

Accessibility in Global Governance: The (In)visibility of Persons with Disabilities

Final Report from Phase 1 of a Mixed Methods Analysis of the Participation of Persons with Disabilities in the United Nations System and Broader Global Governance Processes

Findings – Phase I (Interviews)

Derrick L. Cogburn, PhD
Institute on Disability and Public Policy
School of International Service
American University

1 April 2016

<http://idppglobal.org/>

Accessibility in Global Governance: The (In)visibility of Persons with Disabilities

**Final Report from Phase I of a Mixed Methods Analysis of the Participation of
Persons with Disabilities in the UN System and Broader Global Governance Processes**

Findings – Phase I (Interviews)

Derrick L. Cogburn, PhD

Institute on Disability and Public Policy

School of International Service

American University

This report was prepared as a contribution to the 8th Conference of States Parties to the UN Convention on the Rights of Persons with Disabilities, 9-11 June 2015. Its contents are from the perspective of the author and do not necessarily represent the views of American University, the Institute on Disability and Public Policy, or The Nippon Foundation.

Copyright © 2016 by Derrick L. Cogburn

The opinions expressed in this publication are those of the author and does not necessarily reflect the views of the Institute on Disability and Public Policy, the American University, or The Nippon Foundation.



This work is licensed under a Creative Commons Attribution – Non-Commercial – No Derivatives License. To view this license, visit (<http://creativecommons.org/licenses/by-nc-nd/4.0/>). For re-use or distribution, please include this copyright notice.

<http://idppglobal.org/>

Table of Contents

- v. About the Institute on Disability and Public Policy
- vi. About American University
- vii. About The Nippon Foundation
- viii. About the Author
- viii. Acknowledgements
- ix. Abstract
- x. Executive Summary
- 1. Introduction
- 1. Conceptual Framework
- 3. Purpose
- 3. Research Questions
- 4. Study Methodology and Timeline
- 5. Structure of the Report
- 5. Overview of Participants
- 9. Participation v. “Effective” Participation
- 14. Socio-Technical Factors Inhibiting Participation of Persons with Disabilities
- 17. Socio-Technical Factors Facilitating Participation of Persons with Disabilities
- 19. Major Groups Issue(s)
- 21. Post-2015 Development Agenda
- 22. Summary Recommendations
- 25. References

About the Institute on Disability and Public Policy

The Institute on Disability and Public Policy (IDPP) based at [American University](#) (AU) in Washington, D.C. prepares transformative disability policy leaders and serves as a collaborative "think tank" on disability policy through an interdisciplinary American University community and an unparalleled network of universities and outreach partners, with founding support from The Nippon Foundation.

The Institute on Disability and Public Policy contributes to the vision of an inclusive, barrier-free and rights-based global society. In line with the AU 2030 initiative on Global Disability Policy, Technology and Education, the IDPP at American University helps to facilitate collaborative interdisciplinary research, teaching and outreach programs through cross-campus partnerships. IDPP prepares transformative disability policy leaders and serve as a collaborative "Think Tank" on disability policy.

The major project of IDPP has been the development of IDPP for the ASEAN Region, which has built a pathbreaking network of 20 leading universities and 4 outreach partners since its establishment in April 2011 with the support of The Nippon Foundation. With a focus on the 10 countries of the Association of Southeast Asian Nations (ASEAN), IDPP for the ASEAN Region addresses a critical need to serve as a collaborative "think tank" on disability policy for the ASEAN region, and to develop a cadre of leaders who can impact disability policy toward an inclusive ASEAN community.

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 848 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. The total Fall 2014 student enrollment was 13,011, with 7,083 undergraduates, 3,447 graduate students, 1,585 law students, and 896 students in non-degree certificate programs.

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. Each college's and school's curriculum 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.

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 largely 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.”

About The Author

Dr. Derrick L. Cogburn is Associate Professor at the School of International Service at American University and Executive Director of the AU Institute on Disability and Public Policy (IDPP). His research and teaching includes: global information and communication technology and socio-economic development; multistakeholder institutional mechanisms for Internet governance; transnational policy networks and epistemic communities; and the socio-technical infrastructure for geographically distributed collaboration in knowledge work. Dr. Cogburn has published in major journals such as *Telecommunications Policy*, *International Studies Perspectives*, *Journal of International Affairs*, *Assistive Technology*, and *Information Technologies and International Development (ITID)*. He has published with and/or advised the Center for Strategic and International Studies (CSIS), United Nations World Institute for Development Economics Research, the World Bank, UNESCO, the International Telecommunication Union (ITU), and the United Nations Economic Commission for Africa (ECA). He has served as PI or co-PI on grants from sources as diverse as the National Science Foundation, US Department of Education, JP Morgan Chase, Microsoft Research, the W.K. Kellogg Foundation, and The Nippon Foundation. Dr. Cogburn directs the Center for Research on Collaboratories and Technology Enhanced Learning Communities (COTELCO), an award-winning social science research collaboratory investigating the social and technical factors that influence geographically distributed collaborative knowledge work, particularly between developed and developing countries. Dr. Cogburn is editor of the Palgrave Macmillian book series on *Information Technology and Global Governance*. He is past president of the Information Technology and Politics section of the American political Science Association, and past president of the International Communication section of the International Studies Association. He is a founding member and past Vice Chair of the Global Internet Governance Academic Network (GigaNet).

Acknowledgements

Dr. Cogburn would like to thank The Nippon Foundation for support of this research, and also offer thanks to the participants in the interviews, and the research team that supported the study. In particular, he would like to thank Ms. Maya Aguilar, for helping to lead many of the expert interviews. He would also like to thank his colleagues in the School of International Service at American University, and the partner institutions in the IDPP network in ASEAN.

Abstract

Accessibility in Global Governance: The (In)visibility of Persons with Disabilities

Final Report from Phase I of a Mixed Methods Analysis of the Participation of
Persons with Disabilities in the UN System and Broader Global Governance Processes

Findings – Phase I (Interviews)

Derrick L. Cogburn, PhD

Institute on Disability and Public Policy
School of International Service
American University

More than a billion people in the world live with some form of disability (WHO, 2011), meaning that nearly 15% of every national population in the world is likely to be a person with a disability. Many persons with disabilities organize their policy advocacy within Disabled Persons Organizations (DPOs), including their engagement with the United Nations system. However, even though the movement towards multistakeholder participation in global governance has opened up space for civil society involvement, it has not enabled persons with disabilities to participate fully in the UN system. DPOs have had substantial impact on the UN Convention on the Rights of Persons with Disabilities (CRPD) and the annual Conference of State Parties (COSP). Outside of the COSP, multiple factors limit the ability for persons with disabilities to participate in global governance processes. The purpose of this study is to provide empirical evidence of those factors and make recommendations to the UN for remedies. The methodology for the study is a three-phase, simultaneous mixed-methods design. It will include qualitative methods (i.e. interviews, focus groups, participant observation, and content analysis) and quantitative methods (i.e. surveys and social network analysis). Participants for all phases will be drawn from a stratified, purposive sample which will include: UN officials, government officials, leaders of disabled persons organizations and other civil society groups, selected to ensure representation across the UN System and to ensure regional and stakeholder balance. This paper presents the draft preliminary findings from Phase 1 of the study, the interviews.

