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

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Abstract: The participation of organisations of persons with disabilities (OPDs) is crucial at each stage of policy processes at the local, regional, and international levels. However, decision-making mechanisms have traditionally excluded OPDs, failing to consult with them on decisions that impact on their daily lives. The overall aim of this study was to examine the participation of persons with disabilities and OPDs in development programmes and policies by exploring recommendations from a sample of OPDs on ways to strengthen their participation with government and the UN. Secondary data analysis was conducted using a global survey on the participation of OPDs, administered by the International Disability Alliance to OPD representatives. Two open-ended items were analysed, which explored participants' recommendations on ways to strengthen their participation with government and the UN. Data were analysed using the descriptive and interpretive qualitative methods. Respondents provided recommendations on how to strengthen their participation with their national government and the UN, focusing on several issues including accessibility, human rights, and the need for inclusion of all OPDs and all groups of persons with disabilities. The synergy between the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals presents opportunities for OPDs to increase their participation in development policies and programmes. It is vital, however, to dismantle the barriers to participation in decision-making by OPDs and persons with disabilities.

Keywords: organisations of persons with disabilities; OPDs; DPOs; participation; government; United Nations; development; programmes; policies

1. Introduction

1.1. Political Participation of Persons with Disabilities

Political participation is fundamental to a democratic society [1]. The right to participate in public and political life is well-rooted in human rights law and international agreements, including the Universal Declaration of Human Rights [2] and the International Covenant on Civil and Political Rights [3]. However, decision-making mechanisms have traditionally excluded persons with disabilities and organisations of persons with disabilities (OPDs/DPOs), failing to consult with them on the development, implementation, and

monitoring of decisions that impact their daily lives [4]. Amongst the most marginalised groups globally, the World Report on Disability [5] calls for persons with disabilities (accounting for approximately one billion people or 15% of the global population) to actively participate and to be consulted in the development and implementation of policies, laws and services.

Disability is a 'social construct' [6–8], stemming from "the interaction between persons with impairments, and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" [9] (preamble). Persons with disabilities and their representative organisations experience substantial barriers to participation, mitigating their empowerment. These barriers include, in particular, poverty, lack of education, social isolation, stigma and discrimination, lack of disability-accessible processes, and legal barriers [10]. Furthermore, disadvantage and discrimination may be compounded when disability intersects with other factors that marginalise groups [11], such as indigenous persons with disabilities who may experience multiple discrimination in relation to both their disability and indigenous origin [9,12,13]. As suggested by MacLachlan et al. [14]: "To ensure that policy becomes fully inclusive, these intersectional forms of marginalisation have to be recognised and taken into account; preventing different forms of marginalisation multiplying disadvantage" (p. 462).

Alongside barriers to accessing healthcare, leisure services, education, and employment, persons with disabilities experience barriers to participation in the political sphere [15]. Persons with disabilities are therefore frequently "politically disabled" [16] (p. 1). For instance, Poverty Reduction Strategy Papers, "the conduits through which policy is encapsulated and resource distribution enacted" [17] (p. 109), are often devised without recognising the priorities of persons with disabilities, although these policy tools are a mechanism for the inclusion of disability in development [18]. Accordingly, there has been a call by the UN [19] for the elimination of barriers that inhibit the participation of persons with disabilities in political and public affairs. Although the participation of persons with disabilities in global governance is critical so that development policies and programmes support their empowerment, such participation depends on the recognition and reduction of barriers that hinder their equal engagement in political processes [20].

The degree to which there is meaningful and non-tokenistic participation of persons with disabilities in policy processes is a pivotal indicator of the inclusion of persons with disabilities in society more generally [21]. As suggested by Löve et al. [22] (p. 3), "to change their position of oppression, marginalised groups must be a part of the political structure, engage in setting the agenda and defining the issues, and redefining the concepts that relate to their lives". The inclusion of persons with disabilities at each stage of policy and decision-making processes is increasingly being acknowledged, and OPDs are viewed as the way to enable such participation [23].

OPDs operate to fulfil the rights of persons with disabilities, thus ensuring their social inclusion [24]. OPDs are "established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities", and "employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves" [25]. Networks of OPDs are present and active in most countries, and OPDs have also formed at the regional and international levels such as the World Blind Union or the African Disability Forum, many of which collaborate as members of the International Disability Alliance (IDA) [10,26]. OPDs are guided by the cohesive slogan of "Nothing About Us Without Us" [27]. "Nothing About Us Without Us" urges political, economic and cultural systems to include persons with disabilities in decision-making processes, and to recognise that the experiential knowledge of those with disabilities is critical to effective decision-making [28].

1.2. Convention on the Rights of Persons with Disabilities and SDGs

Adopted in 2006 by the UN General Assembly, the Convention on the Rights of Persons with Disabilities (CRPD) rewrites civil, political, social, economic, and cultural

rights in light of disability and imposes on States Parties the obligation to implement those rights and ensure that persons with disabilities enjoy them on an equal basis with others. The CRPD also recognises that some persons with disabilities may need specialist care including accessible rehabilitation, support services [29], and assistive technologies [30].

