Social Inclusion
2025 • Volume 13 • Article 9105
https://doi.org/10.17645/si.9105

ARTICLE

Open Access Journal

Public Participation in the Time of Covid-19: Response From the International Disability Movement

Hanxu Liu [1] and Claudia Coveney [2]

[1] Care and Public Health Research Institute, Maastricht University, The Netherlands
[2] School of Sociology and Social Policy, University of Leeds, UK

Correspondence: Hanxu Liu (hanxu.liu@maastrichtuniversity.nl)

Submitted: 31 August 2024 **Accepted:** 15 January 2025 **Published:** 11 March 2025

Issue: This article is part of the issue "Public Participation Amidst Hostility: When the Uninvited Shape Matters of Collective Concern" edited by Olga Zvonareva (Maastricht University) and Claudia Egher (Utrecht University), fully open access at https://doi.org/10.17645/si.i419

Abstract

This article examines attempts by the international disability movement to influence Covid-19-related policy by becoming involved in high-level decision-making processes and advocacy activities. Global emergencies like the Covid-19 pandemic limit opportunities for citizen engagement in governance. Like other marginalised groups, persons with disabilities faced increased exclusion in this period, including barriers and lack of opportunities to participate in public decision-making processes via civil society. The de-prioritisation of their lives and opinions was evident in many countries' initial approaches to containment and treatment, contributing to an excess risk of death among persons with disabilities. International legal instruments like the UN Convention on the Rights of Persons with Disabilities, ratified by 191 (state) parties, affirm persons with disabilities' right to participate in all public affairs as crucial for their equality and inclusion. This article defines the scope of public participation of persons with disabilities under international human rights law and employs a document analysis of public and grey literature from civil society organisations and international institutions of governance. This analysis examines the barriers preventing persons with disabilities from participating in Covid-19-related policy and decision-making and explores how a representative organisation—the International Disability Alliance—utilised existing channels and created new spaces to amplify their voices globally. To do this, we utilise the concept of "invited and invented space" and demonstrate the strategic response of the movement to barriers to public participation during the global pandemic.

Keywords

Covid-19; disability rights; emergency policymaking; international disability movement; public participation

1. Introduction

In this article, we focus on the public participation of persons with disabilities and their representative organisations in decision-making and policy settings concerning the Covid-19 pandemic. Within international human rights instruments, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), the term “barriers” is used to describe economic, social, political, and environmental phenomena that hinder the “full and effective participation and inclusion in society” of persons with disabilities in everyday lives. Barriers to participation can be observed in contexts ranging from research activities, reproductive choice, education, employment, political participation, and community life, to intimate relationships and end-of-life decisions (see, e.g., Kim et al., 2016; Plosky et al., 2022; Priestley et al., 2016). In keeping with disability studies and legal frameworks, our focus is on the barriers experienced by persons with disabilities during the pandemic, specifically those relating to participation in public decision-making. In this context, we also examine the response of an international organisation of persons with disabilities (OPD)—the International Disability Alliance (IDA), especially its efforts to influence the international decision-making processes related to Covid-19. The international monitoring body of UNCRPD—the Committee on the Rights of Persons with Disabilities (CRPD Committee)—has defined OPDs as those “led, directed and governed by persons with disabilities,” who have been the main participants in disability rights movement (CRPD Committee, 2018, para. 11; Sabatello, 2013). Here we examine the dynamics of international commitments and the obligations stipulated in international human rights law and governance to include and consult OPDs on policy matters concerning disabled people in the pandemic.

Reflecting on Zvonareva and Egher’s (2025) discussion in the introduction to this thematic issue on indirect hostilities to participation, being those that “operate to limit or circumscribe participation to particular pre-framed questions, controlled formats, or selected groups,” and “justifying selective invitations for some and uninvitations of others who are framed as having less right to participate,” we find parallels with discussions in disability studies around exclusion and tokenistic inclusion (see also, e.g., Farooqi & Ali, 2023; Friedman et al., 2016). We return to the relationship between “indirect hostilities” and disability-related barriers at the end of this article.

Disabled populations were constructed as a particularly vulnerable group during the pandemic globally (Perry et al., 2020). In some cases, this was due to pre-existing health conditions that would exacerbate the impact of the virus on some groups. In other cases, vulnerability stemmed from the living conditions of groups of persons with disabilities—for example, those living in large-scale institutions, or from unequal outcomes due to health inequity experienced by persons with disabilities. Examining the experience of disabled people in Covid-19 responses, Shakespeare et al. (2021) find their exclusion from crucial services such as food deliveries, Covid-19 testing, and the internet. The authors highlight a de-prioritisation of disabled people and their families or support workers in vaccination and treatment schemes and a particular failure to ensure the safety of disabled people in institutionalised living settings. This is the context in which civil society organisations representing the interests of disabled people were conducting advocacy work during the pandemic. The participation of organisations representative of persons with disabilities was therefore particularly pertinent in decision-making processes during the pandemic.

2. International Legal and Governance Context

The international political movement of disabled people has a documented history of collective action and strategic mobilisation, as reflected in their decisive role in the creation of the UNCRPD (Driedger, 1989; Sabatello, 2013; Trömel, 2009). As we will elaborate later in this article, much of this international movement is present within the ranks of the IDA. IDA works closely with supranational organisations such as the UN in disability rights and affairs, aligning its activities with those of the UNCRPD (IDA, 2024). IDA was established in 1999 as a network of global and, since 2007, regional organisations of persons with disabilities and their families. Together with its member organisations, IDA attempts to influence legislation, fund programmes, and advocate for disabled people around the world. The present section outlines the legal and policy context of the participation of OPDs during Covid-19.

According to international policies and human rights norms set before the Covid-19 pandemic, countries have the legal and political obligation to involve persons with disabilities, through OPDs, in decision-making, implementation, and monitoring processes related to the Covid-19 pandemic, including its prevention, mitigation, preparedness, response, and recovery plans. The UNCRPD is the main international normative framework on disability human rights protection. This legally binding instrument represents a paradigm shift to the human rights model in disability policy, recognising persons with disabilities as subjects of rights rather than as objects of charity, medical treatment, and welfare policies, as is the traditional approach to disability (Degener, 2017; Lawson & Beckett, 2020). As of 2023, only a few UN member states, including the USA, have not ratified the UNCRPD. Articles *4*(3) and *33*(3) of the UNCRPD envisage a general obligation for states to "closely consult with and actively involve persons with disabilities" in the development, implementation, and monitoring of laws and policies relating to the UNCRPD, and in other general decision-making processes "concerning issues relating to persons with disabilities."