Executive Summary

Accessibility in Global Governance: The (In)visibility of Persons with Disabilities

Final Report from Phase I of a Mixed Methods Analysis of the Participation of
Persons with Disabilities in the UN System and Broader Global Governance Processes

Findings – Phase I (Interviews)

Derrick L. Cogburn, PhD

Institute on Disability and Public Policy

School of International Service

American University

- **Major Groups Expansion.** All of the participants in the interviews believe persons with disabilities should be added to the Major Groups, if the Major Groups system continues (which is an open question for some participants). There are some differences of the legitimacy of the current Major Groups system, and some people feel like the Major Groups system is outdated and should be scrapped and that the UN system as a whole is ineffectual, but most think the Major Groups system should be expanded to include persons with disabilities as the 10th Major Group. 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.
- **Diplomacy Training.** Another important preliminary finding is the 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 does once they have this access is equally important. We recommend a sustained capacity building effort on this front.
- **Assessment and Recommendations for Accessibility.** UN meetings outside the COSP, or those explicitly related to disability, have a poor level of accessibility for Persons with Disabilities. Numerous recommendations are included in the preliminary report.

- **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.
- **Sensitization.** There should be system-wide sensitization exercises on International Day for Persons with Disabilities, to expose the Secretary-General and other senior UN leadership.
- **Conclusions.** In many ways the preceding points are intertwined. There is tremendous potential for an organized, coherent international disability movement, which recognizes and harnesses the power of grassroots organization and legitimacy, and international savvy and negotiation skills. Support for this process is critical, and could be very important to extracting as much as possible from the limited openings provided in the SDGs, and will be critical to gaining and using Major Groups status.

Summary Recommendations

Structure and Nature of the UN, and UN Conferences, Meetings and Events

- The UN 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 UN priority.
- Related to the above, the current UN “Major Groups” system needs to be revised to include persons with disabilities. With more than 1 billion persons in the world living with some form of disability, and the cross-cutting interests and implications for this community, they deserve a formal stake in the relationship of how cooperative agreements are negotiated, and should not be subject to a case-by-case basis for inclusion in UN discussions and decision-making.
- Substantive training in the CRPD and disability policy issues being discussed, as well as the broader international development issues, should be a high priority.
- 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.
- ECOSOC accreditation should not be used as a political barrier for some organizations wishing to participate in UN conferences, meetings and events.
- 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.

- 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.
- The UN should follow the practice adopted at Sendai WCDRR, in many ways, but in particular, it should survey the participants afterwards to highlight their experiences with accessibility.
- Sensitization of top officials of all UN buildings and organizations should do a simultaneous simulation exercises for multiple disabilities on the International Day for Persons with Disabilities.
- During the upcoming Summit to adopt the Sustainable Development Goals, there should be a formal general assembly resolution identifying the “stakeholders” to participation, and this should expand on the current “major groups” system, and explicitly include persons with disabilities.
- The facilities management unit of the system-wide UN should have an ongoing plan to focus on universal design within all UN building, and specifically on any new buildings.
- The UN needs more disability-friendly hiring practices and screening practices, that do not discriminate against persons with disabilities (i.e. asking about oral and written communication skills), including for interns, which is a major way for many people getting into the UN.
- There should be a system-wide evaluation process for each meeting, to try to assess the degree to which disability issues were included in the meeting, and to assess the degree of accessibility of the meeting, this could be coupled with setting up an advisory commission on these issues.
- Every UN employee should be required to take an online disability awareness course.

Information Accessibility at 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.
- Closed captioning – in multiple languages if possible – should be available at all UN conferences, meetings and events.
- Sign language interpretation (in ISL and/or multiple languages if possible), should also be standard for all UN 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.
- 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.

Physical Accessibility at UN Conferences, Meetings and Events

- Physical accessibility to UN 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 UN should be a model, in as many ways as possible, in implementation of the CRPD. For each of the UN buildings, there should be a formal accessibility audit, and a strategic plan developed to address the issues that audit uncovers. Developing partnerships with the private sector and
- 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, and being able to get onto the podium as a speaker.
- UN buildings are huge, and can be exhausting for persons with mobility impairments.
- Signage in UN 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 UN Accessibility Center needs to be re-imagined, in order to be more helpful to actual users.

- There is a need for additional physical accessibility in UN buildings, even with the recent renovations. The range of features should include; curb cuts, sidewalk markings with special tiles, braille, and auditory notifications.
- A program should be developed to identify and train volunteers or one participant called them “ushers” to support the participation of persons with disabilities (e.g. UN Accessibility Volunteers). The volunteers are particularly helpful as guides for meeting participants who are blind or visually impaired. These volunteers can help to orient participants to the meeting venue, and ensure that they get to their appropriate meeting on time.

Transportation Accessibility at UN Conferences, Meetings and Events

- Geneva buses to and from the airport and the UN buildings have high levels of accessibility, but outside that route, they do not.
- Taxis in Geneva in general do 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 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.
- UN 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.
- When a delegate registers for any UN conference, meeting or event, they should be prompted with information about accessibility options for transportation and housing in that particular location. This information should also be provided on the website for that specific meeting.

Disability Community Recommendations

- 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.
- There are numerous examples of collaboration within the disability community on which to build. The *Disability Caucus* that emerged during the Sendai World Conference on Disaster Risk Reduction (WCDDRR) is one potential model to consider, and there are others (even in other sectors such as Internet Governance, where this is a Dynamic Coalition on Accessibility and Disability (DCAD), which is multistakeholder).
- Regardless of the model, the “two-pronged” strategy of international negotiations, and national/local/grassroots activity remains critical to advancing the issues related to disability rights.
- As part of this process, the international disability community should do more to promote awareness about the opportunity and need for persons with disabilities to get more involved in UN conferences, meetings and events. This includes for those issues that are not seen initially as “disability issues.” This involvement is particularly important in the ongoing negotiations about the development of indicators for the Sustainable Development Goals (SDGs), which will continue to be negotiated well into 2016.

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 (masters 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).

Accessibility in Global Governance: The (In)visibility of Persons with Disabilities

**Final Report from Phase I of a Mixed Methods Analysis of the Participation of
Persons with Disabilities in the UN System and Broader Global Governance Processes**

Findings – Phase I (Interviews)

Derrick L. Cogburn, PhD
Institute on Disability and Public Policy
School of International Service
American University

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 population in the world 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, UN Secretary General Kofi Annan initiated a process to change the way non-state actors engage with the UN through the Cardoso Report. Even though the Report was criticized, it opened up space for civil society organizations to engage more fully with the UN system. In December 2001, this process of “multistakeholder participation” in the UN 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, or WSIS.

Conceptual Framework

This has been part of a broader movement towards multistakeholder participation in global governance and international decision-making processes. In this environment, non-state actors, and civil society organizations in particular, began 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 UN system. The impact of DPOs on international decision-making processes has been limited, with the notable exception of the negotiations around the UN 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. Outside of the COSP, there are multiple factors affecting the ability for persons with disabilities to participate in the UN system and broader global governance processes. Even within the ongoing processes to develop a Post-2015 Sustainable Development agenda, which are attempting to be as inclusive as possible, PWDs are not being treated with the same care and focus as the nine other “Major Groups” within civil society, which are: (1) Women; (2) Children and Youth; (3) Farmers; (4) Indigenous Peoples; (5) NGOs; (6) Trade Unions; (7) Local Authorities; (8) Science and Technology; and (9) Business and Industry (UNGA 47/191 and UNGA 66/288). See Figure 1.0 below.

