World Institute on Disability

Monitoring Disabled People's Human Rights Under Article 33.3 of the United Nations Convention on the Rights of Person's with Disabilities

"When we stay silent, nothing will happen." *Participant 14, Kenya*

Prepared by: Robbie Francis Watene

2024 Global Heumann Fellow

World Institute on Disability

Sponsored By: The Ford Foundation

© 2025 World Institute on Disability. This work is licensed under a Creative Commons Attribution–Non Commercial–No Derivatives 4.0 International License.

Table of Contents

Introduction *3*

Background: What is Monitoring? *2*

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2

Article 33 - National Implementation and Monitoring 3

Methodology *4*

Research Questions 4

Principles and Values 5

Research Design 5

Terminology 8

Author Positionality 9

Strengths and Limitations 9

Sponsor Disclaimer 10

Findings *10*

Progressive Realisation of Article 33.3 10

The Challenges of Implementing Article 33.3 15

Recommendations and Opportunities for Improvement 27

Concluding Comments *33*

Acknowledgements *1*

About The Global Heumann Fellowship *2*

Creating a Global Bridge to the Future 2

About World Institute on Disability *3*

References *4*

Appendix A – Glossary of Terms *9*

Introduction

As the 20th anniversary of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) approaches, it is timely to reflect on its progress and the ongoing challenges of its implementation. This study offers such reflections. However, rather than revisiting the more familiar Articles of the UNCRPD, attention is turned to a quieter but significant provision of the Convention: Article 33 – National Implementation and Monitoring. Specifically, this research seeks to better understand different approaches to Article 33.3 and the role of disabled people in the monitoring processes. The aim is to gather data and evidence to inform and enhance future disability leadership in monitoring and the impact of monitoring on policy and practice.

The idea for this research emerged in 2024 when the World Institute on Disability issued a call for research fellowship applications in honour of the life and legacy of the Institute's co-founder, Judith Heumann. The 12-month Fellowship aims to support emerging disability researchers in undertaking impactful projects that foster global equity, inclusion, and justice. As Project Lead for the Disabled Person-Led Monitoring of the UNCRPD in Aotearoa New Zealand, the Fellowship provided an ideal home for one of my longstanding curiosities – how do other disabled people 'do' monitoring research as mandated by Article 33.3, and how can the status of disability leadership be elevated through this small yet powerful article?

After being named one of the three inaugural Global Heumann Fellows, the research process commenced in late 2024. Advisors were engaged, literature was reviewed, protocols were established, and research documents were developed. This White Paper represents the culmination of this work. This Paper begins with a brief overview of monitoring, the UNCRPD, and Article 33.3, followed by an outline of the qualitative methodology and methods used in the study's design. The findings are then presented according to three key themes: examples of the progressive realisation of Article 33.3, challenges in its implementation, and recommendations and opportunities for

improvement. Finally, the concluding comments reflect on the learnings and future directions of disabled person-led monitoring.

Background: What is Monitoring?

To appreciate the importance of this research, it is first necessary to understand what monitoring involves and its role in advancing the rights of people with disability. The term ‘monitoring’ is generally understood as the process of watching and checking something over time to see how it develops so that any necessary adjustments can be made (Oxford Learner’s Dictionary, 2025). More specifically, monitoring human rights involves actively collecting, verifying, and immediately using information to enhance human rights protection (Office of the High Commissioner for Human Rights 2001). As expressed by the guardians of the global human rights system, the United Nations Human Rights Office of the High Commissioner (2011, p. 4):

> *“Monitoring is a method of improving the protection of human rights. Its ultimate objective is to reinforce the State’s responsibility to respect, protect and fulfil human rights. […] Monitoring the conduct of duty bearers reinforces their accountability. This should result in more “human rights-responsible” behaviour.”*

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an example of a human rights mechanism aimed at encouraging human rights-responsible behaviour.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Adopted in 2006, the UNCRPD is an international agreement that sets out what States (governments) must do to ensure that disabled people enjoy the same human rights as everyone else (United Nations, 2006). Importantly, the UNCRPD does not give disabled people new or different rights; rather, its purpose is to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all disabled people and to promote respect for their inherent dignity (United Nations, 2006).

To become a party to the UNCRPD, a State must first sign the agreement, indicating its agreement with the legal obligations in principle. The State then ratifies the Convention, formally committing to progressively realising all of its articles. Regardless of resource availability, progressive realisation refers to the State's immediate obligation to take appropriate steps to ensure continuous and sustained improvement in the enjoyment of the Convention's rights over time (United Nations Human Rights Office of the High Commissioner 2025).

States are also encouraged to sign the Optional Protocol, which allows individuals to raise concerns with an expert committee for investigation (United Nations 2006). Following ratification, States must submit regular reports to the Committee on the Rights of Persons with Disabilities detailing how disability rights are implemented in their country. At the time of writing this White Paper, 193 Parties had ratified the Convention, with Tajikistan, Tonga, and the United States of America being the only Parties yet to do so. This makes the UNCRPD the most widely ratified of the UN human rights treaties (United Nations, 2025).

Article 33 - National Implementation and Monitoring

Despite its popularity, in some countries conventions such as the UNCRPD represent little more than a paper victory: a statute that is signed and looks good on paper but fails to be implemented in practice (Perlin, 2012, 2014). The inclusion of Article 33, which outlines the Convention's approach to monitoring its implementation, is therefore widely regarded by scholars, practitioners, and advocates as innovative, both within the UNCRPD and across human rights conventions more broadly (Aichele, 2018; Birtha, 2013; Lindqvist, 2015; Pinto, 2015; Series, 2020).

Article 33 comprises three key components. It directs States to:

- appoint one or more focal points within their government for matters related to implementation (Article 33.1)
- establish and maintain independent mechanisms to promote, protect, and monitor the Convention's implementation (Article 33.2)

- ensure that disabled people and their representative organisations are fully involved in monitoring processes (Article 33.3) (United Nations, 2006)

Article 33.3's explicit attention to civil society's involvement in monitoring processes represents a significant step forward in realising the human rights of disabled people and human rights more broadly (Manca, 2017). Despite the initial buzz around the potential of disabled people's active participation in monitoring the implementation of their own human rights, however, an *"important gap between the goals and the spirit"* of Article 33(3) and the degree to which it has actually been implemented remains (Committee on the Rights of Persons with Disabilities, 2018, p. 2).

While approaches to Article 33.3 differ from one State to another, so too does the role of civil society in monitoring disabled people's human rights (Watene et al., 2023a). For instance, resources, funding, connections, capacity, and representation of diverse groups are just some of the challenges identified in implementing Article 33.3 (Committee on the Rights of Persons with Disabilities, 2018; de Beco, 2013; Hickey, 2015; Liu, 2025; Samson, 2015; Watene et al., 2023a; 2023b).

With this context in mind, the questions that sparked this research remained: what does the meaningful involvement of disabled people in monitoring processes look and feel like? Are we, the global disability community, maximising the potential of this brief yet powerful clause?

Methodology

Research Questions

To understand this curiosity more fully, the following four key research questions were developed:

- What current approaches are being taken to Article 33.3 by governments, disabled people, and their representative organisations?
- What successes have disabled people and their representative organisations had in progressively realising Article 33.3?

- What are the challenges of implementing Article 33.3?
- What are the opportunities for improving the implementation of Article 33.3, and more specifically, for disabled people's leadership in monitoring processes?

Principles and Values

This research was conducted under the korowai (cloak) of both the World Institute on Disability's guiding principles (disability-led; accelerating inclusion; and pan-disability movement solidarity), and the Donald Beasley Institute's mātāpono (guiding values), which are:

- Whakatinana – Honouring Te Tiriti o Waitangi (and indigenous rights) through practice
- Whakarakatira – Respectful
- Whakawhanaukataka – Relational
- Whakamana – Ethical
- Whakawhirinaki – Accountable
- Whakakotahi – Inclusive
- Whānau - Through uplifting whānau (family), our journey will be one of prosperity

In addition, the research is based on the following documents and assumptions:

- The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),
- The Social Model of Disability,
- The Human Rights Model of Disability,
- and the Disability Justice Framework.

