

How representative are organisations of persons with disabilities? Data from nine population-based surveys in low- and middle-income countries

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ABSTRACT

Organisations of Persons with Disabilities (OPDs) are critical to promoting and protecting the rights of people with disabilities. However, little is known about the extent to which people with disabilities are aware and members of OPDs. This study uses data from nine population-based surveys in low- and middle-income countries to explore OPD awareness and membership. Across settings, about a third of people with disabilities were aware of OPDs and fewer than 15% were members. Awareness and membership were lower amongst older adults, women, people with difficulties communicating, remembering and with self-care, people with less education, in poverty and in rural areas. Underrepresentation of certain groups may indicate a need to seek out the voices of people less likely to be associated with OPDs. Further, low total membership may be a cause for concern in settings where OPDs are relied upon to deliver essential services in the absence of state structures.

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Points of interest

- Organisations of Persons with Disabilities can serve many roles, including advocacy, policymaking and service provision. The increasing involvement of Organisations of Persons with Disabilities in direct provision of essential services, particularly in low- and middle-income countries, is often a result of poor availability and quality of inclusive public services.

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- This study explores awareness and membership of people with disabilities across nine low- and middle-income countries using population-based surveys.
- About a third of people with disabilities were aware of Organisations of Persons with Disabilities across settings, ranging from 12% in Lesotho to 73% in the Maldives.
- Fewer than 15% of people with disabilities were members across settings, ranging from 3.5% in Zambia to 14% in Vietnam (Cam Le district).
- Awareness and membership were generally lower amongst older adults, women, people with difficulties communicating, remembering and with self-care, people with less education, in poverty and in rural areas.
- Given the increased role of Organisations of Persons with Disabilities in direct service delivery, low total membership may indicate that many people with disabilities – particularly the most marginalised or experiencing the greatest need – are not being reached.
- Additional efforts may also be needed to seek out the voices of groups underrepresented in Organisations of Persons with Disabilities, particularly for advocacy and policymaking.

Introduction

A key principle in the disability rights movement is ‘nothing about us without us’ (Charlton 2000). This approach mandates that people with disabilities must be directly involved in decision-making which affects them, particularly in the co-creation of strategies to remove barriers to participation and to improve inclusion.

As Charlton (2000) highlights, and as documented in many studies (Hahn 1988; Driedger 1989; Shakespeare 1993), Organisations of Persons with Disabilities (OPDs, also known as Disabled People’s Organisations - DPOs) are central to the realisation of the vision of ‘nothing about us without us’. Most modern OPDs emerged from the late 1960s and early 1970s onwards and are democratic, voluntary associations in which most voting participants are people with disabilities. These organisations are part of the third sector, being neither market-oriented, nor part of the state, and many have their ideological basis in the redefinition of disability as political, not medical (Putnam 2005). In their origins, most OPDs are campaigning and/or self-help organisations (Campbell and Oliver 2013; Charlton 2000; Driedger 1989), but many have developed service provision elements, usually as part of independent living or economic empowerment programmes (Zhang 2017; Waldschmidt et al. 2015). Although initially more prevalent in high income countries, OPDs are now increasingly active in many low- and middle-income countries (LMICs), and are engaged in a wide range of activities including advocacy, policymaking, self-help and service provision (Young, Reeve, and Grills 2016; Zhang 2017; Opoku and Nketsia 2021; Birtha 2013). The expansive

roles of OPDs and their active involvement in service delivery may be due in part to the relative scarcity of state programmes available to people with disabilities in these settings (Meyers 2019).

'Nothing about us without us' as a mandate, and OPDs as a vehicle of mobilisation, arose in the context of ongoing experiences of paternalism towards people with disabilities, and a lack of meaningful consultation in the design and delivery of both mainstream and disability-targeted policies and programmes (Waldschmidt et al. 2015; Yeo and Moore 2003). The failure to actively include people with disabilities in decision-making has often resulted in exclusionary policies and programmes, resulting in poor quality and inappropriate provision of services and missed opportunities to support the active social participation of people with disabilities (Opoku and Nketsia 2021; Kett et al. 2019).

It is now increasingly accepted that where people with disabilities and their representative organisations are included as core members in the decision-making process, better and more appropriate solutions are likely to be found (Kuper et al. 2021; Woodburn 2013; Opoku and Nketsia 2021). OPDs have played instrumental roles in advocating for national and international policies and programmes that foster greater participation and integration of people with disabilities (Woodburn 2013). For example, a strong OPD may be able to change attitudes, win concessions from governments or service providers, resist entitlement cutbacks and thus improve the situation for its members and other people with disabilities. At the global level, the coalescence of people with disabilities and their representative organisations was essential for the creation, passage and propagation of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD), which provides the legal framework for protecting and promoting human rights for people with disabilities (United Nations Office of the High Commissioner on Human Rights 2006; Woodburn 2013).

More generally, the involvement of affected persons in decisions which involve them is a key tenet of a Human Rights Approach to development. Processes of development should be 'participatory, accountable and transparent' – democracy, as well as development, is a priority, with participation as non-negotiable (Sengupta 2000). As a result, international bilateral and multilateral actors in international cooperation expect participation of affected parties in any interventions or policies. When it comes to disability, Article 29 of the UNCRPD (United Nations Office of the High Commissioner on Human Rights 2006) specifies that State Parties undertake:

'(b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.'

This commitment means that governments of the 185 states who have ratified the Convention must promote the involvement of OPDs in their broader development strategies, as well as in their domestic disability work. OPDs are also recognised as a Stakeholder Group for reviewing progress towards the 2030 Sustainable Development Agenda to fulfil its promise of 'no one left behind' (United Nations General Assembly 2013).

