

# 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



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Please contact us at the following address or site with your requirements.

Mailing address:  
United Nations Population Fund  
Gender, Human Rights, and Culture Branch/Technical Division  
605 Third Avenue  
New York, NY, 10158

Online inquiry: <https://www.unfpa.org/contact>

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The final document was written by Anastasia Holoboff Radford (WEI, primary author), Suzannah Phillips (WEI, author), and Stephanie Ortoleva (WEI, author), with strong support and contribution from Leyla Sharafi (Gender, Human Rights and Culture Branch, UNFPA).

We appreciate the contributions of the following individuals to the development of these Guidelines within UNDESA, UNFPA, UNICEF, UNPRPD/UNDP, and WHO.

### UNDESA

Akiko Ito

### UNFPA

Nigina Abaszade  
Laila Acharai  
Enshrah Ahmed  
Marcia Elena Alvarez  
Erin Anastasi  
Paula Antezana  
Bridget Asiamah  
Pascale Barate  
Neus Bernabeu  
Satvika Chalasani  
Amelia Coleman  
Henia Dakkak  
Upala Devi  
Emilie Filmer-Wilson  
Ingrid Fitzgerald

Won Young Hong  
Benoit Kalasa  
Anneka Ternald Knutsson  
Mohammed Lardi  
Agueda Nhantumbo  
Idrissa Ouedraogo  
Martha Lucia Rubia  
Seynabou Tall  
Akiko Sakauwe  
Anja Sletten  
Lola Valladares  
Nadia Vaz  
Juan Mere  
Mario Vergara  
Jorge Parra Vergara  
Valentina Volpe  
Abdel-Ilah Yaakoubd  
Jihad Zahir  
Ilya Zhukov

### UNPRPD/UNDP

Natalia Mattioli  
Sreerupa Mitra  
Emanuele Sapienza

### UNICEF

Rosangela Berman Bieler  
Anna Burlyaeva  
Gopal Mitra  
Megan Tucker

### WHO

Maria Alarcos Cieza  
Rajat Khosla  
Berit Sabine Kieselbach  
Claudia Garcia-Moreno  
Megin Reijnders  
Lale Say

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Ola Abu Alghaib (Leonard Cheshire Disability)  
Ariadna Capasso (Management Sciences for Health)  
Magda Chinaglia (Reprolatina)  
Helene Combrinck (North-West University)  
Margarita Diaz (Reprolatina)  
Carolyn Frohmader (Women with Disabilities Australia)  
Nora Ellen Groce (Leonard Cheshire Disability; University College London)  
Farida Gulamo (ADEMO- Mozambican Disabled People Organization)  
Emma Pearce (Women's Refugee Commission)

Maria del Pilar Merizalde (National Disabilities Council)  
Martha Murdock (Management Sciences for Health)  
Doris Rajan (Institute for Research and Development on Inclusion and Society)  
Sarah Shannon (Hesperian Health Guides)  
Amrani Soumia (Morocco Council of Human Rights)  
Teresa Tudor (Illinois Department of Human Services)  
Ekaete Umoh (Family Centered Initiative for Challenged Persons)

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# Summary

The following chart provides a summary of *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*.

FOUNDATIONAL GUIDELINES FOR ACTION	
<p><b>1. Creating an enabling legislative and policy environment.</b></p> <ul style="list-style-type: none"> <li>a. <i>Legal Environment Assessment and Monitoring</i></li> <li>b. <i>Legislative Advocacy and Lobbying</i></li> <li>c. <i>National Policies and Plans</i></li> </ul>	<p><b>2. Programme development, implementation, and monitoring.</b></p> <ul style="list-style-type: none"> <li>a. <i>Engagement of Women and Young Persons with Disabilities</i></li> <li>b. <i>Capacity Building</i></li> <li>c. <i>Programme Delivery</i></li> <li>d. <i>Available Services</i></li> <li>e. <i>Effective Identification of Needs and Referrals</i></li> <li>f. <i>Accessible Services/ Accommodations</i></li> <li>g. <i>Acceptable Services</i></li> <li>h. <i>Quality Services</i></li> <li>i. <i>Rights Based Services</i></li> <li>j. <i>Data Collection and Monitoring</i></li> </ul>
	<p><b>3. Accessible facilities.</b></p> <ul style="list-style-type: none"> <li>a. <i>Identifying Barriers</i></li> <li>b. <i>Physical Accessibility</i></li> <li>c. <i>Sensory Accessibility</i></li> <li>d. <i>Information and Communication Accessibility</i></li> <li>e. <i>Economic Accessibility</i></li> </ul>
GBV Services	SRHR Services
<ul style="list-style-type: none"> <li>1. GBV prevention</li> <li>2. Health services for GBV victims/survivors</li> <li>3. Justice and policing services</li> <li>4. Social Services—protection services</li> <li>5. Social Services—rehabilitation services</li> <li>6. GBV services for women and young persons with disabilities in institutional settings</li> <li>7. Adolescent- and youth-friendly GBV services</li> </ul>	<ul style="list-style-type: none"> <li>1. Contraceptive information, goods, and services</li> <li>2. Maternal and newborn health services</li> <li>3. Comprehensive sexuality education and information</li> <li>4. Information, testing, and treatment services for sexually transmitted infections, including HIV</li> <li>5. Access to other women's health information and services</li> <li>6. Adolescent- and youth-friendly health information and services.</li> </ul>





## Overview

### 1.1 Introduction to GBV and SRHR Rights-Based Service Provision Guidelines

#### 1.1.1 Introduction

*Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence (GBV) and Sexual and Reproductive Health and Rights (SRHR)* aims to provide practical and concrete guidelines for making GBV and SRHR services more inclusive of and accessible to women and young persons with disabilities and for targeting interventions to meet their disability-specific needs.



Midwifery students during a training session in Uganda. © UNFPA/Evelyn Kiapi

## Who Is a Person with a Disability?

'Person with a disability' is the person-first language used by the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). The CRPD explains that: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".<sup>1</sup> These Guidelines use the person-first language utilized by the CRPD. However, some people prefer identity-first language (e.g. autistic person). A person's preference for how they wish to be described must be respected.

These Guidelines address service delivery for people with all forms of physical, intellectual, mental, psychosocial, cognitive or sensory impairments. These Guidelines employ the social and human rights model of disability, which "focuses on the high barriers created by the environment (rather than by bodily impairment), including in physical, information and communication contexts, the attitudes and prejudices of society, policies and practices of governments, and the often-exclusionary structures of health, welfare, education and other systems".<sup>2</sup>

There are over 1 billion persons with disabilities living in the world today.<sup>3</sup> According to the World Health Organization (WHO) and World Bank's *World Report on Disability*, the female disability prevalence rate worldwide is 19.2 per cent.<sup>4</sup> There are between 180 million and 220 million young persons with disabilities worldwide, predominantly in developing countries.<sup>5</sup>

There are roughly 10 million persons with disabilities who experience forced displacement worldwide because of persecution, conflict, violence, or human rights violations.<sup>6</sup> When factoring in underreporting and displacement due to natural disasters, this number is likely much higher. A HelpAge International and Handicap International survey of Syrian refugees found that 22 per cent of those surveyed had an

impairment.<sup>7</sup> Emergencies often create a new group of women and young persons with disabilities who require services, which places an even greater demand on the limited services available.

### ***Discrimination on the basis of disability or gender***

Disability discrimination can take many forms, but it has been defined as "any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field. It includes all forms of discrimination, including denial of reasonable accommodation".<sup>8</sup> Persons with disabilities may

experience additional discrimination due to one or more intersecting factors, including gender, age, economic status, ethnicity, sexuality, race, and nationality.

Critical services for all victims and survivors of GBV include health services (e.g. first-line support, sexual assault examination and care, mental health assessment and care), justice and policing services (e.g. assessment and investigation, perpetrator accountability and reparations, safety and protection, justice sector coordination), social services (e.g. crisis counselling; help lines; legal and rights information, advice, and representation; psychosocial support and counselling), and coordination at both the national and local level.<sup>9</sup> Women and young persons with disabilities often do not receive these necessary services.<sup>10</sup> GBV prevention efforts and services, in both design and implementation, are often inaccessible to women and young persons with disabilities.<sup>11</sup> Service providers regularly demonstrate a lack of knowledge, sensitivity, and expertise about how to serve women and young persons with disabilities, which results in a failure to identify women and young persons who have experienced or are experiencing GBV, conduct outreach, or offer key services.<sup>12</sup> Furthermore, women and young persons with disabilities whose rights are violated often lack recourse because of exclusion from access to justice mechanisms. Such exclusion further perpetuates violence because it permits abusers to continue with impunity.<sup>13</sup> To further compound the problem, there is a dearth of accurate and comprehensive research and data on violence against women and young persons with disabilities to guide the development and provision of appropriate and responsive GBV services.<sup>14</sup> These barriers to accessing and using

GBV services for women and young persons with disabilities are mirrored—and often exacerbated—in humanitarian emergency settings.<sup>15</sup>

Fundamental SRHR services for women and young persons—with and without disabilities—include comprehensive sexuality education; information, goods, and services for the full range of modern contraceptive methods, including emergency contraception; maternal/newborn healthcare (including antenatal care, skilled attendance at delivery, emergency obstetric care, post-partum care, and newborn care); prevention, diagnosis, and treatment for sexual and reproductive health issues (e.g. sexually transmitted infections, including HIV, syphilis, and HPV, cancers of the reproductive system and breast cancer, and infertility); safe and accessible abortion, where it is not against the law; and post-abortion care to treat complications from unsafe abortion.<sup>16</sup>

UNFPA prioritizes voluntary family planning to prevent unintended pregnancies and promote reproductive choice. Consistent with the commitments made by Member States within the Programme of Action of the 1994 International Conference on Population and Development,<sup>17</sup> in all countries where abortion is not against the law it should be safe, and in all countries of the world post-abortion care should be available, regardless of its legal status in country. Between 8-18 percent of all maternal deaths are due to unsafe abortions.<sup>18</sup> All women, everywhere, should have the knowledge and services to avoid unintended pregnancies through greater knowledge and access to high quality, voluntary contraceptive information, goods, and services. References to abortion and

post-abortion care throughout this document should be understood within this context.

Women and young persons with disabilities are regularly prevented from accessing SRHR services due to a variety of factors, including stereotypes about persons with disabilities as asexual or hypersexual, discrimination against persons with disabilities engaging in romantic relationships, insufficient training about how to serve persons with disabilities, inaccessible facilities, forced marriage, stigma, poverty, and isolation in institutions or group homes.<sup>19</sup> This exclusion only increases the vulnerability of women and young persons with disabilities to sexual abuse, sexually transmitted infection, undiagnosed and untreated illnesses (e.g., cancer, malaria, anemia, non-communicable diseases) and unintended pregnancy.<sup>20</sup> In addition to being excluded from receiving critical health services, women and young persons with disabilities can be subjected to coercive healthcare practices and medical procedures such as forced sterilization, forced abortion, and forced contraception.<sup>21</sup> Women and young persons with disabilities face similar barriers in humanitarian emergency settings, particularly barriers created by a lack of reasonable accommodations to meet disability-related health needs.<sup>22</sup>

These Guidelines seek to address these circumstances by providing concrete guidance to those charged with developing and implementing GBV and SRHR services, programmes, and policies to ensure consistency with the fundamental human rights of women and young persons with disabilities.

## 1.1.2 Purpose and Scope

### **Purpose**

The purpose of these Guidelines is to provide practical guidance to ensure that GBV and SRHR services give full effect to the rights of women and young persons with disabilities. While the primary audience of these Guidelines is GBV and SRHR service providers and support staff, these Guidelines are also intended as a valuable resource for all stakeholders—including those in government, international organizations, and non-governmental organizations—involved in designing, developing, implementing, or advocating for GBV or SRHR services for women and young persons with disabilities.

The United Nations Population Fund (UNFPA) is the lead UN agency for delivering a world where every pregnancy is wanted, every childbirth is safe, and every young person's potential is fulfilled. As part of this mandate, UNFPA's work on disability has focused on ensuring that women, adolescents, and youth are empowered to make decisions regarding their sexual and reproductive health and life options. These Guidelines have been developed as part of UNFPA's multi-year programme, ***WE DECIDE: Young Persons with Disabilities: Equal Rights and a Life Free of Violence***. The programme promotes the human rights and social inclusion of women and adolescents and youth with disabilities, with an emphasis on access to services to prevent and address GBV and access to SRHR-related services, information, and education.

