



Practical guide

# Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice

Women's Integrated Sexual Health 2 Action Project (WISH2ACTION)

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## List of acronyms

<b>AIDS:</b>	Acquired Immunodeficiency Syndrome
<b>CHW:</b>	Community Healthcare Worker
<b>UNCRPD:</b>	United Nations Convention on the Rights of Persons with Disabilities
<b>DAISY:</b>	Digital Accessible Information System
<b>DCFP:</b>	Directorate General of Family Planning (Bangladesh)
<b>DMI:</b>	Development Media International
<b>HCF:</b>	Health Care Facilities
<b>HI:</b>	Humanity & Inclusion
<b>HIV:</b>	Human Immunodeficiency Virus
<b>ICESCR:</b>	International Covenant on Economic, Social, and Cultural Rights
<b>INGO:</b>	International Non-Governmental Organisation
<b>IPPF:</b>	International Planned Parenthood Federation
<b>IRC:</b>	International Rescue Committee
<b>LCF:</b>	Leonard Cheshire Foundation
<b>LGBTQI+:</b>	Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex
<b>LSHTM:</b>	London School of Hygiene and Tropical Medicine
<b>MEAL:</b>	Monitoring, Evaluation, Accountability, and Learning
<b>MoU:</b>	Memorandum of Understanding
<b>MSI:</b>	MSI Reproductive Choice
<b>NGO:</b>	Non-Governmental Organisation
<b>OPDs:</b>	Organisations of Persons with Disabilities
<b>SBCC:</b>	Social and Behaviour Change Communication
<b>SGBV:</b>	Sexual and Gender-Based Violence
<b>SRH:</b>	Sexual and Reproductive Health
<b>SRHR:</b>	Sexual and Reproductive Health and Rights
<b>STI:</b>	Sexually Transmitted Infection
<b>WISH:</b>	Women's Integrated Sexual Health Project
<b>WISH2ACTION:</b>	Women's Integrated Sexual Health (Lot 2) Access, Choice, Together, Innovation, and Ownership, Now
<b>WG-SS:</b>	Washington Group Short Set of Questions

## Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice

### Story of change from South Sudan I am able to practice birth spacing now



“I am a 39-year-old woman with a physical disability from Simba, Yei, South Sudan. I encountered problems related to family planning. My husband didn’t want me to use any modern contraceptive methods because he believed that if I used it, I would not be able to bear children anymore. The community also discourages women from using modern contraceptive methods as they believe that it can cause disability in babies whose mothers use contraception. I wanted to use contraception because without it my life was miserable. I couldn’t feed my children and myself properly. Because my health status was poor and I had too many children with no birth spacing, I was ashamed to stay together with people in the community.

Then I participated in trainings from RHASS [SRH implementing partner] and HI under the WISH2ACTION project. I successfully convinced my husband that it is okay for me to use contraception. Now I have been using an implant and IUD, and I found that my health has changed. I am well prepared for my next pregnancy because I have had enough rest and my uterus is now strong.

The change is significant for me as now I am able to practice birth spacing. Because of this, the health of my children has improved and I can send my children to school. Most importantly, I have knowledge on how to use the female condom. With this, I can protect myself when I go to the forest to collect firewood.”

## Introduction

In the most recent World Report on Disability published in 2011, the World Health Organisation and the World Bank estimated that one billion people worldwide are living with one or multiple disabilities, equating to around 15 per cent of the world's population.<sup>1</sup> It is estimated that one in five women has a disability.<sup>2</sup> The number of children with disabilities globally has reached an estimated 240 million.<sup>3</sup>

An estimated 80 per cent of persons with disabilities — approximately 745 million people — live in lower and middle-income countries (LMICs).<sup>4</sup> Nearly seven million persons with disabilities are estimated to have been forcibly displaced by violence or conflict and many more have been disproportionately affected by disasters and the adverse impacts of climate change.<sup>5</sup>

Persons with disabilities have the same sexual and reproductive health rights (SRHR) and needs as their non-disabled peers. Providing accessible and quality sexual and reproductive health (SRH) information, goods, and services to persons with disabilities is an obligation under international human rights standards, including the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the International Covenant on Economic, Social, and Cultural Rights (ICESCR). Indeed, a wide range of UN resolutions reaffirm the sexual and reproductive rights of persons with disabilities.<sup>6</sup> The 74th World Health Assembly in May 2021 adopted a resolution recognising the rights of persons with disabilities to the highest attainable standards of health, including sexual and reproductive health.<sup>7</sup>

The realisation of SRHR for all is also essential to fulfilling the Sustainable Development Goals' mandate, to leave no one behind. Ensuring that quality health care services are available and accessible to the most vulnerable will benefit all those who may need sexual and reproductive health services, whether they are living with a disability or not.

However, the data indicates that persons with disabilities have historically been denied access and agency to fulfil these rights. Persons with disabilities are much less likely to have access to comprehensive sexuality education and contraception, are less likely to be screened for sexually transmitted infections and HIV/AIDS, and are less likely to receive routine screenings for breast, cervical, and ovarian cancers, among other things.<sup>8</sup> Women and girls with disabilities are also more likely to be forced into pregnancy or subjected to forced or coerced procedures, such as sterilisation, abortion, and contraception, and are more vulnerable to violence, including sexual violence.<sup>9</sup> During pregnancy, women with disabilities have a higher risk of preterm birth, gestational diabetes, preeclampsia, and other complications.<sup>10</sup> Inadequate information and a scarcity of accessible resources and services contribute to their vulnerability and the denial of agency and autonomy. These disadvantages begin early in life and continue throughout adulthood.<sup>11</sup>

To advance the rights of persons with disabilities and reduce unmet needs for SRH information and services, Humanity & Inclusion (HI) has developed this Guideline to discuss inclusive practices in SRHR. Based on technical guidance put into practice during the WISH2ACTION

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project, the Guideline draws on HI's long-term experience working alongside persons with disabilities at the global, regional, national, and local level to expand access to SRHR information and services and advocate for greater inclusion in the health sector.

The Guideline aims to provide practical guidance to enable health providers, local and national authorities, and others working in the health sector to ensure high quality and accessible rights-based SRH information and services for all. It collects and shares relevant normative resources and standards as well as lessons learned, technical content, and tools HI has developed and tested working in partnership with persons with disabilities and their representative organisations. The Guideline also draws on technical resources developed by other organisations engaging in this field, such as the Women's Refugee Commission, Sightsavers, and the International Rescue Committee, all of which are committed to assessing and improving accessibility and quality of services for persons with disabilities.

The Guideline is grounded in guidance and standards adopted by international normative bodies and is further enriched with input gathered during an extensive review and consultation process. It reflects insights from representatives of organisations of persons with disabilities, particularly women-led organisations, disability rights advocates, key WISH stakeholders, and technical experts in SRHR, gender equality, and the prevention of gender-based violence. Collectively, the case studies, best practice examples, technical tools, and other resources included in this Guideline are an important resource for those working to advance SRHR for all.

### The WISH2ACTION consortium project

The Women Integrated Sexual Health (WISH) Project is a four-year (2018-2022) UK government-funded project to expand access to sexual and reproductive health and rights for the most vulnerable people. The project is being implemented in 16 countries by a consortium of six international organisations:<sup>12</sup> the International Planned Parenthood Federation (IPPF), MSI Reproductive Choices (MSI), the International Rescue Committee (IRC), Development Media International (DMI), Options, and HI and a group of associated national partners. HI is supporting the other consortium partners in eight<sup>13</sup> of the 16 targeted countries to fulfil the project's mandate and ensure all project interventions and services are inclusive and accessible to all people, including persons with disabilities.

As disability inclusive practices are still relatively limited in SRH services and programming, learning and global goods are key components of the WISH2ACTION project. The consortium partners have worked together to collect and combine knowledge and expertise from international experience, with data and lessons learned applying inclusive practices in the project's diverse local environments and contexts.



## **Purpose and structure of the Guideline**

The overall objective of this Guideline is to support project and programme developers, SRH public and private service providers, and advocates to design, implement, monitor, and evaluate inclusive SRH programmes.

Realising SRHR for all requires a comprehensive, multi-sectoral, and coordinated approach, involving a range of actors and actions. The Guideline is designed to be a resource on the human rights standards and key principles required to achieve disability inclusion, with more specific guidance available for actors working at different levels of SRH service programming and service delivery.

This Guideline is intended primarily to support SRHR actors and practitioners who are active at the local level. The chapters provide relevant background information and refer to selected national and international data. It contains practical recommendations to support implementation and advocacy activities, accompanied by a list of the most relevant resources available on the subject. However, the Guideline does not intend to comprehensively refer to the wider range of academic research and data available on SRHR and disability.

## Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice

The Guideline is divided into three parts:

### **Part I Foundations, key concepts and normative frameworks**

This section offers foundational knowledge for all relevant SRHR stakeholders on key concepts of disability inclusion in SRHR, including legal and normative frameworks, an understanding of barriers persons with disabilities face, and how to address these barriers. Part I is divided into two chapters, as follows:

**Chapter 1** reviews essential concepts relevant to disability inclusion in SRHR

**Chapter 2** provides a summary of the relevant international normative frameworks recognising the human rights of persons with disabilities and mandating equality and non-discrimination in access to sexual and reproductive health information and services

### **Part II Implementing disability inclusive SRHR programmes and services**

This section walks readers through the steps necessary to implement inclusive SRHR programming for different stakeholders. It is also subdivided into chapters, as follows:

**Chapter 3** describes the roles and responsibilities of government, service providers, civil society organizations including international organisations and donors, to advance inclusion and realise the rights of persons with disabilities

**Chapter 4** reviews the process and steps that must be considered within inclusive SRHR programme design, implementation, monitoring, and evaluation in order to ensure inclusive services for all

### **Part III Technical guidance for disability inclusive SRHR for diverse populations, services and contexts**

This section of the Guideline provides inputs related to diverse populations, types of services, and contexts. Part III is organised into the following chapters:

**Chapter 5** offers technical guidance on disability inclusive SRHR related to diverse populations such as youth and persons with diverse sexual orientation and gender identities.

**Chapter 6** reviews technical considerations related to the type of SRHR service, including Family Planning services, obstetric care, abortion, and post-abortion care,

**Chapter 7** provides an overview of inclusive SRHR in humanitarian settings

The Guideline is a living document and does not provide or replace detailed clinical guidance. Users are directed and encouraged to consult additional resources where appropriate.

Collectively, the Guideline invites stakeholders to take action at all levels of health care delivery systems, ensuring that persons with disabilities are able to fully realise their sexual and reproductive rights on an equal basis with others. It should be noted, however, that anyone can contribute to reducing discriminatory stigma and creating more inclusive communities, even those who are not specialists or experts in the field.

Each user of this Guideline is encouraged to take from it what is most useful and adapt it as necessary to particular situations or contexts. Additionally, seeking technical support from HI and other actors with strong expertise in disability inclusion in SRHR is recommended to complement the Guideline and support the design, implementation, monitoring, and evaluation of inclusive SRHR programming. Additional resources and tools are also provided throughout **Part II** and in the annex.

### Putting the Guideline into practice

The Guideline is only one important component of what should be a long-term, multi-sectoral, and integrated approach to fulfilling sexual and reproductive rights for all. Consistent and sustained measures to identify and eliminate discrimination in SRH information and services are necessary so that inclusive practices become routine, rather than the exception. This is necessary to transform the SRH experiences of persons with disabilities and make accessible and inclusive health care a universal reality.

To complement the use of the Guideline, technical support from local OPDs and disability-focused organisations (such as HI and Leonard Cheshire) remains essential to ensure that regular training is provided and monitoring and accountability mechanisms are in place.

Because inclusion works differently in different settings and cultural contexts, persons with disabilities and representative organisations with local knowledge and expertise are essential partners in all efforts to promote disability inclusion. Organisations led by women and young persons with disabilities will be the best sources of information regarding the needs and priorities of the populations they represent, and the barriers they face in accessing SRH information and services. Working closely with persons with disabilities is essential to ensure that programmes to advance sexual and reproductive health and rights are accessible, inclusive of persons with disabilities, and sustainable in the long-term.

# Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice

## Endnotes

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- 8 Lancet Commission. (2018). Accelerate progress—sexual and reproductive health and rights for all: report of the Guttmacher–Lancet Commission, [http://dx.doi.org/10.1016/S0140-6736\(18\)30293-9](http://dx.doi.org/10.1016/S0140-6736(18)30293-9); Kuper, H. & Heydt, P. (2019). The Missing Billion: Access to Health Services one Billion People with Disabilities. <https://www.themissingbillion.org>; UNFPA. (2018). Young Persons with Disabilities: Global Study on Ending Gender-Based Violence and Realising Sexual and Reproductive Health and Rights. New York, United States. <https://www.unfpa.org/publications/young-persons-disabilities>.
- 9 UNFPA. (2018). Young Persons with Disabilities: Global Study on Ending Gender-Based Violence and Realising Sexual and Reproductive Health and Rights. New York, United States. <https://www.unfpa.org/publications/young-persons-disabilities>.
- 10 Gleason, J. L., et al. (2021). Risk of Adverse Maternal Outcomes in Pregnant Women with Disabilities. JAMA Network Open. 2021;4(12):e2138414.; Tarasoff, L.A., et al. (2020). Maternal disability and risk for pregnancy, delivery, and postpartum complications: A systematic review and meta-analysis. Am. J. Obstet. Gynecol. 222(1):27.e1-27.e32. doi:10.1016/j.ajog.2019.07.015.
- 11 Ibid.; Kuper & Heydt, 2019; UNFPA, 2018.
- 12 The organisations participating in the project have complementary areas of expertise and include SRHR service providers IPPF, MSI and IRC and their local partner organisations and public health professionals; two organisations with expertise in advocacy, mass media and social and behaviour change communication (Options and DMI); Humanity & Inclusion which has expertise in the field of disability rights and inclusion; and civil society organisations including organisations of persons with disabilities (OPDs) and other local actors and specialists in the field of disability inclusion and advocacy from the project countries.
- 13 Bangladesh, Pakistan, Afghanistan, Ethiopia, South Sudan, Mozambique, Madagascar and Uganda.

## Foundations, key concepts and normative frameworks

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# 1. Key concepts of disability inclusion

Disability inclusion in SRHR is grounded in respect for the human rights and fundamental dignity of all persons. As stipulated in the UN Convention on the Rights of Persons with Disabilities (CRPD) it requires a basic understanding of the concept of disability, as well as a commitment to the fundamental principles of non-discrimination, meaningful participation, and equal access to quality care.

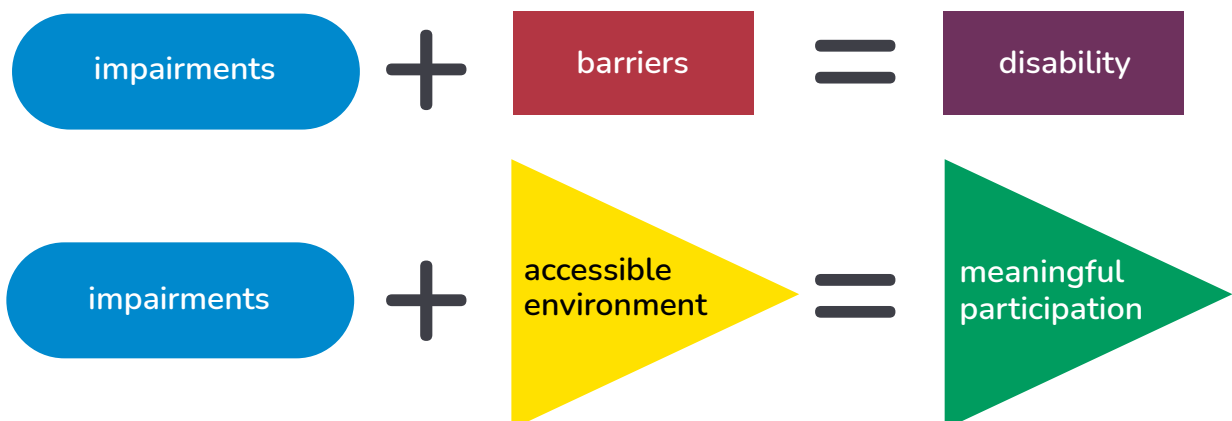
The following two chapters provide an overview of the key concepts related to disability inclusion in SRH and outline the key international normative frameworks referring to sexual and reproductive rights of persons with disabilities.

## 1.1 Disability models and human rights-based approach

*The Convention on the Rights of Persons with Disabilities (CRPD) recognises persons with disabilities as “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.” (Article 1).*

This understanding of disability emphasises that an impairment or health condition alone does not create disability. Rather, what creates disability is the interaction of an impairment with an inaccessible environment, or barriers. The models of disability currently promoted by the disability movement and allies, the social and the human rights models, are based on this definition.

Diagram 1: Disability and meaningful participation



Other models of disability, such as the charity and medical models, are outlined in Box 1. Although they have become less dominant over time, both of these models continue to affect how individuals and communities think about disability and treat persons with disabilities in their midst.

Table 1 illustrates how each of the models influence interactions with persons with disabilities.

## Box 1: Models of disability

**The charity model** of disability depicts persons with disabilities as victims and as objects of charity or pity, whose lives are tragic and who need help. It often depicts persons without disabilities as saviours who provide charitable resources to support persons with disabilities.

**The medical model** of disability approaches disability primarily as a problem of the person, directly caused by disease, trauma, or other health conditions. The medical model sees medical professionals as experts in disability, medical care as the main issue, and finding a ‘cure’ as the main aim.

**The social model** of disability sees disability as socially created and a product of a person’s disability(ies) and the environment in which they live. Adapting the environment by making all modifications necessary for the meaningful participation and inclusion of persons with disabilities in all areas of life is considered a collective responsibility of society at large. Universal design, or the design of an environment so that it can be accessed and used to the greatest extent possible by all people<sup>14</sup>, and reasonable accommodation<sup>15</sup>, are two methods to remove the environmental barriers that create disability.

**The human rights** model emphasises that persons with disabilities are rights-holders, fully entitled to be treated with dignity and as autonomous agents free to make their own decisions. This is the model adopted by the CRPD, calling upon states to take all appropriate measures to eliminate discrimination and ensure that persons with disabilities have equal enjoyment of their rights in all spheres of life. Disability inclusive SRH programmes and services should take a rights-based approach.

Persons with disabilities are often seen as passive recipients of assistance or charity and are thought of only in terms of their health needs.<sup>16</sup> As noted above, the human rights model emphasises that persons with disabilities are active and autonomous agents with legal — and legally enforceable — claims and entitlements. The human rights-based approach demands a fundamental shift from meeting the needs of persons with disabilities to recognising and fulfilling their fundamental human rights.

Table 1: The human rights-based approach of disability.

Needs vs Human Rights based approach	
Needs based	Human Rights based
<ul style="list-style-type: none"> <li>Action is <b>voluntary</b>/optional</li> <li>Needs are <b>contextual</b> and open ended</li> <li><b>People deserve help</b></li> <li><b>Passive</b> beneficiaries – can be invited to participate</li> <li><b>Pragmatic</b> ways to work with structures</li> <li><b>Given scarce resources some people may have to be left out</b></li> <li>Hierarchy of needs</li> </ul>	<ul style="list-style-type: none"> <li>Action is <b>mandatory</b></li> <li>Universal and <b>legally established</b> claims and entitlements</li> <li><b>People are entitled to enforceable rights</b></li> <li><b>Active</b> participants by right</li> <li>Power structures <b>must be</b> effectively changed</li> <li>All people have <b>the same rights</b> to fulfil their potential</li> <li>Rights are indivisible and interdependent though in any situation practical prioritisation may be required.</li> </ul>



## 1.2 Types of disabilities

Persons with disabilities are not a homogeneous group. The kinds of disabilities people experience are diverse and not always apparent. The disability of a wheelchair user may be easy to see, but the disability of a person who is deaf or who has had a traumatic brain injury likely is not. It is important to be aware that some disabilities are invisible and some impairments not apparent.

Types of disabilities might include:

- **Sensory** disabilities, such as vision, hearing, or speech difficulties
- **Physical or mobility** disabilities, such as difficulty walking, climbing stairs, standing for long periods of time, or moving arms or legs
- **Psychosocial** or mental health disabilities, such as depression, anxiety, post-traumatic stress, or social phobias
- **Intellectual, developmental, and learning disabilities**, such as cerebral palsy or autism spectrum disorders
- **Chronic health disabilities**, which can include chronic pain or fatigue
- **Multiple disabilities**, such as deaf/blindness, or mobility and intellectual disabilities

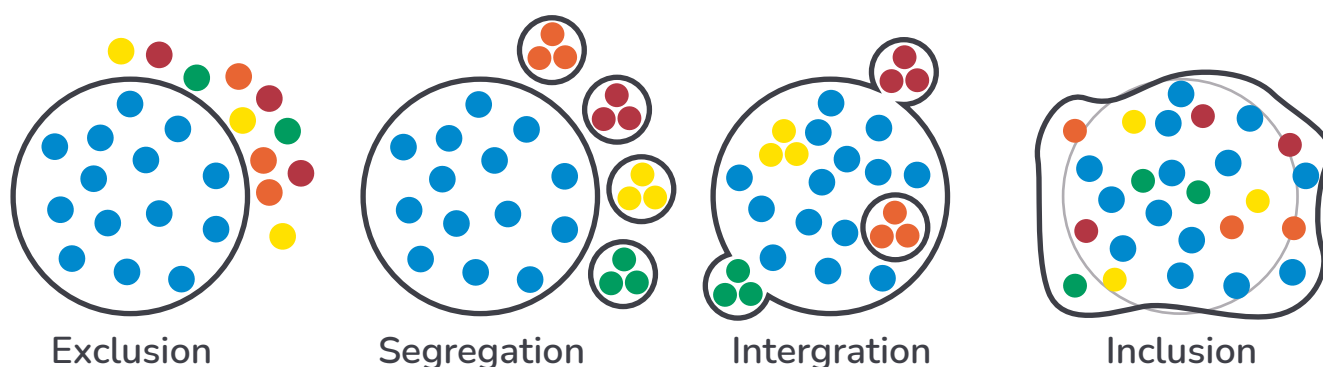
The barriers persons with disabilities experience in participating in their communities and realising their SRHR vary according to the types of disabilities and their interaction with the environment.

## 1.3 Guiding principles of disability inclusion

**Inclusion** refers to the reduction of barriers and the meaningful participation of persons with disabilities in all their diversity in projects, programmes, services, and all other everyday activities, on the same basis as their non-disabled peers. It requires recognition and consideration of their rights, along with the rights of all others, and the adoption of policies and consistent practices to identify and remove barriers that may interfere with their full participation.

Inclusion exists when all persons receive fair, equal, and non-discriminatory treatment, on the same basis as all others, in all aspects of their lives.

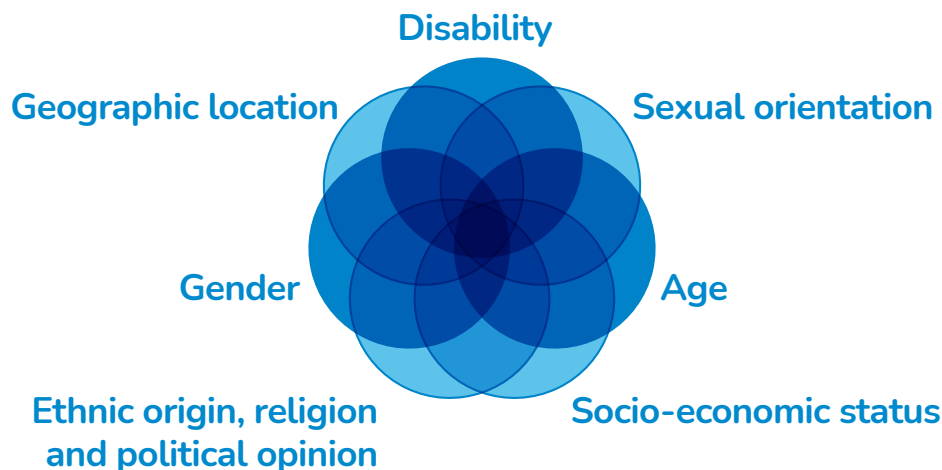
### Diagram 2: Advancing disability inclusion



See HI "Advancing the disability inclusiveness of service providers/entities in post-crisis and development contexts" Practical guide HI Social & Inclusion Division 2019

While persons with disabilities often face disability-related barriers to participation, disability is not the only factor that prevents them from accessing SRHR information and services. To fully promote inclusive SRHR, it is essential to take into consideration the many other intersecting factors that could influence access to information and services, such as gender, gender identity and sexual orientation, age, poverty, social or citizenship status, and other social statuses. Only when the intersection of these different factors is considered is it possible to gain a full understanding of the challenges and barriers that prevent persons with disabilities from accessing SRHR information and services. Likewise, understanding how intersecting factors create barriers is necessary to identify the enablers that are most likely to facilitate access.

## Diagram 3: Intersectionality



HI Disability and Gender Age Intersectionality Internal Policy Paper <sup>17</sup>

A programme or service is disability inclusive when it applies an intersectionality approach that takes into account all of these factors, when promoting the meaningful participation of persons with disabilities of all types and the respect and fulfilment

**Disability inclusion requires the implementation of the following principles:**

- 1 **Barrier identification and barrier reduction**
- 2 **Accessibility and reasonable accommodation**
- 3 **Equality and non-discrimination**
- 4 **Meaningful participation and cooperation with OPDs and persons with disabilities**
- 5 **Twin-track approach**

### 1.3.1 Barrier identification and reduction

Persons with disabilities face multiple barriers to accessing information and services, including quality health services. The barriers are diverse and can have different impacts based on disability type, age, gender, rural or urban context, and other factors. Understanding how persons with disabilities experience barriers and what steps can reduce or eliminate them is essential to plan and implement inclusive programmes.

The World Health Organisation recognises barriers to health services as “factors in a person’s environment that, through their absence or presence, limit functioning and create disability.”<sup>18</sup> The barriers persons with disabilities face take a range of forms, including attitudinal barriers, physical and environmental barriers, communication and information barriers, and policy and institutional barriers (see table 2). These barriers must be addressed by creating an enabling environment.

Examples of the four groups of barriers that persons with disabilities face to accessing SRH information and services, and examples of enabling measures, are provided in the table below:

**Table 2: Barriers and Facilitators for persons with disabilities in fulfilling their SRHR rights**

Barriers	Facilitators
<b>Attitudinal barriers</b>	
<p><b>Discrimination and stigma</b>                      Disrespectful and offensive treatment by health care workers and community and family members.</p>	<p>All health care service providers and staff have received training on disability inclusion and the rights of persons with disabilities.</p>
<p><b>Restricting social norms</b>                      Resistance by family members, including spouses and carers, to the use of family planning services and contraception by women and girls with disabilities.</p>	<p>Trusted advisors, such as OPD members, are recruited to support community mobilisation efforts.</p>
<p><b>Low self esteem</b>                      Low self-esteem and lack of confidence prevent persons with disabilities from accessing information and services.</p>	<p>Peer support networks of women and young persons with disabilities inform and promote SRHR.</p>
<p><b>Misconceptions and myths</b>                      Assumptions that persons with disabilities need specialised care and that SRH service providers do not have sufficient expertise to offer it.                       Misconception that, “persons with disabilities do not have a sexual life.”</p>	<p>Recognition that persons with disabilities are like all other clients and have the same SRH needs as others.                       Public awareness-raising campaigns challenge disability stigma, myths, and misconceptions.</p>

Barriers	Facilitators
<b>Physical and environmental barriers</b>	
<b>Health facility infrastructure is not accessible</b> (steps, narrow entrances, inaccessible toilets, etc.)	Facilities are regularly monitored for accessibility and budgeting allows for infrastructural modification and accessibility.
<b>Health care facilities do not have the necessary equipment</b> (e.g. accessible beds or appropriate medication).	Facility assessments identify gaps in necessary equipment and procure appropriate medications and equipment to meet the needs of persons with diverse disabilities.
<b>Public transportation is not accessible</b> and health care facilities are too far away for persons with disabilities to travel there easily and safely.	Outreach activities, home visits, digital health services, and self-care approaches to SRH are available and accessible.
<b>Local health cluster committees meet in inaccessible buildings</b> and conduct meetings without ensuring the meaningful participation of persons with disabilities.	Committee leaders foresee and plan for accessibility before all meetings. Resources for reasonable accommodations are allocated.
<b>Communication and information barriers</b>	
<b>SRHR information is not provided in accessible formats</b> , resulting in persons with disabilities having limited information about available and accessible SRHR services.	Community mobilisation and outreach efforts integrate multiple accessible communication strategies to reach all types of persons with disabilities.  IEC and SBCC material is provided in different accessible formats (braille, audio, easy-to-read language, etc.)  SRH programme administrators partner with OPDs, women’s organisations, and youth groups to share accessible information about SRH services with their members.  Age-appropriate, comprehensive sexuality education is provided to children and young persons with disabilities.
<b>Limited access to reasonable accommodations</b> during health care service delivery, including sign language interpreters and decision-making supports.	Health care service providers and SRH programme administrators ensure the availability of resources for accommodations (i.e., sign language interpretation, audio materials).

Barriers	Facilitators
<b>Institutional and policy barriers</b>	
<p><b>Government policies and strategies relating to SRH and GBV do not promote the inclusion of persons with disabilities or gender equality.</b></p> <p>Government policies and strategies deny access to SRH programmes, services, benefits, and opportunities.</p>	<p>National laws and policies are aligned with the CRPD and other international standards, mandating non-discrimination and inclusive access to quality SRH information and services for all.</p> <p>National laws and policies are translated into action and adequate budget is allocated.</p>
<p><b>Lack of training or understanding of disability among health care service providers, facility staff, community mobilisers, teachers, and others involved in SRH information and service delivery.</b></p>	<p>National health and education worker training curricula include a module on disability inclusion.</p>
<p><b>The legal capacity of persons with disabilities is restricted</b> and/or procedures for ensuring informed consent are inadequate or fail to protect the decision-making authority and autonomy of persons with disabilities, especially women and girls.</p>	<p>National laws recognise the legal capacity of persons with disabilities and guarantee sufficient supports to exercise decision-making authority.</p> <p>National laws prohibit forced or coerced sterilisation or contraception and other forms of gender-based violence against women and girls with disabilities.</p>
<p><b>SRH programmes are not monitored or evaluated for disability inclusion,</b> making it difficult to know who is accessing SRH services or when interventions to increase accessibility are effective, and for whom.</p>	<p>Data that disaggregates by age, gender, and disability (as a minimum) is collected and assessed at national and local levels to determine who is benefiting from health care services – and who is not.</p>

## 1.3.2 Accessibility

**Accessibility** is one of the core principles of the CRPD and refers to access to “the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas” (Art. 9)<sup>19</sup>.

Accessibility is much more than making sure that buildings have ramps or elevators. It applies to movement and signage within buildings, all forms of public transportation and communication including information relating to work, health care services, education and training opportunities, the Internet and other information and communication technologies, among many other things.

The obligation to ensure accessibility for persons with disabilities lies with both public and private actors. As long as any good, product, or service is open or provided to the public, it must be accessible to all “regardless of whether [it is] owned and/or provided by a public authority or a private enterprise.”<sup>19</sup> Providers are also required to ensure that information, services, products, and facilities are accessible, regardless of whether a person with a disability requests access. In other words, providers cannot simply wait to be asked for goods to be made accessible, but rather, they must have an independent obligation to provide access to all regardless of whether it is specifically requested.<sup>20</sup>

To make accessibility more likely, the CRPD calls for **universal design**, which it defines as “the design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design” (Art. 2).<sup>21</sup> In circumstances where we cannot rely on universal design, accessibility should be ensured through reasonable accommodation.

**Reasonable accommodation** can be a way to ensure accessibility to a person with a disability in a particular situation. The CRPD defines reasonable accommodation as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (Art. 2).<sup>22</sup> For example, if a person who is deaf or hard of hearing needs assistance communicating during a health counselling session, providing a sign language interpreter (if appropriate for the client) is a reasonable accommodation.

As with accessibility, the obligation to provide a reasonable accommodation is on the provider of the goods or services. Using the same example as above, if a person who is deaf or hard of hearing needs assistance communicating, it is the responsibility of the health care provider to ensure the consultation is accessible by providing the relevant support. The client is not required to bring an interpreter or other support, but must be able to rely on the provider for an accommodation. The only exception the CRPD allows to this mandate is an instance where providing an accommodation creates an undue burden on the provider. What constitutes an undue burden depends on the circumstances, but should be weighed against the goal of enabling persons with disabilities to fully exercise their rights in all instances.

**Accessibility** is an **unconditional** obligation which means that, unlike reasonable accommodation, it cannot be excused on the grounds that it is an undue burden or too expensive.<sup>23</sup>

### 1.3.3 Equality and non-discrimination

Discriminatory attitudes and actions play a key role in preventing persons with disabilities from accessing health services. For this reason, it is important that all health workers and other staff working in health facilities, including security guards, receptionists, and records keepers, have non-discriminative, respectful, and welcoming attitudes towards all clients, including persons with disabilities. and are trained on disability inclusion.

**Discrimination** refers to any distinction, exclusion, or restriction on the grounds of disability, sex, gender, or any other grounds, which has the purpose or effect of preventing the recognition, enjoyment, or exercise of any human right on an equal basis (CRPD, Art. 2).<sup>24</sup> **Equality** exists when individuals can enjoy rights and opportunities to the same extent and on the same basis as all others, without regard to their age, sexual orientation or gender identity, disability, economic status, or any other social factor.<sup>25</sup>

### 1.3.4 Meaningful participation of persons with disabilities

Participation refers to the meaningful involvement of persons with disabilities of different ages, genders, sexual orientation, and disability types in the design, implementation, monitoring, and evaluation of activities or policies.<sup>26</sup> This includes both actions that are specifically for the benefit of persons with disabilities, such as an audit of the accessibility of a health care facility, but also actions and policies for the benefit of both persons with disabilities and their non-disabled peers, such as public health campaigns on the prevention of gender-based violence or treatment of STIs.

