involved in the project, including letters, and memoranda. The documents amounted to 80 pages of text in total. Document analysis is a qualitative research method that systematically examines, evaluates, and interprets information contained therein to gain a more contextualized understanding. It regards documents as an important source of information, reflecting Atkinson and Coffey's (1997) argument that documents should be regarded as "social facts" that are both a product and a part of the social fabric (Bowen, 2009). Rather than just describing texts, document analysis digs deeper using context to gain a better understanding of their significance (Prior, 2003; Ritchie & Lewis, 2003).

The national report was the product of a collaborative effort of six ministries that formed a working group tasked with drafting the report under the leadership of the Ministry of Welfare, the name of which had been changed to the Ministry of Social Affairs when the report was written. They included the Ministry of Justice, the Ministry of Education, Science and Culture, the Ministry of Transport and Local Government, the Ministry of Environment and Natural Resources, and the Ministry of Foreign Affairs (it should be noted that the names and portfolios of some of these ministries were changed again when a new government was formed in November 2021). Information for inclusion in the national report was drawn from diverse sources, including the ministries with each focusing on issues specific to their portfolio, government institutions, and the Association of Local Authorities, as well as representative associations of people with disabilities, public interest associations, academia, and the public (Committee on the Rights of Persons With Disabilities, 2021). The Ministry of Welfare, now the Ministry of Social Affairs and Labour, led the process of drafting the text based on the information gathered. Upon completion, a draft report was published in the government consultation portal, thereby providing the public with an opportunity to express its views on the content. The finalized and approved text was submitted to the CRPD Committee in 2021.

Analysis of the selected documents consisted of their initial appraisal and close reading to gain a thorough understanding of their content. Data were then organized into themes with a focus on the three key concerns highlighted by project participants in the outcome report—housing, employment, and education—to be

able to systematically evaluate how they relate to the wider context and other data the research draws on. Finally, case examples were selected.

In addition, five in-depth interviews were conducted, providing an opportunity to gain a more nuanced understanding and insight into the interpretation of those involved in the process. In-depth interviews are used here in combination with document analysis as a means of triangulation, drawing on different methodologies in studying an issue. The use of mixed-method makes it possible to develop a better and more nuanced understanding of the subject matter (Bowen, 2009).

Interviews were conducted with representatives of NAPID, which initiated the project and contracted Fjölmennt to carry it out. NAPID is a rights-based DPO that focuses primarily on the rights and interests of disabled children and people with intellectual disabilities. It is one of two Icelandic DPOs that have legally protected consultation status in policymaking on disability issues. Interviews were also conducted with representatives of Fjölmennt and the ministerial-level working group. Due to the very limited size of the Icelandic population and the importance of maintaining the anonymity of informants, a decision was taken not to identify the number of interviewees in these three categories further and to only refer to them as either representatives of a DPO or of the ministerial working group. A decision was made not to interview project participants for this research as their voices and opinions are reflected in the project outcome report.

Interviews were semi-structured and focused on three core themes: (a) the right to full and effective participation according to articles 4.3 and 33.3 of the CRPD, (b) obstacles to the realization of this right, and (c) the role of the project in actualizing this right. Participants were identified through purposive sampling, allowing the researcher to select informants who have particular experiences and insights of relevance to the study (Charmaz, 2014). The collection of interview 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 to identify central themes to help direct further data collection and theory building (Charmaz, 2014). The analysis consisted of close reading of the transcripts, followed by sorting and organization of emerging themes, revealing patterns in the data that helped develop a deeper understanding of the issues at hand (Creswell, 2009). The analysis revealed three dominant themes: (a) the importance of including the voices of people with intellectual disabilities in the consultation process, (b) the prevalence of tokenistic consultations, and (c) the need to provide adequate accommodation for people with intellectual disabilities.

The interviews, conducted between 2020 and 2021, were recorded, transcribed verbatim, and then analyzed and coded. All participants gave informed consent and agreed to have the interviews recorded.

4. The Fjölmennt Project

The project participants were recruited from two groups of people that had been engaged in disability activism and self-advocacy: Effort (Átak), a self-advocacy organization, and The Ambassadors on the CRPD (Sendiherrarnir um samning Sameinuðu þjóðanna um réttindi fatlaðs fólks), an activist group made up of people with learning disabilities and related impairments who have specialized in the various articles of the CRPD and been active in promoting awareness towards it (Fjölmennt, 2019).