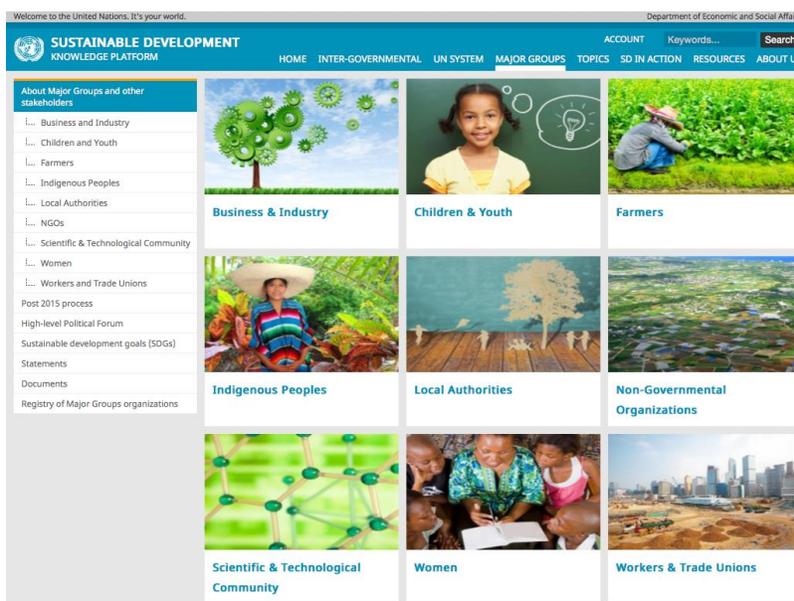


Figure 1.0 Current Major Groups and other Stakeholders within the UN System

This grouping is prima facie evidence of the exclusion of persons with disabilities from within the UN system. This is particularly striking, because “Agenda 21” adopted at the Earth Summit, recognizes that “achieving sustainable development would require the active participation of all sectors of society and all types of people” (Agenda 21, 2000). Nonetheless, the exclusion of persons with disabilities from this processes designed as “the main channels through which broad participation would be facilitated in UN activities related to sustainable development” (Agenda 21, 2000) means that they are not being treated the same way as the other Major Groups in the Post-2015 process.

Formally excluding Persons with Disabilities is a major oversight and presents a substantial challenge to the idea of broad-based multistakeholder global governance. As Cogburn (2005) argued, international policy formulation processes are quite complex. For example, in just one issue area, information and communications policy, “at least ten different intergovernmental and international organisations are involved centrally in these policy

processes, including the WTO, ICANN, ITU, OECD, GIIC, GBDe, World Intellectual Property Organisation (WIPO), International Labour Organisation (ILO), Group of Eight industrialised countries (G8), and even the United Nations Education, Scientific and Cultural Organization (UNESCO) (Cogburn, 2005). One factor limiting the PWD influence in international decision-making may be the lack of formalized networks to both participate in and draw knowledge from during these international meetings. Most of these conferences required sustained activity, and substantial resources to have a substantial impact on the conference outcomes. For example, Cogburn (2005) identifies five key points of strategic influence on the international decision-making processes, where “contending epistemic communities are able to exert influence.” These five points are as follows:

1. Pre-conference activity and preparation;
2. During the conference itself;
3. Rule/Agreement formulation;
4. Post-Conference follow-up activities; and
5. Presence in key global cities.

Many developing countries, civil society organizations, and especially Disabled Persons Organizations (DPOs) find it difficult to impossible to maintain the sustained engagement with each of these strategic points of influence over time. As a result, their impact is after far less than they would wish. For persons with disabilities, issues related to physical and electronic accessibility such as conference documents, websites, social media and preparatory material not being accessible to screen reading software exacerbate these already difficult limitations. Other examples include, meeting sites and hotels being inaccessible to wheelchair users, and lack of closed captioning and/or sign language interpretation. Other related issues include how the meeting is framed, and overall how welcoming the meeting is to accommodating the needs of persons with disabilities (such as delayed speaking styles, and the need to speak via a sign language interpreter).

In some cases, such as the preparations for the Third UN World Conference on Disaster Risk Reduction and the Post-2015 Framework for Disaster Risk Reduction, the lack of explicit policies about the inclusion, involvement and support for PWDs has led to individual UN officials to make unilateral decisions about the degree to which they will, or will not, allow the conference to engage with PWDs. These decisions should not be left to “goodwill” or attitude of an individual official, but should be a matter of official policy.

Purpose

Given the size, scope, and poor economic condition of the PWD population around the world, and in most countries, it is inappropriate to exclude them from the focus required to make substantial progress in the Post-2015 Development Agenda. The purpose of this study is to better understand the social, political, economic, and technological factors that enhance and/or inhibit persons with disabilities from participating actively in the UN System and broader

global governance processes. This study should provide empirical evidence of the current participation of persons with disabilities within the UN System and help us understand what kinds of interventions might be required to enable persons with disabilities to participate equally in global governance and international decision-making. It should also provide an empirical basis to demonstrate the need for persons with disabilities as the 10th Major Group. Finally, it will explore the feasibility of the creation of a special organization similar to UNWOMEN within the UN System to redress this imbalance for persons with disabilities.

Research Questions

This study will focus on four “grand tour” research questions, and each will be supplemented by specific, operationalized research questions:

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

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

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

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

Study Methodology and Timeline

The methodology for the study is a multi-phase, sequential mixed-methods design. It will begin in Phase I with qualitative methods (i.e. interviews, focus groups, and content analysis), which will contribute to the final survey instrument design for phase two, which will focus on quantitative methods (i.e. surveys and social network analysis).

Phase I

The first phase of the study will focus on interviews with selected participants from within each target group. These interviews will be conducted both face-to-face and online. Within our highly structured interviews, we take a “critical incident” approach, and have the participants focus on their most recent UN conference. The results of our interviews will contribute to the development of the final survey instrument to be administered in Phase II. The interview protocol will focus on four key areas of meeting accessibility:

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);

5. As well as documenting the participation of Persons with Disabilities at these conferences.

We will also compare the status of PWDs to the current Major Groups within the UN System, and evaluate the regional UN disability policy frameworks (e.g. the UNESCAP Incheon Strategy to Make the Right Real for Persons with Disabilities in Asia and the Pacific) and the non-UN frameworks, such as the ASEAN Decade on the Rights of Persons with Disabilities.

In addition to our purposively selected sample, we will ask each interviewee for additional recommendations for whom we should interview (thus creating an additional snowball sample for the study). This snowball sample will also help contribute to developing the sampling frame for the second phase of the study, when we will conduct a large-scale web-based survey.

In addition to interviews, we will focus on conducting content analysis of the written policies at the UN system level, specialized agencies, regional organizations, and world conferences about the involvement of persons with disabilities. We will also engage in participant observation at selected UN events during the course of the project. This content analysis will be aided tremendously by our work on big data analytics and text mining, allowing us to go through voluminous amounts of UN conference documents, attendance lists, reports, transcripts, social media and other secondary data.

This first phase of the project will run from 1 March – 15 May. During this period, we will conduct as many interviews as possible from within our targeted groups.

