

2020

GUIDELINE FOR PROMOTING DISABILITY INCLUSIVE ACCESSIBLE SRHR IN BANGLADESH

Developed by



YPSA (Young Power in Social Action)
Bangladesh

Supported by



Share-Net International



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Contents	Page Number
Acknowledgments	3
Abbreviations and Acronyms	4
Executive Summary	5 - 6
Chapter 1. Introduction	
1.1 Context	7 - 8
1.2 Target audience	8
Chapter 2. Literature Review	9 -10
Chapter 3. Methodology and Process for Development of the Guideline	
3.1 Core approach	11
3.2 Guideline development working groups	11
3.3 Involvement of the persons with disabilities	11
3.4 Guideline review and validation Group	11
3.5 Additional key contributors	12
3.6 Funding and Technical Support	12
Chapter 4. Framework to Promote Disability-Inclusive Accessible SRHR in Bangladesh	13 - 21
Chapter 5. Possible Interventions Against the Major Issues	22 - 31
Chapter 6. Service Delivery and Guideline Implementation	32 - 34
Chapter 7. Conclusion	35
<i>References</i>	36
<i>Annexe 1. Documents Reviewed</i>	37 - 38

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- Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note 2009. ISBN 978 92 4 159868 2
- Consolidated guideline on sexual and reproductive health and rights of women living with HIV. Geneva: World Health Organization; 2017. License: CC BY-NC-SA 3.0 IGO.

Abbreviations and Acronyms

BBS – Bangladesh Bureau of Statistics
BDS - Bangladesh Development Studies
CSD – Chittagong Society for the Disabled
DAISY – Digital Accessible Information System
DPO – Disabled Peoples Organization
FY – Fiscal Year
GVPS – Global Values and Preferences Survey
GED - General Economics Division
GoB – Government of the People’s Republic of Bangladesh
HIES – Household Income and Expenditure Survey
ICT – Information and Communication Technology
IDPs – Internationally Displaced Persons
IRCD – ICT and Resource Center for Persons with Disabilities
JICA – Japan International Cooperation Agency
KM4D – Knowledge Management for Development
NGOs – Non-Government Organizations
NHP – National Health Policy
MoH & FW – Ministry of Health and Family Welfare
RCTs – Randomized Controlled Trials
SARPV – Social Assistance and Rehabilitation for the Physically Vulnerable
SDGs – Sustainable Development Goals
SRH – Sexual and Reproductive Health
SRHR – Sexual and Reproductive Health Rights
UNCRPD – United Nations Convention on the Rights of Persons with Disabilities
WHO – World Health Organization
YPSA – Young Power in Social Action

Executive Summary

As there is no reliable data and documents on the SRH needs of persons with disabilities living in Bangladesh; therefore, this guideline has been developed in a generalistic way following several international models. It does not picture completely evidence-based claims of its own, rather identified key sectors and issues that deserve first attention by reviewing several relevant national and international documents. Also, this guideline proposed a few generic possible interventions focusing on the general overall conditions as the first step of action through an intensive desk review.

'Bangladesh Bureau of Statistics (BBS)', led national censuses 1981, 1991, and 2001 estimated prevalence rate of disability at 0.82, 0.47, and 0.60 respectively. Action Aid-Bangladesh and Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV) put the disabled population at 8.8% of the total population, Bangladesh Protibandhi Kalayan Samiti records 7.8% (JICA, 2002), and WHO estimated around 10 -15% of the total population. But, the 5th Population and Housing Census 2011 showed the number of people with disabilities is only 1.4% of Bangladesh's total population which is 7.6% points lower than the HIES 2010 estimate of 9.01 % for the overall disability prevalence. The statistics on the prevalence of disability has indeed been a matter of serious debate in Bangladesh as most of the estimates of disability prevalence generally appear to be underrated or sometimes excessive. For instance, in a survey Action Aid Bangladesh (1996) recorded 14.04% of people suffered from at least one form of impairment. Nevertheless, it is indisputable that disability is an issue that has a profound effect not only on a family but on society as a whole by reducing or eliminating the economic contribution of the members with disabilities, their family members, relatives, and close friends. The cumulative cost of disability is approximately US \$1.18 billion per year, which is about 1.74% of Bangladesh's GDP (BDS, Vol. XXXVII, December 2014). Considering this, to achieve its Vision 2021, the government of Bangladesh has prioritized "disability" as one of the major thematic areas of its development agenda. It has already put necessary policy frameworks in place to ensure disability-inclusive development. It has brought in several laws to protect people with disabilities, namely "Persons with Disabilities Rights and Protection Act 2013" and "Neurodevelopmental Disability Protection Trust Act 2013", and ensured inclusion of disability in its National Education Policy, National Skills Development Policy, and other policy frameworks. Bangladesh has also ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and is highly committed to achieving the Sustainable Development Goals by 2030; thus, leaving no one behind, particularly those with disabilities.

Despite all these initiatives, in Bangladesh, there is a huge gap in implementing or initiating dedicated disability-inclusive policies, programmes, and interventions in the SRH sector. Comprehensive education, information, and training on sexual and reproductive health are the most critical elements of SRHR, and in Bangladesh, persons with disabilities consider information on sexual and reproductive health not just as a need, but as their right. Despite being a right, persons with disabilities often do not have equal access to information, education, and training related to sexual and reproductive health, sexuality, relationship as well as general health, thus hampering their ability to make informed decisions about these issues. They often face discrimination because of their impairments and gender. Although the government and few other organizations have taken a few scattered initiatives in this regard but those were not inclusive and dedicated to persons with disabilities; therefore, their situation remained unchanged. Considering these situations, this guideline is highly endorsing to introduce and promote Disability Inclusive Accessible SRHR in Bangladesh.

This guideline also proposes to consider policies that will affect women and men with disabilities differently. Because, unlike men with disabilities, women with disabilities are confined to the domestic domain. They neither have access to resources nor market-driven skills. The Government of Bangladesh has already taken some legislative steps towards improving the situation of persons with disabilities. But most of these steps does not entail disability-inclusive accessible SRHR; therefore, many important corners of SRHR that are important to address for a person with a disability to survive, sustain and flourish in both the public and private spheres of life, to find his or her place in society are still left unexplored.

