

# ACCESSIBILITY IN GLOBAL GOVERNANCE: THE (IN)VISIBILITY OF PERSONS WITH DISABILITIES

**Barriers to Effective Participation and Recommended Solutions**

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December 2018

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# About the Institute on Disability and Public Policy

The Institute on Disability and Public Policy (IDPP), based at American University in Washington, D.C., is a multidisciplinary, cross-campus research center that creates and disseminates knowledge that enables all persons to participate effectively in local, national, and global governance through the use of accessible information and communication technologies. IDPP leads the AU 2030 Strategic Initiative on Global Disability and Development, and helps to facilitate collaborative research, teaching and outreach programs through its partnerships.

Founded initially in August 2009 as IDPP for the ASEAN Region, we contribute to the vision of an inclusive, barrier-free and rights-based global society. Initially our focus was on the ten countries of the Association of Southeast Asian Nations (ASEAN). We built a path-breaking network of 20 leading universities in Southeast Asia and the United States, and 4 outreach partners. With our contribution to the creation of the Disability and Public Policy Network (DPPnet) at the ASEAN University Network (AUN), we then broadened our focus to the rest of the world as IDPP Global.

As IDPP Global, we are now engaging with the United Nations and our partners around the world on issues ranging from UN Habitat and the implementation of the New Urban Agenda, the UNISDR on the Global Platform on Disaster Risk Reduction, and of course the monitoring and implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD). All of these efforts are to help implement the 2030 Agenda for Sustainable Development and the Sustainable Development Goals (SDGs) in service of facilitating a disability-inclusive development framework to benefit the more than 1 billion persons with disabilities in the world.

Our Core Focus Areas include:

- Global, Regional and National Disability Policy
- Inclusive Sustainable Development
- Accessible Global Governance
- Inclusive Cities and Urban Development
- Inclusive Disaster Risk Reduction
- Information and Communication Technologies for Development
- Accessible Robotics
- Accessible Cyberlearning
- Accessibility, Assistive Technologies and Universal Design

Click [here](http://www.idppglobal.org) to know more about IDPP ([www.idppglobal.org](http://www.idppglobal.org))

## About American University

American University (AU) is a private doctoral research institution chartered by an Act of Congress in February 1893. The AU community is one of exceptional talent. American University's full-time faculty are experts in their fields and engaged in their professional disciplines. The university distinguishes itself through a broad array of undergraduate and graduate programs that stem from these primary commitments:

- interdisciplinary inquiry transcending traditional boundaries among academic disciplines and between administrative units
- international understanding reflected in curriculum offerings, faculty research, study abroad and internship programs, student and faculty representation, and the regular presence of world leaders on campus
- interactive teaching providing personalized educational experiences for students, in and out of the classroom
- research and creative endeavors consistent with its distinctive mission, generating new knowledge beneficial to society
- practical application of knowledge through experiential learning, taking full advantage of the resources of the Washington, D.C., metropolitan area.

The central commitment of American University is to the development of thoughtful, responsible human beings in the context of a challenging yet supportive academic community.

American University is home to seven colleges and schools, with nationally recognized programs, centers, and institutes, a distinguished faculty, and a location that offers countless resources. The curriculum of each school and college is rigorous and grounded in the arts and sciences and connected to professions addressing contemporary issues. Co-curricular activities based on primary commitments—such as study abroad programs in 41 countries, internships in our Washington Semester Program, and opportunities to conduct research with faculty—allow students to craft unique and personalized educational experiences. And, with Washington, D.C., as their classroom, they are able to take advantage of the vast opportunities offered by the federal government, embassies, theatres, research institutes, and other national and international organizations.

Click [here](http://www.american.edu) to know more about American University (www.american.edu).

## About the Nippon Foundation

The Nippon Foundation was established in 1962 as a non-profit philanthropic organization, active in Japan and around the world. Initially, the Foundation's efforts focused on the maritime and shipping fields, but since then the range of activities has expanded to education, social welfare, public health, and other fields—carried out in more than 100 countries to date.

Together with more than 20 partner organizations in Japan and worldwide, The Nippon Foundation is funding and assisting community-led efforts aimed at realizing a more peaceful and prosperous global society.

The Nippon Foundation tackles a broad range of issues facing humanity through its mission of social innovation. The Foundation aims to achieve a society where all people support one another, reducing the burdens and challenges they face together. The Foundation believes everyone has a role to play: citizens, corporations, nonprofit organizations, governments, and international bodies. By forging networks among these actors, The Nippon Foundation serves as a hub for the world's wisdom, experience, and human resources, giving individuals the capacity to change society—the hope that they can make a difference. The Nippon Foundation's goal is to give all of humanity the chance to participate in creating our future.

The Nippon Foundation defines Social Innovation as “Implementing ideas to create new frameworks and bring about change for a better society.” It believes that the widespread implementation of Social Innovation will achieve a truly sustainable society in which “all people support one another.”

The Nippon Foundation aims to achieve this society in which “all people support one another.” This requires new public-private sector and private-private sector frameworks that transcend the conventional perspectives of citizens, companies, NGOs, governments, and international organizations. It believes that implementing the concept of Social Innovation with the involvement of individual donors, corporate CSR activities, and national and local governments will lead to the realization of this society.

The Nippon Foundation acts as a Social Innovation hub, positioned at the center of new frameworks that link citizens, companies, NGOs, governments, and international organizations, to achieve a society in which “all people support one another.”

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## **Acknowledgements**

We would like to thank The Nippon Foundation for support of this research, and also offer thanks to our anonymous interview participants and survey respondents, as well as the research team that supported the study. In particular, we would like to thank Ms. Maya Aguilar, IDPP Associate Director, for help with the fieldwork and data analysis. We would also like to thank our colleagues in the School of International Service, Kogod School of Business, and the School of Communication at American University, and partner institutions around the world.

# Executive Summary

This report presents the findings of the “Accessibility in Global Governance” study carried out by the Institute on Disability and Public Policy (IDPP) at American University with the support of The Nippon Foundation. This study was a sequential mixed-methods design, with two complementary phases. In Phase One, 16 subject matter expert interviews were carried out with U.N. officials, government officials, leaders of Disabled Persons’ Organizations (DPOs), as well as other civil society groups involved in global governance processes between 2015-2016. In Phase Two, a global survey of DPO leaders on global governance accessibility was carried out in the months of September and October 2016. The survey was completed by representatives from 123 DPOs in 51 different countries across all regions of the world.

This study provides empirical lens into the current participation of persons with disabilities within the U.N. System and other key international forums, and highlights the interventions required to enable persons with disabilities to participate equally in global governance and international decision-making processes.

## **Rationale and motivation for participation in global governance:**

- **Eagerness to participate:** Disability advocates around the world are looking to be more engaged and participate more effectively in global governance, with a large majority of survey respondents stating that U.N. (83.87%) and non-U.N. (77%) international conferences, meetings and events are highly relevant to their work.
- **Respondents were more likely to participate in non-U.N. international conferences compared to U.N. events:** Overall, survey respondents were more likely to have participated in non-U.N. international conferences (78.38%) than U.N. international conferences, meetings, and events (46.15%).
- **Participation in U.N. conferences tends to be a ‘one off’:** the average number of U.N. conferences attended was relatively low (mean=5.8; median=2) and 32.3% of those who had ever attended a U.N. event had done so only once, suggesting that a large number of disability organizations lack regular and sustained opportunities for engaging with the U.N. system.
- **Nearly nine in ten survey respondents never participated in a PrepCom or similar participatory meeting:** Given the fundamental role that PrepComs and similar events play in negotiating key outcomes and final documents for important global conferences, this highlights the importance of training disability rights advocates on the importance of PrepCom meetings and conference diplomacy more generally and facilitating their participation in them.
- **Being invited as a speaker was a major incentive to attend international events:** In particular, it was interesting to note that survey respondents said they

were considerably more likely to be invited as a speaker at non-U.N. international conferences (34%) compared to U.N. ones (25%).

### **Key barriers to effective participation:**

- **Major barriers for persons with disabilities start well before their arrival at conference host cities and venues.** Major obstacles identified by survey respondents included:
  - **Cost and lack of funding:** nearly three quarters (73.41%) of respondents stated that lack of funding was a key problem for them when it came to U.N. events; financial constraints were at the top of the list of reasons for not attending U.N. events, followed a distant second by not knowing about the events (37.68%).
  - **Inaccessible conference invitations:** over 40% of respondents indicated that conference invitations were not in an accessible format tailored to persons with disabilities and many commented specifically on the challenges for persons with visual deficits.
  - **Lack of knowledge about registration:** 21% stated they did not know how to register.
  - **ECOSOC accreditation:** More than half of the respondents (57%) stated that a lack of accreditation with the United Nations Economic and Social Council (ECOSOC) was a significant barrier that limited participation by persons with disabilities in U.N. conferences. Lack of ECOSOC accreditation was explicitly cited by 29% of respondents as a major factor that prevented them from being able to attend U.N. conferences. This was strongly echoed by interview participants, who stated that ECOSOC accreditation should not be used as the criteria for participation in U.N. conferences, meetings, and events.