Partnership and cooperation with persons with disabilities and their representative organisations is key to meaningful participation.

Partnership with OPDs in SRHR makes organisations, decision-makers and service providers more accountable, responsive, and effective, and their decision-making better informed.<sup>27</sup>



## Box 2: Organisations of Persons with Disabilities (OPDs)

Organisations of persons with disabilities (OPDs) are organisations or groups that are led, directed, and governed by persons with disabilities.<sup>28</sup> OPDs are committed to the empowerment of persons with disabilities and respect and recognition of their human rights. Many engage in advocacy and awareness-raising, but all are essential resources and mutual support for persons with disabilities.

OPDs are of varying sizes and have very different capacities to undertake programmes and projects. Their members may share a particular disability type, gender, or other social identity, such as organisations for persons who are blind or with low vision, or gender, such as organisations of women with disabilities, or other social identity, such as organisations of indigenous persons with disabilities. They may be led by women or young persons with disabilities, or be multi-generational.

OPD members may all live within a single community, or they may have national or international memberships.

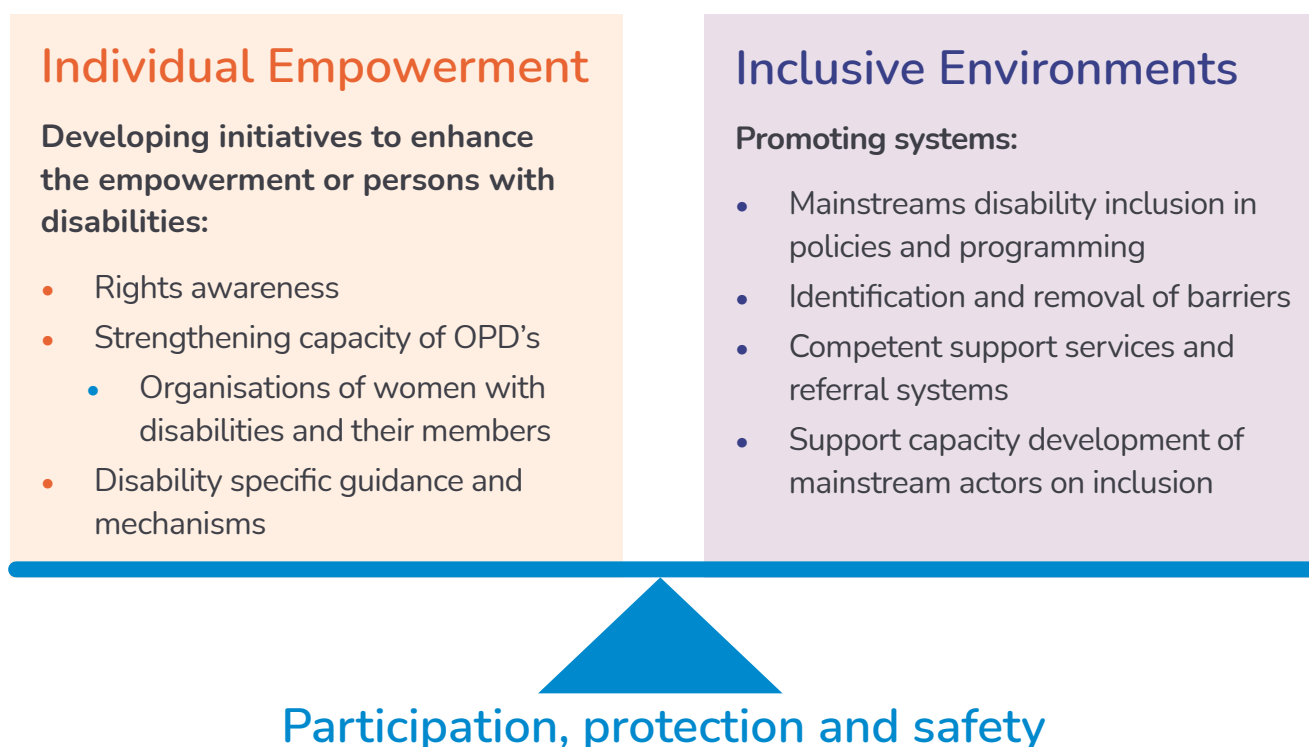
When undertaking any intervention or programming relating to SRH, it is important to identify OPDs within the geographic areas of the programmes and partner with them. Tools for mapping OPDs within a particular country or region can be found in the annexes.

### 1.3.5 Twin-track approach

For disability inclusion to be effective, national decision-makers, SRH programme administrators and civil society organisations working in SRHR and GBV prevention and response must apply a “twin-track” approach. The twin-track approach calls for both:

- **Integrating disability inclusive measures into** the planning, design, implementation, monitoring, and evaluation of **all SRH policies and programmes**, or ‘**mainstreaming**’; *and*
- **Implementing disability-specific programming or initiatives** to meet specific needs and support the empowerment of persons with disabilities.

Diagram 4: A twin track approach



Mainstreaming ensures that persons with disabilities can participate on an equal basis in all SRH services and activities available to the non-disabled population, and that their concerns and experiences are an integral part of the development, design, and implementation of relevant laws and policies.<sup>29</sup> At the same time, disability-specific initiatives recognise that targeted measures are often necessary to support persons with disabilities and enable them to access SRH services and information.

In the health and SRH sector, an example of mainstreaming would be to ensure that budgets for all SRH services include funds to provide reasonable accommodations and meet accessibility requirements for persons with disabilities. A more targeted initiative would be the dedication of resources to outreach activities and community mobilisation efforts specifically designed for persons with disabilities.

## Helpful resources

HI. 'Humanity & Inclusion's policy on Disability, Gender and Age' (2018) [https://hi.org/sn\\_uploads/document/pi01\\_disability\\_gender\\_age\\_2019-03-05\\_12-02-42\\_240.pdf](https://hi.org/sn_uploads/document/pi01_disability_gender_age_2019-03-05_12-02-42_240.pdf)

HI. Guidance note 'Towards more inclusive practices: A Disability , Gender and Age Intersectional Resource' (2020) [https://hi.org/sn\\_uploads/document/2020-HI\\_DisabilityGenderAgeIntersectionality\\_GN09.pdf](https://hi.org/sn_uploads/document/2020-HI_DisabilityGenderAgeIntersectionality_GN09.pdf)

Humanity & Inclusion. (2009). Accessibility: How to design and promote an environment accessible to all?. Available at: [https://handicapinternational/Accessibility\\_HowtoDesignandPromote.pdf?1369073547](https://handicapinternational/Accessibility_HowtoDesignandPromote.pdf?1369073547)

CBM. (2012). Inclusion Made Easy: A quick program guide to disability in development. Available at: [https://www.cbm.org/fileadmin/user\\_upload/Publications/cbm\\_inclusion\\_made\\_easy\\_a\\_quick\\_guide\\_to\\_disability\\_in\\_development.pdf](https://www.cbm.org/fileadmin/user_upload/Publications/cbm_inclusion_made_easy_a_quick_guide_to_disability_in_development.pdf)

Humanity & Inclusion. (n.d.). Inclusive development best practices. Available at: [https://www.hi-us.org/best\\_practices](https://www.hi-us.org/best_practices).

United Nations Division for Social Policy (DSPD) & United Nations Department of Economic and Social Affairs (DESA). (n.d.). Toolkit on Disability for Africa: Disability-Inclusive Development. Available at: <https://www.un.org/esa/socdev/documents/disability/Toolkit/Disability-inclusive-development.pdf>.

## 2. International normative frameworks

There is a robust normative framework recognising the sexual and reproductive rights of persons with disabilities. Multiple international conventions recognise and protect the universal rights to health, equality, and non-discrimination. They are binding on the State Parties that have ratified the instruments, and are expected to be translated into national laws and policies. Their implementation, however, remains limited in many countries and, as a result, persons with disabilities continue to face significant challenges in fulfilling their rights. Knowledge of these instruments, however, is essential and a powerful tool in advocating for the right to health for all.

### The right to health

The right to the highest attainable standard of health is a universal human right that belongs to all people, including all persons with disabilities, without distinction of any kind - including age, religion, gender, sex, sexual orientation or gender identity, or any other factors. The right to sexual and reproductive health is an essential component of the right to health and is fundamental to the exercise of all other human rights.<sup>30</sup>

The Committee on Economic, Social, and Cultural Rights, the group of experts responsible for interpreting and enforcing the ICESCR, has recognised four essential components of the right to health which should guide State action to advance sexual and reproductive health and rights. These are **availability, accessibility, acceptability, and quality (known as the AAAQ framework)**.<sup>31</sup> They are relevant components for inclusion and must be met for persons with disabilities on an equal basis.

### Box 3: The AAAQ Framework

**Availability** requires an adequate number of functioning health care facilities and services be available to all, including those with disabilities, and those in both rural and urban settings. Availability also requires facilities be staffed with trained health care workers and skilled service providers capable of providing the full range of sexual and reproductive health services to all persons, including those with diverse disabilities, and stocked with any medications or equipment necessary to perform those services effectively for all persons. This includes making available to all—including young persons with disabilities—a wide range of contraceptive methods, medicines for post-abortion care, and medicines for the prevention and treatment of sexually transmitted infections and HIV.

**Accessibility** requires that services related to sexual and reproductive health care should be accessible to all persons, including persons with disabilities, without discrimination of any kind, and should be free from barriers, including barriers caused by inaccessible physical infrastructure and affordability of sexual and reproductive health services. States are obligated to ensure health facilities are within safe physical and geographical reach of all people, and that all sexual and reproductive health care services are affordable for all. Accessibility also requires respect for the right of all individuals, including adolescents, to seek and receive information on sexual and reproductive health in formats appropriate for their age, gender, educational level, and disability, among other factors.

**Acceptability** requires that all facilities, information and services relating to sexual and reproductive health be respectful of and sensitive to age, gender, disability, and sexual diversity .

**Quality** obligates States to provide health care facilities and sexual and reproductive health care services that are evidence-based and scientifically and medically appropriate, as well as skilled professionals capable of providing them to all individuals, including persons with disabilities.

### Disability rights are human rights

The CRPD affirms the core principles of respect for inherent dignity and individual autonomy —freedom to make one’s own choices — in which all human rights are grounded. It recognises the right of persons with disabilities to be free from all forms of discrimination, including on the basis of sex and gender (CRPD, Arts. 5 and 6).

## Box 4: The Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty. It was adopted by the United Nations General Assembly in 2006 and entered into force in 2008. It has been ratified by 182 countries and signed by an additional nine countries.<sup>32</sup> The CRPD does not create new human rights, but rather reaffirms that all persons with all types of disabilities enjoy the same human rights and fundamental freedoms on an equal basis as all other persons. Equality between men and women and respect for individual autonomy and the inherent dignity of persons with disabilities are among the CRPD’s core principles.

With respect to the right to health, the CRPD Article 25 obligates States Parties to take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties must:

- a) *Provide persons with disabilities with the same range, quality, and standard of free or affordable health care and programmes provided to other persons, **including in the area of sexual and reproductive health and population-based public health programmes**; and*
- b) Provide these health services as close as possible to people's own communities, including in rural areas.

Each of these obligations is as applicable to sexual and reproductive health services as to all other health services.<sup>33</sup>

### **Box 5: The 74th World Health Assembly Resolution EB148.R6: The highest attainable standard of health for persons with disabilities**

In May 2021, the 74th World Health Assembly adopted a resolution reaffirming the right of all persons with disabilities to enjoy the highest attainable standard of health. The Resolution recognises the persistent attitudinal, institutional, and environmental barriers persons with disabilities face in accessing health care services, and calls on States to, among other things:

- Actively involve persons with disabilities and their representative organisations in decision-making and designing programmes to ensure equal access to public health interventions
- Identify and eliminate obstacles that prevent persons with disabilities from accessing health care services, including sexual and reproductive health care services and information
- Provide health care services to persons with disabilities of the same quality available to all others, including on the basis of free and informed consent, personal dignity and autonomy, legal capacity, and the needs of persons with disabilities

World Health Assembly. (2021). Resolution: The highest attainable standard of health for persons with disabilities. EB148/CONF./8; Convention on Economic, Social and Cultural Rights, Art. 12.

### **The rights of women, children, and adolescents to sexual and reproductive health**

In addition to the CRPD, both the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) protect the sexual and reproductive rights of women and young people. The CRC, for example, obligates States to ensure that girls and boys with disabilities have access to free, confidential, adolescent-responsive, and non-discriminatory SRH services, information, and education, including information on contraception, the prevention and treatment of sexually transmitted infections, and menstrual health. The Committee on the Rights of the Child has further affirmed that girls and boys with disabilities have a right to any services necessary to “promote their full inclusion and facilitate effective transitions from adolescence to adulthood” (CRC, Gen. Comment No. 20).

Similarly, the CEDAW recognises the right of all women and girls to be free from discrimination in access to health care services and information (Arts. 2 and 12) and affirms their right to equality within marriage and family (Art. 16).

Multiple treaty bodies have also called for the decriminalisation of abortion and for States to ensure that all women and girls, including women and girls with disabilities, have access to safe abortion services.<sup>34</sup>

### **Sustainable Development Goals (SDGs)**

State obligations to respect, protect, and fulfil these rights for all are affirmed in the Sustainable Development Goals, which call for inclusion of persons with disabilities as part of the global commitment to ‘leave no one behind’. Goal 3 in particular calls for action to ensure the health and well-being of all, including steps to ensure universal access to sexual and reproductive health care services (Target 3.7) and reduce maternal mortality (Target 3.1). It also recognises as an indicator of progress the proportion of all women of reproductive age, including women and girls with disabilities, whose family planning needs are met.<sup>35</sup> Goal 5, to achieve gender equality and empower all women and girls, establishes a target to ensure universal access to sexual and reproductive health and rights for all women and girls (Target 5.6), and measures progress by reference to, among other things, the number of countries with laws and regulations that guarantee women and girls access to sexual and reproductive health care, information, and education.<sup>36</sup>

**Table 3: Overview of normative standards for disability inclusion in SRH**

<b>Convention on the Rights of Persons with Disabilities (2006):</b>
<ul style="list-style-type: none"><li>• Equality and non-discrimination (art. 5)</li><li>• Women with disabilities (art. 6)</li><li>• Children with disabilities (art. 7)</li><li>• Accessibility (art. 9)</li><li>• Situations of risk and humanitarian emergencies (art. 11)</li><li>• Equal recognition before the law (art. 12)</li><li>• Freedom from torture or cruel, inhuman, or degrading treatment (art. 15)</li><li>• Freedom from exploitation, violence, and abuse (art. 16)</li><li>• Protecting the integrity of the person (art. 17)</li><li>• Respect for privacy (art. 22)</li><li>• Respect for home and the family (art. 23)</li><li>• Education (art. 24)</li><li>• Health (art. 25)</li><li>• Joint Statement by the Committee on the Rights of Persons with Disabilities (CRPD) and the Committee on the Elimination of Discrimination Against Women (CEDAW) (2018) on guaranteeing sexual and reproductive health and rights for all women, particularly women with disabilities</li></ul>
<b>International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966):</b>
<ul style="list-style-type: none"><li>• Right to the highest attainable standard of physical and mental health (art. 12)</li><li>• Right to education (art. 13)</li><li>• Rights to protection of the family, children, and young persons (art. 10)</li><li>• General Comment No. 22 (2016) on the right to sexual and reproductive health</li></ul>



**Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (1979):**

- Right to be free from all forms of discrimination against women (art. 2)
- Right to be free from discrimination in access to health care and family planning (art. 12)
- Right of rural women to have access to adequate health care facilities, information, counselling, and services (art. 14)
- Right of women to equality before the law, including with respect to legal capacity (art. 15)
- Right to be free from discrimination in all matters relating to marriage and the family (art. 16)

**Convention on the Rights of the Child (CRC) (1989):**

- Right to be free from discrimination on the basis of disability, sex, or other status (art. 2)
- Right to be free from arbitrary interference with privacy (art. 16)
- Right to information relating to physical and mental health (art. 17)
- Right to protection from all forms of physical or mental violence or abuse (art. 19)
- Rights of children with disabilities to a full and decent life and respect for dignity (art. 23)
- Right of the child to the highest attainable standard of health and access to health care services (art. 24)
- Right to protection from all forms of sexual exploitation and sexual abuse (art. 34)

**Human Rights Council Resolution (2021) 47th session, L.18, Rev. 1 on accelerating efforts to eliminate all forms of violence against women and girls preventing and responding to all forms of violence against women and girls with disabilities:**

- Reaffirming the right of women and girls with disabilities to be free from all forms of violence, including sexual exploitation and forced sterilisation (preamble, 7(a))
- Reaffirming the right of women and girls with disabilities to sexual and reproductive health information and health care services (preamble)
- Reaffirming the right of women and girls with disabilities to full, effective, and meaningful participation in decision-making processes and leadership roles and in the development and implementation of accessible and inclusive laws and policies (7(e))
- Reaffirming the right to accessible and inclusive services and facilities for survivors of gender-based violence (7(f))

**74th World Health Assembly Resolution No. 6 (2021):**

Reaffirming the right of persons with disabilities to access equal quality sexual and reproductive health services and information without barriers

**United Nations General Assembly Resolution (2017) on the Implementation of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto: situation of women and girls with disabilities:**

- Recognising that women and girls with disabilities are subject to multiple and intersecting forms of discrimination (preamble, para. 6)
- Recognising the right of women and girls with disabilities to legal capacity
- Calling on States to take action to prevent and eliminate all forms of violence against women and girls with disabilities (para. 14)
- Reaffirming the right to the highest attainable standard of physical and mental health, including sexual and reproductive health for women and girls with disabilities (para.17)
- Right of girls with disabilities to accessible, scientifically accurate, and age-appropriate comprehensive education on sexual and reproductive health and gender equality (para. 18)

**International Conference on Population and Development Programme of Action (1994):**

Right of all persons to access health care services, including reproductive health care services, family planning, and sexual health services (principle 8)

- 14 Centre for Excellence in Universal Design. (n.d.). What is Universal Design? National Disability Authority of Ireland. Available at <http://universaldesign.ie/what-is-universal-design/>.
- 15 Reasonable accommodation means necessary and appropriate modification and adjustments to ensure for persons with disabilities the enjoyment or exercises on an equal basis with others of all human and fundamental freedoms and rights.
- 16 Gesellschaft fur Internationale Zusammenarbeit (GIZ) GmbH & CBM. (n.d.). A human rights-based approach to disability in development: Entry points for development organisations. Available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/A\\_human\\_rights-based\\_approach\\_to\\_disability\\_in\\_development.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/A_human_rights-based_approach_to_disability_in_development.pdf).
- 17 HI Internal document Politiques institutionnelles | HI <https://hi.org/fr/politiques-institutionnelles>
- 18 World Health Organisation. (2001). International classification of functioning, disability, and health. Geneva; see also Humanity & Inclusion. (2019). Disability Inclusive Sexual & Reproductive Health Services: Attitudinal & Institutional Barriers & Facilitators Assessment. (Assessment Tool).
- 19 Committee on the Rights of Persons with Disabilities. (2014). General Comment No. 2 (2014): Article 9: Accessibility, CRPD/C/GC/2.
- 20 Committee on the Rights of Persons with Disabilities. (2014). General Comment No. 2 (2014): Article 9: Accessibility, CRPD/C/GC/2.
- 21 CRPD, Article 2; Humanity & Inclusion. (2018). Humanity & Inclusion's policy on Disability, Gender and Age, [https://hi.org/sn/uploads/document/pi01\\_disability\\_gender\\_age\\_2019-03-05\\_12-02-42\\_240.pdf](https://hi.org/sn/uploads/document/pi01_disability_gender_age_2019-03-05_12-02-42_240.pdf)
- 22 CRPD, Article 2; Humanity & Inclusion. (2018). Humanity & Inclusion's policy on Disability, Gender and Age, [https://hi.org/sn/uploads/document/pi01\\_disability\\_gender\\_age\\_2019-03-05\\_12-02-42\\_240.pdf](https://hi.org/sn/uploads/document/pi01_disability_gender_age_2019-03-05_12-02-42_240.pdf).
- 23 Committee on the Rights of Persons with Disabilities. (2014). General Comment No. 2 (2014): Article 9: Accessibility, CRPD/C/GC/2.
- 24 CRPD, Article 2; Humanity & Inclusion. (2018). Humanity & Inclusion's policy on Disability, Gender and Age, [https://hi.org/sn/uploads/document/pi01\\_disability\\_gender\\_age\\_2019-03-05\\_12-02-42\\_240.pdf](https://hi.org/sn/uploads/document/pi01_disability_gender_age_2019-03-05_12-02-42_240.pdf).
- 25 See Committee on the Rights of Persons with Disabilities. (2018). General comment No. 6 (2018) on equality and non-discrimination. CRPD/C/GC/6.
- 26 HI, 2019.
- 27 Id.
- 28 CBM International, Humanity & Inclusion, & International Disability Alliance. (2019). Inclusion of persons with disabilities in humanitarian action.
- 29 United Nations Division for Social Policy (DSPD) & United Nations Department of Economic and Social Affairs (DESA). (n.d.). Toolkit on Disability for Africa: Disability-Inclusive Development. Available at: <https://www.un.org/esa/socdev/documents/disability/Toolkit/Disability-inclusive-development.pdf>.
- 30 Committee on Economic, Social and Cultural Rights. (2016). General comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights. E/C.12/GC/22.
- 31 Committee on Economic, Social and Cultural Rights. General Comment Nos. 14 and 22.
- 32 Database of the United Nations Office of Legal Affairs (OLA), <https://treaties.un.org/>, last updated February 2021.
- 33 CESCR, Gen. comment No. 22.
- 34 Committee on the Rights of the Child. (CRC Committee). (2016). General Comment No. 20 on the implementation of the rights of the child during adolescence, ¶ 60, UN Doc. CRC/C/GC/20 (2016); Committee on the Elimination of Discrimination Against Women (CEDAW Committee). (2017). General Recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19, ¶ 31(a), U.N. Doc. CEDAW/C/GC/35 (July 14, 2017); Committee on Economic, Social and Cultural Rights (ESCR Committee). (2016). General Comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the International Convention on Economic, Social and Cultural Rights), ¶ 28, UN Doc. E/C.12/GC/22 (2016); see also CEDAW Committee, General Recommendation No. 24: Article 12 of the Convention (women and health), ¶ 31(c), U.N. Doc. A/54.38/Rev.1 (1999); CRPD Committee & CEDAW Committee, Joint statement on guaranteeing sexual and reproductive health and rights; see also Women Enabled International (WEI). (2020). Abortion and Disability: Towards an Intersectional Human Rights-Based Approach.
- 35 United Nations. (n.d.) SDG Knowledge, <https://sdgs.un.org/goals/goal3>.
- 36 Ibid.



## Implementing disability inclusive SRHR programmes and services

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# Implementing disability inclusive SRHR programmes and services

Disability inclusion is an iterative process and SRH programming requires multi-level and sectoral collaboration, cooperation with persons with disabilities, and an integrated approach that addresses barriers at institutional, environmental, and individual levels. The following chapters identify the necessary steps stakeholders can and should take to promote disability inclusive practices and make them sustainable. They provide practical recommendations through case studies and good practices tested during the WISH2ACTION project.

### 3. Stakeholder roles and responsibilities

“Only governments have the reach and power to effectively scale up disability inclusive SRHR at the national level.”<sup>37</sup>

Realisation of the right to sexual and reproductive health and rights for all requires government action. Governments have the power and authority to effectively address and remove institutional barriers to inclusive SRH, and ensure structural supports for the implementation of disability rights. This includes a wide range of actions, such as partnering with and promoting the empowerment and capacity-building of persons with disabilities and OPDs, adopting and ensuring the implementation of inclusive and non-discriminatory laws and policies, allocating resources for inclusion in national budgets, and adopting inclusive data collection strategies, among other steps.

*Even in States with limited resources, **national governments have a core obligation to adopt a national strategy that ensures enjoyment of the right to health to all and guarantees the right of access to all health facilities, goods, and services on a non-discriminatory basis.***<sup>38</sup>

In addition to governments, stakeholders at all levels can play an important role in designing, implementing, and monitoring policies, programmes, data collection mechanisms, and funding structures that are disability inclusive. These include national, local, and community leaders, international non-governmental organisations (INGOs) that provide and fund SRH information and services, and OPDs working at all levels to advance the rights of persons with disabilities.

**Part II** Implementing disability inclusive SRHR programmes and services  
**Chapter 3**

The tables below outline the roles and responsibilities of all stakeholders to promote and sustain disability inclusion in SRH programming.

**Table 4 Roles and responsibilities.**

Domain	Important activities/ steps	Responsibility
Awareness raising and advocacy		
Raise awareness of disability rights	<b>Foster effective communication</b> and information campaigns, social media engagement etc. <b>to raise awareness of the rights of persons with disabilities</b> to SRHR, including comprehensive sexuality education and freedom from gender-based violence. ■	■ OPDs and other National and international NGOs
Advocate for inclusive SRHR and GBV related laws, policies, strategies and services.	<p><b>1)</b> Advocate for laws, policies and strategies relating to SRHR (including policies specific to family planning, safe abortion and post-abortion care, and the prevention of and response to gender-based violence) to be aligned with the UNCRPD; support and monitor their implementation. ■</p> <p><b>2)</b> Advocate for national law that prohibit any forced or coerced medical treatment, including involuntary sterilisation of women and girls with disabilities, forced or coerced contraception, and all other forms of medical treatment without informed consent. ■</p> <p><b>3)</b> Advocate for health facilities and GBV response services (such as temporary shelters, housing assistance, trauma response and mental health counselling services) to be available and accessible for persons with disabilities; support the relevant assessments and adaptations. ■</p> <p><i>Always include SRH programme administrators and service providers, as well as educators and law enforcement officials as specific targets of awareness raising and advocacy campaigns.</i></p> <p><i>Always include representation of persons with disabilities in public health campaigns in ways that are empowering, and emphasise the autonomy and decision-making capacity of persons with disabilities.</i></p>	■ OPDs and other National and international NGOs
Recognise SRH as essential health care	Recognise sexual and reproductive health services as essential health care for persons with disabilities that cannot be denied or delayed in a public health emergency. ★▲●■	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p> <p>■ OPDs and other National and international NGOs</p>



Domain	Important activities/ steps	Responsibility
Laws and Policies		
Bring laws and policies into alignment with the CRPD	<ol style="list-style-type: none"> <li>1) Review national laws, policies, and strategies relating to SRHR (including policies specific to family planning, safe abortion and post-abortion care, and the prevention of and response to gender-based violence), and ensure that each is aligned with the UNCRPD. ★</li> <li>2) Set firm timelines and goals for the implementation of laws and policies and the for the adoption of disability inclusion strategies and monitor compliance. ★▲</li> <li>3) Ensure laws and policies are accessible for persons with disabilities (translation in braille, etc.) ★▲■</li> </ol>	★ Government ▲ Local leaders ■ OPDs and other National and international NGOs
Accountability and access to justice		
Guarantee access to justice for all persons with disabilities	<ol style="list-style-type: none"> <li>1) Ensure accountability and enforcement mechanisms are fully accessible and available to all persons with disabilities, enabling persons with disabilities and their advocates to monitor the implementation of laws and policies and access justice. ★▲</li> <li>2) Empower national human rights institutions (NHRIs) to defend the SRHR of persons with disabilities in different venues. ★▲■</li> <li>3) Support OPDs and National Human Rights Institutions NHRIs to participate in monitoring and reporting mechanisms within the United Nations and relevant regional human rights systems ★▲■</li> </ol>	★ Government ▲ Local leaders ■ OPDs and other National and international NGOs

**Part II** Implementing disability inclusive SRHR programmes and services  
**Chapter 3**

Domain	Important activities/ steps	Responsibility
<b>Accessibility</b>		
Ensure the accessibility of existing facilities	<p><b>1)</b> Ensure that the assessments of the availability and accessibility of all existing health care facilities and GBV response services are conducted. ★ ▲ ●</p> <p><b>2)</b> Determine and allocate the resources needed to ensure that persons with disabilities have equal access to facilities with accessible physical infrastructure and within safe physical and geographical reach. ★ ▲</p> <p><b>3)</b> Develop and implement an action plan with firm timelines to adapt the services according to the assessment on accessibility and availability. ★ ▲ ●</p> <p><i>Always ensure the consultation and collaboration with OPDs. Involve other local/national NGOs if needed.</i></p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p>
Mandate accessibility for all new health care facilities and public infrastructure	<p>Implement the principles of universal design to the greatest extent possible and establish clear standards for the construction and renovation of all health care facilities, ensuring that they meet or exceed ISO standards or other relevant standards for accessibility and use ability by all people. ★ ▲ ●</p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p>
Ensure accessible public transportation and infrastructure	<p>Conduct <b>assessment of public transportation mechanisms</b>. Where safe and accessible public transportation is not available, persons with disabilities should be provided with the support they need to access SRH services. This may include accessible transport vouchers, digital services, home visits, or travel stipends. ★ ▲ ●</p> <p><i>Always ensure the consultation and collaboration with OPDs. Involve other local/national NGOs if needed.</i></p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p>
Ensure SRH information to be accessible to all	<p>Assess and ensure the <b>accessibility of public health information and IEC</b>, including information about national health emergencies and risk communication and strategies to fulfil SRHR and national awareness-raising campaigns. ★ ▲ ● ■</p> <p><i>Materials should take into account the diverse access and communication needs of persons with disabilities and adopt a wide array of communication strategies, informed by input from organisations of persons with disabilities.</i></p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p> <p>■ OPDs and other National and international NGOs</p>

Domain	Important activities/ steps	Responsibility
Quality of care		
Adopt national standards for quality of care in SRH services	<ol style="list-style-type: none"> <li>1) Establish <b>national standards and SOPs for quality of care in SRH services</b> that meet or exceed the criteria set by the WHO, and are inclusive of persons with disabilities. ★ ●</li> <li>2) Prioritise accessibility and non-discrimination of all services for persons with disabilities and allocate sufficient resources to the training of medical personnel on disability inclusion and the accessibility of relevant facilities. ★ ▲ ●</li> </ol>	<ul style="list-style-type: none"> <li>★ Government</li> <li>▲ Local leaders</li> <li>● Service Providers including Facility Coordinators</li> </ul>
Set standards for health care education and training of health care workers	<ol style="list-style-type: none"> <li>1) Adopt minimum <b>standards for the education and training of health care workers</b> and ensure that training modules on disability inclusion <b>are included in national medical training curricula</b> and in all licensing exams. ★ ●</li> <li>2) <b>Require training</b> on disability inclusion for all health care workers at all levels. ★ ▲ ●</li> </ol>	<ul style="list-style-type: none"> <li>★ Government</li> <li>▲ Local leaders</li> <li>● Service Providers including Facility Coordinators</li> </ul>
Promote persons with disabilities as health care workers	<ol style="list-style-type: none"> <li>1) Ensure that <b>medical schools and health care education</b> and training programmes are <b>accessible to persons with disabilities</b> of all types. ★ ▲ ●</li> <li>2) <b>Support the recruitment</b> of persons with disabilities into medical training programmes and as health care workers. ★ ▲ ● ■</li> <li>3) <b>Financially support</b> persons with disabilities to access medical and nursing training and education. ★ ▲ ●</li> </ol>	<ul style="list-style-type: none"> <li>★ Government</li> <li>▲ Local leaders</li> <li>● Service Providers including Facility Coordinators</li> <li>■ OPDs and other National and international NGOs</li> </ul>

**Part II** Implementing disability inclusive SRHR programmes and services  
**Chapter 3**

Domain	Important activities/ steps	Responsibility
Allocation of budget and resources		
Adopt inclusive budgets	<p><b>1) Adopt CRPD-compliant and inclusive budgets</b> for SRH care services and education for persons with disabilities, including adolescents with disabilities. At a minimum, budgets should include one or more dedicated lines of funding for persons with disabilities. ★▲●</p> <p><b>2) Dedicate resources to support accommodations</b> in SRH care services and make facilities accessible. ★▲●</p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p>
Monitor budgets for disability inclusion	<p><b>1) Track budget allocations and spending</b> to ensure resources are being equitably distributed and benefiting persons with disabilities on an equal basis with others. ★▲●■</p> <p><b>2) Establish clear targets for inclusive spending</b> and make these public to allow monitoring progress. ★▲●</p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p> <p>■ OPDs and other National and international NGOs</p>
Ensure accessibility and transparency of budgets	<p><b>1) Require for all proposed budgets to be available</b> in multiple <b>accessible</b> formats. ★▲●</p> <p><b>2) Ensure all public hearings</b> and administrative processes are <b>accessible</b> to persons with disabilities and support their equal participation. ★▲</p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p>

Domain	Important activities/ steps	Responsibility
Data collection and monitoring		
Collection of disaggregated data	<p><b>1) Adopt disaggregated data collection strategies</b> with respect to health services, especially sexual and reproductive health services, to develop robust data sets that can be disaggregated by disability, age, and sex and inform policy and programme development. ★▲●</p> <p><b>2) Mainstream WG-SS into national health information management and monitoring.</b> ★▲●</p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p>
Monitor disability inclusion	<p><b>1) Require all national monitoring and evaluation tools and mechanisms to incorporate disability inclusion</b> as an evaluation area, and include disability inclusion within analyses generated from evaluation findings to identify where and which services are being delivered effectively, among other things. ★▲</p> <p><b>2) Establish indicators</b> by which to measure the implementation of all policies and strategies and disaggregate them by disability, sex, gender, and age, enabling policymakers and stakeholders to assess who is benefiting from which policies – and who may not be. ★▲</p>	<p>★ Government</p> <p>▲ Local leaders</p>
Ensure transparency of data and monitoring mechanisms	<p><b>1) Ensure that all data collection tools are fully accessible</b> to all persons with disabilities. ★▲●</p> <p><b>2) Regularly publish data</b> relating to SRH services in formats that are fully accessible to all persons with disabilities, so that persons with disabilities and their representative organisations can monitor the effectiveness of government policies and programmes and ensure accountability. ★▲●</p>	<p>★ Government</p> <p>▲ Local leaders</p> <p>● Service Providers including Facility Coordinators</p>

To ensure inclusive SRHR becomes an everyday practice, the implementation of the key steps discussed above cannot be left to the initiative of motivated individuals. It must become part of a larger and more structured process towards developing a sustainable, enabling environment. For example, cooperation and participation of OPDs and persons with disabilities in the planning, implementation, monitoring, and quality control of SRHR programmes should be reflected in policies and SOPs of SRH service providers. Non-discriminatory employment of women and persons with disabilities should be stipulated in HR policies. Capacity building of health workers must consider disability inclusion as a crucial competency of health service providers and form part of the training curricula of health and SRH professionals and volunteers.