The obligation to consult people with disabilities applies to biological disasters such as epidemics and pandemics, as well as other situations of risk and humanitarian emergencies under Article 11 of the UNCRPD (Lewis, 2020). Specifically, this obligation should be conducted through the representative OPDs, including representative organisations of children with disabilities (CRPD Committee, 2018). States and humanitarian actors are required to ensure "the active participation of and coordination and meaningful consultation" with a diverse group of OPDs in the planning, implementing, and monitoring of emergency-related laws and policies (CRPD Committee, 2018, para. 78). Several international policies have incorporated this principle. The Sendai Framework for Disaster Risk Reduction 2015–2030 emphasises that all disaster risk reduction policies and practices should be inclusive and accessible to people with disabilities as a general principle. This intergovernmental document, adopted by a majority of UN member states (187), aims to guide national, regional, and international actions for disaster risk reduction in 15 years (UN Office for Disaster Risk Reduction [UNDRR], 2015). It applies to the risk of a range of disasters caused by natural or man-made hazards, including biological hazards such as epidemics and pandemics. Disaster risk governance involves several key phases, including "prevention, mitigation, preparedness, response, recovery and rehabilitation" (para. 26). States are obliged to engage with OPDs in the design and implementation of policies, plans, and standards at all levels of the government, as well as provide disaggregated data based on disability, among others, to form the basis of "inclusive risk-informed decision-making" (UNDRR, 2015, para 19; see also Lewis, 2020). Inclusion and participation of persons with disabilities is also one of the main working areas of the 2030 Agenda for Sustainable Development Goals (SDGs) under the principle of "leaving no one behind" and underpinned by human rights (UN General Assembly, 2015). The SDGs provide "a comprehensive blueprint for [a] sustainable recovery from the pandemic" (UN, 2020b).

In the international policy guidance and advice issued in relation to the Covid-19 response and persons with disabilities, the UN and its agencies have reiterated the importance of the participation of OPDs in the relevant policymaking process (see, e.g., UN, 2020a; UN Department of Economic and Social Affairs [UNDESA], 2023; for a detailed review see also Lewis, 2020). As a principle, engagement with and participation of persons with disabilities and OPDs in Covid-19-related decision-making should be followed by all UN entities.

3. Existing Research: Civil Society, Engagement, and Covid-19

We situate our investigation into the international disability movement alongside perspectives on civil society engagement in periods of crisis in governance. The following section contextualises our investigation in terms of relevant research relating to civil society participation during the pandemic, particularly its underutilisation, and strategies used by organisations to overcome these barriers—including the channels they used to do so. We discuss what is known about civil and community engagement in the context of Covid-19: namely that engagement, despite being critical during emergencies and crucial for ensuring context-relevant responses, was not used in most cases by governments in their responses to the pandemic (Sahoo et al., 2023). We use this literature to demonstrate that what Zvonareva and Egher (2025) identify in the introduction to this thematic issue can be found in the context of international civil society engagement in governance processes: Despite discursive support for public participation (via representative civil society organisations), in practice this participation is often limited by institutions of governance rather than enacted meaningfully.

In the early international response to the Covid-19 pandemic, contexts where civil society was activated and empowered to contribute to responses to the pandemic showed better outcomes in terms of service delivery, health and prevention messaging, and localised responses in communities relative to contexts where civil society was blocked from participating or ignored in government responses to the pandemic (Kövér, 2021; Sayarifard et al., 2022). Writing for the World Health Organisation (WHO), Rajan and Koch (2020, p. 27) found that, across national contexts, "civil society and community groups were poorly or not at all represented on Covid-19 advisory task forces" and these task forces "largely involved governments telling communities what to do, seemingly with minimal community input." Garcia et al. (2023) discuss the consequences of reduced revenue and access to funding for civil society during the pandemic and note that where collaboration between civil society and local governments did occur it opened up new roles for civil society. Civil society and community groups offer services including risk communication and peer support and contribute particular knowledge and legitimacy resources to government decisions but were not largely utilised by policymakers. Rajan et al. (2021) pointed to the success of systems where participation mechanisms for civil society improved the efficacy of government responses to the pandemic. Discussing the "anchoring" of participatory mechanisms, Rajan et al. (2021) note the importance of legal frameworks and adequate, ongoing funding for such interactions. However, the "default" mode of governance in most contexts ignored the contribution of civil society "where trust in institutions and adherence to virus mitigation measures can make or break the success of the pandemic response" (Rajan et al., 2021, p. 28; see also Falanga et al., 2021; Marston et al., 2020). Focusing on the participation of people with disabilities and their representative organisations, McVeigh et al. (2021) note that, on top of the barriers other groups face, OPDs face specific barriers to participation, including “poverty, lack of education, social isolation, stigma and discrimination, lack of disability-accessible processes, and legal barriers” (p. 214). The authors conclude that people with disabilities and OPDs experience systemic exclusion from decision-making and consultation on policies, practices, and services that affect their lives. This contributes to unequal access to political processes and results in political disablement.

Examining the impact of the pandemic on civil society participation relating to migrants, Rother (2022) notes that hostilities towards a rights-based approach to migration intensified. This is despite these local groups being embedded in communities and well-placed to access those disproportionately affected by the pandemic including older people, disabled people, single parents, and migrants. Rother (2022) examines the structures of political opportunity for civil society that have been created by institutions of governance (where civil society is “invited”) on the one hand and, on the other, those created by civil society itself (which civil society has “invented”). Paying attention to specific transformations in communication during the pandemic—like the “zoomification” of meetings—Rother notes that some of these developments increased openness and inclusivity for civil society. Both “invited” and “invented” spaces for civil society grew in scope and depth during the pandemic and have likely created permanent new spaces for migrant civil society despite noted barriers. Such a study has yet to be conducted on the disability advocacy movement. Using Rother’s (2022) framework, in this contribution to the literature, we examine how invited spaces have been used by a key international disability advocacy organisation to address the exclusion faced by disabled people and OPDs during the pandemic. We focus on the activity of the international disability movement and international governance structures to examine how the movement used existing modes of participation to create new spaces to advocate for the rights and wellbeing of disabled people in the Covid-19 context. We add the perspective of the disabled people’s movement to this examination of specific group experiences of barriers in the pandemic and explore how the UNCRPD as a framework was upheld or contested. We also investigate the emergence of invented spaces and the strategies used by a key disability advocacy organisation to utilise and create channels of participation and influence Covid-19 policy decisions.

We have established that disabled populations globally were disproportionately impacted during the pandemic (particularly those living in institutions) and that disabled people and OPDs face additional barriers to participation in comparison to other civil society organisations. We argue that these two factors warrant an examination of the particular experiences of OPDs in the context of public decision-making during the Covid-19 pandemic, particularly the strategies they have employed to participate amid barriers. We can understand civil society as the primary conduit for formal participation by social movements like the international disability movement in governance (see Della Porta, 2020). We will look at the response of the movement via its international civil society representative (IDA) in the context of international policymaking processes during Covid-19. This leads to the particular research question we attend to in this article:

> How did the international disability movement respond to barriers to participation encountered by persons with disabilities during the Covid-19 pandemic in international policymaking processes?

4. Methodology

Following the main research question, we conducted a document analysis of grey literature and UN documents to examine the participation of IDA in Covid-19 policy decisions in international organisations. Grey literature refers to materials and research produced by relevant organisations outside of traditional academic publishing and distribution channels.

An analysis of documents and grey literature is appropriate here to analyse activities by the disability movement that were not covered in extant academic research (Bowen, 2009). We selected relevant grey literature and other documents from the start of the pandemic, the very end of 2019, until the end of 2022 to capture the fullness of policy responses and the international disability movement's activity over the initial and later stages of the pandemic. Key policymaking events in the Covid-19 timeline will be reviewed in the next section.