### **Accessibility features at international conferences:**

- **Non-U.N. conferences were rated higher for overall accessibility:** Only 6% of survey respondents thought that U.N. conferences were fully accessible for persons with disabilities. Comparatively, nearly a quarter of survey respondents felt that non-U.N. conferences were fully accessible for persons with disabilities.
- **Venue accessibility goes beyond the provision of ramps and elevators:** U.N. conferences scored particularly low (36.67%) for venue accessibility. While ramps and elevators were the accessibility features that were provided most commonly at the U.N. conferences attended by survey respondents (72.41% and 62.07% respectively), these results suggested that there are other accessibility features on which it is important for conference organizers to focus in the future, for example braille signage and accessible toilets.
- **Accommodation for persons with visual impairments tend to be particularly deficient:** According to survey respondents, screen reader accessible conference

material was provided only in 37.98% of cases, braille material in just under a quarter of conferences (24.4%) and the vast majority of conference websites (79.31%) could not be easily accessed using a screen reader.

### **Remote participation:**

- **Virtual participation was available at few international conferences:** only 15.63% of survey respondents who said they participated in U.N. events were able to do so virtually.
- **However, U.N. conferences tended to be slightly ahead of the game with regard to remote participation compared to other international forums:** Looking at non-U.N. conferences and events, the number of respondents who participated virtually via webconferencing tools was even smaller at only 3.77% compared to 96.23% who attended in person.
- **When virtual participation was available, it showed great potential:** At U.N. conferences for which virtual participation was offered, respondents engaged in a good range of activities. 40% of those who participated in U.N. events remotely via webconferencing software 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 via text (40%).

### **Key recommendations:**

- **Accessibility Starts Before Conferences are in Session.** International organizations and particularly the U.N. system should take a holistic approach to accessibility and address potential barriers well before participants arrive at conference venues. This includes making the registration process and preparatory documents completely accessible, ensuring accessible transfers between transport hubs such as airports and railway stations and meeting venues, as well as experimenting with accessible remote participation technologies beyond live streaming to make truly meaningful and effective participation available to those who are prevented from traveling internationally by financial barriers.
- **Diplomacy Training.** There is a substantial need for training and capacity building amongst persons with disabilities in the knowledge, skills, and abilities required for effective participation in global governance, including especially in diplomacy and negotiations. Accessible access to the meetings themselves is only half the battle. What a person knows, and what they do once they have access to the meeting is equally important. We recommend a sustained capacity building effort on this front.
- **Major Groups Expansion.** All of the participants in the interviews and a vast majority of survey respondents believe persons with disabilities should be added to the Major Groups framework. Some participants questions whether the Major Groups framework should continue at all. There are some differences of opinion

regarding the legitimacy of the current Major Groups framework. However, some participants believe that even with this expansion, each of the existing major groups should continue to be focal points for disability rights issues. In reality, persons with disabilities are women, children, farmers, trade unionists, NGOs, indigenous persons, scientists, business people, and in local authorities. One important side note, the current participation by the disability community in the implementation of the Sustainable Development Goals (SDGs) is being aided by the use within the High-Level Political Forum (HLPF) of an expanded framework for participation called the Major Groups and Other Stakeholders (MGOS). More research is needed to assess the impact of the MGOS framework on the global disability community, or the degree to which it might provide best practices or lessons learned for other multistakeholder global governance processes.

- **Disability Organizational Infrastructure.** The international disability community, including Disabled Persons' Organizations, advocacy organizations, research organizations, networks, donors, et al., should work together to forge a comprehensive and effective platform for monitoring and implementation of the CRPD and broader global disability rights and policy.
- **Awareness-raising.** There should be system-wide training and awareness raising for UN leadership and staff (particularly the security staff) about the rights of persons with disabilities. These training sessions might be particularly valuable if held before major events such as the International Day for Persons with Disabilities or the Conference of States Parties (COSP) to the UN Convention on the Rights of Persons with Disabilities (CRPD).
- **Conclusions.** In many ways the preceding points are intertwined. There is tremendous potential for an organized, coherent international disability movement to participate effectively in global governance. This movement should continue to recognize and harnesses the power of grassroots organizations (and the tremendous legitimacy they bring to the table), coupled with critically important international diplomatic savvy and negotiation skills. Support for this twin strategy is critical to extracting as much as possible from the openings provided in the Sustainable Development Goals (SDGs).

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## Introduction

There are more than a billion people living in the world with some form of disability (WHO, 2011). This number is much larger than previously estimated, meaning that nearly 15% of every countries population is likely to be a person with a disability (PWD). Many PWDs organize their national and international policy advocacy within Disabled Persons' Organizations (DPOs), including their engagement with the United Nations system. In September 2002, then U.N. Secretary General Kofi Annan initiated a process to change the way non-state actors engage with the U.N. through the Cardoso Report. Even though the Report was criticized, it raised important issues related to the importance of civil society engagement with the U.N. system. In December 2001, this process of "multi stakeholder participation" in the U.N. took a major step forward with the adoption of General Assembly adoption of Resolution A/RES/56/183, authorizing the creation of the World Summit on the Information Society.

This has been part of a broader movement towards multi stakeholder participation in global governance and international decision-making processes. In this environment, non-state actors, and civil society organizations in particular, have begun to be seen as legitimate participants in global governance. Their expertise and knowledge are seen as critically valuable to informing this process. However, even though this process has opened up more space for civil society participation, it has not fully enabled Persons with Disabilities to participate actively in the U.N. system. The impact of DPOs on international decision-making processes has been limited, with the notable exception of the negotiations around the U.N. Convention on the Rights of Persons with Disabilities (CRPD) and their participation in the annual Conference of State Parties (COSP) for the CRPD. When one observes the COSP for the CRPD, it provides an illusion that persons

with disabilities are active participants in the UN system. Unfortunately, the reality appears to be just the opposite.

## **1. Background and Rationale**

United Nations Member States have recognized the benefits of civil society engagement in global governance and have taken measures to ensure there is participation from various stakeholder groups. The adoption of Agenda 21 by U.N. Member States established nine “Major Groups” aimed at increasing engagement and partnership with a broad range of stakeholders outside of the intergovernmental spheres, and is indicative of these civil society engagement efforts.

The Major Groups framework include a range of nine non-state actors: 1) women; 2) children and youth; 3) indigenous people; 4) Non-Governmental Organizations (NGOs); 5) local authorities; 6) workers and trade unions; 7) business and industry; 8) scientific and technological community; and 9) farmers. While this list includes many important marginalized communities, it leaves out persons with disabilities.

In 2012, the United Nations General Assembly adopted A/res/66/288 entitled, “The Future We Want.” This document outlined the institutional support necessary to enact the Sustainable Development Goals and specifically indicated that in addition to the Major Groups, “other stakeholders” should also be invited to participate in U.N. processes related to sustainable development. Persons with disabilities are specifically included under “other stakeholders” in paragraph 43 of this resolution. Within the High-Level Political Forum (HLPF) processes, this Major Groups and Other Stakeholders (MGOS) approach has supplanted the more limited Major Groups framework which excluded persons with disabilities.

***“No one must be left behind. People who are hardest to reach should be given priority.”***

In this process, persons with disabilities and their advocacy organizations have the opportunity to engage more fully in U.N. processes by attending meetings, gaining access to official information, and making recommendations. With more than a billion people in the world living with some form of disability, it is essential that persons with disabilities and Disabled Persons Organizations are able to fully engage in the U.N. system, as well as other global, regional, and local decision-making processes. In order for this to be possible, barriers to participation in the U.N. system and other international forums need to be addressed comprehensively. The moral imperative underpinning the 2030 Agenda for Sustainable Development is “no one must be left behind. People who are hardest to reach should be given priority” (U.N. 2016).

International policy formulation processes are complex and require sustained cooperation and collaboration during pre-conference preparations, during the conference, and post-conference follow-up. For persons with disabilities, physical and electronic accessibility

issues exacerbate this challenging climate, and exclude individuals from actively participating in global policy formulation.

## 2. Research Design

This report integrates results from a sequential, two-phased, mixed-methods completed by the Institute on Disability and Public Policy (IDPP) at American University. The first phase of the study consisted of expert interviews, to better understand the social, political, economic, and technological factors that enhance and/or inhibit persons with disabilities from participating actively in the U.N. System and broader global governance processes. The second phase of the study consisted of a survey completed by leaders of Disabled Persons Organizations. The survey identified the barriers to participation in the U.N. system and other international forums, which need to be addressed comprehensively.

This study provides empirical evidence for the current participation of persons with disabilities in global governance processes, and helps us better understand what interventions are required to enable persons with disabilities to participate equally and effectively in global governance and international decision-making processes.

The study asked four “grand tour” research questions:

RQ1: To what degree have persons with disabilities participated, and participated “effectively,” in U.N. conferences, meetings and events?

RQ2: What social, political, economic, and technological factors have enabled persons with disabilities to participate actively in U.N. conferences, meetings and events?

RQ3: What social, political, economic, and technological factors have inhibited persons with disabilities to participate actively in U.N. conferences, meetings and events?

RQ4: What recommendations to the U.N. might improve the participation for persons with disabilities in U.N. conferences, meetings and events?

### 2.a Subject Matter Expert Interviews

We gathered the expertise of advocates, academics, and policy makers through interviews with selected participants from within each group. These interviews were conducted both face-to-face and online. The highly structured interviews took a “critical incident” approach, and had participants focus on their most recent U.N. conference.

