

# Technology and Grassroots Inclusion in Global Governance: A Survey Study of Disability Rights Advocates and Effective Participation

Filippo Trevisan  
American University  
[trevisan@american.edu](mailto:trevisan@american.edu)

Derrick L. Cogburn  
American University  
[dcogburn@american.edu](mailto:dcogburn@american.edu)

## Abstract

*The effective participation of the disability community in global governance is essential to ensure that key development initiatives empower the world's one billion people with disabilities. Technology can play an important role in the creation of a more inclusive global governance. This paper discusses the results of the first global survey of Disabled People's Organizations' (DPO) leaders on these issues. Three levels of analysis are reviewed, including: (1) accessibility and barriers to effective participation; (2) the role of low-cost accessible technological solutions for remote participation; and (3) the use of online technologies – in particular social media platforms – by DPOs to bridge the gap between disability grassroots and global governance processes.*

*After mapping barriers to participation, the role of technology vis-à-vis these obstacles is reviewed. Although only a small number of international conferences offer accessible virtual participation, responses from DPO advocates that used this technology provide strong evidence of the potential that these tools have to improve accessibility in global governance. Furthermore, disability organizations all over the world have adopted social media platforms as channels to liaise with their constituents and involve them in policy-making processes.*

## 1. Background

Just over a decade ago, the rights of the world's one billion people with disabilities [1] were enshrined in the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) [2]. The process that led to the creation and approval of the CRPD, as well as the annual Conference of State Parties (COSP) that monitors its implementation, are important examples of accessible global governance. Accessible and low-cost technological solutions have played an important role in broadening participation to these disability-specific

international forums. Yet, the full inclusion of people with disabilities in global governance requires their effective participation in any relevant processes, not just those that are specifically focused on disability issues.

Examples of recent global conferences in which people with disabilities had very important stakes and that piloted technological interventions including participation via accessible low-cost webconferencing tools and telepresence robots include the U.N. Conference on Housing and Sustainable Urban Development (Habitat III) in 2016 [3] and the 2017 Global Platform for Disaster Risk Reduction [4]. However, except for these pockets of experimental innovation, it is unclear to which extent disability inclusion has been “mainstreamed” in other global governance processes and whether the voices of people with disabilities can be heard in important international venues that take decisions likely to impact their everyday life both in the medium and long terms.

## 2. Purpose

This ambiguity around accessibility is at odds with the U.N.'s broader commitment to the engagement of civil society groups in global governance. Since the 1990s, U.N. Member States have recognized the benefits of civil society engagement in these processes and have taken measures to ensure means of participation from various stakeholder groups. For example, Agenda 21 [5], which was adopted by U.N. Member States at the Rio Earth Summit in 1992, established nine “Major Groups” aimed at increasing engagement and partnership with a broad range of stakeholders outside of the intergovernmental spheres. The nine Major Groups include a range of actors. While this list includes many important marginalized communities, it leaves out many others, with the notable exclusion of persons with disabilities. In 2012, the U.N.'s General Assembly resolution “The

Future We Want” [6] stated that, in addition to the Major Groups, “other stakeholders” should also be invited to participate in U.N. processes on sustainable development. Persons with disabilities are specifically included under “other stakeholders” in paragraph 43 of this resolution.

Although the formal designation of persons with disabilities as “other stakeholders” has provided an important framework for their inclusion in all global governance processes, effective participation can only be achieved if the barriers that have historically prevented people with disabilities from engaging in political processes on an equal playing field are acknowledged and addressed appropriately. The negotiation process that led to the CRPD and the mechanisms that support its monitoring and implementation have been described as “experimentalist governance” [7]. In a nod to the social model of disability principles and disability movement’s “nothing about us without us” mantra, this involves “open participation by a variety of entities (public or private), lack of formal hierarchy [...], and extensive deliberation throughout the process of decision making and implementation” [7]. This approach has been described as a possible solution to the democratic deficit in domains of international governance that are of central concern to persons with disabilities, for example global health [8].

One fundamental pre-requisite for the expansion and mainstreaming of more open approaches to global governance is for international forums, conferences, and events to be fully accessible. Although COSP, the annual U.N. conference that monitors the implementation of the CRPD, arguably constitutes a model of accessibility, it is unclear whether other relevant international gatherings actively seek to address this issue or are even aware of potential barriers to participation for people with disabilities. The CRPD itself, while mentioning the right of persons with disabilities to organize internationally (Art. 29), lacks an explicit reference to potential obstacles in global governance processes. In addition, scholarly literature has paid attention to advancements in political inclusion for citizens with disabilities at the national level, in which technology can play an important role [9], but so far has lacked a similar focus on international processes.

