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INTERACTIVE EXPERT PANEL

Women’s empowerment and the link to sustainable development – the data challenge and opportunity

Making the SDGs count for women and girls with disabilities – the data challenge and opportunity

by

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* The views expressed in this paper are those of the author and do not necessarily represent those of the United Nations.
Excellency, ladies and gentlemen,

Thank you for giving me the opportunity to speak at such a prestigious and important event.

Globally, there is a lack of data on the situation of persons with disabilities, in particular on women and girls with disabilities. The lack of data increases marginalization and contributes to the failure to address the situation and discrimination encountered by women and girls with disabilities. The collection of comparable data is essential for evidence based policy-making and budgeting, as it can directly address the reduction of barriers that women and girls with disabilities face to achieve full participation in all aspects of their lives in society. Without valid and reliable information, it is impossible to design, implement or evaluate policies and legislation, to combat discrimination and to promote social integration, participation and enhancing opportunities.

This situation persists, despite the fact that Article 31 of the UN Convention on the Rights of Persons with Disabilities (CRPD) calls on Member States to collect appropriate information, including statistical and research data. As such, it is the obligation of the 177 ratifying States Parties to collect data, realize the CRPD for women and girls with disabilities and safeguard anti-discrimination of women with disabilities by ensuring: their equal and full enjoyment of their fundamental freedoms and human rights (Article 6), and their access to social protection and poverty reduction programmes (Article 28). Furthermore, the 2030 Agenda for Sustainable Development (Goal 17, target 18) as well as the global indicator framework, provide the international community with a moral obligation to work towards achieving the Sustainable Development Goals (SDGs) for all women and girls, and to address the rights of women with disabilities as a matter of priority. Achieving the SDGs for women and girls with disabilities can only be realized by upholding the principles of the UN CRPD. As such, the 2030 Agenda and CRPD must be used simultaneously.

The situation of women and girls with disabilities

Gender inequality is acknowledged as the most pervasive form of inequality, and the failure to achieve gender equality, for all women, not only impacts on the rights of women and girls everywhere, but also impacts negatively on growth and progress in societies. Women and girls with disabilities make up a significant percentage of the world’s female population and within the disability community the prevalence rate of disability is higher for women than it is for men. Despite their estimated population size, women and girls with disabilities can often be invisible within normative frameworks for human rights and development. Where they are visible, often times this is not within their own right but rather within the context of being described within vulnerable or marginalized groups.

Persons with disabilities comprise 15 percent of the world’s population or 1 billion people of whom 80 percent live in low- and middle-income countries. One in four households has a person with a disability. For marginalized populations, such as women and girls, the prevalence of disability is higher. The global prevalence rate of disability for women is 19%, compared to 12% for men. 10% of women in the world – approximately 300 million – are classified as women with disabilities, as they present physical, mental, intellectual and/or sensory impairments.

Allow me to provide a brief overview along the key policy priority areas where we do have some data available, however, not one of the studies was able to give an internationally comparable picture regarding the different areas, as only limited data is available. All the conclusions are based on some data
and deductions thereof. Furthermore, the intersection of gender and disability, though an important topic in development and human rights, remains an under-researched area.

Poverty

When gender and disability intersect, poverty and marginalization are further compounded. In low and middle-income countries, women are estimated to comprise up to three-quarters of persons with disabilities. Women and girls with disabilities face multiple barriers to realizing their rights: environmental, physical, attitudinal and informational accessibility issues, including lack of resources and inadequate access to services, as well as widespread discrimination, stereotyping and social stigma.

While Paragraph 23 of the 2030 Agenda recognizes that 80% of persons with disabilities live in poverty, we have no further data globally, not only on the poverty situation of persons with disabilities, but also on the situation of women and girls with disabilities.

Education

The objective of SDG4 is to achieve “inclusive and equitable quality education and promote lifelong learning opportunities for all” including those with disabilities. Yet as many as half of the estimated 65 million primary and lower secondary-school age children with disabilities in low-middle-income-countries are out of school amounting to one third of children out of school being boys and girls with disabilities. Therefore, it is recognised that children with disabilities continue to be amongst the most excluded. At school their enrolment records are lower and dropout rates higher, with poor levels of attendance, progression and learning. Very few young people with disabilities transition into higher levels of training and education. Only 5-15% of children who need assistive devices have access to them. Less than 1% of materials are available in accessible formats for blind or partially sighted readers but when they are provided a 20% increase in student achievement is possible.

Studies show that women and girls with disabilities have lower rates of completion of education. Girls with disabilities are less likely to complete primary school and more likely to be marginalized or denied access to education. It also found that when in education, women with disabilities spend fewer years than both men with disabilities and women without disabilities. For example, the World Health Survey highlights that 41.7 per cent of females with a disability completed primary school compared to 50.6 per cent of males with a disability and 52.9 per cent of females without a disability. Likewise, women and girls with disabilities receive on average 4.98 years of education, compared to 5.96 years for men and boys with disabilities and 6.26 years for women and girls without disabilities. The UNDP reports that the literacy rate for women with disabilities is extremely low, and they are rarely reached by adult literacy campaigns or outreach efforts.

