

POST DIALOGUE BRIEF

Addressing Birth Defects from the Lens of Human Rights & Inclusion

February 2020



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Background

UNFPA Sri Lanka hosted a panel discussion at the 9th International Conference on Birth Defects and Disabilities in the Developing World (ICBD) which was held from 23rd to 25th February 2020 in Colombo.

The overall conference focused on the need to build capacity in middle-income countries for the prevention of birth defects and preterm birth and care. The goal of the biennial conference was to provide specific practical tools and approaches that developing country participants can use to influence funding and policy as well as implement health care delivery in their respective countries.

UNFPA's session at ICBD 2020 took the form of a dialogue focused on a human rights and gender

equality angle to disability and birth defects. This was the first attempt by UNFPA Sri Lanka to host a comprehensive dialogue on disability. UNFPA recognizes that optimizing the health and wellbeing of women and people with disabilities is essential to achieving the Sustainable Development Goals (SDGs). The dialogue highlighted rights-based approaches to promote inclusion and accept diversity of people with disabilities; and providing SRH services and comprehensive sexuality education to them. This post-dialogue brief provides a snapshot of the panel discussion and advocacy pointers that can assist in evidence-based policymaking.



Moderator:

Mr Janitha Rukmal
Co-founder
ENABLE Lanka foundation

Panelists:

Professor Athula Kaluarachchi
Senior Lecturer in Obstetrics and Gynaecology
Faculty of Medicine, University of Colombo

Professor Subhanghi Herath
Professor in Sociology
Faculty of Arts, University of Colombo

Dr Shyamani Hettiarachchi
Senior Lecturer, Department of Disability Studies,
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The Issue

According to the UN Convention on the Rights of Persons with Disabilities (UNCRPD), Persons with Disabilities (PWD) include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. Thus, it is not the inherent condition or the birth defect that is causing the disability. Rather, it is the interaction of this impairment with environmental barriers.

There are over one billion people, around 15% of the population with some form of disability worldwide, the majority of which live in developing countries.¹ In Sri Lanka, 8.7% of its population are living with disabilities.² PWDs face barriers that hinder their ability to participate in everyday life. These barriers are more than just physical obstacles. WHO defines barriers as; factors in a person's environment that, through their absence or presence, limit functioning and create disability. These include aspects such as a physical environment that is not accessible, a lack of relevant assistive technology (assistive, adaptive, and rehabilitative devices), negative attitudes of people towards disability, and services, systems and policies that are either nonexistent or that hinder the involvement of all people with a health condition in all areas of life.

PWDs have the same sexual and reproductive health (SRH) needs as other people. Yet they often face barriers when accessing SRH information and services. Even when health services are physically accessible women and young people with disabilities may face financial, social, and psychological barriers to accessing adequate SRH services. This leaves persons with disabilities among the most marginalized groups when it comes to accessing SRH information and services. Yet persons with disabilities have greater needs for Comprehensive Sexuality Education and access to care than persons without disabilities due to their increased vulnerability. Furthermore, SRH services are often inaccessible to people with

disabilities due to stigma and discrimination. When it comes to health care provision, many health care providers hold inaccurate, stereotypical views, especially about women and girls with disabilities, such as assumptions that they are not sexually active. SRH of people with disabilities and birth defects have been largely overlooked in policy, planning and delivery of social, legal, health, and welfare services.

Optimizing the health and wellbeing of women and people with disabilities is essential to achieving the Sustainable Development Goals (SDGs). The impact of birth defects in developing countries can be reduced through a series of interventions and comprehensive programmes that encompass prevention, education about SRH, treatment, and rehabilitation.



**"Women living with disabilities often face human rights violations, such as forced marriages, domestic violence, physical, emotional, and sexual abuse, and issues concerning pregnancy, labour, mental health, maternal health, and newborn health." – Ms Ritsu Nacken
Representative
UNFPA Sri Lanka**

1. World Report on Disability by WHO - https://www.who.int/disabilities/world_report/2011/report/en/#:~:text=About%2015%25%20of%20the%20world's,a%20figure%20of%20around%2010%25.