Regional and global conferences and accompanying outcome documents require sustained activity and collaboration during pre-conference preparations and post-conference activities, which include implementation, monitoring, and evaluation. For persons with disabilities, physical and electronic accessibility issues can exacerbate this challenging climate and exclude individuals from actively

participating in global policy formulation. To date, these issues remain under-researched. In particular, the potential double role of technology as both a source of exclusion and empowering change has been largely overlooked. A useful place to start in order to map these issues systematically and design inclusionary solutions is by considering the perspective and experiences of people with disabilities themselves and their organizations. In the spirit of participatory action research [10], this paper addresses this gap by discussing the results of the first global survey on accessibility in global governance with the leaders of Disabled People’s Organizations (DPO advocates). This provides a useful baseline assessment of needs and obstacles from a group that is typically marginalized in political processes, which will inform further research with other stakeholders including conference organizers.

Key barriers to participation are identified and the challenges and opportunities involved in using low-cost webconferencing solutions are discussed. In addition, the paper examines DPO use of a range of online communication tools from email to commercial social media platforms to connect with disability grassroots in their respective countries and help bridge the gap between disability communities and global governance processes. The paper concludes by considering the implications of these findings for U.N. agencies, other international conference organizers, and disability rights advocates around the world on integrating accessible and empowering technological solutions in their planning processes more effectively.

### 3. Research questions

This paper focuses on two main levels of analysis. First, it provides the first systematic overview of barriers to participation in global governance processes and assesses potential technological solutions from the perspective of disability advocates. In doing this, it addresses two main sets of research questions:

RQ1: What are the main exclusionary barriers that prevent DPO advocates from engaging effectively and on an equal footing with the representatives of other key stakeholders in global governance processes?

RQ1.1 Do DPO advocates participate in global governance processes on a regular basis?

RQ1.2 Which specific barriers, if any, do they experience prior, during, and after international conferences?

RQ1.3 To what extent, if at all, do they find U.N. and non-U.N. international conferences, meetings, and events accessible?

RQ2: Does webconferencing technology make global governance processes more accessible for DPO advocates?

RQ2.1 How frequently are DPO advocates able to participate remotely in U.N. and non-U.N. international conferences?

RQ2.2 To what degree, if at all, do webconferencing technologies support active participation in U.N. and non-U.N. international conferences for DPO advocates?

RQ2.3 What is the relationship between geographical location and remote participation for DPO advocates in international conferences, meetings, and events?

In addition, this paper also explores whether DPOs are able to take advantage of a range of technological platforms from email to commercial social media to bridge the gap between grassroots disability communities and global governance processes. After some initial skepticism [11] DPO leaders in developed nations have embraced digital media to connect with their constituents, mobilize them, and include them in advocacy work in more active ways [12]. While this is part of a broader trend that has enabled advocacy organizations in democratic countries to become more responsive to the demands of those whom they seek to represent [13], it is useful to ask here whether the same dynamic is replicated on a global scale within a range of different technological, social, cultural, and political contexts. Therefore, this part of the study addresses the following questions:

RQ3: Do DPO advocates around the world approach new media technologies as opportunities to include disability grassroots in global governance work?

RQ3.1 Do advocates use social media to include DPO members in international advocacy and policy work?

RQ3.2 Do they use social media to include the broader disability community in their respective countries in international advocacy and policy work?

RQ3.3 Which online platforms are most valuable to DPO advocates to engage people with disabilities in international advocacy and policy work, including in comparison with more traditional forms of engagement?

RQ3.4 Are there specific regional or cultural differences in how DPO advocates approach new media technologies to include people with disabilities in international advocacy work?

## 4. Methodology

To explore the perspective of global disability rights advocates on these issues, a survey on the accessibility of global governance mechanisms was designed and distributed using Qualtrics. Qualtrics is one of the most accessible survey-building packages available and the survey was tested internally for accessibility – both on computers and mobile phones – by team members with a range of disabilities. The development of the survey questionnaire was informed by the results of a preliminary study that included interviews with subject matter experts on disability and global governance from a variety of sectors including international organizations such as U.N. agencies, international DPOs and other civil society groups, and academia [14]. This generated 72 survey questions covering four main areas in addition to basic demographics such as location, age, gender, educational attainments, disability status, role within the organization, and level of involvement with the international disability community. The four key areas covered in the survey included:

- 1) Participation and accessibility in the U.N. System;
- 2) Participation and accessibility at non-U.N. international conferences;
- 3) Low-cost technological solutions for accessible global governance (e.g. webconferencing); and
- 4) New media use to connect with and include disability grassroots actors in global governance processes.