In addition to collective benefits, membership in OPDs can also carry advantages for people with disabilities directly (Putnam 2005; Charlton 2000; Hahn 1988; Butcher et al. 2021). To the individual, membership can be a source of community and acceptance, and strengthen people with disabilities' sense of identity and self-esteem (Tajfel and Turner 1986; Grills et al. 2020; Butcher et al. 2021). Being in a group with others, and discussing issues that are of concern, can lead to the identification of disabling societal barriers (Shakespeare 1993). It may also be empowering to learn about disability rights and the social model of disability (Hahn 1994; Hasler 1993), a process related to what Paulo Freire (1972) called conscientization. Further, uniting around common causes and engaging in political action can foster agency and power (Young, Reeve, and Grills 2016). OPDs also are increasingly playing active roles in service provision, particularly in areas with poor availability of state-run services (Opoku and Nketsia 2021; Waldschmidt et al. 2015; Riddell et al. 2005). For example, a two-year randomized controlled trial in India found that people with disabilities who were supported to form OPDs had increased access to services (e.g. accessible toilet facilities, rehabilitation and social welfare) as well as improved self-reported well-being and social participation (Grills et al. 2020). Further, OPDs played a central role in providing people with disabilities in many countries with essential goods and services during the COVID-19 pandemic, such as information in accessible formats and emergency assistance that were not provided by the state (Brennan 2020; Ned et al. 2021).

It is clear that OPDs have important benefits for both their members directly, as well as collectively for advancing the views and concerns of people with disabilities in various decision-making spaces. However, evidence is lacking on the coverage and composition of OPDs, particularly in low- and middle-income countries (LMICs), despite concerns over their representativeness (Yeo and Moore 2003). This data is important for assessing both the reach of OPDs and the extent to which their membership is reflective of the broader population of people with disabilities. Consequently, the aim of this study is to explore the extent to which people with disabilities are aware of and participating in OPDs in nine LMICs, and seeks to understand how representative OPD membership is of the broader population of people with disabilities in each country.

Research process

Design

This research uses data collected from nine population-based, cross-sectional surveys of disability in LMICs: Botswana (Eide and Mmatli 2015), Nepal (Eide, Neupane, and Hem 2016), Lesotho (Kamaleri and Eide 2011), Malawi (Eide and Munthali 2017), Maldives (Banks et al. 2020), Vietnam (Banks et al. 2019), Uganda (Eide, Nanono, and Omona 2020), Zambia (Central Statistical Office and Ministry of Community Development and Social Services 2018), and Zimbabwe (Ministry of Health and Child Care 2015). These surveys were conducted between 2010–2020. Eight were nationally representative surveys (Botswana, Nepal, Lesotho, Malawi, Maldives, Uganda, Zambia, and Zimbabwe) and one was regional (Vietnam – Cam Le district). All surveys used population-based, probability sampling with response rates ranging from 82-99%. Details on the methodologies for each survey are summarised in Table 1.

Participants

Participants were sampled in each site according to a predetermined sampling frame, based on a sample size calculation, and representative sampling of census-based enumeration areas. Sampled households were approached by members of the survey team, who sought details on the functioning of all members of the household (ages 2 or 5+ depending on the site) to determine disability status.

All sites used the Washington Group questions to screen for disability (Table 1). The Washington Group questions are recommended by the United Nations Statistical Commission and other experts for robust, internationally comparable estimates of disability (Groce and Mont 2017). These question sets have been validated in multiple LMIC settings (Washington Group On Disability Statistics 2009; Groce and Mont 2017). The Washington Group questions focus on functional limitations an individual experiences performing everyday activities, rather than on the presence of impairments – in-line with the UNCRPD definition of disability (United Nations Office of the High Commissioner on Human Rights United Nations, 2006). The Washington Group questions sets vary by number of questions and types of functional limitations covered. For example, the Short Set (used in all but one study) has six questions and focuses on seeing, hearing, walking/climbing stairs, remembering/concentrating, self-care and communicating. The Short Set Enhanced (used in the Maldives) includes the six questions from the short set, with an additional six questions on upper body functioning, anxiety and depression (Washington Group on Disability Statistics 2017). For most questions in the Washington Group question sets, the individual is asked about their level of difficulty performing that activity (response options: difficulty,

Table 1. Survey methodologies.

Country	Year of reporting	Location	Sample size, adults (18+) with a disability	Approach for measuring disability in adults	Definition of disability used in this analysis
Botswana	2015	Nationally-representative	767	WGSS, self-report	'A lot of difficulty' or 'cannot do' for any domain
Lesotho	2010	Nationally-representative	445	WGSS, self-report	'A lot of difficulty' or 'cannot do' for any domain
Malawi	2018	Nationally-representative	2167	WGSS, self-report	'A lot of difficulty' or 'cannot do' for any domain
Maldives	2017	Nationally-representative	318	WGSS Enhanced + write-in options, self-report	'A lot of difficulty' or 'cannot do' for any domain; reporting daily symptoms of anxiety/ depression at an intensity described as 'a lot'; has a health condition that would be eligible for the Disability Allowance (e.g. autism, psychosocial disability)
Nepal	2016	Nationally-representative	869	WGSS, self-report	'A lot of difficulty' or 'cannot do' for any domain
Vietnam	2016	Cam Le district	135	WGSS, head of household report	'A lot of difficulty' or 'cannot do' for any domain
Uganda	2020	Nationally-representative	1611	WGSS, self-report	'A lot of difficulty' or 'cannot do' for any domain
Zambia	2018	Nationally-representative	580	WGSS, self-report	'A lot of difficulty' or 'cannot do' for any domain
Zimbabwe	2015	Nationally-representative	3800	WGSS, self-report	'A lot of difficulty' or 'cannot do' for any domain

some difficulty, a lot of difficulty or cannot do). Anxiety and depression (Maldives only) were assessed through two questions on the severity and frequency of symptoms. For the purpose of this study, disability was defined as experiencing 'a lot of difficulty' or 'cannot do' for at least one activity, or, for anxiety and depression, experiencing daily symptoms at an intensity described as 'a lot'.