Women Enabled International (WEI) works at the intersection of women's rights and disability rights to advance the rights of women and girls

with disabilities around the world. Through advocacy and education, WEI increases international attention to, and strengthens international human rights standards on, such issues as GBV, SRHR, access to justice, education, legal capacity, and humanitarian emergencies. Working in collaboration with women with disabilities rights organizations and women's rights organizations worldwide, WEI fosters cooperation across movements to improve understanding and develop cross-cutting advocacy strategies to realize the rights of all women and girls.

These Guidelines are grounded in international human rights standards and are the result of extensive consultation with international experts in the areas of disability rights, women's and girl's rights, SRHR services, and GBV services. Experts from across the globe were convened for an in-person expert group meeting to discuss the scope and substance

of these Guidelines. Following this meeting, four online working-group meetings took place with a broader group of experts, representing more than fourteen countries, to discuss key cross-cutting issues relating to GBV and SRHR service provision. Experts then reviewed and provided feedback on drafts of these Guidelines. As part of this process, experts were asked to share the draft Guidelines with women and young persons with disabilities from their communities and collect feedback. This feedback was then incorporated into these Guidelines.

### Scope

The recommendations in these Guidelines are aimed at all types of service delivery settings, including low-, middle-, and high-resource settings and humanitarian emergency settings. Where there are substantial unique considerations or guidance for service provision in humanitarian emergency settings, these



An adolescent boy playing football in Port-au-Prince, Haiti. © UN Photo/Logan Abassi

## Definition of terms



Note: Women technically constitute ages 18 and above.  
Source: UNFPA, *Girlhood, Not Motherhood: Preventing Adolescent Pregnancy* 6 (2015).

are noted in text boxes titled *Humanitarian Emergencies*. Service providers and support staff working in low-resource settings should look to the foundational guidelines for action and the international human rights framework obligations to prioritize their programming. The specialized guidance for humanitarian emergency settings can also provide low-resource-setting service providers and support staff with important guidance for how to develop services with limited resources.

These Guidelines address services for women with disabilities ages 24 and above and young persons with disabilities, female and male, ages 10-24.

Where these Guidelines refer to services for 'women,' this includes all women with disabilities across their life cycle, including young women, older women, and all those who identify as

women. These Guidelines are also relevant for people with female-typical sex characteristics who do not identify as women.

Although the focus of these Guidelines is on women and young persons with disabilities, it is important to note that men with disabilities also experience increased risk of GBV and SRHR violations in comparison to their peers without disabilities.<sup>27</sup> Violations against men with disabilities and lack of resources for services for men with disabilities are serious problems. Given the expertise and mandate of UNFPA and WEI, these Guidelines are limited to addressing GBV and SRHR service provision for women and young persons with disabilities. However, service providers and support staff who serve men over the age of 24 with disabilities should consider adapting these Guidelines for their needs.<sup>28</sup>

## Key GBV and SRHR Guidelines

This document builds upon comprehensive guidelines relating to GBV and SRHR developed by UNFPA and other UN agencies. Two key UN resources that serve as the foundation for these Guidelines are:

### 1. UNFPA, UN Women, WHO, UNDP & UNODC, Essential Services Package for Women and Girls Subject to Violence (2016).<sup>23</sup>

This UN Joint Global Programme publication enumerates the essential services for women and girls with and without disabilities who have experienced violence. The package addresses services in four key sectors—health, police and justice, social services, and coordination and governance. The package emphasizes that quality gender-based violence services must be guided by the following principles:

- A rights-based approach
- Advancing gender-equality and women's empowerment
- Culturally and age appropriate and sensitive (responding to individual characteristics such as disability)
- Victim/survivor-centred approach
- Safety is paramount
- Perpetrator accountability<sup>24</sup>

### 2. WHO & UNFPA, Promoting Sexual and Reproductive Health for Persons with Disabilities (2009).<sup>25</sup>

This WHO and UNFPA guidance note provides important guidance for SRHR experts and advocates as well as service providers, especially those working with provision of SRHR services, including family planning, maternal and newborn health, sexually transmitted infections (STIs), including HIV and AIDS, and adolescent services. The guidance note lays out a framework for full inclusion of persons with disabilities in sexual and reproductive health services and aims to:

- Establish partnerships with organizations of persons with disabilities from the outset of service programme development and engage persons with disabilities in training service providers.
- Raise awareness and increase accessibility in provider organizations about the needs of persons with disabilities. This can be done through capacity development by integrating disability-related trainings into existing training and partnering with other stakeholders.
- Ensure that all sexual and reproductive health programmes are accessible to and serve persons with disabilities.<sup>26</sup>

## SPOTLIGHT ISSUE

# GBV and SRHR Violations against Men and Boys with Disabilities

**GBV:** Men and boys with disabilities have an increased risk of violence, particularly sexual violence.<sup>29</sup> In one small scale study of Deaf adults in the United States, close to 45 percent of Deaf men reported experiencing at least one form of sexual assault or another form of unwanted sexual contact.<sup>30</sup> Men and boys with disabilities experience vulnerability to violence for many of the same reasons as women with disabilities. However, men and boys with disabilities can also face GBV because of perceptions that they are unable to fulfil their expected gender role in society.<sup>31</sup> Moreover, because of misconceptions that men and boys are not victims of GBV, they are rarely identified as needing GBV services.<sup>32</sup>

**SRHR:** Men and boys—both with and without disabilities—often do not receive SRHR education and are left to pick up information about their SRHR from other men and boys through comments, jokes, and socializing.<sup>33</sup> Men and boys with disabilities face increased isolation and communication barriers compared to their non-disabled peers, which presents an additional barrier to accessing essential SRHR information. These barriers are compounded by the fact that men and boys with disabilities also experience the same forms of exclusion from SRHR services as women and girls with disabilities.<sup>34</sup>

More data, research, and programmatic approaches are critically needed to identify and respond to the scope of this problem. UNFPA and WEI strongly encourage further research about GBV and SRHR services and violations experienced by men and boys with disabilities.

### 1.1.3 How to Use these Guidelines

These Guidelines are written for use by GBV and SRHR service providers and support staff at all levels. For the purposes of these Guidelines, 'service provider' refers to anyone who is directly providing services to a person in either a formal or informal setting (e.g. nurse, midwife, physician, social worker). 'Support staff' refers to administrative personnel, security staff, volunteers, and other people with whom a person may come into contact while seeking or receiving services. These Guidelines are primarily directed at service providers and support staff who may interact with a woman or a young person with a disability who is experiencing or has experienced GBV or requires SRHR-related services. Examples of service providers and support staff who may find these Guidelines relevant include doctors, nurses, midwives, social workers, reception staff, security personnel, orderlies, community health workers, prosecutors, judges, law enforcement officers, independent living centre staff, rape crisis centre staff, domestic violence shelter staff, and community group leaders. Self-advocates may also find these Guidelines useful as a guide for what to expect from their service providers and support staff.

Readers will note that these Guidelines are not written in plain language and thus may not be accessible to persons with disabilities who require simplified formats. UNFPA and WEI strongly encourage service providers and support staff to work with self-advocates to develop local accessible guides containing relevant information from these Guidelines for distribution in their community.

After this overview chapter, these Guidelines are divided into four more chapters. Note, Chapter 2 contains vital information upon which are built the GBV and SRHR thematic guidelines in Chapters 3 and 4 and must be read as a precursor to these guidelines.

- Chapter 2 enumerates the **foundational guidelines for action** that must guide the development and provision of services for women and young persons with disabilities across all service provision areas. These foundational guidelines address all phases of service provision, beginning with an enabling legislative environment, moving to programme design and implementation, and then addressing considerations at the level of the facility and direct service provision.
- Chapter 3 contains **guidelines for GBV service provision for women and young persons with disabilities**. The chapter begins with an introduction that identifies key GBV issues facing women and young persons with disabilities. This section is followed by an overview of the international human rights framework that underlies the GBV service guidelines specifically. The chapter is then divided into subchapters, each covering a separate GBV service provision area.
- Chapter 4 contains **guidelines for SRHR service provision for women and young persons with disabilities**. The chapter begins with an introduction that identifies key SRHR issues facing women and young persons with disabilities. This section is followed by an overview of the international human rights framework that underlies the

*Readers can use these Guidelines, along with the resources and examples highlighted throughout, to learn more about adapting services to their specific needs, settings, and local contexts.*

SRHR service guidelines specifically.

The chapter is then divided into subchapters each covering a separate SRHR service provision area.

- Chapter 5 contains a **glossary** of key terms, as well as a list of **resources** for further reading.

Each service area addressed in these Guidelines' subchapters contains the following sections:

- A brief **overview** of the issues related to the service area in question
- **Key considerations** that identify common barriers or issues that bear on the experiences of women and young persons with disabilities in that service area. These considerations should be kept in mind while assessing current or proposed services and taking steps to improve service delivery.
- **Guidelines for Action** that are examples of actions that can be taken to ensure that rights-based services for women and young persons with disabilities are available, accessible, acceptable, and of good quality (keeping in mind that actions taken must ultimately depend on the specific context in which the services are provided). These service area-specific Guidelines build on the **Foundational Guidelines for Action**

**(Chapter 2)**, which provide a foundation for all service areas across both GBV and SRHR sectors.

- Illustrative **indicators** demonstrating the level of specificity, subjects, and form that indicators should take for effective monitoring and evaluating progress towards rights-based service provision. Indicators are critical for quality service provision monitoring and evaluation. Each desired outcome must have a corresponding indicator that is measurable, specific, clear, reliable, timely, and programmatically important.<sup>35</sup> Qualitative and quantitative indicators can be used as markers of integrated services, health status, knowledge, access, safety, and resource allocation.

The information in these Guidelines is intended to be a **starting point** and used as a reference document. The service areas addressed in the subsections are not an exhaustive list of the services required for women and young persons with disabilities, and each subsection must be read as intersecting with the other sections. Readers can use these Guidelines, along with the resources and examples highlighted throughout, to learn more about adapting services to their specific needs, settings, and local contexts.

## Use of the AAAQ Framework

Readers familiar with the SRHR legal framework will recognize the use of the AAAQ framework to organize the GBV and SRHR guidelines for action. The AAAQ framework—the obligation to ensure that health-related information, goods, and services be **available, accessible, acceptable, and of good quality**—is essential to ensuring the right to health.<sup>36</sup>

However, the use of these categories in the GBV chapter does not represent an application of the AAAQ framework as a legal obligation in the context of GBV; rather the four categories are used as a useful tool for organizing the guidelines for service provision.



As part of a series of events marking the International Day of Persons with Disabilities (3 December), Heidi Latsky Dance, a New York-based modern dance company, stages in the Visitors Lobby of UN Headquarters a movement installation of 20-30 performers who together form a living gallery. © UN Photo/Amanda Voisard

## SPOTLIGHT ISSUE

# Assessing Current Capacity to Serve Women and Young Persons with Disabilities

An assessment of current or proposed programming is critical to ensure that services are accessible to and meet the specific needs of women and young persons with disabilities. Input from women and young persons with a range of disabilities in each stage of the assessment is critical, and it is essential to ensure that information and materials related to the assessment are available in alternative formats. The following steps for making this assessment are adapted from the Advocates for Human Rights and UN Women's 'Working with the Justice Sector to End Violence against Women and Girls' guidance:<sup>37</sup>

**Step 1:** Conduct an appraisal to assess current capacity to serve women and young persons with disabilities. Before beginning the appraisal, ensure that the programme team has received training about how to conduct and participate in the appraisal.

**Step 2:** Define goals that are narrowly tailored, manageable, and measurable, and prioritize based on importance and benefit to women and young persons with disabilities.

**Step 3:** Develop a participation plan that identifies the level and means of participation of key stakeholders, particularly women and young persons with disabilities; barriers and incentives to participation; and strategies to strengthen and support participation.

**Step 4:** Assess the various partnerships necessary to build an effective network of service providers and other key actors and develop a plan for putting this network into action.

**Step 5:** Identify strategies for developing, implementing, and evaluating programme changes to improve services using stakeholder or SWOT (strength, weakness, opportunity, threat) analyses.

**Step 6:** Develop a plan to monitor and evaluate progress and to be responsive to the changing needs and priorities over time of women and young persons with disabilities.