We selected a representative international OPD as our focus. IDA is an international "umbrella" disability advocacy organisation. "Umbrella" here refers to the structure of the organisation: Its members are global and regional organisations of disabled people and their families. In turn, these organisations consist of regional, national, and local OPDs. At the time of writing, IDA membership consisted of six regional (Africa, Americas, Asia, Europe, Middle East and North Africa, and Pacific) and eight global ODPs representing persons with disabilities and their families in over 200 countries and territories. Global ODPs include the World Blind Union and the World Network of Users and Survivors of Psychiatry; regional members include the African Disability Forum and the European Disability Forum. IDA is governed by its full members and through the IDA Board, which is made up of representatives from each of its full members. All IDA members are organisations majority-led by and composed of persons with disabilities and their families. IDA is recognised to be an organisation representative of the wider disability movement, acknowledging no one organisation can represent every faction of a social movement. Nevertheless, this organisation is a major and key representative organisation of the international disability rights movement, particularly noted for its instrumental role alongside its member organisations in the creation of the UNCRPD (IDA, 2024; Sabatello & Schulze, 2013; Trömel, 2009). Nowadays, IDA activities span from high-level advocacy work with the UN system and other UN agencies like the WHO to ensure actions align with the principles of the UNCRPD and to work with states and other NGOs to mainstream the rights and interests of persons with disabilities in other human rights and development initiatives (IDA, 2024; WHO, 2024;).

The activities of IDA, including its member organisations, are comprehensively documented on its website (https://www.internationaldisabilityalliance.org). The Office of the High Commissioner of Human Rights (OHCHR) website, the World Bank Open Knowledge, and repository searches were also used for searching. The search function of each website was used by combining the keywords "COVID(-19)," "persons with disabilities," and/or "disability(-ies)." The search results were reviewed and further narrowed down according to the configured filters, including the time period (2019–2022) and the group of rights and persons. After that, only results related to the participation and involvement of OPDs were selected: 89 documents were divided into five categories and analysed, as shown in Table 1. Finally, the documents were coded and analysed under three themes (*barriers*, *participation in Covid-19 policymaking*, and *actions*), which were identified according to the research question. The coding processes also identified a couple of new themes related to the strategies used by IDA and other OPDs.

Table 1. UN documents and grey literature selected for document analysis.

Document type	Number
Concluding observations issued by three UN treaty bodies	29
UN news, statements, and resources	14
World Bank document/research	1
Output from or contributed by IDA and its member organisations	45

5. Findings

The findings draw attention to two themes: (a) the barriers encountered by persons with disabilities during Covid-19, which hindered their participation in decision-making processes, and (b) the strategies employed by IDA in order to influence international decision-making processes to address these barriers. Additionally, the findings discuss the organisation's role in relevant international decision-making bodies and the corresponding responses it received. In conversation with existing literature, in particular the concepts of "invited" and "invented" spaces for civil society participation in global governance (Rother, 2022), we will delineate how IDA utilised both spaces to participate in international policymaking processes despite the barriers to public participation experienced by disability communities.

5.1. An Overview of Key Actions From IDA

IDA has actively responded to the challenges posed by the global pandemic. Most of its major actions and campaigns were launched in 2020, coinciding with the global policy responses to the pandemic, and continued until 2021 (see Figure 1). The organisation released the document *Ten Recommendations on Disability-Inclusive Covid-19 Response* (hereinafter, Ten Recommendations) a few days after the WHO announced the Covid-19 outbreak as a global pandemic (IDA, 2020a). The Ten Recommendations were compiled based on inputs received from IDA members around the world at all levels, in response to the pandemic and its "disproportionate impact on persons with disabilities" (IDA, 2020a). This document serves to reveal the common main barriers faced by persons with disabilities and to offer practical recommendations to ensure their inclusion in the Covid-19 response and its practice. It focuses on four themes: access to preventive measures, vital service provisions in restrictive programmes, seeking health care, and the participation of local and national OPDs in decision-making and implementation processes. IDA emphasises the key role of local and national OPDs in the Covid-19 response, such as raising awareness about the pandemic among members and advocating for disability inclusion in national and local crisis response policies and implementation.

The Ten Recommendations represent the two working areas of IDA during the pandemic, namely accessibility and disability non-discrimination. Together with its members and allies, IDA later carried out four campaigns with specific themes (see Table 2), namely the Accessibility Campaign, the End-Discrimination Campaign, the Rebuilding an Inclusive Future for All Campaign, and the Persons with Disabilities and Access to Covid-19 Vaccination Campaign (hereinafter, Access to Vaccination Campaign). These campaigns were based on the working areas and themes highlighted in the Ten Recommendations. IDA has engaged in five types of transnational advocacy activities, including research and publications, reporting, capacity building, media campaigns, and coordinating the global disability movement. In terms of

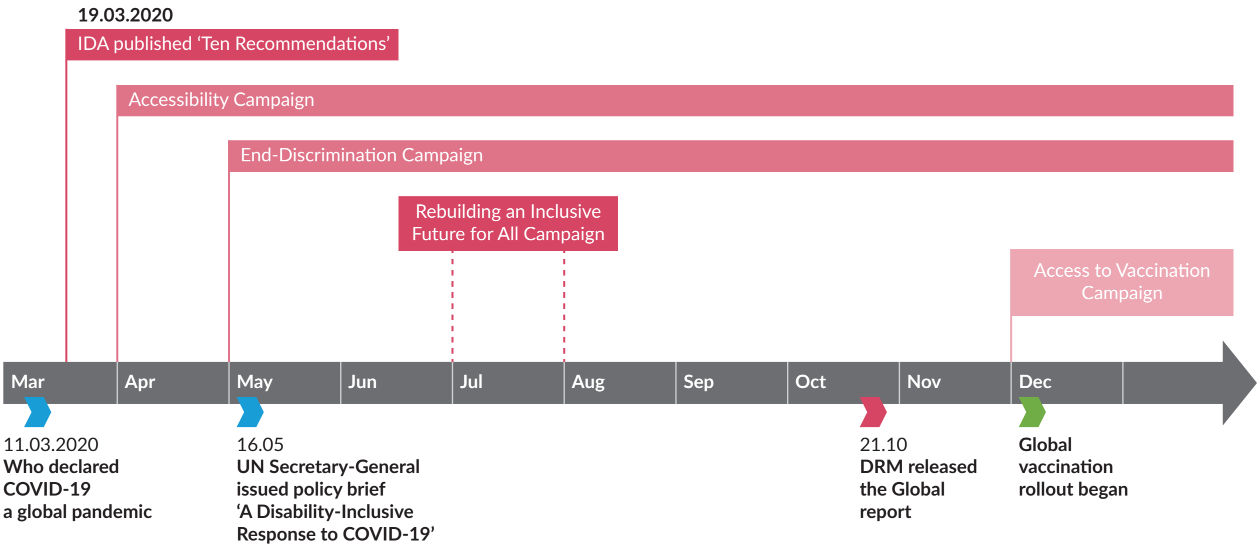

Figure 1. Timeline of Covid-19 and main campaigns from IDA in 2020.