The interview protocol focused on four key areas of meeting accessibility, including:

1. Information (e.g. announcements, websites)
2. Venue(s) (e.g. meeting rooms, break-out sessions, hotels)
3. Logistics (e.g. participation in discussions, and remote participation options)

4. Framing (e.g. how the issues of the meeting are presented)

***Expert Interviewees:***

A stratified, purposive sample of participants was drawn for the interviews. It includes U.N. officials, government officials, leaders of Disabled Persons Organizations and other civil society groups and subject-matter experts, selected to ensure representation across the U.N. System and to ensure regional and stakeholder balance. Our expert interviews included many participants with multiple leadership positions, including some leadership positions with the United Nations. Several participants juggled multiple contracts simultaneously, and many have worn many “hats,” thus representing various different organizations and interests at the same time.

Most participants were involved with Disabled Persons Organizations. Many of the organizations are networks, or formerly networks of DPOs. Some participants were with their organizations for only a few months; while others were with their organization for two decades or more. The interviewees included persons from the following organizations and entities:

- International Disability Alliance (IDA)
- Rehabilitation International (RI)
- Disabled People’s International (DPI)
- Christian Blind Mission (CBM)
- University of Tokyo
- Ritsumeikan University
- World Enabled
- Institute on Disability and Public Policy (IDPP)
- Global Inclusive Initiative for Information and Communication Technologies (G3ICT)
- United Nations International Strategy for Disaster Reduction (UNISDR)
- United Nations Department of Economic and Social Affairs (UNDESA)
- United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP)
- International Telecommunication Union (ITU)
- World Bank
- Government of Ecuador

The sample of 16 participants included a slight majority of male participants (n=9). The age range for the sample is 31-68, with an average of 40. The participants had a high level of education, with most having one or more graduate degrees (n=16), and some having doctorates (n=5). The participants had pursued a wide variety of educational fields, with only public policy, law and development, occurring with any notable frequency.

The participants came from a diverse national pool including Brazil, Ecuador, France, India, Japan, Philippines, Switzerland, United Kingdom, United States, and Venezuela.

Although our participants come from a wide variety of countries, they are heavily concentrated in a few cities, such as Geneva (n=4), New York (n=3), and Washington, D.C. (n=2). Other participants lived in Belgium, Ecuador, India, Japan, the Netherlands, and Thailand.

Included amongst the participants were persons who are blind and visually impaired, deaf and hard of hearing, mobility impaired, as well as those who did not identify as having a disability. In addition to many of the participants having a disability themselves, several had immediate family members with disabilities, close friends and members of their community, and/or expressed a strong desire to advocate for and contribute to a world that is more inclusive of persons with disabilities and empowers them to achieve their goals.

## **2.b Global Survey of Disabled People's Organizations (DPOs)**

A global survey of Disabled People's Organizations (DPOs) was conducted after the initial expert interviews to acquire more detailed information about the factors that have limited or enhanced persons with disabilities from participating in international conferences, meetings, and events, and explore the perspective of global disability rights advocates on these issues.

The survey questionnaire (in English) was designed and distributed using a web-based survey software called Qualtrics. The development of the survey was informed by the results of the subject matter expert interviews on disability and global governance. In total, the survey questionnaire included 72 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. Involvement in Disabled People's Organizations (DPOs) and grassroots engagement; and
4. Inter-organizational collaboration and the U.N. Major Groups' framework.

Each of these areas was explored using both closed and open, qualitative questions. To assess the disability status of survey respondents, the survey incorporated the Washington Group on Disability Statistics Short Set Questions<sup>1</sup>. 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 (1) vision, (2) hearing, (3) mobility, (4) memory and concentration, (5) self-care, and (6) communication to better identify people at risk of participation restrictions. While we acknowledge the limitations that derive from the self-reporting nature of this way of measuring disability, the Short Set

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<sup>1</sup> CDC Short Set of Questions on Disability

has gained widespread recognition in recent years, which enhances the comparability of our data with other international studies on disability.

The distribution list including 973 prominent organizations involved in disability rights advocacy work at the international level was drawn from relevant national and international directories<sup>2</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. Disabled Persons Organizations focused on all or multiple disabilities were favored in the selection process. In most cases, the president or chief executive officers of each organization were emailed directly, while for a small number of organizations it was necessary to use a generic email address such as “info@organization.org.” The survey was distributed to the entire list in early September 2016 and two follow-up reminders sent out later that month and in October 2016.

### ***Survey Respondents***

123 organizations from 51 different countries completed the survey. As shown in Figure 1, all regions of the world were represented in the sample. 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.

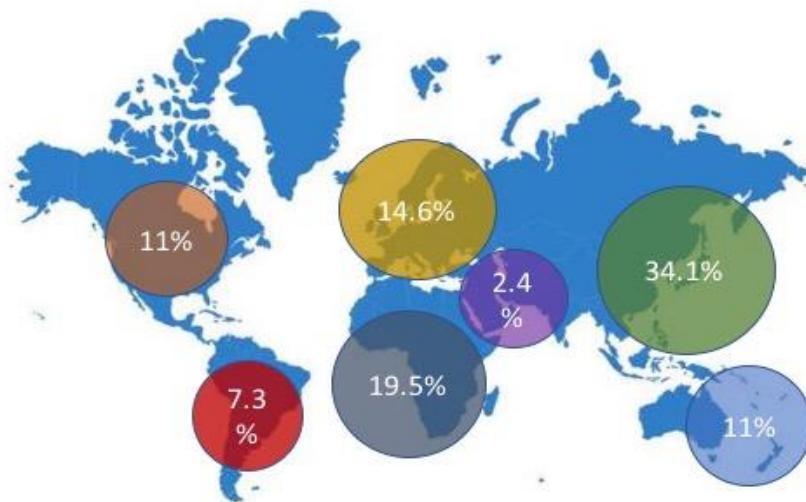


Fig. 1 – AGG Survey respondents’ global distribution

The vast majority of the organizations that responded (83.75%) were non-governmental civil society organizations, with the rest of the sample including a small number of government agencies, foundations, private sector organizations, and academic institutions. Among non-governmental civil society organizations, just over 42% were described by respondents as “self-advocacy” organizations and 39% as “professional

<sup>2</sup> For example: [Mainstreaming disability rights in the European Pillar of Social Rights – a compendium; Gallaudet University World Deaf Information Resource](#)

advocacy organizations." Of these, more than half (55.74%) was involved in pan-disability work, just over a quarter (26.23%) advocated for multiple disabilities, and the remaining 18% focused on a specific disability.

While the roles of individual respondents within their respective organizations varied, 73.5% of them occupied an executive position such as executive director or other officer, board member, and program manager. There were more male respondents (57.32%) than females (42.68%). The median respondent age was 46 in a range comprised between 23 and 75 years old.

Most respondents were highly educated. Nearly half (44.58%) had a master's degree, 19.28% 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, highlighting the role that education and training in these fields plays in boosting the engagement of the in global disability community in international governance. Survey respondents also stated that, on average, they spent about 21% of their time engaging with the international disability community.

More than two-thirds (70.73%) of all respondents said they identified as a person with disabilities (Figure 2).

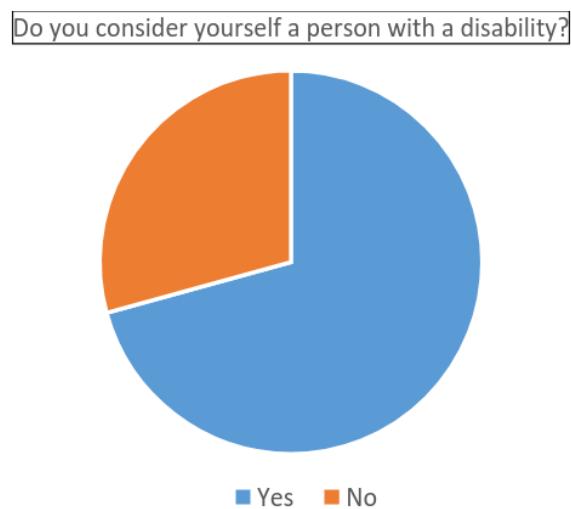


Fig. 2- Disability Identity

In addition, 57.9% of respondents also responded positively to 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, including ambulation, as 52% of respondents reported some level of difficulty walking or climbing steps, with 23% of all respondents reporting they were unable to perform ambulation at all. Furthermore, just over a quarter of all participants (26.6%) had vision issues, 18.52% had problems with their hearing, 18.75% had issues remembering or concentrating,

33.5% found it difficult to self-care at some level, and 12.5% experienced communication problems.

### **3. Findings**

Given the size, scope, and economic condition of the person with disabilities population around the world, it is inappropriate to exclude them from the focus required to make substantial progress in the Sustainable Development Goals. The interviews and surveys provide the empirical evidence necessary to appreciate the current participation of persons with disabilities in global governance and help us identify what kinds of interventions may be required to enable persons with disabilities to participate equally in international decision-making processes.

A key question in this study was asked to understand the current level of participation of persons with disabilities in United Nations conferences, meetings, and events. However, it is important to remember that our focus is not solely on “participation” in terms of being able to register for and attend a conference. Simple participation does not equal influence in the decision-making or outcome of an UN or other international conference. As such, this study tries to go beyond participation, to include an analysis of what we call “effective” participation. Being able to “effectively” participate in a United Nations conference, meeting or event, requires a wide range of skills that are highlighted in this study.

#### **3.a Participation at U.N. Conferences, Meetings, and Events**

For many interview participants, the Convention on the Rights for Persons with Disabilities (CRPD) is the cornerstone of their work. Working on the CRPD catalyzed many of them into international advocacy work, and most see it as a critical vehicle for holding the U.N. responsible for living up to the spirit and letter of the Convention. When talking of meeting accessibility, some participants explicitly argued for the U.N. to meet its own standard for accessibility, as delineated in the CRPD.