The participants numbered 20: 10 women and 10 men of different ages. All had intellectual disabilities or related impairments, and some had multiple impairments. Their circumstances varied; some lived independently, several had personal assistance, others lived in group homes or some form of assisted living arrangements, and a few lived with their parents. Some participants were parents themselves, some were employed or pursuing further education, and others took part in various occupational day programs.

The participants led decision-making on the development of the project to ensure their ownership of the outcome and that the agenda reflected the issues participants themselves deemed important to address. Support in carrying out the participants' decisions and on logistics was provided by staff from Fjölmennt, including transcribing focus group recordings, taking notes, and writing the outcome report. All written documents produced, and conclusions arrived at, were approved by the participants before the outcome document was finalized. All participants had prior knowledge of the CRPD, and in many cases had developed particular knowledge in focused areas around select articles.

Participants decided to limit their review to the progress made on 14 of the CRPD articles that they considered to be of most relevance to their lives and experiences, ranging from independence and the right to family life to political and cultural participation (articles 5, 7, 8, 9, 12, 19, 21, 22, 23, 24, 27, 28, 29, and 30). Six working groups were formed, each comprised of three to four persons. Each group reflected on the implementation of two to four articles of the CRPD and met between seven and nine times for approximately two hours at a time. All working group participants were paid for their work.

Five of the working groups conducted focus groups, consisting of four to eight participants each, to broaden the perspectives reflected in the outcome report. Support staff assisted in asking follow-up questions to encourage more in-depth answers. Working groups, furthermore, invited people to their discussions and undertook field trips to inspect accessibility.

Focus group discussions were recorded and transcribed. The final report was developed by the working groups based on their own contributions and augmented by data from the focus groups. A support person from Fjölmennt facilitated the writing of the report but final

approval of the text was in the hands of the members of the working groups.

5. Findings

A comprehensive review of the national report submitted by Iceland in 2021, following its obligation under article 35 of the CRPD, showed two direct references to the project's outcome report. The national report consisted of 289 paragraphs and provided a detailed overview of the measures taken by Iceland to fulfill its obligations as a State Party to the CRPD.

The first reference to the project's outcome report is in paragraph three, the introduction section, giving it a certain prominence and visibility. It states: "The National Association received a special grant from the Ministry of Social Affairs for the drafting of a report to be prepared by people with developmental disabilities, thereby reflecting their views and opinions regarding the implementation of the Convention" (Committee on the Rights of Persons With Disabilities, 2021).

The second reference is found in paragraph 40 on the implementation of article 4.3 of the CRPD, stating:

The report was prepared by people with developmental disabilities and it reflects their views and opinions regarding the implementation of the Convention. Átak, the Icelandic self-advocacy group, and a group of people called the ambassadors on the Convention, prepared the report together. The report states that the most pressing issues for people with disabilities are housing, employment and education. (Committee on the Rights of Persons With Disabilities, 2021)

Review of the sections where the national report addresses progress on these three priority issues found no specific references to the recommendations made in the outcome report. Upon examination, several instances were identified where reference to it could have been made. For example, when reporting on the implementation of article 24, on education, the national report, in paragraph 204, discusses a two-year diploma for students with intellectual disabilities offered by the School of Education of the University of Iceland but without reference to the outcome report's observations on this program's limitations, particularly the very small number of students admitted to it and the need to expand the program to include education opportunities in other departments and fields within the university.

Progress on the implementation of article 27, on employment, is reviewed at length in the national report. It raises the issue of the persistent underemployment of people with disabilities, pointing out that while Iceland's overall employment rate stands at 86.5%, only about 10% of disabled people are fully employed. The project's outcome report addresses this issue, emphasizing in particular the need to increase the diversity of employment offered to disabled people, particularly people

with intellectual disabilities. Furthermore, the outcome report suggests adopting a new approach by focusing efforts increasingly on educating employers on the value of employing people with disabilities and the skills they can offer (Fjölmennt, 2019). This suggestion aligns with critical theory by proposing a shift to the established approach to addressing underemployment, which until now has almost exclusively focused on training disabled people to fit the labor market, with limited results as the statistics indicate.