Table 2. An overview of IDA's public campaigns.

	Activities	Demands	Audiences
Accessibility Campaign	open letters, social media campaign toolkits	access to all public information and communication at the UN system and among its Member States	High-level officers at the UN system
End-Discrimination Campaign	open letters, social media campaign toolkits, oral statements, written submission	end discrimination against disability that existed in Covid-19 response and recovery policies, including public health, economic and social policy, and healthcare measures	UN member states, health service providers, and other relevant actors
Rebuilding an Inclusive Future for All Campaign	oral statements, NGO side events	disability inclusion in general SDG-related emergency response policy, including implementation and monitoring of Covid-19 response and recovery practice	UN system, member states, and other attendees of the 2020 High-Level Political Forum on Sustainable Development
Access to Vaccination Campaign	Social media campaign toolkits, toolkits for national advocacy, capacity-building, coordinating global disability movement	priority, accessibility, and inclusion of persons with disabilities in relevant Covid-19 vaccination rollout policy planning, revision, and practice	The UN system, National stakeholders and general public, including: national health system, media, the national crisis response headquarters, national education authorities, and relevant private sectors

research and publications, the organisation conducted and participated in several international surveys on the lived experience of persons with disabilities during the global pandemic (IDA, 2021a). These include a global report issued by the Covid-19 Disability Rights Monitor (DRM) initiative, in which IDA coordinated with six other disability rights organisations (Covid-19 DRM, 2020; Mladenov & Brennan, 2021). In an initiative titled Voices of People with Disabilities During the Covid-19 Outbreak, IDA and its member organisations conducted an open call for story submissions from persons with disabilities around the world on how their lives were affected by the pandemic and related policies and measures on the ground.

5.2. Barriers to Participation and Response From IDA

A significant amount of IDA's advocacy efforts have identified the barriers encountered by persons with disabilities in public participation during the pandemic or due to related policies and their implementation. Some of these barriers resulted in the exclusion of OPDs from public decision-making processes. According to the grey literature IDA authored or contributed to, OPDs and persons with disabilities were not properly consulted or involved in the Covid-19-related policy and practice on the ground. These findings are consistent with the observations made by the CRPD Committee. Under the periodic state reporting procedure between 2021 and 2023, The CRPD Committee has criticised the lack of involvement of OPDs in Covid-19 response and recovery plans in its concluding observations concerning 22 countries (in total 29 States under review) from Asia, Europe, Oceania, and South America. For instance, in its concluding observations on Germany's periodic report, the CRPD Committee (2023, para. 23) has concluded that:

> The lack of close consultation with and active involvement of persons with disabilities through their representative organisations in…the planning of Covid-19 pandemic mitigation responses that resulted in adverse impacts on persons with disabilities.

Furthermore, the Committee has addressed some common barriers persons with disabilities have encountered, including the disproportionate impact of the pandemic on persons with disabilities (15 countries); lack of access to Covid-19-related information and healthcare services (9 countries); and lack of data on the impact of the pandemic on the disability population (3 countries). Similarly, IDA's campaigns and other advocacy efforts have highlighted four types of barriers that have directly or indirectly hindered persons with disabilities or OPDs from participating in the development, implementation, and monitoring of national Covid-19-related policies and measures. The organisation then participated in various international channels and platforms in response to these barriers. The following subsections examine how these barriers—specifically the lack of accessibility provisions, disability-related discrimination and exclusion, lack of capacity, and lack of data—have affected the public participation of persons with disabilities and OPDs.

5.2.1. Lack of Accessibility Provisions

IDA identified the lack of access to information, communication, and physical environments as one of the main barriers that persons with disabilities experienced during the global pandemic that inhibited their public participation. Inaccessible information and communication regarding the pandemic response have been reported across all levels. This includes a lack of accessible and alternative formats of information and communication tools for Covid-19-response-related public services, such as providing sign language interpretation, easy-to-read, and audio descriptions in government briefings and press conferences.

For instance, IDA's study indicated that the preventive and restrictive measures implemented imposed communication barriers, which will have implications for their participation in public consultations. IDA (2021a, p. 43) cites a man with deafblindness from Norway and a deaf woman from Brazil respectively:

> Many persons with deafblindness are dependent on an interpreter-guide….Especially when working from home…the pandemic increases the isolation and lack of mobility persons with deafblindness already experience.
>
> I am deaf and communicate through speech and lip reading. With the obligatory use of masks, my communication is greatly affected.

As representative organisations of persons with disabilities, OPDs can only contribute to Covid-19-related decision-making processes when the provisions of accessibility measures are ensured so their staff and members can access relevant information and work and communicate on an equal basis with others. The issues in access to information and communication were the first barriers addressed by the IDA. In the Accessibility Campaign, IDA and the International Disability and Development Consortium (IDDC) urged the UN system to make all public information and (digital) communications accessible. In their open letters to the UN Secretary-General, the UN High Commissioner for Refugees, the UN Population Fund, and WHO, the organisations emphasised that "equal access to information and communication" is a principle and right recognised under the UNCRPD (see, e.g., IDA & IDDC, 2020). For instance, the accessibility provisions should include the following measures on public briefings and webinars delivered by the UN and its agencies by "using radio channels to reach out to people in the most remote areas, providing captioning, International Sign interpretation, plain language" and ensuring the information is easily understandable by avoiding jargon and speaking too quickly (IDA & IDDC, 2020). IDA also attempted to influence the high-level UN bodies to pressure the member states to implement their international obligations and commitments. For instance, the UN was requested to "use all appropriate means" to urge "Member States to immediately ensure access to essential Covid-19 information and adopt a timebound plan to make all public information and communication accessible for all persons with disabilities" (IDA & IDDC, 2020, p. 2).

Similar to Rother's (2022) findings, IDA's research found that the pandemic brought new opportunities for persons with disabilities to participate in society, as many OPDs conducted their activities and services through online platforms. This trend was also observed in human rights governance and decision-making processes among UN bodies (International Service for Human Rights, 2022). However, it exposed the issue of the digital divide between disability communities in different economic and development situations, as some people with disabilities had no adequate access to the internet, phones, and other technologies (DRM, 2020). IDA's survey further revealed that those who could not afford or access the internet and other communication technologies were excluded from keeping in touch with OPDs (IDA, 2021a). The organisation reminded governments to implement their obligations under the UNCRPD to "ensure that persons with disabilities have access to digital technologies that enhance their involvement with OPDs" (p. 50).

5.2.2. Disability-Related Discrimination and Exclusion

The second barrier arises from discrimination towards persons with disabilities, including measures that have had a discriminatory impact on persons with disabilities. This was especially evident in the development and practice of Covid-19 treatment and healthcare policy, such as the triage guidelines in many countries that had explicitly or implicitly instructed health workers to decide treatment based on one's disability. This is indicated in the following excerpt from the international survey that IDA coordinated (cited in DRM, 2020, pp. 41–42):

> The survey received a testimony about a Canadian child with autism who was denied a test for Covid-19 "because the attending physician deemed him too difficult to assess. He had all the symptoms of Covid-19 but was refused confirmation."
>
> A representative of an OPD in the United Kingdom said: "Do not resuscitate notices...were placed on people with no consultation, especially older persons and persons with learning disabilities."