The right of persons with disabilities to participate in political and public life is explicitly recognised in the CRPD [31]. The freedom to form and join OPDs is a political right under Article 29 of the CRPD on "Participation in Political and Public Life", referring to the right of "[f]orming and joining organisations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels" (Article 29 (b)(ii)). Correspondingly, the right of OPDs to participate in policy and broader decision-making processes is enshrined in Article 4 (3) of the CRPD, which stipulates:

> "*In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations*". [9]

Notably, Article 32 of the CRPD on "International Cooperation" obliges States Parties to:

> "*recognise the importance of international cooperation and its promotion, in support of national efforts for the realisation of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organisations and civil society, in particular organisations of persons with disabilities*".

Although the right to participate in political and public life is explicitly provided in the CRPD and well-established in human rights law, persons with disabilities have not been able to fully enjoy this right due to legal, physical, transportation, attitudinal, and informational barriers [32]. For example, in a study on the participation of OPDs in international policy processes [23], key informants reported that the CRPD was too technical for OPDs to easily comprehend and use in their activities. Similarly, in a qualitative study of self-advocates with intellectual disabilities or autism [33], the majority of participants reported having little understanding of human rights and the CRPD and perceived rights to be ambiguous and unconnected to their daily lives. In relation to disability policy-making in the African context, Lang et al. [21] (p. 156) argue that "there is an apparent and discernible 'disconnect' between the rights of disabled people and their inclusion enshrined and guaranteed through the ratification of the UNCRPD, and application of its principles in the actual process of policy development and implementation".

Despite these challenges, the CRPD offers opportunities for OPDs to conduct advocacy across all levels including the national level, and to participate in the human rights and sustainable development process at the UN [34]. For example, OPDs can send shadow reports and evidence to the CRPD Committee, which monitors the implementation of the CRPD by States; and OPDs can participate in interactive dialogue and side events at the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, which is hosted yearly at the UN headquarters [35]. Furthermore, the Civil Society CRPD Forum is held every year by the UN prior to the Conference of States Parties, whereby side meetings may be held to allow OPDs to engage with government representatives, UN organisations, and other civil society organisations to discuss ways to strengthen inclusion [35]. Importantly, the UN Disability Inclusion Strategy outlines the responsibility of the UN system to contribute to fulfilling the rights set out in the CRPD, including enabling the active participation of OPDs [36]. The Strategy [37] aims for "[s]ystematic close consultation with, and active involvement of, OPDs on all disability-specific issues, and broader issues", whereby an "[e]ntity has a partnership with OPDs at headquarter level and guidance on engagement with a diversity of OPDs at regional/country levels" (p. 17). Notably, a further mechanism for the involvement of OPDs with the UN is the EU-funded project Bridging the Gap. Bridging the Gap aims to increase the inclusion

of persons with disabilities in development cooperation; the project *inter alia* develops indicators and tools to support the implementation of the 2030 Agenda on Sustainable Development, which are validated through consultation with stakeholders including UN agencies and OPDs [38].

The obligations set out in the CRPD are reflected and reinforced in the Sustainable Development Goals (SDGs) [39]. The synergy between the CRPD and the SDGs presents significant opportunities for persons with disabilities and OPDs to increase their participation in policies and programmes at the national, regional and international levels, in particular in development policies. The SDGs aim to strengthen social inclusion and to leave no-one behind, including those with disabilities [39,40]. As proposed by the 2018 UN Flagship Report on Disability and Development [39] (p. 41): *"To meet the SDGs by 2030, international and national development programmes will need to prioritise inclusive development. In particular, concrete action is needed to make persons with disabilities and their situations visible in policy-making and to build just and inclusive societies"*.

1.3. Research Aim

The UN [41] has called for more data to ensure the rights of persons with disabilities in development. Moreover, the World Report on Disability [29] highlights the need for more qualitative research to explore the lived experience of persons with disabilities. Importantly, disability is usually excluded as a socio-economic variable in research on political participation [42]. In response to this urgent need for more data, the overall aim of this study was to examine the participation of persons with disabilities and OPDs in development programmes and policies by exploring recommendations from a sample of OPDs on ways to strengthen their participation with government and the UN. Such recommendations can provide insight into possible conditions and mechanisms to enable full and effective participation of OPDs in development programmes and policies.

2. Materials and Methods

2.1. Participants and Procedures

The IDA developed the first global survey to monitor the participation of OPDs across a wide range of development areas and several stages of policy and programme processes [4]. The IDA's Global Survey Report is available in different languages and formats, including the full report and Executive Summary in English [36]. The voluntary, open-access questionnaire was administered via SurveyMonkey through the IDA website. The survey was extensively advertised via listservs such as the IDA CRPD Forum, the International Disability and Development Consortium, Bridge CRPD-SDGs list serves, alongside social media. Individual emails were also sent to the members of IDA, constituting more than 1000 OPDs globally. Furthermore, social media packages were available in different languages on the IDA website to encourage visitors to the website to also disseminate the survey with their members and partners. The IDA post on the Global Survey reached more than 13,000 people.