Housing, the third priority issue identified in the outcome report, is closely connected to the right to independent living and full participation in society at all levels, which article 19 of the CRPD addresses. Implementation of article 19 was reviewed by the national report in 21 paragraphs where it points out that, at the end of 2018, there were still 228 people living in two institutions or group homes in Iceland (Committee on the Rights of Persons With Disabilities, 2021, para. 156). This is an issue of particular interest to people with intellectual disabilities as they make up a significant portion of this population. The outcome report addresses this issue and emphasizes the importance of also providing personalized services within these service arrangements that focus on the right to make decisions in one's life. For example, the report suggests that service users be part of the hiring of staff that provides their services and that they have the right to have a say in with whom and where one lives (Fjölmennt, 2019).

The references to the Fjölmennt project in the national report focus primarily on the fact that it was undertaken but not on its content. The examples cited above may, therefore, be considered missed opportunities to effectively incorporate the perspectives of people with intellectual disabilities in the national report in a way that better reflected the stated goal of the project, as well as to more effectively incorporate the knowledge that lived experience brings, as the CRPD so clearly calls for (Löve et al., 2017). These findings are particularly noteworthy considering that the outcome report was characterized as "good work" by representatives of both the ministerial working group and DPOs. "It was well developed and presented. This was, this was really, just real work," said a representative of the ministerial working group. Similarly, a DPO representative stated: "These are people who can so well convey their perspective...they just need preparation, time, and space to develop sufficient understanding of what is being discussed. In my opinion, this was a very well carried out project."

The in-depth interviews provide additional contextualized information. They reveal that DPO representatives perceived from the start that the Ministry of Social Affairs was supportive of the project. All the interviewees expressed a feeling of trust between the parties involved. "As soon as we suggested to the Ministry that we felt that this needed to be done, they immediately said yes," a DPO representative stated. Furthermore, they pointed out that funding was provided without any stipulations

regarding how the project should be carried out. All further decision-making was left to Fjölmennt, which had been contracted to oversee the project development. As said by a DPO representative: "The funding came with no instructions. Just the title question: What is the experience of disabled people of the implementation of the Convention?" The interviews also revealed a shared acknowledgment of the importance of including the participation of people with intellectual disabilities in consultation processes in general.

However, DPO representatives also drew attention to the danger of the project becoming "window dressing" rather than the genuine input to the national report that it was intended to be. "It's not really a positive development unless there are plans to have this impact what is then presented" (DPO representative). "Their voices must be the ones that are heard. It's the authorities' responsibility to take them seriously and include them in the report" (DPO representative). This was a recurring theme in interviews with DPO representatives who also expressed that they often perceived there to be a lack of deeper understanding among the authorities of the purpose of consultations, pointing out examples that they perceived to be tokenistic:

When one person with intellectual disabilities is in a group with others at a municipal office, with people in positions of authority and professionals....She arrives without being told what will be discussed. And then someone turns to her and asks what do you have to say on this issue? (DPO representative)

Addressing the limited direct reference to the outcome report, a representative of the ministerial working group emphasized that comments and suggestions received were incorporated in a more general way and, as such, were filtered throughout the national report. A representative of the ministerial working group chimed in: "This is a picture in time, not a word-by-word account but rephrased. It is the underlying understanding that we are trying to convey."

Analysis of the national report does, however, reveal examples of other reports used to highlight issues of concern. In some instances, the examples are stated without much elaboration, while in other cases the findings of the respective reports are given considerable room and reflection. In this context, it is important to keep in mind that no other project or report referenced is recognized as having been specifically conducted to provide input to the national report.

An example of substantive use of a report can be found in the section on the implementation of article 13, where the national report, in paragraphs 114 and 115, makes good use of the findings of a working group appointed by the State Prosecutor on the handling of sexual offenses in cases where the suspect and/or victim is disabled. Another is in a section on the implementation of article 8 of the CRPD, where key findings

of a study by the Social Science Research Institute of the University of Iceland are discussed and presented (Committee on the Rights of Persons With Disabilities, 2021, para. 65). In addition, recommendations of a working group convened under the auspices of the Minister of Health on assistive device systems are presented in paragraph 173 on implementation of article 19 (Committee on the Rights of Persons With Disabilities, 2021).