Common barriers faced by girls and boys with disabilities include lack of access to school infrastructure, transport to get to school, and learning supports including inclusive curriculums, trained teachers, including in sign language and support staff, just to mention a few. However, due to the lack of data these barriers are not addressed by policymakers.

Employment

Particularly, target 8.5 of the SDGs calls on Member States that “by 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with
disabilities, and equal pay for work of equal value.” Yet, currently persons with disabilities experience more barriers to accessing productive and decent work than persons without disabilities throughout the world. Persons with disabilities have disproportionately high levels of underemployment and unemployment as well as earning lower wages than persons without disabilities, with wage gaps of more than 10% in some countries. Wage gaps are even larger for women with disabilities and persons with intellectual disabilities. It is important to stress that many persons with disabilities are not in employment or training – meaning they are not “employed” or “unemployed” or “underemployed”, but are considered outside of the labour force. This is why the statistics focus on ratio of employment, rather than looking at numbers of “unemployed.”

According to the The UN Flagship Report on Disability and Development, across 91 countries and territories in eight geographical regions, the employment to population ratio (EPR) for persons with disabilities aged 15 years and older is 36% on average, whereas the EPR for persons without disabilities is 60%. The situation is even worse for women with disabilities, with evidence from six regions showing lower employment to population ratios for women with disabilities than men with disabilities in all six regions.

Multiple intersecting factors restrict women with disabilities’ access to decent work and employment, including: inadequate laws and policies; discriminatory social norms and hiring practices; a lack of access to education and training; unequal access to resources, information, technology and networks; accessibility challenges; lack of reasonable accommodations in the workplace; and lack of access to sign language for trainings and interactions in working environments.

The economic empowerment of women and girls with disabilities is critical to realise positive changes in their lives and societies as a result of their participation in economic activities. These activities include participation in the labor force, receiving remuneration for work on an equal basis with men, and ensuring less gender-based divisions of labor within households and within the labor market. Outside of employment and the labor force, women’s economic empowerment also means that women should have control over their own assets, the potential to generate and accumulate wealth and have agency over their own lives.

Health

Data from the World Health survey cited in the World Report on Disability shows that women, men, girls and boys with disabilities have unequal access to health care services and therefore have unmet health care needs compared to the general population. While global data on health outcomes for women and girls with disabilities is unavailable, there is evidence from national studies, which highlights that women with disabilities rate their health status lower than women without disabilities and men with disabilities.

The historical and, in many areas, continued prevalence of the medical model of disability has resulted in opposing stereotypes regarding women with disabilities and sexuality. Often times, women with disabilities are seen as asexual; however, women with intellectual disabilities are often perceived as promiscuous. Practices of forced sterilization and contraception/family planning, including forced abortion, have been justified and defended by the ‘best interest defence’ which is informed by the medical model of disability. Some studies have found increased risk of HIV and sexually transmitted infections for women and girls with disabilities.
There is inadequate access for women and girls with disabilities to information, education and services around sexuality and sexual/reproductive health. Issues include the physical inaccessibility of clinics and lack of awareness or sensitivity to the needs of women with disabilities, both in the services that are provided and the personnel providing them. Lack of access to sexual and reproductive health and rights, causes women and girls with disabilities to be unable to make their own informed decisions regarding sexual relations, contraceptive use and reproductive health care.

Barriers in accessing quality healthcare include poor maternal health care is a major cause of disability among women. Women experience higher rates of disability than men, commonly resulting from higher rates of depression and anxiety – a fact that has been linked to gender discrimination and gender-based role expectations as well as poverty, hunger, malnutrition, violence, overwork and disproportionate care burdens. There is evidence that women with disabilities receive less screening for breast and cervical cancer than women without disabilities due to a lack of targeted health promotion and prevention campaigns, and a lack of appropriate physical accommodations.

Studies also suggest that women with disabilities seek healthcare more often than women without disabilities but have worse health outcomes and rate their well-being as lower than both men with disabilities and women without disabilities. This is further compounded by the fact that women with disabilities between the ages of 18 and 44 have almost 2.5 times the yearly healthcare expenditures compared to women without disabilities and women with disabilities between the ages of 45 and 64 have more than three times the average yearly expenditures of their counterparts without disabilities.

Violence against women and girls with disabilities

Women and girls with disabilities are at a greater risk than their non-disabled peers to experience violence. Research has found that women with disabilities were up to 4.2 times more likely than women without disabilities to have their activities and whereabouts restricted by partners. Women and girls with disabilities experience disability-specific forms violence beyond gender-based violence. These include abuse within institutions, by caregivers and other family members, forced institutionalization and psychiatric treatment, targeted abuse, including sexual abuse, because of one’s disability type, and forced sterilization, abortion and contraception. Women with disabilities experience disproportionate risks of violence, due to factors relating to systemic discrimination and stigma, which is compounded by poverty, social isolation and political marginalization; inadequate services and support systems that lack awareness, training and capacity; lack of access to justice, and disabling, inaccessible and hostile environments. This is compounded by the risk of being two to three more times more likely to become a child bride, experience early pregnancy and female genital mutilation