The questionnaire was launched on 3 December 2018, which marked the International Day of Persons with Disabilities [43] and remained open until January 2019. The questionnaire was administered in the six official languages of the UN: English, Russian, French, Arabic, Chinese, and Spanish, alongside International Sign (but not other sign languages). An option to respond to questions in International Sign was available for 15 questions, whereby videos up to one minute in duration could be submitted online to the IDA.

The survey had a total of 573 respondents. Demographic information on respondents was collected for the purpose of assessing the reach of the survey. While respondents were not asked for information on their position in their OPD, all respondents confirmed that they were "a member or a staff member of an organisation or association for people with disabilities". Participants were informed that only one person from each organisation should complete the survey, although in some cases more than one person from an OPD responded.

While respondents completed the questionnaires on an anonymous basis, respondents who uploaded video responses in International Sign provided their contact information, so that their video responses could be matched to their text responses. All respondents were informed that they could voluntarily provide their contact information if they were agreeable to possibly being contacted by the IDA in relation to their responses.

In the present study, secondary data analysis was conducted on two open-ended items (questions 26 and 41) from the IDA Global Survey. The data were accessed through the IDA. The analysis presented in this paper represents a more in-depth examination of the data. The two items of the IDA Global Survey were selected for analyses as they asked for respondents' recommendations on how to improve their participation with their government and the UN, and were therefore deemed to be salient to the aim of the global survey, i.e., "to track the participation of all persons with disabilities and their organisations in development programmes and policies across all development/human rights issues through all stages of development of policies and programmes (from design to evaluation)" [4].

Characteristics of respondents for questions 26 and 41 are provided in Table 1. Question 26 had a total of 278 respondents. Following data-cleaning, three of these respondents were removed, resulting in a total of 275 respondents. The minimum age of respondents for this item was 19 years and the maximum age was 75 years; the average age was 45 years (SD = 12). A total of 41 respondents (14.9%) reported receiving support from another person to complete the questionnaire. In total, 228 respondents (85.1%) reported that the CRPD was ratified in their country, while 24 respondents (9%) reported that it was not, and 16 respondents (6%) reported that they were not sure.

Table 1. Characteristics of respondents.

Variable	Question 26 (n = 275) n (Valid %)	Question 41 (n = 151) n (Valid %)
Questionnaire Language:		
English	198 (72.0)	112 (74.2)
Spanish	33 (12.0)	15 (9.9)
French	16 (5.8)	7 (4.6)
Arabic	12 (4.4)	7 (4.6)
Russian	8 (2.9)	5 (3.3)
International Sign	5 (1.8)	3 (2.0)
Chinese	3 (1.1)	2 (1.3)
Gender:		
Men	146 (53.1)	75 (49.7)
Women	129 (46.9)	76 (50.3)
Other	0 (0)	0 (0)
Disability:		
A person with physical impairments	84 (30.5)	48 (31.8)
A person without a disability	51 (18.5)	22 (14.6)
Other	43 (15.6)	27 (17.9)
A blind or partially sighted person	24 (8.7)	17 (11.3)
A deaf person	22 (8.0)	11 (7.3)
A person who is hard of hearing or has other hearing difficulties	20 (7.3)	7 (4.6)
A person with multiple impairments	8 (2.9)	4 (2.6)
A person with a psychosocial disability	7 (2.5)	4 (2.6)
A person with an intellectual disability	6 (2.2)	3 (2.0)
A person with deaf-blindness	4 (1.5)	4 (2.6)
A person with autism	3 (1.1)	2 (1.3)
A person with a chronic disease	3 (1.1)	2 (1.3)

Table 1. *Cont.*

Variable	Question 26 (*n* = 275) *n* (Valid %)	Question 41 (*n* = 151) *n* (Valid %)
A person with short stature	0 (0)	0 (0)
A person affected by leprosy	0 (0)	0 (0)
A person with a cognitive impairment	0 (0)	0 (0)

Question 41 had 160 respondents. Following data-cleaning, nine respondents were removed, resulting in a total of 151 respondents. The minimum age of respondents for this item was 22 years and the maximum age was 74 years; the average age was 47 years (*SD* = 12.1). A total of 26 respondents (17.2%) reported receiving support from another person to complete the questionnaire. In total, 131 respondents (88.5%) reported that the CRPD was ratified in their country, while 12 respondents (8.1%) reported that it was not, and 5 respondents (3.4%) were not sure.

Ethical approval was not required for this study, as it comprised secondary use of anonymous data. Consent of respondents was implicitly given by virtue of completion of the questionnaire.