## 4. Key steps to put inclusive SRHR into practice

All SRH programmes follow a process, including *preparing and planning, implementation, monitoring* and *learning*. The following sections outline key actions that SRH programme planners and administrators should take to make this process inclusive.

The recommendations here are drawn from HI's experience working with WISH2ACTION partners. These are complemented by descriptive cases, references, and tools that have been used successfully during the project and may be helpful for other SRHR programmes.

### Steps to Promote Disability Inclusion in Sexual and Reproductive Health and Rights

#### Preparation & Planning stages

4.1 Mapping the context and relevant actors

4.2. Barriers and accessibility

4.3. Planning and budgeting

#### Implementation stages

4.4. Implementing partnerships with OPDs

4.5. Demand creation and SBCC

4.6. Accessible communication and IEC material

4.7. Inclusive services

4.8. Protection from GBV

#### Monitoring, Evaluation and Learning stage

4.9. Disaggregated data and MEAL

## Preparation and Planning

*“Involving persons with disabilities in programmes from the beginning is key. [INGOs and programme managers] need them to be champions of the programme and reach out to others. OPDs can give advice regarding what is needed and how to go about it, and how to reach other [persons with disabilities]. But this takes consistent consultation.”*

Victor Adis, S. Sudan OPD

SRHR programme managers should integrate disability inclusion at ALL stages of planning for ALL SRHR programmes. This includes planning for accessibility and accommodations during programme scoping, gathering input from OPDs during design and development, and recruiting persons with disabilities as programme staff, leadership, and partners on implementation.

### 4.1. Mapping the context and relevant actors

To carry out proper planning and ensure multi-sectoral and inclusive cooperation, it is essential to collect information about the context in which the programme will take place. This includes the barriers and enablers that prevent and facilitate access to SRH information and services locally, and information about persons with disabilities, OPDs, other relevant stakeholders, and the existence (or lack thereof) of laws and policies acknowledging the sexual and reproductive rights of person with disabilities. Information should be collected through a mapping exercise which can also inform the development of a local situational analysis and needs assessment, and should be carried out in collaboration with persons with disabilities and their representative organisations. The mapping should include reference to the capacity of OPDs to design and implement SRHR-related programmes, and to the local access of persons with disabilities to SRHR information and services.

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## Key Actions<sup>39</sup>

### a. Mapping of the relevant stakeholders, identification of key partners, and establishing partnerships

#### OPDs

- Map the presence of OPDs in the context you are working in, including their number, location, membership, whether members share a specific disability type, their scope of work, capacities, experience in the field of SRHR, available resources, and any other information
- Identify the OPDs that are most relevant for the project, taking into consideration their capacity and skills
- Establish a meaningful partnership, planning ahead the steps needed to strengthen resources and skills

*Keep in mind that OPDs are not a homogenous group. Thus, partnerships with OPDs must reflect this diversity and include women-led OPDs and OPDs working with or led by young persons with disabilities and organization of parents of children with disabilities.*

- Planners should be mindful that young persons and women with disabilities, non-gender conforming persons with disabilities, persons with intellectual and psychosocial disabilities, as well as persons with multiple disabilities, may be under-represented within OPDs. They should consider the ways in which these groups are represented and included.
- Where there are few OPDs or they have very limited capacity, such as in humanitarian settings, planners should seek out persons with disabilities, especially women and young persons with disabilities, and identify potential disability focal persons for further cooperation

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#### Other relevant SRHR stakeholders

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- Research the previous engagement of SRHR stakeholders in the field of disability inclusion, identify any past programme evaluations, and explore the experiences (both positive and negative) they have encountered

4.4

- Map the number and location of health care facilities providing SRH information and services to determine how far persons with disabilities must travel to access services. Find out if these services are accessible and used by persons with disabilities, and whether accessible free or low-cost public transportation is available to them

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- Identify gender-based violence (GBV) and mental health and psycho-social support (MHPSS) services, legal services, shelters, and local services for persons with disabilities, such as rehabilitation centres, inclusive education and special education institutions, etcetera

4.8

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### b. Collecting existing disability data<sup>40</sup>:

*Data helps to reflect the likely extent of SRH needs and mobilise resources for disability inclusion.*

- Identify the number and location of households with persons with disabilities among their members, and the number of persons with disabilities in local populations. Disaggregate the data by types of disabilities, sex, and age.
- Cooperate with other stakeholders, including the national bureaus of statistics, research institutes, UN agencies, and others to collect and match relevant intersectional data (e.g., disability prevalence, poverty, heat maps, refugee data, prevalence of early teenage pregnancies, etc.)

### c. Mapping existing SRHR policies

- Map existing policies that are relevant to SRHR and ensure quality care for all clients, including persons with disabilities. They may include anti-discrimination laws and policies relating to gender equality, GBV, and disability, as well as Standard Operating Procedures (SOPs) focusing on non-discrimination and accessibility principles in service provision, ethical codes for service providers, and the inclusion of disability inclusion indicators into quality management measures and tools (e.g. client exit interviews (CEIs) etc.).
- Use the findings to consult with OPDs and persons with disabilities to help identify which policies need to be changed or adapted in order to ensure sustainable disability inclusion.

#### Example from HI WISH

In all six HI WISH countries, one of the initial steps involved mapping OPDs in the respective service areas. The findings helped to identify relevant disability partners, their scope of work, and their level of capacity, needs, and interests. The mapping process itself used different methodologies, including snow ball principles to enter into direct contact with organisations, learn about main challenges, and share information about the project and SRHR.



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### Helpful resources

- Leonard Cheshire ‘Working together for inclusive sexual and reproductive health’ <https://www.leonardcheshire.org/sites/default/files/2021-11/Working-together-inclusive-sexual-reproductive-health.pdf>
- Tool: HI WISH OPD Mapping tool (see Annex 1 )

## 4.2. Barriers and accessibility

*“Entrances and family planning service delivery rooms of health facilities are not accessible for persons with disabilities. When a person like me visits facilities looking for services, there are communication challenges and social stigma from health care providers. They do not treat us as well as they treat persons without disabilities.”*

Focus group participant, HI Barrier Assessment, Ethiopia

Persons with disabilities are often excluded from SRHR information and services due to the fact that physical and social environments present multiple barriers. To create inclusive health services, the **identification and understanding of barriers** is key and can be carried out through an accessibility assessment (see chapter 1.3.2).

An accessibility assessment collects information on the **accessibility and capacity of a health care facility and health care workers** to deliver quality and inclusive SRH services for persons with disabilities. An assessment is a useful tool through which facility managers can develop plans of action and budgets to improve their facilities and the quality of care they provide. Concerned stakeholders, particularly persons with disabilities and their representative organisations, should be involved from the outset in planning for an assessment and developing an appropriate rating system. The assessment should be carried out by service providers in cooperation with disability experts or competent OPD members following a checklist based on accessibility standards.

### Key Actions

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#### Conduct barriers assessments in the respective service areas

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- A barriers assessment should investigate all types of barriers (attitudinal, physical and environmental, communication and information, institutional and policy - see chapter 1.3.1) in communities and be conducted in consultation with persons with disabilities, health services providers, and community members. The barriers assessment helps identify the barriers that prevent persons with disabilities from accessing SRHR information and services and understand where action should be taken to ensure that their rights are fulfilled. As noted above, barriers include misconceptions and stigma that need to be addressed in order to create a disability inclusive environment and enable SRH services for all.

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- Persons with disabilities are in the best position to provide information about the barriers they face; therefore, barrier assessments should be done in cooperation with OPDs and persons with disabilities.

4.9

- In case the available resources are insufficient to conduct a comprehensive barrier assessment, a modified assessment can be achieved through focus group discussions (FGDs) with OPDs and community members with and without disabilities to explore all types of barriers.

### Conduct health facility assessments

- Assess health facilities to understand the level of inclusiveness and identify gaps that should be addressed

## Box 6: Do's and Don't's

### Four domains to assess for health facility accessibility are:

**Health facility infrastructure:** this includes the entrance (gates, stairs, doorways, signage), the interior of the facility (reception and waiting areas, corridors, toilets, examination rooms, bathing areas, stairways, and elevators) and outdoor spaces.

**Capacity of health workers:** this includes availability and frequency of training on disability and disability inclusive service provision, assessment of perceptions of and attitudes toward persons with disabilities, and the capacity to provide reasonable accommodations.

**Service delivery:** this includes availability of equipment and supplies, cost and relative affordability of services, availability of comprehensive services, and quality of services, including non-discriminatory attitudes.

**Supportive system:** this includes accessibility, accuracy, and availability of information on SRH related topics, coordination and referral mechanisms, and policies and guidelines applicable to health workers as well as facility staff.

M&E and quality management systems: Data is disaggregated by disability age and gender and includes disability inclusion criteria in health service quality assessment tools. Ensure that clients with disabilities have access and are included in client feedback and complaint mechanisms, such as client exit interviews.

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At the conclusion of an assessment, the findings should be shared with all relevant public and private stakeholders. All stakeholders involved, including OPDs, should participate in developing a workplan to address indicators that received an unsatisfactory rating and any other gaps or areas of underperformance.

### Example from WISH Bangladesh and Ethiopia

HI teams in Bangladesh and Ethiopia worked jointly with OPD members and service providers to undertake HCF assessments covering physical accessibility for persons with disabilities, as well as challenges with service provision, such as communication and attitudinal barriers. The tool also looked at areas including coordination, referrals, and policies on disability inclusion.

After conducting these assessments, some service providers realised that inclusion did not always cost a lot of money and that there were issues that could be resolved with few resources. They were able to make some important changes, such as changing the height that posters were hung at to make them more accessible (Bangladesh), adjusting the size of posters (Bangladesh), and purchasing wheelchairs (Uganda).

In Bangladesh, joint assessments led to a shared understanding of what accessibility is, and a commitment to undertake building works to improve accessibility at eight HCFs. Issues that could not be addressed with existing resources were passed to the government to request support - OPDs were able to successfully advocate for the government to fund a ramp at a local facility with stairs that were difficult for persons with disabilities to access.

HCF assessments are useful to identify the barriers in place at HCFs and could encourage joint working between stakeholders to reduce barriers and provide opportunities for advocacy. Undertaking joint assessments and making joint workplans between NGOs like HI, OPDs, and public service providers was a successful practice to ensure action and follow up on disability inclusion. A service provider consortium partner reflected that joint working was a good practice for service delivery, especially in areas such as quality assurance.<sup>41</sup>

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### Helpful resources

- See Sightsavers' *accessibility standards and audit pack: 'Accessibility audit and checklist and consent forms,'* <https://www.sightsavers.org/disability/health/accessibility-standards/>
- Please contact HI technical support if you want to conduct barrier assessments.

## 4.3. Planning and budgeting

*“Involving persons with disabilities in programmes from the beginning is key. [INGOs and programme managers] need them to be champions of the programme and reach out to others. OPDs can give advice regarding what is needed and how to go about it, and how to reach other [persons with disabilities], but this takes consistent consultation.”*

Victor Adis, S. Sudan, OPD

When aiming to promote disability inclusion in SRHR programme for inclusive service delivery and Universal Health Coverage, proper budgeting must be considered.<sup>42</sup>

Planning and budgeting of SRHR programmes must involve persons with disabilities and their representative organisations, in order to estimate realistic costs in the specific national/local context. They must also reflect the needs identified in the disability disaggregated data collection and analysis, showing the hindering and enabling factors that prevent or facilitate access to information and services and the fulfilment of the SRHR of persons with disabilities.

### Key Action

- Develop work plans that include costed actions to address the outcomes of consultations and barriers assessments, and ensure the provision of inclusive SRHR information and services

**Planning and budgeting** service delivery that is accessible and inclusive for persons with disabilities includes costs for:

- Modification of health facility infrastructure, accessible toilets, ramps, sign language, etc. 4.1
- Conducting inclusive home visits and outreach (e.g., at OPD meeting venues, teleservice, mobile clinics, reasonable accommodation costs, etc.) 4.2
- Providing accessible IEC and SBCC material (different formats, audio and visual material, braille, etc.) 4.3
- Cooperating with OPDs in SBCC and training activities (costs for transport and communication, mass media programmes, and OPD cooperation) 4.4
- Involving one or more focal persons with disabilities in health planning committees or other relevant planning and decision-making structures 4.5
- Sensitisation and capacity building of health workers and CHW on disability inclusion in SRHR 4.6
- Training and hiring persons with disabilities as professional health service providers or community volunteers and covering costs for reasonable adjustments, transport costs, software programmes for a blind person, sign language interpretation for a deaf person, etc. 4.7
- 4.8
- 4.9

- Sensitisation and capacity building of staff in SRHR, cooperating with disability experts and OPDs
- Organising community and consultation meetings e.g. FGDs, community dialogues with and without persons with disabilities (transport costs, sign language interpretation, etc.)
- Setting indicators to monitor the actual allocation of budget for inclusion and the use of the funds according to the action plan during the implementation phase

### Example from WISH Bangladesh



HI Bangladesh involved a total of 15 OPDs as partners in the WISH project. To involve the OPDs in the planning phase, HI organised a workshop with different local and national level OPD members. The aim of the workshop was to understand the requirements of persons with disabilities relating to SRH, particularly with respect to family planning, and to identify gaps in information and services. The workshop was organised during the project development phase so that the project activities could be designed to reflect and target the needs of persons with disabilities. OPD members participated in group discussions during the workshop to identify minimum budget requirements in line with the proposed activities to compensate OPDs for their involvement in the SRH programme. Taking into account the strengths and capacities of the participating OPDs, the WISH project in Bangladesh involved them in advocacy-related work at different levels, so that OPDs could raise their voices for themselves. The project allocated a budget for OPDs to pursue these activities, as well as the organisational development of OPDs to ensure their sustainability.

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## Implementation

### 4.4 Implementing partnerships with OPDs

*“The involvement of persons with disabilities in the committee allows them to become mobiliser[s] within their community of persons with disabilities [which] helped us to reach many people. So, we were able to have contact with most persons with disabilities.*

WISH Consortium Partner, South Sudan, HI Endline Evaluation 2021

Partnership and cooperation with OPDs is key to promoting inclusive SRHR and must be fully considered from the design phase of the project. Too often, disability inclusion is considered after programmes have been designed and, in some cases, after implementation has already begun, making it difficult to integrate disability accommodations and to ensure the necessary budget allocations to effectively implement, monitor, and evaluate an inclusive programme.

SRH programme coordinators, INGOs and local service providers, and other stakeholders must be intentional about disability inclusion from the outset and avoid tokenising persons with disabilities or OPD leaders.

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Table 5: Characteristics of programme approaches<sup>43</sup>

Carried out for persons with disabilities	Carried out with or led by persons with disabilities
<b>Prescriptive:</b> Programme managers and staff focus on telling persons with disabilities what to do and how to do it	<b>Collaborative:</b> Persons with disabilities and their representative organisations, programme managers, and staff collaborate and share ideas about what to do and how to do it
<b>Paternalistic:</b> Programme staff and managers assume knowledge, skills, and power lie with them and not with persons with disabilities	<b>Participatory:</b> Programme managers and staff honour and actively seek to leverage the knowledge, skills, and power of persons with disabilities in the community
<b>Tokenistic:</b> Programme managers and staff involve persons with disabilities in programme implementation or oversight as volunteers and not as equal partners	<b>Inclusive:</b> Persons with disabilities and their representative organisations meaningfully participate in the different project phases - programme design, implementation, and evaluation - and are compensated for their time
<b>Commodity-oriented:</b> Programme monitoring and evaluation mainly focuses on goods and services delivered and indicators to be met	<b>Quality-assurance oriented:</b> Monitoring and evaluation mainly focuses on quality, safety, accessibility, and acceptability of services and programmes, community engagement, and community responsiveness, as well as appropriateness of service coverage
<b>Top-down:</b> Programmes focus on building relationships mainly within the health system and with health care providers	<b>Bottom-up:</b> Programmes focus on building relationships within communities and between persons with disabilities and civil society organisations, service providers, local, regional, and national governmental authorities, and others

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The following key steps should be taken in cooperating and building partnerships with OPDs.

## Key Actions

### Assess

- Follow the steps detailed in chapter 4.1 for mapping OPDs and assessing each OPD's capacities, including membership, human and financial resources, current activities and time burdens, ways of conducting outreach and community mobilisation, and strengths and needs with regard to SRH information and programming
- Acknowledge OPDs' knowledge and strength in SRHR, discuss their needs with regard to SRH information and capacity building, and plan accordingly with OPDs to strengthen their skills

### Share and explore

- The objectives of the SRHR programme and the objectives of potential partnership
- Potential fields of cooperation to promote inclusive access to SRHR and to reach persons with disabilities (e.g., in SRH outreach and community mobilisation)
- In consultation with OPDs, balance the interest in establishing a partnership with OPDs, critically taking into account the workload of each OPD. Different OPDs are likely to have very different levels of experience, and many are likely to count on a more informal structure and on limited or no full-time paid staff. It is important to agree on the expectations for all partner activities, taking into full consideration and respecting the characteristic of each OPD

### Support active involvement

- OPDs' staff and members' involvement in assessments, programme planning, and implementation of activities should be compensated accordingly and additional costs such as transport costs should be budgeted for and reimbursed
- Ensure active involvement in Monitoring, Evaluation, Accountability, and Learning (MEAL) processes and plan the sustainable inclusion of OPD member representatives in private or public health planning, monitoring, and accountability structures
- Include OPD representation in programme governance structures, such as steering committees and technical working groups

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### Example from WISH OPD partnerships in South Sudan Setting up a multi-OPD taskforce in South Sudan



*The South Sudan team set up a multi-OPD task team per geographical area, bringing together multiple OPDs to run community activities and work with service providers. The task teams were selected from OPDs focusing on different types of disabilities and were trained in inclusive SRHR, SBCC, and advocacy.*

*The South Sudan team described this as a successful approach and experience, as it ensured the involvement of OPDs working across different types of disabilities and representatives with a diverse background. This approach also promoted a balanced and effective division of responsibilities, and a sense of ownership among OPD representatives who had direct access to the project information and were able to share it directly with the other OPD members. Challenges included providing inclusive communication within the group by addressing and removing communication barriers, and ensuring meaningful participation of representatives with hearing and visual disabilities.*

### Example from WISH Pakistan Working with OPDs to engage persons with disabilities



The Pakistan HI team shared that it was difficult to engage persons with disabilities to attend events initially, due to a lack of awareness about the potential benefit and added value of their participation that often required extra effort to organise transport and the accompaniment of a family member.

The role of OPDs was essential in encouraging the involvement of persons with disabilities and their family members. Once they realised that the events represented an opportunity to strengthen their knowledge about their rights, SRH, family planning, accessibility, and related facilities, persons with disabilities became very eager to participate and participation in community events led to better access to SRH information and services.

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## 4.5. Demand creation and SBCC

*“For [a woman with a disability] who doesn’t know her rights, she will face challenges, and she won’t know that she can speak out.”*

Zekia Musa, South Sudan Women with Disabilities Network<sup>44</sup>

*“The first time I heard about family planning was when I overheard a group of women in my neighbourhood discussing it.”*

- Girl with mobility disability from Arua, Uganda

Because they are often excluded from mainstream services such as education and health, many persons with disabilities, in particular women and girls, are not aware that they have SRH rights or what these mean, and have limited knowledge about existing services and where to find them. Actively promoting their participation in all public SRHR health communication and SBCC intervention and programmes is essential to support their empowerment and increase demand for services.

### Example from WISH Bangladesh

#### Mobile outreach to persons with disabilities in Bangladesh



In Bangladesh, HI staff worked with OPDs to identify and reach out to persons with disabilities by mobile phone to generate demand for SRH services. HI provided the OPDs with sufficient resources to pay the expenses associated with the calls, including airtime, and the OPD members used the time to develop a phone tree\* connecting persons with disabilities within their communities. The phone tree ultimately reached approximately 14,000 persons with disabilities, sharing information about available SRH services.

\*Phone tree: a system for contacting a large number of people in which each person who receives a call then phones a number of other designated people. It is a preliminary organised and agreed method of communicating quickly within a defined community.

### Social Behaviour Change Communication (SBCC)

*“They have to recognise that persons with disabilities are like them, and they deserve to be given these SRH services. When a person with a disability comes in, don’t look at the disability...it is the main barrier our people are facing and you see, it is part of all the barriers – in terms of communication, in terms of transportation, people only see my disability.”*

Zakia Musa, South Sudan Women with Disabilities Network

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Reducing existing attitudinal barriers, such as stigmatisation, stereotyping, and the misconception that persons with disabilities do not have a sexual life, are preconditions to supporting persons and in particular women and girls with disabilities to claim their SRH rights and to feel comfortable accessing SRH information and services. Similarly, conservative disability and gender discriminatory social norms that expect a woman with a disability to tolerate any kind of disrespectful treatment and violence from her husband, and to be grateful for a man who is willing to marry her despite her impairment, must be challenged and transformed. The HI WISH barrier assessments conducted in four WISH countries showed that attitudinal barriers from families, communities, and health service providers are the key factors that prevent persons with disabilities from accessing SRH services.

There is substantial evidence supporting the exchange between persons with and without disabilities, as well as social contact at multiple levels and through multiple avenues, as one of the most effective ways to reduce biases against disability and stigma. This includes self-stigma among persons with disabilities themselves and ultimately improves inclusion and related programmes outcomes. Similarly, involving persons with disabilities in training programmes and community outreach, or other activities that allow persons with and without disabilities to meet and connect, is an effective way to make SRH services more welcoming to all.<sup>45</sup>

SBCC is a fundamental approach in programmes that aim to reduce misconceptions, challenge social norms, and promote human rights and Universal Health Coverage for all. SBCC intervention in SRHR must include and address persons with disabilities at all levels of implementation, following the principles of non-discrimination, accessibility, meaningful participation, and twin-track approach. Areas of SBCC that need to be covered include interpersonal, media, and community mobilisation.

Key learnings from WISH include the key roles of family and community gatekeepers in changing social norms, making communication materials inclusive, and applying an intersectional approach when designing them.

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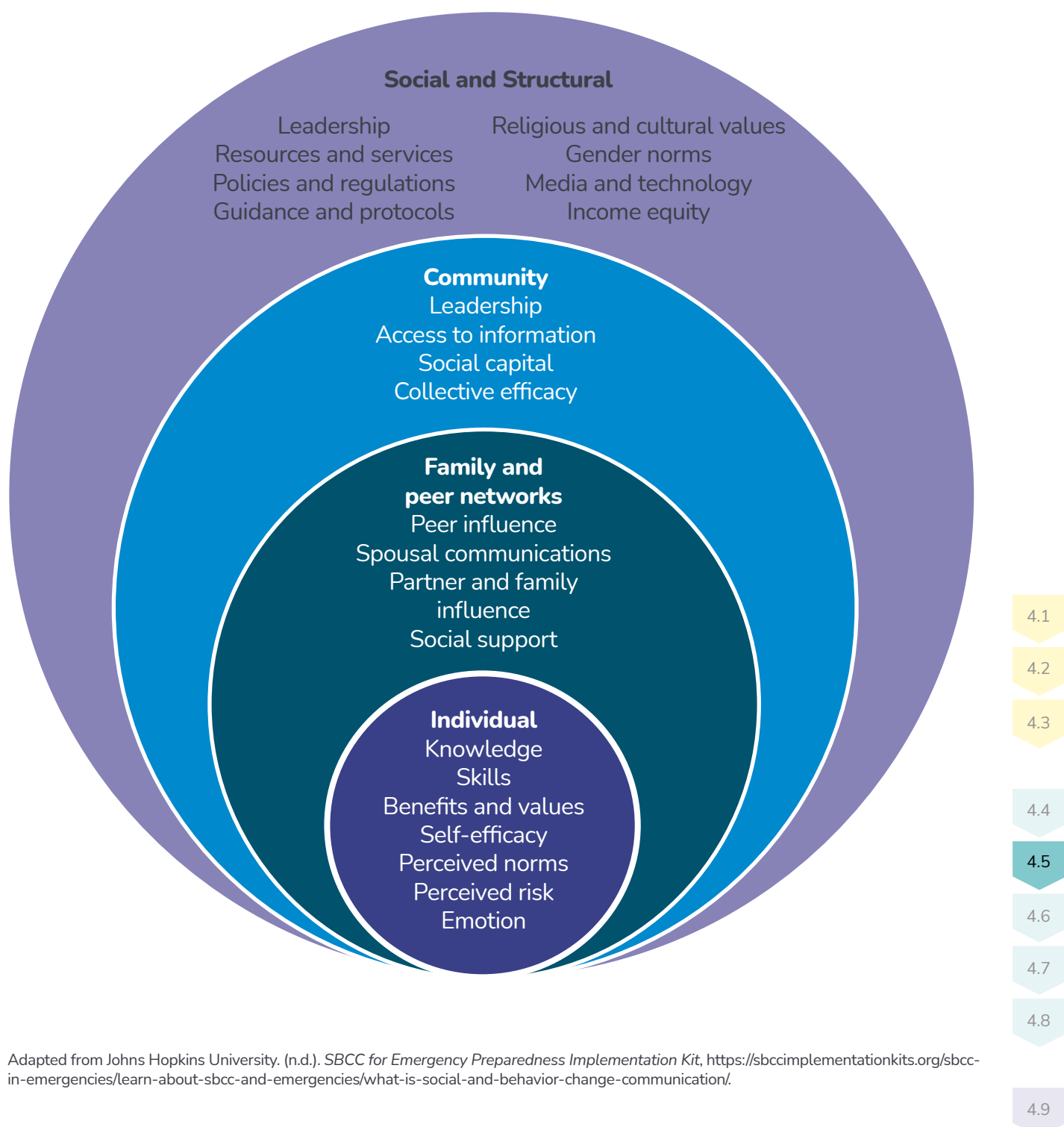
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## Diagram 5: Social and Behaviour Change Communication (SBCC) and disability inclusive SRH

Because social behaviour is affected by multiple factors, effective mobilisation towards inclusion need to target all four levels in the socio-economic model: individual, family and peer networks, community, and social/structural.<sup>46</sup>



Adapted from Johns Hopkins University. (n.d.). *SBCC for Emergency Preparedness Implementation Kit*, <https://sbccimplementationkits.org/sbcc-in-emergencies/learn-about-sbcc-and-emergencies/what-is-social-and-behavior-change-communication/>.

## Key Actions

### Plan and strategise

- Develop SBCC strategies that ensure disability inclusion, in particular the inclusion of women and young persons with disabilities
- Each SRHR and SBCC plan should mainstream inclusion, ensure participation of persons with disabilities in programme staff and community mobilisation, set clear objectives for disability inclusion, and establish mechanisms to assess whether those objectives are being met

### Raise awareness

- Raise awareness of the rights of persons with disabilities among persons with disabilities, their families, partners and caregivers, in communities and schools, and among health actors and mass media professionals
- Reflect on myths and misconceptions and challenge them in community awareness sessions, trainings, posters, regular mass media activities such as radio and TV messages/features/talk shows, and other SBCC communications

### Ensure accessibility

- Ensure accessible venues, transport, and communication for persons with all types of disabilities when planning and conducting consultations and community meetings (including accessible toilets, entrances and exits, hallways, spaces for meals, sign language interpretation, etc.)
- Planners should maintain an accessibility checklist, assessing the physical accessibility of all spaces to be used during community engagement and SBCC programmes (see helpful resources)
- Schedule activities, taking into consideration that for some persons with disabilities it may take longer to travel to and from their homes, or it may be riskier for them to travel after dark
- Mass media activities must consider accessibility (posters in easy-to-read language with appropriate colour contrast, TV shows with sign language or subtitles, and radio talk shows about SRHR and disability rights that feature persons with disabilities, etc.)

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### Meaningful participation

- Reflect on gender, age, and disability norms that limit access to SRHR and challenge them by facilitating the involvement of a variety of key actors, including men, young people, influential gatekeepers, disability rights activists, family members, community leaders, and decision makers in SRH
- Community interventions should be done in partnership with OPD members and language interpreters, including sign language, to ensure inclusive communication

- Prioritise outreach to OPDs and encourage participation of persons with disabilities in all training programmes for service providers and staff, thereby increasing opportunities for positive contact and connections between persons with disabilities and services providers
- Recruit and retain persons with disabilities in service provision in different capacities and encourage their participation in community outreach and mobilisation efforts.
- Design and develop peer to peer outreach programmes for young people and women and girls in particular, with the aim of encouraging information-sharing, creating broad supportive networks, and reducing self-stigma.

### Example from WISH Madagascar

#### Organisations of persons with disabilities leading outreach in Madagascar



HI is partnering with three OPDs, two led by women with disabilities, to reach out to persons with disabilities in their communities and share information about sexual and reproductive health and rights and the availability of SRH services. OPD representatives participate in training on SRHR and strategies for advocacy and community mobilisation, share what they have learnt during the training with other OPDs and persons with disabilities in their respective communities, and conduct awareness-raising activities. Awareness-raising in a community typically takes two to three days, during which OPD members carry out home visits to households with a person with a disability and conduct question and answer programmes in public spaces. On the last day of the programme, an SRH service provider offers information and services to community members, including persons with disabilities.

OPD members have reported that “when they enter communities, people are surprised to see them and ‘assume they are there to beg.’ When they start talking about SRH and family planning, ‘it opens [community members’] eyes’ so they can see that persons with disabilities have the same concerns and have important information to share.<sup>47</sup>”

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### Example from WISH Madagascar Recognising diverse gatekeepers to inclusion



In Madagascar, Humanity & Inclusion took a strategic SBCC approach to engaging stakeholders with an interest in sexual and reproductive health and rights. After developing initial relationships with OPDs and service providers, they worked with OPD partners to deliver a training for the leaders of the Department of Reproductive Health within the Ministry of Health. They conducted an awareness-raising programme on disability inclusion for the National Committee for Family Planning, and for an umbrella group of civil society organisations.

Local SRH service providers operated through the use of toll-free hotlines and telephone information services. In many cases, particularly during pandemic-related quarantines, patients were asked to call a hotline before coming in to see a provider.

HI learned from the telephone operators that they often received what they thought were dropped calls or pranks, where the caller would not speak after being connected. HI designed a training program for the telephone operators that focused on strengthening their skills to facilitate communication and on raising their awareness of the challenges callers may face when attempting to express themselves, which could be linked to communication difficulties or intellectual disabilities.

### Example from WISH Bangladesh Engaging family members



“In Bangladesh, door-to-door visits were an effective SBCC approach for engaging the wider family and it was noted that spouses and mothers-in-law were of key importance, especially in rural areas where stigma around persons with disabilities was more prominent. Family members of persons with disabilities were not always receptive to the idea of them accessing SRH services and found this issue sensitive. Thus, it was important to counsel them and strengthen their understanding on the rights of persons with disabilities. The Bangladesh team reported a higher rate of persons with disabilities accessing SRH services after awareness raising activities. The team also observed that at the beginning of the programme, caregivers were not aware of the rights of persons with disabilities regarding SRH and did not want to discuss it due to the taboo around the issue. To mitigate this, we trained OPD members and built their capacity to conduct awareness raising meetings at the community level”  
- Bangladesh OPD leader

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Example from WISH Madagascar:  
Training journalists in Madagascar



In Madagascar, a selection of journalists who had already worked with consortium partners on SRH were invited to attend a training session, explaining the rights of persons with disabilities, how to portray persons with disabilities, appropriate and non-discriminatory language to use, and how to interact with persons with disabilities. This helped increase quality coverage of SRH in relation to persons with disabilities.

### Helpful Resources

- UN DSPD/DESA 'Toolkit on Disability for Africa, Accessibility Checklist' page 26-27  
<https://www.un.org/esa/socdev/documents/disability/Toolkit/Accessibility.pdf>

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## 4.6. Accessible communication and IEC material

*“The disabled couple did not want to come out from their home; even the caregiver was not interested in sending them to the hospital because they were afraid for the person with disabilities. How will they receive support when they are a hearing-impaired disabled couple? They cannot communicate with them directly and at the hospitals especially, the doctors and nurses do not know sign language.”*

Mr. Badiu Lalam, BPUS (Bangladesh OPD)

Inaccessible communication and SRHR information are key barriers persons with disabilities face when accessing services. In particular, persons with hearing disabilities are often deprived of health information because sign language interpreters are not available. Persons with visual difficulties and with intellectual difficulties might not be able to access information due to the lack of information offered in accessible formats, such as braille, audio, or easy-to-read content with descriptive pictorials. Thus, compiling accessible SRHR material for all communication channels and accessible health education material during consultations is essential.