2. The 2011 census carried out by the Department of Census and Statistics (DCS) - <https://www.lk.undp.org/content/srilanka/en/home/blog/2018/16082018.html>



"People living with disabilities are still marginalized and behind on every single SDG. While inclusive policies are often available, political will and resources are often lacking."

– Dr Shyamani Hettiarachchi



"The problem is not with the disability. The problem is with the inability of policymakers and society to create an inclusive environment. We must concentrate on empowering people with disabilities with skills, knowledge and inclusive services."

– Professor Subhangi Herath



"SRH services are often inaccessible to persons living with disabilities and even when health services are physically accessible, women and young people with disabilities may face financial, social, and psychological barriers to accessing adequate SRH services."

– Professor Athula Kaluarachchi

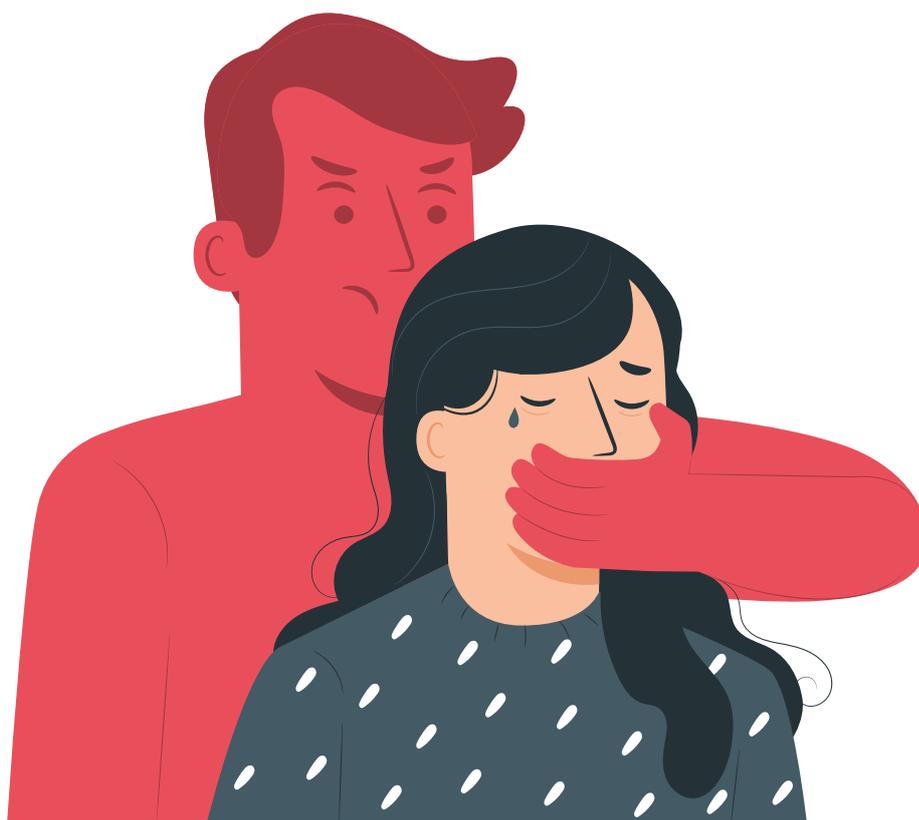
Discussion Points

Discrimination

Society is inherently focused on the dichotomy of “disability and normalcy”. This directly connects to ableism, which is the idea that what a person can achieve or their ability to live a fulfilling life is determined by their disability. Thus anyone who has a disability tends to live “less of a life” than those who do not have disabilities. The problem exists in a society that fails to provide an enabling environment for people with disabilities to fulfill their potential.