2.2. Study Materials

The 'IDA Global Survey on OPD Participation in Development Programmes and Policies' is the first survey to monitor the participation of OPDs on a global basis, across a wide range of development and human rights areas and across several stages of policy and programme processes [4]. The survey aims to provide a unique OPD perspective on the extent to which OPDs are effectively engaged in decision-making processes and the necessary conditions and mechanisms to enable full and effective participation. While this questionnaire was a baseline measure, it will be updated and iterated every two years as a strategic tool for the IDA to conduct regular monitoring of OPD participation. The second iteration of the survey is currently being launched.

The questionnaire comprised a total of 120 closed-ended and open-ended items. Two open-ended items of the survey explicitly asked respondents for their recommendations on ways to strengthen participation, and these items were analysed in the current study. These items were: "Q26: Please give 3 recommendations for your government to improve the way it works with OPDs?" and "Q41: Please give 3 recommendations to OPDs on how to improve the impact of their work with the UN?".

2.3. Data Analysis

The IDA availed of external translators to translate responses from open-ended questions. Video responses in International Sign were transcribed. Two research assistants conducted preliminary cleaning of the data. Data analysis was supported by a research team at the ALL (Assisting Living & Learning) Institute, Maynooth University, Ireland. The authors acted as advisors to the IDA on the original survey study. Each researcher had worked in the area of disability research and policy, across low-, middle-, and high-income contexts, for more than 5 years up to over 25 years.

Data from the two selected open-ended items were analysed using Constant Comparison Analysis, a descriptive and interpretive qualitative research method outlined by Elliott and Timulak [44]. The data were therefore distributed into *meaning units*, namely, units by which the analysis was conducted. Meaning units are segments of the data that, even if interpreted out of context, communicate adequate information to convey a piece of meaning to the reader. Broad headings or *domains* for organising participants' responses into different processes were identified. These domains were structured broadly during the beginning research stages via the survey, but were developed predominantly during data coding. These organising frameworks were flexible and a number of frameworks were tested until they were deemed to appropriately fit the data. The meaning units were

subsequently coded or *categorised* within each domain. Such categories emerged from the meanings in the meaning units. Formulation of categories is an interpretive process whereby the researcher labels categories similarly to the actual language of participants, while also applying their own understanding and knowledge of previous theory and studies [44].

2.4. Inter-Rater Reliability

To establish inter-rater reliability, a sample of responses from both open-ended items was assessed by a second reviewer from the research team. For example, for a sample check of respondents' recommendations for their government, the second reviewer agreed with the categorisation of 86 responses and disagreed with the categorisation of 4 responses. The dissimilar interpretation and categorisation of all responses was resolved on discussion between reviewers.

3. Results

3.1. Recommendations for Governments to Improve the Way They Work with OPDs

Figure 1 schematically presents domains and categories for respondents' recommendations for their government to improve the way it works with OPDs. The table format for Figure 1 (Table S1) can be accessed in the Supplementary Material. Domains and categories are not presented in order of importance and do not signify a hierarchy. Respondents provided their recommendations in relation to 20 categories, within five domains: (1) participation; (2) raising awareness and capacity building; (3) accessibility; (4) inclusion; and (5) legislation, policies, and programmes. Each of these five domains is discussed in more detail below.
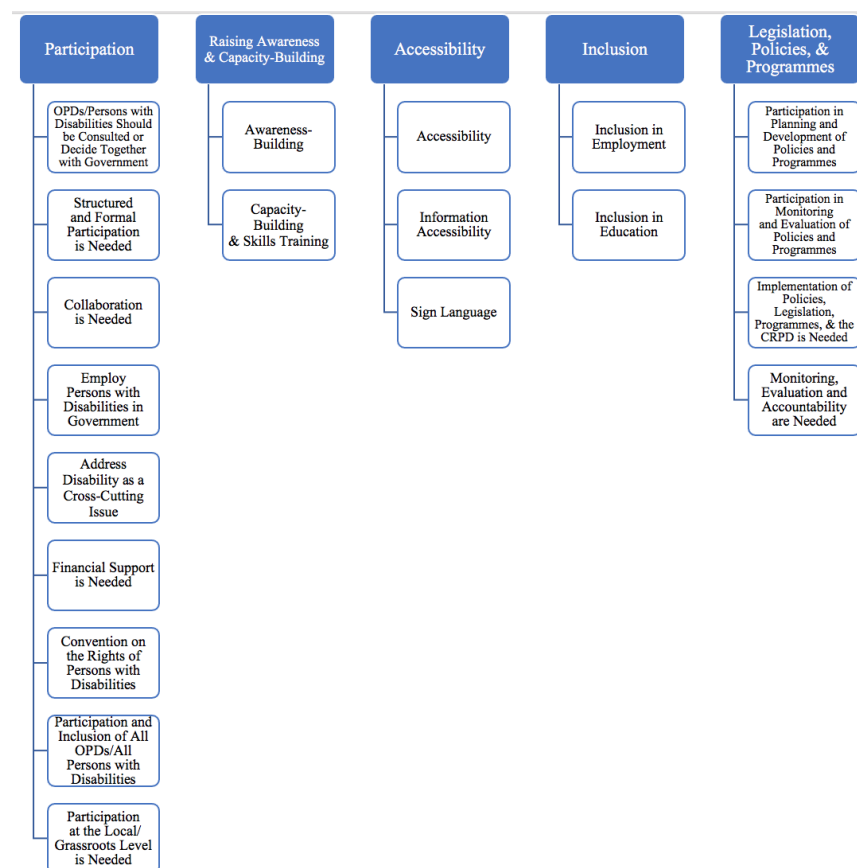

Figure 1. Respondents' recommendations for their government on how to improve the way they work with OPDs.