In its initial Ten Recommendations, IDA (2020a) pointed out that persons with disabilities would be excluded from the policymaking of Covid-19 response if authorities were not aware of how the pandemic measures could "disproportionally impact" them. In the End-Discrimination Campaign, IDA and partner NGOs emphasised that states should comply with their legal obligations and the principle of non-discrimination in their Covid-19 responses and its connection to existing rights under the international human rights framework, such as the right to life, health, education, free information, and an adequate standard of living (Equal Rights Trust et al., 2020). In this process, states should consult with OPDs to assess the impact of their policy response to the pandemic on the ground, such as triage protocols and education policy (IDA, 2020a, 2020b). At this stage, IDA advocated on a global scale with a particular focus on the UN bodies and agencies that had issued numerous policy guidelines to coordinate the global Covid-19 early preparedness, response, and recovery plans. In the later Access to Vaccination Campaign, the main focus was diverted to national stakeholders and the general public. In its open letter, IDA and IDDC (2021) reiterated that persons with disabilities were often left behind in Covid-19 mitigation and response policies and called for the prioritised inclusion of persons with disabilities in relevant vaccination rollout policy and practice. The Ten Recommendations also highlighted the role of OPDs in advocating for a disability-inclusive response to the Covid-19 crisis and encouraged them to "proactively" reach out to all relevant local and national authorities. Accordingly, IDA introduced capacity-building activities for local and national advocacy, as illustrated in the next subsection.

5.2.3. Lack of Capacity

The third barrier is the lack of OPD capacity to participate in public decision-making dealing with Covid-19. OPDs encountered difficulties in terms of funding and staff shortages to carry on their advocacy work (IDA, 2021a). Under lockdown measures, OPDs in many African countries were temporarily closed and could not coordinate or carry out their normal activities (Stakeholder Group of Persons with Disabilities for Sustainable Development [SGPWD], 2020). Another contributing factor to these shortages was that OPDs had to shift their focus on providing services to disability communities when public services were absent (DRM, 2020). According to IDA's 2021 survey, 41 percent of respondents (600) received at least one type of service from their local OPDs, such as accessible information on Covid-19, food and/or other essential items, health or social care information, support for mental health, and employment advice. Still, OPDs are sometimes not equipped with sufficient knowledge or resources to support or advocate for particular groups of disabled people (e.g., particular types of impairments or conditions, or those with intersectional backgrounds) in the disability communities they represent. For instance, this is indicated in the following excerpt from IDA's survey:

> "OPDs are more supportive of those with visible disabilities, and they have limited knowledge of how to support those of us with invisible disabilities....Our OPDs do not appear to be aware of the needs of Maori"—Indigenous woman with a psychosocial disability, New Zealand. (IDA, 2021a, p. 50)

IDA has launched several activities to build the capacity of OPDs for advocacy during the pandemic. A cross-cutting theme in IDA's campaigns and advocacy is the importance of the participation of OPDs in the process of making, implementing, and monitoring Covid-19-related policies. From the outset, IDA outlined three working areas where national, regional, and international OPDs can contribute to public decision-making processes through advocacy, including awareness-raising, offering technical assistance on specific measures such as accessibility provisions, and contributing to data collection and analysis (IDA, 2020a, 2020c; SGPWD, 2020). Simultaneously, all IDA campaign messages have reminded and urged international organisations and states to involve and consult with OPDs to ensure their meaningful participation in Covid-19-related decision-making processes in alignment with the UNCRPD and other policies. Furthermore, IDA has facilitated international, regional, national, and local advocacy efforts through coordination, resource-sharing, and capacity-building events. Webinars at regional and international levels were organised to offer training on advocacy strategies based on the international human rights framework. The wide use of media was highlighted throughout the IDA campaigns, and social media toolkits with messages and picture templates for mainstream social media platforms were provided. For instance, in the Access to Vaccination Campaign, a detailed toolkit was published with step-by-step guidelines on running national and local advocacy concerning Covid-19 vaccination policy for persons with disabilities (IDA, 2021b). The toolkit provides instructions on how to identify targets and partners and influence authorities in a country's vaccination policy planning, revision, and practice, as shown in the following excerpt (IDA, 2021b, pp. 2–3):

> Advocacy targets are different in different countries: in some countries a specific body under the Presidency is governing national action against Covid-19, in other countries it remains under the Ministry of Health.
>
> Identify advocacy partners including organizations of persons with disabilities, NGOs working on disability, access to health or other groups campaigning for equity and inclusion in vaccination in your country. It is very crucial to avoid duplication so speak to each other and coordinate.
>
> [On recommendations for advocacy meeting with authorities] Try to leave the meeting with some action points even if it is just planning another meeting; offer to support their measures by providing further information or joining potential meetings with other decision-makers.

5.2.4. Lack of Data

Persons with disabilities were often not included in Covid-19-related data collection and analysis at the national and UN levels. This created a fourth barrier to the participation of OPDs in public decision-making processes, such as in the implementation and monitoring of Covid-19 response and recovery policies, which requires reliable data. This data-related barrier was highlighted in the Rebuilding an Inclusive Future for All Campaign, which was carried out during the 2020 High-Level Political Forum on Sustainable Development. IDA and its partner organisations participated in the meetings and sessions of the Forum through NGO side events, written submissions, and oral statements (SGPWD, 2020). Side or parallel events refer to activities organised and attended by UN stakeholders, such as meetings, presentations, and discussions, that focus on issues relevant to the work of a specific UN body or session but are held outside of the formal session agenda. The Rebuilding an Inclusive Future for All Campaign placed IDA's Accessibility Campaign and End-Discrimination Campaign into the international development and SDGs framework, calling for actions with regard to disability inclusion in broader and future emergency policy, including the monitoring of Covid-19 response and recovery practice. A survey by IDA and partners revealed the issues of lack of disability-related data or access to such data on the national level (SGPWD, 2020). Based on this finding, IDA urged international and national stakeholders to increase disability data collection in future policymaking on emergency response and recovery, as well as draw their attention to relevant data and information collected by OPDs and other NGOs in their surveys.

5.3. IDA in the UN Decision-Making Processes and the Reactions Received

In contrast to previous studies on the limited participation of civil society organisations in Covid-19 response in local and national governance (Sahoo et al., 2023; Sayarifard et al., 2022), contributions from IDA on the international policymaking during the pandemic were welcomed and acknowledged by the UN system and among OPD and NGO peers. IDDC's 2021 survey, which focuses on the experiences and challenges faced by civil society organisations in the Global South during the pandemic, indicates that IDA and its partners played a crucial role in supporting the advocacy efforts of these organisations for a disability-inclusive Covid-19 response at both UN and local levels, as highlighted by NGO respondents (IDDC, 2021, p. 61):

> Coordinated advocacy efforts, such as the IDA/IDDC efforts seemed to have a wider impact on UN systems and responses. Awareness was also increased at remote UN conference.
>
> Case studies collected by IDA were really impressive and thought provoking; their accessibility guidelines were also very useful.