### Key Actions (accessible communication)

- Be intentional about preparing materials for a broad audience and incorporate different messaging strategies to reach persons who are blind or with low vision, deaf or hard of hearing, have intellectual or cognitive disabilities, are illiterate, or speak different languages
- Inclusive IEC materials should be available through a diversity of means, such as radio messages, popular entertainment, and posters, as well as printed materials, incorporating culturally appropriate imagery and languages
- Work with OPDs and persons with disabilities to determine the preferred communication means that will reach the broadest possible audience in the relevant local contexts
- All information about programme activities should be made available in multiple accessible formats, including through radio announcements or other modes of public communication
- All IEC material should highlight that services are meant for all people. It should feature persons with different types of disabilities and of different ages, sex, sexual orientation, and gender identity. Messages should be phrased in ways that are empowering, presenting individuals as autonomous decision-makers
- Printed material should respect accessibility standards, using easy language, short sentences, colour contrast, large print and accessible fonts, pictures, and diagrams that incorporate local references, images and terms, braille, etc.
- Inclusive IEC and SBCC material and messaging should be developed by consulting and cooperating with OPDs and persons with disabilities (e.g. pretesting of material in FGDs with women and young persons with disabilities, etc.)

- Ensure sign language interpretation for communication with persons with hearing disabilities. In case of absence of an interpreter, or when the person does not know sign language, complement with visual information, pictorials, practicing by showing, gestures, written messages, etc.
- In public health TV messaging, be sure to provide sign language, written subtitles, or closed captioning and, when visual information is relevant, a facilitator should describe what is shown on screen
- Adopt innovative communication technology to promote accessible information (see Digital Accessible Information System (DAISY) example from Bangladesh below)<sup>48</sup>

Table 6: When certain communication strategies may be most useful

Accessible communication method	People with visual difficulties	People with hearing difficulties	People with cognitive difficulties	People with mobility difficulties
Radio	✓		✓	✓
Television	For audio content	For visual content (e.g., subtitles, closed captioning, or simultaneous sign language )	✓	✓
Phone/ SMS messages/ social media	Audio messages	Only SMS messages	Simplified messages with easy language and short clear messages (picture-based if possible )	✓
Printed materials: Posters, billboards, flyers, and SRHR IEC material	Braille	✓	Simplified messages with easy language and short, clear messages (picture-based)	✓
Drama	For spoken content	For visual content ( e.g. mime )	✓	✓
Discussion groups/ community dialogues	✓	with appropriate sign language interpretation	If simplified and accepted by group members	✓

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**Part II** Implementing disability inclusive SRHR programmes and services  
**Chapter 4 | Section 4.6**

One of the most effective strategies to increase community awareness of the availability of services in several locations where WISH has been implemented is the distribution of posters designed by OPD members. Posters created in South Sudan, for example, identify what types of SRH services are available, where they are located, and how persons with disabilities can access them. According to one stakeholder, “these helped a lot” to get the word out about where persons with disabilities can go to access the health care services they need.

Additional examples of inclusive IEC posters created in Bangladesh, Ethiopia, and Madagascar are below.

**WISH poster on menstrual hygiene from Bangladesh**



**English translation**

The leaflet is about menstrual hygiene for all adolescents including adolescent girls with disabilities. In the leaflet there are few general points regarding menstrual hygiene maintenance & 2 additional information targeting adolescent girls with disabilities

**Ethiopian poster on COVID-19**

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**English translation**

Let's ensure the accessibility and continuation of family planning and sexual and reproductive health services for all, including persons with disabilities, in this COVID-19 era.

### WISH SRHR poster from Madagascar



#### English translation

Care for persons with disability.

We will take care of people with disabilities because they are a group of vulnerable people

Recognize that reproductive health is a right to health that people with disabilities should benefit from according to Law 992017-043.

#### Example from WISH Bangladesh

##### Digital Accessible Information System (DAISY)<sup>49</sup>

To support service providers and counselling clients in Bangladesh, HI and the local NGO *Young Power in Action* developed materials, including flipcharts on sexual and reproductive health, using DAISY technology. The materials act as a 'talking book' and can assist in information-sharing with persons who are blind or have visual disabilities. They have been used in counselling and courtyard sessions by government service providers. Government service providers have received a short training and orientation session on the DAISY version so they can use it effectively in counselling sessions at health care facilities. They have also developed and distributed materials in braille and large print for those with visual disabilities.

#### Helpful resources

- 'The DAISY Consortium', <https://daisy.org/info-help/>
- 'How to communicate poster' Light for the world : <https://lab.light-for-the-world.org/publications/how-to-communicate-posters/>
- 'Accessible communication for persons with disabilities' , UNHCR tool : [https://www.unhcr.org/handbooks/aap/documents/UNHCR\\_AAPTTool\\_CT\\_Accessible\\_Communication\\_for\\_PwD.pdf](https://www.unhcr.org/handbooks/aap/documents/UNHCR_AAPTTool_CT_Accessible_Communication_for_PwD.pdf)
- 'Guidance on accessible communication formats' GOV.UK (March 2021): <https://www.gov.uk/government/publications/inclusive-communication/accessible-communication-formats>
- Developmental Disabilities Primary Care Initiative. (2011). *Tools for the Primary Care of People with Developmental Disabilities: Communicating Effectively*. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/communicating-effectively/>.

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## 4.7. Inclusive Services

*“I have realised that it is fundamental for the rights and wellbeing of women, girls, boys, and men with disabilities to have access to effective ISRH services. This is to ensure that our adolescent girls and adults with disabilities can avoid the adverse health and socioeconomic consequences of unintended pregnancy and have a satisfying sexual life like any other person, whereas I used to think that the disabled were not sexually active.”*

– Nurse from South Sudan

**Box 7: For SRHR services to be inclusive, the following aspects need to be considered**

- *Non- discrimination and respectful communication*
- *Capacity building*
- *Ensure accessible SRHR services*
- *Person-centred inclusive approach and informed consent*
- *Collaboration and referral*

### 4.7.1. Non-discrimination and respectful communication

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*“See the person!”*

Tom Shakespeare during a FCDO webinar on ‘Inclusive health’, December 2021)

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Challenges in communicating effectively with persons with disabilities are among the primary concerns service providers expressed during interviews on inclusive health care services and barrier assessments conducted by HI.<sup>50</sup> The WISH programme has addressed this concern and promoted **a person-centred, rights-based approach in all communication with clients**, based on respectful communication and provision of quality information and care that takes into account their individual circumstances, needs and desires, and living environment.

## Key Actions

### Service Providers

- Always focus on the person and engage with persons with disabilities in a respectful way, prioritising their needs and rights
- Avoid disrespectful terms and terms that have negative connotations, such as ‘handicapped’, ‘crippled’, ‘mentally retarded’, ‘crazy’, ‘spastic’, ‘victim’, ‘needy’, ‘different’, ‘strange’, or ‘incapable’. Persons without disabilities should be referred to as such, or as non-disabled persons, rather than ‘normal’ or ‘regular’ persons
- Introduce respectful terms to replace those identified as disrespectful and ensure that all staff, including administrative and janitorial staff if applicable, demonstrate respect for the inherent dignity and worth of all clients with disabilities
- Assumptions that persons with disabilities are inherently vulnerable or incapable undermine agency and autonomy. References to vulnerability should recognise the role of barriers that create disabling environments. It is better to say, for example, “women and girls with disabilities are more vulnerable to gender-based violence than their non-disabled peers”, rather than “women and girls with disabilities are vulnerable”.

### Managers

- Hold service providers and SRH programme staff accountable for disrespectful communication
- Provide regular training to service providers, community mobilisers, and other SRH programme staff using different methods of communication, including basic local sign language
- Recognise that **it is the responsibility of the health care provider, not the client, to provide and pay for whatever services clients may need for communication to be effective.** The denial of reasonable accommodation, including support for effective communication during health care counselling, is a form of discrimination and is prohibited by the CRPD, as well as national laws in many jurisdictions.<sup>51</sup>

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## Box 8: Key points for respectful communication

Some additional tips for respectful communication with persons with and without disabilities include the following:<sup>52</sup>

- Always ask persons with disabilities what would be most helpful to them before providing assistance, and follow their instructions or guidance. For example, ask how a person prefers to communicate, where she would like to sit in a counselling or meeting room, if (and how) she would like assistance to get from one place or room to another, and if she would like information in accessible formats
- Always explain what you are doing when in a meeting or counselling session with a client. If you are entering a room, introduce yourself. If you are leaving a room, let the client know where you are going and when you will be back. If you are preparing equipment, let her know what you are doing and why. If you are sharing diagrams or pictures, describe them and explain why they are relevant. Do not touch a client or her property, including assistive equipment such as a wheelchair, without first asking permission
- Always speak directly to the client and assume she is capable of understanding you. Do not shout or exaggerate words and do not focus on a client's caregiver, if she is accompanied by one
- Use plain language and avoid jargon. Speak in short, simple sentences and pause frequently so the client has time to understand what you have said and respond accordingly
- Use concrete language, such as “show me”, “tell me”, or “do this”, rather than abstract language. Ask a client “are you happy?”, or “are you upset?”, rather than “how do you feel?”<sup>53</sup>
- Pay attention to any way in which a client wishes to communicate. Some persons with intellectual and psychosocial disabilities can exhibit a wide range of behaviours when they communicate with others. If you observe or sense that the person is trying to communicate with you, but you don't understand, it is okay to say “I don't understand.”<sup>54</sup>
- Respect the confidentiality and privacy of all clients with disabilities and hold counselling sessions or meetings in quiet environments where possible, with few distractions, and where clients can communicate safely and privately. If a client is accompanied by a caregiver, ask the client whether she would like the caregiver to be present for the counselling session or not, and respect her decision. If a client requires an interpreter, make sure that the interpreter is aware that all the information shared between the client and her provider is private and confidential and should not be shared with others
- Plan to allow all clients sufficient time for a counselling session or meeting. Keep in mind that some clients may need more time to ask questions about SRH and other health services, understand the information that has been shared with them, and communicate their response

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## Helpful resources

- Developmental Disabilities Primary Care Initiative. (2011). Tools for the Primary Care of People with Developmental Disabilities: Communicating Effectively. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/communicating-effectively/>.
- Women’s Refugee Commission. (2015). Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings: A Toolkit for GBV Practitioners, Tool 6: Guidance on communicating with people with disabilities. <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>.
- Women’s Refugee Commission. (2018). Guidance on Disability Inclusion for GBV Partners in Lebanon: Outreach, Safe Identification, and Referral of Women, Children and Youth with Disabilities. Tool 9: Tips for Communicating with People with Different Types of Impairments. <https://www.womensrefugeecommission.org/research-resources/disability-inclusion-gbv-lebanon-outreach-safe-identification-referral/>
- Pathfinder International (2021). Developing an Adolescent Competent Health Workforce: Training Service Providers in Adolescent Sexual and Reproductive Health
- <https://www.pathfinder.org/wp-content/uploads/2021/02/YFS-Compiled-Final-1.21.21.pdf>

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## 4.7.2. Capacity building

*“I went to talk to the doctor. He was not willing to talk to me. He said: ‘Why are you talking to me? Let me attend my normal patients first, then I will talk to you.’”*

Young woman with physical disability from Kurigram, Bangladesh)

*“Before [the training], we didn’t know that person with disabilities also need our services. We did not think they are also among our targets. We did not think that persons with disabilities also need family planning services”*

Endline Evaluation HI 2021, Consortium Partner, South Sudan, KII

Sensitisation and capacity building of health professionals, volunteers, and other relevant supporting actors remains a key to ensuring inclusive SRH services. The HI barriers assessment revealed that many service providers themselves do not feel confident to provide services to persons with disabilities, whereas persons with disabilities themselves have trust in the competencies of health workers.

Cooperation with OPDs in sensitisation and training activities for health actors often works as an eye opener for the participants, and is helpful to establish cooperation and long term partnerships.

All capacity building trainings should be conducted with input from OPDs. OPDs also benefit from building their capacity on inclusive SRHR and SBCC.

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### Key Actions (capacity building)

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#### Conduct training on disability and disability inclusion for all groups of health workers, professionals, and community volunteers

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- Training content should cover:
  - Disability rights
  - Basic knowledge on disability and inclusion (see chapter 1)
  - Inclusive SBCC and community engagement
  - Referral and disability
  - Collection of disaggregated data (see 4.9)
  - Relevant specific service knowledge focusing on disability and SRHR (see chapters 5 and 6)
- Refresher sessions and trainings, considering staff turn-over, are recommended to be carried out yearly.

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**Train OPDs on the basics of SRHR and SBCC, ensuring that they have the capacity to share information within their networks**

**Provide regular training on sign language to service providers or selected focal persons from each facility**

- Where regular training in sign language is not possible, develop and circulate charts with common signs and images relevant to sexual and reproductive health so that service providers can achieve and maintain a basic level of communication skills

**Provide training to additional SRHR relevant stakeholders**

- If resources allow, train other relevant stakeholders who can contribute to inclusive services (e.g., teachers providing inclusive Comprehensive Sexuality Education (CSE) or architects involved in building accessible health facilities, etc.)

**Promote an inclusive training curricula**

- Promote the incorporation of iSRHR training modules into national health worker and volunteer training programmes and curricula ( see Box no .....

### Example from WISH Uganda

#### OPD members sharing experiences in training



In Uganda, OPDs played the role of 'experts' in disability inclusion and shared their experiences of barriers to access health care. OPD members gave examples of challenges they had experienced in maternity services, such as being asked embarrassing questions about how they got pregnant. The HI team in Uganda shared that the meaningful participation of persons with disabilities in training service providers allows them to challenge misinformation and myths and facilitate constructive dialogue around barriers.

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### Example from WISH Madagascar Disability inclusive curricula on SRHR



In 2019, the Ministry of Public Health in Madagascar began a review of training materials for health care workers, focused on family planning. The Government of Madagascar committed to FP2020 in 2015 and has taken important steps to expand access to family planning and use of contraceptives across the country. The revised training materials are intended to cover the full range of modern contraceptives, technological advancements in family planning and contraception, and good practices and lessons learned relating to postnatal and safe post-abortion care. HI and its WISH2ACTION partner organisations proposed additional modifications and compiled a module on disability inclusion in SRHR, providing health care workers with essential information about the sexual and reproductive rights of persons with disabilities and inclusive SRHR practices. It was approved by the MoH in November 2021

### 4.7.3. Accessible environment

“Sometimes I crawl because the places in the clinic are not accessible.”

- 26-year-old woman with mobility difficulties from Yumbe Uganda

The HI barrier assessment conducted in Madagascar, South Sudan, Uganda, and Ethiopia, in which 1,950 persons including 702 persons with disabilities have been interviewed, showed that persons with disabilities face many barriers in accessing services. The majority of persons with disabilities felt that movement around health facilities is a major difficulty. There is often no transport and no reasonable accommodation to facilitate access to health facilities. Generally, the physical infrastructure of the health facilities is not accessible for persons with disabilities due to a lack of ramps, as well as narrow corridors, inaccessible health service provision rooms, compounds, gates, toilets, and bathrooms, and non-adjustable SRHR equipment and delivery beds.<sup>55</sup>

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Accessibility within SRHR is much more than just making sure that buildings have ramps or elevators. It applies to movement and signage within the health facility, all forms of public transportation and communication events (community dialogues, FGDs) health care services, and education and training in SRHR.

Providing accessibility is an obligation and quality standard in health and must be provided to all, regardless of whether it is specifically requested.

### Key Actions (accessible SRHR environment)

- In cooperation with OPDs, check the findings from health facilities, barrier assessments, or consultations and match with international and national accessibility standards and existing national policies (some countries and governments provide accessibility recommendations.)
- Use the findings from the health facility and barrier assessments (see 4.2) to develop an accessibility action plan in cooperation with OPDs and relevant community actors
- Use existing health planning structures to develop long term strategies, ensuring ongoing accessibility for all
- Consider all relevant aspects of the environment:
  - Transport to the health facility
  - Health facility infrastructure, e.g., ramps and handrails, accessible toilets, width of entrances, surface of floors, signage, etc. (see resources from Sightsavers below)
  - Health equipment: wheelchair, adaptable examination table, etc.
  - Access to training venues and community gatherings
- Consider expenditures for reasonable accommodation of health workers with disabilities
- Consider proper planning and budgeting (see 4.3.) to ensure provision of resources and include expenditures into the yearly local or district health budget plan
- Monitor implementation and ensure that accountability mechanisms are in place

#### Example from WISH in Bangladesh on improving accessibility

In Bangladesh, joint health facility assessments involving OPDs, health care facility staff, service providers, and HI led to a shared understanding of what accessibility is, and a commitment to undertake building improvements to improve accessibility at eight health care facilities. Issues that could not be addressed with existing resources were passed to the government for additional support. In Bangladesh, OPDs were able to successfully advocate for a ramp (funded by the government) to be put in place at a local facility with lots of stairs, which was very difficult for persons with disabilities to access.

#### Helpful resources

- Committee on the Rights of Persons with Disabilities. (2014). *General Comment No. 2 (2014): Article 9: Accessibility*, CRPD/C/GC/2.
- 'Accessibility standards' Sightsavers: <https://www.sightsavers.org/disability/health/accessibility-standards/>

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#### 4.7.4. Person-centred approach and informed consent

*“I am a woman with disability. I will never forget what happened to me. I once went to the hospital for delivery, but they ended up terminating my reproduction capacity without even consulting my relatives.”*

*(Woman with disabilities in Jitegemee – Mabibo, Tanzania)<sup>56</sup>*

The WHO quality criteria cover relevant points such as comprehensiveness, accessibility, coordination, and client-centred approach<sup>57</sup>, in line with inclusive principles that are necessary to ensure the SRHR of persons with disabilities. One of the most relevant criteria to put inclusive SRHR services into practice is the client-centred approach that considers the individual needs, environmental barriers, and active participation, and ensures the respect of each client’s right to take free and informed decisions. A disability inclusive client-centred approach means that services are provided in venues that are more suitable for persons with disabilities, or that the health facility makes adaptations to address and remove barriers that prevent clients with disabilities from benefitting from the service. One important client-centred obligation that is often neglected when it comes to clients with disabilities, and in particular persons with intellectual disabilities, is informed consent to contraception and other procedures.<sup>58</sup>

Informed consent to health care occurs when communication between a client and the health care provider allows the former to know about and understand the services being offered and voluntarily agree to accept those services.<sup>59</sup> For informed consent to be valid, the patient must be legally able to consent to services<sup>60</sup> and have the capacity and maturity to understand what they are consenting to.<sup>61</sup>

**Informed consent** is fundamental in respecting an individual’s legal capacity, autonomy, self-determination, and human dignity.<sup>62</sup> ***It is a violation of the human rights of the client*** to perform or provide non-emergency treatment without having first obtained informed consent from the client, and it may amount to torture and be a prosecutable offense in some jurisdictions.<sup>63</sup>

Service providers have an obligation to support persons with disabilities to make their autonomous decisions. Persons with different types of disabilities may need to be supported differently. ***The capacity to consent can vary according to the supports provided.***<sup>64</sup>

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## Key Actions

- Ensure the services welcome persons with disabilities regarding attitudes and environment and meet the specific adjustment that clients with any type of disabilities need to fulfil the right to access adequate, quality services
- Explore and identify any additional needs of the individual client that must be addressed in order to ensure SRHR services (e.g., a pregnant woman with walking difficulties does not have assistive devices that allow her to attend required antenatal services, organise referral or ensure outreach)

## Key actions

### (informed consent process requires health care providers to do three things)

- **Provide** the client with all relevant information accurately and sensitively, and in a way the client can understand. At a minimum, this information should include the following:
  - Information on the diagnosis for which any treatment is proposed or recommended
  - The nature of the treatment, procedure, medication, or other service
  - The name, dosage, and frequency of any prescribed medication
  - The expected benefits of the treatment or service, as well as the possible risks and side effects
  - Availability of alternative forms of treatment or alternatives to treatment
  - The client's prognosis if treatment or services are declined.<sup>65</sup>
- **Determine** whether clients can understand the information provided and the potential risks, as well as benefits, of the decision they are being asked to make
- Service providers should work with clients to determine what the most effective means for them to communicate are, and offer information in ways that clients, especially those with intellectual and developmental disabilities, can understand
- **Ensure** that the clients' decisions are their own and are voluntary and not coerced by others, including family or caregivers
- Health care workers must provide clients with sufficient information to be able to decide whether to consent to or decline services or procedures
- When clients with disabilities are not able to speak for themselves and do not have the capacity to make their own decisions, it is important for service providers to ensure that whatever decisions are made, the clients' rights are respected and reflect their preferences to the greatest extent possible (see Box 9). Even when a client is receiving support when making a health care decision, the service provider is still responsible for communicating with the client and trying to determine her wishes

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## Box 9: Key points for practical suggestions for seeking informed consent from persons with disabilities<sup>66</sup>

When offering services to women, men, girls, and boys with disabilities, health care providers seeking informed consent should keep the following in mind:

Assume that all women, men, girls, and boys with disabilities have the capacity to consent to services. Until demonstrated otherwise, health care workers should not assume that a patient with a disability cannot give her consent to services. This is true for persons with all types of disabilities, including intellectual or cognitive disabilities. Follow the guidelines for communicating with persons with disabilities outlined in section \_\_\_ above and speak directly to the patient or client, even if they are joined by a family member or caregiver.

Recognise that capacity to consent is a fluid concept and refers to the ability to consent to a particular service or procedure at a particular point in time. In other words, capacity may change over time and may not be the same for all decisions. Simply because a client consents to one service does not mean the person consents to all. Similarly, while clients in the midst of a crisis may temporarily lack capacity to consent, they may recover capacity at a later point in time. Service providers should approach the process of seeking informed consent as an ongoing discussion with a client, and not a one-time event.

Be attentive to how information is communicated. For clients to give informed consent, they must understand the information on which that consent is based, and their understanding may depend on how the information is communicated. It may be helpful for clients to make big decisions by thinking through smaller steps, such as talking through their goals for services, the procedures that will take place, the actions they will need to take, and so on. Service providers should take the time to work with clients and discuss decisions in detail so as to be sure they understand what they are consenting to.

Remember that even clients who lack the capacity to consent have a right to information and should be involved in decision-making. Service providers should always share information, listen to clients and explain how and why decisions have been made.

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### HI case study example from WISH

#### Delivering SRH services at the offices of OPDs in Madagascar



In Madagascar, it was effective to host service providers at the offices of OPDs and provide SRHR services in that familiar setting. One person attending said that this was preferable to health centres as it was a familiar, comfortable, and welcoming environment. It also meant that while waiting for services, they could connect with other persons with disabilities and provide peer support (i.e., for any anxieties about having an SRH consultation).

Service providers in Madagascar noted that they had more time to deliver a higher quality service to persons with disabilities when using offices of OPDs, and it provided an opportunity to talk about and provide other services, such as cervical cancer screening.

### Example from WISH in Bangladesh

#### Person centred approach

The HI team leveraged existing ‘family welfare corners’ in health care facilities, which were set aside as part of the national strategy on adolescents, to provide inclusive and accessible spaces for persons with disabilities. The family welfare corners are intended to provide spaces for people who might find it hard to reach conventional health care services and are therefore well suited to persons with disabilities. HI provided training to health care workers on how to organise the service around persons with disabilities, e.g., making the corners disability inclusive. They engaged disability focal persons within the facilities and the health care committees and, as a result, saw an increase in young persons with disabilities attending SRH services.

### Helpful resources

- Women’s Refugee Commission and International Rescue Committee. (2015). “I See That It Is Possible”: *Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings*.
- *The IDD Toolkit’s informed consent checklist* <https://iddtoolkit.vkcsites.org/wp-content/uploads/InformedConsent-RE.pdf>.

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### 4.7.5. Collaboration and Referral

*“If the personal aid of a woman with disabilities does not bring her to our outreach clinic, there is nothing I can do.”*

- Health worker from Arua, Uganda

Taking a coordinated approach to ensure quality criteria of comprehensive health care is as important for persons with disabilities as for others, maybe more so. HI has found that persons with disabilities generally have much lower levels of knowledge relating to sexual and reproductive health and rights than their non-disabled peers. They are often excluded from comprehensive services that support the access to SRHR. OPDs and service providers of health, including rehabilitation and affiliated services such as MHPSS and education, can be important sources of information and a relevant actor of referral to sexual and reproductive health care providers. The collaboration between different service providers can help to increase information and uptake of SRHR services. Similarly, SRH service providers should be aware of facilities that provide rehabilitation and other services that persons with disabilities may need.

#### Key actions for service providers

- Map relevant health and non-health referral points that might be helpful for clients with disabilities
- Compile a referral directory with information about diverse health, rehabilitative, social, and legal services, and provide information about the level of accessibility of these contacts (see HI referral mapping tool in the annex)
- Cooperate with relevant health and other service providers (general health, MHPSS, rehabilitation, service providing assistive devices, education, GBV, etc.) in order to improve inclusive referral practices
- Provide information about the rights of persons with disabilities, particularly women and young people, to access SRHR services. Inform them about your services and encourage them to refer persons with disabilities to SRH services
- Mainstream disability inclusion for all relevant referral partners (e.g. make sure MHPSS is disability-friendly and accessible)
- Listen to clients' needs and conduct referral practices that include disability-specific service needs (e.g., provision of assistive devices, early identification of disabilities in newborns, rehabilitation, etc.)
- Use the referral networks to enable persons with disabilities to access SRHR (e.g. transport provided by NGOs, livelihood activities that enable persons with disabilities to afford transport to antenatal care services, provision of adequate lenses allowing persons with visual difficulties to read IEC material, etc.)

## Box 10: Key do's and don't's when referring to other service providers<sup>67</sup>

- **Do offer all service options to persons with disabilities**, even if they may face barriers accessing those services. Work with clients to develop a plan to enable them to receive the care they need.
- **Do create formal referral networks with relevant service providers** (e.g., vision screening services, mental health and psycho-social service providers, providers of rehabilitation and livelihood activities, etc.) in order to find out if they are accessible, prior to sending a client with a disability to them.
- **Do get to know local organisations of persons with disabilities** and disability service providers; learn where they are located and understand what they do so you can make referrals or seek assistance when necessary.
- **Do follow up to ensure that the referrals you make are completed** and that the person you referred was not denied or refused services because of his/her disability.
- **Do ask the client with a disability for feedback** on their experience during the referral process and with the provider to whom they were referred. Find out whether they were treated with respect by the service provider, whether they encountered barriers because of accessibility, and whether they have any suggestions to improve the experience. Act on their feedback and address barriers, gaps, and challenges faced by clients with disabilities
- **Don't automatically refer persons with disabilities to disability-specific service providers.** Don't assume that the only services a person with a disability may need are rehabilitative care. Instead, get to know the needs of each individual and listen to them. Address the needs they present first and refer them for other services with providers who will meet those needs.
- **Don't forget to include OPDs and disability service providers in trainings on referral services or within referral networks.** OPDs and DSPs often have strong, trusting relationships with persons with disabilities in the community and can help to raise awareness about the availability of SRH and other services among persons with disabilities.
- **Don't assume that a woman or man with a disability or an adolescent with a disability will not want certain services**, such as family planning or STI prevention counselling. Oftentimes, the only reason they are not asking for those services is because they are not aware they can, or assume they will be made fun of.
- **Don't only depend on family members to provide sign language interpretation or communication assistance.** Work with local OPDs to identify professional sign language interpreters where possible, especially for discussions about medical services or other services related to gender-based violence or sexual violence.

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### Example from WISH Bangladesh

#### Linking SRH services with other health services to increase uptake



As all women giving birth should be protected against tetanus in Bangladesh, a targeted approach used one-to-one counselling to educate and encourage uptake of the tetanus vaccine for young women with disabilities. This resulted in greater uptake of this important vaccine for SRH, which young women had not been aware of previously.

Door-to-door visits were used to encourage young women with disabilities to have the tetanus vaccine, and these women were referred to health facilities. The team found that many young women with disabilities were unaware of this vaccine and its relevance to SRH. Most girls receive it in school but many persons with disabilities had not had access to it previously or had not attended school to access it.

Encouraging and facilitating vaccination had not been in the project plan, but emerged as an issue based on door-to-door visits to persons with disabilities. Community health workers developed a good relationship with service providers so that these providers were able to offer inclusive services to women with disabilities. Community health workers referred the young women with disabilities to health facilities and in some cases supported and escorted them to receive the vaccine at HCFs.

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## 4.8. Protection from GBV

*“One boy raped me 7 years ago. I screamed and some women at the market came to help me. But this was not the first time, I’ve been abused by family members from my mother and father’s side. My uncle drinks a lot and whenever he gets upset, he beats me up.”*

- 16-year-old girl with intellectual disability from Arua, Uganda, HI WISH research

*“Y was married to A at the age of 19 and tolerated his beating for years. Everyone in the village knew about it but no one took action against it because, as Y was a wheelchair user, this marriage was commonly considered a blessing. One day, A came home angry because he had been unable to find work and he beat his wife with a rod. The villagers say she died of internal injuries but there was no report because Y was not taken to the hospital.”*

FGD HI Pakistan survey on ‘violence against women with disabilities’, 2018

The CRPD obligates States Parties to “take all appropriate legislative, administrative, social, educational, and other measures” to protect persons with disabilities from all forms of exploitation and violence, including sexual violence and other forms of gender-based violence (Art. 16)<sup>68</sup>. This includes holding perpetrators criminally responsible for their actions, and taking steps to prevent SGBV, including recognising it as a matter of public health, particularly with respect to sexual and reproductive health (Art. 16(2)<sup>69</sup>).

According to WHO and UN Women,<sup>70</sup> one in three women across the globe have experienced either physical or intimate sexual partner or non-partner violence in their lifetimes. Research shows that women and children from marginalised groups face an even greater risk of encountering violence, including SGBV.<sup>71</sup> Women, girls and boys with disabilities are at least twice as likely to experience sexual violence during their lifetimes as their non-disabled peers, with those with certain disabilities at even greater risk.<sup>72</sup>

Discrimination based on gender and disability is among the root causes of violence and abuse. The World Bank reports, “discrimination against girls and young women with disabilities can start early. Female infants born with disabilities are more likely to die through ‘mercy killings’ than male infants with disabilities. Birth certificates are often missing for girls with disabilities. The lack of legal registration means they are not able to access health care, education, and social services, rendering them more vulnerable to violence and abuse.”<sup>73</sup>

Preventing SGBV against persons with disabilities, and facilitating adequate and accessible response services for survivors of violence in the SRHR service delivery system, should be a key component in all SRHR intervention.

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## Key Actions

- Raise awareness among health workers, CHWs and community members, and other service providers about the higher risk of persons with disabilities to experience any kind of violence and SGBV
- Recognise that all survivors of SGBV, including women and girls with disabilities, are entitled to safe, confidential, accessible, and good quality health care services, including reproductive health care and mental health services
- Ensure that services and referrals to SGBV response services are accessible for persons with disabilities
- Ensure that public health workers are appropriately trained to screen for GBV among clients with disabilities, and to provide disability-sensitive services for survivors of violence that do not re-victimise them or take away their agency
- Treat all clients, including clients with disabilities, with respect and in a sensitive way, assuming that everybody could be a survivor of violence but unable to disclose these experiences due to fear, shame, social dependencies from others, and fear of reprisal
- Cooperate with persons with disabilities and OPDs in SBCC and public campaigns and programmes on the prevention of gender-based violence (e.g., in the 16 days of activism, when cooperating with protection units and shelters, etc.) and ensure that all programmes are fully accessible to persons with different types of disabilities
- Cooperate with OPDs and parents to create awareness about the high prevalence of SGBV among women, men, young people, and children with disabilities, and their sexual rights
- Share relevant SGBV service contacts with OPDs and their members (hotline numbers, legal services, accessible MHPSS services, etc.)
- Promote the right to say “no” among all young persons with and without disabilities and encourage educational institutions to cooperate with the health sector in preventing SGBV
- Ensure that persons with disabilities know about their right to report abuse and to access services after experiencing SGBV. Create a service environment that is accessible and youth and disability friendly
- Collect disaggregated data regarding disability and SGBV

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### Helpful resources:

- Save the Children Resource Centre, Child Fund International, Women’s Refugee Commission, “Gender-Based Violence Against Children and Youth with Disabilities: A toolkit for child protection actors”.
- UNFPA and Women Enabled International. (2018). *Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights*.
- UNFPA , Young persons with disabilities : Global study on Ending Gender Based Violence and Realising Sexula and Reproductive Health and Rights , (2018)
- UN Special rapporteur on the Rights of women and girls with disabilities ‘Sexual and reproductive health and rights of girls and young women with disabilities’ (2017)
- Van der Heijden, I. ‘What works to prevent violence against women with disabilities’ (2017) (2014)
- Devandas Aguilar, C. 2017. Sexual and Reproductive Health Rights of Young Women and Girls with Disabilities. UN Special Rapporteur on the rights of persons with disabilities. Presented at the 72nd session of the UN General Assembly. (2017)
- World Bank and The Global Women’s Institute Washington University ‘Brief on violence against women and girls with disabilities’ (Dec. 2019).
- Creating Resources for Empowerment in Action 2012. Count me IN!: Research report on violence against disabled, lesbian, and sex-working women in Bangladesh, India, and Nepal. Reproductive Health Matters. [online] New Delhi: CREA

### For recommendations on how to use the twin-track approach to realise SRHR and prevent GBV:

- UNFPA. (2018). *Young Persons with Disabilities: Global Study on Ending Gender-based Violence and Realising Sexual and Reproductive Health and Rights*, ch. 7. Available at: <https://www.unfpa.org/publications/young-persons-disabilities>.

### Helpful tools

- HI (2021) ‘Toolsheet SGBV disclosure: What to do and how to react’
- Annexes 2-4

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## Monitoring, Evaluation, Accountability, and Learning (MEAL)

### 4.9. Disaggregated data and MEAL

*“Data – overall routine health metrics, disaggregated by disability - the need to improve routine data collection and focused research on disability has been highlighted in several documents and is also promoted as part of WHO’s general programme of work, 2019-2023. National health-related surveys must include disability indicators so that health data can be disaggregated by disability.”<sup>74</sup>*

Too often, persons with disabilities are excluded from household and demographic surveys as well as other methods of data collection, leaving policymakers and service providers without adequate information on which to base their service and resource allocation decisions.