The Sustainable Development Goals (SDGs) launched at the start of 2016 created a vision for leaving no one behind and, in doing so, call for reaching those who are furthest behind first. Persons with disabilities living in Bangladesh continue to face multiple and intersecting forms of discrimination and are denied their basic human rights, especially concerning health care. To achieve the SDGs by 2030 and fulfil the commitment to leave no one behind, the health sector – as part of the provision of SRH services must work to eliminate barriers faced by persons with disabilities.

1. Introduction

1.1 Context

In Bangladesh, the Constitution is the Supreme Law of the Republic. Article 7 of the Constitution ensures its supreme power and warrants that every law of this country has to be enacted in compliance with the Constitution. Whereas the preamble of the Constitution ensures that rule of law, fundamental human rights and freedom, equality and justice, political, economic, and social rights shall be secured for all citizens, Article 15(d) of the Constitution specifically mentions the right to social security, that is to say, to public assistance in cases of undeserved want arising from unemployment, illness or disablement, or suffered by widows or orphans or in old age, or in other such cases (GoB, 1972). Also, the persons with disabilities Rights and Protection Act 2013 has emphasized the necessity of dedicated surveys and proper data on the prevalence of disability in its “Detection” section (MoSW, 2013).

Despite all these, persons with disabilities are still among the most neglected population in Bangladesh, and maybe, which is why there are no accurate and trustworthy data about the prevalence of disability. For example, The BBS, led national censuses in 1981, 1991, and 2001 estimated the prevalence rate of disability at 0.82, 0.47, and 0.60 respectively (BBS, 1981. 1991. 2001) where WHO estimated around 10-15% of any population has at least one kind of disability (WHO, 2011). The 5th Population and Housing Census 2011 showed the number of persons with disabilities is only 1.4% of Bangladesh's total population which is 7.6% points lower than the HIES 2010 estimate of 9.01 % for the overall disability prevalence (HIES, 2010). When it comes to education, information, training, health and other basic rights persons with disabilities face constant discrimination and obstacles because of their impairment. Negligence and unwillingness of the relevant authorities and stakeholders are the main obstacles in promoting and executing relevant disability-inclusive laws and introducing dedicated ones also. Therefore, this population very rarely get the chance of enjoying a healthy and functioning personal life as they lack the basic skills and knowledge in almost all the sectors of society.

It is estimated that of the 64 districts in Bangladesh, around half have a prevalence of more than 50,000 disabled people. Due to the negligence of the relevant stakeholders, and lack of the implementation of relevant laws, this group has to face additional risks and consequences in society. Especially in the SRH sector it is harder for people living with a disability to take control to protect themselves from the consequences; therefore, not only their health is constantly at

risk but also their freedom and personal life. Actually, the SRH situation of persons with disabilities is much worse than it could be described in words and soon the consequences of this situation would be irreparable if not properly addressed when it is due. That is why a disability dedicated SRH plan and mechanism should be introduced and deployed as soon as possible. This guideline proposes several possible interventions on how this could be done.

1.2 Target Audience

This guideline is expected to support health-care providers, programme managers, and public health policy-makers across the country to better address the SRHR of persons with disabilities in Bangladesh. It is primarily designed for program managers, policy-makers, and other decision-makers within the public and private sectors. Acknowledging that the disability-centred approach of this guideline may require multi-sectoral engagement, the guideline will also be useful for national-level programme managers and policymakers from other sectors, such as the ministries of education, ICT, family and social welfare. These stakeholders can be partners in delivering interventions that support an all-inclusive approach to SRHR.

Funding has always been a huge concern for the relevant stakeholders in Bangladesh; therefore, services and programs designed considering the low-resource setting will benefit most from the guidance presented here. However, this guideline is relevant for all settings regardless of the physical, social, or economic context, and should, therefore, be considered as a national guidance.

2. Literature Review

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in its article 9, 16, 22, 23, and 25 mentioned in details on the prerequisites and significance of accessibility, freedom from exploitation, violence, and abuse, respect for privacy, respect for home and the family, and health to ensure an inclusive and accessible SRHR, Health, information, education, etc. for persons with disabilities (UNCRPD, 2006).

The Government of Bangladesh, as part of its inclusivity initiatives, has enacted the Rights and Protection of Persons with Disabilities Act 2013 as a logical follow up of ratifying the Convention. The Rights and Protection of Persons with Disabilities Act 2013 has repealed the Disability Welfare Act 2001 through its Section 44(1). The act establishes the right of persons with disabilities to live in a healthy environment. It states that depending on the type of disability, quality medical services, and health care facilities must be provided to persons with disabilities. It prohibits discrimination against persons with disabilities; and also empowers them to make complaints to the District Committee against any discrimination faced while availing health care services and to claim compensation. The Act addresses aspects of food security and nutrition for disabled children and adults. It requires the state to take preventive measures to lower the risk of factors responsible for causing disabilities among children and women and to reduce their medical expenses. It also calls for use of accessible modes of communication in all hospitals and medical institutions including sign language interpretation or employment of speech-language therapists where deemed necessary. Under the Act, all aspects of accessibility and mobility is to be ensured for persons with disabilities in medical and health care institutions. Lastly, Schedule 11(Kha) of the Act specifies that the State should encourage insurance companies to set up separate insurance for persons with disabilities to increase their social security (MoSW, 2013).

Under the National Health Policy (NHP) 2011, the State is committed to providing unrestricted access to health care services and other medical services without discrimination and to raise widespread awareness on nutrition, health hazards, and available health care services to ensure a healthy and balanced lifestyle for persons with disabilities. It also stated that free healthcare and services shall be provided for the poor and the disadvantaged members of the society, which especially benefits financially disadvantaged persons with disabilities (MoH & FW, 2011).

The government has articulated its commitment to improving access to sexual and reproductive health and rights through numerous policy and programme documents, including the Population Policy (2012), the National Strategy for Adolescent Health (2017-2030). These documents provide the basis for engaging with the government, NGOs and private sector partners. While there are cultural barriers to provide contraception to unmarried adolescents, as well as reservations about offering sexuality education to very young adolescents, the official policy recognises the strategic importance of investing in adolescents. For the country to capture the demographic dividend, accelerated fertility reduction, accompanied by appropriate socio-economic policies, is essential.