Each of these areas was explored using both closed and open, qualitative questions. To assess the disability status of respondents, the survey incorporated the Washington Group on Disability Statistics Short Set Questions [15]. The Short Set was created in 2001 at the U.N. International Seminar on Measurement of Disability with the aim to measure six specific domains of functioning, including: vision; hearing; mobility; memory/concentration; self-care; and communication. While we acknowledge the limitations that derive from the focus on ability and self-reporting nature of this way of measuring disability, the Short Set has gained widespread recognition in recent years, which enhances the comparability of our data.

### 4.1 Sample

A distribution list including 973 prominent DPOs involved in disability rights advocacy work at the

international level was drawn from relevant national and international directories compiled by academic disability studies centers, international organizations, and consortia of disability rights organizations around the world<sup>1</sup>. Every country was represented in the distribution list, with the number of organizations included per country determined by the total size of its population. DPOs focused on all or multiple disabilities were favored in the selection process. Whenever possible, the survey was emailed directly to the president or chief executive officer of each DPO in order to secure the participation of those responsible for setting the strategic direction for the organization. For a small number of organizations, it was necessary to use a generic email address such as “info@organization.org” and request that the survey be passed onto their president or chief executive. The survey was distributed to the entire list in September 2016.

In total, advocates from 123 DPOs in 51 different countries completed the survey. All the regions of the world were represented in the sample (Figure 1). This included substantial representation from the developing world. Asia, the world’s most populous region and home to the largest number of people with disabilities, counted for just over a third of the sample, with Africa second at nearly 20% of respondents.



Figure 1. Global distribution of respondents

More than half (55.7%) of the organizations that responded said they took a pan-disability approach to advocacy work. Additionally, just over a quarter (26.2%) said they advocated for multiple disabilities. Only 18% said they focused on a specific disability.

<sup>1</sup> For example: <http://www.disability-europe.net> (Academic Network of Disability Experts - ANED); <http://www.gallaudet.edu/rsia/world-deaf-information-resource.html> (Gallaudet University); <http://www.c-c-d.org> (Consortium for Citizens with Disabilities - CCD).

While the roles of individual respondents within their respective organizations varied, 73.5% of them explicitly stated that they occupied an executive or other leadership position such as president, executive director, or other leadership officer. There were more male respondents (57.3%) than females (42.7%). The median respondent age was 46 in a range comprised between 23 and 75 years old.

Most respondents were highly educated. Nearly half (44.6%) had a master’s degree, 19.3% held a bachelor’s degree, and just over 7% a doctorate or other terminal degree. The most common fields of training included public policy and governance, law, education, and business. These results corroborate findings from the interviews carried out with subject matter experts in the preliminary phase of this study [14], which further highlights the role that education and training in these fields plays in boosting the engagement of the global disability community in international governance.

More than two-thirds (70.7%) of all respondents said they identified as a person with disabilities. In addition, 57.9% of respondents marked two or more of the Washington Group Short Set Questions, indicating that they had multiple disabilities. The most prevalent self-reported disability related to physical mobility impairments as 52% of respondents reported some level of difficulty walking or climbing steps, with 23% of all respondents reporting they were unable to get around on their own at all. Furthermore, just over a quarter of all participants (26.6%) was vision-impaired, 18.5% had hearing problems, 18.7% had issues remembering or concentrating, 33.5% found it difficult to self-care at some level, and 12.5% experienced communication problems.

## 5. Findings

### 5.1 Accessibility and barriers to participation

Survey respondents acknowledged the importance of active involvement in global governance processes, with a large majority stating that U.N. (83.9%) and non-U.N. (77%) international conferences, meetings and events are highly relevant to their work. Perhaps surprisingly, more respondents indicated that they had participated in at least one non-U.N. international conference (78.4%) than those that participated in at least one U.N. conference (46.5%). Yet, despite showing eagerness to participate, respondents also highlighted a number of different barriers to participation that challenge their ability to engage regularly and effectively in these events.

**5.1.1 DPOs participate more regularly in non-U.N. international conferences.** The overall number of international conferences, meetings and events that respondents had participated was between 1-50 for non-U.N. events and 1-35 for U.N. events. Attendance rates varied greatly between respondents who said they had participated in substantially more non-U.N. conferences and events (mean=12.2; median=5) than U.N. events (mean=5.8; median=2). In addition, a third of those who had ever attended a U.N. event did so only once. This suggested that many survey respondents who participated in U.N. events tended to do so as a ‘one off’ instead than on a regular basis.

While not entirely surprising, these results – particularly the disparity between attendance at U.N. and non-U.N. international conferences – invited a reflection on the mechanisms that alerted respondents about international conferences, accessibility at these events, and modalities of participation.