Individuals predominantly reported on their own functioning, except in Vietnam, where the head of the household reported on all household members' functioning. Data on disability was collected on all household members ages 2 or 5+, depending on survey; however, analyses for this paper are restricted to adults (18+ years).

Outcome measures

People who were identified in the population-based surveys as having a disability then answered questions about their social participation. OPD

membership and awareness was assessed through the following two questions:

1. Are you aware of organizations for people with disabilities (DPO)?
2. [If aware] Are you a member of an organization for people with disabilities (DPO)?

People who were not aware of OPDs were assumed to be non-members.

Data analysis

Tabulations of the proportion of people with disabilities who reported being aware, and were members of OPDs were calculated for each country. Proportions were also disaggregated by age (18–64, 65+), gender, type of functional difficulty (seeing, hearing, walking, communication, remembering, self-care), education (ever vs never attended) and receipt of a disability-targeted cash transfer (Maldives, Nepal and Vietnam only). Differences by socioeconomic status were also calculated in six settings, through principal component analysis of household assets and housing characteristics (Maldives, Vietnam) or an additive asset count (Botswana, Nepal, Malawi, Zimbabwe). Differences amongst sub-groups were assessed for statistical significance using multivariate regressions adjusted for age and sex. Data was analysed using SPSS 27 and STATA 16.

Ethical considerations

Ethical approval was received from the London School of Hygiene & Tropical Medicine for two studies (Vietnam, Maldives) and from national ethics committees / advisory bodies in each country. Seven studies were registered with the Norwegian Agency for Shared Services in Education and Research (Botswana, Lesotho, Malawi, Nepal, Uganda, Zimbabwe, Zambia). All participants provided written consent (signed or thumbprint) or recorded oral consent (Maldives only) before beginning any interview.

Results

The results of this analysis are presented in [Table 2](#) (awareness) and [Table 3](#) (membership).

Approximately a quarter to a third of all people with disabilities were aware of OPDs in all settings, except the Maldives. The proportion of people with disabilities who were aware of OPDs ranged from a low of 12.4% in Lesotho, to a high of 73.3% in Maldives. For membership, fewer than 15% of all people with disabilities were part of an OPD in every country ([Table 2](#)).

Table 2. Awareness of OPDs amongst people with disabilities in 9 countries.

	Botswana n = 767	Malawi n = 2167	Lesotho n = 445	Maldives n = 318	Nepal n = 869	Vietnam n = 135	Uganda N = 1611	Zimbabwe n = 2800	Zambia n = 567
Overall	29.2%	30.9%	12.4%	73.3%	35.6%	30.4%	26.4%	21.0%	33.3%
<i>Gender</i>									
Men	28.8%	35.3%	10.1%	72.4%	45.2%	33.3%	28.1%	23.9%	35.5%
Women	29.8%	26.9***	14.5%	73.9%	25.5%***	27.8%	24.6%	18.7%**	31.5%
<i>Age</i>									
18-64	34.7%	33.2%	14.1%	78.7%	38.5%	38.6%	28.1%	22.3%	36.0%
65+	12.9%	25.4%***	8.5%	61.8%**	24.2%***	17.3%***	22.4%*	18.9%*	28.1%
<i>Functional difficulties</i>									
Sensory	28.2%	32.0%	12.3%	68.5%	29.2%***	25.7%	25.2%	21.2%	32.0%
Walking/upper body	28.3%	32.1%	13.0%	70.1%	47.5%***	31.4%	31.1%***	21.5%	34.6%
Remembering	20.8%*	18.5%***	7.0%*	63.8%	15.3%***	28.0%	20.4%*	15.0%***	21.3%**
Self-care	20.2%**	23.2%**	9.8%	60.0%	34.9%	24.5%	28.6%	17.1%***	9.2%***
Communicating	23.8%	21.8%***	9.4%	68.6%	21.5%***	26.3%	20.3%	14.6%***	21.8%
<i>SES status</i>									
Quintile 1 (richest)	34.4%	46.8%		75.8%	33.5%	36.4%		31.8%	
Quintile 2/3	35.7%	32.6%		69.8%	34.7%	35.0%		15.7%	
Quintile 4/5 (poorest)	17.9%***	29.4%***		77.4%	38.2%	25.0%		12.2%***	
<i>Education</i>									
Never attended	19.4%	23.2%	8.7%	66.1%	22.3%	26.3%	19.5%	12.9%	24.4%
Ever attended	37.6%***	34.7%***	13.8%	74.8%	64.4%***	31.0%	32.7%***	24.2%**	36.9%**
<i>Location</i>									
Rural	17.6%	29.9%	10.8%	74.9%	32.4%		25.5%	15.3%	
Urban	35.6%***	41.4%***	15.5%	66.1%	50.7%***		32.1%*	34.3%***	
<i>Disability Allowance recipient</i>									
Yes				74.4%		54.0%***			
No				72.9%		16.5%			

Statistical significance testing (adjusted for age, sex): * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$; reference categories for multivariate analysis are men, age 16-64, richest SES quintile, no primary education, no Disability Allowance, rural location; for functional limitation, reference is all others without the specified limitation.