3.1.1. Participation

Respondents called for strengthened participation of OPDs with government. Specifically, respondents communicated the need for OPDs and persons with disabilities to be consulted or decide together with government (74 responses); the need for structured and formal participation (43 responses); the need for collaboration (17 responses); the importance of employing persons with disabilities in government (18 responses); the importance of addressing disability as a cross-cutting issue (18 responses); the need for financial support (131 responses); the importance of participation and inclusion of all OPDs and all groups of persons with disabilities (19 responses); and the need for participation at the local/grassroots level (21 responses). As suggested by one respondent: "Ensure that consultations are sought from all disability organisations—not just a select few" (R50 [respondent 50]). Similarly, another respondent asserted: "Make consultations and invite all constituencies, not just the traditional ones. Make sure that persons with disabilities are having the opportunity to participate, that everything is the most accessible as possible and that reasonable accommodations are provided" (R74). Another respondent stated: "Facilitate strategies to strengthen the formation and federation of DPOs at different levels, starting from village to the State and national level" (R115). One respondent suggested: "Always conduct meaningful consultations where disabled people's rights are respected, their needs addressed and their views not only sought, but more importantly heard" (R92). Several respondents stressed the importance of fully implementing the CRPD (33 responses). This is exemplified by one respondent's recommendation: "The government should fund DPOs to ensure they are appropriately resourced to undertake the consultation, advice and co-design required to enable the government to fulfil Article 4 (3) of the CRPD" (R122).

3.1.2. Raising Awareness and Capacity-Building

The importance of awareness-building (28 responses) and capacity-building and skills training (37 responses) was emphasised by respondents. As suggested by one respondent: "Intensify advocacy training to influence public policies and ensure that they factor the full inclusion of persons with disabilities in" (R241). Another respondent asserted that "all the government officials should be sensitised on disability issues" (R96). Correspondingly, a respondent recommended that "government should make provision for the capacity building/training of staff to enable them understand perfectly the issues around disability and development" (R66).

3.1.3. Accessibility

Respondents referred to accessibility in relation to the importance of accessibility more broadly (51 responses); information accessibility (33 responses); and sign language (22 responses). For example, one respondent commented: "The government to ensure accessibility so that DPOs can participate on equal basis with others" (R7). Another respondent called for "information in a way that most of us understand" (R32). Similarly, a respondent suggested: "More forward planning to ensure appropriate time to enable the full participation of DPOs and disabled people, including for example factoring in extra time for translation of documents/information and extra time for sharing information, engagement and discussion" (R122).

3.1.4. Inclusion

Within the domain of 'inclusion', respondents referred to the importance of inclusion in employment (32 responses) and inclusion in education (40 responses). For example, one participant called for their government "to provide reasonable accommodation in education and employment" (R49). Another respondent asserted: "The government should raise awareness among persons with disabilities, their families and community members on the rights of persons with disabilities, for example their right to access good employment opportunities, right to access quality education and also equality before the law" (R178). Correspondingly, a respondent suggested: "There should be equal distribution of support

to DPOs without any type of discrimination. Development of programs to combat illiteracy, poverty and disability in each country" (R210).

3.1.5. Legislation, Policies and Programmes

Respondents highlighted the importance of the participation of OPDs in the planning and development of policies and programmes (49 responses); participation in the monitoring and evaluation of policies and programmes (19 responses); the need for implementation of policies, legislation, programmes, and the CRPD (30 responses); and the need for monitoring, evaluation, and accountability (26 responses). As advised by one respondent: "Government should ensure legally that representatives of DPOs are included in formulation of policy and plans at national level" (R25). Another respondent called for their government to "closely consult with persons with disabilities and their DPO organisation in any development, planning, implementation, and monitoring and evaluation" (R78).