Work at the international level includes promoting the CRPD and advocating with the U.N. Agencies to promote its implementation, and monitoring their progress. At the grassroots level, much of the work focuses on training about the Convention.

Some of the participants interviewed work at both types of organizations. U.N. conferences, meetings and events are of various sizes and scopes. Some of the interview participants engaged in follow-up meetings to the Beijing Conference on Women (Beijing plus 20) while others had participated in unique U.N. conferences, such as the World Summit on the Information Society (WSIS).

With regard to survey respondents, just under half (46.5%) said they had ever attended one U.N. conference, meeting or event (in person or virtually via web conferencing tools – Figure 3). This was in contrast to over three quarters (78.38%) who said they had attended at least one non-U.N. international conference (Figure 4).

Have you ever attended a U.N. international conference, meeting, or event?



Fig. 3 – Proportion of respondents who attended U.N. international conferences, meetings, or events

Have you ever attended a non-U.N. international conference, meeting, or event?

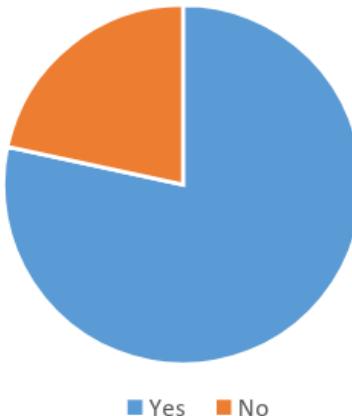


Fig. 4 – Proportion of respondents who attended non-U.N. international conferences, meetings, or events

Attendance at U.N. conferences, meetings, and events, ranged from one to 35 events. However, the average number of conferences attended was relatively low (mean=5.8; median=2) and 32.3% of those who had ever attended a U.N. event had done so only once. This suggested that even those survey respondents who had participated in U.N. events tended to do so rarely or as a 'one off' rather 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.

### ***U.N. Conferences***

Survey respondents who had attended U.N. conferences (46.5%) were asked to briefly describe the nature of these meetings, topics discussed, and list the name of the most recent U.N. event they attended in open questions. Among those who answered this last question (n=30), the event mentioned most frequently was the Conference of State Parties (COSP) to the Convention on the Rights of Persons with Disabilities (CRPD), which was mentioned six times. This echoed the focus of interview participants on the promotion of the CRPD as cornerstone of their international work.

Other popular survey responses included regional U.N. conferences on disability rights (n=4), CRPD Committee briefings and hearings (n=2), the High-Level Political Forum on sustainable development (n=2), Sendai conference on Disaster Risk Reduction (n=2), and the meetings of the Commission on the Status of Women (n=2). Other U.N. conferences mentioned by respondents included ITU conferences, UNESCO conferences, ILO workshops, and UNDESA expert meetings.

Although the prevalence of disability-specific events such as those on the CRPD is understandable, the fact that only a very small number of respondents had participated in conferences focused on other issues suggested that there is still a long way to go towards ensuring that disability is mainstreamed in global governance processes and securing opportunities for the global disability community to be heard in these forums.

### ***Non-U.N. Conferences***

Survey respondents described various non-U.N. international conferences they attended, which included meetings hosted by Disabled People International (DPI) and the International Disability Alliance (IDA). In addition, many respondents reported attending meetings for the ASEAN peoples' forum, ISPO world congresses, and ILO strategies for skill acquisition and work for disabled people. While a majority of non-U.N. conferences attended by respondents also focused specifically on disability issues, these numbers suggested a broader and more regular level of engagement with international affairs outside the U.N. system for disability rights advocates.

In addition to higher attendance rates, the distribution of conference attendance at non-U.N. events was more dispersed. Notably, there was more representation from Oceanic and African countries. There was less virtual participation in non-U.N. international conferences compared to U.N. conferences. However, this could be because the conferences attended were more regionally focused and therefore geographically closer. This brings to light the effect of distance as a barrier for people with disabilities.

With regard to the type of activities that respondents were able to carry out during non-U.N. conferences, meetings and events, it was interesting to note that respondents said they were considerably more likely to be invited as a speaker (34%) compared to a U.N. conference (25%). It is reasonable to assume that this opportunity for enhanced and more

meaningful participation acted as an additional incentive in promoting attendance at non-U.N. conferences, meetings and events.

### **3.b Pre-Conference Accessibility**

#### ***Location***

U.N. conferences, meetings, events, and their various Preparatory Committee meetings are regularly held the global nodal cities of New York, Geneva, Washington D.C., and Paris. Meetings can span multiple weeks, several times throughout the year, requiring extensive travel. Attending such meetings and events requires participants to travel long distances in order to attend in person, particularly from Africa, Southeast Asia, and Oceania. Traveling internationally can be extremely difficult for people with disabilities.

Interview participants spoke about the challenges of traveling from the airport to U.N. buildings. In Geneva, the buses are very accessible, but this can give a false impression that all the transportation in the city is accessible. It is not. Many of the taxis in Geneva do not want to take persons using wheelchairs.

Also, there seems to be increasing incidents of organized targeting of persons with disabilities arriving at the main train station in Geneva, Gare de Cornavin. These incidents are mostly pick-pockets, but other thefts are occurring as well. It would be very helpful to have trained guides who are wearing uniforms to meet the participants with disabilities arriving at the train station.

The centrality of New York City and Geneva to U.N. processes was also highlighted as problematic by survey respondents. Although some of the U.N. conferences attended by DPO leaders who took part in the survey 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 location of meetings, required participants to travel long distances in order to attend in person, particularly from Africa, South-East Asia, and Oceania, which made up a majority of survey respondents. Traveling internationally is particularly expensive and can be impractical or even impossible for people with disabilities who often require multiple accommodations due to inaccessible transport links. This helps explaining why over half of those who took part in the survey had been unable to attend a U.N. conference, meeting, or event.

#### ***Lack of Funding***

Funding for participation in U.N. conferences, meetings and events is always a crucial factor. These global nodal cities are some of the most expensive in the world like New York, Geneva, Washington, D.C., and Paris. Yet, U.N. conferences, meetings, events, and their various Preparatory Committee meetings can span multiple weeks, several times throughout the year. Active, and sustained participation in these meetings is very expensive.

The interview participants highlighted the need for financial support for attending and participating in conferences for disability rights issues. Direct financial support to DPOs for participation in the U.N. and global governance processes tends to come from donor governments and private foundations. Our interview participants noted the governments of Japan (JICA), Norway, Australia (AusAid), and the United States (USAID), and private foundations (The Nippon Foundation and the Gates Foundation).

These findings were reiterated in the survey with nearly three quarters (73.41%) of respondents stating that lack of funding was a key problem for them when it came to U.N. events. This result was compounded by the fact that only 56.5% of those who had attended a U.N. conference said they had been able to secure external funding to support travel costs. Overall, this put financial constraints at the top of the list of reasons for not attending U.N. events, followed a distant second by not knowing about the events (37.68%).

These results re-affirmed the point that, for many persons with disabilities and the organizations that represent them, barriers start well before they arrive at conference host cities and venues.

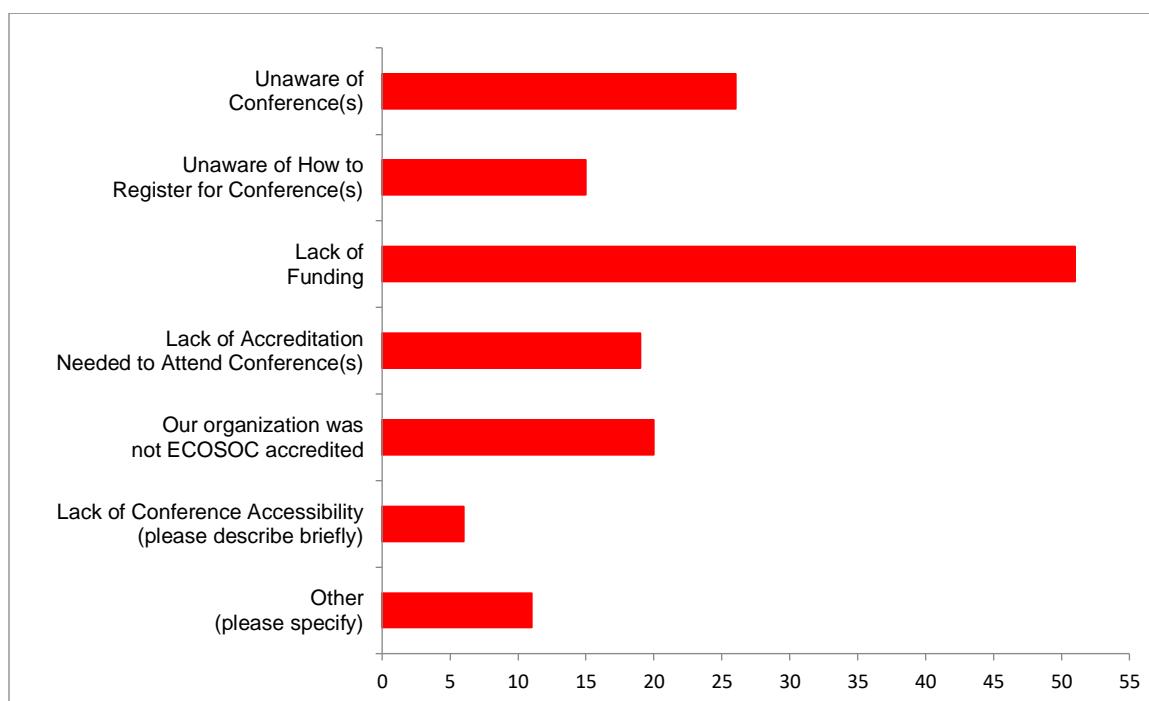


Fig. 5 – Key reasons for not attending U.N. conferences, meetings or events

Given that funding was identified as a major barrier to the participation of disability organizations in U.N. events and both New York and Geneva are likely to continue to be central locations for much of this work, a low-cost solution to reduce barriers imposed by distance includes increasing the functionality and availability of remote participation, which allows people to take part in conferences through accessible cyber infrastructure.