The lack of international and national disability information and data in the health sector has become an issue that can no longer be neglected. Legal frameworks, including the UNCRPD, request states and health service providers to document their disability data and inclusion. As quantitative and qualitative data are key to understanding, planning, budgeting, and monitoring SRHR, programme stakeholders must ensure the collection of disability disaggregated data within the collection of routine and evaluation data (e.g. CEI). The ideal internationally recognised tool to collect disaggregated data is the Washington Group Short Set (WG-SS) of questions. The WG-SS is not a diagnostic or assessment tool, but it is designed to identify the prevalence of disability and to address areas such as the level of access persons with disabilities have to health care facilities, or how inclusive programmes are (HI and LCF, 2018). The successful use of the WG-SS requires an understanding of the concepts behind the tool and training to build a basic competency in how to administer it.<sup>75</sup> (Washington Group, 2015).

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## Box 11: The Washington Group Short Set of questions on functioning

The standardised international Washington Group questions, such as the Short Set (WG-SS), the Short Set Enhanced (WG-SSE) (which includes additional questions on psychosocial difficulties, such as depression and anxiety), or the Child Functioning Module (WGCFM) (specific to the needs of children aged 2-4 years and from 5-17 years) are very helpful instruments for collecting data about disability in the health sector. International research shows that the collection of reliable disability data is not easy, due to fear of discrimination or not wanting to be categorised as persons with disabilities. To address this, the WG-SS is an internationally approved tool that provides reliable data on disability prevalence. The knowledge gained when using WG-SS in SRHR data collection can help to obtain information about access to SRHR information and services that can help determine who is at risk of exclusion or restricted participation, identify barriers that persons with disabilities face, and measure equity. This data could also help to identify needs and reshape plans for inclusive programming, budget allocation, and inclusive SRHR interventions.

The WG-SS should routinely be incorporated into client exit interviews, reports on client feedback and complaints, evaluation and quality assurance exercises, and even in routine client registration forms.

### WG-SS questions

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care, such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

### Responses:

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

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Quality management (QM) mechanisms in health systems comprise the collection of quantitative and qualitative data, such as client feedback e.g. through CEI or from a complaints mechanism, to ensure the quality of care. Providing accessible mechanisms for persons with disabilities to give feedback on the delivery of sexual and reproductive health information and services is an important way to identify and eliminate barriers and improve accountability towards inclusive health coverage among providers. The measurements should be accessible for persons with disabilities and quality indicators should include disability markers. Despite the integration of the WG-SS in all data collection systems, SRHR stakeholders should pilot and promote the inclusion of disability indicators into national QM procedures to ensure sustainable change towards inclusive quality indicators for health services.

### Key Actions

- Collection of disability disaggregated data using the WG-SS should become routine for all data collection and monitoring systems (FGDs, client feedback meetings, etc.)
- Relevant health stakeholders, government staff, and service providers should be sensitised and trained on the importance and the application of the WG-SS and the inclusion of persons with disabilities into feedback mechanisms
- Training should be tailored to the context, address any concerns that participants have about using WG-SS, and include proper analysis of the data. Refreshers are recommended
- Collection of disaggregated data should be carried out by the professionals who collect the routine data. (e.g., trained receptionists are recommended, because proper collection might take up to 10 minutes and health workers are often very busy)
- WG-SS should be provided in the local language, following translation guidance from WG to ensure appropriate terminology
- Data collected from the WG-SS can and should be used to improve programmes, influence budgeting, map challenges, and inform practice
- Ensure that health quality management measurements and audits include disability indicators on accessibility standards, reasonable accommodations, non-discrimination and inclusive referral practices, and accountability of the implementation of UNCRPD and in SRH
- Sensitise and train health quality managers, assessors, and health M&E professionals on disability inclusion and relevant indicators and tools as components to improve the quality of services and accountability of UNCRPD and universal health coverage
- Monitoring should track disaggregated data by sex, age, and disability type, at a minimum, so that programme managers can assess whether programmes are missing certain groups, such as adolescent girls with intellectual disabilities

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- Implement feedback mechanisms that are disability inclusive and gender and age sensitive, and solicit feedback from clients about their experiences when seeking information and services relating to sexual and reproductive health. Where clients report disrespectful communication from any staff member, ensure that prompt and appropriate action is taken. For a more in-depth analysis, please see the comprehensive guidance and resources for designing and implementing disability inclusive feedback mechanisms in diverse contexts recently published by IRC<sup>76</sup>

### Case study

#### Learning from the WG-SS at the IRC



The IRC is using the WG-SS to understand if the organisation is serving the needs of persons with disabilities, adapting their services to better meet these needs, and mapping where more support is needed.

The IRC has found the questions to be useful in understanding the types of disability that are predominant in different settings, and has been using this information to modify services - in one setting, they found that seven per cent of clients are living with disability, and that most disabilities were intellectual. They have also noted the importance of ensuring that the questions are used in a standardised way and translated appropriately so clients understand them, and that all data enumerators are trained appropriately.

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### Example from Bangladesh



The Directorate General of Family Planning (DGFP) at the Ministry of Health and Family Welfare (MOHFW) are responsible to ensure the quality of SRH/FP services in Bangladesh. Clinical consultants at the district level collect and monitor data through Family Planning Clinical Supervision Quality Improvement Tools (FPCSQIT). The FPCS-QIT play an essential role in monitoring and improving the quality of services. However, this FPCS-QIT had no indicator related to disability, and information collection system was manual.

WISH2ACTION consortium partner Options has provided technical and financial support through an agreement with the DGFP to strengthen the quality improvement system and move to an information technology (IT) enabled FPCS-QIT system. WISH2ACTION consortium partners (Humanity & Inclusion, Options, and Marie Stopes Bangladesh) are working jointly to review the indicators. HI has provided technical support to include indicators related to persons with disabilities.

Options submitted the revised tool to DGFP for approval. The IT system converted all the paper-based forms to a web-based android system with an online tracking system, administered and managed by the DGFP central office at the directorate level. The digitised system allows DGFP to capture and track quality improvement information and data and the FPCS-QIT field activities in real-time. Through this digital FPCS-QIT, DGFP can monitor the inclusiveness of FP-SRH services, as well as the capacity of service providers to provide inclusive SRH services to persons with disabilities.

### Helpful resources:

- WG-SS <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>
- HI/WG Disability Data in Humanitarian Action. Online training course. <https://www.washingtongroup-disability.com/resources/online-trainings-and-webinars/>
- IRC 'Inclusive Client Responsiveness' (2021) <https://www.rescue.org/resource/inclusive-client-responsiveness-focus-people-disabilities-and-older-people>
- Mont, D. (2018). *Disability inclusive or CRPD compliant budgeting?* Center for Inclusive Policy. Available at: [https://inclusive-policy.org/wp-content/uploads/2019/06/Inclusive-CRPD-budgeting-Brief\\_1006\\_-web.pdf](https://inclusive-policy.org/wp-content/uploads/2019/06/Inclusive-CRPD-budgeting-Brief_1006_-web.pdf).

## Part II Implementing disability inclusive SRHR programmes and services

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- 37 Humanity & Inclusion. (2021). Learning from a disability-inclusive SRHR Programme (WISH2ACTION).
- 38 Office of the United Nations High Commissioner for Human Rights and the World Health Organisation. (n.d.). The Right to Health. Fact Sheet No. 31; Committee on Economic, Social and Cultural Rights, General Comment No. 14; International Covenant on Economic, Social, and Cultural Rights, Article 2(1).
- 39 The order of the actions listed below can be different to the one indicated in this Guideline and may vary according to the context. Often different actions are carried on in parallel as they complement each other and they all contribute to the same objective.
- 40 In the best case the data you find has been collected using the Washington Group Questionnaire Short Set of questions WG-SS (see more information in chapter 5.3.1) or is based on the Model Disability survey) as this increases reliability of disability data. In many countries the WGSS is still not in use for routine demographic and population health data collection therefore, we have to work with what is in place and promote the use of the internationally recommended WGSS tool ( see Section 5.9 of this Guideline for more details).
- 41 See HI 'Learning from a disability inclusive sexual and reproductive health and right programme ( WISH2ACTION) July 21
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- 43 Adapted from United Nations Development Programme, IRGT: A Global Network of Transgender Women and HIV; United Nations Population Fund, UCSF Centre of Excellence for Transgender Health, Johns Hopkins Bloomberg School of Public Health, World Health Organisation, Joint United Nations Programme on HIV/AIDS, United States Agency for International Development. (2016). Implementing comprehensive HIV and STI programmes with transgender people: practical guidance for collaborative interventions. New York: United Nations Development Programme. Available at: [https://www.unfpa.org/sites/default/files/pub-pdf/TRANSIT\\_report\\_UNFPA.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/TRANSIT_report_UNFPA.pdf).
- 44 Zakia Musa's affiliation is indicated as of the date of the interview. Musa has since become a staff member of HI.
- 45 Committee on the Science of Changing Behavioural Health Social Norms, Board on Behavioural, Cognitive, and Sensory Sciences, Division of Behavioural and Social Sciences and Education, National Academies of Sciences, Engineering and Medicine. (2016). Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change. Washington, D.C.: National Academies Press.
- 46 USAID. (2012). C-Modules: A Learning Package for Social and Behavior Change Communication (SBCC). Washington, D.C.: C-Change/FHI 360. Available at: [https://www.fhi360.org/sites/default/files/media/documents/Module0-Practitioner\\_2.pdf](https://www.fhi360.org/sites/default/files/media/documents/Module0-Practitioner_2.pdf).
- 47 Interview with HI staff in Madagascar.
- 48 DAISY is a compatible software, that will read out loud the publication and allows interactive navigation for persons with visual impairments HI WISH Bangladesh has developed SRHR information in digital accessible Information system format that allows persons with visual disabilities who have access to computer to get aural SRHR information and to navigate in the system in order to get the information they are interested in.
- 49 DAISY is a compatible software, that will read out loud the publication and allows interactive navigation for persons with visual impairments HI WISH Bangladesh has developed SRHR information in digital accessible Information system format that allows persons with visual disabilities who have access to computer to get aural SRHR information and to navigate in the system in order to get the information they are interested in.
- 50 Humanity & Inclusion, WISH Barriers Assessment 20/21
- 51 See, e.g., Convention on the Rights of Persons with Disabilities, Art. 2; Americans with Disabilities Act, 42 U.S.C. §§ 12101 et seq.; Rehabilitation Act of 1973 (US), 29 U.S.C. § 794.
- 52 These tips are adapted from the following sources: Developmental Disabilities Primary Care Initiative. (2011). Tools for the Primary Care of People with Developmental Disabilities. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/informed-consent/>; Women's Refugee Commission. (2015). Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings: A Toolkit for GBV Practitioners, Tool 6: Guidance on communicating with people with disabilities. <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>; Women's Refugee Commission. (2018). Guidance on Disability Inclusion for GBV Partners in Lebanon: Outreach, Safe Identification, and Referral of Women, Children and Youth with Disabilities. Tool 9: Tips for Communicating with People with Different Types of Impairments. <https://www.womensrefugeecommission.org/research-resources/disability-inclusion-gbv-lebanon-outreach-safe-identification-referral/>
- 53 Developmental Disabilities Primary Care Initiative, 2011.
- 54 Women's Refugee Commission, 2018, Tool 9.
- 55 See HI Barriers assessments from South Sudan , Madagascar, Uganda and Ethiopia ( 2020/21
- 56 Comprehensive Community Based Rehabilitation in Tanzania, Kinondoni survey on access to education and health services as well as involvement of people with disabilities in planning process at local level Tanzania 2014
- 57 WHO [https://www.who.int/healthinfo/systems/WHO\\_MBHSS\\_2010\\_section1\\_web.pdf](https://www.who.int/healthinfo/systems/WHO_MBHSS_2010_section1_web.pdf)
- 58 The material in this section is drawn from "I See That It Is Possible": Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings (June 2015), developed by Women's Refugee Commission and International Rescue Committee. The full toolkit can be found at: <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>.

## Part II Implementing disability inclusive SRHR programmes and services

### Endnotes

- 59 American Medical Association. (n.d.). Code of Medical Ethics Opinion 2.1.1: Informed Consent. Available at <https://www.ama-assn.org/delivering-care/ethics/informed-consent>; "I See That It Is Possible": Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings (June 2015), developed by Women's Refugee Commission and International Rescue Committee. The full toolkit can be found here: <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>.
- 60 The Committee on the Rights of the Child has emphasised that the right to autonomous decision-making must be respected for children and adolescents in keeping with their evolving capacities. See, e.g., General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24), UN Doc. No. CRC/C/GC/15, and General comment No. 20 (2016) on the implementation of the rights of the child during adolescence. In GC 20 in particular the Committee emphasized that adolescents have the right to consent to SRH services without the permission of a parent or guardian (see para. 31).
- 61 Id.
- 62 Committee on the Rights of Persons with Disabilities. (2014). General comment No. 1: Article 12: Equal recognition before the law, UN Doc. No. CRPD/C/GC/1; United Nations. (2016). Approach of the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment regarding the rights of persons institutionalized and treated medically without informed consent, CAT/OP/27/2.
- 63 Id. See also American Medical Association. (n.d.). Code of Medical Ethics Opinion 2.1.1: Informed Consent. Available at <https://www.ama-assn.org/delivering-care/ethics/informed-consent>; Hattix, L. (2018). Expanding Notions of Self-Determination: International Customs of Informed Consent in Medical Experimentation Pre-1945. *Chicago Journal of International Law* 19(1), Article 5.
- 64 Developmental Disabilities Primary Care Initiative. (2011). Tools for the Primary Care of People with Developmental Disabilities. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/informed-consent/>.
- 65 UNFPA. (2018). Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights, <https://www.womenenabled.org/wei-unfpa-guidelines.html>; Developmental Disabilities Primary Care Initiative. (2011). Tools for the Primary Care of People with Developmental Disabilities. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/informed-consent/>.
- 66 The suggestions in this box are drawn from "I See That It Is Possible": Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings (June 2015), Tool 9: Informed consent process with adult survivors with disabilities, developed by Women's Refugee Commission and International Rescue Committee. The full toolkit can be found at: <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>.
- 67 The recommendations in this box are adapted from Women's Refugee Commission. (2018). Guidance on Disability Inclusion for GBV Partners in Lebanon: Outreach, Safe Identification, and Referral of Women, Children and Youth with Disabilities. Tool 8: Do's and Don't's of Safe Identification and Referral of Survivors with Disabilities. <https://www.womensrefugeecommission.org/research-resources/disability-inclusion-gbv-lebanon-outreach-safe-identification-referral/>.
- 68 UNCRPD <https://www.google.com/search?client=firefox-b-d&q=UNCRPD+Article+16>
- 69 UNCRPD <https://www.google.com/search?client=firefox-b-d&q=UNCRPD+Article+16>
- 70 UN Women <https://www.unwomen.org/en/what-we-do/ending-violence-against-women/facts-and-figures>
- 71 Hughes, K., et al. (2012). Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet* 379(9826), pp. 1621-1629; "Increase voice and visibility of marginalized women" CREA accessed February 20th 2018.
- 72 See, e.g., Mailhot Amborski, A., et al. (2021). Sexual Violence Against Persons with Disabilities: A Meta-Analysis. *Trauma, Violence and Abuse*, March 4, 2021. <https://doi.org/10.1177%2F1524838021995975>; Humanity & Inclusion 'Hi addresses violence against women with disabilities at United Nations' [https://www.hi-us.org/hi\\_addresses\\_violence\\_against\\_women\\_with\\_disabilities](https://www.hi-us.org/hi_addresses_violence_against_women_with_disabilities)
- 73 Koistinen, M. et al. World Bank Blogs 'Five Facts to know about violence against women and girls with disabilities' (Dec 2019)
- 74 LSHTM H. Kuper (2019) "The missing billion", <https://www.lshtm.ac.uk/TheMissingBillion>
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- 76 IRC 'Inclusive Client Responsiveness' (2021) <https://www.rescue.org/resource/inclusive-client-responsiveness-focus-people-disabilities-and-older-people>

**Part II** Implementing disability inclusive SRHR programmes and services  
**Chapter 4**



## Technical guidance for disability inclusive SRHR for diverse populations, services, and contexts

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## 5. Diverse populations

Focusing exclusively on the disability-related factors that prevent or facilitate persons with disabilities to access SRHR information and services is not sufficient to fully promote inclusive SRHR, as this can be realised only by taking into consideration many other intersecting factors. These include, for example, gender, age, sexual orientation, and other factors that influence access to information and services. Only by working at the intersection of these different factors it is possible to gain a full understanding of the challenges and barriers that prevent a person with disabilities from accessing SRHR information and services, and how to address them while identifying the enablers that facilitate access.

Very limited work has been done so far to promote an intersectional perspective on SRHR that includes a disability inclusive perspective. Until very recently, the LGBTQI+, feminist, youth, and disability movements have been working in silos when it comes to advocating for SRHR, thereby missing the opportunity to collaborate through joint and fully inclusive initiatives. The WISH programme is a good example of how those silos can be broken by developing inclusive partnerships, joining forces and building on partners' complementary experiences. Chapter 5 is dedicated to providing additional information on the subject.

### 5.1. Age

#### 5.1.1. Youth with disabilities and SRHR

*"I went to the health centre for condoms and got the response from the FP health worker, 'You are a blind boy, what are you doing with condoms?'"*

- HI WISH focus group with adolescents with disabilities in Juba, South Sudan, 2020

#### Box 12: Key point – Adolescents with disabilities

Adolescents with disabilities are first of all adolescents and, as all young people, struggle to access SRH information and services due to a lack of youth friendly facilities, the stigma attached to premarital sex, and the attitudes of providers and family members, among other factors. Young persons with disabilities experience additional barriers related to their disability that must be taken into consideration. Extra efforts should be made to create youth-friendly, age-appropriate, gender-sensitive, and disability-inclusive environments where all adolescents can feel comfortable discussing SRH and accessing quality services.

There are an estimated 93-150 million children and adolescents with disabilities around the world.<sup>77</sup> They face numerous obstacles to realising sexual and reproductive health and rights, in part due to a persistent lack of access to accurate information about puberty, menstruation, sexuality, prevention of STIs and HIV/AIDS, and contraception, among other things. Too often, young persons with disabilities are assumed to be either asexual or hypersexual, such that educating them about sex and sexuality is either unnecessary or risky. Evidence suggests that adolescents with disabilities typically have low levels of knowledge about sexual and reproductive health, are less likely to use contraception, and are particularly vulnerable to sexual harassment, violence, and abuse.<sup>78</sup> Because they are presumed to be virgins, children and adolescent girls with disabilities are often targets of sexual violence in communities where beliefs in ‘virgin cleansing’ are common.<sup>79</sup>

### Example from WISH

#### Adolescents with disabilities and barriers to SRHR



Adolescents and young persons with disabilities often have very limited access to information about their sexual and reproductive health, including information about menstrual hygiene, contraception, and the prevention of sexually transmitted infections. In Ethiopia, for example, data collected in 2016 show that just one in two persons with disabilities between 15 and 24 years old have any information about sexual and reproductive health.<sup>80</sup> Research conducted by Kassa et al<sup>81</sup> in the same year shows that out of a total of 426 young persons with disabilities ages 10-24 interviewed, only 22 per cent had ever had a discussion with their parents on SRH – a figure markedly lower than a similar sample of adolescents without disabilities (40 per cent). In part, this is because children with disabilities are more likely to be kept out of school altogether, or to leave school at the primary level before receiving any comprehensive sexuality education. It is also due to parents’ reluctance to discuss sexuality and reproduction because of the assumption that their children with disabilities will not be sexually active and will not marry. Sexual and reproductive health programmes for adolescents and young persons also tend to exclude young persons with disabilities because they are usually not accessible.

During focus groups and interviews HI held with young persons with disabilities in Uganda and Ethiopia, the participants said that the main challenges they face in accessing family planning (FP) services include:

- Reluctance to access FP services due to fear that people will understand that they are sexually active
- Health providers’ attitudes are often very “rude”

- Condoms are expensive to purchase and at times hard to use for persons with certain types of physical disabilities
- Talking about sex or sexuality is a taboo in the community

In the absence of accurate and comprehensive sex education, adolescents with disabilities become more vulnerable to sexual violence and exploitation and are less likely to use contraceptives or protect themselves from STIs or early pregnancy. They also miss the opportunity to learn about the positive aspects of sexuality and healthy relationships, including the importance of mutual respect and sexual pleasure.

### **Box 13: Key facts – Adolescents with disabilities**

#### **Adolescents with disabilities**

Gender norms and disability stigma intersect, particularly during adolescence, often increasing the vulnerability of all adolescents with disabilities.

Girls and boys with disabilities are nearly three times more likely to be subjected to sexual violence than their non-disabled peers, and more than one in five children with disabilities become victims of physical violence<sup>82</sup>

Adolescent girls with disabilities are almost uniformly denied the right to make decisions about their bodies and sexual lives.<sup>83</sup> They are at heightened risk of early or child marriage, as well as sex trafficking and other forms of exploitation and abuse, including sexual abuse from caregivers<sup>84</sup>

Adolescent girls with disabilities are highly vulnerable to sexually transmitted infections, including HIV, in part because many are unable to negotiate safe sex practices or monogamy with sexual partners. In a series of interviews in Mozambique, stakeholders reported that the social stigma attached to disability was so extreme that men approached sex with young women with disabilities as a curiosity<sup>85</sup>

Adolescent girls and young women with disabilities are also disproportionately disadvantaged, and many feel pressured to engage in transactional sex in exchange for food or other necessities<sup>86</sup>

In addition to considering the Global Standards for health care services for all adolescents (see table 7 below ) adopted by the WHO that apply to all health care services, including SRH services, SRH programme coordinators should also ensure that SRH programmes are accessible to adolescents with disabilities. This includes:

- Designing programmes and messaging, including social behaviour change communications on SRH, with adolescents with disabilities in mind. They should be age and gender appropriate, accessible to adolescents with different types of disabilities, and tailored to meet the needs of adolescents with disabilities
- Partnering with adolescents with disabilities and organisations led by young persons with disabilities in needs assessments and SRH programme development and implementation to foster inclusion and ownership of SRH services
- Encouraging and sponsor peer-to-peer SRH education and activities relating to sexual and reproductive health
- Ensuring that young persons with disabilities are included in existing programmes focusing on youth and SRHR, as historically, they have been excluded

**Table 7: Global Standards for health care services for adolescents.** These standards apply to all health care services, including SRH services.

Global standards to improve quality of health care for adolescents from WHO		
Standard 1	Adolescent health literacy	The health facility implements systems to ensure that adolescents are knowledgeable about their own health, and they know where and when to obtain services.
Standard 2	Community support	The health facility implements systems to ensure that parents, guardians and other community members and community organizations recognize the value of providing health services to adolescents and support such provision and the utilization of services by adolescents.
Standard 3	Appropriate package of services	The health facility provides a package of information, counselling, diagnostic, treatment and care services that fulfils the needs of all adolescents. Services are provided in the facility and through referral linkages and outreach
Standard 4	Providers' competencies	Health-care providers demonstrate the technical competence required to provide effective health services to adolescents. Both health care providers and support staff respect, protect and fulfil adolescents' rights to information, privacy, confidentiality, non-discrimination, non-judgemental attitude and respect.
Standard 5	Facility characteristics	The health facility has convenient operating hours, a welcoming and clean environment and maintains privacy and confidentiality. It has the equipment, medicines, supplies and technology needed to ensure effective service provision to adolescents.
Standard 6	Equity and non-discrimination	The health facility provides quality services to all adolescents irrespective of their ability to pay, age, sex, marital status, education level, ethnic origin, sexual orientation or other characteristics.
Standard 7	Data and quality improvement	The health facility collects, analyses and uses data on service utilization and quality of care, disaggregated by age and sex, to support quality improvement. Health facility staff is supported to participate in continuous quality improvement.
Standard 8	Adolescent participation	Adolescents are involved in the planning, monitoring and evaluation of health services and in decisions regarding their own care, as well as in certain appropriate aspects of service provision.

From the World Health Organisation: [https://apps.who.int/iris/bitstream/handle/10665/183935/9789241549332\\_vol1\\_eng.pdf;sequence=1](https://apps.who.int/iris/bitstream/handle/10665/183935/9789241549332_vol1_eng.pdf;sequence=1)

### 5.1.2. Mid-life and ageing

SRH needs extend across the lifespan, even if the type of services needed may change. As for all women, the SRH needs of women with disabilities include care during perimenopause and menopause and regular screening for reproductive cancers, breast cancer, and STIs. For men, they include screening for testicular cancer, erectile dysfunction, and STIs. Health care providers should follow the same screening protocols that they follow for non-disabled clients as they age, while being attentive to the particular needs of persons with disabilities.

For example:

- Service providers should ask all midlife women with disabilities about menopausal symptoms and recommend appropriate treatment. Counselling should include discussion of the risks and benefits of hormone-based therapies, given each client's specific medical profile and the medications she is taking.<sup>87</sup>
- Service providers should understand that older adults with disabilities may continue to be sexually active and therefore may require counselling for their sexual health and the prevention and treatment of STIs.

## 5.2 Gender

### 5.2.1. Men and boys

#### Box 14: Key point – Engaging men and boys

**Engaging men and boys with and without disabilities in family planning and SRH is critical to realising SRH for all.** SRH programme managers should ensure that all SRH services are welcoming to both men and women with disabilities as clients, and engage men and boys with and without disabilities as supportive partners of women and girls with disabilities.

Men and boys both with and without disabilities are in need of family planning and other SRH services, as well as key partners who can support and facilitate access to SRH for women and girls with disabilities. As clients of SRH services, all men and boys, especially men and boys with disabilities, may feel uncomfortable discussing contraception and fertility and may believe family planning clinics are not welcoming or male friendly.<sup>88</sup> In many communities, family planning and contraception are seen as the responsibility of women, discouraging men and boys from seeking out information. Men and boys with disabilities are also at a higher risk of

sexual violence than their non-disabled male peers.<sup>89</sup> Where men and boys with disabilities are survivors of sexual violence, accessing safe and confidential SRH services is likely to be substantially more difficult.

Men and boys are also often gatekeepers for the decisions of women and girls with and without disabilities to use contraception or other forms of family planning, whether as partners, brothers, heads of household, or religious and community leaders. Because women and girls with disabilities are more likely than nondisabled women to be denied decision-making autonomy, and in many cases depend on men to access and use family planning and other forms of sexual and reproductive health care services, engaging men and boys as supportive stakeholders is essential.

To strengthen outreach and uptake of SRH, SRH programme managers should:

- Engage men and boys, including men and boys with disabilities, into SRH programmes in ways that are supportive both of their own SRH needs as well as the autonomy of their partners
- Ensure that men and boys have access to the same quality SRH services offered to women and can count on non-judgmental attitudes from providers, comprehensive holistic services, confidentiality, choice of knowledgeable service providers, inclusion of community-led services, flexible opening hours, affordability, combined fixed-site and mobile outreach, and informed consent<sup>90</sup>
- Ensure that men and boys with disabilities are included in existing programmes, focusing on men, boys, and SRHR and their roles as gatekeepers and potential facilitators, as well as users

### **Reproductive Health Services South Sudan (RHSS)**

Reproductive Health Services South Sudan (RHSS) is a sexual and reproductive health care service provider. Recognising that men often make decisions within households about family planning and whether they or their wives will use contraception, RHSS has been engaging men in peer-to-peer dialogue about family planning, including when, why, and how to use contraception, and the health and other benefits of allowing their wives to space children and otherwise manage their reproductive lives. RHSS providers encourage men to accompany their wives to the hospital and medical appointments so that they can learn about family planning strategies with their wives directly from health care providers. The programme is accessible to both men and women with disabilities and includes men with disabilities in its outreach.





## 5.2.2. Diverse sexual orientations and gender identities

The term ‘sexual and reproductive health and rights’ addresses the right to sexual self-determination, or the right to independently explore and make choices about one’s sexuality.<sup>91</sup> Women and men with disabilities have the same rights as non-disabled men and women to choose how they express themselves sexually and whether and with whom they enter into sexual and romantic relationships. The Committee on Economic, Social, and Cultural Rights has confirmed that the right to be free from discrimination in the context of the right to sexual and reproductive health “encompasses the right of all persons, including lesbian, gay, bisexual, transgender, queer, and intersex [LGBTQI+]”<sup>92</sup> persons, to be fully respected for their sexual orientation, gender identity, and intersex status.”<sup>93</sup>

Despite this, discriminatory attitudes, stigma, and prejudice, as well as discriminatory laws and policies that criminalise same-sex relationships or certain forms of gender expression, continue to prevent LGBTQI+ persons from accessing the health services they need, with potentially far-reaching outcomes.<sup>94</sup>

A recent study in the US found that certain LGBTQI+ persons were considerably more likely than heterosexual women to have had an unplanned pregnancy, a teen pregnancy, or an abortion, which researchers attributed to a lack of inclusive sexual education available to sexual minorities, and a failure of health care providers to adequately counsel and provide contraception to sexual minority clients.<sup>95</sup> Research has also shown that lesbian and bisexual women do not believe that they are at risk of STIs, which leads to reduced use of preventative strategies,<sup>96</sup> and that lesbian and bisexual women are less likely than heterosexual women to seek routine preventative screenings for breast cancer and cervical cancer.<sup>97</sup>

Sexual diversity is often missing entirely from comprehensive sexuality education programmes and SRHR information dissemination activities, to which few persons with disabilities typically have access. At the same time, disability inclusion is rarely considered in SRH programmes and services for sexual minorities.<sup>98</sup> Collectively, this leaves LGBTQI+ persons with disabilities with little information and support with which to develop positive and healthy attitudes about themselves, their sexuality, and their gender identity.<sup>99</sup>

### Box 15: Key terms – LGBTQI+<sup>100</sup>

**LGBTQI+** refers to lesbian, gay, bisexual, transgender, queer, intersex and all other gender identities and sexual orientations individuals identify with

**Sexual orientation** refers to a person's physical, romantic, and/or emotional attraction towards other people

**Gender identity** reflects an internal, deeply felt, and experienced sense of one's own gender. A person's gender identity may or may not correspond with her or his sex assigned at birth

**Transgender** describes a person whose gender identity is different from the sex they were assigned at birth. Transgender may describe a wide variety of cross-gender behaviours and identities

**Queer** describes a person whose sexual and gender identities or sense of their own gender are not aligned with the sex they were assigned at birth. Lesbian, gay, bisexual, and transgender persons may all identify as queer<sup>101</sup>

**Intersex** refers to persons who are born with sexual anatomy, reproductive organs, hormonal and/or chromosome patterns that do not fit the typical definition of male or female

Health care providers must ensure that their services are fully addressing the sexual and reproductive health needs of clients with all sexual orientations and gender identities.<sup>102</sup>

A rights-based, person-centred approach to disability inclusive SRH service delivery requires that service providers, SRH programme managers, and all other interested stakeholders treat all people equally without regard to their sex, gender, or gender expression, and protect their rights to health, safety, dignity, and autonomy.

**Health care providers should:**

- Be prepared to offer information, counselling, and services that include accurate information about safe and healthy sexual relationships in accessible formats for sexual and gender minority clients with disabilities
- Recognise that fully inclusive SRH services should be free from assumptions about the sexual orientation and gender identity of clients, such as the heteronormative assumption that all sexual relationships are exclusively between women and men. Service providers and health care workers should take a person-centred approach that aims to meet the needs of all people, including those with non-normative sexual orientations or gender identities<sup>103</sup>
- Understand that many LGBTQI+ individuals may choose not to disclose their sexual orientation or gender identity, fearing stigma and the risk of violence and discrimination. All service providers must ensure the safety and confidentiality of all clients
- Be sensitive to and knowledgeable about the health needs of all clients, including the specific health needs of LGBTQI+ persons with disabilities<sup>104</sup>

**Let Good Be Told In Us Nyanza Rift Valley and Western Kenya (NYARWEK Network) and creating safe spaces for LGBTQI+ persons with disabilities**



The NYARWEK Network is a civil society organisation based in Kenya that advocates for the human rights of persons with diverse sexual orientations and gender identities. Among other strategies, NYARWEK reaches out to diverse communities through extracurricular activities like sports, arts, and other activities that encourage and enable self-expression. In the health sector, NYARWEK has focused on the prevention and treatment of HIV/AIDS, as well as sexual and reproductive health care services, most recently advising the Kenyan government on a new health strategy that is more inclusive of LGBTQI+ persons, adolescents, and young people, and persons with disabilities. NYARWEK has adopted an explicitly intersectional approach in its service work and advocacy, partnering with a women-led disability rights organisation to create safe spaces for sexually diverse persons with disabilities to talk about their sexuality, provide mental health counselling and support for those who have experienced gender-based violence and abuse, and advocate for the accessibility of health care services and facilities, as well as law enforcement and justice services.

## 6. SRHR services

*“They’re not used to taking disabled people seriously and it’s almost like you’re not supposed to have health problems outside of your disability.”<sup>105</sup>*

While persons with disabilities have the same rights and needs as all people with regard to SRH care services, they often face unique barriers in accessing these services. For example, persons who are blind or with low vision may struggle with the dosing of medication, and those with difficulties using their hands may find it difficult to use condoms. Guidance on how to address these fundamental challenges in obtaining and using SRH services is outlined below. However, it does not replace the most up-to-date evidence-based health care recommendations. Service providers should always consult the most current medical and scientific materials available, prior to administering any treatment.

Before recommending the use of any medication, including contraception, or providing any health care services, providers should review the medical history of all clients, and provide services that are consistent with a person-centred approach and informed choice.