Research Design

Scope

This research initially aimed to engage up to 20 disabled people, DPOs (representative organisations), and/or allies of the disability community. This sample is not

representative of the global disability population. As with all qualitative research, there is no claim that the findings are generalisable; rather, it seeks to generate and contribute rich, nuanced insights into a specific issue that are trustworthy, authentic, credible, applicable, and transferable (Lim, 2024). A typically small sample size enables the researcher to build the relationships necessary to gather the depth and quality of data required for the study.

Participant Recruitment

Purposeful recruitment was used to select information-rich sites and cases for in-depth study (Patton, 2002) as well as snowball sampling (Biernacki & Waldorf, 1981). Participants were recruited using research documents shared through existing (WID) and DBI networks, social media, and other public platforms. Interested participants were asked to fill out a participant interest form, which enabled maximum variation sampling. Maximum variation sampling is a qualitative method designed to capture a wide array of diverse perspectives and experiences by selecting participants who differ in age, gender, socioeconomic status, and cultural backgrounds. This approach enhances the depth of the collected data, enabling the identification of patterns and contrasts across different groups (Williams, n.d.). In this study, it was used to select harder-to-reach populations, such as disabled people with intersecting identities (for example, disabled Indigenous people, ethnic minorities, LGBTQI+ communities, and so on).

The primary focus of this research was disabled people and/or Disabled people's Organisations (DPOs) involved in monitoring processes under Article 33.3 of the UNCRPD. The secondary focus was on key informants with subject-matter expertise regarding Article 33.3. To participate in this research, participants had to be over 18 years of age, able to provide informed consent to participate, and have access to stable internet.

Participants

Through this recruitment process, 17 people were selected from 11 countries:

- Aotearoa New Zealand

- Bangladesh
- Cameroon
- Ireland
- Jordan
- Kenya
- Nepal
- Papua New Guinea
- Taiwan
- Tanzania
- Uganda

Sixteen participants were disabled, and one was a subject matter expert (SME). Disabilities included physical, sensory, psychosocial, learning (intellectual), neurodivergence, and chronic health conditions. Some participants identified as LGBTQIA+ and/or Indigenous, and the age range was wide, from their late 20s to 70s. All participants provided consent to be identified within this research.

Data Collection

Once the participants were confirmed, primary data were collected through qualitative, semi-structured interviews, and focus groups. Data collection was underpinned by key elements found in participatory and inclusive qualitative research methods, such as focusing on research issues that matter to people with disabilities, collaboration between people with disabilities and non-disabled people, ensuring people with disabilities have power and control within the research process, and that all research processes and outputs are accessible (Walmsley & Johnson, 2003).

Virtual or in-person interviews or focus groups were arranged, along with accessibility supports to ensure full and meaningful participation (for example, sign language interpreters). Each interview or focus group took between 45 and 90 minutes, either in person (Aotearoa New Zealand) or via Zoom or WhatsApp. Individual participants received a US$100 voucher of their choosing, and focus groups received a US$300 donation to a DPO of their choosing.

Data Analysis

Following data collection, the interviews were transcribed using OtterAI before being hand-reviewed for accuracy. The transcripts were then inductively and deductively analysed for key themes using Braun and Clarke's (2006) six-phase approach to thematic analysis. The approach included: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and writing a White Paper.

A Grounded Theory approach was also drawn on, allowing for identified themes to be explored for alignment with the UNCRPD and the Committee on the Rights of Persons with Disabilities' General Comment Number 7 (2018), while incorporating a disability justice (disability intersectionality) lens. The disability justice framework calls attention to the ways in which ableism is linked to multiple other systems of oppression (for example, gender, identity, status, citizenship, sexual identity, and so on) (Berne, 2015).

Member Checking

Member checking is a qualitative research technique in which researchers return raw or analysed data to the original participants for review to ensure accuracy and validity (McKim, 2023). All participants were invited to review the initial draft of this White Paper to ensure that the key themes, findings, and recommendations accurately reflected their voices and experiences. Participant feedback was incorporated accordingly.

Terminology

In Aotearoa New Zealand, the identity-first terminology 'disabled person' is the preferred way of referring to people with impairments (Office for Disability Issues, 2016). Identity-first terminology expresses the social model of disability, which differentiates between impairment and disabling barriers that exist in society (Best et al., 2022). Terms used in this White Paper include 'disabled people', 'disabled person', 'Disabled people's Organisations' (DPOs, also known as OPDs), and 'learning disability' instead of 'intellectual disability' (see Appendix B for a glossary of terms). While these are the preferred terms for this study, terminology found in the direct literature and participant

quotes has been preserved. Amendments and clarifications to direct quotes are indicated by square brackets [...].

Author Positionality

I am a 36-year-old cis-pākehā Mum of two. I identify as tangata Tiriti, and my pronouns are she/her. I serve as the Disabled Research Lead at the Donald Beasley Institute (DBI). Since 2018, the DBI has conducted the Disabled Person-Led Monitoring of the UNCRPD in Aotearoa research project for the New Zealand DPO Coalition. In this role, I manage a team of disabled research monitors and oversee various disability rights research programmes. All aspects of my identity contributed to the planning and execution of this research, including the interpretation and presentation of the findings.

Strengths and Limitations

The qualitative design of this research offers deep insights into the lived experiences and perspectives of disabled people from different countries. By centring disabled people's narratives and contexts, the study captured nuances that quantitative methods often overlook, which is an important strength when exploring complex human rights issues. Another strength was my position as a partial insider researcher, which facilitated deeper contextual understanding, easier access to participants, quicker rapport building, and more open communication (Taylor, 2011).

This study had some limitations. Time and resource constraints meant that most interviews were conducted remotely, requiring participants to have stable Internet access, prior knowledge of disability rights, and existing connections with disability rights advocacy. Self-selection bias during participant recruitment can mean that important voices and experiences may not be included in the research (Hiratsuka, 2025). Maximum variation sampling was used to mitigate this limitation. Partial insider research also carries additional risks, including assumptions about shared culture or experience that may obscure underlying issues or lead to missed data (Asselin, 2003). To address these challenges, all stages of the research were reviewed by external disabled and disability research advisors and mentors.

Sponsor Disclaimer

The sponsor of this research, the World Institute on Disability (WID), recognises that this study is qualitative and based on the experiences of a limited group of participants. Therefore, the findings should not be interpreted as representing the views or contexts of disabled people worldwide or countries outside the study's geographic scope. WID has taken all reasonable steps to ensure that the information in this White Paper is reliable but does not guarantee its accuracy and accepts no liability for any errors.

Findings

The findings of this research provide unique insights into how disabled people and their representative organisations bring Article 33.3 to life in practice. Given that implementation varies across different socio-political contexts, this research aimed not only to understand what meaningful involvement in monitoring processes looks like, but also to learn from those doing the work. Over six weeks, 17 disabled people, DPO representatives, and subject matter experts from 11 countries participated in online and in-person interviews and focus groups. Their reflections span moments of progress, frustration, and innovation, painting a complex picture of disability leadership in action.

Through a combined inductive and deductive analysis, three themes consistently emerged from the interviews and focus groups: promising examples of the progressive realisation of Article 33.3; ongoing challenges that hinder its implementation; and opportunities to strengthen its impact in the future.

Progressive Realisation of Article 33.3

The first key theme raised by participants related to the progressive realisation of Article 33.3. In the context of the UNCPRD, progressive realisation recognises that while States (governments) must work towards the full realisation of the Convention's articles, it may not be immediately possible to achieve full implementation. It acknowledges that resources and capacities can vary. However, it requires States to take concrete steps to advance the human rights of disabled people to the maximum extent possible (Division for Inclusive Social Development, 2022). Consequently, this set of findings refers to the

steps that States had already taken to advance Article 33.3 and the successes achieved.

Participants reported a variety of approaches to Article 33.3 with different degrees of success. For instance, participants from Aotearoa New Zealand described a well-established monitoring structure called the Independent Monitoring Mechanism (IMM), which involves the country's National Human Rights Institution (NHRI, the Human Rights Commission) and the Ombudsman's Office (under Article 33.2), as well as the national DPO Coalition, the latter of which is responsible for contributing Disabled Person-Led Monitoring research under Article 33.3 using the Disability Rights Promotion International (DRPI) methodology.

For other States, such as Nepal, Bangladesh, and Cameroon, monitoring efforts are mainly aimed at involving disabled people through external independent councils and committees at the national and federal levels. Other States appeared to concentrate on internal government committees and councils comprising both disabled and non-disabled officials, with limited participation from independent DPOs.