**Step 7:** Develop a work plan and budget that considers the cost of accommodations for a range of disabilities and training for service providers and support staff, distinguishing between one-time and ongoing costs.

## 1.2 International Human Rights Framework

The rights of women and young persons with disabilities are human rights that are protected in numerous international human rights treaties, including the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social, and Cultural Rights, the Convention against Torture and other Cruel, Inhuman, and Degrading Treatment or Punishment, the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Elimination of All Forms of Discrimination against Women, and the Convention on the Rights of the Child. Each of these international human rights treaties impose specific legal obligations on States that have ratified the treaty.

For States that have ratified one or more of these treaties, as most States have, the State and its representatives are bound by specific legal obligations to **respect, protect, and fulfil** the rights protected in the human rights treaty.<sup>38</sup>

The obligation to **respect** requires the State to refrain from interfering directly or indirectly with the right in question.

- Gender-based violence example: The government must take measures to ensure that no State actors—which includes medical practitioners—commit acts of GBV against women and young persons with disabilities. This may require, for instance, criminalizing sterilization of women and young persons with disabilities without their informed consent.<sup>39</sup>

- Sexual and reproductive health and rights example: The government must eliminate requirements for third-party consent for SRHR services. For instance, this means that allowing parents or guardians to withhold consent for a young woman with a disability to obtain contraceptives violates the obligation to respect the right of women and young persons with disabilities to access contraceptives.<sup>40</sup>

The obligation to **protect** requires the State to prevent non-State actors—that is, private citizens—from infringing on the right in question. The obligation to protect encompasses a State's obligation to exercise due diligence to prevent rights violations from occurring, to investigate, prosecute, and punish non-State actors who commit such violations, and to provide redress to victims when such violations occur.

- GBV example: A woman with a visual impairment takes out a restraining order against her physically abusive husband. The local police department fails to enforce the order. The State is obligated to take all appropriate measures to ensure that the police enforce the order.<sup>41</sup>
- SRHR example: A young woman with Down syndrome visits a pharmacy to fill a prescription for contraceptive pills. The pharmacist refuses to fill the prescription because he objects to persons with disabilities having sex. The State must take measures to prevent the pharmacist from interfering with the woman's right to access contraception.<sup>42</sup>

The obligation to **fulfil** requires that the State take necessary action—legislative, administrative, budgetary, or judicial—to fully achieve the

rights in question. In addition, States must take affirmative measures to eradicate practical and social barriers to realizing fundamental rights.<sup>43</sup>

- GBV example: The State must allocate sufficient resources to ensure that both male and female victims/survivors of sexual violence have access to a range of supports and services, including establishing accessible supports and services necessary to navigate the justice system. The State must also guarantee that survivors of sexual violence have access—both in law and in practice—to essential physical and mental healthcare, including access to post-exposure services for sexually transmitted infections.<sup>44</sup>
- SRHR example: The State's education department distributes policies and guidelines on the provision of comprehensive sexuality education in schools, in addition to coordinating the development of sexuality education course materials. The State must take steps to ensure the course materials are inclusive of women and young persons with disabilities, including by mainstreaming images of persons with disabilities throughout the materials, ensuring that materials include information about SRHR of persons with disabilities, and making course materials accessible.<sup>45</sup>

Governments must ensure that all laws, policies, and programmes that bear on the rights of women and young persons with disabilities to be free from GBV and to have access to sexual and reproductive health comply with international human rights legal obligations. This obligation extends to service providers and

support staff, both directly, through government affiliation or funding, and through government oversight.

Further details about the specific international human rights frameworks that govern GBV and SRHR services are addressed in sections 3.2 and 4.2 respectively.

### ***Twin Track Approach***

The obligation to fulfil also imposes an obligation on States to adopt what is known as a 'twin track approach' to fulfil their "ongoing and dynamic duty to adopt and apply the measures needed to secure the development, advancement and empowerment of women [and young persons] with disabilities".<sup>46</sup> The UN Committee on the Rights of Persons with Disabilities, which monitors compliance with the CRPD, has explained that the twin track approach "is an essential precursor to reducing inequality regarding participation and enjoyment of rights".<sup>47</sup> A twin track approach entails both systematic mainstreaming of the interests of women and young persons with disabilities "across all national action plans, strategies, and policies concerning women, childhood, and disability" and "targeted and monitored action aimed specifically at women [and young persons] with disabilities".<sup>48</sup> Some examples of disability-specific services include adaptive devices, special education programmes, and community-based rehabilitation.<sup>49</sup>

Employing the twin track approach to the provision of services is the recommended approach wherever possible. Offering services through only one approach will not provide women and

young persons with disabilities with the range of services, involvement, and integration necessary to realize their rights.<sup>50</sup> Service providers do not need to be responsible for offering both types of services but should understand the key referral points and be able to make effective referrals.<sup>51</sup>

The twin track approach is a concept recommended in and utilized widely in the humanitarian emergency context. Valuable guidance on using the twin track approach can be found at the CBM organization's guide, *'Inclusion Made Easy'*,<sup>52</sup> and the United Nations High Commissioner for Refugees' guidance, *'Working with Persons with Disabilities in Forced Displacement'*.<sup>53</sup>

CBM offers the following illustrative example of the use of the twin-track approach in their work: "Shathi is a 9-year old girl with cerebral palsy who loves to play with her friends and uses a wheelchair to move around. She lives in rural Bangladesh. ... The community health worker identified her developmental difficulties early on and referred her to a [community-based rehabilitation] service. This service then provided strategies to assist her development including the wheelchair (disability-specific initiative). They also set up a local support group for parents who have children with a disability, of which Shathi's mother is a member. Shathi herself has spoken about her experience to them and in front of her school class (participation). When the time came for Shathi to go to school, the principal of the school knew that it is Shathi's right, like any other child, to be educated well (policy accessibility and mainstreaming). The local teacher was very supportive as he had received

training on child-centred teaching; she knew of a resource centre that could give support when needed (disability-specific initiative). When Shathi grows up she would like to be a teacher and get married".<sup>54</sup>

Service providers and support staff should keep this approach in mind while reviewing these Guidelines. If there are existing GBV or SRHR programmes available in one's community, these Guidelines can help identify how to improve available mainstream or disability-specific services to meet the needs of women and young persons with disabilities. Where such services do not exist, these Guidelines should inform the development of such programmes. In general, integrating women and young persons with disabilities into mainstream services should be prioritized, and women and young persons with disabilities need to participate in decisions about coordinating access to such services.<sup>55</sup>

### **Equal Recognition Before the Law**

Human rights law recognizes the right of people everywhere to equal recognition before the law.<sup>56</sup> Article 12 of the CRPD expressly provides that States must realize this right for persons with disabilities and explains what it looks like to give effect to this right for persons with disabilities.<sup>57</sup> Therefore, States are required to: **(1)** reaffirm that women and young persons with disabilities "have the right to recognition everywhere as persons before the law";<sup>58</sup> **(2)** recognize that women and young persons with disabilities have the right to "enjoy legal capacity on an equal basis with others in all aspects of life";<sup>59</sup> **(3)** "take appropriate measures to provide access by [women and young persons]

with disabilities to the support they may require in exercising their legal capacity,"<sup>60</sup> such as supported decision-making models; **(4)** "ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse,"<sup>61</sup> while respecting the rights of the woman or young person with a disability's will and preference, without coercion or conflicts of interest; and **(5)** ensure the equal right of women and young persons with disabilities to own and control their property.<sup>62</sup>

Understanding the right of women and young persons with disabilities to equal recognition before the law is necessary so service providers and support staff can ensure that they do not participate in violating women and young person's rights.

Service providers and support staff must understand the meaning of and how to implement the following key concepts:

- **Legal capacity** refers to "the capacity to be both a holder of rights and an actor under the law. Legal capacity to be a holder of rights entitles a person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognizes that person as an agent with the power to engage in transactions and create, modify, or end legal relationships".<sup>63</sup> Supported decision-making mechanisms may be necessary to empower persons with disabilities to exercise their rights to legal capacity.<sup>64</sup>

*Note on mental capacity:* Mental capacity and legal capacity are not the same things.

However, the two are often conflated, and thus a person is assumed to lack legal capacity because of a mental or intellectual disability. Such an assumption is discrimination and a violation of Article 12 of the Convention on the Rights of Persons with Disabilities.<sup>65</sup>

*Note on young persons with disabilities under age 18:* The age at which a person with or without a disability has the legal capacity to make decisions for themselves varies by country. Service providers and support staff must be familiar with the laws in their country. Generally, children under 15 lack legal capacity to make decisions for themselves. If a child or adolescent lacks legal capacity, their opinion should still be assessed within the limitations imposed by their age and level of understanding.<sup>66</sup> In the context of SRHR services, the United Nation's Committee on the Rights of the Child has said there should be a "legal presumption that adolescents are competent to seek and have access to preventive or time-sensitive sexual and reproductive health commodities and services,"<sup>67</sup> which shifts the burden to service providers or other officials to prove a lack of capacity to consent where they wish to deny adolescents access to certain SRHR services.

- **Informed consent** is more than the process of acquiring a signature for a procedure, according to guidelines developed by the International Federation of Gynecology and Obstetrics (FIGO). It is a process of communication between a service provider and a service recipient that results in the service recipient giving, withdrawing, or refusing to give permission for a procedure



A female doctor reads a patient's chart. © Daniel Tardif/Getty Images

based on full knowledge of the procedure. FIGO defines informed consent as “a consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on: (a) the diagnostic assessment; (b) the purpose, method, likely duration and expected benefit of the proposed treatment; (c) alternative modes of treatment, including those less intrusive, and (d) possible pain or discomfort, risks and side effects of the proposed treatment”.<sup>68</sup> While the process of obtaining

informed consent may be time-consuming, particularly when there are communication difficulties, this does not absolve a service provider of their obligation to obtain informed consent. Moreover, only the service recipient can provide informed consent, regardless of family member's or advocate's opinions. It is the service provider's obligation to ensure that the rights of the woman or young person with the disability are respected by a communication process that leads to the provision or withholding of informed consent. Consent can also be withdrawn at any time.<sup>69</sup>

## Informed Consent in Practice

**What does it mean to obtain free and informed consent?** To ensure that free and informed consent is always obtained, develop internal policies and train all service providers and support staff on understanding legal capacity and informed consent. Service providers must understand how to obtain informed consent and when to advocate for a person who is assumed to lack legal capacity to provide informed consent.

- Never assume a person lacks capacity to provide free and informed consent. Service providers and support staff must understand that just because a person has an intellectual disability or cannot communicate verbally does not mean that they cannot give their informed consent.

Utilize tools such as The Women's Refugee Commission and International Rescue Committee's *'Guidance for GBV Service Providers: Informed Consent Process with Adult Survivors with Disabilities—Tool 6: Guidance on Communicating with Persons with Disabilities'*<sup>70</sup> to educate service providers and support staff on how to communicate with people with a range of disabilities. Lack of accessible communication skills and resources is not a sufficient reason for failure to acquire informed consent.

- Three key components to obtaining free and informed consent (adapted from The Women's Refugee Commission and International Rescue Committee's *'Guidance for GBV Service Providers: Informed Consent Process with Adult Survivors with Disabilities'*):<sup>71</sup>
  - Provide all possible information, including benefits, risks, and alternatives, to a woman or young person with a disability in their preferred format and in a way, they can understand; offer and utilize supported decision-making tools if desired.
  - Determine if the woman or young person can understand the information and their decisions (also known as 'capacity to consent').
  - Ensure that the decisions of the woman or young person with a disability are voluntary and not coerced by others (e.g. family members, caregivers, or service providers).
- Determining capacity to consent: Service providers and support staff may encounter service recipients who are unable to provide informed consent even with the necessary supports. To make this determination, all of the foregoing steps to acquire informed consent should have been exhausted. In making such a

determination, a service provider must consult the ethical and legal standards in their country for acquiring informed consent and determining a person's capacity. A service provider must not assume that because a person has an intellectual disability or is unable to communicate that they do not have the capacity to provide informed consent.