Allowing people to virtually attend meetings, present at working sessions, and communicate in real-time with other conference participants constitute cost effective solutions to ensure people with disabilities are able to engage in global governance processes more effectively.

***“A low-cost solution to reduce barriers imposed by distance includes increasing the functionality and availability of remote participation.”***

### ***Electronic Communication***

During the pre-conference period, it is important for the organizations to prepare informational materials, highlighting their perspectives on issues, to be discussed at the U.N. event. For example, in advance of the Sendai World Conference on Disaster Risk Reduction, several interview participants indicated a preference for these materials to include data, and to be formatted in a way that was as easy to understand as possible, and conveying as informational as possible, as clearly as possible.

There should be a requirement that any state or non-state actor that submit documentation to the U.N., to do so in an accessible format. There should also be basic training of the staff at the U.N. and within other organizations to make documents accessible using Word and PowerPoint.

In the survey, there were two main ways in which respondents said they had found out about U.N. conferences including through other organizations (50%) and electronic mailing lists (25%). While finding out through other organizations hinted at the importance of partnership and inter-organizational collaboration for the effective participation of the global disability community in global governance, the relevance of email lists also highlighted the importance of electronic communication to raise awareness of these processes among disability advocates.

Over 40% of respondents indicated that conference invitations were not in an accessible format tailored to persons with disabilities and 21% stated they did not know how to register. Many commented on the specific challenges for persons with visual deficits. Because many people with visual impairments use screen reader technology, ensuring that all features of electronic communication are fully accessible will likely help these individuals become more knowledgeable about U.N. conferences, and to more fully participate.

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 a clear manner, and others stated that the website lacked image descriptions.

Some U.N. Agencies, such as the International Telecommunication Union, have started to focus on accessibility for their websites and conference documentation. ITU has a clear focus on Web Content Accessibility Guidelines. It has an accessibility policy. UNESCAP now has an Accessibility Center, and for the 3rd World Conference on Disaster Risk Reduction, there was a contract supported by The Nippon Foundation for the Assistive Technology Development Organization to do accessibility testing on all documents submitted.

Additionally, The U.N. Global Alliance on ICT and Development (GAID) is an initiative designed primarily to get more private sector companies engaged in International Communication Technology for development initiatives related to the Information Society. Individually, many companies are investing heavily in developing accessible technologies, many built right into their mainstream products such as Apple, Microsoft, Google.

### ***ECOSOC Accreditation***

While many of the interview participants in our study worked for organizations that were accredited by the United Nations Economic and Social Council (ECOSOC), many felt that ECOSOC accreditation should not be used as the criteria for participating in UN conferences, meetings and events. Many felt this requirement for ECOSOC accreditation was an unnecessary political barrier that was particularly challenge for many persons with disabilities and their organizations to overcome.

Disability organizations may find that it is possible to collaborate with other ECOSOC-accredited organizations to overcome this obstacle to participation, this nevertheless restricts their ability to register for relevant U.N. events in their own right. Alternative options should be explored to remove this considerable obstacle and enable a better representation of the global disability community at U.N. conferences.

These findings were again corroborated by the survey results. More than half of the respondents (57%) in the survey stated that a lack of ECOSOC accreditation (and other necessary accreditation) was a significant barrier that limited participation by persons with disabilities in U.N. conferences. In fact, 47% of respondents were unsure whether they had proper ECOSOC accreditation, while 34% indicated they did not have proper accreditation necessary to attend and contribute to U.N. conferences. Lack of ECOSOC accreditation was explicitly cited by 29% of respondents as a major factor that prevented them from being able to attend U.N. conferences.

### ***Preparatory Committee Participation***

Another distinguishing factor found in interviews for those participants who were influential in U.N. conferences, was their knowledge of and participation in, Preparatory Committee (PrepCom) meetings.

Within most U.N. conferences and events, PrepComs are known as critical periods of conference diplomacy, preceding the actual conference. Most of the negotiation and final decisions for a major U.N. conference, meeting or event are determined in advance of that meeting. The terms of reference, the outcome documents, and many other aspects of the conference are negotiated and agreed upon at PrepComs.

In addition to the international or global PrepComs, there are regional PrepCom which try to identify regional issues and interests in these areas. For example, in preparation for the Sendai World Conference on Disaster Risk Reduction in March 2015, several participants in the interviews, indicated their active participation in regional preparatory conferences, such as the Asia Pacific Ministerial conference on Disaster Risk Reduction in Indonesia, as early as 2012.

The survey found that among those who had attended a U.N. event, only just over a quarter (26.67%) – meaning 12% of the total survey sample – participated in a PrepCom or a similar preparatory meeting. Participation in these preparatory activities is imperative as they lead to recommendations for action and the contributions support international conference planning.

Given the fundamental role that this type of events play in negotiating key outcomes and final documents for important global conferences such as the recent Habitat III conference, it is particularly concerning to see that the global disability community is not represented at them in the vast majority of cases. This highlights the importance of training disability rights advocates on the importance of PrepCom meetings and conference diplomacy more generally.

### **3.c Conference Accessibility**

Despite the significant pre-conference barriers for persons with disabilities described above, there are still obstacles to overcome once at the conference to participate in global governance. Some of these obstacles range from the physical structure of the building to discrimination of persons with disabilities face at U.N. meetings.

In many cases, lessons for accessibility can be learned from non-U.N. international conferences. Participants gave numerous examples of problems with accessibility in non-U.N. international conferences. However, some non-U.N. international conferences stood out in terms of accessibility, namely the International Conference of Technology and Disability and the m-Enabling summit, organized by the Global Initiative for Inclusive Information and Communication Technologies (G3ICT).

#### ***Accessibility of U.N. Conferences***

Survey respondents were asked to rate the accessibility of a number of specific components of the most recent U.N. conference they attended on a scale from 1 to 5 where 1=fully inaccessible and 5=fully accessible. The percentage of respondents who

indicated that each conference component was not fully accessible (i.e. scored it between 1-4) is shown in Table 1 below.

Conference component	Percentage of respondents who considered it not fully accessible
Conference invitation	43.33%
Conference documents (e.g. background material, program and agenda, etc.)	60.00%
Venue physical accessibility	63.33%
Conference website	50.00%

Table 1 – Proportion of respondents who thought key conference components were not fully accessible for persons with disabilities

As these results clearly show, respondents perceived a large accessibility deficit in all these key U.N. conference components. Additional open questions about each of these conference components and related accommodations offered further information about accessibility to complement and help explain these numerical results.

### ***Accessibility of Non-U.N. Conferences***

Survey respondents were asked to rate the most recent U.N. and non-U.N. international conferences they attended in terms of accessibility for persons with disabilities on a scale from 1 to 10 where 1 stands for completely inaccessible and 10 for fully accessible. Only 6% of respondents thought that U.N. conferences were fully accessible for persons with disabilities, and just 43% rated U.N. conferences 8 or above (Figure 6).

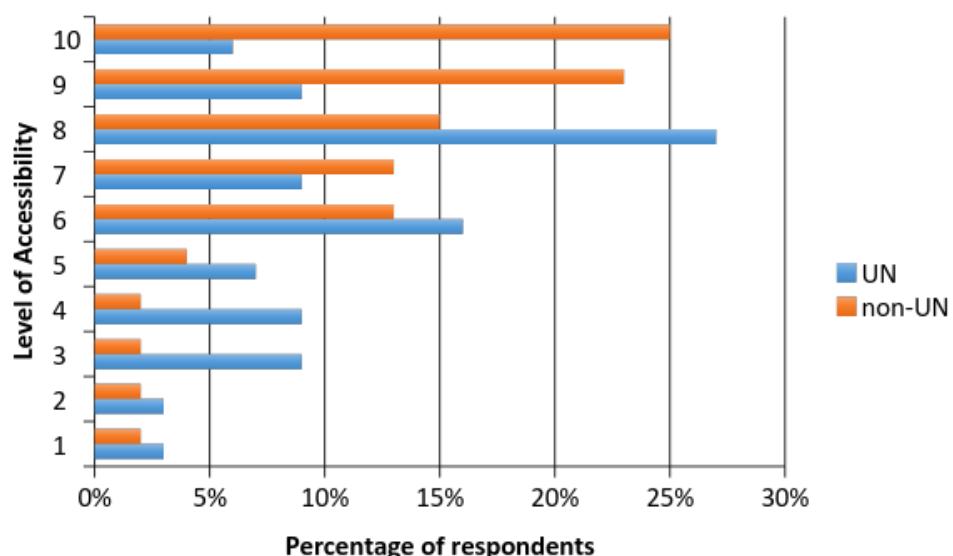


Fig. 6 – Overall accessibility ratings of U.N. and non-U.N. conferences, meetings and events

Comparatively, nearly a quarter of survey respondents felt that non-U.N. conferences were fully accessible for persons with disabilities and as much as 61% rated non-U.N. conferences at least 8 or above. On average, non-U.N. international conferences were also scored more highly (mean=7.79; median=8) than their U.N. counterparts (mean=6.38; median=7) for overall accessibility.