Although participants could not recall a State that they believed maximised the potential of Article 33.3, those involved in monitoring processes identified three key factors that positively affected the progressive realisation of Article 33.3 in their countries. These factors were government buy-in, disability employment, education, and awareness.

Government "Buy-in"

The first factor identified as positively contributing to the progressive realisation of Article 33.3 was government buy-in. Although many States were quick to sign and ratify the UNCRPD, actual implementation, including monitoring, often falls short due to a complex mix of lack of political will, limited resources or capacity, and conflicting priorities. However, examples of successful implementation of Article 33.3 were driven by government officials who were genuinely committed to advancing disability rights and monitoring rather than projecting an image on the global stage. Reflecting on the

success of Disabled Person-Led Monitoring in Aotearoa New Zealand, one participant said:

> *“It also took some buy-in [from] key government officials who were there at the time, who saw that it was necessary and saw what needed to happen, who did read the Convention text and understood that it had to happen in this way, and it [monitoring] would be better if we did it involving Disabled people's Organisations.” (Participant 2, Aotearoa New Zealand)*

Government buy-in was frequently discussed in relation to legislative change, with many monitoring initiatives established alongside changes in disability law and policy. For example, participants from Cameroon, Aotearoa New Zealand, Kenya, and Nepal all mentioned legislative changes that signified a shift in government thinking about disability rights, especially as efforts were made to align domestic law with their obligations under the UNCRPD.

Government buy-in and commitment to legislative change were often driven by non-disabled champions within the government. For instance, a participant from Papua New Guinea said that their Government’s signing and ratification of the UNCRPD, along with subsequent legislative reforms and monitoring efforts, was partly due to strong relationships between civil society and individual officials.

> “*Let's look at somebody who is walking along with us, and let's put them in the forefront, and they will take [it forward], and that definitely worked.” (Participant 11, Papua New Guinea)*

Taken together, these reflections demonstrate that government buy-in, along with legislative reform, is essential for establishing effective monitoring. However, they also indicate that depending solely on individual champions, even highly influential ones, can leave progress vulnerable, emphasising the need for stronger institutional mechanisms to sustain Article 33.3 over time.

Disabled Leadership

The leadership of disabled people, both within the government and civil society, was also recognised as having a positive impact on the progressive realisation of the Convention, including Article 33.3. For example, in Cameroon, disability employment incentives and quotas, including those for government departments, have led to disabled individuals being employed as public officials.

> *"Yes, they [Government] practice what they preach. And this is because [...] most of the disability institutions are being led by people, like some top position in that Ministry of Social Affairs is being occupied by people with disability. So they make sure they really implement the law." (Participant 12, Cameroon)*

A participant from Aotearoa New Zealand also highlighted the importance of disability employment within the government, while emphasising the different roles that disabled officials and civil society representatives play in the monitoring process.

> *"We say that it's useful when a person who works for an agency, whether they be independent or government […] are in those spaces, but that is not the voice of disabled people. Those people are officials who happen to be disabled, or employees who happen to be disabled, not disabled people who are there to speak for disabled people. So they add value, but they cannot be expected to be the voice of disabled people. [...] So that's an important distinction that I believe has been well recognised in New Zealand to date by the IMM partnership arrangement. That the value that the DPOs bring to that discussion is because we are unfettered by organisational employment relationship pressures, but a disabled person who is a government official is a government official first and foremost." (Participant 2, Aotearoa New Zealand)*

While participants agreed that disability leadership within the government adds value to monitoring processes, independent disability leadership is equally, if not more, essential.

Education and Awareness

The third factor underpinning the progressive realisation of Article 33.3 was UNCRPD education and awareness for duty bearers and rights holders. Most participants reported that they had participated in and/or delivered UNCRPD training. For example, a Deaf participant from Aotearoa New Zealand recalled a disability rights monitoring training she attended almost a decade ago, and the lasting impact this had on her:

> "*I think it was in 2016 or 17 that was my first opportunity to be involved in a group of people with all kinds of disabilities, and it kind of opened my eyes to all the commonalities that we had with each other. And it really felt powerful and impactful that workshop where we learnt all about that Article [33].*" (Participant 16, Aotearoa New Zealand)

Reiterating the importance of disability rights training and strengthening the capacity of disabled leaders, a participant from Papua New Guinea spoke about the extent of disability rights training conducted across the provinces of Papua New Guinea:

> *"And so we did, you know, training for leaders at the sub-national level. We have 22 provinces in Papua New Guinea. And so the first thing that we decided to do was to make leaders within the movement in the country understand what CRPD means."* (Participant 11, Papua New Guinea)

Similarly, efforts have been made in Nepal to sensitise both duty bearers and rights holders to the Convention's content. This participant highlighted the importance of open dialogue between both parties:

> *"Sensitising the duty bearers and also the OPDs. So that was one of the initiatives [...] where people with disabilities and the duty bearers were collectively sitting in the same room and exchanging those ideas as right holders and as duty bearers, because there are differences of understanding the Convention. Because one is from the demand side and one is from the supply side. So for me, these are very important."* (Participant 3, Nepal)

Participants' experiences reveal that education and awareness of the UNCRPD, along with government buy-in and disability leadership, were key factors in fostering meaningful participation, ultimately leading to more effective monitoring under Article 33.3.

The Challenges of Implementing Article 33.3

While participants had experienced some success in monitoring disabled people's human rights, the challenges of progressively realising Article 33.3 greatly outweighed any gains that had been made. According to participants, disabled people continue to experience a number of difficulties when holding their governments accountable to their disability rights obligations, including:

- a lack of prioritisation of disability rights (shown by a lack of resources; training and awareness
- disability employment; and UNCRPD compliance)
- detrimental ideologies and practices (such as the charity model of disability
- favouritism/cronyism and corruption)
- exclusiveness, competitiveness, and fatigue within DPOs

Lack of Prioritisation

A lack of government prioritisation of disability rights and matters was identified as the main obstacle to implementing Article 33.3, as it directly affected resource allocation, training, awareness, disability employment, and UNCRPD compliance. Even when governments ratified the Convention, demonstrating their commitment to progressively realise its articles, the persistent failure to prioritise disability matters and rights in policy and practice was consistently cited as impeding monitoring efforts.

> ***"I think the problem is we say, it's a political will. No political will. [...] It is not lack of funding. It is lack of prioritisation." (Participant 9, Tanzania)***

For some participants, the lack of prioritisation of disability issues was due to shifting priorities within the changing political contexts. For example, in Bangladesh, a change in government led to a shift in focus, which directly impacted the activities of an established UNCRPD Monitoring Committee. A participant from Nepal noted that despite having a functioning Committee, "*we lost everything because our government became autocrat"* (Participant 5, Bangladesh).

> ***"Priorities will always change, and it will inform allocation of resources. [...] Issues of development priority normally change with the government, and it will also depend with the political party that took the power. [...] Even with that, once they get to power, they change." (Participant 14, Kenya)***

The lack of prioritisation was further demonstrated by a participant from Kenya, who said that disability rights are often directly affected by changing political administrations and internal priorities:

As shown by these participants' experiences, even after States ratified the UNCRPD, disability issues were often sidelined in policy, funding, training, and monitoring efforts. This lack of prioritisation was frequently connected to shifting political contexts, with changes in government disrupting established monitoring mechanisms and diverting resources elsewhere. As participants from Tanzania, Bangladesh, Nepal, and Kenya observed, political will, rather than funding, ultimately determined whether disability rights, and therefore monitoring, remained a consistent priority for governments.

Lack of Resources and Funding

Budget allocation and shifting political priorities were directly related to the lack of prioritisation. This shift caused unstable resourcing, disrupted initiatives, and stalled progress in building the sustainable monitoring structures envisioned under Article 33.3.

> *"[Disability] issues are not a priority for the government, that is one of the biggest challenges. And that is why, when there is not a priority, there is less budget [...]."* (Participant 3, Nepal)

All participants reported a lack of resources and funding for disabled people and their representative organisations, which negatively affected their capacity to monitor disability rights under Article 33.3. Participants from Nepal and Papua New Guinea, in particular, highlighted how resource scarcity and irregular funding impacted DPOs' ability to function consistently, including their monitoring efforts.