**5.1.2 Barriers begin before conferences start.** Survey results revealed that barriers for DPO advocates begin well before the actual start of international conferences, meetings and events. Location was a particularly challenging feature of U.N. events and quickly emerged as a key determinant of the difference in attendance rates between U.N. and non-U.N. events.

Although some of the U.N. conferences mentioned by respondents moved between cities in North America, Europe, South-East Asia, and Africa, the majority of these meetings was held at U.N. headquarters in either New York City (n=12) or Geneva (n=4). The centrality of New York and Geneva to U.N. processes requires participants to travel long distances to attend in person, particularly from Africa, South-East Asia, and Oceania, which made up a majority of survey respondents. Traveling internationally is expensive and can be impractical or even impossible for people with disabilities who may require multiple accommodations due to inaccessible transport links. These results were corroborated also by the fact that three quarters of those who had never attended a U.N. conference, meeting or event stated that lack of funding was a key problem (Figure 2).

Given that both New York and Geneva are likely to continue to be central locations for U.N. events, a low-cost solution to reduce distance barriers includes increasing the functionality and availability of remote participation, which allows people to take part in conferences through accessible cyberinfrastructure. Yet, as is discussed below, only a small number of events have started to offer this type of webconferencing opportunities and there is great scope for expansion in this area.

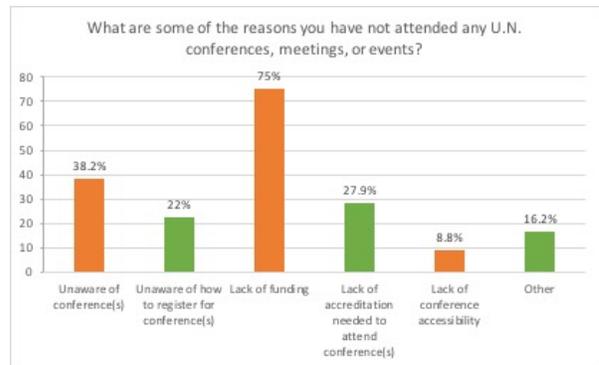


Figure 2. Main reasons for not attending U.N. conferences

Additional barriers at U.N. conferences included problems with registration materials, which 40% of respondents indicated were not fully accessible. Among these, many commented on specific challenges for people who are blind or have vision impairments. Electronic communication, besides being compatible with assistive technology such as screen readers, must also be accessible to people with cognitive deficits, including language comprehension. Several respondents indicated that website text was not written in sufficiently plain language, and others stated that the website lacked image descriptions.

**5.1.3 (In)accessibility at international conferences.** Survey respondents were asked to rate the most recent U.N. and non-U.N. international conferences they attended from 1 to 10 in terms of accessibility (1=fully inaccessible; 10=fully accessible). Only 6% of respondents rated U.N. conferences fully accessible and just 43% rated them 8 or above. Comparatively, nearly a quarter of survey respondents felt that non-U.N. conferences were fully accessible and as many as 61% rated non-U.N. conferences at least 8 or above.

The only accessibility features that U.N. conferences seemed to provide fairly consistently were ramps and elevators, which respondents said were available at 72.4% and 62% of the U.N. conferences they attended respectively.

Although it would seem reasonable to assume that the number and severity of the disabilities affecting any one DPO advocate may be linked to their perspective on accessibility, correlation analysis between the aggregate measure of disability derived from the Washington Short Set and overall accessibility ratings did not show a noteworthy relationship.

However, the same type of analysis for each of the functional domains in the Washington Short Set showed an important inverse relationship between visual impairments and perspectives on the overall

accessibility of U.N. conferences ( $r=-.625^*$ ,  $p<0.01$ ). This was corroborated by the fact that survey respondents said that screen reader accessible conference material was provided only in 38% of cases, braille material in just under a quarter of conferences (24.4%) and the vast majority of conference websites (79.3%) could not be easily accessed using a screen reader. In open questions, respondents clarified that various foundations and other organizations such as The Nippon Foundation provided accessible documents to participants in need at certain conferences. However, they also noted that the U.N. itself did not universally provide these services. This created an inconsistency between conferences that likely affects the participation and engagement of persons with disabilities at U.N. events.

Comparatively, U.N. conferences scored better on accessibility features for deaf and hard of hearing people, although still far from ideal with sign language interpretation provided in 58.62% of cases and closed captioning in 41.38% of relevant events.

## 5.2 Technological solutions

In light of these persisting barriers, respondents were asked about their experience with virtual remote participation through accessible webconferencing tools. Although many international conferences nowadays provide live online streaming, this stops short of meaningful engagement, which ought to afford stakeholders participating remotely genuine chances to actively influence these processes. Thus, the survey asked respondents about virtual tools that go beyond online streaming and enable them, for example, to speak, present, or ask questions. While respondents said they that this type of technology was available only at a relatively small number of conferences, meetings, and events, their experiences illuminated a wealth of opportunities characterized by scalability.