***“In order for persons with disabilities to be as independent and autonomous as possible, systems need to be in place that make it possible for them to independently request the floor and to then speak for themselves.”***

Carrying out a correlation analysis between the measure of disability derived from the Washington Short Set and overall accessibility ratings showed that there was an important inverse relationship between visual impairments and perspectives on the overall accessibility of U.N. conferences (correlation coefficient .625\* significant at the 0.01 level). This was an interesting result that is discussed in detail in the next section with regard to the accessibility of conference material for persons with visual impairments.

Overall, these results invited further reflection on what made U.N. conferences comparatively less accessible than non-U.N. events in the eyes of global disability rights advocates. The rest of this section discusses this issue in detail by focusing on specific accessibility components.

### ***Inaccessible Buildings***

The survey results found that while ramps and elevators were the accessibility features that were provided most commonly at U.N. conferences attended by survey respondents (72.41% and 62.07% respectively), the very low score for overall venue physical accessibility suggested that there are other features such as braille signage and accessible toilets on which it is important for conference organizers to focus (Figure 7).

Expert interviews provided a detailed overview of building accessibility issues at U.N. conferences. In addition to the access to the rooms, there should be accessible access to the meeting processes. For example, one of the most basic acts of participation in such a meeting is requesting permission to take the floor. If that is done by raising one's placard, that simple act may pose barriers to some persons with disabilities.

Then, after gaining permission to take the floor, being able to press the microphone and speak can also be a barrier. In order for persons with disabilities to be as independent and autonomous as possible, systems need to be in place that make it possible for them to independently request the floor and to then speak for themselves.

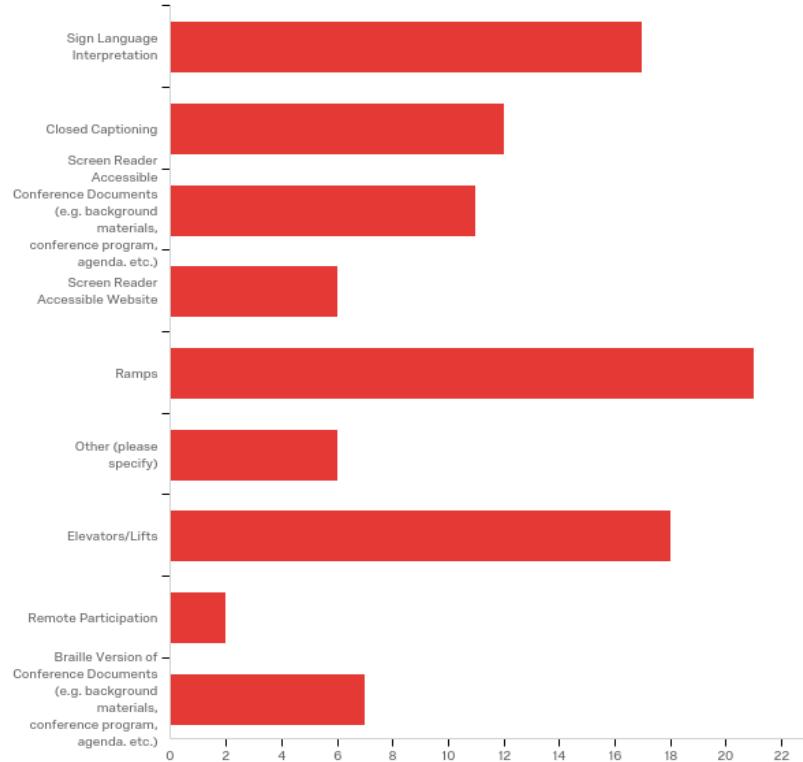


Fig. 7 – Accessibility features provided at the last U.N. conference attended by respondents

Also, the physical environment of these meetings in Geneva and New York tend to be extremely spread out. It can be exhausting for persons with disabilities to be able to move around the entire building. And, the signage can also be an unintended barrier. If the signage to find a particular room is non-existent or inaccessible, that becomes a barrier for Persons with Disabilities. In most cases, a person who is blind cannot acquire any information about the building and meeting rooms without interacting with a person.

Also, changing rooms on short notice can have a substantial impact on persons with disabilities (e.g. a room change from room 7 on one side of the building to room 23 on the completely opposite end/side of the building can make it extremely difficult for a person with a disability to make it to the meeting on time.

The furniture in U.N. meeting rooms needs to be as mobile as possible – at least some of it – to accommodate reconfiguring the space to include wheelchair users and other persons with mobility impairments. And meeting organizers and staff need to be empowered to remove furniture when necessary (this latter issue is an internal policy problem, not a physical problem per se).

In New York at U.N. Headquarters, access to the building and meeting rooms is a real challenge for mobility impaired persons. Actually, the entrance for members states is on the second floor and the entrance for civil society is on the third floor. Unfortunately, while the second floor is accessible to wheelchair users, the third floor is not; but civil society

participants cannot use the second floor entrance. The hallways are also very narrow in New York, and the space between seats is very limited, making it difficult for a wheelchair user or mobility impaired person to access the meeting.

Overall, participants stated that physical accessibility of U.N. buildings should be an even higher priority than it has become in recent years. The U.N. should be a model, in as many ways as possible, with implementing the CRPD. This physical accessibility to the buildings, meetings rooms, break-out rooms and other facilities should be of the highest priority – especially at the New York headquarters and in Geneva.

### ***Conference Materials***

Interview participants noted that despite the efforts of several of the key conference websites, the websites are not sufficiently accessible. This website accessibility is equally important for any intranets or extranets that are set up for meeting participants to receive key information for the meeting via these password protected portals. Sometimes even the password protected elements, and account creation forms for these websites are not accessible.

More importantly, the documents added to the website are frequently not accessible. The lack of access to documentation – for a variety of reasons, is a major barrier to persons with disabilities participation in these democratic discussion and decision-making processes.

Adding to initial results discussed above for conference invitations and registration information, one area in which U.N. conferences seemed to be particularly deficient is providing accessibility features for people with visual impairments. In particular, according to survey respondents screen reader accessible conference material was provided only in 37.98% of cases, braille material in just under a quarter of conferences (24.4%) and the vast majority of conference websites (79.31%) could not be easily accessed using a screen reader (Figure 7).

In open questions, respondents clarified that various foundations and other organizations, including The Nippon Foundation, provided accessible documents to participants in need. However, they also noted that the U.N. itself did not universally provide these services. For example, one respondent explained that conference material was projected onto a large screen, yet found it difficult to see unless seated *directly* in front of the screen. Some respondents acknowledged attempts made by the U.N. to provide accessible background information but pointed out also that these attempts did not address all types of disabilities equally. In addition, these services were not consistent at every conference or working session meeting. It is likely that this inconsistency has a substantial effect on the participation and engagement of persons with disabilities at U.N. conferences.

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.

### ***Drafting Language***

Many participants in the interviews involved in U.N. conferences, stressed the importance of paying close attention to the drafting of text of a document, highlighting that written language captures the spirit of what is being discussed or negotiated at the conference.

An example of this is found in the Sendai Framework for Disaster Risk Reduction. Participants in the study noted the success of having persons with disabilities engage in the World Conference on Disaster Risk Reduction at a high level, and continuously throughout the conference with presentation, and shaping the final language of the Framework. One participant indicated “We got all that we wanted into the Sendai Post framework and even more. I think it has been very successful. And it triggers further success.”

***“We got all that we wanted into the Sendai Post framework and even more. I think it has been very successful. And it triggers further success.”***

### ***Virtual Participation***

Despite accessibility barriers, survey respondents showed eagerness to be more engaged and participate more effectively in global governance, with a large majority stating that U.N. (83.87%) and non-U.N. (77%) international conferences, meetings and events were highly relevant to their work. As was briefly stated above, one way to enable more persons with disabilities and their organizations to become more involved in these processes is by boosting and expanding opportunities for remote participation.

Despite the benefits associated with remote participation – particularly its potential for offsetting significant financial and travel barriers for persons with disabilities – only 15.63% of those who said they participated in U.N. events were able to do so virtually compared to 84.38% who did it in person. Looking at non-U.N. conferences and events, the number of respondents who participated virtually via web conferencing tools was even smaller at only 3.77% compared to 96.23% who attended in person. These results indicate that there is great scope for expanding virtual participation efforts for persons with disabilities and their organizations in global governance events.

While the low levels of virtual participation could be ascribed to a variety of factors, including availability and affordability of technology, as well as cultural preferences when it comes to using technology to participate remotely, it is important to note that respondents stated that remote participation was available only at 6.9% of the U.N. conferences they had attended. This suggested that the provision of low cost opportunities for remote participation is far from routine at international conferences,

stressing the need for international institutions such as the U.N. and other conference organizers to provide this type of facilities on a regular basis.

### ***Type of Activity in Virtual Participation***

At U.N. conferences for which virtual participation was offered, survey respondents engaged in a good range of activities. In particular, 40% of those who participated in U.N. events remotely via web conferencing software 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 via text (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, however, the range of virtual participation activities was much 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 and potentially use as a model 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.

### ***Collaboration with Others at Conferences***

For many global governance meetings, they will take place every year, around the same time, and in most cases in the same location. For participants who are active in meetings, the regularity is helpful as organizations begin to pay attention to these meetings and organize their participation in them.