Phase II

The second phase of the study will focus on administering a broad-based survey to assess the factors that have limited or enhanced persons with disabilities from participating in UN meetings. Our analysis of the interviews from Phase I, will help us to narrow down the questions, and provide more closed-ended responses for the survey instrument. We will use the American University web-based survey system, Qualtrics, to administer a survey to our selected group of multistakeholder respondents around the world (again, stratified by UN officials, government officials, DPO leaders, and civil society leaders). Included in the survey will be a series of items designed to collect data for one-mode social network analysis. During the 8th Session of the Conference of State Parties (COSP) to the CRPD meeting in 9-11 June 2015, we will convene a side event to discuss the preliminary findings of the first two stages of the project. This second phase of the project will begin on 9 March 2015, and last until 29 May 2015.

Phase III

In the final phase, we will convene a series of focus groups (both virtual and physical) to discuss the results of the project. We will also participate in a major event to discuss the findings of the report at an event to be held at the UN Summit for Adoption of the Post-2015 Development Agenda, 25-27 September 2015. In addition, we will also schedule a meeting with

the UN Secretary General's office to deliver the final version of the draft report, including recommendations, and explore multiple avenues for dissemination of the report including in published form and online.

Structure of the Report

The remainder of this report is structured to help the reader understand the richness of our data, and to become familiar with the draft preliminary findings. The next section presents an overview of participants. This should help the reader to understand the depth and breadth of expertise included in this report. Our study has promised confidentiality to our participants, so great care has been taken to preserve the anonymity of contributions. No names of individuals have been included, nor any information linking any particular comment to any particular organization or entities. However, we did not want to completely lose the authenticity of the voices included in the report. So, where possible, we have included the voice of participants as direct quotes, and indicated by quotation marks. However, we provide no citations to those quotations, nor even any pseudonyms – again in order to preserve confidentiality. For any discussion of this methodology, please contact the author directly (dcogburn@american.edu).

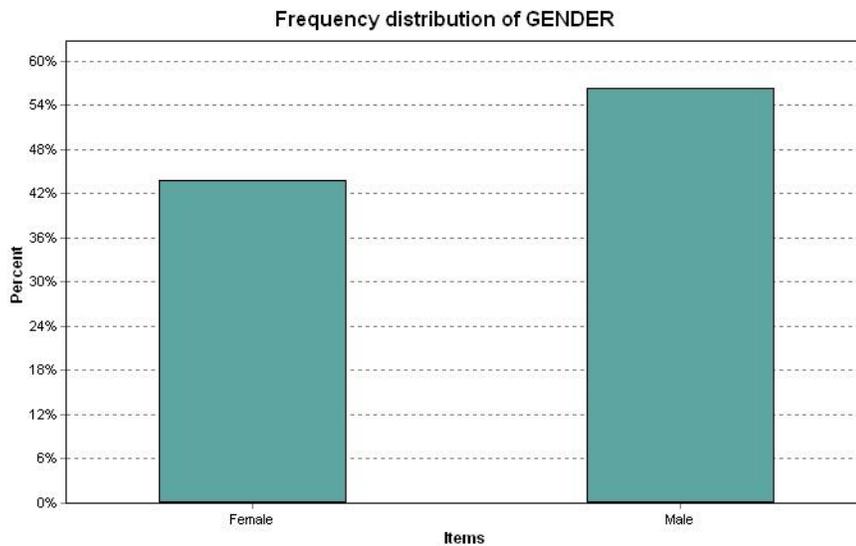
Overview of Participants

A stratified, purposive sample of participants was drawn for Phase I of the study, and it includes UN officials, government officials, leaders of disabled persons organizations and other civil society groups and subject-matter experts, selected to ensure representation across the UN System and to ensure regional and stakeholder balance. To date, we have conducted 15 interviews, which have 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

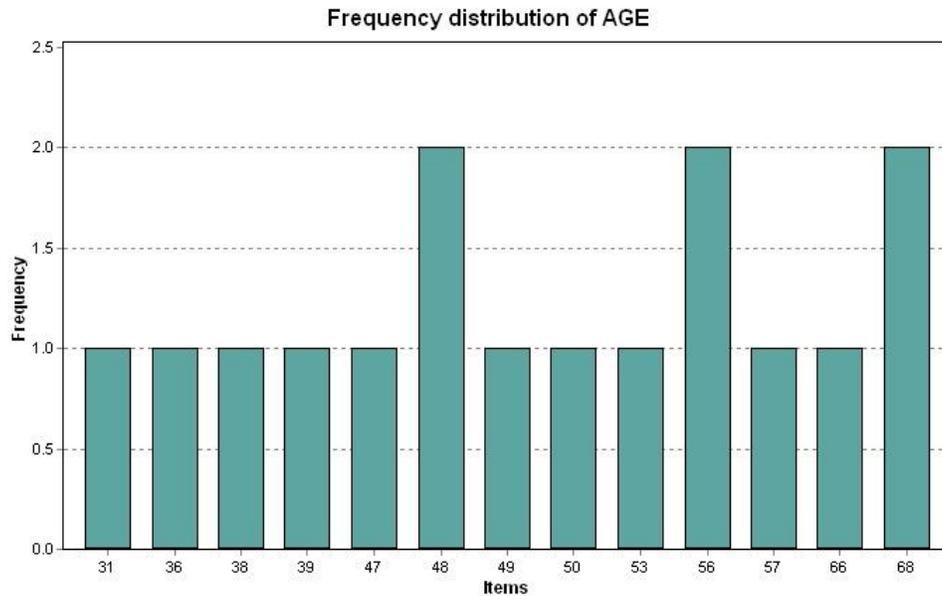
Gender

Within the current sample (N=16), a slight majority of participants (56%) are male (n=9).



Age

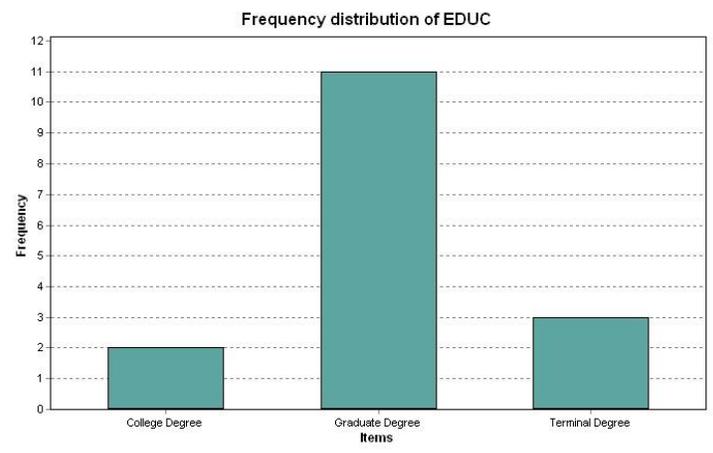
The age range for our sample is 31-68, with the mean age being 40.



Education

They have a high level of education, with most participants having one or more graduate degrees (n=11), and several with advanced degrees in law, and some having doctorates (n=3). The focus for their academic study includes law, diplomacy, development, disability studies,

human rights, communications, journalism, library and information science, political science, public policy, public administration, psychology, anthropology, public health, occupational therapy, engineering, and business administration.