Table 3. Membership in OPDs amongst people with disabilities in nine countries.

	Botswana n = 767	Malawi n = 2167	Lesotho n = 445	Maldives n = 318	Nepal n = 869	Vietnam n = 135	Uganda N = 1611	Zimbabwe n = 3800	Zambia n = 567
Overall	8.9%	4.0%	8.1%	7.2%	9.2%	14.1%	6.9%	7.0%	3.4%
<i>Gender</i>									
Men	8.7%	4.4%	7.8%	9.8%	11.2%	12.7%	7.4%	8.7%	3.4%
Women	9.8%	3.4%	8.2%	5.6%	7.1%*	15.3%	6.3%	6.1%*	3.5%
<i>Age</i>									
18-64	11.0%	4.9%	8.3%	7.8%	10.6%	18.1%	7.6%	7.4%	4.4%
65+	4.4%**	2.0%***	7.7%	5.9%	3.9%**	7.7%	5.2%	6.3%	1.6%
<i>Functional difficulties</i>									
Sensory	5.9%	4.2%	9.3%	3.7%	5.6%**	5.7%	6.2%	7.1%	4.2%
Walking/upper body	11.5%	4.3%	9.2%	8.6%*	14.2%***	15.1%	8.2%**	8.0%	4.1%
Remembering	6.1%	4.5%	0.9%**	5.7%	8.5%	10.0%	6.5%	5.2%**	1.1%
Self-care	5.8%*	2.3%	4.9%	10.9%	10.9%	13.2%	8.3%	5.6%*	2.6%
Communicating	9.4%	4.1%	4.7%	11.4%	4.8%**	5.3%	8.5%	4.5%*	1.7%
<i>SES status</i>									
Quintile 1 (richest)	9.0%	6.0%		9.1%	9.0%	18.2%		9.5%	
Quintile 2/3	10.8%	4.5%		7.6%	11.5%	18.3%		6.5%	
Quintile 4/5 (poorest)	8.4%	3.1%***		4.7%	6.8%	9.4%		9.5%	
<i>Education</i>									
Never attended	6.5%	3.1%	6.5%	14.3%	4.6%	5.5%	4.6%	4.5%	3.1%
Ever attended	11.3%*	4.5%	8.7%	5.7%*	19.2%***	15.5%	8.8%***	7.9%**	3.7%
<i>Location</i>									
Rural	5.9%	3.4%	8.1%	8.9%	8.2%		6.4%	5.7%	
Urban	11.2%*	11.1%***	8.1%	4.7%	13.8%*		9.8%	9.7%***	
<i>Disability Allowance recipient</i>									
Yes				25.6 %***		30.0%***			
No				1.3%		4.7%			

Statistical significance testing (adjusted for age, sex): * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$.

The proportion that were members ranged from a low of 3.5% in Zambia to a high of 14.1% in Vietnam.

By gender, women were less likely to be aware of OPDs (significant in Malawi – 26.9% vs 35.3%, Nepal – 25.5% vs 45.2%, Zimbabwe 18.7% vs 23.9%, all $p < 0.01$) and in many settings less likely to be members of OPDs (significant in Nepal – 7.1% vs 11.2% and Zimbabwe – 6.1% vs 8.7%). In all settings, older adults (65+ years) were less likely to be aware and be members in OPDs compared to working-age adults (18–64 years), which was statistically significant in three settings for membership (Botswana – 4.4% vs 11.0%, Malawi – 2.0% vs 4.9%, and Nepal – 3.9% vs 10.6%,) and six settings for awareness (older adults vs working age adults: Malawi – 25.4% vs 33.2%, Maldives – 61.8% vs 78.7%, Nepal – 24.2% vs 38.6%, Vietnam – 17.3% vs 38.6%, Uganda – 22.4% vs 28.1%, Zimbabwe – 18.9% vs 22.3%).

Awareness of and membership in OPDs varied by type of functional difficulty across sites. People with mobility limitations had the highest level of awareness and membership in OPDs across all countries (statistically significant for awareness in Nepal and Uganda, for membership in Uganda only). In contrast, people with difficulties in remembering, self-care, and/or communicating showed consistently lower awareness of and membership in OPDs in most sites. This trend was particularly true for people with difficulty remembering, who had significantly lower likelihood of being aware of OPDs in six countries (Botswana, Malawi, Nepal, Uganda, Zimbabwe, and Zambia). For membership, people with difficulties in self-care (Botswana, Zimbabwe) and communicating (Nepal, Zimbabwe) had lower likelihoods of being OPD members than people with other disabilities.

Five countries had data on socioeconomic status. In Zimbabwe, Botswana and Malawi, people with disabilities from the poorest quintiles of socioeconomic status were less likely than individuals from higher socioeconomic groups to be aware of OPDs (poorest two quintiles vs richest quintile: Botswana – 17.9% vs 34.4%, Malawi – 29.4% vs 46.8%, Zimbabwe – 12.2% vs 31.8%; all $p < 0.001$). In Malawi, people in the poorest quintile were half as likely to participate in OPDs compared to the richest (3.1% vs 6.0%).