### 6.1 Menstruation and menstrual hygiene

Many adolescent girls are uninformed and unprepared when they start menstruating, and do not have the means to care for themselves.<sup>106</sup> Girls and young women with disabilities, particularly those with intellectual disabilities and those who are excluded from education and comprehensive sexual education programmes, are less likely than non-disabled girls to be informed about menstruation or menstrual hygiene. In some cases, such information is intentionally kept from them because they are assumed to be unable to understand it.<sup>107</sup>

The absence of information and support leaves girls with disabilities and their carers overwhelmed and can contribute to girls dropping out of formal education systems as they are unable to manage menstrual hygiene issues in the school setting. It also presents a formidable barrier to SRH for girls with disabilities and their wellbeing as, for example, they may face more difficulties in dealing with pre-menstrual symptoms. Some of them may also experience untreated pain, be frightened by symptoms, withdraw, or refuse to eat.<sup>108</sup>

Teaching girls and young women with disabilities about menstrual health and menstrual hygiene can be a key entry point for broader education about SRH, including contraception, and empowering girls with disabilities to make informed decisions about their bodies and health.<sup>109</sup> In contexts where it is taboo for unmarried girls and young women to seek SRH services, especially contraceptive services, counselling or workshops on menstrual hygiene can be a way to share information about SRH without putting girls or young women at risk.

SRH programme managers should include information and discussions on the menstrual cycle in SRH activities, including SBCC and community mobilisation, and offer educational talks for young people with disabilities that focus on body knowledge, bodily integrity, puberty, and the menstrual cycle.<sup>110</sup> Providers should talk about the pros and cons of menstrual products (traditional and modern), and cost and access to these products should be introduced and discussed.

## 6.2 Contraception

Persons with disabilities, like all others, should have the right to decide the number, spacing, and timing of their children freely and responsibly.<sup>111</sup> They should also be able to exercise the right to the safe, effective, affordable, and acceptable methods of contraception of their choice. It is vital that clients with disabilities are fully informed about their options and provide their informed consent to the use of any form of contraceptive, freely and without coercion. This is a key responsibility of reproductive health service providers.

Service providers should be attentive to the possibility that the nature of the disability or medications a person may be taking could affect the appropriateness of contraceptive methods. For example, different contraceptive methods contain different hormones (oestrogen and/or progesterone) which can affect women with epilepsy.<sup>112</sup> Detailed guidance for providing family planning services, including the WHO's Medical Eligibility Criteria for contraceptive use, can be found in *Family Planning: A Global Handbook for Providers*.<sup>113</sup>

Considerations which may be relevant to the use of particular methods by clients with disabilities are outlined below. This is not a comprehensive list and should not replace the best available medical information and advice.

### Barrier methods

- Some barrier methods may be difficult to use for persons with mobility difficulties (e.g., those with limited manual dexterity, an amputated limb, or other mobility limitations). Persons with reduced hand coordination whose preference is to use barrier contraception may need the support of their sexual partner and their willingness to assist. If the client agrees to it, the involvement of the partner in the consultation can be beneficial.
- Persons with spina bifida are more likely to have an allergy to latex products, such as condoms or diaphragms, which can provoke allergic reactions and even shock.<sup>114</sup> Clients should be advised about the possibility of an allergic reaction when presenting the different options of contraceptive methods that contain latex. They may not know if they have a latex allergy or not and therefore may be unaware of the potential risks in using male condoms. Female condoms are made out of Polyurethane or synthetic latex, safe for those with allergies.<sup>115</sup>

- Help clients practice with condoms, using a banana, corn cob, or penis model. Giving clients the opportunity to touch and familiarise themselves with how a condom feels when used correctly or incorrectly may contribute to more effective use, especially when light is low or unavailable, as well as for those with visual disabilities.<sup>116</sup>

### **Oral contraceptives**

- Combined oral contraceptives may not be an appropriate method of contraception for women with poor blood circulation or immobile extremities, or when we do not know the reason why a woman has higher risk for thrombosis due to concerns about an increased risk of deep vein thrombosis or blood clots.
- Some women and girls with intellectual and psychosocial disabilities may have more difficulties in remembering to take daily medications. If these circumstances are confirmed by the client and their preference is still oral contraception, health care workers should discuss strategies to help them remember - for example, setting an alert on their phones, or using a system of automatic reminders by SMS.
- Service providers should make sure clients understand that if they forget to take their oral contraceptive, they can get pregnant. If patients are concerned about forgetting to take their contraceptive, they should be advised about alternative methods of birth control that are not user dependent, such as Intrauterine Devices (IUDs).
- Hormonal contraceptives such as combined oral contraceptives, progestin-only contraceptives, contraceptive patches, vaginal rings, implants, and emergency hormonal contraception may interact with other medications, which can put the client's health at risk or reduce the effectiveness of the medication or contraceptive. Some medications, such as certain antiepileptic drugs (e.g., carbamazepine acetate), may also interfere with hormonal contraception.

### **Intra-uterine devices (IUDs)**

- IUDs may increase menstrual flow. For women and girls who depend on the support of their assistants or caregivers, this can make it more difficult to manage menstrual hygiene
- A hormonal IUD may be advised for menstrual management due to reduced shedding of the endometrium, leading to reduced menstrual bleeding after a few months of use
- Women who have diminished pelvic sensation may be unable to detect IUD related pelvic inflammatory diseases or ectopic pregnancy, should they occur.
- Spasticity of the lower extremities can increase the difficulty of insertion of IUDs.<sup>117</sup>
- Like all clients, women with disabilities with normal childbirth processes should be advised on immediate IUD/implants within 48 hours of delivery. It is easier to insert an IUD immediately after child birth than during the interval periods of giving birth. However, the counselling and consent for postpartum family planning PFP should have been sought during the prenatal period.

## 6.3 Sterilisation

There are health workers and family members of women with disabilities, especially those with intellectual or developmental disabilities, who believe that disability is an unsurmountable barrier to motherhood and that women with disabilities should not become pregnant. To prevent pregnancy, many see sterilisation as the only solution to preserve the health and well-being of women with disabilities. Sterilisation is also often a preferred option for family caregivers as a way of reducing the burden of menstrual hygiene management. Women with disabilities have the right to consent to sterilisation, provided they are fully advised and counselled regarding the procedure and the outcome of sterilisation. Sterilisation without informed consent is a profound violation of the human rights of women with disabilities.<sup>118</sup>

**In every instance, the decision is hers to make.**

**If you receive a woman with a disability who is requesting sterilisation:**

- Ask about her sexuality
- Ask about her decision to use family planning and sterilisation
- As much as possible, make sure to properly inform and counsel her on the consequences of sterilisation, and the availability of other contraceptive methods that can help her to manage her fertility. If you have doubts about her understanding of your counselling and you are facing difficulties in obtaining a final decision, try to identify a person of trust among her caregivers who is used to communicating with her and can support the decision-making process. No matter the support she receives in processing and understanding the information, this remains her decision, not theirs.

**If a family member or caregiver asks for contraceptive services or sterilisation on behalf of a woman or girl with a disability:**

- It remains the service provider's responsibility to counsel the client with a disability and provide **only those services to which she consents**. Performing an involuntary sterilisation without the informed consent of the patient, or imposing forced contraceptive services, is a violation of international human rights law and may violate national laws. Both are forms of gender-based violence. Different facilities and working contexts and locations may have different procedures in place to report and follow up on this misconduct. It is important to promote these procedures to be inclusive for persons with disabilities.<sup>119</sup>

## Box 16: The seven points of informed consent to sterilisation<sup>120</sup>

Because sterilisation is permanent, the WHO directs service providers to cover the following seven points prior to asking a client whether she consents to the procedure. Counselling must cover ALL seven points for a client's consent to be considered 'informed'.

- Temporary contraceptives are available to the client, including long-acting reversible contraceptives
- Sterilisation is a surgical procedure
- The procedure has risks as well as benefits. Both risks and benefits must be explained in a way the client can understand
- If the procedure is successful, it will prevent the client from ever having any (more) children
- The procedure is considered permanent and probably cannot be reversed
- The client can decide against the procedure at any time before it takes place (without losing rights to other medical, health, or other services or benefits)
- The procedure does not protect against sexually transmitted infections, including HIV



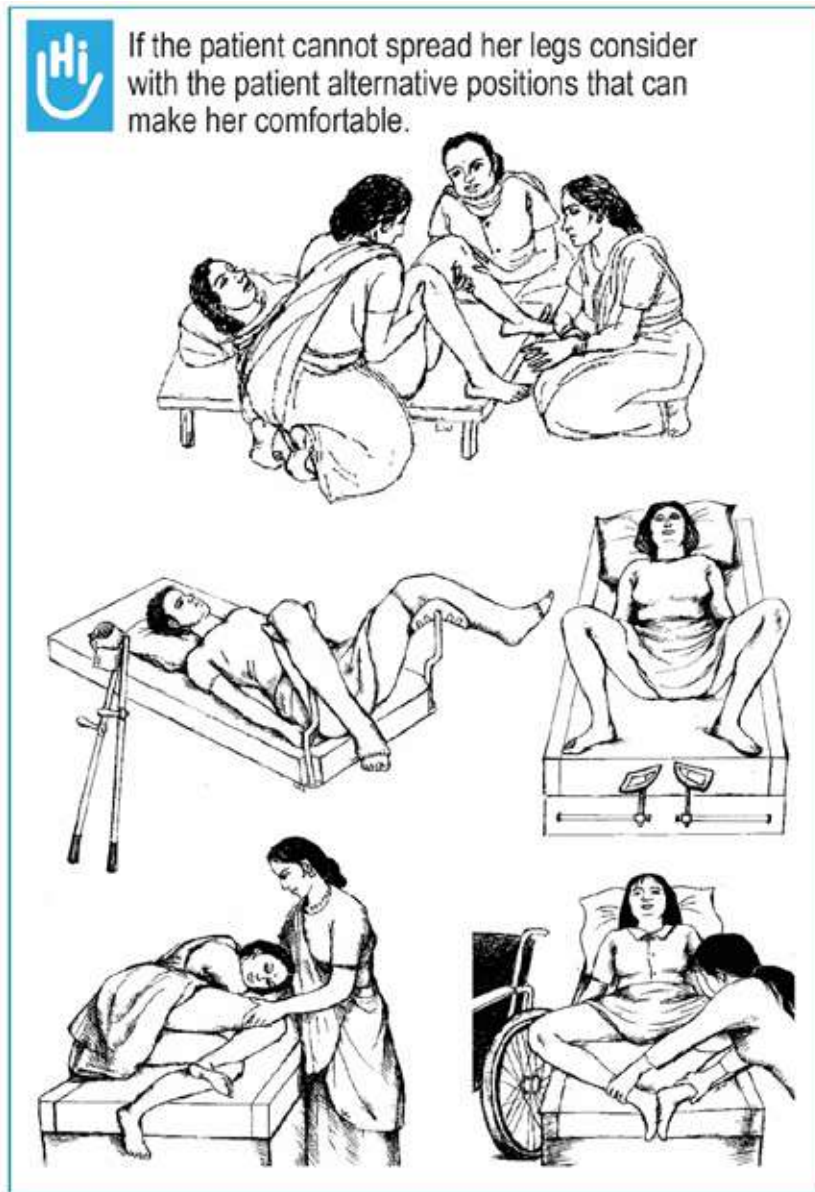
## 6.4 Gynaecological health care

Women with disabilities have a right to the same quality of gynaecological care as all other women. Ensuring that such care is accessible and sensitive to the needs of all women and girls with disabilities is essential.

In addition to following the guidance outlined above regarding the accessibility of facilities, there are several other considerations service providers should be mindful of. Some of them are listed below. More information on how to provide inclusive gynaecological care can be found in the *WHO DISABILITY-INCLUSIVE HEALTH SERVICES TOOLKIT A Resource for Health Facilities in the Western Pacific Region*<sup>121</sup>

- Some women with disabilities may not be able to access a standard hospital bed for a gynaecological examination. If the health care facility does not provide accessible beds or if the woman is more comfortable lying on the floor, health care workers should examine her on the floor, ensuring the hygiene and comfort of the client. To examine a person on the floor, turn the speculum handle up. Otherwise, the speculum will be difficult to open. To make sure the speculum does not touch the floor, place a folded cloth under the woman's hips to raise them slightly. An illustration of possible positions to use can be found below.
- All clients, but particularly women with intellectual disabilities, are often afraid the first time they see a speculum, especially during the first gynaecological exam. Show it to them and explain how and why it is used.
- Women with spinal cord injuries or cerebral palsy may have stiff muscles during an exam. This can happen if they are in an uncomfortable position, or if a speculum or any other instrument is inserted roughly. Be careful to adjust the position and to be gentle.
- Dysreflexia is a medical emergency. It is common in persons with spinal cord injuries. It is a sudden hypertensive peak caused by a reaction to a possible pain that could not be felt because of neurological damage. To prevent dysreflexia, pay attention to hard or cold examination surfaces and cold temperature in the exam room, as well as strong pressures on the perineum during the exam, especially while using a speculum.

### Diagram 6 - Physical Exam



A Health Handbook for Women with Disabilities (2007)- Maxwell, Belser David

## 6.5 Maternal and newborn health

The rights of women and girls with disabilities to the full range of maternal and newborn health services, including information, goods, preconception, antenatal care, skilled birth attendance, emergency obstetric care, postpartum care, and newborn care, are not consistently respected. These essential services are critical to ensuring safe pregnancy and delivery for women with disabilities and can also help prevent the majority of maternal and newborn deaths or preventable impairments.<sup>122</sup> Today, due to the lack of disability disaggregated data, information on the incidence of preventable maternal death among women with disabilities caused by lack of access to services is missing. This also leaves us without strong evidence for advocacy and very limited action to promote disability inclusive maternal health. Collecting and analysing disaggregated data in relation to preventable maternal death is therefore an urgent need.

### Box 17:

HI asked OPD partners in Uganda, do you think women with disabilities access antenatal, childbirth and postnatal care as frequently as persons without disabilities, and do you think they receive the same quality services? If not, why not?

No. Nurses look down on pregnant women with disabilities and use bad words to refer to them, and they shy away from going for services and end up using traditional birth attendants (TBAs).

No. Women, fear being asked stigmatising questions like, “Who made you pregnant?” or “How did it happen?”

### Service providers should:

- Make sure that pregnant women with disabilities have access to at least the same minimum recommended amount of antenatal and postnatal visits or more, according to their needs. Follow the same procedure as for all clients in categorising high/low risk pregnancies, to help to detect problems. Assume that for all pregnant women, the greater number of visits, the better the outcomes.
- Provide antenatal and postnatal care that is accessible, timely, friendly, simple, safe, and personalised/individualised to each pregnant woman, with emphasis on the woman’s overall health and well-being, her preparation for childbirth, and readiness for potential complications linked to her disability.
- Do not assume that a pregnant woman or a mother with a disability needs extra help or support during pregnancy, delivery, and postpartum. This may not be the case. Take the time to ask her and, if this is the case, discuss the possibility of involving the person who

will assist her in regular visits to ensure preparation and common understanding on how to respond in the best way to the mother and child's needs. For example, assisting in interpretation during labour, practicing different breathing techniques and pushing exercises before labour, etc.

- During pregnancy, pay equal attention to identifying existing medical, surgical, or obstetric conditions, such as severe anaemia, vaginal bleeding, pre-eclampsia, STIs, HIV and AIDS, TB, malaria, etc. as you would do for a person without disabilities. Do not assume that a woman with a disability is always more likely or less likely to be affected by these conditions.
- For the client to be forthcoming about the symptoms she is experiencing, health care providers should use positive and non-judgmental communication methods that foster trust. For example, ask, "Have you noticed any sores or ulcers on your genitals?" instead of, "I know that you cannot feel if you have any sores or ulcers."
- Use modern technology to share information with people who are difficult to reach. Examples include using mass media, mobile phones, internet, and community activities to disseminate accessible messages about maternal and newborn health; providing information about antenatal care and health education in relation to pregnancy and childbirth; and disseminating warning signs through SMS messages, etc.
- Make sure that maternal and newborn care, including antenatal care information and services, is accessible for all women, including women with different types of disabilities.
- During pre-maternal care, clarify and plan with the woman a form of accessible transport to the place of birth, and organise the necessary support prior to the date of the anticipated birth. Consider equipping the centre with adjustable examination tables and stepladders, and be prepared to have the necessary mats and equipment in place to ensure that a hygienic birth can take place on the floor should the woman be unable to deliver on a delivery bed.
- Extend consultation times to allow for sign and tactile language interpretation and practice when necessary.
- When it comes to providing information to a client with a disability on how to obtain a birth certificate or other related documents for their child, prepare in advance by collecting information about the accessibility of the relevant services. Guide the client towards the options that are inclusive.

### 6.5.1. Preconception care

Many women with disabilities, especially those with intellectual disabilities, do not receive comprehensive education about sexuality and reproduction and may have questions about their ability to become pregnant, as well as fears about how their disability may affect their pregnancy and vice versa.<sup>123</sup> Preconception care and counselling, ideally involving the health care worker, the client, her partner, and the midwife or obstetrician, can go a long way towards alleviating those concerns and supporting women with disabilities to make choices about their reproductive lives and, for those who decide to have a child, how to prepare for their pregnancy.

Preconception counselling includes but it is not limited to looking at the woman's health status prior to the pregnancy, in order to plan all relevant aspects of it. This is particularly important for women with disabilities to anticipate specific risks and obtain all the necessary assistance from health care providers.<sup>124</sup>

**During preconception counselling with women with disabilities, service providers should:**

- Treat all women with disabilities seeking advice about becoming pregnant respectfully. Avoid any suggestion that women with disabilities are unfit to be mothers or are being irresponsible when thinking about having children.<sup>125</sup>
- Recognise that women with disabilities may be concerned that preconception counselling will be used to discourage them from having children, or that health screening tests may be used to declare them ineligible for pregnancy.<sup>126</sup> Be supportive and communicate confidence in each client's abilities.
- Focusing on nutritional status, weight control, smoking, and alcohol use is important during counselling with all women. The treatment of any active symptoms or secondary conditions which may be related to disability is particularly important during preconception counselling with clients with some types of disabilities.<sup>127</sup>
- Daily consumption of folic acid (400 mg) prior to conception is as important for women with disabilities as other women, and if a woman has spina bifida or is taking anticonvulsants, it may be appropriate to increase the dosage both before attempting conception and during the early months of pregnancy.<sup>128</sup> Service providers should consult available resources for specific medical guidance.
- When checking for each client's intake of medications, service providers should consider that women with some types of disabilities may be taking medications they are less familiar with when it comes to their potential effect on the health of the foetus. To avoid the risk of future harm, particular attention should be paid to medications with a teratogenic potential (e.g., disease-modifying agents, anti-convulsants, or immunosuppressive agents) for which it may be necessary to discuss with the client the need to modify or stop them before trying to become pregnant.<sup>129 130</sup>

- Service providers should also take into consideration that some women with physical disabilities may have a higher risk of non-communicable diseases, such as hypertension, diabetes, or of deep vein thrombosis, due to physical conditions caused by immobility/sitting in a wheelchair. This must be taken into consideration when planning pregnancy and during prenatal care.

For some women with disabilities who face multiple barriers in accessing services, it might also be relevant to discuss at an early stage how to access regular antenatal care, including logistical arrangements for necessary home visits and telehealth opportunities, as well as the potential risk factors. This will help women with disabilities to plan effectively for pregnancy and birth delivery.

## 6.5.2 Antenatal care

Women with disabilities should be granted access to the same quality and range of antenatal care services that are offered to all other female clients.

### These include:

- Encouraging all women, including women with disabilities, to observe a healthy diet, including folic acid, vitamins, calcium, phosphate, iron, etc. In particular, women with mobility difficulties should avoid excess weight gain as this can negatively influence their balance or ability to move. They should also observe a diet high in fibres and fruits to avoid constipation.
- Encouraging all pregnant women, including those with disabilities, to continue exercising as often as they are able and comfortable doing so.
- Taking a comprehensive medical history, including discussion of the client's general health status; the nature of her disabling condition; any medications she is using, including all those used to treat her disabling condition and any secondary conditions related to it; and her concerns related to the pregnancy, including the effect of her pregnancy on her disability and vice versa.<sup>131</sup>

Service providers should listen to the asks of their clients with disabilities and not be misled by the widespread misconception that women with disabilities are less able to have and care for a child, therefore assuming that they are seeking to terminate their pregnancy.

**To ensure that women with disabilities have access to quality antenatal care throughout their pregnancies, service providers should be attentive to the following additional points:**

- Transportation to and from health care facilities for antenatal care may be particularly challenging for women with disabilities, due to a lack of accessible public transportation. Service providers should work with women clients to identify the most comfortable mode(s) of transportation during each stage of pregnancy, as these may change over time and be different from the mode of transportation that clients use when not pregnant. For example, it may be more difficult for a client to ride a motorbike during pregnancy, or she may need support to get into a vehicle that she could get into easily before pregnancy.
- Some women with physical disabilities are more prone to muscle spasms during pregnancy. Regular exercises can reduce spasms and spasticity. Service providers should proceed slowly during the exam and ask the patient to inform them if she has a spasm or if the exam is painful. Do not massage or rub the spastic muscles. The massage will tighten the muscles.
- During the antenatal period, women with disabilities that affect their mobility are at higher risk of several health issues, including urinary tract infections (UTIs), impaired balance and gait due to change in their centre of gravity, increased risk of falls, and changes in bowel and bladder management.

Women who are wheelchair users are at increased risk of pressure ulcers during pregnancy and may grow out of their wheelchairs due to weight gain.

Clients should be screened regularly during pregnancy for any such issues and counselled on how to avoid potential risks and ensure well-being.

Recommendations for care for these and other issues are outlined in more detail overleaf in Table 8.

**Table 8: Care for problems arising from disabilities in pregnancy**

<p><b>Problem:</b> Autonomic dysreflexia (autonomic hyperreflexia)</p> <p><b>Disabling Conditions:</b> Spinal cord injury, especially with lesions above T10, especially lesions at or above T6</p> <p><b>Description:</b> Activation of the sympathetic nervous system can be triggered by uterine contractions, oxytocin, UTI, distention of the bladder, constipation or fecal impaction, ectopic pregnancy, pelvic or rectal examination, pressure ulcers. Early signs and symptoms include headache, sweating and piloerection above the level of the spinal lesion, nasal stuffiness, and facial flushing. Severe signs include hypertension, irregular cardiac rate, facial flushing, shortness of breath, increased muscle spasticity. May stress the fetus. Serious complications include seizures, intracranial hemorrhage, coma, and maternal death ( Norwitz &amp; Repke, 2005 )</p> <p><b>Implications for Care:</b> Women with SCI should be assessed for signs and for factors that can precipitate AD (full bladder or bowel, pelvic examination, labor). Pelvic examination should be performed when others are available to assist in case AD occurs and with patient’s head elevated as high as possible. If history of severe AD, pelvic examinations should be performed only when emergency assistance is readily available. Anesthetic gel applied to the vagina and speculum may reduce risk of AD ( Madorsky, 1995 ). If AD occurs, the exam should be halted immediately, the head of the bed raised, and rapid-acting antihypertensive agents such as nifedipine administered labor, epidural anesthesia can prevent AD ( Norwitz &amp; Repke, 2005 ). If AD occurs, prompt delivery of the baby and placenta is essential</p>
<p><b>Problem:</b> Deep vein thrombosis</p> <p><b>Disabling Conditions:</b> Disabilities that limit mobility; wheelchair users</p> <p><b>Description:</b> Venous stasis and pressure of the growing fetus prevent venous return from the legs and increase the risk of deep vein thrombosis ( Baschat &amp; Weiner, 2004 )</p> <p><b>Implications for Care:</b> The lower extremities should be assessed for warmth, redness, edema, or asymmetry. Elastic compression stockings and elevation of lower extremities are useful, especially in late pregnancy, to promote venous return</p>
<p><b>Problem:</b> Latex allergy</p> <p><b>Disabling Conditions:</b> Spina bifida</p> <p><b>Description:</b> Allergic reactions may cause relatively mild symptoms (erythema and pruritus) or may rapidly progress to anaphylactic reaction (i.e., urticaria, wheezing, dyspnea, laryngeal edema, bronchospasm, tachycardia, angioedema, hypotension, and cardiac arrest)</p> <p><b>Implications for Care:</b> Women should be screened for latex allergy, especially those with spina bifida and a history of repeated surgeries. Gloves and all items (e.g., urinary catheters, IV lines) must be assessed for latex before use. Antihistamines and epinephrine must be readily available</p>
<p><b>Problem:</b> Urinary tract infections</p> <p><b>Disabling Conditions:</b> Neurologic disorders (e.g., spina bifida, MS, SCI, cerebral palsy)</p> <p><b>Description:</b> Many disabilities increase risk for UTI; risk increases during pregnancy, especially in women with neurogenic bladders ( Donaldson, 2005 ). During pregnancy, UTIs are more likely to ascend to the kidneys and cause pyelonephritis, premature onset of labor, and fetal mortality ( Foxman, 2002 ). Infected pressure ulcers increase the risk for UTI</p> <p><b>Implications for Care:</b> Increased fluid intake is recommended along with use of vitamin C, cranberry juice or cranberry extract tablets to decrease the urine pH and prevent adhesion of bacteria to the uroepithelium ( Howell &amp; Foxman, 2002; Smeltzer &amp; Sharts-Hopko, 2005 ). Probiotic therapy helps restore normal vaginal flora and may prevent UTI ( Stapleton, 2003 )</p>



**Problem: Urinary incontinence**

**Disabling Conditions:** Neurologic disorders (e.g., spina bifida, MS, SCI, cerebral palsy)

**Description:** Urinary incontinence may increase in pregnancy in women with preexisting bladder dysfunction because of the pressure of the growing fetus ( Madorsky, 1995 )

**Implications for Care:** A bladder management program should be implemented if not in place and evaluated if urinary incontinence increases

**Problem: Compromised respiratory function**

**Disabling Conditions:** Neurologic disorders (e.g., high cervical or thoracic SCI, myasthenia); cystic fibrosis

**Description:** The diaphragm is elevated and chest configuration altered during the second half of pregnancy ( Donaldson, 2005 ). Preexisting respiratory dysfunction can worsen during late pregnancy and labor. Ventilatory support may be required ( Madorsky, 1995; Norwitz & Repke, 2005 )

**Implications for Care:** Respiratory function should be monitored in women whose disability affects thoracic excursion. Availability of ventilatory support is essential in women at high risk

**Problem: Spasticity**

**Disabling Conditions:** Neurologic disorders (i.e., spina bifi da, MS, SCI, cerebral palsy)

**Description:** Spasticity (increased muscle tone and resistance to passive movement) is often more pronounced at the extremes of range of motion. It is increased by pain, a cold room, contact with a cold speculum, stress, and rapid movement

**Implications for Care:** Women with spasticity should be moved slowly and gently. Alternate positions for the pelvic examination may reduce risk of spasticity. Lidocaine applied to the perineum to may reduce discomfort and risk of spasticity ( Welner & Temple, 2004 ). To avoid falls, women who have spasms or spasticity should not be left alone on examination tables

**Problem: Risk of pressure ulcers**

**Disabling Conditions:** Neurologic disorders characterized by impaired sensation (e.g., SCI, MS)

**Description:** Pressure points may change during pregnancy as weight and body distribution change. Risk for pressure ulcers may be increased in women with anemia

**Implications for Care:** Skin and bony prominences should be assessed frequently in women with impaired sensation. Women should be taught to assess their skin and change positions to prevent skin breakdown. Anemia should be prevented through adequate iron intake ( Carty, 1998; Norwitz & Repke, 2005 )

**Problem: Constipation**

**Disabling Conditions:** Neurologic disorders characterized by neurogenic bowel problems (e.g., SCI, MS)

**Description:** Supplemental iron may cause severe constipation during pregnancy in women with preexisting neurogenic bowel problems

**Implications for Care:** Nutritional modifi cations, increased fluid intake, cautious use of iron, and stool softeners are indicated to prevent severe constipation

**Problem: Unrecognized onset of labor**

**Disabling Conditions:** Disabling conditions characterized by impaired sensation (e.g., SCI, spina bifida)

**Description:** Unrecognized onset of labor may result in premature or unassisted delivery, increasing risks to baby and mother. Women with spasticity may be more aware of the onset of contractions because of increased spasms and spasticity ( Baschat & Weiner, 2004 )

**Implications for Care:** Weekly cervical examinations after 28 weeks ' gestation are recommended to detect premature labor. Uterine activity monitoring may be used. Women should be instructed to perform abdominal palpation and report changes that may indicate contractions ( Norwitz & Repke, 2005 ). Bed rest may be prescribed if labor begins early

**Problem: Severe fatigue**

**Disabling Conditions:** Disabling conditions including MS, RA, SLE, fibromyalgia)

**Description:** The fatigue common in pregnancy may be increased in women whose disabling conditions have fatigue as a major characteristic

**Implications for Care:** Fatigue may be especially severe during the first trimester. If it is incapacitating, women should be evaluated for treatable causes. Women can be advised to take scheduled rest periods during pregnancy and the postpartum period, use energy-saving strategies, and balance rest with exercise within the limits of their disabilities

**Problem: Increased symptoms or worsened disability during pregnancy**

**Disabling Conditions:** Systemic lupus erythematosus

**Description:** Due to changes in immune status that characterize pregnancy, disorders characterized by autoantibody production (e.g., SLE) tend to worsen during pregnancy, and risk of pregnancy loss is increased ( Silver & Branch, 1997 )

**Implications for Care:** Women whose SLE worsens during pregnancy are at increased risk for hypertension and premature delivery; thus, they should be monitored closely by a clinician skilled in managing women in this high-risk category

**Problem: Increased symptoms or worsened disability after childbirth**

**Disabling Conditions:** Multiple sclerosis, RA

**Description:** Immune-mediated disorders that are cell mediated (MS, RA) tend to improve during pregnancy but tend to worsen in the postpartum period ( Silver & Branch, 1997 )

**Implications for Care:** Symptoms may be stable or decreased during pregnancy but flare up during the postpartum period. Women should be informed about this possibility and monitored following delivery. Disease-modifying medications should be resumed and significant flares or exacerbations treated

**Problem: Falls**

**Disabling Conditions:** Conditions with impaired balance or coordination, muscle weakness, or paralysis (e.g., MS, SCI, spina bifida, cerebral palsy)

**Description:** Change of the woman's center of gravity late in pregnancy due to expanding uterus combined with impaired balance and lack of coordination due to disability increase the risk for falls ( Rogers, 2006 )

**Implications for Care:** Women at risk for falls should be encouraged to use assistive devices (canes, walkers, or wheelchair) to prevent falls and fractures ( Welner & Temple, 2004 )

Note. AD = autonomic dysreflexia; SCI = spinal cord injury; UTI = urinary tract infections; MS = multiple sclerosis; RA = rheumatoid arthritis; SLE = systemic lupus erythematosus. © 2007, AWHONN, the Association of Women's Health, Obstetric and Neonatal Nurses

Adapted from Smeltzer, S. (2006) Pregnancy in Women with Physical Disabilities JOGNN 36, 88-96

In preparation for labour and delivery, service providers should also consider the following:

- Women with physical disabilities are often told they must give birth by caesarean section, despite the fact that this is not always necessary and leads to overuse of surgical procedures.<sup>132</sup> **Take your time to fully understand the needs of your client** to make the best recommendations, sharing all the relevant details with her, and only propose a caesarean section when you consider it to be absolutely necessary.
- During labour and delivery, some women with disabilities require specialised care, which must be organised in advance to ensure the relevant support is available when needed. For example, women with spinal cord injuries or musculoskeletal disabilities (e.g., spina bifida, osteogenesis imperfecta, or cerebral palsy) often have specific issues that may require special planning prior to receiving or administering epidural anaesthesia for delivery. Primary care providers should help clients to find specialised providers who are knowledgeable or willing to learn about how to provide the best support to the client with disability during antenatal, labour, delivery, and postnatal.
- Covering the cost of care before, during, and after delivery can represent a significant financial burden. As many women with disabilities and their families live in poverty due to a lack of inclusive employment opportunities and rife discrimination, it is important to take the time to inform the pregnant woman/couple about the forthcoming costs so she/they can plan ahead and seek social support if necessary. Where service providers are familiar with the system, it could be helpful to refer clients to any relevant resources.

### 6.5.3 Childbirth and postnatal care

Most disabilities do not interfere with women's ability to have a normal labour or delivery. Despite this, many women with disabilities have reported that decisions about the type of delivery were made for them without their consent and without consultation.<sup>133</sup> The need to have a caesarean delivery should be based on each woman's overall health status, the progress of the labour, and the wellbeing of the foetus, rather than on the fact that she has a disability.

Service providers should let the woman choose birth positions that make her feel the most comfortable, improve the ease of her delivery, and are accessible for support interventions.

If you are attending a woman who has difficulties in moving, do not hesitate to explore alternative positions with her for giving birth. Some examples are illustrated below.

### Diagram 7: Alternative positions



A Health Handbook for Women with Disabilities (2007)- Maxwell, Belser David 134

The midwife or obstetrician and the woman delivering should plan how labour will be managed, including pain management and alternative positioning (e.g., side-lying may be required if spasticity is a problem).

After delivery, whether vaginal or caesarean, women with some types of disabilities may require a longer period of time to recover than non-disabled women. Whether they are at home or in a clinical setting, they should be in an accessible space which allows them to have easy access to their infants.<sup>135</sup>

As with other women, breastfeeding should be encouraged for women with disabilities. In some circumstances, they may need support in carrying or positioning the child. There are a number of adaptive strategies available, such as creative use of pillows, attaching handles to baby bottles so women with disabilities affecting the use of their hands can hold them, and adjustable cribs and feeding chairs.<sup>136</sup>

## 6.6 Prevention of preventable impairments

In 2017, UN Women reported that “[e]very minute, more than 30 women are seriously injured or disabled during labour”. That adds up to millions of women, yet this has “generally gone unnoticed.”<sup>137</sup>

Health workers should make every effort to provide quality services to women and girls with disabilities, but at the same time, they must also focus on preventing and reducing the development of any kind of injury. They should do everything they can to:

- Prevent worsening of the impairment and further loss of functional autonomy (e.g., avoid wrong positioning of women with spinal cord injuries)
- Prevent preventable impairments (also referred to in other guidance as maternal disabilities) in any woman or child during childbirth, through proper training
- Provide early identification and care of newborns in order to refer to adequate health services for rehabilitation (e.g., cleft lip, club foot, cerebral palsy, etc.)