3.2. Recommendations to OPDs to Improve the Impact of Their Work with the UN

Figure 2 presents domains and categories for respondents' recommendations to OPDs on ways to improve the impact of their work with the UN. The table format for Figure 2 (Table S2) can be accessed in the Supplementary Material. Respondents provided their recommendations in relation to 14 categories, within four domains: (1) Participation; (2) advocacy, raising awareness and capacity-building; (3) accessibility; and (4) human rights. Each of these four domains is discussed in more detail below.
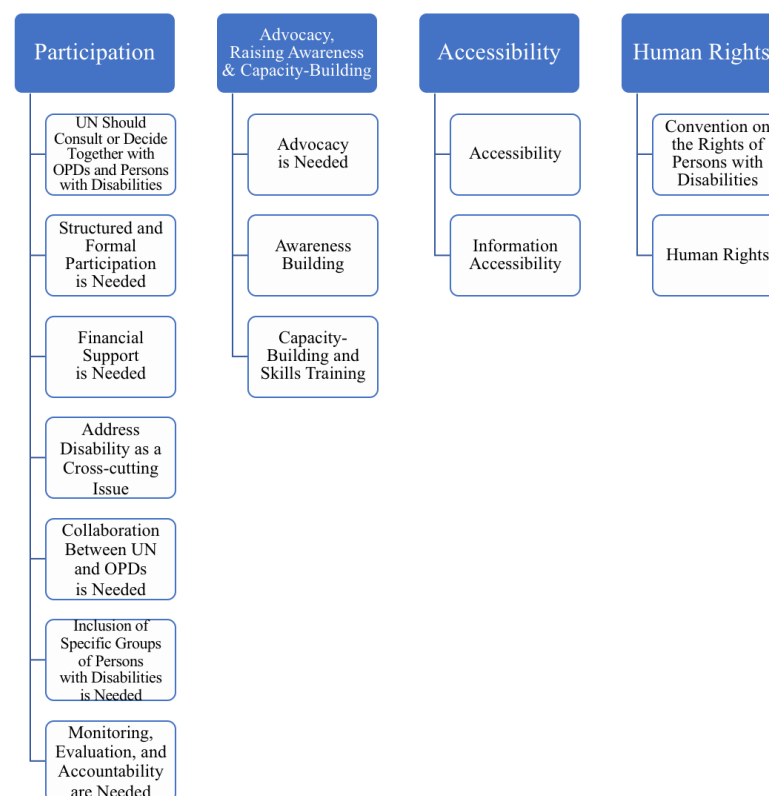

Figure 2. Respondents' recommendations to OPDs to improve the impact of their work with the UN.

3.2.1. Participation

Respondents emphasised the need for participation of OPDs with the UN. They highlighted the need for the UN to consult or decide together with OPDs and persons with disabilities (38 responses); the need for structured and formal participation (20 responses); the need for financial support (43 responses); the importance of addressing disability as a cross-cutting issue (15 responses); the need for collaboration between the UN and

OPDs (18 responses); the need for inclusion of specific groups of persons with disabilities (16 responses); and the need for monitoring, evaluation, and accountability (19 responses). As expressed by one respondent: "Invite persons with disabilities to participate, even when the subject is not disability. We also want to talk about everything else. Disability is a cross-cutting issue. That's inclusion" (R44). Another respondent remarked: "DPOs should be empowered to actively participate in the work of the UN organisations involved in disability—such participation should not be restricted to the government and the National Council for Disability Affairs. Civil society organisations are not in the picture" (R146). One respondent recommended: "Examine the situation of the different segments of people with disabilities" (R140).

3.2.2. Advocacy, Raising Awareness, and Capacity-Building

Respondents emphasised the need for advocacy (16 responses); the importance of awareness-building (26 responses); and the importance of capacity-building and skills training (28 responses). As emphasised by a respondent: "DPOs have to engage in advocacy work more in influencing the policy changes" (R80). One respondent suggested: "Provide disability awareness training for all UN departments to ensure that they are including this group in their programmes etc." (R9). Another respondent made the following recommendation: "Enhance capacity-building of DPO on rights and entitlement" (R6).

3.2.3. Accessibility

Respondents focused on the importance of accessibility more broadly (18 responses) and information accessibility (20 responses). As advised by one respondent: "Invite persons with disabilities from underrepresented groups to participate always you can, and make sure that everything is the most accessible as possible. Make sure that reasonable accommodations are provided" (R44). Another respondent asserted: "UN should inform national DPOs in all countries for possibilities to participate in various programmes" (R5). Correspondingly, one respondent recommended: "Information should be shared on equal basis" (R40). Similarly, a respondent commented: "Information to reach local DPO" (R119).

3.2.4. Human Rights

Respondents' recommendations also focused on the CRPD (24 responses) and on human rights more broadly (15 responses). This is exemplified by one respondent's suggestion to "establish the UN Secretariat for the CRPD in every country, like the UNDP, UNICEF and others" (R2). Another respondent made the following recommendation: "Include and promote, without procrastination, the rights of people with all, not specific, types of disabilities" (R140). Correspondingly, a respondent suggested: "Disabled persons organisations need to strengthen the knowledge on the issue of their rights to exercise citizenship" (R135).

