

High-level Political Forum 2018

SUBMISSION

On behalf of the

Stakeholder Group of Persons with Disabilities

Inclusive, Safe, Resilient and Sustainable Societies and Persons with Disabilities

Executive Summary

To truly make cities and human settlements inclusive, safe, resilient and sustainable, we must ensure that all people are included, diversity is celebrated, and all have support to live and be included in cities and human settlements. Resilience is essential for achieving sustainable development,¹ and to achieve this, the furthest behind must be meaningfully included, such as persons with disabilities. The 2030 Agenda for Sustainable Development embodies a commitment to include those furthest behind and to reduce their risks to economic, social and environmental shocks.² While the 2030 Agenda defines the Sustainable Development Goals (SDGs), it is the UN Convention on the Rights of Persons with Disabilities (CRPD) that outlines the rights of persons with disabilities, and if realized can achieve the SDGs for persons with disabilities.

Globally, persons with disabilities make up 15 percent of the world's population, 80 percent of whom lives in poverty. Nearly 36 percent of the global population lacks access to sanitation and 884 million people lack access to clean drinking water, which more often affects the poorest communities. Thus, approximately 177 million persons with disabilities are adversely affected and without access to clean water and sanitation.³ Additionally, more than half of all persons with disabilities lives in towns and cities that are rarely accessible, and this number is estimated to grow to between 750,000 and 1 billion by 2030.⁴ Linked to this, the global population of people forcibly displaced reached a record 66 million in 2016, with as many as 10 million being persons with disabilities.⁵

Due to barriers in accessing the built environment, information, and communication, persons with disabilities are denied access to basic urban services, including housing, roads, public spaces, transportation, sanitation and water, health, education, emergency and disaster response. Yet, it is

¹ United Nations Convention on the Rights of Persons with Disabilities, preamble.

² Transforming Our World: the 2030 Agenda for Sustainable Development, Goal 1.5

³ http://www.un.org/millenniumgoals/pdf/MDG_FS_7_EN.pdf (see World Health Organization and World Bank (2011) World Report on Disability. Geneva: WHO Press)

⁴ Utilizing 5 billion urban dwellers, we calculated that 15 to 20% of these would-be persons with disabilities. Our data sources were derived from: WHO and World Bank (2011). "World Report on Disability", WHO Press, Geneva, and "Urbanization | UNFPA - United Nations Population Fund", retrieved on September 16, 2016 from: <http://www.unfpa.org/urbanization>.

⁵ 2016 in Review TRENDS AT A GLANCE. <http://www.unhcr.org/5943e8a34.pdf>

generally feasible to meet accessibility requirements at one percent of the total cost. The reality is that retrofitting for accessibility is more expensive costing up to 20 percent of the original cost compared to integrating accessibility and universal design principles into new buildings.⁶ Furthermore, few supports and services exist to enable persons with disabilities and their families to realize their right to live and be included in the community. Where services exist, too often they continue to be segregated, medicalized and based on congregate care. Inclusive societies reflect the interdependence of our rights and that to be fully and meaningfully included, one must also have access to inclusive education, affordable housing, the right to make decisions, employment and other areas.

Inclusive, safe, sustainable and resilient societies cannot be defined only by bricks and mortar and inclusive societies are not defined only by physical access. Inclusive societies must be built on the principles secured in CRPD Article 3 by respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for differences and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities. To realize this inclusion for persons with disabilities, policy makers must be informed by collecting evidence-based data that are disaggregated by disability using the short set of questions developed by the Washington Group and by properly consulting persons with disabilities and their representative organizations on the design, implementation and monitoring of SDG plans.⁷

Chapter 1

Goals 6 and 7

Access to Water and Sanitation and Sustainable Energy for Persons with Disabilities