### Obstetric fistula and disability

Obstetric and traumatic fistula presents as a hole between the tissues of the vaginal canal and the bladder, vaginal canal, and rectum, or all three.<sup>138</sup> It can have different causes and may lead to disability. Obstetric fistula can be caused by prolonged and obstructed labour without access to timely quality medical treatment. or when girls whose bodies aren't yet fully developed give birth. Young girls under the age of 16 are at greatest risk of developing obstetric fistula. Traumatic fistula, however, is typically the result of violent rape or sexual atrocities, e.g., in contexts where rape is frequently used as a weapon of war.

In more than 80 per cent of cases, obstetric fistula can be medically treated e.g. through surgery, but unfortunately, many women do not have access to adequate services. Urine continence can also be improved by adding 10 to 15 sessions of perineal physiotherapy to the surgical intervention.

A woman with obstetric fistula is not only left urine incontinent but may, in the worst cases, also experience neurological disorders, orthopaedic injuries, bladder infection, painful sores, kidney failure, or infertility. Women with obstetric fistula often experience stigma, discrimination, and exclusion, which may cause psychosocial distress. Moreover, due to their condition, they may lose the ability to leave the house and earn a living, which may affect their well-being and the well-being of their family, as well as the ability to access medical treatment. Holistic interventions on obstetric fistula that address the physical and mental health of the woman, as well as her livelihood and social inclusion, are highly recommended.

## 6.7 Safe abortion and post-abortion care

Although access to safe abortion and post-abortion care is essential in SRH services for all women and girls, including those with disabilities, availability of such services remains limited and in some countries, it is being rolled back. Ninety million women of reproductive age live in countries where abortion is legally prohibited in all circumstances, even when a woman's life or health are at risk, and nearly two-thirds of all women cannot obtain an abortion on request.<sup>139</sup> Although modern contraceptives have become increasingly accessible, usage remains low in many countries. This results in a high number of unsafe abortions with serious consequences. Between 8 and 18 per cent of all maternal deaths are due to unsafe abortions.<sup>140</sup>

With one in four women living in countries where abortion is forbidden or permitted only in order to save a woman's life, safe and legal abortion services are out of reach for many women. However, due to a lack of disaggregated disability data, the challenges and risks women with disabilities face when it comes to unsafe, coercive abortions and the lack of post-abortion care remain largely undocumented. Considering the unmet need for SRHR information and services among women and girls with disabilities discussed in this Guideline, we have no reason to doubt that access to safe abortion and post-abortion care is lacking, and that many women with disabilities face a very high risk of suffering from the consequences of being underserved. This includes the development of preventable impairments that can lead to long-term or permanent disabilities.

### **When considering disability and the risks that follow unsafe abortions, stakeholders should:**

- Ensure that women and girls with disabilities are informed of, and included in, safe abortion care, including post-abortion care, to the full extent of the law, in order to save lives and prevent further health problems and the risk of preventable impairments
- Reduce the risk of harm from unsafe abortions by ensuring that women and girls with disabilities have access to immediate post-abortion care that is supportive, non-judgmental, and delivered with compassion and respect for dignity<sup>141</sup>

## 6.8 STIs and HIV/AIDS

*“The doctor was surprised at me. He had laughed at me saying, ‘Can you also have HIV?’...Even there in the room they laughed.”*

Woman with physical disability, Lusaka, Zambia

International data shows that persons with disabilities are, on average, more likely to experience poor health and face a higher risk of contracting sexually transmitted infections (STIs) and HIV. Many interrelated factors, such as a lack of education, discrimination, stigma, and lack of access to preventive and curative services or health education programmes, as well as a high prevalence of SGBV among women and girls with disabilities, contribute to this fact. STIs, including human papillomavirus (HPV) and HIV remain a major public health challenge, particularly in lower and middle-income countries.

Relevant knowledge of the prevention of STIs among persons with disabilities, and in particular among young persons, is shockingly low. As a result, they face a higher risk, confirmed by national and international data, of contracting STIs and HIV/AIDS, resulting in a prevalence of HIV/AIDS infections among young persons with disabilities that is two times higher than that of their peers without disabilities.<sup>142</sup> There is a pressing need to actively include persons with disabilities in health education, counselling, and prevention programmes, as well as testing and response services, in order to fulfil their right to health and promote their health and well-being.

HIV/AIDS service providers should consider all the steps included in Part II ‘What stakeholders should do’ to address this urgent need.

## 6.9 SRH services for survivors of gender-based violence

Gender-based violence is associated with a wide range of negative health outcomes for all women, but especially women and girls with disabilities.<sup>143</sup> Professional interventions to address GBV for all clients, including persons with disabilities, must be based on recommended clinical management guidance<sup>144</sup>, ethical rules and safeguarding, and no harm principles that are stipulated and recommended by all international health and humanitarian response agencies (see WHO<sup>145</sup>) and the Inter-Agency Standing Committee (IASC).<sup>146</sup> Interventions that aim to prevent

or address violence against women and children with disabilities should include precautions above and beyond routine risk assessments to guarantee that no harm is caused. The sensitive nature of collecting information about violence against women and girls also demands additional precautions.

## **Box 18: Key point - recognising a client who may be subjected to violence**

Persons with disabilities, especially women and girls, are far more vulnerable to gender-based violence than their non-disabled peers. It is therefore important for service providers to be aware that a client with a disability who seeks health services may have health concerns related to violence, which she may not share.

The WHO has identified the following as possible signs of violence to be aware of:<sup>147</sup>

- Ongoing emotional health issues, such as stress, anxiety or depression
- Harmful behaviours, such as misuse of alcohol or drugs
- Thoughts, plans, or acts of self-harm or (attempted) suicide
- Repeated sexually transmitted infections
- Unwanted pregnancies
- Unexplained chronic pain or conditions (e.g., pelvic pain or sexual problems, gastrointestinal problems, kidney or bladder infections, or headaches)
- Repeated health consultations with no clear diagnosis

Service providers should also consider the potential of violence if a client's partner, spouse, or caregiver is intrusive during consultations, if she often misses her own or her children's appointments, or if her children have emotional and behavioural problems.

**If a service provider sees a client with injuries or conditions s/he suspects may be related to violence, s/he should find a way to meet with the client alone and ask her/him about it.**

**NEVER RAISE THE ISSUE OF VIOLENCE WITH A CLIENT UNLESS SHE IS ALONE.**  
Her partner or caregiver may be the abuser or may be the mother or sister of an abuser.

### **Helpful resource**

World Health Organisation. (n.d.). Health care for women subjected to intimate partner violence or sexual violence: A clinical handbook, <https://www.who.int/reproductivehealth/publications/violence/vaw-clinical-handbook/en/>.



**When considering interventions related to sexual and gender-based violence, stakeholders should:**

- Assess whether the intervention may place a client with disabilities at increased risk of violence and ensure that it does no harm. This includes taking any steps necessary to avoid re-victimising survivors during care and treatment.
  - Service providers should not force any person to be examined against her will and respect the agency and decision-making authority of the survivor. They should make sure that persons with disabilities who have experienced rape or sexual abuse receive the same quality of care as any other person, including the use of hygiene kits, vaccinations, STI prophylaxis, HIV pre-test and post-exposure prophylaxis, emergency contraception, and proper documentation of evidence if required. Service providers should also ensure that persons with disabilities who have experienced sexual violence receive appropriate support and care for any pregnancy that may result, and safe abortion care where legal and requested by the client.
- Recognise that disclosing violence or SGBV may be even more difficult for clients with disabilities due to fear of not being believed, or because the person who has committed the violence is a person on whom they must rely for care or support. When screening for violence, service providers should ensure that clients with disabilities can be counselled privately – away from any caregiver – and guarantee the confidentiality of any information disclosed.
- Service providers should be aware of disability-sensitive and accessible referral services for the care and support for survivors, including mental health counselling, law enforcement services, housing assistance, and livelihood activities, among others. Where appropriate, they should support persons with disabilities to report and access legal services by informing them about their rights and providing information about existing services.
- Make sure information on GBV and services is accessible for all persons with disabilities and share accessible information with education institutions, SRH programme staff, OPD,s and others who may be in a position to identify persons experiencing violence and support prevention or response efforts.

### Helpful resources

Maxwell J, Belsur J, David D (2007) A Health Handbook for Women with Disabilities. Hesperian Foundation [https://en.hesperian.org/hhg/A\\_Health\\_Handbook\\_for\\_Women\\_with\\_Disabilities](https://en.hesperian.org/hhg/A_Health_Handbook_for_Women_with_Disabilities)

UNESCO and Humanity & Inclusion. (2019), Seeing the invisible: Sexuality-related knowledge, attitudes and behavior of children and youth with disabilities in China.

Save the Children Resource Centre, Child Fund International, Women's Refugee Commission, "Gender-Based Violence Against Children and Youth with Disabilities: A toolkit for child protection actors".

UNFPA and Women Enabled International. (2018). Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights. [https://www.unfpa.org/sites/default/files/pub-pdf/UNFPA-WEI\\_Guidelines\\_Disability\\_GBV\\_SRHR\\_FINAL\\_19-11-18\\_0.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/UNFPA-WEI_Guidelines_Disability_GBV_SRHR_FINAL_19-11-18_0.pdf)

## 6.10 Prevention and management of cancers of the reproductive system

*“My real challenge is with the mammogram. My chair can go in there but the different positions, then, they have to take more pictures because at the time I’m not positioned right and it hurts more when you sit down ... because you have to be a certain way and in a chair you can’t do it like you’re standing up.”*

Despite the fact that women and men with disabilities carry the same risk of developing cancer of their reproductive system, they are often excluded from preventive screening services, or the services are not accessible or disability friendly. WHO reports that health promotion and prevention activities seldom target persons with disabilities. Women with disabilities receive fewer screenings for breast and cervical cancer than women without disabilities.

Unfortunately, there is limited global data and almost no data from developing countries about persons with disabilities and their access to SRH-related cancer services. However, the alarming indicators from economically well-off countries are striking.

### Box 19: Knowledge of cancer in Uganda

**HI asked OPD partners in Uganda in May 2020**, do you think that persons with disabilities have the same knowledge about cancer prevention programmes and services as persons without disabilities?

- “No – cancer has not been one of the key health education messages and there are no specific messages for persons with disabilities.”
- “The current prevention messages are for married people or those who have sex, and persons with disabilities have low self-esteem that limits them from having sex and disclosing their sex status, whether active or not.”

Based on the myth and belief that women with disabilities are less sexually active, health care providers may often inappropriately minimise their risk of cervical cancer and their need for the recommended screening. However, it is reasonable to assume that women with disabilities face the same or higher risks of cervical and ovarian cancers and breast cancer as their non-disabled peers, so they should have the same access to counselling on the HPV vaccine and regular cancer screenings.

Stakeholders providing cancer prevention services to women should follow the steps in Part II – include persons with disabilities in cancer screening programmes, and be prepared to support women with disabilities with reasonable accommodations if necessary. Stakeholders should cooperate with OPDs, particularly women-led OPDs, youth groups, and secondary education institutions in designing and planning for inclusive cancer prevention programmes, and support the dissemination of accessible cancer prevention screening information.

## Box 20: Key points for practical recommendations for breast and pelvic exam and mammography

Inform women and girls about the exam and the procedure in advance, especially if the client is a woman or a girl with intellectual and developmental disabilities or psychosocial disabilities

If the client is concerned or preoccupied about the exam and needs to get familiar with the environment beforehand, offer the possibility to visit the clinic in advance and show her the instruments that you will use

- Remind her that she can come with a family member, a friend, or a personal assistant if this makes her feel more comfortable
- Talk the client through each step of the exam. Ask her if she is ready to start and wait for her to agree before you go on. This should help to reduce fear

### Conducting a mammogram

Before the appointment with the client, try to collect some key information from her. Ask if she can/cannot:

- Sit upright with or without assistance
- Lift and move her arms
- Transfer from her chair/scooter
- Undress/dress without assistance

When preparing for a mammogram, in addition to the regular information and instructions (e.g., wear a blouse that opens in the front; wear a bra that you can remove easily; do not wear deodorant or body powder), remind her that if she has any disability-related concerns, she should discuss them with her primary care physician, women's health specialist, radiologist, physician's assistant, or other health care provider.

## 6.11 E-health and self-care

E-health, the use of information and communication technologies (ICT) for health, is becoming an increasing priority for the WHO. The World Health Assembly Resolution WHA58.28 on E-Health was adopted in 2005 and today, thanks to the increase of mobile phones globally, 85 per cent of WHO Member States report to have implemented an e-health initiative. COVID-19 has further confirmed the important role that e-health can play when an in-person counselling session is not possible.

### **E- health may include:**

- Targeted client communications such as the transmission of diagnostic results, telemedicine consultations
- Personal Health Tracking such as self-monitoring of health or diagnostic data
- Reporting of health systems feedback by clients

E-health can play a role in overcoming some physical barriers that prevent access to health facilities for many people, including those living in remote areas and persons with physical disabilities. However, to ensure that e-health is accessible to all persons with disabilities, it is important to include the key accessibility features previously discussed in this guideline, such as captioning and sign language. The WHO and the International Telecommunication Union (ITU), a specialised agency of the United Nations responsible for all matters related to information and communication technologies, are currently working on an accessibility guidance on e-health to support inclusion in e-health.

Self-care interventions, some of which include E-Health initiatives, such as access to online SRHR information, may also be an effective way to increase access to and use of sexual and reproductive health care services for persons with disabilities, especially those in hard-to-reach locations or whose disability makes it difficult to visit a health facility. Self-care is defined as “the ability of individuals, families, and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health care provider”.

### **The concept of self-care incorporates three elements:**

- Self-management: self-medication, self-treatment, self-examination, self-injection, self-administration, and self-use
- Self-testing: self-sampling, self-screening, self-diagnosis, self-collection, and self-monitoring
- Self-awareness: self-help, self-education, self-regulation, self-efficacy, and self-determination.

**Self-care strategies may include:**

- Ensuring the online availability of accurate and appropriate educational materials on contraception, safe abortion/post-abortion care, STIs, HIV, maternal health, and gender-based violence, among other topics
- Providing resources for self-sampling and self-testing for STIs, or guidance on how to conduct breast or testicular self-examination
- Obtaining and using at-home ovulation predictor kits, cycle tracker applications, at-home pregnancy tests, or injectable contraceptives
- Access to self-managed medication abortion (misoprostol and mifepristone)
- Online counseling and access to health care providers through telephone or SMS
- At-home management of clinical waste

While emphasising self-care can be a helpful approach, it is only one of many strategies that may be appropriate for some persons with disabilities, and inappropriate for others. A supportive self-care approach should be part of the continuum of care, but should not be used as a sole replacement for disability mainstreaming activities within health facilities and across community mobilisation efforts.

## 7. Inclusive SRHR in humanitarian settings and disaster response

*“Our job is to ensure that [persons with disabilities] are counted like any other in a humanitarian response during a crisis. It is [their] fundamental right...to access the same protection and care we provide to others”.*

Mark Lowcock, Under-Secretary General for Humanitarian Affairs And Emergency Relief Coordinator

Persons with disabilities are disproportionately affected by humanitarian crises and natural and man-made disasters. An estimated 80 per cent of persons with disabilities live in poverty and more than 10 million are forcibly displaced as a result of persecution, conflict, and human rights abuses.

In research conducted by HI, more than half (54 per cent) of persons with disabilities in humanitarian settings reported experiencing a physical impact as a result of crisis, while 38 per cent reported psychological stress and/or disorientation, 31 per cent reported increased dependency on others due to loss of accessible environment, and 27 per cent reported facing abuse during flight and crisis.

The COVID-19 pandemic and public health emergency had a similarly devastating impact on persons with disabilities, especially those in institutional settings, and resulted in wide-spread violations of their rights. Despite the disproportionate impacts of humanitarian crises on persons with disabilities, they have not typically been prioritised within response efforts.

SRHR service providers working in humanitarian settings often neglect the importance of routinely including persons with disabilities in their services. As a result, there is a need to mainstream disability inclusion in humanitarian SRHR programmes. The Lancet Guttmacher Commission report to accelerate disability inclusion in SRHR in 2018 and the development of the IASC Guidelines outlining the ‘Inclusion of Person with Disabilities in Humanitarian Action in 2019’, including the relevant component of inclusive SRHR, mark a significant step in advancing accountability for the inclusion of persons with disabilities within the inter-agency coordination mechanism.

## Box 21: Key Facts and figures

- Evidence suggests that persons with disabilities are two to four times more likely than their non-disabled peers to die in natural disasters.
- Young persons with disabilities living as refugees or displaced persons disproportionately experience discrimination in refugee camps and emergency shelters. This is particularly true for young women and adolescent girls with disabilities who face significant barriers to accessing SRHR and an increased risk of GBV.
- Conflict and disaster increase the vulnerability of persons with disabilities of all ages and gender to violence, but it disproportionately affects women and girls with disabilities.
- Women and girls in conflict and crisis struggle to have their SRHR needs met. The specific needs of girls or women with disabilities are frequently overlooked.

## Box 22: International frameworks mandating the inclusion of persons with disabilities in humanitarian and disaster risk reduction

### **UNCRPD Article 11 – Situations of risk and humanitarian emergencies**

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies, and the occurrence of natural disasters.

### **Inter-agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action**

Persons with disabilities must be able to access humanitarian assistance and interventions on the same terms as other members of the population. This requires a twin-track approach that combines inclusive mainstream programmes with targeted interventions for persons with disabilities.

### **United Nations Security Council Resolution 1889 Women and Peace and Security**

Recognising the particular needs of women and girls in post-conflict situations, including, *inter alia*, physical security, [and] health services including reproductive and mental health,...[the UN Security Council] encourages Member States in post-conflict situations, in consultation with civil society, including women's organisations, to specify in detail women and girls' needs and priorities and design concrete strategies...to address those needs and priorities, which cover *inter alia*,...access to basic services, in particular health services, including sexual and reproductive health and reproductive rights and mental health.

### **Sustainable Development Goals, Goal 11.5**

By 2030, significantly reduce the number of deaths and the number of people affected, and substantially decrease the direct economic losses relative to global gross domestic product caused by disasters, including water-related disasters, ***with a focus on protecting the poor and people in vulnerable situations.***

### **Sendai Framework for Disaster Risk Reduction 2015-2030**

Disaster risk reduction practices need to be multi-hazard and multisectoral, inclusive, and accessible in order to be efficient and effective.... ***Governments should engage*** with relevant stakeholders, including women, children, and youth, ***persons with disabilities***, poor people, migrants, indigenous peoples, volunteers, the community of practitioners, and older persons in the design and implementation of policies, plans, and standards.

### **World Humanitarian Summit (2016) and Agenda for Humanity commitments**

The **Charter on the Inclusion of Persons with Disabilities in Humanitarian Action**, launched during the Summit, commits members to five core principles: non-discrimination, participation, inclusive policies, inclusive responses and services, and cooperation and coordination.

Sexual and reproductive health and rights are as fundamental to persons with disabilities during a humanitarian crisis as to all other persons. The Committee on the Elimination of Discrimination Against Women (CEDAW) has called on States to recognise sexual and reproductive health services as “essential services” that States must ensure are available to all women and girls at all times.

Past humanitarian crises have shown that reduced access to family planning, abortion, antenatal, HIV, gender-based violence, and mental health care services **results in** increased rates of unintended pregnancies, unsafe abortions, sexually transmitted infections (STIs), pregnancy complications, miscarriage, post-traumatic stress disorder, depression, suicide, intimate partner violence, and maternal and infant mortality.



## Box 23: Public health emergencies and disability inclusion in SRH

The COVID-19 Disability Rights Monitor, a coalition of organisations advocating for the rights of persons with disabilities, conducted a global survey over several months to gather data on the experiences of persons with disabilities during the pandemic. They received more than 2,300 responses from persons with disabilities, who reported widespread violations of their rights:

- 34% of respondents said information about COVID-19 is not accessible for them
- 70% of respondents need a support person (mostly family members)
- 66% responded that if this support person becomes infected, they do not have any support
- 78% responded that there were no specific state-led actions, programmes, or initiatives in their country for persons with disabilities to address the impact of the COVID-19 pandemic

Respondents also reported experiencing pandemic-related barriers in communicating with carers, and profound isolation as many were separated from their families and caregivers.

CARE International's rapid gender analysis for COVID-19 in East, Central, and Southern Africa (ECSA) in April 2020 also highlighted the pandemic's negative impact on women from vulnerable groups, including persons with disabilities and their sexual and reproductive health and rights.

Persons with disabilities were at a greater risk of contracting COVID-19 due to difficulties in maintaining physical distancing, as they need additional physical and/or personal support, and they often experience a lack of health information and basic supplies such as water and soap.

According to data from the UK Office of National Statistics, persons with disabilities in England and Wales had a three times higher risk of dying of a COVID-19 infection (mortality rate 59 per cent) than persons without disabilities (mortality rate 41 per cent).

## Box 24: Barriers to SRHR information and services for persons with disabilities during crises

Persons with disabilities face multiple obstacles in accessing information and services during crises, including inaccessible transportation and facilities, limited water, sanitation, and hygiene facilities, and a lack of accessible information and resources. Additionally, systemic racism, discrimination, and stigma are likely to further compound logistical barriers to sexual and reproductive health care for women and marginalised groups, such as people with disabilities.

In interviews with women and girls with disabilities, the Women's Refugee Commission identified a number of vulnerabilities due to the intersection of gender and disability discrimination:

- Forced displacement makes women and girls (and boys) with disabilities more dependent on others, with a higher risk of exploitation
- Women and girls with disabilities are at an increased risk of SGBV due to being perceived as an 'easy target'
- Women and girls with disabilities lack access to resources to cover basic needs, such as water, shelter, food, health, and menstrual hygiene supplies, and the continuation of medication or contraceptives
- They experience increased vulnerability due to breakdown of economic structures, transport, family and community support, housing, etc.

**HI asked OPD partners in May 2020, what are the specific challenges that persons with disabilities are facing with regard to SRHR during crises and the current COVID-19 pandemic?**

- Mobility (no public transport)
- Accessibility of facilities
- Media coverage is concentrated on COVID-19 and additional necessary information about other services is silent
- People must have missed their medical appointments, exposing them to the risk of unintended pregnancies
- People look at us with a double stigma, they assume we might have COVID-19 and they fear us more than before. Since we have no sanitisers or masks, people try to avoid us

Meaningful inclusion of persons with disabilities in humanitarian responses requires the removal of barriers to information and services. National decision-makers, international organisations, SRH programme managers, and service providers should identify the barriers persons with disabilities experience in their areas of work and take steps to address them, reduce their effects, or improve the resilience of clients to overcome them (see Figure \_\_\_)

**Example from WISH South Sudan**  
**Pre-planning to ensure access to SRHR for women and girls**  
**with disabilities in South Sudan**



In South Sudan, the International Rescue Committee (IRC) has been working with HI on building capacity among SRH service providers working in humanitarian settings, with the aim of making their services more disability inclusive. The work includes mapping organisations working on disability at national and local levels and identifying where there were capacity gaps and where service delivery needed to be adapted. IRC and its partners engaged persons with disabilities to act as community mobilisers, which often requires travel to where persons with disabilities are, rather than asking them to convene in a central location. IRC discovered that during the annual flooding season, many persons with disabilities were entirely cut off from service providers and health care facilities because roads became impassable for them. In response, IRC began supplying community mobilisers in those communities with extra materials and supplies, including contraception and other necessary health equipment, so that if the communities were cut off, persons with disabilities could still access the services they need.

For SRH service delivery in crises, the *Minimum Initial Services Package* (MISP), outlined in Box 25, must be met for all persons, including persons with disabilities.

## Box 25: The Minimum Initial Services Package (MISP) for SRH in crisis situations

In humanitarian crises, the MISP defines which essential, life saving SRH services are most important to prevent maternal and newborn mortality and morbidity, while also respecting the fundamental human dignity of women and girls in humanitarian settings. The MISP is **not** a replacement for the comprehensive SRH services that should be made available as soon as feasible after a crisis, or in protracted crisis situations.

The MISP offers detailed guidance on the prevention of sexual violence and care for survivors, as well as necessary practical steps to prevent the transmission of HIV and other STIs, maternal and newborn mortality and morbidity, and unintended pregnancies. The MISP also supports planning for comprehensive SRH services.

Each of these services should be made available to women and girls with disabilities, as they are for women without disabilities. Service providers and SRH programme managers should ensure the accessibility of all services included in the MISP for women and girls with diverse disabilities, and they should be intentional about identifying women and girls with disabilities who may need SRH services in a crisis, especially services relating to sexual and gender-based violence.

More details on the MISP can be found here: <https://iawgfieldmanual.com/manual/misp>

Extensive analysis of the inclusion of persons with disabilities in emergencies across 39 case studies in diverse settings globally suggest that stakeholders should:

- Recognise the obligation to include persons with disabilities into disaster risk reduction, preparedness and disaster management plans, and recovery and reconstruction, and ensure that all such plans and programmes are fully compliant with the CRPD.
- Identify and collaborate with organisations of persons with disabilities in all programmes and planning related to disaster risk reduction and preparedness. These are important entry points for persons with disabilities to engage and be seen as positive contributors to their communities and can ensure that persons with disabilities are aware of and have access to disaster risk plans.
- Health care providers and SRHR programme managers should make sure that people with disabilities are taken into account when planning and providing services in humanitarian settings. Stakeholders should prioritise the removal of all barriers to humanitarian assistance and protection for persons with disabilities, in collaboration with OPDs and technical experts on disability inclusion.

- Budgets for all humanitarian relief and disaster risk preparedness and response programmes should include funding for reasonable accommodations and any measures necessary to ensure the accessibility of all facilities and services, including WASH and health care facilities.
- Data that is disaggregated by sex, age, and disability, at a minimum, should be collected as part of all humanitarian responses, and should inform preparedness planning. Humanitarian actors should analyse whether assistance is reaching persons with disabilities and adapt it to eliminate any gaps in services.
- Experience from the Women’s Refugee Commission and the IRC working in conflict affected areas of Burundi, Ethiopia, Uganda, and the North Caucasus on disability inclusion and gender-based violence interventions demonstrated that a comprehensive approach that provides capacity development to practitioners, enabling them to adapt services to meet the needs of survivors with disabilities (such as home visits, home-based activities, specialised case management services, etc.), resulted in positive changes.

### Helpful resources

UN Women (2021) ‘Covid-19, Gender and Disability Checklist’ <https://reliefweb.int/sites/reliefweb.int/files/resources/covid-19-gender-and-disability-checklist-en.pdf>

Inter-Agency Standing Committee (IASC). (2019). Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action. Available at: <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>

Women’s commission for refugee women and children ( 2008 ) available at : DISABILITIES AMONG REFUGEES AND CONFLICT-AFFECTED POPULATIONS Resource Kit for Fieldworkers

DISABILITIES AMONG REFUGEES AND CONFLICT-AFFECTED POPULATIONS Resource Kit for Fieldworkers <https://www.womensrefugeecommission.org/research-resources/disabilities-among-refugees-and-conflict-affected-populations/>

Women’s Commission for Refugee Women and Children <https://www.womensrefugeecommission.org/research-resources/disabilities-among-refugees-and-conflict-affected-populations/>

*“Thank you, people, [WISH professionals] for reaching us with your services in the communities. People like me who have difficulty with working would never have heard of such important information if you hadn’t reached us here. Now I am rich with information on family planning and reproductive health. Even though I will not take it now since I have no husband, I will be able to help my daughter and her friends to take good care of themselves so that they do not get unwanted pregnancies or diseases. If a boyfriend comes, I now know where to go”*

Woman’s feedback to SRHR services

*“I just wanted to thank you for being so kind and professional. The level of care I experienced at your clinic was such a comfort. You are an amazing bunch of women.”*

Woman’s feedback

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- 82 Id. at 25.
- 83 Report of the Special Rapporteur on the Rights of Persons with Disabilities (2020) <https://www.ohchr.org/en/special-procedures/sr-disability>
- 84 UNFPA, 2018 at 17, and sources cited therein.
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- 86 Id.
- 87 Piotrowski, K. & Snell, L. (2006). Health Needs of Women with Disabilities Across the Lifespan. *Journal of Obstetric, Gynecologic and Neonatal Nursing* 36(1), 79-87.
- 88 Rottach, E. & DeGraw, E. (2021). A Policy Framework for Engaging Men and Boys in Family Planning Programs and Services: HP+ Policy Brief. USAID and Health Policy Plus.
- 89 See, e.g., Mitra, M., Mouradian, V.E., & McKenna, M. (2013). Dating Violence and Associated Health Risks Among High School Students with Disabilities. *Maternal and Child Health Journal* 17(6), 1088-1094, finding that boys with disabilities were more likely to have experienced dating violence than both girls and boys without disabilities, though substantially less than girls with disabilities.
- 90 Rottach, E. & DeGraw, E. (2021). A Policy Framework for Engaging Men and Boys in Family Planning Programs and Services: HP+ Policy Brief. USAID and Health Policy Plus.
- 91 Tarasoff, L.A. (2016). “We Exist”: The Health and Well-Being of Sexual Minority Women and Trans People with Disabilities. In *Eliminating Inequities for Women with Disabilities: An Agenda for Health and Wellness*, pp.179-207. Washington, D.C.: American Psychological Association.
- 92 The acronym “LGBTQI+” refers collectively to lesbian, gay, bisexual, transgender, queer, intersex, and all other people with diverse sexual orientations or gender identities. Different cultures use different terms to describe persons who do not conform to local gender norms or engage in different forms of gender expression. For purposes of this Guideline, the term LGBTQI+ is intended to be inclusive of all of those whose sexual orientation or gender identity may create barriers to accessing sexual and reproductive health information and services.
- 93 Committee on Economic, Social, and Cultural Rights. (2016). General Comment No. 22, para. 23.
- 94 United Nations Special Rapporteur on the right to health. (2010). Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/14/20, para. 6.
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- 100 United Nations Office of the High Commissioner on Human Rights. (2020). Information Series on Sexual and Reproductive Health and Rights: Lesbian, Gay, Bisexual, Transgender and Intersex Persons. Available at: [https://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO\\_LGTG\\_WEB.pdf](https://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO_LGTG_WEB.pdf); UNDP, et al., 2016 TRANSIT Report.
- 101 Planned Parenthood. (n.d.). Sexual Orientation, <https://www.plannedparenthood.org/learn/teens/sexual-orientation>.
- 102 Tarasoff, L.A. (2016). “We Exist”: The Health and Well-Being of Sexual Minority Women and Trans People with Disabilities. In *Eliminating Inequities for Women with Disabilities: An Agenda for Health and Wellness*, pp.179-207. Washington, D.C.: American Psychological Association.

## Part III Technical guidance for disability inclusive SRHR

### Endnotes

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- 108** Id. at 11.
- 109** Punzi, M.C. & Hekster, O. (n.d.). Technical brief for the Integration of Menstrual Health in SRHR, <https://www.psi.org/pdf>
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- 112** Oestrogen can have a pro-convulsant (seizure-causing) effect in some women. This means that when a woman's levels of oestrogen are high, there may be a higher risk of seizures occurring. Contraceptive injections, such as Depo Provera, contain progestogen and are given at regular intervals. Although they contain progestogen, the contraceptive effect is not reduced by anti-convulsive (seizure-reducing) medication. Additionally, if they use the injection for more than 6 months, advise them to increase their consumption of foods that contain calcium to prevent osteoporosis. Always refer to WHO guidance prior to prescribing any medication.
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- 115** See Female condom <https://www.mayoclinic.org/tests-procedures/female-condom/about/pac-20394129>
- 116** See Maxwell, J. (2007). 'A health handbook for women with disabilities', Hesperian.
- 117** Id.
- 118** Committee on the Rights of Persons with Disabilities (CRPD Committee), General Comment No. 3 (2016) Article 6: Women and Girls with Disabilities, para. 25, U.N. Doc. CRPD/C/GC/3 (Nov. 25, 2016) [hereinafter CRPD Committee, General Comment No. 3].
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- 127** Id.
- 128** Id.
- 129** McCarter-Spaulding, \_\_\_\_ (2005).
- 130** Smeltzer, 2006.
- 131** Smeltzer, 2006.
- 132** Smeltzer, 2006; UN Women. (2017). Executive Director's blog series: Violence against women and girls with disabilities. Available at <https://www.unwomen.org/en/news/stories/2017/op-ed-phumzile-16days-day9>.
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- 134** A Health Handbook for Women with Disabilities (2007)- Maxwell, Belser David
- 135** Smeltzer, 2006.
- 136** See Judith Rogers' The disabled woman's guide to pregnancy and birth (2006) for more examples.
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- 139** Center for Reproductive Rights. (n.d.) World Abortion Laws Map, <https://maps.reproductiverights.org/worldabortionlaws>.
- 140** Guttmacher Institute. (2018). Fact Sheet: Induced Abortion Worldwide, <https://www.guttmacher.org/fact-sheet/induced-abortion-worldwide>; see also UNFPA, 2018b.
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- 142** See Kuper, H. et al. LSHTM 'The Missing Billion' ( 2019)
- 143** See, e.g., Garcia-Moreno & Stockl, 2009.
- 144** See UNFPA Minimum Standard for Prevention and Response to SGBV in emergencies [https://www.unfpa.org/sites/default/files/pub-pdf/GBVIE.Minimum.Standards.Publication.FINAL\\_ENG\\_.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/GBVIE.Minimum.Standards.Publication.FINAL_ENG_.pdf)
- 145** WHO <https://www.who.int/hac/techguidance/pht/SGBV/en/>
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- 147** World Health Organisation. (n.d.). Health care for women subjected to intimate partner violence or sexual violence: A clinical handbook.