The findings, thus, suggest missed opportunities in making more effective use of the project's outcome report in line with the CRPD Committee's guidance that consultations be effectively taken into account and reflected in outcomes adopted. This is of interest in light of the support for the project shown by the authorities, which draws attention to the need to gain a better understanding of what changes to process norms are needed to combat potential unintentional underlying bias when it comes to listening to what people with intellectual disabilities have to contribute about their circumstances and needs. To address this concern, the next section of this article draws on research in the field and guidance provided by General Comment No. 7 where the CRPD Committee addresses what constitutes inclusive and participatory policy-making and provides guidance on how to ensure full, effective, and inclusive participation (Committee on the Rights of Persons With Disabilities, 2018).

6. Discussion

Asserting the right to make decisions regarding one's affairs is a key focus of the CRPD and reflects its emphasis on reversing an ingrained and long-standing practice of others making decisions on behalf of disabled people. This practice has been particularly persistent concerning people with intellectual disabilities, who, as a group, have also often found themselves lacking representation within DPOs, resulting in their interests and views being overlooked (Deal, 2003; Szmukler et al., 2014).

The project this research focuses on was intended to respond to the CRPD's call for diversity of representation, with a focus on people with intellectual disabilities as a marginalized group within the larger group of disabled people. As the findings reveal, the project succeeded in providing meaningful substantive inputs to Iceland's national report to the CRPD Committee that reflected the views and suggestions of people with intellectual disabilities, which Petri et al. (2017) had found to be lacking in reporting processes. However, the research also found that ensuring effective participation in the writing of a consultation report did not suffice; obstacles remain to achieve the goal of full and effective inclusion in the co-creation of policy, or, as in this case, the national reporting that the CRPD calls for. The findings revealed that in the national report's accounting of progress on issues in the three areas that were highlighted as of particular concern for people with intellectual disabilities, there was a lack of direct reference to the suggestions

made by project participants, which this research identifies as a missed opportunity.

It is important to keep in mind, as Quinn (2009) points out, that the ultimate goal of the monitoring process is to transport the values of the CRPD into domestic policy. This process, as the Committee so clearly stresses, should be guided by consultations with disabled people and their representative organization where the value and knowledge of lived experience of diverse impairments and disabilities is recognized and effectively taken into consideration, the aim being to incorporate this knowledge in national policy-making. It is a position that recognizes the argument that, to change ingrained and accepted norms, marginalized groups such as people with intellectual disabilities must be active participants throughout the decision-making process to be able to effectively change and redefine accepted norms and structures (Young, 1990). It is not enough to create a platform to express opinions; there must also, as the Committee emphasizes, be a strategic and transparent effort to take into account and reflect the results of such consultations in decision-making. The Committee, furthermore, recognizes that ingrown biases need to be uprooted to prevent the tendency of consultations from becoming more of a formality or tokenistic, a concern that was also expressed in the interviews with DPOs representatives.

The findings are also noteworthy in light of the support for the project shown by the authorities, both in terms of funding and its recognition of the quality of its outcome report. They draw attention to the need to examine further and address possible ingrown and often unconscious biases affecting whose knowledge is heard and effectively included in decision-making and to respond by embedding measures in the decision-making process to combat them. Such biases are, as Petri et al. (2017) point out, often especially relevant in the case of people with intellectual disabilities. These biases are culturally embedded and socially invested and serve to determine which differences are assigned a label of otherness, preventing access to full inclusion and effective contribution (Altermark, 2017).

As a group, people with intellectual disabilities are often not viewed as fully valued contributors, and their incompetence to participate in decision-making is often assumed. They may, therefore, find it difficult, as Sinclair (2005) points out, to gain a position where their knowledge is recognized and accepted on an equal basis with others. The dilemma, he points out, is that when marginalized and disempowered groups seek to challenge their presumed incompetence and to claim equality to others, they are often met with attempts to discredit their claim to knowledge (Sinclair, 2005). The result is the devaluation of their voices, and their position of marginalization is reaffirmed. Such ingrained biases, including which knowledge base is deemed valuable, reflect existing power balances, and serve to reinforce the status quo (Minow, 1990; Young, 1990), highlighting the need for changes to the underlying power structures.