Vanderbilt University's *Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers*<sup>72</sup> offers the following steps in the consent process, including situations where a person does not have capacity to consent: **(1) Determine capacity:** Keep in mind that capacity is not static—assessed capacity can vary per the supported decision-making tools provided; engage family members or trusted friends or caregivers to better understand the person and their communication style; follow all applicable legal and ethical procedures and standards.<sup>73</sup> **(2) Document consent:** Keep in mind that consent must be provided voluntarily, be related to the proposed treatment or service and well-informed, and cannot be obtained through fraud, coercion, or misrepresentation. **(3) Identify the current surrogate decision maker:** If the prior steps lead to a conclusion that a person lacks the capacity to provide informed consent because the person lacks the capacity to understand and

make decisions, proceed with identifying the person's designated surrogate decision maker. Generally, preference for a surrogate decision maker is prioritized as follows: Spouse (unless legally separated), adult child, parent or step-parent, adult sibling, other adult relative, adults who demonstrate special care and concern for the person. However, service providers and support staff must consult their jurisdictions legal and ethical requirements first. **(4) Informed consent should always be obtained:** For medical service providers, there may be emergency situations where treatment can occur without it; service providers should consult local legal counsel to fully understand.<sup>74</sup> However, it is important to note that sterilization can never "be justified on grounds of medical emergency".<sup>75</sup>

Visit the Toolkit webpage for a link to an informed consent checklist and sample questions.<sup>76</sup>

If a determination is made that a person lacks capacity to provide informed consent, **service providers must ensure that the woman or young person with the disability remains involved in the decision-making process as much as possible and that the person's best interests and preferences are prioritized.**<sup>77</sup>

**Supported decision-making** is a mechanism to support persons with disabilities who require assistance to make decisions independently and retain legal authority to make decisions. Supported decision-making “comprises various support options which give primacy to a person’s will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.).”<sup>78</sup> Supported decision-making regimes replace substituted decision-making systems, such as guardianship.

► **EXAMPLE:**

*In the United States of America, the **Center for Public Representation and Nonotuck Resource Associates** developed a pilot project for supported decision-making. Beginning with nine adults with intellectual or developmental disabilities, the project proved very successful, with the participants using supported decision-making for seventy-two decisions in the*

*first two years.<sup>79</sup> The model developed by the Center for Public Representation and Nonotuck involves four components: “(1) Individuals with [intellectual or developmental disabilities] enter into Representation Agreements in which they specify areas where they need help making decisions and designate supporters to help them reach their decisions. (2) Support areas include healthcare, finances, employment, living arrangements and relationships. (3) Network supporters, who sign statements that they will respect the person’s choices and decisions, can be family members, friends, and past and current providers. (4) Individuals sign their Representation Agreements before a notary public who stamps, signs, and dates the document, making it official, and hopefully, a document that will be honored in the community by doctors, merchants, landlords, etc.”<sup>80</sup> The project participants reported satisfaction with the project and utilized their supports for a range of decisions including, for one adopter, discussing her boyfriend’s interest in having children and the care and money requirements involved with being a parent.<sup>81</sup> Supported decision-making was most frequently used for healthcare decisions.<sup>82</sup>*

*[Supported decision-making] should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.)*

## Supported Decision-Making in Practice

**What does supported decision-making look like?** Supported decision-making systems come in various forms, such as informal circles of support or formal support networks. No matter the form, all supported decision-making programmes share the following characteristics:

- Do not overly regulate the lives of the person with the disability.
- Do not have restrictions on who can use the supported decision-making system.
- Do make the person with the disability's will and preference the priority.
- Do offer all forms of communication.
- Do make available and accessible legal recognition of the support person or persons.
- Do offer availability through State mechanisms and at no cost or nominal cost.
- Do not infringe on other rights (such as sexual and reproductive health and rights).

- Do include the right to refuse and terminate the support relationship.
- Do include safeguards throughout the process.
- Do not discriminate.<sup>83</sup>

**Representation agreements** can be an effective mechanism for formalizing supported decision-making. Representation agreements are written documents that lay out the personal planning needs and areas of support provided when an individual with a disability requests support with making decisions in a particular area. In some jurisdictions, representation agreements are legally enforceable. For example, in British Columbia in Canada, representation agreements allow a person with a disability to give a representative of their choice the legal authority to help them with healthcare, personal care, or financial or legal matters in a temporary or ongoing basis.<sup>84</sup>

## Humanitarian Emergencies

During a humanitarian emergency, human rights law continues to apply and is complementary and mutually reinforcing with the laws that apply in emergencies.<sup>85</sup> **Article 11** of the Convention on the Rights of Persons with Disabilities enumerates the obligations of States under international human rights law and international humanitarian law (the body of law that applies during humanitarian emergencies) to take all necessary measures to keep persons with disabilities safe and protected during situations of risk, including armed conflict, natural disasters, and other humanitarian emergencies.<sup>86</sup>

The Office of the United Nations High Commissioner for Human Rights prepared a report on the rights of persons with disabilities under Article 11 of the CRPD. The Report explains in detail the human rights obligations of States along with findings from a thematic study on persons with disabilities in situations of risk and humanitarian emergencies. The following recommendations were made for implementing Article 11:<sup>87</sup>

- Ensure adequate and timely delivery of accessible information. Utilize multiple and innovative means of communication.
- Ensure the principles of participation, accountability, non-discrimination and empowerment.
- Ensure sufficient resource allocation for inclusive and accessible emergency preparedness and response.

- Ensure capacity of field operations personnel and other stakeholders regarding supporting persons with disabilities.
- Ensure that a human-rights based approach to reconstruction and rebuilding is employed by ensuring accessibility and use of universal design.
- Ensure that prevention health strategies do not negatively influence allocation of resources for disability-related strategies.
- Ensure that persons with disabilities are part of frameworks to collect information to facilitate data collection.

Although nonbinding, the '*Charter on Inclusion of Persons with Disabilities in Humanitarian Action*' marks an important development in the inclusion of persons with disabilities in humanitarian action by affirming States' determination and commitment to make humanitarian action inclusive and place persons with disabilities at the centre of humanitarian response. Developed by seventy stakeholders, including States and civil society, in advance of the 2016 World Humanitarian Summit, the Charter commits signatories to the following five areas in humanitarian action: **(1)** Non-Discrimination; **(2)** Participation; **(3)** Inclusive Policies; **(4)** Inclusive Response and Services; and **(5)** Cooperation and Coordination.<sup>88</sup>





# Foundational Guidelines for Action For Providing Rights-Based GBV and SRHR Services for Women and Young Persons with Disabilities

## 2.1 Introduction

This chapter enumerates the foundational guidelines that should inform the provision of GBV or SRHR services to women and young persons with disabilities. These guidelines are grounded in international human rights frameworks.

Lack of resources is an unfortunate reality for GBV and SRHR service providers around the world. However, lack of resources is not sufficient justification to exclude women and young persons with disabilities from such services. Service providers—and the national and subnational governments responsible for providing services—must consider and budget for accessible services for women and young

persons with disabilities from the programme development stage. Moreover, while some of the guidelines in this document may be unaffordable to service providers in low-resource settings, these Guidelines offer a starting point for developing creative solutions and programmes that are guided by and aim to meet the principles laid out below.

The essential principle that should guide all quality rights-based services for women and young persons with disabilities is: **When in doubt, ask the person with the disability.** In fact, the Convention on the Rights of Persons with Disabilities requires such consultation in the development and implementation of legislation and policies to realize women and

young persons with disabilities' full and equal enjoyment of their human rights.<sup>89</sup> Women and young persons with disabilities are the experts on their own needs, the barriers they experience, and the accommodations they require for equal access to services.

The following criteria are also essential to all stages of the development and implementation of rights-based services, programmes, and policies generally:

- Participation of women and young persons with disabilities at all stages of programme development and assessment.
- Inclusive services for people with and without disabilities.
- Respect for a person's legal capacity, informed consent, and privacy, along with mechanisms for supported decision-making and confidentiality safeguards.
- Sufficient funding for accessible services.
- Training and supportive supervision of service providers and support staff about the rights and needs of women and young persons with different types of disabilities and how to provide respectful care. Incorporate disability issues in curricula for service providers and support staff.
- Effective referrals through streamlined inter-agency coordination.
- Accessible services (physical, information, communication, financial, sensory environment).

The following Foundational Guidelines are organized into the three stages of developing and administering programmes to meet the needs of women and young persons with

disabilities: **(1)** developing disability- and gender-sensitive laws and policies; **(2)** programme development, implementation, monitoring and evaluation; and **(3)** designing facilities.

## 2.2 Laws and Policies

Creating an enabling legislative environment is essential to providing quality rights-based services for women and young persons with disabilities. The following actions are crucial to creating this environment:

### Guidelines for Action:

#### ► **Legal Environment Assessment and Monitoring**

1. Conduct a review of existing laws and regulations, in collaboration with women and young persons with disabilities, to identify current laws and regulations that create barriers to accessing services, including those that create barriers in practice that may not be apparent on the face of the law or regulation. Advocate for mandatory minimum standards of accessibility to ensure that all services have a minimum level of accessibility, including those from private service providers.

#### ► **EXAMPLE:**

*In Argentina, REDI, a grassroots disability organization, evaluated the extent to which Argentina's laws, policies, and national plans realize the SRHR of women with disabilities in Argentina in a report entitled 'El derecho de las personas con discapacidad a la salud sexual y reproductiva: 20 preguntas fundamentales sobre las políticas públicas del Estado argentino.'* (Rights of Persons with Disabilities to Sexual and Reproductive Health:

20 Fundamental Questions on Public Policies of the Argentinian State).<sup>90</sup>

2. Ensure that laws and regulations are responsive to and inclusive of women and young persons with disabilities. Draft model legislation to improve advocacy.

► **EXAMPLE:**

*In the United States of America, the State of Illinois' 'Domestic Violence Act of 1986' (750 ILCS 60) includes the following within the definition of family or household members: " In the case of a high-risk adult with disabilities, 'family or household members' includes any person who has the responsibility for a high-risk adult as a result of a family relationship or who has assumed responsibility for all or a portion of the care of a high-risk adult with disabilities voluntarily, or by express or implied contract, or by court order".<sup>91</sup>*

► **EXAMPLE:**

*In the Philippines, the 'Responsible Parenthood and Reproductive Health Act' (RA No. 10354, also known as the Reproductive Health Law) was developed in consultation with the National Council on Disability Affairs and a range of disabled persons' organizations, including those focused on women. Section 18 of the Act includes strong provisions in relation to the reproductive health of persons with disabilities, including a legal mandate to protect the rights of women with disabilities to access the full range of sexual and reproductive health information, services, and commodities on an equal basis to women without disabilities.*

*The section requires cities and municipalities to dismantle barriers to reproductive health services for persons with disabilities through various initiatives, including providing physical access, transportation, adapting examination tables and laboratory procedures, increasing access to information and materials in accessible formats, offering continuing education for service providers about the rights of persons with disabilities, and awareness-raising campaigns which combat misconceptions about the sexual and reproductive health and rights of persons with disabilities.<sup>92</sup>*

3. Ensure that service animals are legally permitted access to all public buildings and private facilities, even where animals would otherwise be prohibited.
4. Implement monitoring mechanisms that provide oversight to GBV and SRHR service providers to ensure that informed consent is being attained appropriately.
5. Enforce information and communication confidentiality requirements for GBV and SRHR service providers and support staff, regardless of the service recipient's disability.

### Guidelines for Action:

► **Legislative Advocacy and Lobbying**

1. Engage women and young persons with disabilities, disabled person's organizations, and families of persons with disabilities (where appropriate), in all stages of the review and development of laws and policies relating to GBV and SRHR service provision. Support and engage lawmakers with disabilities

► **EXAMPLE:**

**Freedom of Movement Society.** In Ekaterinburg, Russia, a group of persons with disabilities formed the Freedom of Movement Society to enforce their access to public buildings and places. The group created a list of the most important places in the city that needed to be accessible and advocated for change with city officials. As a result, city officials engaged the society in city committees responsible for improving access and gave society members final approval of any committee projects. The society also created accessibility guidelines for architects, which were used regularly.<sup>93</sup>

2. Advocate for non-discrimination laws and regulations that are comprehensive and applicable to both public and private GBV and SRHR service providers and support staff. The CRPD provides a framework for model non-discrimination laws.