IDA's impact on raising awareness of disability-inclusive Covid-19 policy at the UN level is evident in the written responses IDA and IDDC received from the UN Secretary-General, WHO, and other agencies (see, e.g., UN Secretary-General, 2020). The UN bodies commended the organisations' continuous involvement and contribution to the Covid-19 response policy and indicated their corresponding follow-up actions. Several of IDA's advocacy and toolkits were also listed on the UN website, as with other UN resources, advice, and guidelines for disability-inclusive Covid-19 policy (UNDESA, 2023).

IDA has also directly participated in official policymaking processes related to international Covid-19 response and recovery policies in the context of international development and SDGs through its involvement in the UNPRPD and the SGPWD. IDA is also the only OPD member organisation of the UNPRPD and its board. Along with the IDDC, the two organisations participated in a UN joint project to promote disability inclusion in Covid-19-related policies in 27 countries between 2020 to 2021 (UNPRPD, 2022). IDDC is a civil society organisation group working on promoting disability rights and inclusion in international development and humanitarian action. IDA and its member organisations provided technical expertise in the development and implementation of Covid-19 policy documents and guidelines issued by UN bodies and agencies, including UNESCO, UNICEF, the International Labor Organization, and WHO. According to the 2022 UNPRPD report, UN organisations, such as the OHCHR, reported that their engagement in the disability networks through IDA and IDDC, such as seeking consultancy, strengthened the implementation of global programmes supporting Covid-19 response and recovery. Such engagements also created "prospective opportunities for disability inclusivity" in Covid-19-related social and economic recovery plans at country levels (UNPRPD, 2022, p. 67).

6. Discussion: Creating Participation Spaces and Reflecting on Hostilities

The results of the document analysis on IDA's international advocacy during the Covid-19 pandemic show that this OPD network has attempted to influence global and national decision-making processes on the pandemic preparedness, response, and recovery measures, as well as relevant practices through a range of transnational public participation activities.

IDA first highlighted the situation that persons with disabilities and their representative organisations did not participate in the Covid-19-related policy and practice on the ground. It further identified the four main barriers that prevented persons with disabilities and OPDs from participating in Covid-19-related decision-making, namely: lack of access to information, communication, and physical environments; disability-related discrimination and exclusion; lack of capacity of OPDs to engage in decision-making; and lack of disability-related data. Following the previous findings, the first two barriers indicate that persons with disabilities and OPDs face additional barriers to participation relative to other individuals and civil society organisations (McVeigh et al., 2021). Barriers experienced by people with disabilities directly affect their ability to participate in decision-making processes: If they cannot communicate with each other and policymakers, they cannot make decisions relating to their lives or receive information on policies. It seems that these adverse impacts at individual levels did not greatly hinder the work of others in similar situations (Kövér, 2021; Marston et al., 2020; Rajan et al., 2021; Sayarifard et al., 2022). The last two barriers pertain to a lack of capacity or data, highlighting challenges that hinder OPDs in particular from contributing to public decision-making processes and organising collective actions.

Three interlinked strategies were used in IDA's participation and advocacy to influence international disability-inclusive Covid-19 policy. The first strategy is the consistent use of human rights language in advocacy in contrast to the approach taken by many UN bodies in their policy and information outputs on Covid-19 and disability rights (Lewis, 2020). This is evidenced in IDA's open letters, publications, and capacity-building activities cited in the last section, which have made explicit references to human rights norms. The international normative framework, in particular the UNCRPD, provides the foundation for IDA's advocacy, which allows it to identify concrete barriers and connect them to existing legal and political obligations made by supernational organisations, states, and other stakeholders. Articles *4*(3) and *33*(3) of the UNCRPD provide the legal basis for creating invited spaces for the participation of OPDs in public decision-making processes, namely the obligation to consult, which will be elaborated below.

The second strategy is building alliances with other OPDs and NGOs. In addition to the IDDC, its frequent and main partner in public campaigns and UN engagement, IDA worked with a range of human rights NGOs advocating for the rights of, among others, women, children, refugees, and sexual and gender minorities (see, e.g., Equal Rights Trust et al., 2020). This is in line with IDA's first strategy, which focuses on human rights issues. The third strategy is to employ multiple activities simultaneously with the aim of supporting IDA's participation in the UN decision-making processes. As demonstrated in the last subsection, each campaign launched different advocacy activities tailored to different audiences. Survey findings were fed into its international advocacy and contributed to IDA's participation in the UN system, providing a factual basis for its consultancy, awareness-raising efforts, and policy recommendations. This third strategy is also built on the second strategy since many of IDA's activities (e.g., surveys) involved support and contributions from and coordination with other NGOs and stakeholders. The three strategies reflect IDA's two-way approach when participating in international policymaking processes related to Covid-19: amplifying the voice of persons with disabilities and the movement from all over the world to the UN (bottom-up) as well as relaying UN policies and principles to persons with disabilities on the ground (top-down).

IDA has participated in the international policymaking processes through both "invited" and "invented" spaces (Rother, 2022). The former was achieved through participation in UN official decision-making processes, while the latter was created through public campaigns where IDA coordinated or collaborated with peers in the international disability movement and its allies. Invited spaces in the international policymaking processes remained open to IDA during the global pandemic. Unlike civil society organisations on the national and local levels (Kövér, 2021; Sayarifard et al., 2022), the participation of IDA in high-level formal procedures was not blocked or ignored in the UN system. The outcomes of IDA's consultancy, research, and awareness-raising campaigns corroborate with previous research findings (Sahoo et al., 2023) that show the crucial role of OPDs in the development and delivery of context-relevant responses to the global pandemic since they have first-hand knowledge on the needs of disability communities. However, participation was not always meaningful or inclusive—contrary to the principles envisaged in the UNCRPD and other international policies—due to barriers in accessibility provisions and discrimination encountered by certain groups of persons with disabilities.

Invented spaces in the international policymaking processes were created by IDA during the pandemic. Similar to Rother's findings, new spaces, such as virtual participation, were created for all civil society, which became both an opportunity and a challenge for OPDs, such as creating additional barriers to the accessibility of information and communication technologies. Through various invented spaces such as open letters, publications, NGO side events, webinars, and social media campaigns, IDA pressured the UN system, national governments, and other stakeholders to remove existing barriers in order to include all persons with disabilities and OPDs in Covid-19-related policymaking, whose voices were often excluded on the ground or in new participation spaces. By engaging in both invented and invited spaces, IDA facilitated the "travel" of ideas from invented spaces into invited spaces, aiming to influence policy changes related to the public participation of persons with disabilities on the ground. This finding reflects those of Rother (2022), who notes a similar strategy in the participation of civil society organisations within global migration governance. Furthermore, IDA seeks to secure permanent invited spaces for disability communities in the broader framework of risk management on human rights and humanitarian emergencies and future emergency policymaking.