> *"So funding is one of the challenges. They [DPOs] are not much resourced, and that is why they are not adequately and effectively able to function."* (Participant 3, Nepal)

> *"Although it's stated in the policy that there was to be financial support, but it's really not planned, ad hocly, and they [government] just give [DPOs] enough for office upkeep. And it's not continuous, it's like when they have the desire to."* (Participant 11, Papua New Guinea)

Without sufficient and consistent funding, participants and their representative organisations could not fully realise the potential of Article 33.3 in practice.

Lack of Training and Awareness

Related to low prioritisation was a lack of training and awareness of Article 33.3 among both rights holders and duty bearers. For example, several participants shared that disabled people in their countries either do not know about human rights, or if they do know about the UNCRPD, they *"are not aware about the Article 33"* (Participant 5, Bangladesh). As articulated in the quote below, not only is training and awareness about disability rights lacking, but when disabled people do learn about the UNCRPD, it can lead to a sense of hopelessness and despair:

> *"I mean it's not taught at university level or even at any level of education. And so even for people who work with people directly [disability support workers], and*

including disabled people, they don't know about it. And the disabled community are also not aware of it. And sometimes when they learn about the UNCRPD, one of the things that has taken me aback through doing this [monitoring] project, was people's despair or disappointment in the UNCRPD. When they learned that we have this amazing convention that strives for the rights for disabled people, but their reality is so far away, some people felt like it's just a piece of paper or nice words on the paper. Or it makes them even more sad to know that they have these rights on the paper, but their reality is so different." (Participant 4, Aotearoa New Zealand)

When reflecting on the lack of disability rights training and awareness, a participant from Kenya suggested that the lack of knowledge was generational and, in part, due to a historical lack of access to education for disabled people in general. Similarly, a Deaf participant felt that inaccessible information sharing was a major barrier for Deaf communities.

"I think a lot of people are not interested in that kind of stuff [disability rights], or kind of a bit apathetic about it, and that kind of feeds into people's overwhelm and kind of disinterest in the topic. [...] I think, for me, and probably a lot of other Deaf people were suffering from a bit of information overwhelm. We didn't really get the point of what a lot of these kinds of documents and pieces of legislation and policy were all about. I guess I knew theoretically what the UN was and what a policy was, but knowing the nuts and bolts of it, just being able to know that felt too overwhelming. So as soon as I had it explained to me in my language [Sign Language], then I started to understand what it was and how it impacted me. But it took a long time to get that information specifically for me." (Participant 16, Aotearoa New Zealand)

Participants also reported that this lack of knowledge and apathy was also present among duty bearers, who were often ignorant of their obligations under the Convention.

"The government doesn't understand the role. [...] we [Disabled people's Organisation] were able to understand it because we socialised, you know, the

> *UNCRPD across and within the movement, but there was not much socialisation among the government departments to understand what their commitments and their obligations are."* (Participant 11, Papua New Guinea)

Collectively, these perspectives reveal how insufficient training and widespread misunderstanding of Article 33.3 continue to constrain its effective realisation across diverse contexts.

Lack of Disability Employment

The third indicator of the broader lack of prioritisation was the limited representation of disabled people in government decision-making roles and the lack of disabled individuals with real influence or authority. As one participant from Aotearoa New Zealand explained:

> *"I don't believe that governments actually know what they're doing, especially when we [disabled people] don't sit in the top government."* (Participant 1, Aotearoa New Zealand)

During the interviews, participants whose governments employed disabled people were asked whether those employees had any real influence on decision-making processes. Their responses indicated that such roles were often tokenistic, entry-level, and largely powerless.

Interviewer: *"And do people like this woman you've just talked about, do they have impact and influence over decisions?"*

Participant: *"No, she is just employed."* (Participant 5, Bangladesh)

Moreover, disabled people employed in public service roles were often expected to distance themselves from their disability identity and community to fulfil their official duties:

"I met this disabled person who works for the government, and they said, "As soon as I became an official, I removed myself from the community"." (Participant 17, Aotearoa New Zealand)

This finding is significant because participants frequently defaulted to describing disabled government officials or disabled individuals employed within National Human Rights Institutions (NHRIs) as the leading voice of disabled people in monitoring processes, despite these individuals often lacking influence or voice. Disabled people and their representative organisations, however, continued to be under-resourced, with a much more minor, inconsistent, and sometimes tokenistic role in monitoring activities. As highlighted earlier by a participant from Aotearoa New Zealand, disabled officials in government and NHRI roles *"add value, but they cannot be expected to be the voice of disabled people"* (Participant 2, Aotearoa New Zealand).

UNCRPD Compliance

The fourth and final challenge related to a broader lack of prioritisation was UNCRPD compliance. As an international human rights law, the UNCRPD is not automatically legally binding within domestic systems; rather, compliance is expected to be progressively realised through national legislation and practice (Division for Inclusive Social Development, 2022). Although many participants noted that their governments had introduced rights-based policies and laws following ratification, as shown by the quotes below, they also stressed that meaningful compliance was, in some cases, extremely difficult due to the prioritisation issues discussed above.

> *"When you will see our issue, our policy, the laws, it is good [...] the problem is in implementation."* (Participant 9, Tanzania)

> *"That's what I've told you from the beginning, when you look at documentation and you look at human rights organisation, they will say that Uganda has the best policies and never implemented."* (Participant 6, Uganda)

> *"We are rich in policy, but our main problem is to implement it, to execute our commitment and policy. That is the main challenge, that is the main barrier."* (Participant 5, Bangladesh)

As these reflections show, the motivations for States to sign and ratify the UNCRPD vary greatly, and this variation influences how much disability rights are genuinely prioritised in practice. Across different settings, limited funding and resources, lack of training and awareness, insufficient employment of disabled people in public service roles, and ongoing challenges with UNCRPD compliance all point to a broader pattern: even when formal commitments are made, the realisation of disability rights is often limited by structural and political decisions. These factors highlight the gap between ratification and its meaningful implementation.

Detrimental Ideologies and Practices

According to participants, a further group of challenges that hinder the implementation of Article 33.3 arises from detrimental ideologies and practices. Tan (2023, p. 1) describes detrimental ideologies as *"belief systems and thought patterns that, when embraced or perpetuated, contribute to adverse societal outcomes, heightened inequalities, and hinder sustainable development."* In this research context, participants referred to several ideologies and practices that negatively affected their monitoring efforts under Article 33.3 in a political setting. These included outdated models of disability, favouritism, cronyism, and corruption.

Outdated Models of Disability

Models of disability are heuristic devices that represent specific theories aimed at explaining phenomena through abstract systems and mechanisms (Barnes, 2008). While many models of disability exist, some of the most commonly cited include:

- The moral model of disability perceives disability as a consequence of sin, divine punishment, or a reflection of a person's moral character, often leading to blame or shame (Olkin, 2012).

- The charity model of disability views disabled people as unfortunate, dependent, and helpless objects of pity needing charitable assistance from the community (Davis, 2013).
- The medical model of disability considers disability as an issue residing within an individual that requires fixing or curing to fit society (Smart, 2009).
- The social model of disability contends that people are disabled by socially constructed barriers, such as inaccessible environments and negative attitudes, rather than by their impairments. The social model aims to accept impairment and remove disabling barriers in society (Oliver, 2013; Shakespeare, 2013).
- The human rights models of disability views disabled people as rights holders entitled to the same freedoms and opportunities as others (Al Ju'beh, 2017).

Some participants reflected on how their governments viewed and responded to disability and how these views influenced their ability to participate in monitoring processes. For example, several felt that the charity model of disability negatively shaped their government's approach to engaging with disabled people in monitoring:

> *"If you just going to say it's for disabled people, then it's an act of charity. It's on the agenda of the charitable individual, not on the disabled people's agenda."* (Participant 2, Aotearoa New Zealand)

Other participants felt that the medical model continues to impact the role of disability leadership in monitoring processes:

> "*I guess we're still in the medical model that people think that […] we have to do it for all of you, you know, you don't have the capacity and the ability to do it."* (Participant 11, Papua New Guinea)

As a participant from Nepal explained, although the UNCRPD has prompted a shift in thinking in many countries, outdated models such as the charity and medical models of disability continue to impede the progressive realisation of disabled people's rights and limit their active, meaningful participation in monitoring:

> *"[…] 90% of the work in terms of implementing Article 33 is yet to be done. [...] And this can be only possible when we develop the capacity of the OPDs [...] These are human rights principles. This is CRPD compliance. The Disability Card, which has been distributed by the Government of Nepal, is a medical approach. We're talking about a human rights-based approach. [...] the mindset of the charity-based approach still exists among the duty bearers. So that means the Convention has not been transformative yet."* (Participant 3, Nepal)

Ultimately, these perspectives highlight a central tension: while the UNCRPD promotes a social and human rights model of disability, many governments still operate within outdated frameworks that diminish disabled people's leadership and hinder meaningful disabled person-led monitoring practices.