The majority of persons with disabilities and their families lives in poverty and faces a heightened risk of fuel poverty. Most persons with disabilities live in poor quality housing and encounter challenging decisions on how to spend money, for example, choosing between energy consumption and other basic needs, such as food. At the same time, very often persons with disabilities have additional living costs from having a disability, including essential extra fuel cost.⁸ Related, the groups most likely to experience particularly negative health impacts from fuel poverty include older persons, infants, persons

⁶ WHO and World Bank (2011): p.173

⁷ CRPD, Article 33 (3)

⁸ The Energy Penalty: disabled people and fuel poverty. Centre for Consumers and Essential Services University of Leicester June 2013. <https://www2.le.ac.uk/departments/law/research/cces/documents/the-energy-penalty-disability-and-fuel-poverty-pdf>

with disabilities and those living with long-term illness.⁹ In countries in which a disability living allowance is regarded as general income in calculation of fuel poverty, persons with disabilities entitled to the benefits are always considered better off, yet they require extra income to achieve a better standard of living similar to others.¹⁰ Additionally, access to electricity is important for persons with chronic illness who use medical equipment and persons with disabilities who use electrically-powered communication tools.

There is a direct relationship between the right to safe drinking water and sanitation and the right to adequate standards of living. This is inextricably related to the right to the highest attainable standard of physical and mental health, as well as the right to life and human dignity.¹¹ In most cases, persons with disabilities encounter physical, institutional, economic, social and/or cultural limitations in accessing water and sanitation. Additionally, globally infrastructure design around clean water and sanitation often is still developed without the participation of persons with disabilities and consideration of their rights, despite the existence of knowledge of what is needed in various settings.¹²

Inadequate water supply and sanitation facilities can seriously compromise the safety and dignity of women and girls with disabilities. Without sanitation facilities, women and girls with disabilities may be forced to wait until nightfall to relieve themselves in private, thus making them vulnerable to physical or sexual assault in secluded areas.¹³ Lack of clean water can also result in stigma and exclusion of persons with disabilities (e.g., people with spina bifida and spinal cord injury) because of incontinence issues that limits independent living, productivity and participation in their communities. Persons with disabilities with chronic medical conditions may need access to clean water for their daily care, such as Clean Intermittent Catheterisation for continence management, to prevent infections, which can lead to secondary health issues or even premature death. Persons with disabilities can encounter barriers including the physical distance to latrines or defecation areas, rough paths to latrines, narrow entrances and lack of space inside latrines, steps to latrines, slippery floors, and difficulty squatting with no hand rails.¹⁴

⁹ Hills J Professor (2012) Getting the measure of fuel poverty Final Report of the Fuel Poverty Review, Hills J, CASE and Department of Energy and Climate Change.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/48298/4663-fuel-poverty-final-report-summary.pdf

¹⁰ Hills J Professor (2012) Getting the measure of fuel poverty Final Report of the Fuel Poverty Review, Hills J, CASE and Department of Energy and Climate Change.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/48298/4663-fuel-poverty-final-report-summary.pdf

¹¹ United Nations Human Rights Council. The Human Right to Safe Drinking Water and Sanitation: Resolution/Adopted by the Human Rights Council; A/HRC/RES/16/2; United Nations: Geneva, Switzerland, 8 April 2011.

¹² WaterAid. All people, one goal, all access. Water and sanitation access for people with disabilities Mali. Water Aid, 2010.

¹³ We Can't Wait Authors: Domestos WaterAid WSSCC A report on sanitation and hygiene for women and girls.

<http://worldtoilet.org/documents/WecantWait.pdf>

¹⁴ WaterAid. Undoing Inequity: inclusive water, sanitation and hygiene programmes that deliver for all in Zambia Full mid-term review report, April 2015.