► **EXAMPLE:**

The **Americans with Disabilities Act (ADA)** prohibits discrimination and guarantees equal opportunities for Americans with disabilities in both public and private settings.<sup>94</sup>

► **EXAMPLE:**

The **Network for the Rights of Persons with Disabilities (REDI)** is an Argentinian political organization led by persons with disabilities that aims to improve the rights of persons with disabilities by advocating for their full recognition under the law. A primary focus is proposing and advocating for disability-inclusive legislation. The recommendations span national and international legislation

and policy, and subjects including work, benefits, licenses, health, education, accessibility, and transportation. The organization also produces publications updating the public on legislative changes and reports on the impact of legislation.<sup>95</sup>

3. Advocate for and ensure that national accountability mechanisms allow for reporting, monitoring, and redress of violations experienced by women and young persons with disabilities, including sexual and reproductive rights violations. Ensure that such mechanisms are independent and responsive to women and young persons with disabilities and the issues they experience. Such mechanisms should include a means of tracking and responding to violation trends. Relatedly, remedies offered by the accountability mechanism should be relevant to persons with disabilities.
4. Advocate for a legislative and regulatory scheme that gives women and young persons with disabilities equal recognition before the law in accordance with the rights laid out in Article 12 of the CRPD. Relatedly, advocate for government-funded and promoted supported decision-making models, including legally binding mechanisms, such as a healthcare proxy or power of attorney to assist women and young persons with disabilities who require support in exercising their legal capacity. To assist with your advocacy, utilize the **Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities**, which includes a subchapter on Legal Capacity and supported decision-making.<sup>96</sup>

5. After **humanitarian emergencies**, engage women and young persons with disabilities in the development of new laws and policies to ensure removal of the barriers that confronted them before and during the emergency and to promote development and implementation of new, more inclusive laws and policies.
  - **United Nations Security Council Resolution 1325** urges governments to develop National Action Plans (NAPs) regarding the protection and participation of women.<sup>97</sup>
  - **United Nations Security Council Resolution 2250** urges governments to find ways to increase representation and meaningful input from youth in peace processes and dispute resolution.<sup>98</sup>
2. Enumerate licensing and education requirements for GBV and SRHR service providers that include training on disability rights, accessibility, and participation.
3. Register essential medicines, as outlined by the **WHO List of Essential Medicines**,<sup>100</sup> to ensure they are legally available.
4. Allocate sufficient resources for disability issues and rights training and supportive supervision for service providers and support staff and accessibility mechanisms for government-funded programmes. Where possible, budgets should include funding for transportation, subsidies, social protection schemes, and public information campaigns.

### Guidelines for Action:

#### ► **National Policies and Plans**

1. Adopt and implement a national strategy and action plan, with adequate budget allocation, on GBV against and the SRHR of women and young persons with disabilities, that is devised, periodically reviewed, and monitored through a participatory and transparent process.

#### ► **EXAMPLE:**

*The **Australian 'National Plan to Reduce Violence against Women and their Children'** assessment includes women with disabilities. This has resulted in collection of important information relating to women with disabilities; improved access to domestic violence and sexual assault services; better services through evidence-based approaches; improved access to justice; grants for prevention programmes; and promotion of respectful relationships in various settings.<sup>99</sup>*

5. Develop national and local data collection systems disaggregated by gender, disability, age, sexual orientation, socio-economic status and living environment. A coordinated mechanism should be in place for regular data review and analysis to improve services.

#### ► **EXAMPLE:**

*With the support of UN Partnership on the Rights of Persons with Disabilities, Bolivia strengthened its disability reporting by integrating disability information in the statistics collected in three key sectors—education, health, and justice. The Ministry of Justice sought to improve justice for persons with disabilities by introducing disability variables into the **Integral System of Prevention, Care, Punishment, and Eradication of Gender-Based Violence**. This also led to a guide for users of the system addressing disability-rights and GBV- and disability-inclusive data collection.<sup>101</sup>*

## 2.3 Programmes

Ensuring that GBV and SRHR service programmes are non-discriminatory and disability-sensitive requires a comprehensive assessment and ongoing monitoring of all stages of a programmes life cycle to ensure that barriers do not arise and that existing barriers are addressed for women or young persons with disabilities in accessing services. The following guidelines are essential to ensuring non-discriminatory programming:

### Guidelines for Action:

#### ► **Engagement of Women and Young Persons with Disabilities**

Self-advocacy is a key element of the disability rights movement globally. It refers to the concept that persons with disabilities are capable of and most effective in advocating for their own rights and needs. Self-advocates advocate for their own rights, the rights of others, and for the assistance they require to support their own advocacy. Disabled Persons Organizations are a key mechanism for supporting and organizing self-advocates. Self-advocates must be actively involved in all decisions affecting their rights. This principle of participation is captured by the disability rights movement's motto—Nothing About Us Without Us.

1. Engage women and young persons with a range of disabilities in GBV and SRHR programme development and implementation.
  - Women and young persons with disabilities should participate in developing programmes and offering input and feedback at all stages (planning, design, implementation, and monitoring) and relating to all components (training, staffing, facility, etc.).

- Implement a participatory design and evaluation process with women and young persons with disabilities for all programmes. This enables women and young persons with disabilities to determine programme priorities and give feedback to improve a programme. Effective participation can also facilitate engagement of caregivers and increase confidence of participants.
- The following are some examples of key entry points to engage women and young person's participation:
  - Map local organizations, including organizations of women and young persons with disabilities, to engage in the coordination mechanisms.
  - Set criteria that a certain percentage of community committees, associations, volunteers, and workers will be women and young persons with disabilities.
  - During humanitarian emergencies, include women and young persons with disabilities in rapid needs assessments, and disaggregate data by age, gender, socio-economic status and disability to understand who is and is not using GBV and SRHR services.
- Participation is equally as important during humanitarian emergencies. Feedback should, however, be solicited in an ongoing cycle throughout the emergency and post-emergency period. This includes engagement in the setting of priorities for aid distribution<sup>102</sup> and the peacebuilding process.<sup>103</sup>
- Recognize and respect women and young persons with disabilities' intersecting identities and ensure that services are

sensitive and responsive to each identity. For example, a woman with a disability may also identify as a member of a minority group or indigenous community; live in a rural area; be a refugee or an internally displaced person; or identify as lesbian, gay, bisexual, transgender, or intersex (LGBTI).<sup>104</sup>

### Guidelines for Action:

#### ► **Capacity Building**

1. Develop the capacity of both rights holders (women and young persons with disabilities) and duty bearers (service providers and support staff).

- **Rights holders:** Support women and young persons with disabilities to understand and enforce their rights through targeted capacity-development programmes. Such programmes generally fall into three categories: **(1)** programming developed for women and young persons with disabilities to improve their knowledge and understanding of their rights and available services; **(2)** ongoing feedback and engagement between women and young persons with disabilities and service providers and support staff; and **(3)** leadership and empowerment programmes for women and young persons with disabilities.
  - Establish support groups and peer-to-peer networks led and structured by women and young persons with disabilities coupled with ongoing support, as needed.
  - Make spaces for capacity development safe for and inclusive of women and young persons with disabilities from a variety of backgrounds and identities.

- Involve both people with and without disabilities in age- and gender-appropriate capacity-development programmes,<sup>105</sup> and engage allies, such as caregivers and family members, in such programmes.
- Develop programmes that make space for varying communication and engagement styles, recognizing that participation looks different for everyone. For example, a service recipient with an intellectual disability may require more time to provide feedback or alternative communication formats. Programmes should be built to allow the space and flexibility for different forms of participation.<sup>106</sup>



A 15 year old girl and her mother communicating through sign language. © kali9/Getty Images



A young boy hugs his mother.

© Colin Hawkins/Getty Images

- Create multiple trainings tailored for the audience's disability-related needs to effectively relay pertinent information.
- Offer ongoing training and mentorship programmes for women and young persons with disabilities to serve and be supported as leaders, service providers, support staff, and advisers.
- **Duty bearers:** Deliver comprehensive training programmes for service providers and support staff about disability inclusion, including the needs and experiences of women and young persons

with disabilities, accessibility mechanisms and techniques, and reasonable accommodations.<sup>107</sup>

- Ensure that training programmes address all different forms of disabilities and associated accessibility needs and offer specific actionable guidance.
- Make training and supportive supervision an ongoing job requirement. Offer continuing education to assist service providers and support staff, e.g. in developing additional and relevant communication skills.
- For service provider roles requiring a certificate or degree, such as a medical degree, create curricular programmes that teach students about providing services to persons with disabilities. Programmes must focus on skill development and practical experience and not be limited to concepts of disability inclusivity.
- Involve instructors with a disability whenever possible, as doing so both increases the effectiveness of the training and contributes to the shift in power dynamics that otherwise might contribute to stigma and discrimination.
- Offer experiential learning opportunities for service providers and support staff that allow them to build confidence in providing services to persons with disabilities.

## HUMANITARIAN EMERGENCIES

### Developing the Capacity of Duty Bearers during Emergencies

Given the increased barriers, vulnerabilities, and demands for services experienced by persons with disabilities during humanitarian emergencies, it is essential to make sure that service providers and support staff understand their duty to provide services to women and young persons with disabilities and that they know how to do this.

Key guidance for humanitarian actors on gender-mainstreaming, including collection of disability disaggregated data, is available in the *'Inter-Agency Standing Committee (IASC), The Gender Handbook for Humanitarian Action.'*<sup>108</sup>

Specific guidance on disability inclusion in the humanitarian emergency setting includes the following (service providers and support staff in non-emergency settings may also find this guidance illuminating):

- Ensure all actors involved in humanitarian emergencies have received disability-awareness training that emphasizes their responsibility to provide services to persons with disabilities.<sup>109</sup>
- Implement compulsory human rights trainings for members of the armed forces, including disability-inclusive sexual and GBV prevention and response.<sup>110</sup>
- Train SRHR and GBV service providers and support staff in emergency settings on how to offer inclusive SRHR and GBV services in emergency settings.
- Build capacity for disability inclusion by increasing understanding and recognition of the needs of survivors with disabilities, providing social and economic empowerment opportunities for women and young persons with disabilities and their caregivers to increase independence and create peer networks, and promoting and recognizing women with disabilities as leaders.

For more important guidance on building capacity, review *'I See That It Is Possible': Building capacity for disability inclusion in GBV programs in humanitarian settings* (May 2015)<sup>111</sup> and *Strengthening the Role of Women with Disabilities in Humanitarian Action: A Facilitator's Guide* (February, 2017)<sup>112</sup>

## Guidelines for Action:

### ► **Programme Delivery**

1. Integrate services for women and young persons with disabilities into mainstream service provision. Service providers must take care not to place total responsibility to serve women and young persons with disabilities on service providers specializing in serving persons with disabilities; ensuring that services are accessible is an obligation of all service providers and support staff. Service providers and support staff lacking experience or training to serve persons with disabilities should look to disability inclusive service providers for their expertise and guidance.
2. Strengthen the capacity of case coordinators—individuals responsible for helping service recipients to navigate within and across particular service area systems—to assist women and young persons with disabilities to address any barriers they encounter. This is particularly



A woman smiles during a sporting event in Cali, Colombia, on August 17, 2017.

© AFP Contributor/Contributor/Getty Images

important during humanitarian emergencies. A designated coordinator should be knowledgeable about the barriers to services experienced by women and young persons with disabilities, the range of service options, and how to communicate and build trust with a client. It is essential that coordinators understand and implement supported decision-making and implement safeguards so that the case coordinator position does not become a substituted decision-making mechanism in practice.

3. Ensure that women and young persons with disabilities are not excluded from eligibility criteria because their experiences are not captured in the criteria. For example, GBV services should not exclude women and young persons with disabilities because they rely on a definition of GBV that does not encompass violence by caregivers or GBV experienced by boys and men.

## Guidelines for Action:

### ► **Available Services**

1. Make sure that services are available in sufficient quantity and quality to all women and young persons with disabilities regardless of the person's disability, place of residence, nationality, ethnicity, caste, class, migrant or refugee status, indigenous status, age, religion, language and level of literacy, sexual orientation or gender identity, marital status, or any other characteristic.

*Note on low-resource settings:* When allocating limited resources, service providers and support staff must ensure that the needs of women and young persons with disabilities are prioritized

equally with the needs of service recipients without disabilities. Service providers should work with women and young persons with disabilities to develop creative and low-cost solutions to ensure that, to the extent services are available, women and young persons with disabilities have equal access as their peers without disabilities.

2. Develop services tailored to reach women and young persons with disabilities living in isolation in institutional settings, camps, nursing or group homes, family residences or who are homeless. For example, develop accessible GBV know-your-rights resources and reporting hotlines or programmes designed to increase family member's understanding and acceptance of the SRHR needs of women and young persons since many family members act as the gatekeepers for services.