However, the 7th Five-Year Plan (2016-2020) has an all-encompassing promise to address 'accelerating growth and empowering citizens'. It also covers all the important thematic areas that endorse a comprehensive, integrated approach where poverty reduction, health and nutrition are seen as central. When it comes to disability, the 7th Five-Year Plan highly emphasized on autism spectrum disorder (ASD), and briefly mentioned that other disability issues will be properly addressed through appropriate advocacy campaign, effective coordination among concerned ministries, departments, and NGOs for proper preventive, curative and rehabilitative services including expansion of services to cater the need of different types of disabled along with making health-facilities disable-friendly. It also promised to uphold health rights and ethics, such issues will be incorporated in all medical, nursing and other education curricula along with proper sensitization initiatives for the existing health service providers (GED, 2015).

Everything considered, in these laws and commitments, many gaps are preventing the proper inclusion of persons with disabilities in the health sector. Such as, firstly, there are no monitoring mechanisms to oversee compliance with health standards and guidelines for public health care services and facilities for persons with disabilities. Secondly, there is no provision in the various plans for raising public awareness about the plan provisions; persons with disabilities are largely, therefore, unaware of their various health entitlements. Thirdly, there is no separate budget allocated for persons with disabilities relating to health. Fourthly, the Seventh Five-Year Plan has not emphasized enough on the need to develop a physical rehabilitation system for all persons with disabilities, although the Disability Rights Act provides for the adoption of family and community-based rehabilitation through private initiatives, establishment of institutions to enable rehabilitation, and setting minimum standards of care depending on the type and nature of the disability.

3. Methodology and Process for Development of the Guideline

3.1 Core approach

As there is no reliable data and documents on the SRH needs of persons with disabilities living in Bangladesh; therefore, this guideline has been developed in a generalistic way following several international models. It does not picture completely evidence-based claims of its own, rather identified key sectors and issues that deserve first attention by reviewing several relevant national and international documents. Also, this guideline proposed a few generic possible interventions and so forth focusing on the general overall conditions as the first step of action through an intensive desk review.

3.2 Guideline development working group

To develop this guideline YPSA has created a guideline development working group by appointing YPSA's Social Development Department's head as focal person under whom personnel from YPSA's Disability Programme, Health programme, Human rights programme, Gender and Development programme worked to create the guideline. YPSA's Knowledge Management for Development (KM4D) Department helped this group by providing proper facilitation on time.

3.3 Involvement of the persons with disabilities

Many of the individuals involved with this guideline are persons with disabilities. This guideline development process ensured active involvement of persons with disabilities by appointing them in the guideline development working group, involving them in the guideline review and validation group, and also by engaging several organizations of persons with disabilities in the decision making process.

3.4 Guideline review and validation group

The Guideline Review and Validation Group included individuals with a broad range of expertise in issues related to Disability, SRHR, Inclusion, and Accessibility. These individuals background includes research, activism, policy-advisory, programme management, leadership, etc. The group ensured that the guideline considered and incorporated the contextual values and preferences of persons affected by the recommendations. This group provided their

feedback and comments on the draft of the guideline that was shared with them after being drafted, reviewed, and revised by the Guideline development working group.

3.5 Additional key contributors

The below organizations played a significant role in the guideline development process.

- Federation of DPOs, Sitakund – A federation of 40+ DPO
- Chittagong Society for the Disabled (CSD)

3.6 Funding and Technical Support

The funding that was needed for developing this guideline was provided by the Share-Net International, Netherlands. Share-Net also provided necessary technical supports during the guideline development process.

4. Framework to Promote Disability-Inclusive Accessible SRHR in Bangladesh

The relation between a guideline and a framework is that a guideline provides a practical and ethical outline for decision making and course of action/s by creating a sense of responsibility and accountability where a framework focuses on a few smaller set of things because it is impossible to focus on everything and do everything at one go.

Implementing comprehensive SRHR and relevant programmes to meet the health priorities of the persons with disabilities living in Bangladesh requires that interventions be put in place to overcome major barriers to service uptake, including social exclusion and marginalization, accessibility, affordability, gender inequality, etc. These barriers need to be taken into account when putting in place strategies for improving the accessibility, acceptability, uptake, equitable coverage, quality, effectiveness and efficiency of SRH services for persons with disabilities. Applying the framework given below to improve the SRHR outcomes for persons with disabilities will bring changes at multiple levels. Such as: 1. At the personal level, there is a need to focus on supporting persons with disabilities to achieve outcomes such as increased self-confidence and personal agency to make and enact decisions that promote their own health, and improved economic and social assets for personal empowerment. 2. At the affiliation level, there is a need to focus on partners, families, peers and health worker interactions with persons with disabilities to decrease stigma, discrimination, and to promote equality and inclusion. 3. At the community level, there is a need to create positive and equitable social norms, support, understanding including interventions aimed at broader community members and institutions. 4. At the societal level, there is a need to promote laws, policies and institutional practices supportive of the SRHR of persons with disabilities about the health, social, economic and educational spheres, and to build broad societal norms and structures to support persons with disabilities to realize their full SRHR.

For this guideline, in the context of addressing SRHR of persons with disabilities living in Bangladesh, the framework proposed here is expected to help in bringing together additional considerations for defining an enabling environment, including interrelated, multi-level factors that affect the capacity of persons with disabilities to access relevant and necessary SRH services, information and products that are key to shaping their SRHR outcomes as well as other aspects of their health and well-being.

4.1 Establish partnerships with organizations of persons with disabilities

The first step to address the SRH issues of persons with disabilities living in Bangladesh is to establish a dialogue with local organizations of and for persons with disabilities such as DPOs, NGOs, and other advocacy organizations working on behalf of/for persons with disabilities. International organizations of/for persons with disabilities working in/on Bangladesh/Bangladeshi context can also help with their relevant knowledge and expertise on this issue.