For persons with disabilities to access clean water and sanitation, the availability, quality, safety, acceptability, accessibility and affordability criteria must be followed with non-discrimination, participation, accountability, impact and sustainability. It is important to highlight the broader scope of CRPD Article 9, including accessibility of information to ensure that all sections of the disability community are included. This could include signage in braille or easy-to-read formats, the latter of which are beneficial to an audience beyond people with intellectual disabilities, including children and people with limited literacy.¹⁵ Furthermore, accessible information should also be provided for deaf and hard of hearing people in sign language and written language. Also, water, sanitation and hygiene (WASH) programs often include education or training on sanitation, and these must be designed to be accessible to people with different communication needs.

It is necessary to include water and sanitation services in social safety nets, microcredit programmes or revolving funds to guarantee affordability of water and sanitation for persons with disabilities.¹⁶ It is also critical that persons with disabilities are actively consulted in planning processes in order to ensure that the challenges they encounter are included from the beginning. While the principles of universal design provide a template for physical accessibility, the many societal barriers faced by persons with disabilities accessing basic services are often misunderstood by planners. It is only with the active participation of persons with disabilities, that many barriers are identified and addressed in planning processes. Participation of persons with disabilities also tackles stigma and discrimination and improves perceptions of the value persons with disabilities bring to society.

Recommendations:

- Ensure universal access to affordable, reliable and efficient energy services for persons with disabilities, including the use of alternative energy facilities where warranted, limiting the frequency of power cuts;
- Develop clear disability planning guidelines, which include mandatory processes for the engagement of persons with disabilities in planning processes;
- Ensure equal access for persons with disabilities to clean water and sanitation services, appropriate and affordable services, devices and other assistance for disability-related needs;
- Include specific measures to guarantee that women and girls with disabilities have access to safe, private and accessible WASH;

https://assets.publishing.service.gov.uk/media/57a0899ce5274a27b2000185/Report_Undoing_Inequity_MTR_Zambia_April_2015.pdf

¹⁵ CRPD/C/GC/2, p. 6, para 20

¹⁶ de Albuquerque, C. Report of the Independent Expert on the Issue of Human Rights Obligations Related to Access to Safe Drinking Water and Sanitation; Addendum Progress report on the compilation of good practices; United Nations: New York, USA, 2010. http://www2.ohchr.org/english/bodies/hrcouncil/docs/15session/A.HRC.15.31.Add.1_en.pdf

- Provide, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies;
- Consider the different accessibility and communication requirements for persons with disabilities to ensure their effective participation in activities designed to support and strengthen the participation of local communities in improving water and sanitation management;
- Ensure that social assistance programs provide fair and sufficient financial assistance based on specific characteristics and based on that person's income rather than on the income of his or her family;
- Measures need to be in place for the elimination of barriers to basic services, drinking water and sanitation in rural and remote areas, and these need to include organizations of persons with disabilities to measure and monitor their implementation.

Chapter 2

Goal 11

Make cities and human settlements inclusive, safe, resilient and sustainable for persons with disabilities

Inclusive societies are based on inclusion in all aspects of community life: recreational, social, educational, economic and political, and also reduce isolation and establish lifelong patterns of inclusion. Further, communities that are designed inclusively are better able to support and welcome our natural diversity. They are more responsive to the needs of all its citizens, including older persons and families with young children. Inclusive societies must be built on the principles of the 2030 Agenda for Sustainable Development, especially leave no one behind in conjunction with the principles of the CRPD. Sustainable Development Goal 11 reflects a recognition of the importance of making all settlements inclusive, safe, resilient and sustainable.¹⁷ However only by applying the CRPD, will persons with disabilities be able to enjoy the realization of Goal 11.

Accessibility, one of the eight general principles of the CRPD,¹⁸ is a precondition to live independently, enjoyment of other rights and important in all areas for persons with disabilities.¹⁹ Requirements for accessibility, thus, go far beyond ensuring that someone's dwelling is accessible for "those who are entitled to it" and who are given "some degree of priority consideration in the housing sphere."²⁰ Accessibility means ensuring access to the physical environment, transportation, information and

¹⁷ Sustainable Development Goal 11

¹⁸ CRPD, Preamble (v)

¹⁹ CRPD, Article 3 (f).