► **EXAMPLE:**

*The Women's Refugee Commission and the International Rescue Committee piloted and evaluated actions to promote disability inclusion in GBV programming. In Ethiopia, traditional "coffee discussions" were being used as a vehicle for conversations about GBV and the available services in the refugee community. Women with disabilities and their caregivers volunteered to host coffee discussions in their homes, inviting other women who lived near them to join the activity. Thus, women with disabilities who were isolated in their homes had the opportunity to learn more about GBV and to strengthen protective peer networks within their neighbourhoods.*

*"We have hosted coffee discussions in our home, right here. This has brought people closer to us. When they come to the home, we discuss many things—things that are really important—but they also have a chance to see that we are good parents even though we are a bit different. Now, people understand us better, they even come to say hello and see how we are. It makes me feel safer having neighbours that I know now."*

— Seida Ibrahim  
(refugee woman with disabilities)<sup>113</sup>

3. Make services available to women and young persons with disabilities living in remote and rural areas.<sup>114</sup>
  - Base services in the community wherever possible and ensure services are accessible.
  - Conduct mobile outreach services for isolated areas where women and young persons with disabilities reside, including in institutions and in their homes. Mobile outreach services consist of a mobile team of trained service providers and support staff offering services in traditionally underserved areas.<sup>115</sup> Outreach providers and staff can provide information and various forms of contraceptives, along with referrals and follow-ups.<sup>116</sup>
  - Allow village service providers and support staff to make appointments for women and young persons with disabilities.
  - Where transportation is unavailable, develop creative strategies to assist women and young persons with disabilities to access services, for example through technology or trained community members.

- Where resources allow, offer free or subsidized transportation to women and young persons with disabilities to access services and allowances for personal care attendants. Advocate for government subsidies.
4. Invest in economic empowerment programmes for women and young persons with disabilities.<sup>117</sup> Help women and young persons with disabilities access vocational programmes and other necessary livelihood training programmes. Where available, provide support and access to income-generating opportunities such as seed funding for business start-ups.<sup>118</sup>

### Guidelines for Action:

#### ► **Effective Identification of Needs and Referrals**

1. Develop effective and supportive inter-agency partnerships focused on improving the capacity and integration of services to avoid the dilution of funding and resources. Streamline inter-agency coordination and effective referrals between diverse sectors and agencies. Inter-agency coordination can take many forms, including referral pathways, engagement with local disabled people organizations, quality standard operating procedures, case coordinator programmes.
  - Endeavour to coordinate with women- and young persons-led disabled people organizations and agencies and organizations that prioritize and reflect gender equality. In humanitarian emergencies, develop relationships with local grassroots disabled people organizations and

advocacy groups to create effective referral networks to engage migrants, refugees, and displaced persons with disabilities in local self-advocacy communities. These networks can also help to advocate to the host country government to improve integration.

- Establish clear protocols and agreements about referral processes with relevant social, health, and justice sectors.
  - When developing referral networks, identify well-defined responsibilities for each agency and organization in the network.
  - Ensure that inter-agency coordination procedures are consistent, known by all service providers and support staff, and communicated clearly to women and young persons with disabilities.
  - Develop safeguards to hold service providers and support staff accountable for providing necessary referrals, where available and appropriate. For example, a checklist of required identification questions or supervisory oversight.
  - Create referral systems that require informed consent to be received before a referral can be made and include safeguards for a person's privacy and confidentiality in making the referral.
  - Utilize case coordinators trained to address the needs of women and young persons with disabilities to ensure a continuum of care across networks.
2. Develop relationships with community-based rehabilitation service providers. Community-based rehabilitation service providers can be effective resources for sharing knowledge and resources, as well as linking women and young persons with disabilities to services.

Community-based rehabilitation service providers generally have a good understanding of the accessibility needs of persons with disabilities in their communities and, in many cases, have built relationships with women and young persons with disabilities in the community, which GBV and SRHR service providers can build upon.

► **EXAMPLE:**

*In Ethiopia, Community Based Rehabilitation Network Ethiopia and Light for the World partnered together on a local pilot project to tailor trainings and activities about SRHR and rights to the needs of young persons with intellectual disabilities and their families.<sup>119</sup> Key lessons learned from the project included dismantle taboos regarding sexuality and persons with disabilities; resolve the service gap through training field workers; provide practical how-to techniques; involve family members; and provide trainings to both boys and girls.<sup>120</sup>*

3. Take measures to identify service recipients with disabilities who have or are experiencing GBV or SRHR violations. Service provision, particularly in sexual and reproductive health services, present a valuable point of contact for identifying victims/survivors of violence, assessing risks, and developing a plan to manage and mitigate risks.<sup>121</sup>
  - Providers and staff must be trained on how to provide first-line support.<sup>122</sup> It is essential that routine GBV or SRHR violation screenings only be conducted when service providers and support staff have robust training and effective referral networks in place or else providers and staff risk causing additional trauma to a victim/survivor.

Appropriate and effective referrals must be in place to connect the victim/survivor with the services they need immediately.

- Develop specific identification guidelines for providers and staff to use when identifying someone facing a safety risk, including for situations where the survivor is dependent on the perpetrator.<sup>123</sup> Providers and staff must also be trained in safety planning and mitigating any risk to the woman or young person that an identification may create.<sup>124</sup>
- Establish consistent and coordinated identification procedures and inter-agency coordination.
- Promote the establishment of spaces where women and young persons with disabilities can feel safe and supported.
- Respect the confidentiality and privacy rights of women and young persons with disabilities.

### Guidelines for Action:

► **Accessible Services/Accommodations**

1. Offer reasonable accommodations whenever needed. An accommodation, often referred to as a “reasonable accommodation” conveys “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”.<sup>125</sup> Accommodations are fundamental to ensuring that persons with disabilities can access and use services on an equal basis as persons without disabilities. The form of accommodation a person requires or prefers should be directed by the person with the disability.

2. As much as economic resources allow, offer assistive technology (AT). Assistive devices and technology usage is a form of reasonable accommodation. The purpose of AT is to sustain or improve a person's functioning level and independence to enable that person to better engage in their life and improve their health and well-being generally.<sup>126</sup> For example, communication access real-time translation (CART) technology, is an important type of AT for literate Deaf people. To better understand AT and how to prioritize investment in products, refer to the World Health Organization's '*Priority Assistive Products List*'.<sup>127</sup>

3. Develop identification policies and procedures to identify a woman's or young person's reasonable accommodation needs:

- Create an accessible form or identification process to identify a person's audio, visual, sensory, physical, or comprehension needs. Ensure that there are streamlined and swift procedures to accommodate a person's needs once identified.
- Conduct this identification in advance of the person's first visit to avoid the person making a potentially difficult trip only to discover the accommodation they require is unavailable.
- Adapt appointment schedules. For example, women and young persons with disabilities may require the following accommodations:
  - Longer appointment periods.<sup>128</sup>
  - After-hours appointments.<sup>129</sup>
  - Special timing of appointments.<sup>130</sup>
  - Combined appointments.

- Track service provider training levels and capabilities to ensure that providers with the requisite skills are available or assigned to the service recipient who requires that skill. For example, if a person requires sign language to communicate they should be scheduled with the provider who knows sign language.

### Guidelines for Action:

#### ► **Acceptable Services**

1. Design services to respect a service recipient's dignity and be responsive to the different ways in which individuals experience services on the basis of their age, disability, gender, socio-economic status, and cultural differences.

### What is dignity?

A person's dignity is fundamentally linked with their human rights and fundamental freedoms. The International Conference on Population and Development Programme of Action says dignity "includes far more than the meeting of basic needs; it includes the right to education; to full participation in social, economic and political life; to freedom of information; to be free from discrimination and violence; to security of residence as well as freedom of human mobility; it requires that individuals be provided access to opportunities to build and renew their capabilities across the life course. Dignity includes the foundational human right to sexual and reproductive health and the freedoms to choose whom to love, whether and when to have children, and the guarantee that sex and reproduction are a source of human happiness and can be engaged in without fear of illness or a risk to health. These entitlements and freedoms are a precondition for a thriving, inclusive society, composed of resilient individuals who can innovate and adapt, and ensure a shared and vibrant future for all persons".<sup>131</sup>

► **EXAMPLE:**

How service providers and support staff can design services to respect a service recipient's dignity:

- Structure service provision to recognize the women or young person with a disability as the expert on their adaptation needs and to empower them to direct their treatment and ask for assistance when necessary.
  - Train all providers and staff to respect the will and preference of women and young persons with disabilities. Ensure that mechanisms are in place for women and young persons with disabilities to be able to safely report disrespectful services (i.e., without fear of retaliation, victimisation, or harm).
  - Service providers and support staff must speak directly to the woman or young person with a disability and not to the person's accompanying family member or caregiver.
  - When a person with a physical disability requires a physical exam, providers and staff must allow the person with the disability to direct the transfer to the examination bed and their body's positioning during the exam.
  - If a pelvic exam needs to be conducted by the service provider, an assistant always should be present in the exam room during the exam.
2. Prioritize safety, particularly for women and young persons receiving GBV services. For example, do not make the address of a shelter publicly available or send follow-up letters or calls to a person's home address or phone unless given informed consent to do so.
  3. Allocate sufficient economic and human resources for all programmes to ensure

services are available, accessible, acceptable, and of good quality for women and young persons with all forms of disability. This includes funding for ancillary costs such as transportation, accessible materials distributed in advance, and interpreters.<sup>132</sup>

### Guidelines for Action:

#### ► **Quality Services**

1. Guarantee that services offered to women and young persons with disabilities are of good quality and equal to those offered to persons without disabilities. Ensure that services are:
  - evidence-based;<sup>133</sup>
  - scientifically approved and appropriate;<sup>134</sup>
  - medically appropriate;<sup>135</sup>
  - culturally appropriate;<sup>136</sup>
  - consistent with human rights;<sup>137</sup>
  - comprehensive;<sup>138</sup>
  - and include a full range of modern service options paired with accurate information about those options and the individual's rights relating to those options.<sup>139</sup>
2. Make sure that services, information and goods offered are consistent with modern medical ethics and sensitive to an individual's disability, culture, gender, and age.<sup>140</sup>

### Guidelines for Action:

#### ► **Rights-Based Services**

1. Implement programme and policy safeguards to ensure that all services are only provided on a voluntary basis with the free and informed consent of the woman or young person with a disability, including for disclosure of information.

- Establish a code of ethics, for acquiring informed consent and exchange of information.
  - Offer reasonable accommodations and supported decision-making for women and young persons with disabilities who require such assistance. This should be done rather than relying on guardians for substituted decision-making. Deliver supported decision-making services in a way that protects the woman or young person's privacy.
  - Allow extra time for appointments, where required. The process of obtaining informed consent may at times be difficult and time-consuming, particularly where a person's disability requires alternative forms of communication or information to be relayed repeatedly, but such difficulties do not absolve service providers and support staff from meeting these criteria.
  - Establish procedures and policies that reflect and respect the underlying principles and rights associated with legal capacity, even in situations where the service recipient has been deprived of the right to legal capacity (such as in guardianship systems).
  - For more information on acquiring informed consent, see Equal Recognition Before the Law (Section 1.2).
2. Train and support service providers and support staff at all levels (from programme directors to secretarial staff) to fully understand the legal rights of women and young persons with disabilities in their community, with emphasis on how legal capacity relates to informed consent, privacy, confidentiality, and guardianship.
- Training must include how a determination that a person cannot provide informed consent is to be reached after all available reasonable accommodations and supported decision-making tools have been utilized without success. Explore resources that assist service providers and support staff to better understand the informed consent process for adults with disabilities:
    - The Surrey Place Centre and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities have developed and made available key resources for service providers on how to provide quality healthcare for adults with intellectual and developmental disabilities. The web portal includes information to help service providers understand informed consent and a downloadable informed consent checklist.<sup>141</sup>
    - The Women's Refugee Commission and International Rescue Committee developed guidance for GBV service providers on the informed consent process for adult victims/survivors with disabilities, which includes useful guidance for practitioners, including a flow chart to help providers work through obtaining informed consent. The tool was developed for humanitarian contexts but is useful in all contexts.<sup>142</sup>
3. Create safeguards to maintain and guarantee service recipient's confidentiality.
- At the reception area, ensure that service recipients have an option to state the reason for their visit privately.