By education, people who had never attended primary school showed significantly lower awareness of OPDs in all settings (significant in Botswana – 19.4% vs 37.6%, Malawi – 23.2% vs 34.7%, Nepal – 22.3% vs 64.4%, Uganda – 19.5% vs 32.7%, Zimbabwe – 12.9% vs 24.2% and Zambia – 24.4% vs 36.9%; all $p < 0.01$). Never attending primary school was associated with lower likelihood of membership in three of five countries (significant in Botswana – 6.5% vs 11.3%, Nepal – 4.6% vs 19.2%, Uganda – 4.6% vs 8.8%; all $p < 0.05$). By location, people with disabilities living in urban areas were more likely to be aware of OPDs in the 7 settings with this data available (significant for Botswana – 35.6% vs 17.6%, Malawi – 41.4% vs 29.9%, Nepal – 50.7% vs 32.4%, Uganda – 32.1% vs 25.5% and Zimbabwe – 34.3%

vs 15.3%; all $p < 0.05$), and were more likely to be members in four settings (significant in Botswana – 11.2% vs 5.9%, Malawi – 11.1% vs 3.4%, Nepal – 13.8% vs 8.2%, and Zimbabwe – 9.7% vs 5.7%; all $p < 0.05$). In the Maldives, people with no education were more likely to be OPD members (14.3% vs 5.7%). Finally, Disability Allowance receipt was linked to significantly higher likelihood of OPD membership in the two countries with this data (Nepal – 25.6% vs 1.3% and Vietnam – 30.0% vs 4.7%; $p < 0.001$).

Discussion and conclusions

Overall, this study finds that in most included settings approximately a quarter to a third of people with disabilities were aware of OPDs, and less than 10% were members. Both awareness and membership were generally lower amongst older adults, women, people with difficulties communicating, remembering and with self-care and people living in poverty. Receipt of disability-targeted cash transfers was associated with greater likelihood of being an OPD member in two of three settings.

Relatively little other evidence is available on the coverage and composition of OPDs. Others have voiced concern about equality in access to OPDs amongst people with disabilities – for example, Yeo and Moore (2003) noted that OPDs are dominated by ‘men with physical impairments’. Similarly, qualitative studies have indicated concerns from stakeholders on the underrepresentation of certain demographic groups in OPDs, particularly people with intellectual (Waldschmidt et al. 2015; Callus and Camilleri-Zahra 2017) and psychosocial disabilities (Waldschmidt et al. 2015). However, data reinforcing these observations have been lacking.

The observed differences in OPD awareness and membership amongst people with disabilities in this study may be explained by several factors. First, by functional limitation, people with cognitive impairments (e.g. people difficulties in remembering, communicating) and self-care difficulties, who tended to have lower awareness and membership in OPDs, may be excluded due to lack of targeted outreach or needed accommodations for self-representation. This postulation is plausible given the evidence that people with more severe impairments, and ones which affect communication, tend to face additional marginalisation (Kim et al. 2016; Temple et al. 2020). Further, many OPDs have traditionally been focused on one disability type – particularly associations for blind, deaf or people with physical impairments – with umbrella, multi-disability organisations emerging more recently (Charlton 2000; Driedger 1989; Campbell and Oliver 2013). This origin of OPDs may explain the relatively higher awareness of and membership in OPDs amongst people with physical, and to a lesser extent, sensory functional limitations. Additional research is needed to map the focus of OPDs in these and other countries (e.g. cross-disability vs focused on specific

impairments) to explore in greater depth whether different types of disabilities are represented across available OPDs. Second, lower awareness of and membership in OPDs amongst older adults may be due to common conceptualisations that functional limitations due to ageing are not disability (Loeb, Eide, and Mont 2008; Mont 2007), leading older adults with disabilities avoid self-identifying as having a disability or OPDs to overlook them during recruitment. Third, women, people living in poverty and people with lower education often face additional marginalisation on account of gender and socioeconomic status (Banks, Kuper, and Polack 2017; Kavanagh et al. 2015; Kabia et al. 2018), potentially limiting knowledge of and membership in OPDs. For example, people with low levels of education or with limited financial means may be less able to access information about OPDs (e.g. low literacy, poor access to internet, phones and other modes of communication) (United Nations 2019), while women may be dissuaded from engaging in certain activities or groups due to restrictive gender norms (Kabia et al. 2018). Additionally, lower awareness and membership in rural areas may reflect that many OPDs are urban-based and are underfunded to conduct outreach, particularly in remote areas. Finally, Disability Allowance enrolment might increase knowledge and access to membership in OPDs if people with disabilities are linked to OPDs during registration; alternatively, OPDs may be helpful in connecting members to services, including social protection (Banks et al. 2021; Opoku and Nketsia 2021; Riddell et al. 2005; Hameed et al. 2023).

Several limitations should be taken into account when interpreting the findings of this research. Importantly, sample sizes were likely underpowered to detect smaller differences amongst people with disabilities, particularly for OPD membership given that so few respondents were members, and by type of functional limitation. As such, the lack of statistically significant associations by some characteristics does not necessarily indicate that in actuality there is no difference in awareness or membership between sub-groups. Additionally, some respondents may have misinterpreted the questions' meaning to include any organisation focused on disability (e.g. NGOs, service providers), rather than an organisation led by and for people with disabilities. If so, the proportion of people with disabilities aware of and participating in OPDs would be overestimated. Further qualitative research is needed to explore people with disabilities' awareness of and distinction between organisations *of* people with disabilities in compared to organisations *for* people with disabilities. Similarly, information was not collected on the level of involvement of OPD members. The characteristics of OPD leadership – who are most likely to be involved in consultation and collective decision-making processes – may be different still from general members. Further, not all individual-level characteristics of interest were explored (e.g. race, ethnicity) which could be other sources of important

differences. Included countries were also highly diverse in terms of country- and regional-level factors, such as politics and governance structures, which may also influence the types of OPDs that can be formed and the activities they are permitted to engage in. Further research is therefore needed to understand the political and community-level factors that affect the formation of OPDs in these and other countries, and people with disabilities' ability and willingness to engage with them.