²⁰ CESCR, General Comment 4, paragraph 8 (e).

communications, financial services, as well as, exercising the right to adequate housing and to other facilities open to or provided to the public, both in urban and in rural areas.²¹

Similarly to SDG 11 to create safe, resilient and sustainable societies, the CRPD Committee has highlighted the need for adherence to strict accessibility standards, the removal of barriers in a systematic manner, and continuous monitoring of such efforts. The Committee noted that “the strict application of universal design to all new goods, products, facilities, technologies and services should contribute to the creation of an unrestricted chain of movement for an individual from one space to another, including movement inside particular spaces, with no barriers.”²² The precondition for persons with disabilities to live independently and being included in the community, per CRPD Article 19, and to participate fully and equally in society, denial of access to the physical environment, transportation, information and communication technologies and facilities and services open to the public should be viewed in the context of discrimination.²³ Also, training and consultation with persons with disabilities are required to address the lack of awareness and technical know-how on accessibility for persons with disabilities.

Urbanization trends have led to shortages of adequate housing (in one aspect or another) for millions of families and individuals.²⁴ The CRPD Committee’s General Comment 2 cites evidence that accessibility is usually better in bigger cities than in remote, less developed rural areas. Although extensive urbanization can sometimes also create additional new barriers that prevent access for person with disabilities, in particular to the built environment, transport and services, as well as more sophisticated information and communication services in heavily populated, bustling urban areas.²⁵ Sustainable Development Goal 11 reflects a recognition of the importance of making all settlements inclusive, safe, resilient and sustainable. In a study in South Africa’s Eastern and Western Capes, persons with disabilities who were surveyed from the urban area reported experiencing more barriers to obtain food and medicine, daily living, mobility, and accessing public and private buildings, while those in rural areas encountered more attitudinal barriers. Despite the more pronounced negative attitudes in rural areas, the authors concluded that it would appear to be more challenging for a person with a disability to live in an informal settlement within an urban area than in a rural area.²⁶ Cities draw people from rural areas because of perceptions of opportunities in education or employment, the possibility to receive medical care, and perceptions of less stigmatization. In a study of beggars with disabilities in

²¹ CRPD, Article 9 (1)

²² CRPD/C/GC/2, page 5, para 15.

²³ The Right to Adequate Housing for Persons with Disabilities Living in Cities – Towards Inclusive Cities. United Nations Human Settlements Programme (Un-Habitat), 2015

²⁴ The Right to Adequate Housing for Persons with Disabilities Living in Cities – Towards Inclusive Cities. United Nations Human Settlements Programme (Un-Habitat), 2015

²⁵ CRPD/C/GC/2, p. 5, para 16.

²⁶ Maart, S., Eide, A. E., Jelsma, J., Loeb, M. E., Ka Toni, M. (2006), Environmental barriers experienced by urban and rural disabled people in South Africa, *Disability and Society*, 22(4), 357-369. (p.357, 365).

Addis Ababa, Ethiopia, it was found that the vast majority (86 percent) of the beggars interviewed came from areas more than 100 km away from Addis Ababa. Most of their respondents reported social stigmatization, lack of availability of work, social isolation and a lack of educational or employment opportunities in rural areas as factors that led them to migrate to the city.²⁷

While rural settlements usually do not have the same constraints as dense urban settlements, such as availability of habitable land or potable water, these studies suggest that rural settlements also do not provide sufficient opportunities for independent living for persons with disabilities. Public transportation for mobility, concentrated and diverse employment opportunities, better enforcement of regulations, less social prejudice and less rigid social hierarchies in urban areas all help urban residents with disabilities to live independently. It is equally likely, however, that persons with more severe disabilities, as well as older persons, are left to be cared for in rural communities while younger family members move to cities in search of work.²⁸