- If a person arrives with a companion, ask the person with the disability in a private setting whether they wish to waive their confidentiality by having their companion join them while they receive services (even if the person is less than 18 years old). Do not rely on companions to interpret for service recipients with disabilities. Ensure that this process is completed with sensitivity and is directed by the person with the disability. Being separated from a companion may cause the person anxiety.
- Ensure the ability of the service provider and/or support staff to understand and speak the language of the service recipient (e.g., sign language) to further safeguard the recipient's confidentiality.
- Implement procedural safeguards to maintain information privacy.
- Offer private consultative spaces. In low-resource settings where no private room exists, consider designating a part of the facility or an outdoor patio as a private area or placing a stick or barrier in a location that separates the reception area from the service area.
- Obtain releases to share a person's private information, including for referrals to other services.
- Adapt existing data collection mechanisms, if available and appropriate.
- Develop mapping tools to better engage persons with disabilities by understanding their needs, age, disabilities, risks, and other important data points.
- Disaggregate data by a range of relevant factors, including types of disability, sex and gender, age, socio-economic status and other intersecting factors affecting accessing and use of services.<sup>143</sup>
- Ensure that each programmatic target relating to women and young persons with disabilities has correlating data collection to measure success in meeting each target.
- Obtain consent for collecting data and maintain confidentiality and privacy, especially for medical information and for people under guardianship.
- Establish a secure system for data collection, recording, and storage.
- Implement a coordinated mechanism for regular data review and analysis.

### Guidelines for Action:

#### ► **Data Collection and Monitoring**

1. Collect disaggregated data on a broad range of barriers and experiences affecting service provision for women and young persons with disabilities. Consistent and precise collection of data about the services provided to women and young persons with disabilities is critical in supporting continuous improvement and access of services.
2. Implement an effective and accessible complaints mechanism to collect ongoing feedback about the programme and facility.<sup>144</sup> Ensure that service recipients can safely report complaints in a variety of formats (e.g. writing, verbally, anonymously).
3. Develop effective monitoring mechanisms, including mechanisms that can hold service providers and support staff to account.
  - Create indicators that track women and young persons's engagement with GBV and SRHR services.

- Establish specific and manageable benchmarks to monitor and evaluate progress in service delivery.
- Ensure that monitoring and accountability mechanisms are independent and accessible to women and young persons with disabilities.
- Systemically monitor the situation of persons with disabilities in humanitarian emergencies as well.<sup>145</sup> Ensure that women and young persons with disabilities are included in standard needs assessments conducted post emergency, such as the post-disaster needs assessment.

## 2.4 Facilities

Ensuring that services are user-friendly for women and young persons with all forms of disabilities is fundamental to guaranteeing that a GBV or SRHR service is disability-inclusive both in theory and in practice. Physical, social, economic, and cultural accessibility are crucial components of meeting this need,<sup>146</sup> and the following actions are critical to ensuring that services are accessible to women and young persons with disabilities:

### Guidelines for Action:

#### ► **Identifying Barriers**

1. Conduct an accessibility audit with women and young persons with different types of disabilities to identify the physical, sensory, information, and communication barriers and adaptations needed.<sup>147</sup> Solicit input from persons with disabilities prior to new construction or renovations.<sup>148</sup>

#### ► **EXAMPLE:**

*In the United States of America, the Safety First Initiative developed an **Accessibility and Responsiveness Review Tool** to provide GBV service providers and support staff with a framework to think about how to make their services inclusive, trauma-informed, and responsive, along with a **Scoring Tool** to assess current and ongoing services.<sup>149</sup>*

#### ► **EXAMPLE:**

*The International Organization for Standardization's '**ISO 21542:2011 Building Construction—Accessibility and usability of the built environment**' standards are a useful tool for assessing the accessibility of a service provider location. This publication contains standard requirements and recommendations for constructing accessible buildings and can be used where there are no national or local standards for physical accessibility. There is a fee to access the document.<sup>150</sup>*

2. Identify and eliminate obstacles and barriers to services that women and young persons face.<sup>151</sup> The preferred form of access should be directed and chosen by the woman or young person with the disability.
3. Use and understand new technologies that can increase accessibility, for example digital communication boards.

### Guidelines for Action:

#### ► **Physical Accessibility**

1. Ensure that services are physically accessible. This means that all components essential to the delivery of services, including buildings,

classrooms, courtrooms, health service facilities and medical equipment, can be used regardless of the form of a person's disability or assistive equipment. Ensure that a location is physically accessible through the following steps:

- Utilize universal designs as much as possible. Universal design means “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 specialized design, and this should include bathroom facilities, shelters and other facilities”.<sup>152</sup>
- Identify and remedy structural and architectural barriers both inside and outside of the service provider facility. Examples of important considerations include:<sup>153</sup>
  - Are there barriers to entering the facility or to accessing different floors of the facility, such as uneven pathways, narrow entrances, or stairs?
  - Are the doors wide enough? Light enough to push? Do they use a lever door handle and not a knob? Are they automated?
  - Are counters low enough to accommodate someone in a wheelchair?
  - Are there wheelchair-accessible bathrooms available and in working condition?
  - Is there sufficient room in examination or labour and delivery rooms for a wheelchair to turn around?
- Ensure the accessibility of facility furniture and equipment, such as hospital beds and exam tables.

► **EXAMPLE:**

*The Adaptive Design Association is a useful resource for low-cost adaptive designs. The*

*organization's mission is to “ensure that persons with disabilities receive the custom adaptations they need to live healthy lives and fulfil their developmental, academic, and vocational potential, and to promote education, inclusion, widespread replication, and social justice”.<sup>154</sup> One of the ways they do this is through a free online video library which has numerous instructional videos on how adaptive designs can be created out of low-cost materials, such as cardboard.<sup>155</sup>*

- Design facilities to support a range of accessibility needs, including, e.g. allowing service animals to accompany service recipients; appropriate medicine storage; charging stations for electronic assistive devices; sufficient space in bedrooms, hallways, and bathrooms; handrails; and stable, height-adjustable beds and examination and delivery tables).
2. Ensure, as much as possible, that services can be easily reached. Offer services in the community, through home visits, or near to reliable and accessible public transport or subsidized private transport.<sup>156</sup>
  3. Enhance telephone, email, and other remote access to services, as appropriate, to facilitate access to remote services for people who cannot reach facilities for in-person attention.
    - Ensure that alternative phone formats are available (e.g. teletypewriter (TTY), video).
    - Allow renewal of prescriptions over the telephone.<sup>157</sup>
    - Offer information and services through email and online chats.

## HUMANITARIAN EMERGENCIES

### Physical Accessibility

During humanitarian emergencies, women and young persons with disabilities have the same physical needs as they do during non-emergency periods. However, humanitarian emergencies can create new and unique considerations for physical accessibility:

- Ensure that humanitarian infrastructures are developed taking the increased vulnerability of women and young persons with disabilities during humanitarian emergencies into account. A person's disability can increase a person's vulnerability to sexual and GBV when navigating an emergency services environment. For example, locations to receive supplies of food and water may be far from a woman's shelter, or bathrooms in refugee camps may be located far away from a person's home. These increase a person's vulnerability to sexual assault, especially at night, and if a person's disability impairs the speed at which they can move, this can further increase their vulnerability. Design services and service facilities to effectively prevent sexual and gender-based violence. Techniques for doing so include locks on bathroom doors and engaging women and young persons with disabilities in camp leadership to offer input on services design.<sup>158</sup>
- Offer mobile services that can reach isolated women and young persons with disabilities who are unable to travel to access services. Particularly during emergencies, persons with all forms of disability face greater barriers to travelling to services because transportation services are unavailable, caregivers have competing obligations or are no longer present, or the physical environment is no longer navigable due to environmental damage. For example, mobile courts can facilitate access to justice for displaced persons,<sup>159</sup> while mobile health clinics and/or outreach services can provide needed health services.<sup>160</sup>
- Utilize universal design when developing displaced person camp layouts and services. Resources such as the International Federation of Red Cross and Red Crescent Societies' *'All Under One Roof: Disability-inclusive shelter and settlements in emergencies'*, offer important guidance for how service providers and support staff can address barriers which prevent persons with disabilities from accessing services during emergencies.<sup>161</sup>

### Guidelines for Action:

#### ► **Sensory Accessibility**

1. Ensure accessibility for people with sensory disabilities. Sensory disabilities affect a person's sight, hearing, smell, touch, taste, communication, or spatial awareness. A woman or a young person may have one or more of these disabilities and at various levels. What accommodation and the extent of the accommodation a person requires depends on the person. To ensure that a facility is accessible to a person with a sensory disability, the following are some examples of recommended actions:
  - Make the environment scent-free, as much as possible.<sup>162</sup>
  - Use non-fluorescent lighting.<sup>163</sup>
  - Offer a variety of seating options (e.g. padded, arm rests).<sup>164</sup>
  - Have fidget and stress relief toys available (e.g. stress balls, games, stuffed animals, fidget spinners).<sup>165</sup>
  - Reduce noise in the environment, particularly loud acoustics or excessive background noise.<sup>166</sup>
  - Offer a decompression and relaxation room for people requiring a sensory break.<sup>167</sup>
  - Have food and water available.
  - Reduce long wait times.<sup>168</sup>
  - Offer breaks during long exams or appointments.

### Guidelines for Action:

#### ► **Information and Communication Accessibility**

1. Ensure information and communication accessibility. This means that a person with a disability must be able to seek, receive, and

impart information in a manner suited to their communication needs.

- Guarantee that information and communication is available in the following accessible formats, where needed:
  - Braille;
  - Large print;
  - Audio;
  - Digital formats, compatible with screen readers;
  - Sign language with an interpreter of a preferred gender (e.g. International sign language, American sign language);
  - Captioning;
  - Simplified formats (e.g. plain language, easy read);
  - Pictorial guides;
  - Local language interpretation.
- Offer a menu of hardware options or devices that users may have access to during their visit. The devices available will affect the provision of different accessible formats. Devices may include, for example, simple mobile phones, smartphones, tablets, computers, DAISY players, or Victor Readers.
- Make available in accessible formats information about:
  - Fundamental rights;
  - Available services;
  - Instructions for services;
  - Confidentiality and privacy rights;
  - Informed consent;
  - Complaint and feedback procedures;
  - Accountability mechanisms and processes;
  - Public information and awareness campaigns.

- Distribute digital information materials ahead of appointments or information sessions.
- Hire an onsite dedicated support person to assist persons with disabilities when they come to their appointments from entry and up until the time they leave.
- Never use a family member or caregiver as a translator for a person with a disability, unless clear free and informed consent is given by the person with the disability in private in advance.
- Establish appropriate safeguards to address circumstances where consent and confidentiality are at risk for women and young persons with disabilities, such as during translation or sign language interpretation.

## Accessible Information, Education and Communication

Persons with disabilities have a right to access all information relating to GBV and SRHR programmes on an equal basis with others. GBV and SRHR messages should be communicated in multiple formats and incorporate different dissemination methods. The Women's Refugee Commission and International Rescue Committee's *'Tool on Accessible Information, Education and Communication Materials'* suggests using the following simple questions to identify appropriate adaptations or targeted approaches to ensure your information reaches people with different types of disabilities. This guidance was developed for the humanitarian emergency context but is applicable in all contexts.

1. Who will be able to understand this information in its current form?
2. Who won't be able to understand this information in its current form?
3. How does the information reflect the needs of different people in the community?  
Will persons with disabilities and their caregivers see themselves and their experiences reflected in the images?
4. What do persons with disabilities think about the information, education and communication materials? Do they have any advice or feedback? While it is helpful to have their advice and guidance before you start, it is also important to take the finished materials back to persons with disabilities and their caregivers and ask them to review, critique and comment, then make adjustments accordingly.