However, this research also carries several key strengths, namely in that it includes data from nine nationally-representative representative surveys (and one district-level survey), collecting data on over 10,000 people with disabilities in low- and middle-income countries. The findings from this analysis on the reach and representativeness of OPDs carries several implications for policy and practice.

First, OPDs are essential stakeholders in determining priorities for action and are often viewed as representing the voice and concerns of people with disabilities within their given catchment area. Governments, international agencies and other organisations often work through OPDs when seeking input from people with disabilities (Zhang 2017; Waldschmidt et al. 2015). However, the priorities of some groups of people with disabilities (e.g. women, people with intellectual impairments, older adults, people in rural areas and with little education) may not be given sufficient weight if OPD membership is skewed toward certain demographic groups (e.g. men, people with physical impairments, people with higher levels of education, working-age adults, urban-based). It should be noted that representativeness is a challenge affecting not only OPDs, but also other representative groups (e.g. women's organisations, trade unions) and national and local governments (Ricucci and Van Ryzin 2017; Celis et al. 2008; Kahn and Louw 2011). As with these other representative groups, efforts may be needed to diversify membership and conduct outreach to people not adequately represented.

Second, people with disabilities not associated with OPDs may be excluded from the direct benefits of membership. In addition to services provided directly by OPDs, OPDs are often entry points for governments and other organisations to identify people with disabilities. For example, stakeholders like governments, funders, relief organisations often work with OPDs to identify people with disabilities who would be eligible for their services or programmes (Opoku and Nketsia 2021; Riddell et al. 2005). Indeed, one of the main functions of OPDs can be to link organisations providing services and opportunities with people with disabilities. When funds were released at the start of the COVID-19 pandemic to support people with disabilities, for instance, they were at times allocated to OPDs (Pring 2020). However, if the majority of people with disabilities do not belong to these organisations, and in many cases are not even aware of their existence, then these avenues for reaching and involving people with disabilities may be limited. Further,

the data from this study suggests that individuals experience intersecting layers of vulnerability according to gender, age, socioeconomic status, and education are least likely to be members of OPDs, and so it is arguably those who are most in need to the kinds of supports and opportunities which OPD memberships may provide that are not being adequately reached.

Finally, many studies recruit participants with disabilities through OPDs, particularly with the increasing use of remote research methods with the onset of the COVID-19 pandemic (Banks et al. 2022). However, this research suggests that OPDs are often not representative of the broader population of people with disabilities, which then would carry implications for the generalisability of any findings emerging from solely OPD-recruited samples.

To be clear, this research is not in any way diminishing the importance of OPDs. OPDs must continue to be key actors in driving the disability movement, research agendas and broader national and development planning, and should receive governmental and other forms investment. However, additional actions are likely needed to reach and capture the views and concerns of people with disabilities less likely to be affiliated with OPDs – particularly women, older adults, people living in poverty, rural residents and with impairments affecting cognition and communication. OPDs may also consider strategies to diversify their membership, including identifying and addressing barriers to membership among certain demographic groups. Importantly, states, international funders and other actors must increase investment in OPDs so that they have the resources that are required to carry out their critical activities, and funding could help in outreach efforts. States must also invest in disability-inclusive planning and service delivery so that OPDs are not overburdened as being one of the few vehicles for providing essential goods and services to people with disabilities.

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References

Banks, L. M., C. Davey, T. Shakespeare, and H. Kuper. 2021. "Disability-Inclusive Responses to COVID-19: Lessons Learnt from Research on Social Protection in Low-and Middle-Income Countries." *World Development* 137: 105178. doi:[10.1016/j.worlddev.2020.105178](https://doi.org/10.1016/j.worlddev.2020.105178).