Reflecting on the discussion introduced at the beginning of this article regarding the relationship between indirect hostilities and limited, circumscribed, and selective participation, we find that it resonates with the findings of the current study on the relationship between the four barriers and participation of persons with disabilities and OPDs in Covid-19 decision-making processes. The participation of persons with disabilities is clearly required and supported in international human rights and development policies and governance. None of the four barriers discussed in this study were intentionally placed by decision-makers to directly prevent their participation during the global pandemic. However, these barriers hindered the individual or collective participation of persons with disabilities in national and international Covid-19 policymaking processes in a meaningful and inclusive manner. Their lack of participation also highlighted pre-existing inequalities and barriers faced by disability communities in their daily lives, including underrepresentation in public participation, similar to the experience of other marginalised groups (IDA, 2021a; Perry et al., 2020; Rother, 2022).

7. Conclusion

This article has examined the barriers to participation faced by persons with disabilities and the response from IDA, a prominent international network of organisations of persons with disabilities representing the international disability movement. Our findings align with existing research that reveals the exclusion of civil society organisations by many national governments despite their ability to engage communities during the global pandemic. The disability rights movement experienced barriers regarding the lack of capacity or data and additional barriers at the individual level in terms of a lack of accessibility and disability-related discrimination, which hindered its participation in the development and practice of Covid-19 policies. IDA mobilised “invited” spaces and creating “invented” spaces for public participation during the pandemic, aiming to remove these barriers. IDA has also strategically utilised international human rights and development frameworks, as well as NGO allies, to prompt its participation in both types of spaces according to its goal of promoting a “disability-inclusive response” to the global pandemic and future decision-making processes related to emergencies (IDA, 2020a). Discussing and applying the conceptualisation of participation spaces and the consequences of indirect hostilities to participation, findings in this study have broader implications for research on lack or limited public participation in situations of risks and emergencies in the context of disability and human rights studies, including other marginalised groups in societies. This study provides insights into understanding the connections between individual and collective human rights violations and the lack of or limited public participation of certain groups in society. We examined the strategies and experiences of a prominent OPD network operating in highly formalised institutional governance settings in international policymaking. Future studies should extend this examination and comparison to include OPDs operating in less formalised settings. It is beyond our study scope to address the impact of a global social movement being represented by one high-level organisation, albeit one with an extensive network. This raises questions about representation and accountability and how they relate to participation within the movement, which are worthy of future examination.

Acknowledgments

The authors wish to thank the editors of the issue and the peer-reviewers for their valuable comments on the draft. Valuable feedback was also received at the workshop for this thematic issue.

Funding

Publication of this article in open access was made possible through the institutional membership agreement between Maastricht University and Cogitatio Press.

Conflict of Interests

The author declares no conflict of interests.

References

Bowen, G. A. (2009). Document analysis as a qualitative research method. *Qualitative Research Journal*, *9*(2), 27–40. https://doi.org/10.3316/QRJ0902027

Covid-19 Disability Rights Monitor. (2020). *Disability rights during the pandemic: A global report on findings of the Covid-19 Disability Rights Monitor*.

CRPD Committee. (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* (UN Doc CRPD/C/GC/7).

CRPD Committee. (2023). *Concluding observations on the combined second and third periodic reports of Germany* (UN Doc CRPD/C/DEU/CO/2-3).

Degener, T. (2017). A new human rights model of disability. In V. D. Fina, R. Cera, & G. Palmisano (Eds.), *The United Nations Convention on the Rights of Persons With Disabilities: A commentary* (pp. 119–136). Springer.

Della Porta, D. (2020). Building bridges: Social movements and civil society in times of crisis. *Voluntas*, 31, 938–948. https://doi.org/10.1007/s11266-020-00199-5

Driedger, D. (1989). *The last civil rights movement: Disabled People's International*. C. Hurst & Co.

Equal Rights Trust, Association for Women's Rights in Development, Child Rights International Network, Equality Now, Global Campaign for Equal Nationality Rights, HelpAge International, Institute on Statelessness and Inclusion, International Disability Alliance, International Disability and Development Consortium, International Lesbian, Gay, Bisexual, Trans and Intersex Association, Minority Rights Group, OutRight Action International, & Women's Refugee Commission. (2020, May 7). *Call to action: Addressing discrimination and inequality in the global response to Covid-19* [Open letter]. https://www.equalrightstrust.org/news/call-action-addressing-discrimination-and-inequality-global-response-covid-19

Falanga, R., Cebulla, A., Principi, A., & Socci, M. (2021). The participation of senior citizens in policy-making: Patterning initiatives in Europe. *International Journal of Environmental Research and Public Health*, *18*(1), Article 1. https://doi.org/10.3390/ijerph18010034

Farooqi, N., & Ali, M. (2023). Disability studies in social sciences: A review of paradigms and perspectives. *The Critical Review of Social Sciences Studies*, *1*(2), 155–166.

Friedman, M. G., Beckwith, R. M., & Conroy, J. W. (2016). Inclusion is transformative: Self-advocacy leaders' perspectives on board inclusion and tokenism. *Inclusion*, *4*(3), 183–190. https://doi.org/10.1352/2326-6988-4.3.183

Garcia, S., Carrigan, C., & Wiepking, P. (2023). Global civil society response to the Covid-19 crisis. *Voluntas*, *34*(6), 1310–1321. https://doi.org/10.1007/s11266-023-00589-5

International Disability Alliance. (2020a, March 19). *Toward a disability-inclusive COVID19 response: 10 recommendations from the International Disability Alliance*.

International Disability Alliance. (2020b, March 31). *Letter to Director-General of the World Health Organization* [Open letter]. http://www.internationaldisabilityalliance.org/sites/default/files/ida_letter_to_who_march_31_2020.pdf

International Disability Alliance. (2020c, December 1). *Reach the furthest behind first: Persons with disabilities must be prioritized in accessing Covid-19 vaccinations* [Open letter]. https://www.internationaldisabilityalliance.org/sites/default/files/ida_recommendations_on_accessing_covid-19_vaccinations_final_01.12.20.pdf

International Disability Alliance. (2021a). *Survey on the experiences of persons with disabilities adapting to the Covid-19 global pandemic*. https://www.internationaldisabilityalliance.org/covid19-survey

International Disability Alliance. (2021b, April). *Toolkit for national Covid-19 vaccination campaign for persons with disabilities*. https://www.internationaldisabilityalliance.org/resources/toolkit-national-covid-19-vaccination-campaign-persons-disabilities

International Disability Alliance. (2024). *What we do*. https://www.internationaldisabilityalliance.org/whatwedo

International Disability Alliance & International Disability and Development Consortium. (2020, April). *Letter to the UN Secretary General* [Open letter]. https://www.internationaldisabilityalliance.org/acessibility-campaign

International Disability and Development Consortium. (2021). *Adjust and respond: The experience of organisations working with people with disabilities in adapting to the Covid-19 pandemic.*

International Service for Human Rights. (2022, September 9). HRC needs to address challenges to civil society participation in light of restrictions. *ISHR*. https://ishr.ch/latest-updates/hrc-needs-to-address-challenges-to-civil-society-participation-in-light-of-restrictions

Kim, K. M., Kim, D. K., Shin, Y. R., & Yoo, D. C. (2016). Social exclusion of people with disabilities in Korea. *Social Indicators Research*, *129*, 761–773.