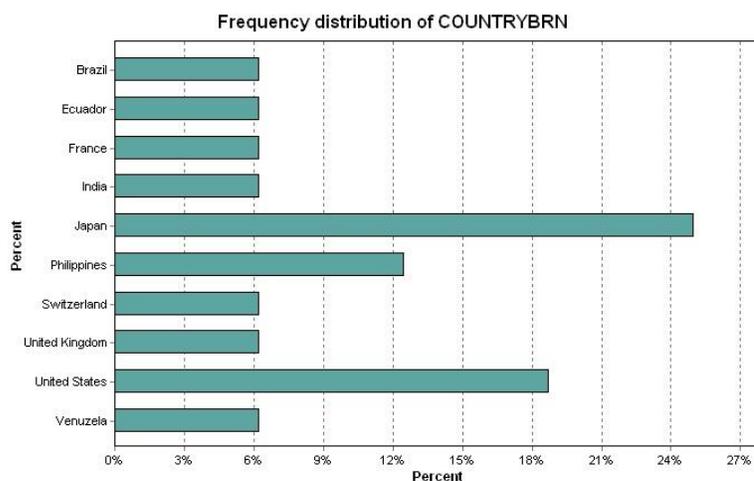


Experience

Many of the participants, who are leaders in the disability community, have held multiple leadership positions, including some with various aspects of the United Nations. Several participants have juggled multiple contracts simultaneously, and many have worn many “hats” simultaneously, thus representing various different organizations and interests at the same time.

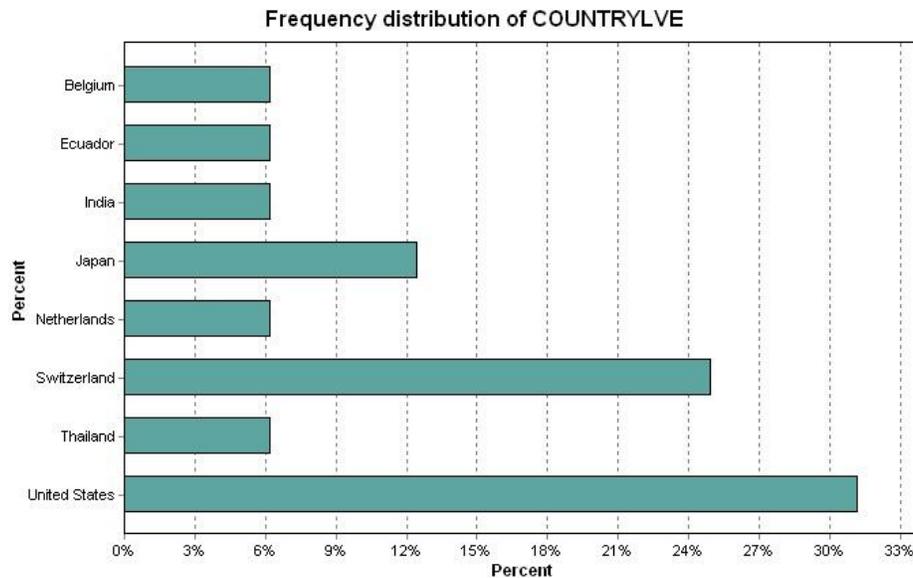
Nationality

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



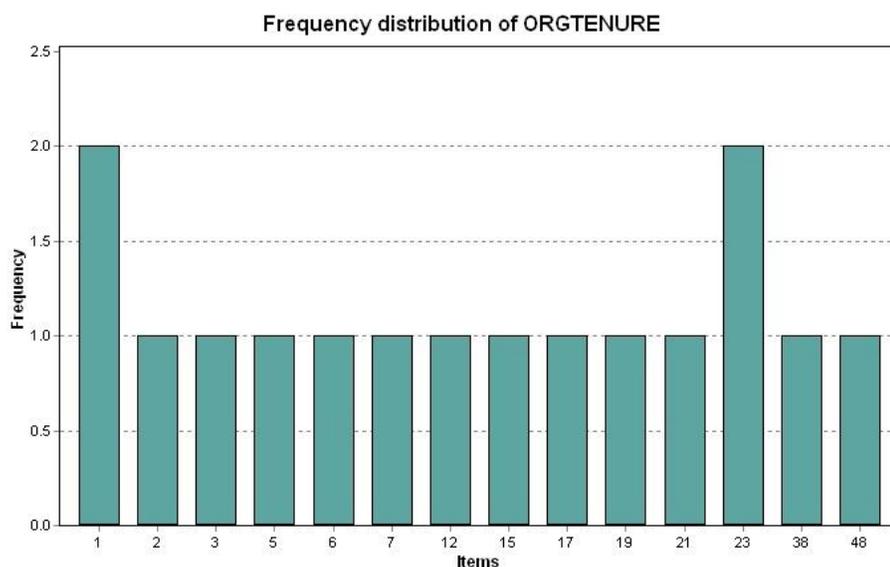
Currently Residing

Although our participants come from a wide variety of countries, they are heavily concentrated in the United States (New York, n=5) and Switzerland (Geneva, n=4), but also live in Belgium, Ecuador, India, Japan, the Netherlands, and Thailand.



Organizational Type and Tenure

Most of our participants are involved with Disabled Persons Organizations (DPOs), almost all of which focus on multiple disability issues. Many of the organizations are networks, or were formerly networks, with multiple members – mostly disabled persons organizations – participating in their work. Some have been with there only a short time, including only a few months; while others have been with their organization for two decades or more.



Disability Identity

Included amongst the participants are persons who are blind and visually impaired, deaf and hard of hearing, mobility impaired, as well as those who do not consider themselves as having a disability. All of the participants thus far, identify with the disability community, and in a wide variety of ways. 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 was more inclusive of persons with disabilities and empowering them to achieve their goals.

Participation v. “Effective” Participation

A common refrain amongst participants is that some meetings in both New York and Geneva – especially those focused on disability issues – have become more accessible in recent years. However, these meetings still have many accessibility deficits, and those UN conferences, meetings and events not focused on disability issues, have even further to go.

One of the key questions raised in this study is 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.

For many participants, the 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 UN responsible for living up to the spirit and letter of the Convention. When talking of meeting accessibility, some participants explicitly argued for the UN to meet its own standard for accessibility, as delineated in the CRPD.

One key issue is the degree to which the organizations work at the international and “diplomatic” level and those that work at the national and/or grassroots levels. Work at the international level includes promoting the CRPD and advocating with the UN 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 organizations interviewed work at both, but this is a key area separating the organizations.

Related to this issue is location. In the past, we have argued that there are “global nodal” cities in the policy making processes that contribute to global governance. Some of these global nodal cities are Geneva, New York, Washington, DC, and Paris. Having an active presence in one of these cities is seen as critical to being able to make a contribution to global governance processes, especially those related to the United Nations.

UN conferences, meetings and events are of various size and scope. Some of our participants have engaged in follow-up meetings to the Beijing Conference on Women (Beijing plus 20) while others have participated in unique UN conferences, such as the World Summit on the Information Society (WSIS).

It is also important to differentiate between the types of meetings, such as those involving state negotiations (where non-state actors are mostly observers, at best) to others that have a more “multistakeholder” nature, where non-state actors can operate more as partners, or at least have more opportunities for interaction.

It is also important for DPOs to work together collaboratively, and in advocacy networks. However, it is also important that they stay connected with knowledge production (either conducting research themselves or working in alliance with research organizations).

Pre-Conference Preparation

Knowing the Agenda, Issues and Speakers

Another critical factor in effective participation in a UN meeting is knowing what is on the agenda, what are the substantive issues that will be discussed, and doing the background research to understand them and formulate perspectives or positions on those issues. Also, knowing who the speakers are – and if you know any of them – and what their background is like.

One thing to keep in mind is that for the meetings of member states, especially when negotiations are taking place, formally, non-state actors are playing a limited observational role. Each organization should be clear about their support or lack of support for issues that are being negotiated in the meeting (and the reasons for that support or objection). The skill at being able to produce and distribute a policy paper that outlines the organization’s (or individual’s) perspective on the issue(s) being negotiated is critical.