4. Discussion

The overall aim of this study was to examine the participation of persons with disabilities and OPDs in development programmes and policies by exploring recommendations from a sample of OPDs on ways to strengthen their participation with government and the UN. The following discussion examines some of the main findings in this regard. Our findings indicate that there is an urgent need for consultation and shared decision-making of OPDs and persons with disabilities with government, and a need for the UN to consult or decide together with OPDs and persons with disabilities. The findings also reveal that participation of persons with disabilities is not equal across the diverse constituencies of the disability rights movement. In relation to their government's work with OPDs, respondents emphasised the importance of the inclusion of all OPDs and all groups of persons with disabilities and the need for participation at the local/grassroots level in government. Similarly, in relation to the impact of OPDs' work with the UN, respondents highlighted the need for inclusion of specific groups of persons with disabilities, such as young people with

disabilities, people with visual impairments, persons with deaf-blindness, and persons with disabilities from under-represented groups. It is vital to ensure that contributions of all OPDs are taken into account, as OPDs are viewed as the way to enable the inclusion of persons with disabilities at each stage of policy and decision-making processes [23].

Strengthened collaboration between OPDs and the UN was recommended by respondents, as exemplified by a respondent's suggestion that "DPOs' national/provincial network should link with all UN agencies and bridge with member DPOs". Collaboration between OPDs and government was also discussed by respondents, with one respondent suggesting for example "strategic partnership with the government and other stakeholders". Political, economic and cultural systems must include persons with disabilities in decision-making processes, as the experiential knowledge of those with disabilities is critical to effective decision-making, as captured by the slogan "Nothing About Us Without Us" [28].

Respondents also emphasised the need for collaboration amongst OPDs, illustrated by a respondent highlighting the "need to develop network with others DPOs". It has been argued that participation and power-sharing among representatives of persons with disabilities may be challenging due to their representation of different impairment-constituencies and differing priorities and concepts of inclusion [45]. However, recognition of differences amongst OPDs may also be seen as "a sign of democratic health and an embrace of civil society's diversity" [46] (p. 474). Indeed, networks and coalition-building are pivotal mechanisms to increase collective influence amongst OPDs in relation to organisational and advocacy capacity [47]. Joint advocacy amongst OPDs can therefore strengthen their participation in programme and policy processes.

Such advocacy by OPDs may also align with public opinion at large. For example, Flöthe and Rasmussen [48] conducted a cross-national comparative study of interest group and public preferences using a dataset of 50 issues in five West European countries. Contrary to the depiction of interest groups in politics as biased representatives of the public, the researchers found that the positions of the interest groups were in accordance with public opinion more than half the time.

The need for structured and formal participation with government was highlighted by respondents. For example, one respondent called for "structured rather than ad hoc interactions". Another respondent made the suggestion to "formalise consultation with DPOs", while another participant emphasised that "it's important to develop legislation, which will prescribe in detail the mechanisms of participation of persons with disabilities with the municipal and central governmental bodies". Similarly, respondents called for structured and formal participation with the UN, exemplified by a respondent recommending the establishment of "a permanent framework for consultation with DPOs" and another participant recommending the building of "an expert group [to] offer support to UN agencies to ensure inclusive development from the perspective of persons with disability".

Correspondingly, in a cross-national study on the participation of persons with disabilities in electoral and political processes in EU Member States, Priestley et al. [42] (p. 8) reported that "creating meaningful engagement with disabled people in policy process is also a CRPD obligation, yet this has not been formalised in the political institutions of most EU Member States". Similarly, in a study on the European Disability Strategy 2010–2020, Waddington and Broderick called for the European Commission, Parliament and Council to involve key stakeholders and OPDs in the design of the new EU Disability Strategy post–2020 and to adopt a code of conduct to facilitate structured participation of OPDs in all phases of the decision-making process [49].

Notably, the type of approach used for consultation may impact on stakeholder diversity in consultation processes. For example, Fraussen and colleagues [50] conducted a study examining the tools used by the European Commission to include different stakeholders in policy-making and how consultation approaches relate to the participation of stakeholders. The researchers compared the 'open approach' to consultation (which only includes public consultation tools, whereby all interested stakeholders can participate),

the 'closed approach' (which only includes targeted consultation tools including expert groups), and the 'hybrid approach' (which combines open and closed approaches, such as online consultation and expert groups). They found that closed consultation approaches resulted in lower dominance of business interests than hybrid approaches. As noted by Fraussen et al. (pp. 474–475): "A high level of business dominance might be problematic, as it may imply that organisations representing other constituencies with an important stake in a policy issue and capable of providing relevant (and different types of) viewpoints and expertise are to a (much) lesser extent being heard by policymakers".

The need to address disability as a cross-cutting issue was also communicated by respondents. Effective inter-sectoral coordination can facilitate coherent mandates across governmental departments for the provision of services [51]. The obligation to address disability as a cross-cutting issue is stipulated in the CRPD, which requires States Parties to promote, protect, and ensure the rights of persons with disabilities across all spheres of life [52]. The CRPD also obliges States Parties to mainstream disability within the entire spectrum of their policies. Mainstreaming disability implies treating persons with disabilities as equal rights-holders who should participate across all aspects of life and decision-making processes and is deemed to be the most efficient and cost-effective approach to ensuring equality for persons with disabilities [41].