- Banks, L. M., S. Hameed, S. Kawsar Usman, and H. Kuper. 2020. "No One Left behind? Comparing Poverty and Deprivation Between People With and Without Disabilities in the Maldives." *Sustainability* 12 (5): 2066. doi:10.3390/su12052066.
- Banks, L. M., H. Kuper, and S. Polack. 2017. "Poverty and Disability in Low-and Middle-Income Countries: A Systematic Review." *PloS One* 12 (12): E0189996. doi:10.1371/journal.pone.0189996.
- Banks, L. M., M. Walsham, H. Van Minh, D. T. T. Duong, T. T. Ngan, V. Q. Mai, K. Blanchet, and H. Kuper. 2019. "Access to Social Protection Among People With Disabilities: Evidence From Viet Nam." *International Social Security Review* 72 (1): 59–82. doi:10.1111/issr.12195.
- Banks, L. M., S. Willan, G. Inglis-Jassiem, K. Dunkle, J. Ganle, T. Shakespeare, R. Shahpar Khan, S. Hameed, M. Machisa, N. Watson, and B. Carpenter. 2022. "Adapting Disability Research Methods and Practices during the Covid-19 Pandemic: Experiences from the Field." *IDS Bulletin* 53 (3): 129–52.
- Birtha, M. 2013. "Nothing About CRPD Monitoring Without Us': A Case Study on the Involvement of the Disability Movement in Policy-Making in Zambia." *African Disability Rights Yearbook* 1, 115–138.
- Brennan, C. S. 2020. "Disability Rights during the Pandemic: A Global Report on Findings of the COVID-19 Disability Rights Monitor."
- Butcher, N., P. Singh, N. Grills, and F. Soji. 2021. "DPO Membership Has Immediate Transactional Benefits as Well as Personal Impact." *Review of Disability Studies: An International Journal* 17 (2).
- Callus, A.-M, and A. Camilleri-Zahra. 2017. "Nothing about us without us: Disabled People Determining Their Human Rights through the UNCRPD." https://www.edu.mt/library/oar/bitstream/123456789/32954/1/Nothing_about_us_without_us.pdf
- Campbell, J., and M. Oliver. 2013. *Disability Politics: Understanding Our past, Changing Our Future*. New York: Routledge.
- Celis, K., S. Childs, J. Kantola, and M. L. Krook. 2008. "Rethinking Women's Substantive Representation." *Representation* 44 (2): 99–110. doi:10.1080/00344890802079573.
- Central Statistical Office and Ministry of Community Development and Social Services. 2018. *Zambia National Disability Survey 2015*. Lusaka: Central Statistical Office and Ministry of Community Development and Social Services.
- Charlton, J. I. 2000. *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley and Los Angeles: University of California Press.
- Driedger, D. 1989. *The Last Civil Rights Movement: Disabled Peoples' International*. London, UK: Hurst & Company.
- Eide, A. H., S. Neupane, and K.-G. Hem. 2016. "Living Conditions among People with Disability in Nepal." SINTEF Report No. A27656. Oslo: SINTEF Technology and Society, Department of Health.
- Eide, A. H., and T. Mmatli. 2015. "Living Conditions among People with Disability in Botswana." SINTEF Report A27196. Oslo: SINTEF Technology and Society
- Eide, A. H., and A. Munthali. 2017. "Living Conditions among Persons with Disabilities in Malawi." SINTEF Report No. 20180065. Oslo: SINTEF Digital, Department of Health.
- Eide, A. H., N. Nanono, and J. Omona. 2020. "Living Conditions among Persons with Disabilities in Uganda, a National, Representative Household Survey." SINTEF Report No. 2020–01387. Oslo: SINTEF Digital.
- Freire, P. 1972. *Conscientization and Liberation*. Geneva: Institute of Cultural Action.
- Grills, N. J., M. Hoq, C.-P P. Wong, K. Allagh, L. Singh, F. Soji, and G. Murthy. 2020. "Disabled People's Organisations Increase Access to Services and Improve Well-Being: Evidence from a Cluster Randomized Trial in North India." *BMC Public Health* 20 (1): 1–9. doi:10.1186/s12889-020-8192-0.
- Groce, N. E., and D. Mont. 2017. "Counting Disability: Emerging Consensus on the Washington Group Questionnaire." *The Lancet. Global Health* 5 (7): e649–e650. doi:10.1016/S2214-109X(17)30207-3.

- Hahn, H. 1988. "The Politics of Physical Differences: Disability and Discrimination." *Journal of Social Issues* 44 (1): 39–47. doi:10.1111/j.1540-4560.1988.tb02047.x.
- Hahn, H. 1994. "The Minority Group Model of Disability: Implications for Medical Sociology." *Research in the Sociology of Health Care* 11: 24.
- Hameed, S., L. M. Banks, S. K. Usman, & H. Kuper. (2023). "Access to the Disability Allowance in the Maldives: National Coverage and Factors Affecting Uptake." *Global Social Policy* 23 (1): 127–147.
- Hasler, F. 1993. "Developments in the Disabled People's Movement." In Swain, J., Finkelstein, V., French, S. and Oliver, M. (Eds). *Disabling Barriers, Enabling Environments*, 278–284. London: Sage.
- Kabia, E., R. Mbau, K. W. Muraya, R. Morgan, S. Molyneux, and E. Barasa. 2018. "How Do Gender and Disability Influence the Ability of the Poor to Benefit from Pro-Poor Health Financing Policies in Kenya? An Intersectional Analysis." *International Journal for Equity in Health* 17 (1): 1–12. doi:10.1186/s12939-018-0853-6.
- Kahn, S., and V. Louw. 2011. "Women's Representativeness in the South African Public Service." *Journal of Public Administration* 46: 669–682.
- Kamaleri, Y., and A. H. Eide. 2011. "Living Conditions among People with Disabilities in Lesotho. A National, Representative Study." SINTEF Report No. A17239. Oslo: SINTEF Technology & Society.
- Kavanagh, A. M., L. Krnjacki, Z. Aitken, A. D. Lamontagne, A. Beer, E. Baker, and R. Bentley. 2015. "Intersections Between Disability, Type of Impairment, Gender and Socio-Economic Disadvantage in a Nationally Representative Sample of 33,101 Working-Aged Australians." *Disability and Health Journal* 8 (2): 191–199. doi:10.1016/j.dhjo.2014.08.008.
- Kett, M., M. T Carew, J.-B. Asiimwe, R. Bwalya, A. Gitonga, B. A. Nyehn, J. Olenja, L. Swartz, and N. Groce. 2019. "Exploring Partnerships between Academia and Disabled Persons' Organisations: Lessons Learned from Collaborative Research in Africa." *IDS Bulletin* 50, (1): 65–78.
- Kim, K. M., D. K. Kim, Y. R. Shin, and D. Chul Yoo. 2016. "Social Exclusion of People with Disabilities in Korea." *Social Indicators Research* 129 (2): 761–773. doi:10.1007/s11205-015-1123-2.
- Kuper, H., S. Hameed, V. Reichenberger, N. Scherer, J. Wilbur, M. Zuurmond, I. Mactaggart, T. Bright, and T. Shakespeare. 2021. "Participatory Research in Disability in Low-and Middle-Income Countries: What Have we Learnt and What Should We Do?" *Scandinavian Journal of Disability Research* 23 (1): 328–337. doi:10.16993/sjdr.814.
- Loeb, M. E., A. H. Eide, and D. Mont. 2008. "Approaching the Measurement of Disability Prevalence: The Case of Zambia." *Alter* 2 (1): 32–43. doi:10.1016/j.alter.2007.06.001.
- Meyers, S. J. 2019. *Civilizing Disability Society: The Convention on the Rights of Persons With Disabilities Socializing Grassroots Disabled Persons' Organizations in Nicaragua*. Cambridge University Press.
- Ministry of Health and Child Care. 2015. *Living Conditions among Persons with Disabilities in Zimbabwe*. Harare: Ministry of Health and Child Care.
- Mont, D. 2007. *Measuring Disability Prevalence*. Citeseer.
- Ned, L., E. L. Mckinney, V. Mckinney, and L. Swartz. 2021. "Experiences of Vulnerability of People with Disabilities during COVID-19 in South Africa." *South African Health Review* 136 (1).
- Opoku, M. P., and W. Nketsia. 2021. "Nothing about us, Without Us': Voices of Leaders of Disabled People's Organisation in Management of Disability Fund." *Social Sciences & Humanities Open* 4 (1): 100160. doi:10.1016/j.ssaho.2021.100160.
- Pring, J. 2020. "DPOs Secure £1.5 Million to Help With Impact of Pandemic on Disabled People." *Disability News Service*. <https://www.disabilitynewsservice.com/dpos-secure-1-5-million-to-help-with-impact-of-pandemic-on-disabled-people/#:~:text=on%20>