Some organizations of persons with disabilities represent people with all types of disabilities, and some work with specific groups of people with disabilities. Speaking with representatives of such organizations, or bringing them together for discussion, can immediately familiarize any stakeholders with local groups and give an understanding of their health and social services situation and concerns both locally and nationally. “Nothing about us without us” is a key principle among persons with disabilities. The Convention on the Rights of Persons with Disabilities reflects this principle. It underscores the importance of including persons with disabilities at all stages of policy development, programme planning, and implementation. Too often, persons with disabilities and organizations of persons with disabilities are consulted only after a policy or programme has been designed. Persons with disabilities must be more than just recipients of SRH programmes and resources. Policies and programmes at all levels will become inclusive and better when organizations of persons with disabilities take part in planning from the outset. Once familiar with local organizations of persons with disabilities and their agendas, it will be easier to establish an on-going advisory team that includes representatives of these organizations. Also, support should be provided to these organizations to implement their own activities for the SRH of persons with disabilities. Training persons with disabilities to provide SRH education and other types of SRH information and services has succeeded in many countries so Bangladesh won't be any different.

4.2 Raise awareness and increase accessibility in-house

Ministry of Health and Family Welfare, Social welfare, and other stakeholders must raise awareness within their administrations – that is, in-house – about the needs and rights of persons with disabilities. Staff members need to be aware of the issues surrounding disability and SRH. They need to understand the importance of including disability issues in all policies and programmes, including those in humanitarian situations. Such awareness must also reach

partners at the local and grassroots level. The SRH of persons with disabilities is not a unique, complex, or highly specialized issue. It is, however, an issue that needs more attention and greater creativity, and it needs more attention now. It cannot wait until after other populations or issues are addressed. The inclusion of SRH concerns of persons with disabilities in on-going programs and policies does not have to be an overwhelming task. It should be an integral part of current work and usually does not need separate or parallel programmes.

4.2.1 Capacity development training for staff and policies for inclusion

Among the best ways to promote awareness and build capacity in-house is to integrate disability-related sessions into existing training. Whenever possible, experts from organizations of persons with disabilities should conduct this training or work with and advise training staff. Also, it is important to promote full coverage of persons with disabilities in their own organizations' human resources policies. Offices, workspaces, and communication should be accessible to persons with disabilities.

4.2.2 Building partnership among different local, national, and international organizations

Partnerships with local, national, and international organizations can amplify the inclusion of persons with disabilities in SRH activities. It is also important to ensure that national and local counterparts working with relevant UN and other international organizations, and all organizations funded at the local and national levels to implement their policies, have policies and activities for inclusion of persons with disabilities, with clear indicators and benchmarks. Coordination among actors is key to moving the agenda forward, preventing duplication of effort, and addressing gaps effectively. Besides, motivating new partners such as those in the private sector as a part of their social responsibility is important.

4.3 Designing inclusive, accessible, and disability dedicated programmes

Review all current programs to ensure that persons with disabilities have access to all programmes and services offered to the community. With modest adaptations, wide-ranging SRH programmes can fully serve most persons with disabilities in Bangladesh. While different groups may need different types of adaptation, it is important to recognize that there are not endless numbers of adaptations, and many cost little or nothing. Common sense and a willingness to innovate can go a long way to assuring services for persons with disabilities in the

SRH sector in Bangladesh. Persons with disabilities in the community and their organizations are more than capable of guiding efforts to ensure accessible environments.

4.3.1 Types of programme

Existing programmes can meet the SRH needs of most persons with disabilities in Bangladesh with very little adaptation. Modest adaptations can accommodate a wide range of people with disabilities, and these adaptations usually can be identified easily with the help of persons with disabilities. As, persons with disabilities are a crucial constituency in all programmes; therefore, persons with disabilities need to be consulted, and the needs of persons with disabilities should be addressed in all programs at all levels. Simple awareness can go a long way, too. Asking a few questions during any intervention could quickly identify unmet needs. For example:

- If it is about improving the quality of health services then are these services offering the same quality of care to persons with disabilities as to other users? If not, what should be done?
- Is it assessing facilities from the perspective of persons with disabilities? Has it considered adaptations for persons with disabilities such as ramps, easy-to-understand written or graphic formats for information, Braille, or sign language interpreters, depending on the necessity?
- Are policies, norms, and procedures being updated from the perspective of persons with disabilities? Do they refer specifically to issues of concern to persons with disabilities?
- Is it integrating disability-related sessions into the pre-service training of staff?

Disability-specific administrations are justified when people or communities are troublesome to reach through a wide range of programs. For example, individuals with intellectual disabilities often benefit from SRH education efforts that are targeted to their level of understanding and learning patterns – slower-paced and presented in a straightforward format, repeated, and reinforced. Such targeted approaches are already familiar to SRH workers and public health professionals, who routinely design population-specific programmes to address

difficult-to-reach populations. Such disability-specific outreach efforts are the exception, however, rather than the rule: most persons with disabilities do not need disability-specific services but rather will benefit from inclusion in SRH efforts designed to reach the general community.

4.3.2 Activities to raise awareness and address misconceptions, stigma, and lack of knowledge

In Bangladesh, many health professionals, organizations, and communities need training or awareness-raising on how to address the SRH of persons with disabilities. Most of the barriers to providing good quality services to persons with disabilities are related to workers' attitudes and basic lack of general knowledge about disabilities. The required information can easily be integrated into existing training strategies and curricula. Training about persons with disabilities and their needs should be addressed both in in-service SRH training for current providers and in pre-service training offered in medical, nursing, midwifery, public health, and hospital administration programmes. Persons with disabilities themselves should be co-facilitators or presenters of such training whenever possible. Raising awareness about SRH for persons with disabilities requires fighting misconceptions, stigma, and discrimination in communities. A key message is that negative attitudes and barriers in societies are often more disabling than the actual impairments. Another key message for all levels is that persons with disabilities are entitled to self-determination, privacy, respect, and dignity in all situations. It is also important to promote awareness of the capabilities and contributions of persons with disabilities. In particular, persons with disabilities, their families, the health and development community, and members of the general public need education about rights and harmful practices such as forced sterilization, forced abortion, and forced marriage. Furthermore, these people need to know whom to contact and where to go to obtain protection against such abuses.

The mass media can play important roles in raising this awareness. SRH professionals, working with different organizations of persons with disabilities, can include information about the SRH of persons with disabilities in mass media outreach efforts and programmes. Even something as simple as including someone with a visible disability among people shown in a poster or TV spot about SRH can help to create a positive image. Similarly, wherever people are brought together to discuss SRH issues, the inclusion of persons with disabilities will quickly

raise awareness. Hotlines and web sites that provide information on SRH or disability issues are additional avenues for raising public awareness.