The findings of this research raise the question of what qualifies as actual and inclusive participation. According to Kumpuvuori and Virtanen (2017), full participation requires that the participation of DPOs must be continuous, from the very beginning of the policy formulation process to its conclusion. In addition, the opinions and suggestions made by DPOs must be taken into account by policymakers and not ignored. They identify as illusionary forms of participation where there is no real opportunity to affect the outcome of a co-production process because, even though opportunity is given to participate in the process, contributions and opinions are not taken into account (Kumpuvuori & Virtanen, 2017). This question is also addressed in the guidance provided by the CRPD Committee in General Comment No. 7, where it emphasizes that consultations should be initiated in a timely manner and that the process should be adapted to fit the needs of different participants, including by providing all relevant information in an accessible form with reasonable accommodation, such as Easy Read text. It warns against consultations becoming a formality or tokenistic and emphasizes that the results of consultations be taken into account and reflected in decisions adopted. The guidelines also call on States Parties to inform participating DPOs of the outcome of consultation processes and to provide explanations and “considerations and reasoning of decisions, on how their views were considered and why” (UN Committee on the Rights of Persons With Disabilities, 2018). In addition, the Committee has emphasized the importance of instituting independent frameworks such as National Human Rights Institutions and other formalized mechanisms to ensure that the voices of disabled people and their representative organizations are both heard and recognized in the production of reports and policy analysis (Caughey & Liu, 2022). In this way, General Comment No. 7 lays out a process for the co-production of policy where the outcome is co-owned by all parties involved. The CRPD, thus, reflects the critical theory emphasis on the need for changes to process norms so that marginalized groups such as disabled people are systematically included as part of the decision-making process and can gain the access necessary to change their position of marginalization within society. In both cases, the emphasis is on instituting accountability and transparency throughout the decision-making processes.

Thus, while the Fjölmennt project represents an effort to change the accepted practice of others speaking on behalf of people with intellectual disabilities, change also calls for an evaluation and monitoring of the prevalence of ingrown biases at every level of the process to more thoroughly uproot existing power balances regarding whose knowledge is included. It is not enough to invite consultation, as the CRPD Committee so clearly empathizes; there must also be an effort to listen and a willingness to embed the voices and opinions of disabled people in decisions taken.

7. Conclusion

The findings of this research suggest that when it comes to effective participation in policy development, as called for by the CRPD, underlying power balances have to an extent remained unchanged when it comes to people with intellectual disabilities, who, as Sinclair (2005) points out, face significant hurdles when it comes to their knowledge being recognized on an equal basis with others. Substantively, their suggestions and comments were not explicitly given voice in the national report to the CRPD Committee, calling to mind the concern raised by representatives of DPOs interviewed, who echoed the Committee’s warning that consultations mustn’t become a formality or tokenistic, drawing attention to the underlying biases that continue to affect the perception of disabled people as lacking the capacity to manage their own affairs.

This recognized but often unconscious bias against disabled people, and in particular people with intellectual disabilities as a subset within that group, draws attention to the need to embed further safeguards in the consultation process. The guidance provided by the CRPD Committee could help in this regard by providing more transparency to the reasoning behind decisions taken, including explanations of how and why DPO suggestions and comments are or are not included in policy documents, including implementation reports.

While this research specifically addresses the case of people with intellectual disabilities, its findings may have relevance for other marginalized groups that have limited access to decision-making processes. Groups such as immigrants or homeless people may find themselves in a similar situation where, because of ingrained biases and the devaluation of their knowledge, their suggestions and views are not fully recognized. As in the case of people with intellectual disabilities, this may result in a lack of access to effective participation in consultation processes and, thus, a lack of means to change their position of marginalization and to affect policy in matters that concern their affairs.

The findings indicate the need for additional measures to change established patterns of how consultations are integrated into policy development by institutionalizing a more structured and transparent process. Without such a formalized process, the underlying power balances are likely to go unchanged and it will continue to be left to the interpretation of governmental and political actors to decide whether and to what extent suggestions and reports are incorporated in the final decision-making process, without having to account for these decisions.

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Conflict of Interests

The author declares no conflict of interest.

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About the Author



Laufey Elísabet Löve is an assistant professor of disability studies at the Faculty of Diversity and Education in the School of Education, University of Iceland. Laufey holds a PhD in disability studies from the University of Iceland and an MA degree in political science from the Graduate Faculty of the New School for Social Research in New York.