Favouritism, Cronyism, and Corruption

Another practice participants identified as undermining disabled person-led monitoring was favouritism, defined as granting advantages to individuals based on irrelevant characteristics, such as belonging to a privileged group, and cronyism, the preferential treatment of friends or associates (Nadler & Schulman, 2006). In this study, the participants described situations in which government officials extended preferential treatment, appointments, or opportunities to particular individuals or groups within the disability community. Examples included hiring decisions for government roles and the allocation of funding to specific disabled people or DPOs. Favouritism and cronyism can also be understood as forms of ableism, that is, practices that reward individuals or groups who conform to socially constructed ideals of normalcy, productivity, desirability, intelligence, excellence, or fitness (Lewis, 2022). Participants identified favouritism and cronyism mainly in two contexts: government hiring practices and the selection of individuals or groups for monitoring.

> *"You realise that in such a [monitoring] meeting, the same people are the ones invited now and then, due to the fact that maybe they are so close, or they are known by the organisers."* (Participant 14, Kenya)

> *"So whoever has access in the government, whoever has networking in the government, then they are the one who is receiving the fund, not the organisation like us."* (Participant 3, Nepal)

As a participant from Uganda highlighted, this practice lends itself to corruption that can derail and undermine the monitoring efforts. Favouritism and cronyism can lead to questions of capability and merit for disabled people working for the government:

> *"Disabled people, you find them in the government asking, are you employed on merit, or are you employed after your friends or family members or people whom you believe they possibly behind the door for you to be given a government job? [...] it is corruption that disables the people who are employed in government."* (Participant 6, Uganda)

In summary, these accounts demonstrate how favouritism and cronyism can undermine the integrity of disabled person-led monitoring, foster conditions for corrupt practices, and ultimately hinder the realisation of Article 33.3.

Who is In and Who is Out?

The next set of challenges specifically concerns DPOs and the preferential treatment of disabled people with certain abilities, characteristics, and qualities by representative organisations and the governments. Many participants highlighted the exclusive nature of DPOs, where some disability and identity groups were given priority while others were excluded from government engagement and monitoring processes. One of the most frequently mentioned exclusions was Indigenous disabled people.

For instance, a participant from Nepal noted that the State disability policy is based on a narrow, impairment-focused (medical) framework that neglects intersecting identities such as Indigeneity, language, gender, ethnicity, and class. Consequently, only those who can navigate state systems and dominant languages can access engagement and consultation processes, systematically excluding Indigenous disabled people. Similarly, government and DPO practices often fail to recognise the intersection of disability and

Indigeneity, leading to the absence of Indigenous disabled people from formal consultation groups and decision-making arenas.

> *"In the Government, the OPDs, they do not think that the issue of indigenous people with disabilities is a human right issue. [...] When the Act was formulated, no one wants to understand this is a human rights issue. So that is the challenge, and that is why we [indigenous disabled people] are not categorised in the groups. […] we are not invited."* (Participant 3, Nepal)

Furthermore, Nepal is not alone in facing challenges in reaching Indigenous disabled people. In Aotearoa New Zealand, a participant also identified the lack of a dedicated DPO for Indigenous disabled people within formal monitoring structures as a barrier to implementing Article 33.3.

> *"To exclude the Indigenous peoples from the DPO Coalition here, is a travesty. [...] And also it's an insult to those of us who are Māori and disabled and even our Pacifica cousins. [...] There was no Māori DPO, no Pacifica DPO, no refugee, migrant DPO, so all of those groups, out."* (Participant 1, Aotearoa New Zealand)

A participant from Uganda also highlighted significant barriers to engaging disabled people in monitoring, noting that human rights documents, communications, and processes overwhelmingly prioritise the English language. Similar to the situations in Nepal and Aotearoa New Zealand, this practice further marginalises Indigenous language users and disabled people with low literacy. As the Ugandan participant observed, *"Uganda has the best policies and rules for people with disabilities in Sub-Saharan Africa,"* yet the country has 64 recognised Indigenous languages and one of the highest illiteracy rates among disabled people. To exacerbate the issue, Uganda has not yet translated key documents into the national language.

> *"If you come to Uganda, yes, they are ranking Uganda as the best country with the best policies, but these policies, in what? They're in English, and if in English, how many disabled people can talk, hear and understand English?"* (Participant 6, Uganda)

A participant from Bangladesh also reflected on the challenge of engaging Indigenous disabled people, particularly those from rural areas, stating:

> ***"They are not visible. Very few numbers of indigenous people with disabilities are getting education and also involved with the disability movement. That's the great challenge, big challenge." (Participant 5, Bangladesh)***

Overall, participants expressed regret over the ongoing exclusion of these groups, citing systemic issues such as limited funding and resources, geographical barriers, and a lack of education as impediments to their engagement in monitoring processes. They emphasised that unless these structural inequities are addressed, monitoring frameworks will continue to reproduce the very marginalisation they aim to challenge.

Fatigue, Frustration, and Competitiveness

The final collection of challenges described by participants related to a deep sense of fatigue, frustration, and competitiveness among disabled people and their representative organisations. As previously noted, disabled people and DPOs often lack the operational resources and funding to enable them to contribute effectively to monitoring processes. For example, three different participants from Aotearoa New Zealand acknowledged that while much can be achieved without financial resources, the lack of funding and reliance on volunteers from already marginalised populations who lack both time and energy took a significant toll (Participant 2, Participant 7, and Participant 16, Aotearoa, New Zealand).

Interviewer: *"What are the main barriers to Deaf people being involved at that advocacy level, at that government level?"*

Participant: "*They're tired. You need the resources to be able to fight like that. [...] People feel like they're fighting for the same thing over and over and over again, so motivation gets lost."* (Participant 16, Aotearoa New Zealand)

> *"This assumption that disabled people have got all the energy in the world and the time, the capability, the capacity to collectivise, is really, really naive, staggeringly naive, and it's getting harder for organised structures to be created and maintained."* (Participant 2, Aotearoa New Zealand)

It was reported that fatigue and frustration caused by limited resources also led to conflict and competition among disability groups and DPOs, which detracted from their monitoring efforts. For example, participants from Jordan and Bangladesh both noted conflict and rivalry between representative organisations that created additional barriers (Participant 13, Jordan; Participant 5, Bangladesh). Likewise, Participant 2 from Aotearoa New Zealand summarised that competitiveness, division, and conflict are *"the strategy of the people who want no progress"* (Participant 2, Aotearoa New Zealand).

Recommendations and Opportunities for Improvement

Despite the wide range of challenges identified, participants were equally adamant that Article 33, especially the involvement of disabled people and their representative organisations in monitoring, remains vital for the progressive realisation of disabled people's human rights. As one participant from Jordan expressed:

> *"Article 33, it is the soul of the Convention. If we don't have [a] monitoring mechanism [we] will have words on the paper, nothing else. [...] Article 33.3 means that you are watching the government, how they implement the Convention, and through that you have to see where is the weaknesses of the government and [strengthen] them. […] Because government will not monitor the government. Government would say that 'We are perfect,' and they did nothing. So they need civil society, strong people in the civil society."* (Participant 13, Jordan)

The following are the two categories of recommendations derived from the participants' interviews. The first offers guidance to States on improving the implementation of Article 33.3 and increasing disabled people's involvement in monitoring processes. The second section presents recommendations for disabled people and DPOs.

Recommendations for States

Mobilise Resources: As outlined in point 39 of General Comment Number 7, “States parties should support and fund the strengthening of capacity within civil society, in particular organisations of persons with disabilities, to ensure their effective participation in the processes of the independent monitoring frameworks” (CRPD Committee, 2018, p. 8). Across contexts, participants emphasised that effective independent monitoring depends on substantial and, sustained resourcing for DPOs. They highlighted the need for dedicated funding, staffing, training, and support mechanisms, including, where necessary, the creation or strengthening of DPOs to ensure that monitoring structures are genuinely led and operated by disabled people. Adequate government budgeting was viewed as essential not only for enabling DPO participation but also for fostering the systemic mindset shifts required for the meaningful implementation of Article 33.3.