4.3.3 Activities to improve access

Physical access to buildings and clinics as well as other indoor and outdoor facilities is crucial for ensuring SRH to persons with disabilities. Accessibility should be considered not only for hospitals and clinics but also for places where public health education is provided, locations where condoms are sold or distributed, domestic violence shelters, drug and alcohol intervention programmes, and all other facilities that provide services related to SRH. Keep in mind that physical accessibility alone does not meet the needs of all persons with disabilities. Communication materials and media must also be accessible. Many adaptations to increase access can be made at little or no additional cost. For example, a clinic or a community education programme can be moved from an upper floor to a ground floor room, allowing individuals with physical disabilities to attend. “Accessibility” also means that resources such as condoms and other commodities are available and provided to persons with disabilities with the same rights to confidentiality, self-determination, and respect that everyone deserves.

All those who provide home-based or institution-based health, nutrition, and social services must be trained and monitored to ensure that persons with disabilities are identified and included in all care and community outreach efforts.

4.3.4 Areas to establish indicators and benchmarks

All health programmes should monitor and evaluate whether persons with disabilities are receiving adequate and appropriate services and that they are satisfied with the services. To do so, programmes must establish indicators and benchmarks. Routinely generated statistics should include persons with disabilities as part of the general clientele and also report specifically on services to persons with disabilities. Community scoreboard can be initiated at all the health facilities and community based participatory monitoring and evaluation can ensure the accountability and transparency of all stakeholders.

SRH education for children, young people, and adults with disabilities is often severely limited or nonexistent in the home in Bangladesh. Access to SRH information in school is limited by the fact that persons with disabilities often are denied even the most basic education. As a result, many persons with disabilities cannot read or write, and even those who are literate may not

have enough education to be health literate. When developing programs for persons with disabilities these efforts should be well integrated into other programmes addressing the needs of persons with little education or low literacy who need information.

In rural and urban areas transportation is a major problem for persons with disabilities in Bangladesh because some people are unable to visit clinics, community centres, or other places where SRH services are available. Given the high rates of poverty among this population, many are unable to afford buses, taxis, or other transportation that could take them to services. Even where transportation is available and affordable, the vehicles often are inaccessible to those with physical impairments. Again, when considering transportation schemes intended to improve health service access, considering the needs of persons with disabilities will enable planners to enlarge their view to address all members of the community. Jatiyo Protibondhi Unnayan Foundation runs Protibondhi Seba o Sahaja Kendro at 64 districts and 32 mobile therapy vans which provide health care services. This initiative should be breadth as much as possible in every Upazilas of Bangladesh.

Access also is an issue for persons with disabilities in institutions, group homes, and other residential facilities. They often cannot reach services on the outside and may not have access even to internal health services. Institutionalized persons with disabilities must not be forgotten. SRH workers need to work with communities and with other professionals to remove barriers to access for such groups.

4.4 Address disability inclusion in the national sexual and reproductive health policy, laws, and budgets as a dedicated component

4.4.1 Inclusion in policies and laws

Bangladesh government has addressed disability in many of its policies, but the SRH sector still needs a long way to go; therefore, national SRH policy should be thoughtfully developed keeping in mind the needs of persons with disabilities. Government agencies and policymakers must recognize the knowledge and expertise of persons with disabilities and urge collaboration in policymaking with organizations of persons with disabilities. Relevant senior government officials should take the lead in making sure that all SRH legislation considered in the country reflects the established human rights framework for the inclusion of persons with disabilities. Also, it is important to continuously support the integration of the SRH of persons with disabilities during the development of national human rights institutions, protection systems,

and police and judiciary systems. Working with the legislative groups at the national and regional levels, SRH experts should review existing and new legislation to identify where and how such legislation ensures the rights of persons with disabilities. In addition, it is crucial to look at whether and how these laws are actually implemented. Mapping and involving government institutions and working with police and judiciary will help assure implementation.

4.4.2 Dedicated budgeting for inclusive SRHR

Policies and programmes must be budgeted realistically if they are to make a difference. It is important to remember that the costs of not including persons with disabilities far outweigh the costs of inclusion. Therefore, the priority of dedicated budgeting for inclusive SRHR should be utmost. Furthermore, leaving out persons with disabilities could fail to meet many of the SDGs. Budgets should account for the inclusion of persons with disabilities in all programmes and not just in disability-specific programmes. All budget elements related to SRH, including both public and private medical insurance schemes, should be reviewed to ensure that persons with disabilities are included on an equal basis with others. Additionally, funds should be made available to ensure accessibility. For example, retrofitting clinics to make them physically accessible or paying sign language interpreters.

4.5 Promote research on sexual and reproductive health of persons with disabilities at grassroots, local, and national levels.

In Bangladesh, no significant research has been done about the SRH issues of persons with disabilities. This includes both disability-specific studies and the inclusion of persons with disabilities in larger, population-based studies. To develop a better evidence base, research on SRH of persons with disabilities needs promotion and funding. Also, indicators on persons with disabilities should be included in health surveys and other studies of SRH issues at local and national levels.

To increase the evidence-based recommendations, studies should use the most rigorous design possible to answer the research question. For questions on the effectiveness of particular interventions, randomized controlled trials (RCTs) and other comparative designs should be used. However, it is critical to note that context is required to understand what is truly being tested in an RCT, to enable accurate interpretation of the results, and to support the potential transferability of the findings to other populations or settings. Therefore, qualitative and quantitative process documentation should accompany these trials.

More implementation science and demonstration research would provide information on how to – and how not to – implement recommended practices effectively, in addition to addressing a wide range of other potentially relevant research questions (Peters DH, 2013). Research should be designed and implemented not only to answer relevant research questions but also to facilitate possible future action based on the research findings. Research questions and discussions of findings should take into consideration future implementation actors, contexts, and resources. Adoption of implementation research as a valid method to deliver robust results is key to addressing this (WHO, 2011). Researchers should contextualize their research within the range of relevant existing health services, resources and actors, the relationships between actors, and the variety of influences across the social-ecological framework that may need to be addressed to facilitate beneficial outcomes (Saleem H, 2017). While not every study can cover all elements of a topic, studies should endeavour to consider both clinical and behavioural elements of SRHR and disability and, at a minimum, to consider the limitations of their work in the absence of either. In writing up the research, the authors should fully describe the interventions and the context in which they operate so that they can be transferred to other settings, with appropriate adaptations as needed to ensure the highest probability of success. When it is more appropriate to use qualitative or non-comparative study designs to answer a research question, researchers should be explicit about their methods to ensure the robustness of their results. For example, the theoretical grounding, hypotheses used, level of engagement of the researcher, sampling approach and analysis techniques should be elucidated. This will both improve the rigour of studies and allow for easier translation of findings into effective action (WHO, 2017).