**5.2.1 Accessible virtual participation is available only at a small minority of conferences.** 15.6% of those who said they participated in U.N. events did so virtually compared to 84.4% who attended in person. Looking at non-U.N. conferences and events, the number of respondents who participated virtually via webconferencing tools was even smaller at only 3.8% compared to 96.2% who attended in person.

Although low virtual participation rates could depend on several factors, including availability and affordability of technology, as well as cultural preferences, it is important to note that respondents stated that remote participation was available only at 6.9% of the U.N. conferences they attended. This suggests that the provision of low cost opportunities

for remote participation is not routine at international conferences, stressing the need for institutions such as the U.N. and other conference organizers to provide this type of facilities on a more regular basis.

One important additional factor that supports this recommendation is that DPO advocates from developing parts of the world said they were more likely to participate virtually in U.N. conferences than their counterparts in more affluent regions. In particular, virtual participation by African and Asian DPO advocates occurred in 25% and 20% of all the U.N. conferences attended by organizations from each of these regions respectively. In contrast, no North American and only 12.5% of European respondents said they attended virtually.

These results capture the growing potential for low-cost accessible webconferencing technology to boost participation in global governance processes for disability organizations from the Global South, which played an important role in the genesis of the CRPD but are typically affected by an even greater number of barriers that their counterparts in the North [16]. Having said that, it is also important to point out that there is a persisting Internet access gap between disabled and non-disabled people, including in developed nations like the U.S. [17], which ought to be addressed in order to ensure that remote participation is truly representative of each country's entire disability community.

**5.2.2 Despite limited availability, accessible virtual participation has invaluable potential for DPOs.** At U.N. conferences for which virtual participation was offered, respondents engaged in a good range of activities. In particular, 40% of those who participated in U.N. events via webconferencing were able to give a presentation and 80% were able to ask a question in real-time, either via voice or using sign language into a camera (40%) or by typing (40%). Being a presenter in particular seemed to be an important incentive to participating remotely as all of those who had attended a non-U.N. conference, meeting or event virtually stated that they were able to give a presentation.

Comparatively, the range of virtual participation activities was more restricted at non-U.N. events as no respondents said they had been able to ask a question in real time, watch a live stream, or catch up with the conference later through a recorded live stream.

These results suggest that, while there is great scope for expanding remote participation opportunities for persons with disabilities in global governance events, U.N. conferences tend to be somewhat ahead of the game compared to other international forums. In particular, it is important to explore in depth recent U.N. conferences that included substantial efforts to

make remote participation available such as COSP, the Sendai DDR conference, Habitat III in Quito, Ecuador, and Global Platform in Cancun, Mexico [4].

### **5.3 Engaging global disability grassroots online**

In addition to the ability to facilitate effective remote participation in international conferences, meetings, and events, it is also important to understand whether digital technology can empower grassroots members within DPOs and in turn enhance the inclusion of the global disability community in global governance processes. While this is a complex issue that goes beyond the scope of this paper, the survey carried out for this study sought to benchmark the use of several “off the shelf” technologies including email and social media platforms by DPO advocates involved in global governance to better understand whether this can contribute to bridging the gap between people with disabilities “on the ground” in their respective countries and relevant international forums.

#### **5.3.1 Overall approach to grassroots engagement.**

87.7% of respondents said that their organization sought to engage its members in the formulation of key policies and advocacy positions at least annually (17.5%) or more frequently throughout the year (70.2%). An even greater number of respondents (91.5%) said that their organization sought input in policy work from the broader disability community, both regularly (57.6%) and on a more policy-specific basis (33.9%). This corroborated the expectation of DPOs as organizations “by and for” disabled people.

#### **5.3.2 Social media to include disability grassroots.**

Within this broader participation context, respondents all over the world indicated that social media platforms enabled them to liaise with their primary constituents while formulating contributions to global governance processes. DPO advocates expressed enthusiasm about these practices, which corroborated the impression of a leadership that is becoming increasingly comfortable with participatory technology as was pointed out in previous work on disability and media activism [18].

In particular, 88% of respondents said that they used at least one social media platform to engage members in their planning for international policy and advocacy work. All but one of the small number of DPO advocates that said they did not use social media to involve disabled members in advocacy and policy work were based in developing countries – primarily African, South West Pacific, and Pacific Island countries – and cited Internet access restrictions and accessibility concerns as the main reasons. However,

more than 50% of these also stated that they had plans to embrace these media in the near future in the open-ended portion of the survey. For example, one respondent from Papua New Guinea identified the use of social media platforms as “an area that we will be working on in our current strategic plan 2016-2020.”