The need for financial support was also emphasised by respondents. Financial support of OPDs and persons with disabilities is a key facilitator of participation. OPDs require sufficient funding to provide services for persons with disabilities—services that are "critical to their day-to-day lives, critical to giving people the care they need to stay alive, a chance to live a life of their choosing, a voice" [53]. Moreover, persons with disabilities have worse socioeconomic outcomes and poverty than those without disabilities [5,54,55]. For example, in the UK, half of all people living in poverty either have a disability or reside with a person who has a disability [56]. High rates of poverty amongst persons with disabilities are exacerbated by their exclusion from both local and national development processes [17]. Poverty experienced by persons with disabilities also results in their exclusion from political processes. As noted by Schlozman et al. [57] (p. xxiv), "the single best predictor of making a political contribution is family income . . . those who are well educated have multiple characteristics—for example, high levels of work-based civic skills and political interest—that predispose them to be politically active". The financial security of persons with disabilities has been further jeopardised by the COVID-19 pandemic. As asserted by Shakespeare et al. [58] (p. 1332), "participation—whether digital or in person—typically requires financial and other resources. The economic shocks of this pandemic particularly impact the poorest in society, who are often old, disabled, or female".

The study reveals that accessibility, including information accessibility, remains a key issue to ensure participation. As the CRPD Committee [59] noted, accessibility is a precondition to the enjoyment of all human rights, including the right to political participation enshrined in the Convention. While the right to participate in political and public life is set out in the CRPD, persons with disabilities have not been able to fully enjoy this right due to legal, physical, transportation, attitudinal, and informational barriers [32].

Another barrier that was highlighted by participants is awareness-raising, including awareness-raising of disability issues and rights amongst government officials; public awareness of the needs and rights of persons with disabilities; awareness-raising amongst persons with disabilities, their families, and communities on human rights; more extensive disability awareness training at the UN; and awareness-raising of UN processes amongst OPDs. In this respect, the implementation of Article 8 of the CRPD on awareness-raising is key. Awareness-raising is crucial to the creation of an inclusive participatory process. As noted by the UNPRPD [60], stakeholders need to have a better understanding of how OPDs can meaningfully participate in decisions that impact them.

Capacity-building and skills training were also emphasised by respondents as limitations to participation, including the need for capacity-building of OPDs so that they can work more effectively with government; skills development and training amongst OPDs

on advocacy, the CRPD, SDGs, and UN programmes; skills development programmes for persons with disabilities; and the training of government officials on disability issues, accessibility, and the CRPD. As noted in the World Report on Disability [29] (p. 265): "Disabled people's organisations may need capacity-building and support to empower people with disabilities and advocate for their needs".

Limitations

While respondents were informed that only one person from each organisation should complete the questionnaire, there were multiple responses from some OPDs. Notably, the average age of respondents for the full survey (*n* = 573) was 45 (*SD* = 13.4). This may possibly be explained by the intention to collect one response per OPD, which may have resulted in respondents being those in a representative role held by more senior people in an organisation.

Question 26 of the questionnaire asked respondents to "please give 3 recommendations for your government to improve the way it works with OPDs"; while question 41 asked respondents to "please give 3 recommendations to OPDs on how to improve the impact of their work with the UN". These questions were therefore phrased from different viewpoints. Despite these limitations, this study addresses an urgent gap for more qualitative research on the lived experiences of persons with disabilities and the inclusion of persons with disabilities in development programmes and policies.

5. Conclusions

Persons with disabilities experience similar barriers to political participation as other groups, as legislatures and politicians often fail to communicate with citizens when policies are being developed or undervalue the potential contribution of civil society [27]. However, persons with disabilities and OPDs also experience specific barriers to participation, including poverty, lack of education, social isolation, stigma and discrimination, lack of disability-accessible processes, and legal barriers [10]. For this reason, it has been argued that "politically, people with disabilities remain firmly in the shadows" [53].

Participants of this study called for participation in the planning, development, monitoring and evaluation of policies and programmes, and for more effective monitoring, evaluation and accountability mechanisms. It is also important that participatory processes are transparent. This requires publicity of the contributions of OPDs and of the commitment by governments, so that the extent to which there is meaningful participation in policy processes is transparent. Otherwise, OPDs may be invited merely to legitimise a process, without being able to contribute to the outcome of that process. As emphasised by the UNPRPD [60], when OPDs are engaged to inform policy processes, such participation is frequently tokenistic or fails to provide sufficient time or space for meaningful participation.

Although the number of persons with disabilities is increasing globally, persons with disabilities are frequently excluded from policy content and policy processes [61]. Indeed, it is evident that persons with disabilities experience "systematic exclusion from consultation and decision-making mechanisms related to design, planning and monitoring of policies, programs and services that affect their lives and their communities" [62] (p. 5). While much progress has been made on including disability on the agenda, using this momentum to legitimately include persons with disabilities in policy has been challenging [23]. However, the synergy between the CRPD and the SDGs offers significant opportunities for persons with disabilities and OPDs to strengthen their participation in policies and programmes, in particular in development policies. In order to capitalise on this momentum and to leverage the CRPD and SDGs, it is vital to dismantle the barriers to participation in decision-making that have been highlighted in this study.

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