It is important that research identifies achievements, strengths, and platforms upon which to build as well as challenges (Narasimhan M, 2016). Strength- and asset-based approaches and paradigms should be used when planning, conducting, and analyzing research studies. The Global Values and Preferences Survey (GVPS) referenced in this guideline is an example of a positive approach to understanding important health topics, both through study leadership coming from the affected community and through surveys identifying positive practices that can be built upon for action (Orza L, 2014).

Source of framework/Customized framework: *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note, 2009*

5. Possible Interventions Against the Major Issues

SRHR is a relevantly new area for Bangladesh that has only been recognized by the government as well as the development sector, the development sector putting much more emphasis on it, especially those working towards better living or working conditions. When it comes to persons with disabilities, SRHR becomes an unexplored territory even though people with disabilities have the same sexual and reproductive health needs as others. Although, the Government of Bangladesh has already taken some legislative steps towards improving the situation of people living with a disability. However, most of these steps does not entail SRHR while many countries around the world have taken remarkable steps to incorporate the SRH needs of persons with disabilities.

There are many important corners of SRHR that need to be addressed for a person with a disability to survive, sustain and flourish in both the public and private spheres of life, to find his or her place in society. This guideline has proposed possible interventions against the major issues as the first step of action in promoting disability-inclusive accessible SRHR in Bangladesh.

❖ **Issue:** Although one person in every 10 has a disability in Bangladesh, persons with disabilities often remain overlooked because policy-makers frequently underestimate the number of persons with disabilities and thus, assign them to the low priority groups needing attention. Also, they may assume incorrectly that persons with disabilities are not sexually active and so do not need SRH services.

✓ **Possible Intervention:**

1. BBS needs to run dedicated surveys to detect the accurate prevalence of persons with disabilities in Bangladesh. Applying the Washington Group Questionnaire for the survey will add value globally as well as help the right based detecting and the accurate prevalence of persons with disabilities in Bangladesh. Involving national human rights institutions and other relevant government and non-government departments and organizations could fast-track this process.

2. Conduct sensitization workshops and seminars to educate relevant government and non-government officials on disability in light of inclusive SRHR.

3. Promote disability inclusion and SRHR of persons with disabilities via print, electronic, and social media platforms targeting the mass people of Bangladesh. Even a few short messages could raise awareness significantly such as “Disability is everyone’s business”, “Persons with disabilities are not sick”, “Persons with disabilities have sex too”, “Access means more than ramp”, “Persons with disabilities want the same things in life that everyone wants”, “Persons with disabilities are entitled to self-determination, privacy, respect, and dignity”, etc.

❖ **Issue:** In Bangladesh, almost all persons with disabilities face prejudice and stigma in their daily lives especially when it comes to their SRH. Major among these is the fact that many of our country people still believes that persons with disabilities are not sexually active and they are a curse to their parents and family. Therefore, it is often assumed that people living with disabilities neither have the drive nor the need for regular health and SRH facilities. These prejudices underly the deprivation of a wide range of human rights, such as freedom of movement, association to health and education, and pursuit of a livelihood.

✓ **Possible Intervention:**

1. Government itself as well as the print and electronic media platforms need to run dedicated media campaigns to educate the mass people in order to put an end to their current misconceptions, stigma, and attitude towards persons with disabilities.

2. Properly implementing the ‘Persons with Disabilities Rights and Protection Act 2013’ aiming to reduce discrimination against persons with disabilities at all levels.

❖ **Issue:** In Bangladesh, very limited research has been done on the SRH of persons with disabilities. This includes both disability-specific studies and the inclusion of persons with disabilities in larger, population-based studies. Also, indicators

on persons with disabilities are not included in health surveys and other studies of SRH in Bangladesh.

✓ **Possible Intervention:**

1. Ministry of Health and Family Welfare as well as the Ministry of Social Welfare should develop a better evidence base, research on the needs and gaps on SRH of persons with disabilities.
2. Government should promote and fund research on SRH of persons with disabilities at all levels.

❖ **Issue:** The SRH of persons with disabilities have been overlooked by both the disability community and those working on SRH due to their lack of ownership. This leaves persons with disabilities among the most marginalized groups when it comes to SRH services even though persons with disabilities have the same needs for SRH services as everyone else. Persons with disabilities have a greater need for SRH education and care than persons without disabilities due to their increased vulnerability to abuse.

✓ **Possible Intervention:**

1. Persons with disabilities are a crucial constituency in all programs; therefore, persons with disabilities need to be consulted, and the needs of persons with disabilities should be addressed in all programs at all levels.
2. Ministry of Health and Family Welfare and the Ministry of Social Welfare must ensure that relevant government and non-government policies are thoughtfully developed keeping in mind the needs of persons with disabilities, and take into consideration and must support an enabling environment for SRHR of persons with disabilities.

❖ **Issue:** Comprehensive education, information, and services on sexual and reproductive health are critical elements to achieve sexual and reproductive health

rights. Persons with disabilities consider information on sexual and reproductive health not just as a need, but as their right, including the right to information and services on contraception and to make choices on what method to use, and the right to be free from sexual violence. Despite being a right, in Bangladesh, persons with disabilities often do not have equal access to information, education, and services related to sexual and reproductive health, sexuality, and relationship, thus hampering their ability to make informed decisions about these issues.

✓ **Possible Intervention:**

1. Series of workshops and meetings with interactive and engaging participation of persons with disabilities should be organized jointly by relevant government offices such as Information Ministry, Ministry of Education, ICT Division, Ministry of Health and Family Welfare, etc. to find out the accurate needs regarding accessible information and services by, for, and of the persons with disabilities.
2. Government must ensure the availability of information and communication materials in accessible formats e.g. Accessible audio, DAISY, Braille, large print, sign language, simple language, pictures, etc.