Here, the linkage between the international organizations and the national 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 the 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.

In a somewhat related area, it is important for participants in these processes to understand how UN “language” is written and gets negotiated. For example, understanding what it means to have a document with [bracketed text] and understanding the implications of those structural devices, is critical. One aspect of this development is the need for persons with disabilities and related advocacy organizations to get included in drafting committees during prepcoms and negotiations. These selections are often highly political and social in nature, with the chairs of meetings selecting the drafting committee participants.

Preparing Informational Materials

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 UN conference, meeting or event. For example, in advance of the Sendai World Conference on Disaster Risk Reduction, several 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.

Interestingly, one 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 done 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.

Meeting with Missions

Several participants 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. So, getting to know the missions and their staff is critical to “getting things done” in Geneva, New York, and Washington. In these instances, members of the government mission may have their own perspective about certain policy issues. So, it is critical for these missions to understand the CRPD, and its standards. Helping the missions to understand disability issues and disability rights is a critical step. Then, being able to rely on these missions to raise important issues is a critical next step. So making sure they have information to support their perspectives in support of disability rights and issues is a

critical strategy. Also, working with the regional groupings (such as GRULAC) to ensure they understand the issues as well, is another important strategy.

Another critical point here is that these meetings should not be limited to the senior persons, such as the ambassador only. In fact, the staff can be as important if not more important than the principal; because if the staff is not willing to support an issue, they will not push for it with the principal.

Working with Conference Chair and Co-Chair Countries

One variation on the theme of working with missions and government officials, is the need to work closely with the representatives of the countries chosen as chair and co-chair of the conference. For example, in the case of WDCRR Thailand and Norway were nominated as chairs. The country chairs of a UN conference have a great deal of influence over the substance of the conference and how it proceeds. The working relationship developed between the WDCRR chairs and the international disability community, helped to advance the cause of stronger integration of persons with disabilities into the process.

Participating in Preparatory Committee (PrepCom) Meetings

Another distinguishing factor for those participants who were influential in UN conferences, meetings and events was their knowledge of, and participation in, Preparatory Committee (PrepCom) meetings. Within most UN conferences, meetings and events, PrepComs are known as critical periods of conference diplomacy, preceding the actual conference. Much to the surprise of novices, most of the negotiation and final decisions for a major UN 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 get negotiated and agreed upon at the PrepComs. Also, in addition to the international or global PrepComs, there are usually regional PrepCom or even regional preparatory conferences, 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 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.

There are numerous examples of collaboration within the disability community on which to build. The *Disability Caucus* that emerged during the Sendai World Conference on Disaster Risk Reduction (WCDRR) is one potential model to consider, and there are others (even in other sectors such as Internet Governance, where this is a Dynamic Coalition on Accessibility and Disability (DCAD), which is multistakeholder). Some of the most active participants in the disability advocacy community were first exposed to international negotiations and global governance issues in the UN World Summit on the Information Society (WSIS). As one of the first truly multistakeholder UN conferences, WSIS provided an amazing training ground for many disability advocates, and other civil society leaders who were all subsequently involved in the UN GAID and the Internet Governance Forum.

During the Conference or Meeting

Negotiating and Drafting “Language”

During a UN conference or meetings, some participants are extremely busy, while others appear to be somewhat less engaged. For example, many participants in UN conferences pay particularly close attention to the drafting of text, written “language” to capture the spirit of what is being discussed or negotiated at any given time. This process is particularly intense during a Preparatory Committee meeting (PrepCom) for a UN Summit or Conference, where final outcome documents are being negotiated and agreed upon. For example, for Sendai, work on the Sendai Framework for Disaster Risk Reduction, 2015-2030, was of critical importance during the prepcoms and actual conference. Many participants noted the success in both having persons with disabilities engage in the WCDRR at a very high level, continuously throughout the conference, taking speaking slots and helping to craft the final language of the Framework, which has a high level of disability inclusion. One participant

indicated “We got all that we wanted into the Sendai Post ’15 framework and even more. I think it has been very successful. And it triggers further success.”

Social Media Use

Tweet at the event and taking notes. Some participants have to interpret for their colleagues who are deaf (thus taking away from their own participation in the meeting).

Another interesting finding of the interviews, is the importance of stamina during a long United Nations meeting. Getting sufficient rest, and being able to stay fresh and engaging with the issues and participants is more difficult than it may sound. Not only is this rest/stamina important for keeping share and engaging with the issues, but to ensure that one remains patient and respectful of other meeting participants. Many times, conference participants, especially those drafting documents or summarizing daily debates and discussions, will have to work through the night to prepare a draft text for discussion the next day. Exhaustion can cause participants to make mistakes, sometimes costly ones.

Another related issue is that the effective participant needs to know the CRPD very well, so that all the issues being discussed can be weighed against the spirit and letter of the convention. You have to be able to respond if something is not in line with the Convention, and to be as specific as possible.

Post-Conference and Meeting Follow-Up

The activities after a conference are also critical, especially in terms of relationship building. Some 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.

Other participants indicated that they generally write a blog post after the event.

Again, the two-stage process requires some of the networked organizations to also keep their members and grassroots organizations informed about what happened during the meeting, and what are the next steps. Social media can play a role in this information sharing, and many of our participants indicated having an active social media presence.

Presence in Global Nodal Cities

Two-Track “Boomerang” Process

Keck and Sikkink (1998) talked about a boomerang process, where local NGOs could work with international NGOs and transnational advocacy networks to get issues “raised” in

their own country – by international actors – which they themselves might have been unable to raise.

In this instance, there is another form of “boomerang” that is occurring, which is more of a two –stage process. The physical presence in a global nodal city, allows a networked organization to position itself with critical stakeholders in that city (e.g. New York, Geneva, or Washington, D.C.). They can use this location to raise issues from the grassroots, to convey their concerns, or to bring them directly into the process. However, they have a simultaneous responsibility to convey information to persons on the ground, to keep them informed of what is happening during the negotiations. One participant called this a “two-track” approach.

This is a delicate dance, and one that is not always performed to perfection. Ignoring either of these dual responsibilities can present tremendous challenges to the network.

Conference Influence

Many participants tried to identify the factors that aided in their influence at the conference. One participant explicitly mentioned, “talking to people”. Saying, everything is connected, so they were pleased when a person they had met the week before and spoke to about disability issues; mentioned disability three times during their Conference interventions.

Socio-Technical Factors *Inhibiting* Participation of Persons with Disabilities

Some participants see the regular interaction with UN organizations and mission officials from member states as a critical element of their participation in the UN system. This regular interaction is facilitated by their physical location and their geographic proximity to these key players (again, in one of the global nodal cities of New York, Geneva, Washington, D.C., or Paris. They recognize that an important component of this process is relationship building. It is much more difficult for someone that is not regularly based on one of these global nodal cities to build these relationships. The organizations that are based in these global nodal cities can play an important role in facilitating these relationships, but there is that overarching limitation. Serving in the role of negotiating on behalf of other DPOs requires some of the participants to work hard to “co-organize” events with them, and to involve the organizations not-based in one of these global nodal cities to stay engaged with them.