Thus, DPO advocates from virtually every country involved in this study acknowledged the potential of social media platforms for providing people with disabilities with meaningful opportunities to contribute to significant policy-making processes. The reason that respondents cited most frequently (24.5%) to support this use of social media platforms was that, despite the accessibility concerns mentioned by a few respondents, these tools enabled them to reach out to a much larger number of people with disabilities that they could ever have done otherwise. In addition, a fifth of respondents also said that social media supported a free exchange of ideas that made their policy proposals better and strengthened their negotiating positions. For some (14.2%), these processes boosted the external credibility of their organizations, while for others (10.3%) they supported internal democratization.

**5.3.3 Social media in context.** Survey respondents were also asked to rate the usefulness of the most popular social media platforms in helping them engage with members and the disability community more broadly, and compare them to other, more traditional forms of engagement, both online and offline.

Although traditional channels such as face-to-face meetings and the telephone continued to represent important ways of engaging constituents for most DPO advocates surveyed for this study (81% and 71.9% respectively), online channels enjoyed similar levels of importance. Email emerged as the most popular form of technology here as it was considered important or extremely important by the same proportion of respondents as face-to-face meetings (79.5%). This was closely followed by Facebook, which nearly three quarters of DPO advocates involved in this study (68.4%) indicated as either important or extremely important to their efforts to involve their membership in policy and advocacy work. Another form of digital engagement that about half (44.5%) of respondents considered important were online surveys and polls, which constitute a form of direct input in policy formulation. Video-conferencing via social media platforms (e.g. Google Hangout) was seen as comparatively less useful, with fewer than 30% of respondents marking it as at least important.

DPO advocates rated the usefulness of all these channels for engaging with the broader disability community beyond their membership in a very similar manner except for Twitter. While Twitter was

considered important for engaging with members by fewer than a third of respondents (32.7%), 70% of them saw it as at least “somewhat important” for liaising with the broader disability community in their respective countries. This difference is noteworthy as it suggests that DPO advocates recognize and capitalize on the strengths of different digital platforms to communicate with internal (email, Facebook) and external (Twitter) publics [19].

**5.3.4 Regional differences in approaches to social media.** Interestingly, survey results showed no major differences in the approaches to social media platforms for engaging members and the broader disability community among DPO advocates in different regions of the world. The overall results highlighted in the previous sections with regard to overall adoption of social media platforms and technological preferences of DPO advocates were replicated more or less equally in all the regions of the world. This was somewhat surprising as it contravened commonly held digital divide assumptions, which in turn highlighted the growing importance of online and especially mobile media in developing countries [20].

Having said that, one specific regional pattern that is useful to discuss emerged in Pacific Island countries. Compared to respondents in other regions of the world, those from Pacific Island countries placed an even greater importance on the use of all forms of online channels for engaging both their members and the broader disability community in policy and advocacy work. 100% of the respondents from this region of the world indicated that both email and Facebook were important or extremely important to them, with 87.5% and 71.4% also attributing the same level of importance to online polls and video-conferencing via social media respectively.

One possible explanation for these results could be the peculiar geography of Pacific Island countries, which makes it especially challenging for persons with disabilities to come together in person to discuss important policy issues given that they are scattered across dozens or even hundreds of islands. Thus, these results suggested not only that online media play an important role in bringing disability communities around the world closer to crucial policy-making processes irrespective of their location, but also that their affordances are particularly significant for the strengthening of grassroots disability advocacy in countries where geographical barriers have traditionally constituted a unique challenge to the growth and development of this sector.

## 6. Discussion and recommendations

Survey results showed that DPO advocates all over the world continue to face a broad range of barriers that prevent them from participating regularly and effectively in important global governance processes. Importantly, survey respondents clarified that barriers begin well before the start of international conferences, meetings, and events as they involve difficulties with finding out about and registering for these events, as well as traveling to their locations. U.N. conferences in New York City and Geneva presented particular difficulties for many DPO advocates, which restricted the representation of the global disability community at these events. Although accessibility deficits affected both U.N. and non-U.N. events, the latter scored somewhat better in terms of accessibility, which was somewhat surprising. These results point in the direction of non-U.N. events – particularly those that are specific to disability issues and organized by international disability organizations – as possible sources of inspiration to enhance accessibility across global governance processes.