> *“I would advise that the government has to allocate particular budget [...] So if there are resources, and through the resources, if we are able to transform, if we're able to set the mindset of the people and the duty bearers, it will work.” (Participant 3, Nepal)*

Legalise and Regulate DPOs: In some countries, the lack of regulation regarding the legal status of DPOs heightens the risk of corruption, favouritism, cronyism, and underinvestment. However, regulations should be co-designed with DPOs to ensure the protection of their interests under the UNCRPD. Participant 10 from Taiwan declared,

> *“DPOs should be legalised. That is, there should be legislation about DPOs and to regulate DPOs.”*

Sensitise Duty Bearers to Their Obligations Under the Convention: A lack of knowledge regarding duty bearer (government) obligations under the Convention, particularly Article 33.3, contributes to the lack of prioritisation of disabled people’s human rights. Sensitisation, training, and awareness of the government responsibilities contained in the Convention’s Articles were recommended.

"There needs to be more training for the government to understand their obligations with harmonising the Convention within the national laws and legislations that we have." (Participant 11, Papua New Guinea)

Work Collaboratively with DPOs and Researchers: Participants highlighted the importance of robust data and evidence, as well as close cooperation among the government, civil society, and academia in monitoring processes. This involves investing in strengthening DPOS's capacity, supporting academic and statistical agencies to produce disability data and evidence centred on lived experience and barriers, and fostering a government culture that values learning and meaningful input from diverse stakeholders.

> *"I think you've got to invest in the capacity of DPOs, NGOs. You also have to be investing in ancillary producers of ideas and thoughts, like academic bodies, statistical bodies, and get statistical bodies asking the right questions, which is not about prevalence, it's about the obstacles that confront people in their daily lives. And then you've got to get government interested. It's not just in the rhetoric, but in the reality of becoming a learning organisation and being open to all sorts of inputs, seeing it as vital to their own sense of mission. If you get those three working in harmony, you're not going to get them all at the same time. You're not going to be perfect on all three. But if you're tendering in that direction, you're doing extremely well, and that is much more important than periodic reporting to Geneva or New York." (Participant 15, Ireland)*

Employ Disabled people in Meaningful Roles: While noted that employing disabled people in government roles should not replace the independent voice of disabled people and their representative organisations, employing people with lived experience of disability was viewed as beneficial for monitoring structures within the NDIS. Participant 14 from Kenya and Participant 3 from Nepal reached similar conclusions: more disabled people are needed at leadership tables.

"But more importantly is also representation in the leadership fraternity, whereby we have persons with disability sitting in some of these seats, so that as decisions come along, the social location, somebody will be able to pick and point that there are some issues that are being left aside for persons with disability." (Participant 14, Kenya)

"We need more people at the table, on different tables, with different plans." (Participant 3, Nepal)

Recommendations for Disabled people and Their Representative Organisations

While many of the identified challenges arose from structural ableism and disablism in sociopolitical spaces, participants also put forward a range of recommendations that focused on the role of representative organisations and DPOs in strengthening disabled people's leadership in monitoring processes. Below are suggestions for both disabled people and their representative organisations to maximise the potential of Article 33.3 and enhance disability leadership.

Increase Inclusivity and Diversity: One of the most common recommendations was for DPOs and disability collectives, committees, and councils to become more inclusive and diverse. Participants repeatedly noted the absence of certain voices in the monitoring processes. While this absence is mainly due to systemic ableism and disablism enacted by the States, participants also noted that, even without government-led Diversity, Equity, and Inclusion (DEI) initiatives, DPOs could still be more diverse, equitable, and inclusive. This recommendation is especially important for Indigenous disabled people, people with learning (intellectual) disabilities, disabled people living in rural areas, people with psychosocial disabilities, disabled children, disabled refugees, and disabled people who are not actively involved in a DPO.

> *"[T]he monitoring mechanisms should comprise of the diverse people with disabilities, voices and their representative organisations, because each and*

every organisation and each and every individual have their own kind of lived experience, which differs from one individual to another individual. […] We talk about nothing about us, without us, I think this is the crux, unless we are able to accept our diversity within the disability our government is not going to accept us. So the sooner we realise our diversity in terms of impairment and social categories and be collective, only then we can fight this race." (Participant 5, Nepal)

Be Strategic: Building on the call for DPOs to be more diverse and inclusive, participants suggested that disabled people and DPOs take a more strategic approach to upholding Article 33.3 and advancing disabled people's leadership in monitoring processes. As summarised by one participant, *"Yes, we bring everyone on board, but we need a strategic thinking team"* (Participant 1, Aotearoa New Zealand).

For participants, being strategic means:

- Building the knowledge and capacity of disabled people and their representative organisations, including human rights training, so they can lead peer education, participate in monitoring and reporting processes, and effectively engage duty bearers. (Participant 14, Kenya)
- Promoting unified, cross-impairment advocacy by encouraging disability organisations and advocates to move away from impairment-specific approaches towards a broader, rights-based focus that encompasses the entire disability community and enhances the collective influence on policy. (Participant 1, Aotearoa New Zealand)
- Ensuring the independence of DPOs by sourcing funding and resources that are not linked to government budgets or political agendas, allowing them to offer constructive, unbiased scrutiny of a government's progressive realisation of disability rights. (Participant 1, Aotearoa New Zealand; Participant 9, Tanzania)
- Building DPO membership and reach by encouraging and strengthening the connection between disabled people and DPOs, recognising that active engagement with representative organisations enhances understanding of the

Convention and supports more effective participation in monitoring. (Participant 2, Aotearoa New Zealand)

- Learning about government mechanics through practical training that goes beyond the Convention text to include how government systems, decision-making processes, and public agencies operate so that disabled people can engage more effectively in monitoring and advocacy. (Participant 2, Aotearoa New Zealand)
- Identifying and working closely with non-disabled government officials (champions) to leverage awareness and achieve political buy-in (Participant 15, Ireland; Participant 11, Papua New Guinea).
- Embedding peer support and supervision into monitoring activities to safeguard the well-being of disabled monitors, prevent burnout, and ensure sustained participation in long-term monitoring processes. (Participant 4, Aotearoa New Zealand)
- Being committed to the long-term benefits of monitoring by fostering ongoing, structured involvement in disability advocacy rather than relying on short-term or issue-specific engagement. (Participant 2, Aotearoa New Zealand)
- Working collaboratively across disability communities to raise awareness of diverse issues and intersectionality, recognising that sustainable change is better achieved through unified, collective voices rather than isolated organisational or individual efforts. (Participant 5, Bangladesh; Participant 2, Aotearoa New Zealand)
- Leverage monitoring and reporting processes not only for UN reporting but also as strategic tools to shape and influence internal government policy narratives, ensuring that evidence produced is actively used to drive ongoing, timely policy changes instead of being limited to periodic reporting cycles. (Participants 15, Ireland; Participant 4, Aotearoa New Zealand)
- Prioritising robust monitoring data and evidence to ensure fair resource allocation (Participant 14, Kenya).
- Continuing to advocate for disabled people’s leadership in monitoring processes (Participants 3, 2, 7, 12, 17, and 4)

Concluding Comments

This research set out to explore the monitoring experiences of disabled people across different contexts by examining current approaches to Article 33.3, the successes and challenges of its implementation, and opportunities to maximise its potential and enhance disabled people's leadership in monitoring efforts.

Participants were unable to identify any government that they believed was fully and effectively meeting its obligations under Article 33.3. Although some monitoring successes have been, often linked to government buy-in, disability leadership, and education and awareness efforts, these were limited. Overall, the challenges and setbacks described by the participants far outweighed any perceived progress. They consistently highlighted the lack of government prioritisation of disability issues and monitoring processes, leading to chronic shortfalls in resources, funding, training, awareness, and meaningful employment opportunities for disabled people.

Participants also emphasised that these shortcomings are often rooted in detrimental ideologies and practices. Outdated models of disability, favouritism and cronyism, and the resulting corruption were identified as contributing factors. Regarding DPOs, many participants described organisational structures and monitoring processes as unnecessarily exclusive, often characterised by fatigue, frustration, and competitiveness among disability cohorts and representative organisations.