The “insider” nature of these meetings can present a barrier to some new persons becoming active in these processes. For those organizations operating as networks, it is important for them to circulate the agenda and relevant documents to their members, so that their members will be aware of the issues being discussed. This means understanding the specific issues being discussed and/or negotiated.

***“A lot of prejudice against persons with disabilities, so we are trying to show them that we have the convention and even if they don’t recognize themselves as persons with disabilities, it is not super-nice for them to say that persons with disabilities are not normal persons.”***

Also, these networked organizations try to facilitate the face-to-face participation of their member organizations. They look for opportunities for them to speak. They support their organizational members in terms of logistics and help them prepare their contributions, reports, or statements.

Participants from the interviews identified the factor that helped them influence the conference. One participant explicitly mentioned, “talking to people” as an important factor. Another mentioned being pleased when a person they had met the week before and discussed disability issues with; mentioned disability three times during their Conference interventions.

On the other hand, another interview participant shared a story of conference participants having “a lot of prejudice against persons with disabilities, so we are trying to show them that we have the convention and even if they don’t recognize themselves as persons with disabilities, it is not super-nice for them to say that persons with disabilities are not normal persons.”

### **3.d Collaboration and Post-Conference Follow Up**

#### ***Follow Up with Conference Organizers***

The activities after a conference are also critical, especially in terms of relationship building. Some interview participants indicated contacting the meeting organizers, and even those missions and organizations that were supporting alternative perspectives to clarify that the issues are not personal; but that the focus on these issues is critical. This includes sending letters to the missions to explain once again what the issues are and what is at stake. This is especially important for those missions that are seen to be supportive of the disability rights agenda.

#### ***Post-Conference Diplomacy***

Several participants in the interviews indicated the importance of working with government missions on a regular basis. In some cases, the missions are independent

from their governments. In some countries, these diplomatic postings are garnered through school certification processes, and not through government appointments. Meetings with senior officials such as ambassadors and staff can prove fruitful. Therefore, building relationships with people in these positions is crucial to remaining on the agenda at conferences in Geneva, New York, and Washington.

It's important that members of the government missions understand the CRPD and its standards. Through building those relationships, supplying the missions with information and staying involved, the missions understand disability issues and why disability rights are so important. The missions will then raise important issues.

Interestingly, one interview participant also highlighted how important it was to raise awareness amongst the disability community about the importance of meetings that might, at first, seem "tangential" to the disability rights movement. For example, in the World Conference on Disaster Risk Reduction, there was initially very little interest in much of the disability community about "disaster risk reduction or emergency." Of course, amongst those persons with disabilities or organizations that have experienced a disaster(s) themselves, they understood the importance, but one participant suggest that it was difficult to get disability organizations or organizations "that haven't gone through a disaster, they don't realize what could be the consequences for them not to be included" in discussions related to disaster risk reduction.

### ***Using a Two-Track Strategy***

The linkage between the international organizations and grassroots organizations is clear. This is what several participants alluded to as a "two-pronged approach" or "two-track strategy." As these issues are being negotiated at the international level, there is an important opportunity and need for grassroots organizations to make their views about the issues known to the negotiators, as well as the impact of their decisions.

So, the timing of the awareness raising and publicity campaigns is critical. Some interview participants indicated they had worked to develop "advocacy toolkits" for use in raising awareness at national and local levels, about issues being negotiated at the international level. Again, to reinforce the rationale of this strategy, the more aware national governments are about the impact of a particular position on an issue, the more likely they are to support that issue in the international negotiations.

### ***Becoming a Major Group***

One major issue addressed in this study the so-called "Major Groups" problem. Namely, this issue revolves around the fact that there are nine "major groups" within the U.N. system, identified coming out of the Rio Earth Summit. These major groups are given unique opportunities for participation in U.N. consultations and decision-making.

There is a growing momentum to add persons with disabilities as the 10th Major Group. Some critics would argue that persons with disabilities actually fit within each of these

nine existing groups, and as such do not warrant a separate category. However, as several participants indicated, each of these nine existing groups has their own agenda, that unfortunately, includes only very limited references to accessibility or persons with disabilities.

As it stands now, persons with disabilities and accessibility advocates must first negotiate with the leadership of these nine “major groups” if they want their issues to be included. For many opponents of the expansion of the major groups, disability issues are already covered by these existing groups. For example, they might say disability issues are covered by Women. Unfortunately, there are specific issues that women with disabilities face, that women without disabilities face to a lesser extent or do not face at all.

***“Persons with disabilities were quite invisible...and I think this invisibility really compromised advocacy for too long.”***

Unfortunately, this process reinforces the “invisibility” of persons with disabilities in the U.N. and broader global governance processes. As one participant noted, “Persons with disabilities were quite invisible...and I think this invisibility really compromised advocacy for too long.”

There are ways in which the current Major Groups system both facilitates and inhibits the participation of Persons with Disabilities. One participant suggested, “It’s a dignity issue...” regarding inclusiveness in negotiating cooperative agreements, and within the context of the CRPD, “...it shouldn’t be that way, we shouldn’t have to do that.” Many interview participants felt this was especially true within the context of the widespread adoption of the CRPD as the first human rights treaty of the twenty-first century and the fastest growing treaty in history.

Amongst the participants, of all stakeholder groupings, there is unanimity that persons with disabilities should be added as the 10th Major Group within the U.N. System. There are mixed perspectives on how that should be done, and varying degrees of optimism that it will be done.

## **4. Recommendations**

With more than a billion people living in the world with some form of disability, including persons with disabilities and Disabled Persons Organizations in global governance processes is critical. Their expertise and knowledge is valuable to informing policy in the disability community and the world at large. The impact of DPOs on international decision-making processes has been limited. However, there is tremendous potential for an organized, coherent international disability movement. Support for this process is critical.

Here are some recommended solutions to allow persons with disabilities to fully engage in the political process.

#### **4.a Pre-Conference Accessibility and Capacity Building**

It is critical that the correct preparations be made in advance of international UN conferences to ensure greater inclusion. This includes practical measures like requiring an accessible format for all website materials, as well as more far-reaching recommendations such as staff training and the allocation of additional funding to support the participation of persons with disabilities.

- Diplomatic training should be available to those persons with disabilities interested in being more effective in international UN conferences, meetings and events.
- Additional funding should be identified and provided to enable national and grassroots persons with disabilities and their organizations to participate in UN conferences, meetings, and events.
- Non-state Infrastructure for DPOs and Persons with Disabilities representation in both Geneva and New York should be strengthened. Geneva has strong DPO network institutions, but these are severely lacking in New York, and are perhaps more important to be there.
- ECOSOC accreditation should not be used as a political barrier for some organizations wishing to participate in UN conferences, meetings and events.
- Websites and public information for meetings should be reviewed and tested to be as accessible as possible for all types of disability issues; this is true even for intranets or extranets where meeting participants will be given access to information via these password-protected portals.
- Documents added to UN websites should be in accessible formats, and in screen readable formats. (Recognizing that this is challenging, because many submissions come in from external organizations, and making all those submissions accessible can be a challenge).
- There should be a requirement that any party (states or non-states) that submit any documentation to the UN, must do so in an accessible format or it will not be accepted and posted.
- There should also be basic training of the staff at the UN and within the missions (and other organizations) in making documents accessible using Word and PowerPoint.
- Following the practice adopted at WCDRR, a team should be identified and contracted with (such as the ATDO – Assistive Technology Development

Organization) to ensure the accessibility of all major documents related to the substance of the conference.

#### **4.b Conference Accessibility**

The bulk of recommendations are made to improve the accessibility of international U.N. conference sites and their host cities. The recommendations include but are not limited to including closed captioning and sign language interpretation during U.N. conferences, meetings, and events, improving physical accessibility and signage at U.N. buildings, and training on-site security to be more sensitive and aware to the needs of persons with disabilities.

- The U.N. should recognize that with the CRPD in place, and specifically Article 9 on Accessibility, there should be a shift in mindset, towards one focus on inclusion and active participation of as many excluded groups as possible. This should be an urgent U.N. priority.
- Accessibility considerations for meetings should not be an option, and up to the conference or meeting organizer, or the chair of a meeting or session. These accessibility considerations need to be standard for every meeting. Accessibility requirements should also be written into every host-country agreement, when a country agrees to host a UN meeting of any type.
- In recognition of the fact that financial barriers are the number one reason that prevent DPOs – particularly those from developing countries – from participating in U.N. conferences, meetings, and events, the availability of accessible webconferencing participation should be extended to all meetings. To be effective, remote participation must go beyond the capacity of live streaming the event online and enable virtual participants to present and ask questions. Recent U.N. conferences that supported remote participation through accessible webconferencing tools and constitute useful examples include the Sendai Sendai WCDRR, the Habitat III conference in Quito (2016), and Global Platform 2017 in Cancun, Mexico.
- Meeting organizers should take note of issues that make it difficult for some persons with disabilities to participate in meetings; such as strong perfumes, distracting loud noises, or temperature (rooms should generally be colder than normal to support persons with cerebral palsy).
- Closed captioning – in multiple languages if possible – should be available at all U.N. conferences, meetings and events.
- Sign language interpretation (in ISL and/or multiple languages if possible), should also be standard for all U.N. conferences, meetings and events, and this sign language interpretation should be recorded and made available along with any audio or video archive.