Despite this disappointing, if not unexpected, global governance landscape, survey results also revealed that there is great potential for low-cost technological solutions to enhance the accessibility of international conferences, meetings, and events. Genuine inclusion requires a holistic approach to technology that accounts for its role in potentially making every step of global forums more accessible, starting with registration and preparation materials and continuing with participation to the events and follow up processes. Promising technological innovation pilots were spotted in the use of accessible webconferencing technology at some recent U.N. conferences, including both CRPD COSP and other conferences. Crucially, respondents in the Global South were more likely than their counterparts in the Global North to avail themselves of these opportunities to participate remotely. Although limited to a relatively small number of innovative conferences, this use of webconferencing technology makes a positive contribution to the U.N.’s goal of “leaving no-one behind” in its work to achieve the Sustainable Development Goals [21].

These results are significant because they show that DPO advocates in parts of the world that face the biggest challenges to participation and therefore stand to benefit the most from accessible remote participation opportunities are already taking advantage of these technologies when they are available. This characterizes the inclusion of accessible webconferencing technology as a smart and effective investment on the part of these technology pioneers in

global governance, which in turn supports the expansion of these initiatives to other U.N. and non-U.N. international events. At the same time, organizers should also be alert to persisting digital divide difficulties and ensure that webconferencing platforms support different channels for participation including low-tech options such as landline and basic mobile telephones to foster remote participation for the broadest possible range of stakeholders.

Finally, DPO advocates also acknowledged the potential of commercial social media and other online platforms for bridging the gap between disability communities and policy-making processes, both at the country-specific and global level. Facebook emerged as a particularly relevant platform in this area. In addition, the survey also highlighted the role of specific functions of other social media platforms (e.g. Google Hangout) in strengthening disability grassroots participation in countries characterized by unique challenges such as Pacific Island nations. Overall, respondents also recognized the need to provide a range of different online participation avenues for members and the broader disability community in their respective countries, and seemed set on capitalizing on the affordances of different platforms to connect with different internal and external audiences.

These trends mark a radical departure from the much more conservative attitude that characterized the approach of disability rights leaders to new and social media technologies in the recent past [12]. While conservative approaches were justified by concerns over access and accessibility gaps, recent advancements in these areas including increases mobile connectivity in developing nations [22] support a more proactive attitude among DPO advocates. This is made even more meaningful by the fact that Internet users with disabilities are more likely than those without a disability to take advantage of the more participatory functions of online media [23] while younger people with disabilities are simultaneously more interested in politics and more likely to be online [24]. The data collected for this study suggests that DPO advocates all over the world are going where people with disabilities already are online – particularly on Facebook – instead of trying to force participation through other, ad hoc channels. Previous research on digital disability rights advocacy has shown also that DPO leaders tend to be attentive to the needs of the significant proportion of people with disabilities who are not Internet users [11]. It is important to determine whether this concern carries on into international contexts and consider creative solutions to ensure that those who are unconnected are not left behind as technology and remote participation

become more fully integrated into global governance processes.

With these caveats, these results highlight that there is great potential in the use of social media technologies to expand grassroots participation in policy-making. This is important as we enter the implementation phase of important international accords such as the New Urban Agenda, which requires disability communities around the world to be engaged to ensure that the potential of these documents for disability inclusion and empowerment is realized.

## 7. Limitations and Future Research

Although DPO advocates from all regions of the world were represented in this study, with over 60% of respondents located in the developing world, one major limitation of this survey was that it was distributed only in English. While this concern is mitigated somewhat by the status of English as the primary working language of international forums that support global governance processes, it is important to acknowledge this potential limitation and consider making survey instruments in follow up and other future up work available also in other major international working languages such as French and Spanish. In addition, the online distribution method used for this survey did not reach disability organizations without a website or a working email address. It is possible that these groups have different views and experiences of both barriers to participation in global governance and technology, and future work should try to incorporate their perspectives.

This study provides a useful baseline assessment of global governance and technology needs and experiences from the point of view of DPO advocates. Future work should build on these findings and interrogate also the perspective of conference organizers and other relevant stakeholders to better understand why the needs of DPO advocates are not met or – perhaps – even recognized and identify which cultural, economic, political, and technological factors stand in the way of mainstreaming of disability in global governance processes.

## 8. References

- [1] World Health Organization, World Report on Disability, WHO, Geneva, 2010.
- [2] United Nations, Convention on the Rights of Persons with Disabilities, United Nations, New York, 2006. Retrieved from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