Despite this, the participants expressed a strong appreciation for the intent and potential of Article 33.3 and identified a range of opportunities for improvement. For States, recommendations included mobilising adequate resources, legalising and regulating DPOs, sensitising duty-bearers to their responsibilities under the Convention, fostering closer collaboration between government, DPOs, and academia, and employing more disabled people in meaningful roles within the government.

Participants also made recommendations for DPOs, including broadening diversity and inclusion efforts and adopting more strategic approaches to Article 33.3 of the CRPD. Many expressed a desire to connect with other disabled monitors globally to share

successes, challenges, and strategies and to support each other in the collective effort to promote the human rights of all disabled people everywhere.

In summary, this study has highlights the urgent need for increased financial, structural, and educational investment to secure and enhance the leadership of disabled people in monitoring processes. Such investments must come from both States and independent sources to mitigate the risks of favouritism, cronyism, and corruption. Moving forward, it is imperative that the opportunities for improvement identified by participants are prioritised by States and supported by NHRIs, IGOs, and NGOs.

As the Fellowship's namesake, Judith Heumann, famously stated,

> ***"I wanna see a feisty group of disabled people around the world… if you don't respect yourself and if you don't demand what you believe in for yourself, you're not gonna get it."***

The findings and recommendations of this research echo that call, demanding that governments and civil society renew their commitment to Article 33.3, harness its potential, and redefine the leadership of disabled people in monitoring processes. Although brief, Article 33.3 affirms disabled people's right to participate in monitoring the implementation of their own human rights and to hold their governments accountable. This research shows that, while implementation varies across socio-political contexts and State commitment, without an intentional and active focus on Article 33.3, State accountability is likely to be either absent or controlled by non-disabled people; both outcomes risk eroding hard-won advances in disability rights. As one participant powerfully observed, Article 33.3 is the *"soul of the Convention"* (Participant 13, Jordan), and, as another summarised,

> ***"When we stay silent, nothing will happen" (Participant 14, Kenya).***

Acknowledgements

Thank you to all who so generously contributed to this important research project, and who continue to hold their governments to account and speak truth to power.

Participants:

- Adnan Alaboudy (Participant 13, Jordan)
- Bernard Mwangi (Participant 14, Kenya)
- Fon Cletus Tita (Participant 12, Cameroon)
- Gerard Quinn (Participant 15, Ireland)
- Huhana Hickey (Participant 1, Aotearoa New Zealand)
- Ipul Powaseu (Participant 11, Papua New Guinea)
- Jonathan Godfrey (Participant 2, Aotearoa New Zealand)
- Kayanga Peter (Participant 6, Uganda)
- Monica Leach (Participant 16, Aotearoa New Zealand)
- Msafiri Ngololo (Participant 8, Tanzania)
- Nazma Ara Begum Poppy (Participant 5, Bangladesh)
- Nyamlanga Lwakatare (Participant 9, Tanzania)
- Pratima Gurung (Participant 3, Nepal)
- Prudence Walker (Participant 7, Aotearoa New Zealand)
- Shane McInroe (Participant 17, Aotearoa New Zealand)
- Umi Asaka (Participant 4, Aotearoa New Zealand)
- Wang Shiou-Wu (Participant 10, Taiwan)

A special thank you to the World Institute on Disability for providing funding, resources, guidance, and connections to make this research possible, and the Donald Beasley Institute for ongoing support and commitment to building the capacity of disabled researchers and disabled person-led monitoring. A final thank you to the Disability Justice Project for supporting the creation of a short documentary to showcase the findings of this research.

About The Global Heumann Fellowship

Creating a Global Bridge to the Future



fellowship@wid.org

The WID Global Heumann Fellowship Program honors WID co-founder Judy Heumann's enduring legacy by empowering disability leaders and advocates worldwide to advance disability rights and justice within their regional communities. Through this program, fellows will work on impactful projects aimed at fostering equity, inclusion, and justice globally. Their responsibilities include conducting research, drafting a white paper, cultivating relationships, driving collaborative opportunities, and contributing to program development aligned with WID's mission and strategic focus areas.

During a twelve-month fellowship term, each fellow will engage in a unique combination of opportunities for thought leadership on national and global policy, research strategies, advocacy, program development, and contributions to initiatives aimed at advancing the rights of persons with disabilities globally. Fellows will focus on identifying and leading research with the support of WID, as it regards the fellow's respective region, expertise, and collaboration with WID.

For more information on the Global Heumann Fellowship's Requirements, Eligibility, and to Apply, visit: https://wid.org/global-heumann-fellowship/

To become a Corporate Sponsor, please visit: https://wid.org/corporate-partnerships/

About World Institute on Disability

The World Institute on Disability (WID) was established in 1983 as one of the first global disability rights organizations founded and continually led by people with disabilities.

We are proud of our history, including our founders – Disability Rights Movement leaders Ed Roberts, Judy Heumann, and Joan Leon. We are dedicated to designing, building, and supporting whole community solutions by removing barriers to include people with disabilities.

To build a more inclusive global society, the World Institute on Disability (WID):

- Helps assure that products and services are more accessible
- Promotes equity policies
- Provides consulting services
- Offers training and tools
- Supports emergency, disaster, and climate efforts

Our Mission is to, on a global scale, to continuously advance the rights and opportunities of more than one billion people with disabilities.

Our Vision is a world in which people with disabilities live freely where access, inclusion, equity, and resilience are embedded throughout every global community.

Find us on the web and join us on social media!

https://wid.org

https://www.linkedin.com/company/world-institute-on-disability/

https://www.instagram.com/worldinstituteondisability/?hl=en

https://www.facebook.com/WorldInstituteonDisability/

References

Aichele, V. (2018). Article 33 national implementation and monitoring. In I. Bantekas, M. Ashley Stein, & D. Anastasiou (Eds.), *The UN Convention on the Rights of Persons with Disabilities: A Commentary*. Oxford. https://doi.org/10.1093/law/9780198810667.003.0034

Al Ju'beh, K. (2017). *Disability inclusive development toolkit*. CBM. https://cbm-global.org/wp-content/uploads/2022/05/CBM-DID-TOOLKIT-accessible.pdf

Asselin, M. E. (2003). Insider research: Issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Staff Development, 19*(2), 99-103. https://doi.org/10.1097/00124645-200303000-00008

Barnes, C. (2008). *Disability and the academy: A British perspective.* Paper presented at the Le Handicap: Un Moteur Pour Les Sciences Sociales, Paris, France. https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-paris-presentation.pdf

Berne, P. (2015). *Disability Justice - a working draft by Patty Berne*. Sins Invalid. https://static1.squarespace.com/static/5bed3674f8370ad8c02efd9a/t/6329eb83b478e84b6a2502ba/1663691651875/Patty_Berne_DJ-Working-Draft.docx.pdf

Best, K. L., Mortenson, W. B., Lauzière-Fitzgerald, Z., & Smith, E. M. (2022). Language matters! The long-standing debate between identity-first language and person first language. *Assistive Technology, 34*(2), 127–128. https://doi.org/10.1080/10400435.2022.2058315

Biernacki, P., & Waldorf, D. (1981). Snowball sampling: Problems and techniques of chain referral sampling. *Sociological Methods and Research, 10*(2), 141-163. https://doi.org/10.1177/004912418101000205

Birtha, M. (2013). 'Nothing about CRPD monitoring without us': A case study on the involvement of the disability movement in policy-making in Zambia. In C. Ngwena, I. Grobbelaar-du Plessis, H. Combrinck, & S. Djoyou Kamga (Eds.), *The African disability rights year book*. Southern African Legal Information Institute. https://www.saflii.org/za/journals/ADRY/2013/6.html?utm_source=chatgpt.com

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101. https://doi.org/10.1191/1478088706qp063oa

Committee on the Rights of Persons with Disabilities. (2018). *General comment No. 7 (2018) on the participation of persons with disabilities, including children with*

disabilities, through their representative organizations, in the implementation and monitoring of the Convention CRPD/C/GC/7. United Nations. https://digitallibrary.un.org/record/3899396?ln=en&v=pdf

Davis, L. J. (Ed.) (2013). *The disability studies reader (4th ed.)*. Taylor and Francis.

de Beco, G. (2013). *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*. Brill. https://doi.org/10.1163/9789004220829

Division for Inclusive Social Development. (2022). *Introducing the United Nations Convention on the Rights of Persons with Disabilities*. https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2022/01/Introducing-CRPD-English-.pdf

ESCWA (2022). *Statistical Terms Glossary*. https://www.unescwa.org/sd-glossary?combine=duty+bearer&domain=All

Hickey, H. (2015). Marginalizing the subaltern within: How to effectively engage with and monitor diverse cultural identities with disabilities when individual identity dominates the collective identity framework. In M. H. Rioux, P. C. Pinto & G. Parekh (Eds.), *Disability, Rights Monitoring and Social Change Building Power Out of Evidence,* (pp. 221-236). Canadian Scholars' Press.