These barriers inhibit the rights of persons with disabilities to exercise other rights, including adequate housing, the right to inheritance, security of tenure, the right to access water and sanitation, the right to personal mobility (CRPD Article 20), the right to a home (CRPD Article 23), the right to access information (CRPD Article 21) and the right to access schools (article 24 CRPD). To effectively carry out inclusive education, accessibility to the infrastructure of the school that provides the education is required. Different factors may play out differently in each country; it would, therefore, be hard to generalize whether the share of persons with disabilities within the larger population is higher in urban areas than in rural areas or vice-versa. This again highlights the need for better data on urbanization disaggregated by age, gender, and disability status to better understand how these trends impact persons with disabilities. Mind sets, policies and approaches toward urbanization need to change in order for the growth of cities and urban areas to be turned into opportunities that will leave no one behind.²⁹

Inclusive societies require inclusive approaches across mainstream systems to ensure that persons with disabilities are part of their communities not merely “in” their communities. Inclusive education is a fundamental part of inclusive societies. When persons with disabilities experience meaningful inclusion at school they are more likely to gain employment and have better health outcomes. They are less likely to live in poverty. Other key areas include legal capacity, access to justice, health, employment, and civic engagement. Governments must organize these general systems and services in ways that are

²⁷ Groce, Nora, Murray, Barbara (2013), Disabled Beggars in Addis Ababa, Ethiopia, International Labor Organization Skills and Employability Department, Employment Working Paper No. 141, accessed from http://www.ilo.org/wcmsp5/groups/public/-/-ed_emp/---ifp_skills/documents/publication/wcms_213889.pdf

²⁸ The Right to Adequate Housing for Persons with Disabilities Living in Cities – Towards Inclusive Cities. United Nations Human Settlements Programme (Un-Habitat), 2015

²⁹ The Right to Adequate Housing for Persons with Disabilities Living in Cities – Towards Inclusive Cities. United Nations Human Settlements Programme (Un-Habitat), 2015

inclusive. Typically services being offered to the general public, such as vocational training are not delivered inclusively. Repeatedly, governments develop silos of segregated programming and services that mimic what is available to the general public. Too often as a result, the disability-specific services designed for persons with intellectual disabilities are based on assumptions and stereotypes about what persons with intellectual disabilities can do. In the case of vocational training, this often results in sheltered workshops or a focus on “life-skills” programs that do not provide employment skills.

Inclusive societies require a transformative shift that cannot be limited to just the built environment, but also must be based on the right to live and be included in the community. Few supports and services exist to enable persons with disabilities and their families to realize their right to live and be included in the community. Where services do exist, too often they continue to be segregated, medicalized and based on congregate care. Inclusive societies reflect the interdependence of our rights and that to be fully and meaningfully included, one must also have access to inclusive education, affordable housing, the right to make decisions, employment and other areas.

If persons with disabilities are warehoused and segregated from communities we will not have inclusive societies. The warehousing and institutionalization of persons with disabilities is inconsistent with the notion of inclusive cities and human settlements. Inclusive societies require a commitment to close existing institutions and refrain from investing in their refurbishment, maintenance, or development of new institutions. The continued existence of institutions is an egregious violation of CRPD Article 19. Consistently, research confirms the benefits and improvement in the quality of life for people leaving institutions continue to outweigh the costs. Further, examples have demonstrated successful transitions to community by individuals with the most complex needs (people with severe disabilities, challenging behaviors, medical issues, or advanced age) proving that living in the community, with the right supports, is possible for everyone. Immediate efforts are required by Member States to close institutions and invest in supporting people to choose where and with whom they live.

Procurement is a powerful tool for achieving Goal 11. Laws on public procurement should be linked to accessibility standards on the built environment, transport and ICT, and when developing standards persons with disabilities should be part of the process. An example of a good practice in Europe includes Article 42 in Public Procurement Directive, EC standardisation mandates for accessibility in procurement 376 e-accessibility, 420 built environment and 473 Design for all (the term used in European legislation before the CRPD used Universal Design).