- [3] D. Cogburn, F. Trevisan, M. Aguilar, and E. Spaniol, "Building Accessible Cyber Infrastructure in the Global Disability Community: Evaluating Collaboration Readiness and Use of the DID Policy Collaboratory," Hawaii International Conference on System Sciences, AIS Electronic Library, 2017. Retrieved from: [http://aisel.aisnet.org/hicss-50/cl/virtual\\_teams/2/](http://aisel.aisnet.org/hicss-50/cl/virtual_teams/2/)
- [4] D. Cogburn, "Beyond Being There for "All of Us:" Exploring Webconferencing and Mobile Remote Presence Devices for Accessible Global Governance," Hawaii International Conference on System Sciences, AIS Electronic Library, 2018. Retrieved from: [https://aisel.aisnet.org/hicss-51/cl/virtual\\_teams/4/](https://aisel.aisnet.org/hicss-51/cl/virtual_teams/4/)
- [5] United Nations, Agenda 21, United Nations, New York, 1992. Retrieved from: <https://sustainabledevelopment.un.org/content/documents/Agenda21.pdf>
- [6] United Nations, "Resolution Adopted by the General Assembly on 27 July 2012 – The Future We Want," United Nations, New York, 2012. Retrieved from: [http://www.un.org/ga/search/view\\_doc.asp?symbol=A/RES/66/288&Lang=E](http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/66/288&Lang=E)
- [7] G. De Burca, R. Keohane, and C. Sabel, "New Models of Pluralist Global Governance," N.Y.U.J. Int'l L. & Pol., 45, 2013, pp. 723-786.
- [8] J. Lord, D. Souzzi, A. Taylor, "Lessons from the Experience of U.N. Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance," Journal of Law, Medicine and Ethics, 38(3), 2010, pp. 564-579.
- [9] J. Lord, "Accessible ICTs and the Opening of Political Space for Persons with Disabilities," in J. Lazar and M. Stein (Eds.), Disability, Human Rights and Information Technology, Philadelphia: University of Pennsylvania Press, 2017, pp. 24-40
- [10] Townsend, A., Action Research: The Challenges of Understanding and Changing Practice. The Open University Press, Maidenhead, 2013.
- [11] F. Trevisan, "Scottish Disability Organizations and Online Media: A Path to Empowerment or "Business as Usual"?", Disability Studies Quarterly, 34(3).
- [12] Trevisan, F., Disability Rights Advocacy Online: Voice, Empowerment and Global Connectivity, Routledge, London, 2016.
- [13] Bimber, B., Flanagin, A.J., and Stohl, C., Collective Action in Organizations: Interaction and Engagement in an Era of Technological Change, Cambridge University Press, Cambridge, 2012.
- [14] Cogburn, D., "Accessibility in Global Governance: The (In)Visibility of Persons with Disabilities," Institute on Disability and Public Policy, Washington, D.C., 2016.
- [15] Washington Group, "Short Set of Questions on Disability," Center for Disease Control and Prevention, Atlanta, 2010. Retrieved from: [https://www.cdc.gov/nchs/washington\\_group/wg\\_questions.htm](https://www.cdc.gov/nchs/washington_group/wg_questions.htm)
- [16] P. Molina Toledo, "At the United Nations... The South Also Exists," In M. Sabatello and M. Schulze (Eds.), Human Rights and Disability Advocacy, Philadelphia: University of Pennsylvania Press, 2014, pp. 170-187.
- [17] M. Anderson, and A. Perrin, "Disabled Americans Are Less Likely to Use Technology," Pew Research Center, Washington, DC. Retrieved from: <http://www.pewresearch.org/fact-tank/2017/04/07/disabled-americans-are-less-likely-to-use-technology/>
- [18] K. Ellis, and G. Goggin, "Disability and Media Activism," In Graham Meikle (Ed.), The Routledge Companion to Media and Activism, New York: Routledge, 2018, pp. 355-364.
- [19] J. Yan, "Social Media in Branding: Fulfilling a Need," Journal of Brand Management, 18(9), 2011, pp. 688-696.
- [20] International Telecommunication Union, "Measuring the Information Society 2012." ITU, Geneva, 2012. Retrieved from: [https://www.itu.int/en/ITU-D/Statistics/Documents/publications/mis2012/MIS2012\\_with\\_out\\_Annex\\_4.pdf](https://www.itu.int/en/ITU-D/Statistics/Documents/publications/mis2012/MIS2012_with_out_Annex_4.pdf)
- [21] United Nations, "The Sustainable Development Goals Report 2016 – Leaving No One Behind," United Nations, New York, 2016. Retrieved from: <https://unstats.un.org/sdgs/report/2016/leaving-no-one-behind>
- [22] International Telecommunication Union, "ICT Facts and Figures 2017." ITU, Geneva, 2017. Retrieved from: <https://www.itu.int/en/ITU-D/Statistics/Documents/facts/ICTFactsFigures2017.pdf>
- [23] K. Dobransky, and E. Hargittai, "Unrealized Potential: Exploring the Disability Digital Divide," Poetics, 58, 2017, pp. 18-28.
- [24] L. Schur, T. Shields, and K. Schriener, "Generational Chorts, Group Membership, and Political Participation by People with Disabilities," Political Research Quarterly, 58(3), 2005, pp. 487-496.