❖ **Issue:** Some persons with disabilities lack the necessary skills and knowledge to perform efficiently in their personal life. Yet, there have not been any significant initiatives taken to support and mainstream this physically, mentally, and intellectually challenged population and improve the quality of their personal life, sexuality, and hygiene, apart from some scattered initiatives by government and non-government organizations that barely addresses the issue through providing some charity services.

✓ **Possible Intervention:**

1. Government should regularly monitor and ensure that all the infrastructure of health facilities and services are accessible for all types of persons with disabilities so that they could avail them easily and stay informed.

2. Government must ensure that all SRH service providers are well trained and well-groomed for being free from negative attitudes towards persons with disabilities.

❖ **Issue:** Mental health is related to many aspects of SRH. These include, among others, depression, mental health and psychological consequences of gender-based violence, or feelings of loss and guilt after miscarriage, stillbirth, or unsafe abortion. For persons with disabilities, social barriers may increase the chances of mental health difficulties in these circumstances. It is crucial to pay close attention to the mental health or psychological well-being of persons with disabilities as well as their families, and other care providers.

✓ **Possible Intervention:**

1. Government needs to introduce dedicated sections in future health policies and programs to promote the mental and psychological well-being of persons with disabilities as well as take measures to incorporate the promotion of the mental and psychological well-being of persons with disabilities in all existing policies and programmes.

❖ **Issue:** While many issues faced by persons with disabilities in Bangladesh apply equally to men and women, some issues are gender-specific. Among the special issues, more often faced by women with disabilities than by men, are forced marriage, domestic violence, and other types of physical, emotional, and sexual abuse, the burdens of household responsibilities, and issues concerning pregnancy, labour, delivery, and childbearing. Nonetheless, men with disabilities are also at greater risk of sexual abuse than men who do not have disabilities. In Bangladesh, while women more or less receive instruction or education about SRH either at home or in school, young men are left to pick up information “on the streets” – casually, through other men’s comments, jokes, and hints. Young men with disabilities are often spared from even this information, unreliable and incomplete as it may be.

Young men with mental and intellectual impairments are particularly likely to be deprived of SRH information.

✓ **Possible Intervention:**

1. Government needs to address women and men with disabilities in a dedicated way while formulating or amending policies or laws.
2. Well capacitated, skilled, and enabled organizations of/for persons with disabilities should be patronized by the government as well as the national and international donor agencies to integrate SRHR and gender in their main organizational agendas to ensure human rights and achieve the SDGs.

✓ **Issue:** Like everyone else, persons with disabilities have SRH needs throughout their lives, and these needs change over a lifetime. Different age groups face different challenges. For example, adolescents go through puberty and require information about the changes in their bodies and emotions, and about the choices they face concerning sexual and reproductive health-related behaviour. Adolescents with disabilities need to know all this information, but they also may need special preparation concerning sexual abuse and violence and the right to protection from it. It is important to assure that SRH services are friendly to youth with disabilities. On reaching the age for having a family, women and couples with disabilities, like everyone else, have the right to decide whether and when to have children and a right to sound, unbiased information on which to base these decisions. Health-care providers owe all clients, whether they have disabilities or not, encouragement, support, and appropriate services over the years – both when they want to have children and when they want to prevent pregnancy.

✓ **Possible Intervention:**

1. Age-friendly inclusive SRH services should be ensured by all the stakeholders at all levels across the country.
2. Community-based family planning services along with SRHR information should be initiated at the community level.

3. Open discussion through peer education on SRH, life skills, and comprehensive sexuality education could play a significant role to create an enabling environment.

❖ **Issue:** Too often even programmes with the best intentions have treated persons with disabilities as passive recipients of services. In fact, persons with disabilities constitute a significant stakeholder group that should have a place at the table whenever health programs are planned and decisions are made. Their involvement is the best assurance that programmes will meet their needs effectively.

✓ **Possible Intervention:**

1. Promoting the slogan “Nothing about us without us” at all levels.
2. Government and non-government policies and interventions should be thoughtfully developed and designed ensuring the proper involvement of persons with disabilities in the decision-making process and keeping in mind the needs of persons with disabilities.

✓ **Issue:** The SRH of individuals who have become disabled through accident or illness after puberty is often overlooked. These individuals sometimes do not see themselves as members of a disability community, and often lack the social supports that many people who have grown up with a disability rely on. Indeed, these young people and adults often hold the same prejudices and misperceptions about disability as do some persons without disabilities. Persons disabled later in life may be more likely to confront depression than those disabled from birth or in childhood.

✓ **Possible Intervention:**

1. All relevant surveys should be conducted and all policies should be drafted keeping in mind the people who became disabled by accidents or illness and take adequate measures accordingly.
2. Professionals who provide mental health and psychosocial care should try to reach and treat these individuals accordingly and provide appropriate counselling.

❖ **Issue:** In emergency settings, persons with disabilities often suffer compounded problems of neglect and abuse combined with a particularly difficult physical environment. Emergency preparedness and response plans must provide explicitly for persons with disabilities in all aspects, from evacuations to access to resources upon resettlement, such as food, water, and health services. SRH care is an essential component of such services. To assure awareness of the needs of persons with disabilities, organizations that routinely respond to such emergencies must include persons with disabilities and their families in all their planning processes.

✓ **Possible Intervention:**

1. The needs of persons with disabilities should be addressed at the start of the emergency during the site selection, planning, and design of camp infrastructure and services.
2. Set up a standard, centralized data collection system to collect disaggregated data on the number, age, gender, and profile of displaced persons with disabilities in order to enhance their protection and assistance. Attention should be paid to maintaining the confidentiality of information. Disability awareness training should be provided to all data collection officers.
3. Conduct community-based information and awareness-raising campaigns to promote greater tolerance, respect, and understanding of persons with disabilities. Promote the inclusion of people with all types of disabilities in camp management structures, community decision-making processes, and at all stages of the program cycle, ensuring age and gender diversity.
4. Promote full and equal access to mainstream services for persons with disabilities (e.g. shelter, water and sanitation, food and nutrition, nonfood distributions, health and mental health services, education, vocational and skills training and adult education, income generation and employment opportunities, and psychosocial programmes).
5. Provide targeted services, as needed, for persons with disabilities (e.g. specialized health services, physical rehabilitation and prosthetics clinics, assistive devices, nutritionally appropriate food, learning support needs, education, case management, protection monitoring, and reporting mechanisms).