Participation in decision making processes:

While the political participation rates of women without disabilities remain low, participation rates for women with disabilities are low to non-existent. Both women and men with disabilities can experience barriers such as legal capacity restrictions (being considered not capable to vote or to hold office due to having specific disabilities, for example intellectual and psychosocial), lack of access to polling stations and inaccessible voting materials. Women with disabilities often find themselves underrepresented in civil society organizations; both those which represent disability issues as well as those that represent women’s issues.
In order for global development to be truly transformative and leave no one behind, it must ensure that equality and human rights of women and girls with disabilities are recognized as core values. In summary, women and girls with disabilities face greater barriers than men with disabilities and women without disabilities including exclusion from participating in a sustainable and inclusive economy; an increased risk of violence and abuse; lack of access to justice; minimal participation in political and public life; and prejudice and discriminatory attitudes in sexual health, reproductive rights and in the right to family life. Overcoming these challenges and achieving the Sustainable Development Goals for all is impossible without adequate data.

**The lack of adequate data on women and girls with disabilities**

The aforementioned challenges faced by women and girls with disabilities are further exacerbated by a lack of quality, disaggregated data on women and girls with disabilities. Consequently, the situation of women and girls with disabilities cannot be improved and they are being left behind in the implementation of the SDGs.

Despite their estimated population size and the multiple barriers that women and girls face to full inclusion, they are often times invisible within global normative frameworks for human rights and development. Where they are visible, many times is not within their own right but rather within the context of being described within vulnerable or marginalized groups. The limited availability of global data for women and girls with disabilities has impacted possibilities for comparison across regions and countries. It has also negatively impacted the comparison of outcomes for women and girls with disabilities in key sectors such as education, economic empowerment and health.

While many countries collect disability data in their censuses and surveys, the definition of disability is often not harmonized. This means that data across countries is not comparable and thus inadequate for global monitoring efforts. Moreover, despite a growing number of countries adding questions on disability in censuses and surveys, often the data is not processed and disseminated with simultaneous disaggregation by sex, age and disability.

Access to high quality data and analysis is essential to monitor progress and hold decision-makers accountable. A global indicator framework has been developed to monitor the SDGs and track implementation of the targets. As a guiding principle, the IAEG-SDGs agreed that indicators in the global monitoring framework should be disaggregated, where relevant, by “income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics”. In addition, indicators should cover specific groups of the population and address other elements of disaggregation when specified in the target. These data are essential to monitoring progress on the commitment to “leave no one behind”. Data and statistics on groups such as women and girls with disabilities that remain largely invisible in official statistics should be prioritized.

**Recommendations:**

I will now offer solutions and propose a few recommendations to remedy these issues. In addition to bolstered data collection efforts, women and girls with disabilities should actively and meaningfully participate in gender and development programs. Development practices should include persons with disabilities, including gender-based practices, to increase visibility and decrease marginalisation of persons with disabilities. Moreover, gender programs should incorporate the disability perspective to
reduce poverty, gender-based violence and barriers to reproductive health care for women with disabilities.

The interests and perspectives of women with disabilities should be represented by both women’s organizations and organisations of persons with disabilities. For example, we recommend that the Women’s Major Group establishes a thematic group on women and girls with disabilities. Women with disabilities should have equal leadership and decision-making opportunities within both women’s organizations and organisations of persons with disabilities.

To achieve these recommendations, women with disabilities must be specifically and meaningfully referenced in policies and programs at all levels and quality, disaggregated data should be produced to monitor progress made on commitments to improve the situation of women and girls with disabilities.

More research is needed to investigate the intersection of gender and disability. Much of the available literature is at a conceptual and abstract level (particularly in relation to law). As such, more concrete analysis of gaps and innovative practices is needed.

Internationally comparable data will play a critical role in monitoring the SDGs for women and girls with disabilities and should guide the development of disability-inclusive and gender-inclusive policies and programmes and ongoing assessments of their impacts.

The Stakeholder Group of Persons with Disabilities highlights that the short set of questions developed by the Washington Group on Disability Statistics and the UNICEF/Washington Group Child Functioning Module (that supports identification of children with disabilities) are sustainable and suitable for disaggregating by disability status and monitoring progress in attaining the SDGs on an ongoing basis. These modules are internationally comparable, well tested, efficient, low cost, and easy to incorporate into ongoing data collection of national statistical systems. Delays in using this tool could have detrimental consequences to the implementation of the SDGs, which will subsequently leave persons with disabilities uncounted and behind. The request to use the aforementioned tools has been endorsed not only by several Member States, but also by donors such as DFAT, DFID, and a large number of UN agencies.

It is critical to foster partnerships between statisticians, policymakers and organisations of persons with disabilities to ensure appropriate data collection and disaggregation in order to address policy gaps and shortcoming in achieving the SDGs for women and girls with disabilities.

The ‘nothing about us without us’ or ‘together we will count and be counted’ must be guiding principles in the data processes at all levels.

Thank you