In many cases, lessons for accessibility can be learned from non-UN international conferences. This is certainly not to say that all non-UN international conferences are more accessible than UN conferences; not at all. Participants gave numerous examples of problems with accessibility in non-UN international conferences. However, some non-UN international conferences stood out in terms of accessibility, namely the International Conference of Technology and Disability (known as the CSUN Conference, for its organizer, California State University Northridge) and the m-Enabling summit, organized by the Global Initiative for Inclusive Information and Communication Technologies (G3ICT).

Biases and Discrimination Against Persons with Disabilities

Many UN meeting participants have very strong biases against persons with disabilities, and bring these biases to discussions and negotiations where disability issues are being discussed. One participant shared a story where one group of meeting participants had “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...”.

ECOSOC Accreditation

While many of the participants in our study worked for organizations that were ECOSOC accredited, many felt that ECOSOC accreditation should not be used as a political barrier to keep persons with disabilities and their organizations out of participation in UN conferences, meetings and events.

Awareness of Opportunities to Engage

Some participants felt that many persons with disabilities, particularly in regional and rural areas in the global south, that they had opportunities to be engaged in UN activities. However, for some of these organizations, this lack of awareness allows them to continue playing a brokering role in New York and Geneva, rather than having those groups represent themselves.

In-Accessibility at UN Conferences and Meetings

Information

Despite the efforts of many, several of the key conference websites, even those explicitly and tangentially focused on disability issues 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.

Even more important, the documents added to the website are frequently not accessible.

The lack of access to documentation – for a variety of reasons, the documents are either missing or non-accessible – is a major barrier to democratic participation in these discussion and decision-making processes.

Physical

Physical accessibility of UN buildings should be an even higher priority than it has become in recent years. The UN 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.

But 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.

Also, the physical environment of these meetings in Geneva and New York are huge. 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 UN 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 UN 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 the seats is very limited, making it difficult for a wheelchair user or mobility impaired person to access the meeting.

Transportation

Funding for participation in UN conferences, meetings and events is always a crucial factor. These global nodal cities are some of the most expensive in the world (New York,

Geneva, Washington, D.C., Paris) and yet, UN conferences, meetings, events, and their various Preparatory Committee (PrepCom) meetings can span multiple weeks, several times throughout the year. Active, and sustained participation in these meetings is very expensive.

In Geneva, from the Airport to the UN buildings the buses are very accessible, but this can give a false impression that all the transportation in the city is accessible. It is not. Taxis in particular are very bad in terms of accessibility. Many of the taxis in Geneva do not want to take persons using wheelchairs. There also appears to be some prejudice amongst some Swiss persons towards persons with disabilities.

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 (they can be staff or volunteers) to meet the participants with disabilities arriving at the train station.

Socio-Technical Factors *Facilitating* Participation of Persons with Disabilities

While the United Nations operates around the world, there are two major cities that are critical for access to UN Conferences, Meetings, and Events – New York and Geneva. Some of our participants were active in both locations, pushing for accessibility to UN buildings, conferences, meetings, and events. However, many organizations focus on one or the other.

In Geneva, UNOG (United Nations Office in Geneva) has a Task Force on Accessibility, and it is working to include accessibility to UNOG, including the United Nations High Commissioner for Human Rights, where all the meetings of the expert Committee on the Rights of Persons with Disabilities take place, as well as the Human Rights Council.

UNOG has a team for organizing everything related to conferences and meetings, and they have a team that focuses on trying to make the meetings as accessible as possible.

Funding and Financial Support

Financial support for disability rights issues is obviously an important element. There are of course numerous roles played by the private sector, and G3ICT was borne out of the UN Global Alliance on ICT and Development (GAID), an initiative designed primarily to get more private sector companies and leaders engaged in ICT 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, and others).

However, direct financial support to DPOs for participation in the UN and global governance processes tends to come from donor governments and private foundations. Our interview participants highlighted the governments of Japan (JICA), Norway, Australia (AusAid),

and the United States (USAID), and private foundations (The Nippon Foundation in particular and the Gates Foundation).

Meeting Information

Those participants who are active in meetings become aware of the regular schedule of these meetings. For many of these meetings, they will take place every year, around the same time, and in most cases in the same location. This 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 that are not aware of the annual agenda of these meetings, the public website of the organization does provide some overview information.

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.

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.

Some of the UN Agencies, such as the ITU, have started to focus very heavily on accessibility for their websites and conference documentation. ITU has a clear focus on WCAG accessibility. It has an accessibility policy. UN ESCAP 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 ATDO organization to do accessibility testing on all documents submitted.

Organizing Side-Events

Another way of trying to achieve organizational policy objectives is through the development of side-events.

Accessibility at UN Conferences and Meetings

There are a number of very positive elements that are starting to occur at UN conferences.

Information

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.

Finally, conference websites (including intranets and extranets) should be made accessible, including any account creation or registration processes. This accessibility needs to be tested and verified.

Physical

The recent renovation in the New York headquarters of the UN has helped physical accessibility to a certain extent. However, this renovation was not sufficient, and many physical accessibility issues were left unaddressed.

Transportation

In Geneva, transportation between the Airport and the UN buildings is very accessible, but most of the other lines are not, and the taxis are not open to providing transportation for wheelchair users.

However, in New York, there is a great deal of accessibility in the transportation system.

Major Groups Issue(s)

One major issues addressed in this study is that of the so-called “Major Groups” problem. Namely, this issue revolves around the fact that there are nine “major groups” within the UN system, identified coming out of the Rio Earth Summit. These major groups are given unique opportunities for participation in UN consultations and sometimes decision-making. The current major groups are as follows: (1) Women; (2) Children and Youth; (3) Farmers; (4) Indigenous Peoples; (5) NGOs; (6) Trade Unions; (7) Local Authorities; (8) Science and Technology; and (9) Business and Industry (UNGA 47/191 and UNGA 66/288).

Obviously, Persons with Disabilities are not listed as a separate Major Group, even though Persons with Disabilities represent more than 1 billion people in the world, and make up a substantial portion of nearly every country’s population. There are various perceptions about what makes these groups influential, including the substantial awareness about the plight of women around the world, as well as children. NGOs are also seen as influential, but for different reasons. Women’s groups are seen as having substantial “power” because they have a broad voice and representation, and have been able to get backing from Member States, and “children and youth are also a priority of Secretary-General Ban Ki-Moon” so that helps to increase their influence.

There are ways in which the current Major Groups system both facilitates and inhibits the participation of Persons with Disabilities. Within these groups, (1) Women are almost universally seen as the most influential, followed by (2) Children and Youth, (5) NGOs, and (9) Business and Industry. These four Major Groups, and most of the others have in the past been supportive of including disability issues within their contributions. Unfortunately, some of these groups have not been supportive of including disability issues, or as in the case of NGOs,

they are dealing with such a diverse constituency themselves, it is sometimes difficult to take on new issues. However, 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 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 UN System. There are mixed perspectives on the procedures for how that should be done, and varying degrees of optimism that it will be done.

Important of Support from the UN Secretary General

Having the support of the Secretary-General is seen as a tremendously important strategy. Several participants noted that if the Secretary-General takes an interest in one of your issues, “you will get a lot of support, because he mentions [that issue] every time he speaks.”

There is a growing momentum to add Persons with Disabilities as the 10th Major Group – that is, if the system stays in place at all. 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.

Unfortunately, this process reinforces the “invisibility” of Persons with Disabilities in the UN 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.”