6. Ensure that displaced persons with disabilities have full access to all durable solution options and to objective information regarding durable solutions in a format that is accessible and easy to understand.

7. Build alliances with local disability providers to support the integration of refugees and IDPs (internally displaced persons) into local disability services. Encourage local displaced persons' organizations to integrate disabled refugees and IDPs into their activities. Ensure that services provided to displaced persons with disabilities are also made available to persons with disabilities in the local community.

Source: Disabilities among Refugees and Conflict-affected Populations: Resource Kit for Field Workers. Women's Commission for Refugee Women and Children, New York, June 2008.

❖ **Issue:** There are persons with disabilities in every ethnic and minority community and other marginalized groups such as indigenous people. For these people SRH and other health services must be ensured by removing barriers to care related to their communities' status as well as to their disabilities. Persons with disabilities in marginalized communities are often insufficiently linked with local organizations of persons with disabilities.

✓ **Possible Intervention:**

1. Special outreach should be conducted by BBS to identify the accurate prevalence and government needs to initiate dedicated programmes to ensure the health rights as well as other human rights of these populations.

❖ **Issue:** Many persons with disabilities in Bangladesh spend many days of their lives in nursing homes, rehabilitation centres, or other institutions such as prisons. In such institutional settings persons with disabilities usually do not receive education or information about their reproductive rights. They are often not provided

resources such as condoms or other family planning options, nor is testing for HIV or other STIs usually available. Sexual abuse and violence are common.

✓ **Possible Intervention:**

1. SRH professionals need to address these populations specifically to ensure that they receive appropriate services in protocols that are accessible for them.
2. Training on Disability Inclusive SRH and psychosocial counselling should be made mandatory for the relevant health care providers.

6. Service Delivery and Guideline Implementation

The ultimate goal of this guideline and its proposition is to improve the quality of interventions, health services, and sexual and reproductive health and rights outcomes for persons with disabilities living in Bangladesh. The admiration, fortification, and completion of internationally recognized human rights, such as the right to the highest attainable standard of health and the right to non-discrimination, require that all people have access to high quality and affordable health services. An effective process for developing and implementing a national or local response to the SRHR of persons with disabilities should follow a disability-centred approach. This process involves both an ethical and rights-based approach, and coordination among all key stakeholders, including meaningful participation of persons with disabilities and their organizations. Ensuring that the needs and rights of persons with disabilities concerning sexual and reproductive health are supported involves meeting standards about the availability, accessibility, acceptability, and quality of health-care facilities, supplies, and services. Specifically, in addition to other health system strengthening initiatives, investment is urgently needed in areas such as training of health-care providers, accessible infrastructure and information, etc. Such investment should be considered a top priority because quality SRH care and support of rights for persons with disabilities, has far-reaching benefits for individuals, families, communities, and mostly the country.

Action on the propositions in this guideline requires a strategy that is backed by evidence and responsive to the needs and rights of persons with disabilities. Therefore, programmes should aim to achieve, most of all, equitable health outcomes, promote gender equality, and deliver the highest-quality care efficiently at all times.

An effective process for developing and implementing a national response to the SRHR of persons with disabilities should follow some guiding principles. Such as:

- An ethical and rights-based approach should inform all decision-making. The planned response, and the decision-making process itself, should be non-discriminatory and accountable to persons with disabilities in all their diversity, respecting and upholding their autonomy and rights. Principles of fairness and equity should be followed.

- Research on the SRHR of persons with disabilities should be conducted with and by persons with disabilities, as equal research partners. Research that is

pursued and funded in this area should include justification for why it is important to persons with disabilities living in Bangladesh. It is necessary to ensure that human rights are actively and effectively integrated into health service planning and the provision of health care in light of the SRHR of persons with disabilities. Similarly, SRHR researchers should aim to incorporate human rights considerations and associated outcome measurements into their study designs and should ensure that the language they use is appropriate to the SRHR context. Research on broader research questions should include persons with disabilities in the study population and should present subgroup analyses to show how the findings may be specific to this group. Also, research should be respectful of the unique situations of participants.

- It is critical to ensure that the decisions made, the plans formulated and the programmes developed are acceptable to community members, equitable, and responsive to community needs. Representatives of persons with disabilities in all their diversity, including from key population constituencies, should be involved at all stages, from designing the response through its implementation, to monitoring and evaluation. It is proved that successful community empowerment develops the capacity of community members and organizations to participate in these processes in a meaningful way, and community-led organizations play a crucial role in delivering services that best meet the needs and priorities of persons with disabilities.

- Addressing SRHR among persons with disabilities requires a multisectoral response. Accordingly, planning of the response needs to involve multiple sectors and stakeholders.

- The ministry of health and ministry of social welfare should take joint responsibility for managing the overall planning process and facilitating the participation of stakeholders and community members. Designating individuals to work specifically on developing and coordinating services may facilitate this.

- The evidence and rationale for decisions should be publicly available, including information on expected effectiveness, anticipated risks, and the distribution of health benefits and burdens for persons with disabilities living in Bangladesh.

- Policies, interventions, and approaches should be based on sound evidence or experience.

- Programmes should aim to achieve equitable health outcomes across all populations and settings and to promote disability inclusion.
- Programmes should seek to deliver effective services most efficiently and to ensure that they are sustainable over the long term.
- Services should deliver the highest quality care at all times. Quality may be a process, requiring ongoing review of service delivery and outcomes.

7. Conclusion

Persons with disabilities have been an excluded group for a long time now even though they have a lot to offer to the country as well as its economy. First of all, their needs and active presence in society needs to be acknowledged. Better treatment, rehabilitation, skill development, income-generating and safety net programs that the government promises will not be enough. Educating the masses and relevant stakeholders on disability inclusion should be the starting point. More importantly, we need to fully include people living with disabilities in general programming and design specific interventions together with them to achieve inclusive SRHR. Inclusiveness is an important component that needs to be addressed in every development initiative which is also recognized by the United Nations in its Sustainable Development Goals (SDGs). Therefore, advocacy and research as well as thoughtful designs will be of utmost importance for Bangladesh if we want to ensure the SRHR of persons with disabilities and achieve the SDGs by 2030.

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