Not all people with disabilities face discrimination similarly. People with intellectual disabilities, for example frequently suffer more from exclusion as they are often not allowed to exercise their right to make decisions for themselves within the justice or health systems. Their voices are simply not heard. Women with disabilities experience different forms of discrimination, and specifically pregnant women with disabilities find it very difficult to access health care services. Young women living with hearing disabilities are also vulnerable to sexual abuse because many know that the police will have difficulties in taking their statements. There is a lack of sensitization in the law enforcement sector on these issues and capacity building is needed so that there can be effective communication with the survivors.

Recognizing disability as a diversity of human beings, similar to the characteristics of gender, age, ethnicity, and religious beliefs, would be crucial to attain a disability-inclusive society.



Discussion Points

Sexual and Reproductive Health and Rights of People Living with Disabilities

Sexual and reproductive health is a vital component of the health and well-being of a person, and a pillar for sustainable development that deserves an important focus anywhere in the world, however, the needs of people with disabilities in developing countries have been neglected for decades. Too often, society and individuals around PWDs tend to see them as not sexually active. Thus, there is a lack of evidence on their SRH needs and outcomes that could be used to inform policymakers, service providers and people with disabilities themselves, and to guide interventions. When it comes to the improvement of accessibility to SRH services, health care workers and other service providers must recognize the unique needs of persons with disabilities due to their different types of disabilities. The understanding of and the provision of special assistance by the health care workers is required to overcome each barrier they face. It is the duty of healthcare professionals to provide SRH services to persons with disabilities in response to their particular needs over the course of their life cycle – including both if and when they want to have children and when they want to avoid pregnancy. Therefore, the right attitude and understanding of health care workers plays a significant role when improving accessibility to SRH services. However, proper professional training to fulfill the SRH needs of PWDs has not been provided sufficiently yet.

In fact, accommodating persons with disabilities in the existing services itself is not focused on, but can be easily modified. Raising awareness and providing technical knowledge on how to assist people with disabilities through practical training sessions and basic sign language training to frontline health care staff is the first and the most important step. Beyond that, much can be achieved through incorporating persons with disabilities in the process of programme design and monitoring. There is so much work to do for every person with disabilities to fulfill their sexual and reproductive rights, enjoy sexual life, and access quality SRH services with special care tailored to each person's form of disability.



Discussion Points

Policy, Planning and Implementation

People with disabilities are all too often excluded from decision-making bodies and processes, ranging from community meetings to policymaking. They cannot take part in making decisions that affect themselves directly and are not always able to vote in an election. The 2030 Agenda for sustainable development was designed to ensure we “leave no one behind”. People with disabilities are certainly one of the population groups who tend to be vulnerable, and their rights and dignity has to be upheld if we are to achieve the SDGs.

In a culture of caring and supporting the most vulnerable, policy and planning processes must integrate the voices of those who were left behind. Furthermore, monitoring and evaluation aspects must be strengthened as the lack of rigorous and comparable data and statistics, combined with a lack of evidence on programmes that work, often impedes understanding and action on disability inclusion.



Recommendations for Action

1

Establish mechanisms that can reflect and advocate on progressive perspectives of disability inclusion and meaningful support through partnerships with organizations of persons living with disabilities.

2

Ensure the participation of persons living with disabilities in the process of policymaking and programme development for a disability-inclusive society. This can be achieved through the provision of a quota system in policymaking forums that encapsulates aspects such as the right to privacy, inherent dignity, and the principle of equity and equality.

3

Raise awareness on disability-inclusive sexual and reproductive health and rights, and introduce universal standards of accessibility to the current CSE programmes in ways that recognise persons living with disabilities as an integral part of all related initiatives.

4

Strengthen the capacity of service providers to ensure that all SRH programmes and services reach and serve persons living with disabilities.

5

Capacitate health care providers and strengthen service delivery through innovation to reduce the number of birth defects to cater to high risk pregnant mothers and families with disabilities planning to have children.

6

Address and include matters of persons living with disabilities in national SRH and gender-related policies, laws, and budget planning processes.

7

Promote research on the SRH of persons with disabilities for a stronger evidence base to help improve SRH programmes for persons with disabilities. Ensure national socio-economic data collection initiatives include disaggregated data by disability.



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