Impact of Sendai WCDRR on Major Groups Issue

The Sendai World Conference on Disaster Risk Reduction (WCDRR) was seen in many ways as a turning point for the discussions around the Major Groups issue. Some participants noted that at Sendai, the disability community was treated in many ways as the “tenth” Major Group, where they “had the same representation as the nine major groups and you could really see the difference at the conference, because we were included in everything. There was no

problem”. Also, in contrast, “in New York, we have to fight all the time to get the same representation, and we just won a major success where we can actually submit a paper to the High-Level Political Forum [on Sustainable Development] as pretty much like a major group because were specifically mentioned in the High Level Political Forum Resolution and this was a lot of work and a lot of fighting but were trying to be added but its difficult. But I think we can get there and I think it will help the movement so much, the disability movement so much, for sure.”

Much of the credit for the active participation and integration of Persons with Disabilities into the Sendai WCDRR goes to The Nippon Foundation (TNF). The Nippon Foundation provided a grant to the UN ISDR in Geneva “to promote the inclusion and participation of people with disability in the consultation processes and the conference itself leading up to what became the Sendai Framework for Action.” Through this grant, specialists were contracted with the UN to work on accessibility for persons with disabilities at the WCDRR.

One of the key benefits of being added as the 10th Major Group would be that Persons with Disabilities would automatically get a seat at all the conferences. A speaking role would always be available as long as the structure of the conference allows civil society participation. This automatic role is in contrast to the status quo, where Disabled Persons Organizations have to “fight” for a role or slot within the existing Non-Governmental Organization slot (which itself already has so many different policy issues it is trying to address).

Some of the opposition to making Persons with Disabilities the 10th Major Group is the fear of “opening up the process” which could lead to so many other groups claiming they also deserve a seat (including aging, and volunteers) and that it will be “endless, and that we will have, you know, 20 Major Groups”. Other opponents feel the disability issue will be overwhelming, and will be too much to try to accomplish. Many state parties do not like to be held to standards they do not think they will be able to accomplish.

Nonetheless, the momentum in this direction is growing. However, there are some unanswered questions about the process for achieving this goal. Some Member States believe this addition of a 10th (or additional) Major Groups has to be legally adopted by Member States, while other Member States disagree.

Post-2015 Development Agenda

The culmination of many of these discussions is the status of disability issues in the Post-2015 Development Agenda. Following the failure to include disability issues in the original Millennium Development Goals (MDGs), and the subsequent adoption of the CRPD, there was substantial hope that the post-2015 development agenda would be more disability inclusive. This hope was accelerated as the General Assembly hosted the High-Level Meeting on Disability and Development in September 2014. Now that the Sustainable Development Goals (SDGs), the successor to the MDGs, are close to being finalized, with their corresponding goals and

indicators, there are differences of opinion and perspective about the degree of success in including disability issues into the SDGs and indicators.

Some participants see real progress. There is an Open Working Group on the Sustainable Development Goals. Within this Working Group, some participants noted that there are now nine (9) references to Persons with Disabilities, and while “its not perfect” they compared this to the very limited references to indigenous people, which only have two (2) references. So, this is seen as a relative success, especially given the size of the disability advocacy group. Some participants credited this to the disability community being very mobilized and energized. The hope is that these nine references will remain, and there can be additional inclusions for measuring the impact on persons with disabilities in the indicators for the SDGs.

Other participants see this as a failure of the international disability community. From this perspective, the mere mention of disability issues is not sufficient; but instead there needs to be concrete indicators and financing to support these disability-inclusive development goals.

In addition, a number of other participants mentioned the upcoming Financing for Development meeting being held in Addis Ababa as critical to putting more firm commitments to disability-inclusive development. These negotiations on financing will end in July. There is substantial hope that the SDs plusGs will be adopted at the United Nations Summit to Adopt the Post-2015 Development Agenda in September 2015. The indicators for the SDGs will continue to be negotiated until March 2016, so there is still time. One implication of these ongoing negotiations however, is that the international disability community needs to be represented at all the meetings of the UN Statistical Commission. Again, there is a capacity development issue here. Having sufficient representation from the international disability community, with the expertise to contribute to the development of indicators and metrics for the SDGs, is a challenge; especially when many would not see this necessarily as a “disability” issue.

Overall, in terms of strategy, one participant referenced the biggest problem being the human capacity to cover all of UN conferences, meetings, and events relevant to disability issues. One participant said of the many upcoming meetings,

“they’re all necessary, but it makes it a very difficult year so we have to be at all the negotiations, the financing for development, which is happening right now is another areas that I have a colleague very focused on. And then also the World Humanitarian Summit is happening so were’ involved in that and climate change. Unfortunately we don’t have the capacity but that’s another area we need to be involved in. It’s [all] happening [in] parallel”

Addressing this capacity building challenge is one of the biggest hurdles facing the international disability community. There is a broad sense that the international disability community does not have enough people, enough human resources, to address all the issues it

needs to address. The global mantra coming out of the CRPD negotiations was “Nothing About Us, Without Us.” In reality, the implications of this slogan are that far more persons with disabilities need to be equipped with the knowledge, skills, and abilities to participate effectively in global governance processes.

Also, is the issue that much of the post-2015 development agenda is being led by the “climate change organizations” and since Disabled Persons Organizations are not climate change organizations, per se, they are not getting the opportunities they need to speak to those issues. But, one participant said, “But I feel like we need to get in there somehow, and that’s something that we haven’t focused on enough as a lobbying group. We need to figure that out somehow.”

Again, the process followed in the Sendai WCDRR is seen as a model for other conferences to follow, in terms of involvement of persons with disabilities (almost as a 10th Major Group). Sendai is heavily influencing the development of the World Humanitarian Summit, scheduled for Istanbul, Turkey 26-27 May 2016. One key success factor identified out of Sendai was that the persons hired to run the conference, had experience both inside and outside the UN (working with NGOs and with numerous international organizations). So, in the words of one participant, “they underst[ood] both worlds.”

Summary Recommendations

Structure and Nature of UN Meetings

- The UN 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 UN priority.
- Substantive training in the CRPD and disability policy issues being discussed, as well as the broader international development issues, should be a high priority.
- 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.
- 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.

- 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).
- The UN should follow the practice adopted at Sendai WCDRR and survey the participants afterwards to highlight their experiences with accessibility.

Information Accessibility

- 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.
- Closed captioning – in multiple languages if possible – should be available at all UN conferences, meetings and events.
- Sign language interpretation (in ISL and/or multiple languages if possible), should also be standard for all UN 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.
- 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.

Physical Accessibility

- Physical accessibility to UN 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 UN 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.
- UN buildings are huge, and can be exhausting for persons with mobility impairments.
- Signage in UN 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 UN Accessibility Center needs to be re-imagined, in order to be more helpful to actual users.

Transportation Accessibility

- Geneva buses to and from the airport and the UN buildings have high levels of accessibility, but outside that route, they do not.
- Taxis in Geneva in general do 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.
- UN 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.

Community Recommendations

- 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 (masters 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).
-

References

1. UNGA 47/191
2. UNGA 66/288
3. WHO/World Bank, 2011
4. Cogburn, D.L., (2005) "Partners or Pawns? The Impact of Elite Decision-Making and Epistemic Communities in Global Information Policy on Developing Countries and Transnational Civil Society." *Knowledge, Technology & Politics*. Vol 18, # 2, Summer 2005, pp. 52-82.
5. Keck, M. and Sikkink, K. *Activists Beyond Borders: Advocacy Networks in International Politics*. Cornell University Press, 1998.