**Sexual and Reproductive Health and Rights for All:  
Disability Inclusion from Theory to Practice**

## **Annex 1**

HI WISH OPD Mapping Tool

## **Annex 2**

Referral Tool: How to conduct telephone questionnaires and focus groups

## **Annex 3**

Referral Tool: Checklist for intra- and inter-health facility referrals for SRHR including persons with disabilities

## **Annex 4**

Referral Tool: Directory for service providers

**All of these annexes are available in Word and Excel versions. For further information please contact the HI Health Department at [info@hi.org](mailto:info@hi.org)**

## Annex 1

### Organisation of Person's with disabilities D Mapping Template/ Assessment for Inclusive SRHR

\* This Organisation of Person's with disabilities (OPD) Mapping tool is prepared with the intention to capture information on 4Ws approach (Who, What, Where and When) on the OPDs at cluster, district or national level.

\*This document must be filled at the same time together with the Capacity Assessment Matrix Annex which is available from the HI Health Department at [info@hi.org](mailto:info@hi.org)

Name of the OPD <i>(in full)</i>	Country/ Province/ District
<b>Contact details of the organization</b> <i>Name and contact details, mailing address, phone/fax, email</i>	
<b>Date of establishment / registration details:</b>	

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<b>Staffing and structure</b> <i>(Organizing and implementing activities / working structure)</i>		
Leadership	<p>Who manages the OPD?</p> <p>How many females do you have in management roles/on the Executive Board?</p> <p>Is your OPD a women led OPD?</p>	
Staffing	How many full-time/Part-time staff, their gender, background and training & their positions	
Volunteers	Does your organization have paid/unpaid volunteers who have different roles?	
Staff and Volunteer development	How do you ensure that staff and volunteers support and motivate each other and have sufficient skills?	
Membership	<p>What is the number of members(estimated) who belong to this organisation?</p> <p>Are you representing persons with specific disabilities ( e.g. person with visual or hearing disabilities etc. )</p>	

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<b>Mission, objectives and thematic:</b>		
<b>Overview of organization work</b> ( <i>What activities does it conduct? Estimate how many people it reaches with different activities - How many are people with disabilities?</i> )		
<b>Existing partnerships / or Involved in any regional/ or international networks</b> ( <i>Relationship /networking with other local, national, and international actors in disability and health</i> )		
Advocacy	Do you carry out advocacy activities to policy changes that from barriers to access services by persons with disabilities?	
Broader context and potential partnerships	Does your organization work with government, private, or community Organizations?	
Partnership with health services	Does your organization work with any health services institutions, health authorities, platforms or organizations supporting health service delivery?	
Experience	Does your organisation have prior experience working in the field of SRHR and family planning?	

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<b>Key activities and current projects</b> (specify the sources of funding):			
Project	Key activity areas	Funded externally (yes/no)	Source of funding
1.	1.1.		
	1.2.		
	1.3.		
2.	2.1.		
	2.2.		
	2.3.		
3.	3.1		
	3.2		
	3.3.		
<b>Key achievements and successes</b> <i>Key highlights/successes of organization work</i>			
<b>Operational presence</b> ( <i>list locations, intervention geographical sites</i> ):			
<b>Impairment specific or cross-cutting focus</b> ( <i>Which disabilities does the organization work focus on? If more than one kind of disability, which is the main focus? Which is the least focused? Does the organisation have a gender focus(women) or young people?</i> )			

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Experience of the organization in disability work		
Disability knowledge and skills	How often do you train staff and volunteers in disability knowledge and skills necessary to carry out advocacy activities?	
	How do you consider your own capacity regarding disability knowledge and skills?	
	In your opinion, what are your main weaknesses regarding this topic?	
IEC material development and utilization	Do you create messages to raise awareness about disability inclusion or change people's thinking/ attitudes/ behaviors?	
	What was your experience in the process of developing/ creating these messages?	
	How would you rate your capacity regarding this undertaking?	
	What would be your major weakness regarding this exercise of message development?	



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Previous experience with barrier assessments, training, inclusive health		
What is your experience in e.g. conducting barriers and facilitators assessment? (Assessors? Key Informants? Interviews? Participation in FDGs? Etc.)		
Trainings received (including on basic knowledge in SRHR)	Staff members	
	Volunteers	
What's the organization's experience with Inclusive Health?		
Role of the community involvement		
Involvement of people with disabilities in the activities, and decisions of the organization	How do your members participate in the activities, works, and decision-making process in the organization?	
Gender equity/ equality	How does your organization respect, encourage, and promote the equal participation of all ensuring gender equality	
Community engagement	How is the community involved in your activities?	
Reaching out to the youth & adolescents	How are the youth & adolescents involved in your activities?	

**Sexual and Reproductive Health and Rights for All:  
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<b>Assessment of leadership and decision making within the organization</b> <i>(Constitution, Governing committee/ board, Mission and values)</i>			
<b>Main challenges faced</b>			
<b>Identified areas of capacity-building / training needs (*)</b> <b>TO BE COMPLETED BY THE ASSESSOR</b>			
Training/Capacity building area	Gaps/Needs	Mode/ Approach *Formal training  *Hands on support	By whom?
1.			
2.			
3.			



## Annex 2

*(For use on persons with disabilities that have received referrals for SRHR services or other services like Assistive services)*

### Focus Group Discussion Guide for Persons with Disabilities on Referral

Location: .....

Date: .....

Number of Female	
Number of Male	

#### Instructions

- A Focus group should be between 8 to 10 Persons with Disabilities who have received Referrals before.
- Focus Group Discussion may be disaggregated by gender and age group depending on the culture and context.
- Each focus group discussion to be conducted by two (02) data collectors. One leading the discussion and the other taking minutes.

#### Questions

1. From where did you receive information about relevant referral services such as SRHR, MHPSS, rehabilitation services etc. ( from OPDs, Hotlines, community health workers, social networks etc. \_ ?
2. What is your experience in being referred to SRHR or other services ( e.g. to rehabilitation services , provision of assistive devices, MHPSS etc.) that was made?
3. Were you able to receive the services you wanted?
4. Do you think the referral was useful?
5. What should be done differently if a similar referral is to be made?

Thanks

## Telephone Interview Guide

I am ..... calling from ..... I would like to ask you about the referral for services and what was your experience. The information will help us improve the next referrals. Would you like to participate/ answer? If yes, we can proceed and if no we can end the call.

I would like to ask you some questions about difficulties you may have doing certain activities as well as about your living conditions. I realize some of these questions seem unrelated to health care and may be sensitive.

1	Do you have difficulty seeing, even if wearing glasses?	<b>0</b> = No - no difficulty; <b>1</b> = Yes – some difficulty <b>2</b> = Yes – a lot of difficulty; <b>3</b> = Cannot do at all <b>999</b> = Declines to answer
2	Do you have difficulty hearing, even if using a hearing aid?	<b>0</b> = No - no difficulty; <b>1</b> = Yes – some difficulty <b>2</b> = Yes – a lot of difficulty; <b>3</b> = Cannot do at all <b>999</b> = Declines to answer
3	Do you have difficulty walking or climbing steps?	<b>0</b> = No - no difficulty; <b>1</b> = Yes – some difficulty <b>2</b> = Yes – a lot of difficulty; <b>3</b> = Cannot do at all <b>999</b> = Declines to answer
4	Do you have difficulty remembering or concentrating?	<b>0</b> = No - no difficulty; <b>1</b> = Yes – some difficulty <b>2</b> = Yes – a lot of difficulty; <b>3</b> = Cannot do at all <b>999</b> = Declines to answer
5	Do you have difficulty (with self-care such as) washing all over or dressing?	<b>0</b> = No - no difficulty; <b>1</b> = Yes – some difficulty <b>2</b> = Yes – a lot of difficulty; <b>3</b> = Cannot do at all <b>999</b> = Declines to answer
6	Using your usual language, do you have difficulty communicating, for example understanding or being understood?	<b>0</b> = No - no difficulty; <b>1</b> = Yes – some difficulty <b>2</b> = Yes – a lot of difficulty; <b>3</b> = Cannot do at all <b>999</b> = Declines to answer

7. Who provided you or how did you get to know about information on existing SRHR services?
8. What was your experience about the last referral for SRHR services or other services (such as for rehabilitation services, provision of assistive devices, accessible MHPSS services etc.) that was made?
9. Were you able to receive the services you wanted?
10. Do you think the referral was useful?
11. What should be done differently if a similar referral is to be made?

Thanks

## Annex 3

*(The tool is for use at health facility level to look into the Referral System at the health facility)*

### Checklist for intra- and inter- health facility referrals for SRHR including persons with disabilities

Components	Comment/ Status
<p><b>Client Flow/ Movement</b></p> <p>Does the health facility have a client workflow (pictorial representation of all services at the health facility) and where they are found for easy movement of clients at the health facility? (Look at the client flow with a disability lens)</p>	
<p><b>Directory of Service Providers</b></p> <p>Does the health facility have a directory/ list of service providers where they can refer clients including persons with disabilities who need SRHR services that they don't offer or other services that persons with disabilities may need (eg. MPHSS, rehabilitation, services providing assistive devices , medical, social and disability friendly police or legal services, organisations of persons with disabilities )?</p> <p>Are these referral contacts accessible for person's with disabilities ( e.g. ramps, accessible toilets , provision of sign language , disability focal persons , staff trained on disability inclusion etc. )</p>	
<p><b>Documentation of Referrals</b></p> <p>Does the health facility conduct documentation of SRHR and other referrals including disaggregation of data concerning persons with disabilities.? (to another health facility, OPD, Police, other service providers). <i>(correct the formats)</i></p> <p>How do you receive feedback on whether the referred clients with and without disabilities used the referral, were able to receive services at the referral site and were satisfied with services or not?</p>	

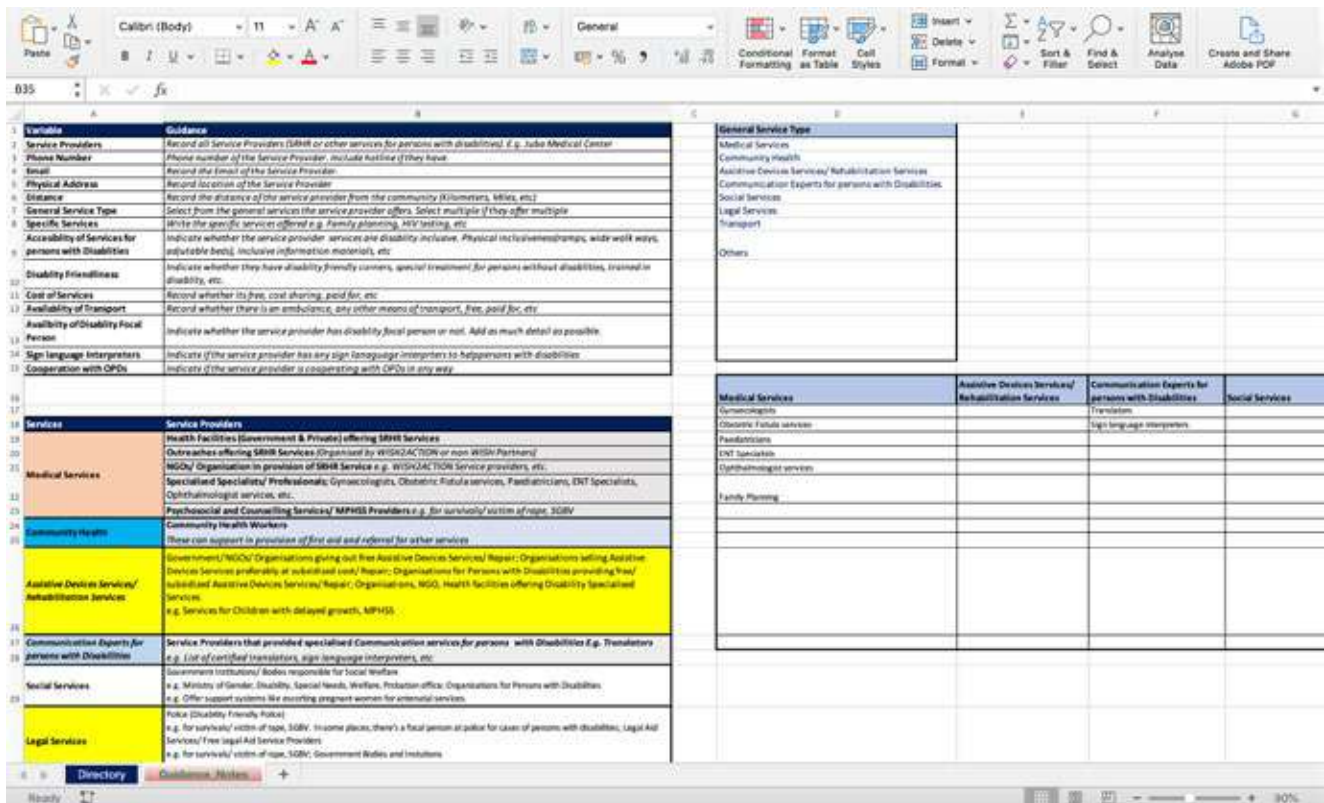
<p><b>Movement for Referrals</b></p> <p>Does the health facility have an ambulance or other transport that can support referrals that may be utilized for persons with disabilities?</p> <p>Any other contact and information about relevant transport opportunities for client who have difficulties in accessing the referral services ?</p>	
<p><b>SRHR Outreaches</b></p> <p>Does the health facility conduct outreach in the community to provide SRH information and services and include persons with disabilities?</p> <p>If yes, what is the referral system for people in the community including persons with disabilities to receive further services in health care facilities if required?</p>	
<p><b>Community to health facility Referral System</b></p> <p>Is there a mechanism or system within the community to refer people including persons with disabilities for SRHR services? If yes, what is this system and how does the health facility support this system?</p> <p>Does the referral mechanism from communities to SRHR service providers involve civil society organizations such as women or youth groups, parent’s groups, OPDs, local NGOs providing social or livelihood services, religious groups etc.?</p> <p>Does the referral mechanism include other basic services e.g. educational and vocational training services, educational centres for children and adolescents with disabilities, livelihood programmes for survivors of GBV etc.?</p>	
<p><b>Cooperation between OPDs and health facilities</b></p> <p>Is there any cooperation between OPDs and health facility in regards to referral of persons with disabilities? If yes, how is it done?</p> <p>Any documentation or feedback system in use?</p>	

# Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice

## Annex 4

### Directory for service providers

The Excel versions of these documents are available from the HI Health Department at [info@hi.org](mailto:info@hi.org).





## Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice

Microsoft Word ribbon: Paste, Calibri (Body), Font settings, Paragraph, Styles, General, Conditional Formatting, Format as Table, Cell Styles, Insert, Delete, Format, Sort & Filter, Find & Select, Analyze Data, Create and Share Adobe PDF.

File name: A6

Document title: Checklist for complementing existing Directory and Referral Lists for Mainstreaming Disability in Referral Networks

Location	Service Provider	Phone Number	Email	Physical Address	Distance	General Service Type	Specific Services	Accessibility of Services for persons with Disabilities	Disability Friendliness	Cost of Services	Availability of Transport	Availability Portal
4	Example Medical Center	011233333	example@medical.org	Kampala, Uganda, Zone 1	22 Kilometers	Medical Services	Physiotherapy	Physical infrastructure not accessible	Not friendly for persons with	Free	Accessibility available that can help	Yes
5	ABC OPT	345678901	abc@opt.org	Kampala, Uganda, Zone 2	15 Kilometers	Assistive Devices Services/ Rep	Free walking sticks	Yes, very accessible for PWDs	Yes	Free	No transport means available	Yes
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- 1 World Health Organisation and The World Bank. (2011). World report on disability. Geneva, Switzerland: World Health Organisation. <https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability>.
- 2 UN WOMEN. (2019). The empowerment of women and girls with disabilities: Towards full and effective participation. New York: UN WOMEN. <https://www.unwomen.org/en/digital-library/publications/2019/12/brief-the-empowerment-of-women-and-girls-with-disabilities>
- 3 UNICEF. (2021). Seen, Counted, Included. Using data to shed light on the well-being of children with disabilities. New York: UNICEF. <https://data.unicef.org/resources/children-with-disabilities-report-2021/>
- 4 Ibid.
- 5 United Nations. (May 2020). Persons with disabilities in the context of internal displacement. Report of the Special Rapporteur on the human rights of internally displaced persons. A/HRC/44/41, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G20/112/64/PDF/G2011264.pdf?OpenElement>.
- 6 See, e.g., United Nations. (2017). Resolution adopted by the General Assembly on 19 December 2017: Implementation of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto: situation of women and girls with disabilities. A/RES/72/162; Human Rights Council. (2021). Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development: Accelerating efforts to eliminate all forms of violence against women and girls: preventing and responding to all forms of violence against women with disabilities. A/HRC/47/L.18/Rev.1.
- 7 Executive Board, World Health Organisation. (2021). Resolution 6: The highest attainable standard of health for persons with disabilities. EB148.R6, adopted January 2021.
- 8 Lancet Commission. (2018). Accelerate progress—sexual and reproductive health and rights for all: report of the Gutmacher–Lancet Commission, [http://dx.doi.org/10.1016/S0140-6736\(18\)30293-9](http://dx.doi.org/10.1016/S0140-6736(18)30293-9); Kuper, H. & Heydt, P. (2019). The Missing Billion: Access to Health Services one Billion People with Disabilities. <https://www.themissingbillion.org>; UNFPA. (2018). Young Persons with Disabilities: Global Study on Ending Gender-Based Violence and Realising Sexual and Reproductive Health and Rights. New York, United States. <https://www.unfpa.org/publications/young-persons-disabilities>.
- 9 UNFPA. (2018). Young Persons with Disabilities: Global Study on Ending Gender-Based Violence and Realising Sexual and Reproductive Health and Rights. New York, United States. <https://www.unfpa.org/publications/young-persons-disabilities>.
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- 11 Ibid.; Kuper & Heydt, 2019; UNFPA, 2018.
- 12 The organisations participating in the project have complementary areas of expertise and include SRHR service providers IPPF, MSI and IRC and their local partner organisations and public health professionals; two organisations with expertise in advocacy, mass media and social and behaviour change communication (Options and DMI); Humanity & Inclusion which has expertise in the field of disability rights and inclusion; and civil society organisations including organisations of persons with disabilities (OPDs) and other local actors and specialists in the field of disability inclusion and advocacy from the project countries.
- 13 Bangladesh, Pakistan, Afghanistan, Ethiopia, South Sudan, Mozambique, Madagascar and Uganda.
- 14 Centre for Excellence in Universal Design. (n.d.). What is Universal Design? National Disability Authority of Ireland. Available at <http://universaldesign.ie/what-is-universal-design/>.
- 15 Reasonable accommodation means necessary and appropriate modification and adjustments to ensure for persons with disabilities the enjoyment or exercises on an equal basis with others of all human and fundamental freedoms and rights.
- 16 Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH & CBM. (n.d.). A human rights-based approach to disability in development: Entry points for development organisations. Available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/A\\_human\\_rights-based\\_approach\\_to\\_disability\\_in\\_development.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/A_human_rights-based_approach_to_disability_in_development.pdf).
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- 21 CRPD, Article 2; Humanity & Inclusion. (2018). Humanity & Inclusion's policy on Disability, Gender and Age, [https://hi.org/sn/uploads/document/pi01\\_disability\\_gender\\_age\\_2019-03-05\\_12-02-42\\_240.pdf](https://hi.org/sn/uploads/document/pi01_disability_gender_age_2019-03-05_12-02-42_240.pdf)

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- 23 Committee on the Rights of Persons with Disabilities. (2014). General Comment No. 2 (2014): Article 9: Accessibility, CRPD/C/GC/2.
- 24 CRPD, Article 2; Humanity & Inclusion. (2018). Humanity & Inclusion's policy on Disability, Gender and Age, [https://hi.org/sn\\_uploads/document/pi01\\_disability\\_gender\\_age\\_2019-03-05\\_12-02-42\\_240.pdf](https://hi.org/sn_uploads/document/pi01_disability_gender_age_2019-03-05_12-02-42_240.pdf).
- 25 See Committee on the Rights of Persons with Disabilities. (2018). General comment No. 6 (2018) on equality and non-discrimination. CRPD/C/GC/6.
- 26 HI, 2019.
- 27 *Id.*
- 28 CBM International, Humanity & Inclusion, & International Disability Alliance. (2019). Inclusion of persons with disabilities in humanitarian action.
- 29 United Nations Division for Social Policy (DSPD) & United Nations Department of Economic and Social Affairs (DESA). (n.d.). Toolkit on Disability for Africa: Disability-Inclusive Development. Available at: <https://www.un.org/esa/socdev/documents/disability/Toolkit/Disability-inclusive-development.pdf>.
- 30 Committee on Economic, Social and Cultural Rights. (2016). General comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights. E/C.12/GC/22.
- 31 Committee on Economic, Social and Cultural Rights. General Comment Nos. 14 and 22.
- 32 Database of the United Nations Office of Legal Affairs (OLA), <https://treaties.un.org/>, last updated February 2021.
- 33 CESCR, Gen. comment No. 22.
- 34 Committee on the Rights of the Child. (CRC Committee). (2016). General Comment No. 20 on the implementation of the rights of the child during adolescence, ¶ 60, UN Doc. CRC/C/GC/20 (2016); Committee on the Elimination of Discrimination Against Women (CEDAW Committee). (2017). General Recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19, ¶ 31(a), U.N. Doc. CEDAW/C/GC/35 (July 14, 2017); Committee on Economic, Social and Cultural Rights (ESCR Committee). (2016). General Comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the International Convention on Economic, Social and Cultural Rights), ¶ 28, UN Doc. E/C.12/GC/22 (2016); see also CEDAW Committee, General Recommendation No. 24: Article 12 of the Convention (women and health), ¶ 31(c), U.N. Doc. A/54.38/Rev.1 (1999); CRPD Committee & CEDAW Committee, Joint statement on guaranteeing sexual and reproductive health and rights; see also Women Enabled International (WEI). (2020). Abortion and Disability: Towards an Intersectional Human Rights-Based Approach.
- 35 United Nations. (n.d.) SDG Knowledge, <https://sdgs.un.org/goals/goal3>.
- 36 *Ibid.*
- 37 Humanity & Inclusion. (2021). Learning from a disability-inclusive SRHR Programme (WISH2ACTION).
- 38 Office of the United Nations High Commissioner for Human Rights and the World Health Organisation. (n.d.). The Right to Health. Fact Sheet No. 31; Committee on Economic, Social and Cultural Rights, General Comment No. 14; International Covenant on Economic, Social, and Cultural Rights, Article 2(1).
- 39 The order of the actions listed below can be different to the one indicated in this Guideline and may vary according to the context. Often different actions are carried on in parallel as they complement each other and they all contribute to the same objective.
- 40 In the best case the data you find has been collected using the Washington Group Questionnaire Short Set of questions WG-SS (see more information in chapter 5.3.1) or is based on the Model Disability survey) as this increases reliability of disability data. In many countries the WGSS is still not in use for routine demographic and population health data collection therefore, we have to work with what is in place and promote the use of the internationally recommended WGSS tool ( see Section 5.9 of this Guideline for more details).
- 41 See HI 'Learning from a disability inclusive sexual and reproductive health and right programme ( WISH2ACTION) July 21
- 42 See Bruijns, Pauline (2020) , "Disability Inclusion in Universal Health Coverage" SIDA/KIT Royal Tropical Institute, <https://www.kit.nl/wp-content/uploads/2020/10/Disability-Inclusion-in-Universal-Health-Coverage.pdf>
- 43 Adapted from United Nations Development Programme, IRGT: A Global Network of Transgender Women and HIV; United Nations Population Fund, UCSF Centre of Excellence for Transgender Health, Johns Hopkins Bloomberg School of Public Health, World Health Organisation, Joint United Nations Programme on HIV/AIDS, United States Agency for International Development. (2016). Implementing comprehensive HIV and STI programmes with transgender people: practical guidance for collaborative interventions. New York: United Nations Development Programme. Available at: [https://www.unfpa.org/sites/default/files/pub-pdf/TRANSIT\\_report\\_UNFPA.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/TRANSIT_report_UNFPA.pdf).
- 44 Zakia Musa's affiliation is indicated as of the date of the interview. Musa has since become a staff member of HI.
- 45 Committee on the Science of Changing Behavioural Health Social Norms, Board on Behavioural, Cognitive, and Sensory Sciences, Division of Behavioural and Social Sciences and Education, National Academies of Sciences, Engineering and Medicine. (2016). Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change. Washington, D.C.: National Academies Press.
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360. Available at: [https://www.fhi360.org/sites/default/files/media/documents/Module0-Practitioner\\_2.pdf](https://www.fhi360.org/sites/default/files/media/documents/Module0-Practitioner_2.pdf).
- 47 Interview with HI staff in Madagascar.
- 48 DAISY is a compatible software, that will read out loud the publication and allows interactive navigation for persons with visual impairments. HI WISH Bangladesh has developed SRHR information in digital accessible Information system format that allows persons with visual disabilities who have access to computer to get audial SRHR information and to navigate in the system in order to get the information they are interested in.
- 49 DAISY is a compatible software, that will read out loud the publication and allows interactive navigation for persons with visual impairments. HI WISH Bangladesh has developed SRHR information in digital accessible Information system format that allows persons with visual disabilities who have access to computer to get audial SRHR information and to navigate in the system in order to get the information they are interested in.
- 50 Humanity & Inclusion, WISH Barriers Assessment 20/21
- 51 See, e.g., Convention on the Rights of Persons with Disabilities, Art. 2; Americans with Disabilities Act, 42 U.S.C. §§ 12101 et seq.; Rehabilitation Act of 1973 (US), 29 U.S.C. § 794.
- 52 These tips are adapted from the following sources: Developmental Disabilities Primary Care Initiative. (2011). Tools for the Primary Care of People with Developmental Disabilities. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/informed-consent/>; Women's Refugee Commission. (2015). Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings: A Toolkit for GBV Practitioners, Tool 6: Guidance on communicating with people with disabilities. <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>; Women's Refugee Commission. (2018). Guidance on Disability Inclusion for GBV Partners in Lebanon: Outreach, Safe Identification, and Referral of Women, Children and Youth with Disabilities. Tool 9: Tips for Communicating with People with Different Types of Impairments. <https://www.womensrefugeecommission.org/research-resources/disability-inclusion-gbv-lebanon-outreach-safe-identification-referral/>
- 53 Developmental Disabilities Primary Care Initiative, 2011.
- 54 Women's Refugee Commission, 2018, Tool 9.
- 55 See HI Barriers assessments from South Sudan, Madagascar, Uganda and Ethiopia (2020/21)
- 56 Comprehensive Community Based Rehabilitation in Tanzania, Kinondoni survey on access to education and health services as well as involvement of people with disabilities in planning process at local level Tanzania 2014
- 57 WHO [https://www.who.int/healthinfo/systems/WHO\\_MBHSS\\_2010\\_section1\\_web.pdf](https://www.who.int/healthinfo/systems/WHO_MBHSS_2010_section1_web.pdf)
- 58 The material in this section is drawn from "I See That It Is Possible": Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings (June 2015), developed by Women's Refugee Commission and International Rescue Committee. The full toolkit can be found at: <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>.
- 59 American Medical Association. (n.d.). Code of Medical Ethics Opinion 2.1.1: Informed Consent. Available at <https://www.ama-assn.org/delivering-care/ethics/informed-consent>; "I See That It Is Possible": Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings (June 2015), developed by Women's Refugee Commission and International Rescue Committee. The full toolkit can be found here: <https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf>.
- 60 The Committee on the Rights of the Child has emphasised that the right to autonomous decision-making must be respected for children and adolescents in keeping with their evolving capacities. See, e.g., General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24), UN Doc. No. CRC/C/GC/15, and General comment No. 20 (2016) on the implementation of the rights of the child during adolescence. In GC 20 in particular the Committee emphasized that adolescents have the right to consent to SRH services without the permission of a parent or guardian (see para. 31).
- 61 Id.
- 62 Committee on the Rights of Persons with Disabilities. (2014). General comment No. 1: Article 12: Equal recognition before the law, UN Doc. No. CRPD/C/GC/1; United Nations. (2016). Approach of the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment regarding the rights of persons institutionalized and treated medically without informed consent, CAT/OP/27/2.
- 63 Id. See also American Medical Association. (n.d.). Code of Medical Ethics Opinion 2.1.1: Informed Consent. Available at <https://www.ama-assn.org/delivering-care/ethics/informed-consent>; Hattix, L. (2018). Expanding Notions of Self-Determination: International Customs of Informed Consent in Medical Experimentation Pre-1945. *Chicago Journal of International Law* 19(1), Article 5.
- 64 Developmental Disabilities Primary Care Initiative. (2011). Tools for the Primary Care of People with Developmental Disabilities. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/informed-consent/>.
- 65 UNFPA. (2018). Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights, <https://www.womenenabled.org/wei-unfpa-guidelines.html>; Developmental Disabilities Primary Care Initiative. (2011). Tools for the Primary Care of People with Developmental Disabilities. 1st ed. Toronto: MUMS Guideline Clearinghouse. Available at: <https://iddtoolkit.vkcsites.org/general-issues/informed-consent/>.
- 66 The suggestions in this box are drawn from "I See That It Is Possible": Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings (June 2015), Tool 9: Informed consent process with adult survivors with disabilities, developed by Women's Refugee Commission and International Rescue Committee. The full toolkit can be found at: <https://www.>

## Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice

womensrefugeecommission.org/wp-content/uploads/2020/04/GBV-Disability-Toolkit-English.pdf.

- 67 The recommendations in this box are adapted from Women's Refugee Commission. (2018). Guidance on Disability Inclusion for GBV Partners in Lebanon: Outreach, Safe Identification, and Referral of Women, Children and Youth with Disabilities. Tool 8: Do's and Don't's of Safe Identification and Referral of Survivors with Disabilities. <https://www.womensrefugeecommission.org/research-resources/disability-inclusion-gbv-lebanon-outreach-safe-identification-referral/>.
- 68 UNCRPD <https://www.google.com/search?client=firefox-b-d&q=UNCRPD+Article+16>
- 69 UNCRPD <https://www.google.com/search?client=firefox-b-d&q=UNCRPD+Article+16>
- 70 UN Women <https://www.unwomen.org/en/what-we-do/ending-violence-against-women/facts-and-figures>
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- 72 See, e.g., Mailhot Amborski, A., et al. (2021). Sexual Violence Against Persons with Disabilities: A Meta-Analysis. *Trauma, Violence and Abuse*, March 4, 2021. <https://doi.org/10.1177%2F1524838021995975>; Humanity & Inclusion 'Hi addresses violence against women with disabilities at United Nations' [https://www.hi-us.org/hi\\_addresses\\_violence\\_against\\_women\\_with\\_disabilities](https://www.hi-us.org/hi_addresses_violence_against_women_with_disabilities)
- 73 Koistinen, M. et al. World Bank Blogs 'Five Facts to know about violence against women and girls with disabilities' (Dec 2019)
- 74 LSHTM H. Kuper (2019) "The missing billion", <https://www.lshtm.ac.uk/TheMissingBillion>
- 75 HI and the Washington Group have collaborated to develop online training on using the WG-SS available at this link: <https://www.washingtongroup-disability.com/resources/online-trainings-and-webinars/>
- 76 IRC 'Inclusive Client Responsiveness' (2021) <https://www.rescue.org/resource/inclusive-client-responsiveness-focus-people-disabilities-and-older-people>
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- 78 See, e.g., UNFPA (2018); Committee on the Rights of the Child, GC 20 at para. 31; UNESCO & Humanity & Inclusion (2019).
- 79 See UNFPA, 2018 at 47, and sources cited therein. "Virgin cleansing" refers to the belief that having sex with a virgin will cure a person suffering from an STI or HIV.
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- 82 *Id.* at 25.
- 83 Report of the Special Rapporteur on the Rights of Persons with Disabilities (2020) <https://www.ohchr.org/en/special-procedures/sr-disability>
- 84 UNFPA, 2018 at 17, and sources cited therein.
- 85 *Id.* at 39.
- 86 *Id.*
- 87 Piotrowski, K. & Snell, L. (2006). Health Needs of Women with Disabilities Across the Lifespan. *Journal of Obstetric, Gynecologic and Neonatal Nursing* 36(1), 79-87.
- 88 Rottach, E. & DeGraw, E. (2021). A Policy Framework for Engaging Men and Boys in Family Planning Programs and Services: HP+ Policy Brief. USAID and Health Policy Plus.
- 89 See, e.g., Mitra, M., Mouradian, V.E., & McKenna, M. (2013). Dating Violence and Associated Health Risks Among High School Students with Disabilities. *Maternal and Child Health Journal* 17(6), 1088-1094, finding that boys with disabilities were more likely to have experienced dating violence than both girls and boys without disabilities, though substantially less than girls with disabilities.
- 90 Rottach, E. & DeGraw, E. (2021). A Policy Framework for Engaging Men and Boys in Family Planning Programs and Services: HP+ Policy Brief. USAID and Health Policy Plus.
- 91 Tarasoff, L.A. (2016). "We Exist": The Health and Well-Being of Sexual Minority Women and Trans People with Disabilities. In *Eliminating Inequities for Women with Disabilities: An Agenda for Health and Wellness*, pp.179-207. Washington, D.C.: American Psychological Association.
- 92 The acronym "LGBTQI+" refers collectively to lesbian, gay, bisexual, transgender, queer, intersex, and all other people with diverse sexual orientations or gender identities. Different cultures use different terms to describe persons who do not conform to local gender norms or engage in different forms of gender expression. For purposes of this Guideline, the term LGBTQI+ is intended to be inclusive of all of those whose sexual orientation or gender identity may create barriers to accessing sexual and reproductive health information and services.
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## For further information please contact the HI Health Department at [info@hi.org](mailto:info@hi.org)

A word version of the guideline, more compatible with assistive IT technology, is available upon request.

Colour contrast and design follows accessibility criteria for persons with visual disabilities.

An easy-to-read version of the guideline is not yet available and its preparation will require additional consultations and involvement of persons with intellectual disabilities.



Practical guide