- disabled%20people-,DPOs%20secure%20%C2%A31.5%20million%20to%20help,of%20pandemic%20on%20disabled%20people&text=Disabled%20people's%20organisations%20(DPOs)%20working,related%20needs%20of%20disabled%20people.
- Putnam, M. 2005. "Conceptualizing Disability: Developing a Framework for Political Disability Identity." *Journal of Disability Policy Studies* 16 (3): 188–198. doi:10.1177/10442073050160030601.
- Riccucci, N. M., and G. G. Van Ryzin. 2017. "Representative Bureaucracy: A Lever to Enhance Social Equity, Coproduction, and Democracy." *Public Administration Review* 77 (1): 21–30. doi:10.1111/puar.12649.
- Riddell, S., C. Pearson, D. Jolly, C. Barnes, M. Priestley, and G. Mercer. 2005. "The Development of Direct Payments in the UK: Implications for Social Justice." *Social Policy and Society* 4 (1): 75–85. doi:10.1017/S1474746404002209.
- Sengupta, A. 2000. "Realizing the Right to Development." *Development and Change* 31 (3): 553–578. doi:10.1111/1467-7660.00167.
- Shakespeare, T. 1993. "Disabled People's Self-Organisation: A New Social Movement?" *Disability, Handicap & Society* 8 (3): 249–264. doi:10.1080/02674649366780261.
- Tajfel, H., and J. C. Turner. 1986. "The Social Identity Theory of Intergroup Behaviour." In S Worchel & WG Austin. *Psychology of Intergroup Relations*, 7–24. Chicago: Nelson-Hall.
- Temple, J. B., M. Kelaher, A. Utomo, R. Williams, and L. Brooke. 2020. "Components of Disability Exclusion: Discrimination, Avoidance and Accessibility in Later Life." *Australasian Journal on Ageing* 39 (2): 101–111. doi:10.1111/ajag.12750.
- United Nations General Assembly. 2013. *Resolution 67/290: Format and Organizational Aspects of the High-Level Political Forum on Sustainable Development*. New York, NY: United Nations.
- United Nations Office of the High Commissioner on Human Rights United Nations. 2006. *United Nations Convention on the Rights of Persons with Disabilities*. New York, NY: United Nations.
- United Nations. 2019. *Disability and Development Report 2018*. New York, NY: United Nations Publications.
- Waldschmidt, A., A. Karačić, A. Sturm, and T. Dins. 2015. "Nothing about Us without Us" Disability Rights Activism in European Countries—A Comparative Analysis." *Moving the Social* 53: 103–138.
- Washington Group On Disability Statistics. 2009. *Understanding and Interpreting Disability as Measured Using the Washington Group Short Set of Questions*. Atlanta, GA: Centers for Disease Control and Prevention.
- Washington Group on Disability Statistics. 2017. Creating Disability Identifiers Using the Washington Group Extended Set (WG-ES) SPSS Syntax [Online]. Accessed May 4 2020. <http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Documents-6-Analytic-Guidelines-for-the-Washington-Group-Extended-Set.pdf>.
- Woodburn, H. 2013. "Nothing about us without Civil Society: The Role of Civil Society Actors in the Formation of the UN Convention on the Rights of Persons with Disabilities." *Political Perspectives* 7: 75–96.
- Yeo, R., and K. Moore. 2003. "Including Disabled People in Poverty Reduction Work: 'Nothing about us, without us'" *World Development* 31 (3): 571–590. doi:10.1016/S0305-750X(02)00218-8.
- Young, R., M. Reeve, and N. Grills. 2016. "The Functions of Disabled People's Organisations (DPOs) in Low and Middle-Income Countries: A Literature Review." *Disability, CBR & Inclusive Development* 27 (3): 45–71. doi:10.5463/dcid.v27i3.539.
- Zhang, C. 2017. "Nothing About us Without Us': The Emerging Disability Movement and Advocacy in China." *Disability & Society* 32 (7): 1096–1101. doi:10.1080/09687599.2017.1321229.