Kövér, Á. (2021). The relationship between government and civil society in the era of Covid-19. *Nonprofit Policy Forum*, *12*(1), 1–24. https://doi.org/10.1515/npf-2021-0007

Lawson, A., & Beckett, A. E. (2020). The social and human rights models of disability: Towards a complementarity thesis. *The International Journal of Human Rights*, *25*(2), 348–379. https://doi.org/10.1080/13642987.2020.1783533

Lewis, O. (2020). Supranational human rights bodies and protecting the rights of people with disabilities in the Covid-19 pandemic. *European Human Rights Law Review*, *4*, 372–393. https://doi.org/10.3316/agispt.20200922037039

Marston, C., Renedo, A., & Miles, S. (2020). Community participation is crucial in a pandemic. *The Lancet*, *395*(10238), 1676–1678. https://doi.org/10.1016/S0140-6736(20)31054-0

McVeigh, J., MacLachlan, M., Ferri, D., & Mannan, H. (2021). Strengthening the participation of organisations of persons with disabilities in the decision-making of national government and the United Nations: Further analyses of the International Disability Alliance global survey. *Disabilities*, *1*(3), Article 3. https://doi.org/10.3390/disabilities1030016

Mladenov, T., & Brennan, C. S. (2021). The global Covid-19 Disability Rights Monitor: Implementation, findings, disability studies response. *Disability & Society*, *36*(8), 1356–1361. https://doi.org/10.1080/09687599.2021.1920371

Perry, M. A., Ingham, T., Jones, B., & Mirfin-Veitch, B. (2020). “At risk” and “vulnerable”! Reflections on inequities and the impact of Covid-19 on disabled people. *New Zealand Journal of Physiotherapy*, *48*(3), Article 3. https://doi.org/10.15619/NZJP/48.3.02

Plosky, D., Ari Ne’eman, W., Silverman B. C., Strauss, D. H., Francis, L. P., Stein, M. A., & Bierer, B. E. (2022). Excluding people with disabilities from clinical research: Eligibility criteria lack clarity and justification. *Health Affairs*, *41*(10), 1423–1432. https://doi.org/10.1377/hlthaff.2022.00520

Priestley, M., Stickings, M., Loja, E., Grammenos, S., Lawson, A., Waddington, L., & Fridriksdottir, B. (2016). The political participation of disabled people in Europe: Rights, accessibility and activism. *Electoral Studies*, *42*, 1–9.

Rajan, D., & Koch, K. (2020). The health democracy deficit and Covid-19. *Eurohealth*, *26*(3), 26–28.

Rajan, D., Koch, K., Marschang, S., Costongs, C., Rohrer-Herold, K., Nathan, N. L., & Pastorino, G. (2021). "Build forward better" must include heavy investment in government capacities to engage with communities and civil society. *Eurohealth*, *27*(1), 54–59.

Rother, S. (2022). Global migration governance from below in times of Covid-19 and "Zoomification": Civil society in "invited" and "invented" spaces. *Comparative Migration Studies*, *10*(1), Article 1. https://doi.org/10.1186/s40878-021-00275-9

Sabatello, M. (2013). A short history of the international disability rights movement. In M. Sabatello & M. Schulze (Eds.), *Human rights and disability advocacy* (pp. 13–24). University of Pennsylvania Press.

Sahoo, K. C., Sahay, M. R., Dubey, S., Nayak, S., Negi, S., Mahapatra, P., Bhattacharya, D., Barrio, M. O. D., & Pati, S. (2023). Community engagement and involvement in managing the Covid-19 pandemic among urban poor in low-and middle-income countries: A systematic scoping review and stakeholders mapping. *Global Health Action*, *16*(1), Article 2133723. https://doi.org/10.1080/16549716.2022.2133723

Sayarifard, A., Nazari, M., Rajabi, F., Ghadirian, L., & Sajadi, H. S. (2022). Identifying the non-governmental organizations' activities and challenges in response to the Covid-19 pandemic in Iran. *BMC Public Health*, *22*(1), Article 704. https://doi.org/10.1186/s12889-022-13080-5

Shakespeare, T., Ndagire, F., & Seketi, Q. E. (2021). Triple jeopardy: Disabled people and the Covid-19 pandemic. *The Lancet*, *397*(10282), 1331–1333. https://doi.org/10.1016/S0140-6736(21)00625-5

Stakeholder Group of Persons with Disabilities for Sustainable Development. (2020). *The experience of persons with disabilities with Covid-19: A short qualitative research study*.

Trömel, S. (2009). A personal perspective on the drafting history of the United Nations Convention on the Rights of Persons With Disabilities. In G. Quinn & L. Waddington (Eds.), *European yearbook of disability law: Volume 1* (pp. 115–136). Intersentia.

UN. (2020a). *Policy brief: A disability-inclusive response to Covid-19*. https://doi.org/10.18356/817dccdf-en

UN. (2020b). *Covid-19 and human rights: We are all in this together*. https://unsdg.un.org/resources/covid-19-and-human-rights-we-are-all-together

UN Department of Economic and Social Affairs. (2023). *Covid-19 outbreak and persons with disabilities*. https://social.desa.un.org/issues/disability/covid-19-outbreak-and-persons-with-disabilities

UN General Assembly. (2015). *Transforming our world: The 2030 agenda for sustainable development* (A/RES/70/1).

UN Office for Disaster Risk Reduction. (2015). *Sendai framework for disaster risk reduction 2015–2030*. https://www.undrr.org/publication/sendai-framework-disaster-risk-reduction-2015-2030

UN Secretary-General. (2020). *Response received from the United Nations Secretary-General to IDA* [Open letter]. https://www.internationaldisabilityalliance.org/acessibility-campaign

United Nations Convention on the Rights of Persons with Disabilities, 2006.

UNPRPD. (2022). *Lessons learned from the UNPRPD Covid-19 Response and Recovery Joint Programme*.

WHO. (2024). *Strengthening disability inclusion through collaboration*. https://www.who.int/activities/strengthening-disability-inclusion-through-collaboration

Zvonareva, O., & Egher, C. (2025). Ambivalence and agonism of public participation in contemporary societies. *Social Inclusion*, *13*, Article 10095. https://doi.org/10.17645/si.10095

About the Authors

Hanxu Liu (PhD) is a lecturer and researcher in the Health, Ethics, and Society Department at Maastricht University. Her research focuses on the impact of global disability movements in the implementation and monitoring of international human rights instruments at local, regional, and global levels. She uses socio-legal research methodology, applying legal and theoretical frameworks alongside empirical research to explore the interactions between law, social movements, and human rights practices.

Claudia Coveney (PhD) is a lecturer in disability studies and policy in the School of Sociology and Social Policy at the University of Leeds. Her research examines opportunities for social movement organisations, particularly disabled people’s organisations and their allies to mobilise and influence decision-making as institutions of governance develop new structures.