Hiratsuka, T. (2025). The volunteer participation paradox: Ethical tensions between self-selection and targeted sampling. *Research Methods in Applied Linguistics*, *4*(2), 100206. https://doi.org/10.1016/j.rmal.2025.100206

Lawrence, A. (2012). Electronic documents in a print world: Grey literature and the internet. *Media International Australia, 143*(1), 122-131. https://doi.org/10.1177/1329878X1214300114

Lewis, T. (2022). Working definition of ableism - January 2022 Update. https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update

Lim, W. M. (2024). What Is Qualitative Research? An Overview and Guidelines. *Australasian Marketing Journal*, *33*(2), 199-229. https://doi.org/10.1177/14413582241264619

Liu, H. (2025). Effective participation in the international monitoring of the UNCRPD? The experience of the disability movement from three case studies in Europe. *Scandinavian Journal of Disability Research 27*(1): 30–43. https://sjdr.se/articles/10.16993/sjdr.1055

Manca, L. (2017). Article 33 National Implementation and Monitoring. In V. Della Fina & G. Palmisano (Eds.), *The United Nations Convention on the Rights of Persons with Disabilities a commentary,* (pp. 591–606). Springer.

McKim, C. (2023). Meaningful member-checking: A structured approach to member-checking. *American Journal of Qualitative Research*, *7*(2), 41-52. https://www.ajqr.org/download/meaningful-member-checking-a-structured-approach-to-member-checking-12973.pdf

Nadler, J., & Schulman, M. (2006). *Favoritism, cronyism, and nepotism*. Santa Clara Markkula Center for Applied Ethics. https://www.scu.edu/government-ethics/resources/what-is-government-ethics/favoritism-cronyism-and-nepotism/#q1

Office for Disability Issues (2016). *New Zealand Disability Strategy 2016-2026*. https://www.whaikaha.govt.nz/about-us/programmes-strategies-and-studies/programmes-and-strategies/new-zealand-disability-strategy

Office of the High Commissioner for Human Rights. (2001). *Training manual on human rights monitoring*. United Nations. https://www.ohchr.org/sites/default/files/Documents/Publications/training7Introen.pdf

Office of the High Commissioner for Human Rights. (2011). *Manual on human rights monitoring* (revised edition). United Nations. https://www.ohchr.org/en/publications/policy-and-methodological-publications/manual-human-rights-monitoring-revised-edition

Olkin, R. (1999). The personal, professional and political when clients have disabilities. *Women & Therapy, 22*(2), 87-103. https://doi.org/10.1300/J015v22n02_07

Oxford Learner's Dictionary. (2025). *Monitor*. Oxford University Press. https://www.oxfordlearnersdictionaries.com/definition/american_english/monitor_2

Miller, P., Parker, S., & Gillinson, S. (2004). *Disablism: How to tackle the last prejudice*. Demos.

Patton, M. Q. (2002). *Qualitative research and evaluation methods.* (3rd ed.). Sage Publications.

Perlin, M. L. (2012). Promoting social change in Asia and the Pacific: The need for a disability rights tribunal to give life to the U.N. Convention on the Rights of Persons with Disabilities. *The George Washington International Law Review,*

44(1), 1-37. https://digitalcommons.nyls.edu/cgi/viewcontent.cgi?article=2101&context=fac_articles_chapters

Perlin, M. L. (2014). "The ladder of the law has no top and no bottom": How therapeutic jurisprudence can give life to international human rights. *International Journal of Law and Psychiatry, 37*(6), 535-542.

Pinto, P. C. (2015). Conclusion: Debating disability rights monitoring: Strengths, weaknesses, and the challenges ahead. In M. H. Rioux, P. C. Pinto & G. Parekh (Eds.), *Disability, Rights Monitoring and Social Change Building Power Out of Evidence,* (pp. 277-286). Canadian Scholars' Press.

Samson, R. M. (2015). Securing the full participation of persons with disabilities and their representative organizations in disability rights monitoring. In M. H. Rioux, P. C. Pinto & G. Parekh (Eds.), *Disability, Rights Monitoring and Social Change Building Power Out of Evidence,* (pp. 237-248). Canadian Scholars' Press.

Series, L. (2020). Disability and human rights. In N. Watson & S. Vehmas (Eds.), *Routledge Handbook of Disability Studies (Second Edition),* (pp. 72 - 88). Routledge.

Smart, J. F. (2009). The power of models of disability. *Journal of Rehabilitation, 75*(2), 3-11.

Tan (陳信宏), A. (陳信宏), A. (2023). *A brief look at detrimental ideologies.* https://doi.org/10.31219/osf.io/65jpc

Taylor, J. (2011). The intimate insider: Negotiating the ethics of friendship when doing insider research. *Qualitative Research, 11*(1), 3-22. https://doi.org/10.1177/14687941103844

United Nations. (2006). *Convention on the Rights of Persons with Disabilities – Articles*. United Nations Depart of Economic and Social Affairs Disability. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html.

United Nations. (2025). *Depositary.* United Nations treaty collection. https://treaties.un.org/pages/viewdetails.aspx?src=treaty&mtdsg_no=iv-15&chapter=4&clang=_en

United Nations Human Rights Office of the High Commissioner. (2025). *Economic, social and cultural rights.* https://www.ohchr.org/en/human-rights/economic-social-cultural-rights

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities past, present and futures.* Jessica Kingsley.

Watene, R. F., Mirfin-Veitch, B., & Asaka, U. (2023a). Disabled person-led monitoring of the UNCRPD in Aotearoa New Zealand: Maximising the potential of civil society in the implementation of Article 33.3 85. In S. Robinson & K. R. Fisher (Eds.), *Research Handbook on Disability Policy,* (pp. 85 -99). Edward Elgar Publishing.

Watene, R. F., Mirfin-Veitch, B., & Asaka, U. (2023b). Disabled person-led monitoring: Bringing life to Article 33.3 of the UNCRPD. *Disability & Society, 38*(5), 737–760. https://doi.org/10.1080/09687599.2021.1921701

Williams, B. (n.d.). *Maximum variation sampling in qualitative research guide*. Insight7. https://insight7.io/maximum-variation-sampling-in-qualitative-research-guide/

Appendix A – Glossary of Terms

Ableism: A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and physical fitness. These constructed ideas are deeply rooted in eugenics, anti-blackness, misogyny, colonialism, imperialism, and capitalism" (Lewis, 2022).

Cronyism: Partiality towards friends and associates (Nadler & Schulman, 2006).

Disablism: The "discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others" (Parker & Gillinson, 2004, p. 9).

Duty Bearer: Actors who have a particular obligation or responsibility to respect, promote, and realise human rights and to abstain from human rights violations, while rights holders are the holders of said rights (ESCWA, 2022).

Favouritism: Favouring a person because of an extraneous feature-membership in a favoured group (Nadler & Schulman, 2006).

Grey Literature: Information produced by governments, academia, businesses, service providers, non-governmental organisations, and industry, that is not commercially published and/or where publishing is not the primary activity of the producing body, including technical and project reports, working papers, discussion papers, manuals, information sheets, and conference papers (Lawrence, 2012).

IGOs: International Government Organisations.

Learning Disability: Instead of intellectual disability, learning disability is the preferred terminology of People First, a group of self-advocates with learning disabilities in Aotearoa New Zealand and globally.

NGOs: Non-Governmental Organisations.

NHRI: National Human Rights Institutions.

Pākehā: New Zealander of European descent

Snowball Sampling: A recruitment technique used in academic research, where current participants recruit new participants.

Tangata Tiriti: Non-Māori person of te Tiriti o Waitangi - the founding document of Aotearoa New Zealand; an agreement between Māori and the British Crown.