Recommendations:

- Ensure that national legislation and policies align with CRPD provisions on non-discrimination, including the provision that the denial of reasonable accommodation constitutes disability-based discrimination;
- Harmonize national and local legislation and policies with CRPD provisions on accessibility and in line with SDG 11, and adopt strategic measures that leverage the impact of accessible facilities and services to urban settlements such as transportation, building, roads, and information and communication technologies;
- Recognize digital transformations occurring in urban settlements worldwide as an opportunity to empower and enable local authorities to promote digital inclusion and provide innovative solutions to many urban settlement challenges;
- Commit to ending the institutionalization of persons and children with disabilities, including by strengthening family support measures and by developing alternative forms of family care to ensure children experience an atmosphere of emotional and material security;
- Gain commitment from authorities at all levels, but especially at the local level, to facilitate development and provision of accessible services in the community;
- Follow universal design to carry out the application of accessibility standards for all public buildings regardless of size, date of construction, or capacity for communications and transportation, for information and communications technologies, and for rural as well as urban areas;
- Ensure that private entities understand and apply new accessibility standards and sufficient financial and human resources to be allocated to implement, promote and monitor compliance with accessibility legislation;
- Conduct training on universal design and accessibility standards on an ongoing basis, and dissuasive penalties for noncompliance should be incorporated in legal frameworks and be applied to those who do not implement accessibility standards;
- Review existing mechanisms for public and private procurement for buildings, infrastructures, and ICTs to include accessibility implementation and monitoring, including in the context of international cooperation;
- Coordinate with technical education institutions to include: (1) accessibility of the built environment; (2) accessibility of information and communication technologies within the standard technical curriculum of professionals; (3) and support the ongoing accessibility training, development, and certification of professionals;
- Collect good practices and disseminate knowledge in order to encourage others to follow the example and to create a longer lasting effect. Those who set legislation or policies in line with CRPD provisions in regard of accessible and inclusive cities and SDG 11 must promote, enshrine and share the process and information to be a role model for the others;

- Include persons with disabilities in planning processes;
- Secure resources for DPOs to participate in standardization mandates for accessibility.

Chapter 3

Goal 17 means of implementation

The importance of funding for CRPD-compliant SDG implementation and data

Full implementation of the 2030 Agenda and the CRPD requires a progressive increase in dedicated domestic resource allocation and international development cooperation to support the full inclusion of persons with disabilities in sustainable and resilient societies. Yet, in many countries austerity measures have been imposed, which reduce government expenditures on human rights, development and social welfare when and where they are most needed, and persons with disabilities are often among the very hardest hit. A rights-based response to economic crises could lift persons with disabilities and their families out of poverty, which would contribute to the achievement of inclusive growth and sustainable development.

International cooperation measures also must be reviewed for their inclusivity. Many community-based rehabilitation efforts and programs funded through development assistance have contributed to segregation and exclusion. Governments should require that all services they fund be accessible and available for all persons with disabilities.

States must collect and disaggregate data in line with the 2030 Agenda for Sustainable Development and the CRPD by using the Short Set of Questions developed by the Washington Group. In addition, States must ensure that their national policies for persons with disabilities are informed by evidence-based data that realize the political commitments of the 2030 Agenda and legally-binding obligations outlined in the CRPD. As such, to create effective and meaningful policies that guarantee the rights of persons with disabilities, it is critical to disaggregate the SDG indicators by disability.

Recommendations:

- Ensure that data be disaggregated by age, gender and disability so that measures can be adopted to prevent such discrimination and to ensure participation of persons with disabilities at local, national, regional and global levels;
- Ensure social protection programs are aligned with CRPD Articles, including when there are financially motivated revisions of these programs;

- Provide training and ongoing mentoring for stakeholders with disabilities so that they are prepared to lead discussions and edit policies toward safe, sustainable and resilient societies so that they carry the primary role in implementation;
- Require that all services funded through international development or aid be accessible and available for all persons with disabilities.