- For all live streamed events, closed captioning and where possible sign language interpretation should be included simultaneously.
- Physical accessibility to U.N. buildings, meetings rooms, break-out rooms and other facilities should be of the highest priority – especially at the New York headquarters and in Geneva. The U.N. should be a model, in as many ways as possible, in implementation of the CRPD.
- But in addition to the access to the rooms, there should be accessible access to the meeting processes, such as requesting permission to take the floor and then speaking into the microphone.
- Signage in U.N. buildings is also either missing, inaccurate, confusing or inaccessible. Additional attention should be paid to making signage as clear and accessible as possible.
- Changes in meeting venue should be considerate of the impact that change will have on persons who are mobility impaired.
- Furniture in buildings should be movable to accommodate space for persons who are wheelchair users or otherwise mobility impaired.
- Great care should be taken to ensure persons with disabilities are seated according to their needs. For example, having captioning or sign language interpretation, but not having persons needing those accommodations seated near them misses the point.
- In New York, pre-screen wheelchair users so they may be given access to the accessible second floor (member states) entrance. While this happens at the COSP for CRPD, it does not happen for other meetings. And even for the COSP, while wheelchair users may use the second floor; their assistants may not – causing them to be separated.
- The U.N. Accessibility Center needs to be re-imagined, in order to be more helpful to actual users.
- Geneva buses to and from the airport and the U.N. buildings have high levels of accessibility, but outside that route, they do not.
- Taxis in Geneva in general to not seem to be willing to take wheelchair users.
- Additional security needs to be placed at Gare de Cornavin the train station in Geneva to help protect persons with disabilities who are arriving to Geneva by train, and who have been targeted for pickpocketing, theft and other crimes.

- In addition to security, having trained and uniformed staff/volunteers/ushers to help arriving participants who are blind, deaf, or mobility impaired would be very helpful.
- Options for accessible transportation need to be made available to all meeting participants, and they should not have to rely only on the DPOs and networks to find that information.
- U.N. Security in New York needs to be trained to be much more sensitive to and aware of the needs of persons with disabilities. Even being “friendlier” could be helpful, as this screening process can be particularly stressful for meeting participants with disabilities.

#### **4.c Collaboration and Post-Conference Follow Up**

The final recommendations underpin the importance of post-conference action as a means of continued inclusion and an opportunity for future development.

- The U.N. should follow the practice adopted at Sendai WCDRR and survey the participants afterwards to highlight their experiences with accessibility.
- U.N. buildings are huge, and can be exhausting for persons with mobility impairments.
- The international disability community, including donors, advocacy organizations, Disabled Persons Organizations, research organizations, networks, et al, should work together to forge a comprehensive and effective platform for monitoring and implementation of the CRPD and broader global disability rights and policy.
- In addition, the organizations above should work together to develop human capacity for effective engagement in global governance for a larger number, and broader range, of persons with disabilities. This capacity building should include formal academic training (master’s degree programs) and informal capacity building and a substantial focus on skills development (including: cross cultural/intercultural communication, negotiation, conference diplomacy, networking, global regional and national disability policy).

### **5. Recent Developments and Future Research**

The methodology for this report covered a multi-year period. Over that period, some progress has been made in addressing these issues. Nonetheless, all the issues covered in this report still obtain for the vast majority of U.N. conferences meetings and events. As an example, at the most recent United Nations Internet Governance Forum (IGF), held 12-14 November 2018 at the United Nations Educational Scientific and Cultural Organization (UNESCO) in Paris, France, there were tremendous accessibility challenges faced by members of the Dynamic Coalition on Accessibility and Disability

(DCAD). This group issued a report to the Multistakeholder Advisory Group (MAG) that organizes the IGF documenting these challenges, which were along many of the same social, political, economic, and technological components reported here. However, in closing this report, we want to highlight some of the progress that has been made and discuss briefly our plans for integrating those developments into our future research agenda.

There are two areas in which notable progress has been made in enhancing access for persons with disabilities to global governance. The first area is in the overall convergence of disability-inclusive development language in international policy frameworks. The second area is in the increased engagement of transnational advocacy networks of disability advocacy experts engaged in these interrelated policy domains.

Globally, the Sustainable Development Goals (SDGs) have helped to align the activities of governments, international development organizations, and international organizations. There are eleven references to persons with disabilities in the SDGs, and the UN General Assembly Resolution authorizing the High-Level Political Forum on Sustainable Development makes specific references to the inclusion of persons with disabilities.

16. *Encourages* the major groups identified in Agenda 21 and other stakeholders, such as private philanthropic organizations, educational and academic entities, **persons with disabilities**, volunteer groups and other stakeholders active in areas related to sustainable development to autonomously establish and maintain effective coordination mechanisms for participation in the high-level political forum and for actions derived from that participation at the global, regional and national levels, in a way that ensures effective, broad and balanced participation by region and by type of organization (UNGA, A/RES/67/290). (italics in original, bold added here)

The International Development Alliance (IDA), amongst other persons with disabilities organizations and networks, helped to create the Coordination Mechanism for the Major Groups and Other Stakeholders (MGoS) engaged in the High-Level Political Forum (HLPF) and serves as its founding co-chair representing the “Other Stakeholders” outside the Major Groups Framework (<https://sustainabledevelopment.un.org/mgos>). For many activists, the inclusion of persons with disabilities in the HLPF MGoS Coordination Mechanism obviates the need for any broader reform in the Major Groups Framework discussed in this report.

In addition, IDA has recently enhanced its support for its CRPD Forum (<http://www.internationaldisabilityalliance.org/ida-crpd-forum-listserv>). This listserv claims to be “the largest interactive online community dedicated to the implementation of the Un Convention on the Rights of Persons with Disabilities (CRPD), and the inclusion and promotion of the rights of persons with disabilities.” The IDA CRPD helps to coordinate the participation of organizations around the world focused on persons with disabilities in various processes and activities related to the CRPD, including the International Day for

Persons with Disabilities and the annual Conference of States Parties (COSP) held at U.N. Headquarters. Since the CRPD is both a human rights treaty and a major development instrument, the active engagement for persons with disabilities in all of its processes is critical.

Also, the various global processes related to accessibility in cities, such as the *New Urban Agenda* (NUA) that emerged out of Habitat III and the World Urban Forum (WUF) processes focused on implementation of the NUA, have facilitated the active involvement of persons with disabilities. In the processes leading up to Habitat III, the UN Department of Economic and Social Affairs (DESA) helped form the Disability Inclusive and Accessible Urban Development (DIAUD) Network, supported by World Enabled, the Institute on Disability and Public Policy (IDPP) at American University, and other organizations. The DIAUD Network helped to increase references to persons with disabilities in the NUA from five (5) when it was first involved to fifteen (15) in the adopted version, including a stand-alone paragraph.

36. We commit ourselves to promoting appropriate measures in cities and human settlements that facilitate **access for persons with disabilities**, on an equal basis with others, to the physical environment of cities, in particular to public spaces, public transport, housing, education and health facilities, public information and communication (including information and communications technologies and systems) and other facilities and services open or provided to the public, in both urban and rural areas. (italics and bold added here)

Since this time, the DIAUD Network has been actively engaged in supporting the implementation of the NUA, including promoting its awareness, rallying support from mayors and cities around the world, participating in the 9<sup>th</sup> World Urban Forum (WUF9), and the launch on 3 December 2018 in Berlin of the Cities4All Global Compact on Inclusive and Accessible Cities (<http://cities4all.barrierbreak.com>). The DIAUD Network is preparing for participation in WUF10.

Similarly, the Sendai Framework on Disaster Risk Reduction adopted at the Third World Conference on Disaster Risk Reduction has been the focus of a number of disability organizations working together in the Disability-Inclusive Disaster Risk Reduction Network (DIDRRN). This network engaged actively in the 2017 Global Platform on Disaster Risk Reduction (GP2017) in Cancun, Mexico, highlighting the importance of involving persons with disabilities, and older persons, in the implementation of the Sendai Framework, and reminding the participants of the Dhaka Declaration on Disability-Inclusive Disaster Risk Reduction. Following recommendations in this report, IDPP engaged extensively with GP2017, including the introduction of accessible webconferencing and telepresence robots for use by the global disability community (Cogburn, 2018). The DIDRRN is currently preparing for active participation in GP2019 in Geneva.

Finally, the ten-year review of the World Summit on the Information Society (WSIS+10) highlighted the ongoing importance of the use of information and communication

technologies (ICTs) to support the inclusion of persons with disabilities and their social and economic development. The work of G3ICT (the Global Initiative for Inclusive Information and Communication Technologies), which emerged out of the UN Global Alliance on ICTs and Development, was highlighted in this regard. Also highlighted was the importance of the annual UN Internet Governance Forum (IGF). At IGF, the Dynamic Coalition on Accessibility and Disability (DCAD) has been actively engaged in trying to raise issues related to accessibility in disability policy, but also in trying to make the IGF itself more accessible. Even with the recent accessibility problems at the 13<sup>th</sup> IGF in Paris, the DCAD has helped to create much broader awareness about accessibility and the needs of persons with disabilities within the Internet Governance space. In fact, at the IGF in Paris, the Association for Progressive Communications (APC), a well-known, and highly organized, global policy and advocacy network, dedicated its annual “Disco TECH” to accessibility for the more than 1 billion persons with disabilities in the world.

These are all exciting recent developments in the movement towards accessible global governance. They are driving some of our current research on mapping and evaluating the efficacy of transnational advocacy networks active in the international disability policy and advocacy space. This research will be aligned with the previous work on transnational advocacy networks in the information society (Cogburn, 2017).

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