For more information, including guidance on dissemination plans, please see:  
***Tool 7: Accessible information, education and communication (IEC) materials.***<sup>169</sup>

### Guidelines for Action:

#### ► **Economic Accessibility**

1. Ensure that services are economically accessible. This means that information, goods, and services must be affordable.
    - Schedule after-hours appointments to prevent people having to miss work to receive services.<sup>170</sup>
    - Assist women and young persons with disabilities with accessing income assistance and other social protection programmes.<sup>171</sup>
    - Where possible, offer free, subsidized, or sliding-scale fees for services and medicines or equipment. If a person receives a reduced fee, ensure that this information remains private.<sup>172</sup>
    - Do not assume people have access to transportation, internet, a computer, etc.<sup>173</sup>
- During **humanitarian emergencies**, the need for economic accessibility becomes even more acute for everyone, but especially for women and young persons with disabilities. Women and young persons are often cut off from public assistance or caregivers upon which they are economically reliant, increasing their vulnerability. With the substantial economic demands on governments and service providers during and after an emergency, funding for accommodations for services, interpreters, and other accommodations for women and young persons with disabilities can be scarce and not prioritized. Policymakers as well as local and national politicians must ensure that sufficient funding is allotted in national emergency plans to disability-related services and accessibility and that funding is prioritized and utilized effectively throughout an emergency or in extremely low-resource settings.



Young persons learn by computer at a school in Vadodara, India.

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## STARTING POINT

# Guidelines for Service Providers and Support Staff working with Women and Young Persons with Various Disabilities

## Women and Young Persons with Physical Disabilities:

- Do not assume because of the person's physical disability that the service recipient also has an intellectual disability.<sup>174</sup>
- Sit at eye level with service recipient when possible.<sup>175</sup>
- Do not move any crutches, sticks, walkers, or wheelchairs without the person's permission or without arranging for their return.<sup>176</sup>
- Do not lean on or touch a wheelchair without permission from the person who uses the wheelchair.<sup>177</sup>
- Take directions from the person with the disability on how to conduct a transfer to an examination bed or machine.<sup>178</sup>

## Women and Young Persons with Sensory Disabilities:

For a woman or young person who is Deaf or hard of hearing:<sup>179</sup>

- Make sure you have the person's attention before speaking.<sup>180</sup>
- If the service recipient is not facing you, touch the person gently on the shoulder.<sup>181</sup>
- Do not shout or exaggerate your speech.<sup>182</sup>
- Look directly at the service recipient, and do not cover your mouth.<sup>183</sup>
- Ascertain and document as soon as

possible the person's preferred method of communication.<sup>184</sup>

- Use slow and clear speech to aid lip-reading for those who require it.<sup>185</sup>
- Have an on-call or pre-arranged CART translator or sign language interpreter.<sup>186</sup>

## For a woman or young person who is blind or has difficulty seeing:<sup>187</sup>

- Do not touch the person before announcing yourself.
- Do not assume the service recipient cannot see you at all.<sup>188</sup>
- Speak in your normal voice.<sup>189</sup>
- Allow the person's service animal to accompany them at all times.
- Do not take away a cane or other mobility tool from the service recipient at any time.<sup>190</sup>
- Say goodbye before walking away or leaving.<sup>191</sup>
- Have large print, audio, or Braille-formatted information for those who require it.<sup>192</sup>
- Provide information in digital formats in advance for a person to read with a screen-reader before their appointment.
- Use visual and technical aids for those who require them.<sup>193</sup>

### **For a person who does not speak clearly:<sup>194</sup>**

- Do not assume because a service recipient's speech is slow or difficult to understand that the person has any difficulties learning or understanding.<sup>195</sup>
- Ask the person to repeat anything you do not understand.<sup>196</sup>
- Ask questions the person can answer by "yes" or "no".<sup>197</sup>
- Let the person take as much time as needed to explain their problem.<sup>198</sup>
- Be patient.<sup>199</sup>

### **Women and Young Persons with Intellectual Disabilities:**

- Use simple words and short sentences.<sup>200</sup>
- Repeat instructions and important information in various ways, utilizing different learning tools to help the service recipient understand (e.g. anatomically correct models or dolls, role-play scenarios).
- Offer the person simple instructions and information guides to take home with them for reference (e.g. plain language, easy read, pictorial guides, video instructions).
- Be patient.<sup>201</sup>
- Do not treat the person like a child.<sup>202</sup>
- Provide the service recipient with a phone number or way to contact the provider again with follow-up questions.

### **Women and Young Persons with Psychosocial Disabilities:**

- Emphasize and take steps to foster and develop trust between yourself and the service recipient.<sup>203</sup>
- Offer training for all providers, staff, and family members to increase acceptance, change attitudes, and foster trust.<sup>204</sup>
- Improve communication between GBV and SRHR service providers and mental healthcare service providers.<sup>205</sup>
- Offer support groups.<sup>206</sup>
- Ensure that you and all support staff always treat service recipients with respect and acknowledge their strengths.<sup>207</sup>
- Offer information and referrals about supported decision-making mechanisms and a healthcare proxy, if available. A person designates a healthcare proxy to make healthcare decisions for them when they are unable to make decisions for themselves; it is a mechanism to ensure that a person's wishes are followed.







# Gender-Based Violence Services for Women and Young Persons with Disabilities

## 3.1 Background

Gender-based violence (GBV) takes several forms—physical, emotional, psychological, sexual, economic. GBV is an umbrella term referring to acts of violence “perpetrated against a person’s will and that is based on socially ascribed (i.e. gender) differences between males and females. The term ‘gender-based violence’ is primarily used to underscore the fact that structural, gender-based power differentials between males and females around the world place females at risk for multiple forms of violence. As agreed in the Declaration on the Elimination of Violence against Women (1993), this includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of

liberty, whether occurring in public or in private life. The term is also used by some actors to describe some forms of sexual violence against males and/or targeted violence against LGBTI populations, in these cases when referencing violence related to gender-inequitable norms of masculinity and/or norms of gender identity”.<sup>208</sup> Indeed, despite commonly held perceptions to the contrary, men and boys can also be victims/survivors of GBV.<sup>209</sup>

Women and young persons with disabilities experience the same forms of GBV as individuals without disabilities. Women and young persons with disabilities also experience unique forms of GBV as a result of their disability, such as sexual abuse by a

caregiver; withholding of medication or an assistive device; purposefully substandard care; denial of necessities like food, toileting, or grooming; control of sensory devices; financial control; restriction of communication devices; 'virgin rape'; early or forced marriage; forced or coerced medical procedures, such as forced sterilization, contraception, or abortion; and enforced isolation.<sup>210</sup> Service providers and support staff must commit to understanding the unique ways that women and young persons with different disabilities experience GBV. This understanding is a critical first step to being able to adapt and develop programmes that effectively serve women and young persons with disabilities.

### **Increased Risk**

Studies show that three per cent of persons with disabilities report having experienced violence within the past year, this percentage increases substantially for persons with mental disabilities.<sup>211</sup> Persons with disabilities are three times more likely to experience physical violence, sexual violence, and emotional violence than persons without disabilities.<sup>212</sup> Women with disabilities in particular are up to 10 times more likely to experience sexual violence.<sup>213</sup> Boys and men with disabilities are twice as likely as boys and men without disabilities to be sexually abused in their lifetime.<sup>214</sup> In fact, estimates suggest that 40 per cent to 68 per cent of young women with disabilities will experience sexual violence before the age of 18,<sup>215</sup> while 16 per cent to 30 per cent of young men with disabilities will experience sexual violence before the age of 18.<sup>216</sup> Similarly, UNICEF has found that children with disabilities are 1.7 times more at risk of violence than their peers without disabilities.<sup>217</sup>

Where a disability affects the individual's ability to communicate, the risk of violence may be even higher, as abusers can take advantage of the person's inability to disclose the abuse.<sup>218</sup> Children with intellectual disabilities, for example, are almost five times more likely to be subjected to sexual violence than non-disabled children.<sup>219</sup> Reasons for these higher rates of violence include stigma, discrimination, negative traditional beliefs, lack of support (including respite care) for caregivers, lack of knowledge about disability, increased vulnerability due to care needs, dependence, and impunity.<sup>220</sup>

Women with disabilities are also more likely to experience poverty and isolation than men with disabilities or persons without disabilities, even in countries with a higher standard of living.<sup>221</sup> This can increase their vulnerability to economic violence and exacerbate financial barriers to leaving violent situations and accessing services.

GBV-related risks increase during humanitarian emergencies,<sup>222</sup> especially for women and young persons with disabilities,<sup>223</sup> due to changes to gender roles, family stress, misperceptions about the capacity of persons with disabilities, loss of community support networks and protection mechanisms, increased social isolation, poverty and lack of income, and environmental barriers.<sup>224</sup>

### **Service Provision**

Despite the prevalence of GBV experienced by women and young persons with disabilities, GBV laws and policies seldom reflect the unique forms of violence experienced by women and young persons with disabilities within the legal definition of GBV. For example,

violence committed by caregivers or against adolescent boys and young men with disabilities. As a result, eligibility criteria for GBV services may exclude women and young persons with disabilities, perpetrators of these types of violence may not be held accountable, and prevention services targeting persons with disabilities may be underfunded.

The guidelines in this section are organized according to the distinct but inter-connected stages of intervention and services required

by a woman or young person with a disability who is at risk of or is experiencing GBV. Services must meet the immediate emotional and psychological health needs, immediate physical health needs, ongoing safety needs, and ongoing support and mental-health needs of GBV victims/survivors.<sup>225</sup> To ensure a continuum of care for women and young persons with disabilities across all GBV service areas, each of these service-area subsections should be read in conjunction with the other subsections.

### Victim/Survivor Terminology

The term victim/survivor is used to indicate a person who has experienced or is currently experiencing GBV. There has been debate about the use of the terms victim and survivor. The UN Secretary-General's *'In-Depth Study on Violence Against Women'* explains that for some, "the term 'victim' should be avoided because it implies passivity, weakness and inherent vulnerability and fails to recognize the reality of women's resilience and agency. For others, the term 'survivor' is problematic because it denies the sense of victimization experienced by women who have been the target of violent crime".<sup>226</sup> Out of respect for an individual's preferred terminology, both terms are used throughout these Guidelines.

## 3.2 GBV Human Rights Framework

It is well established that GBV is a form of gender-based discrimination that violates fundamental rights,<sup>227</sup> including:

- The right to be free from GBV, protected in the Convention on the Rights of Persons with Disabilities (CRPD),<sup>228</sup> Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),<sup>229</sup> and Convention on the Rights of the Child (CRC).<sup>230</sup>
- The right to physical and psychological recovery, rehabilitation, and social reintegration of victims of violence, abuse, or exploitation, protected in the CRPD<sup>231</sup> and the CRC.<sup>232</sup>
- The right to equality and non-discrimination, protected in the International Covenant on Civil and Political Rights (ICCPR),<sup>233</sup> the International Covenant on Economic, Social, and Cultural Rights (ICESCR),<sup>234</sup> CRPD,<sup>235</sup> and CEDAW.<sup>236</sup>
- The right to life, protected in the ICCPR,<sup>237</sup> CRPD,<sup>238</sup> and the CRC.<sup>239</sup>
- The right to be free from torture and other cruel, inhuman or degrading treatment or punishment, protected in the ICCPR,<sup>240</sup> the Convention against Torture and other Cruel, Inhuman, and Degrading Treatment or Punishment (CAT),<sup>241</sup> the CRPD,<sup>242</sup> and the CRC.<sup>243</sup>
- The right to liberty and security of the person, protected in the ICCPR<sup>244</sup> and the CRPD.<sup>245</sup>
- The right to consent to marriage and to equal rights within marriage, protected in the ICCPR,<sup>246</sup> the ICESCR,<sup>247</sup> CEDAW,<sup>248</sup> and the CRPD.<sup>249</sup>

- The right to be free from practices that harm women and young persons with disabilities, protected in CRPD,<sup>250</sup> CEDAW,<sup>251</sup> and CRC.<sup>252</sup>
- The right to equality before the law and access to justice, protected in the ICCPR<sup>253</sup> and CRPD.<sup>254</sup>
- The right to an adequate standard of living and social protection, protected in the ICESCR<sup>255</sup> and CRPD.<sup>256</sup>
- The right to protection and safety for persons with disabilities in situations of risk, including humanitarian emergencies, protected in the CRPD.<sup>257</sup>

States have specific obligations under international human rights law to prevent, protect against, investigate, punish, and redress GBV—obligations that are collectively referred to as a State’s due diligence obligations.<sup>258</sup> An essential component of this obligation is to establish comprehensive laws and policies to prevent and punish GBV.<sup>259</sup>

The Committee on the Elimination of Discrimination Against Women urges States to take a number of steps to address GBV, including:

- Criminalizing all forms of GBV in all spheres (public and private) and ensuring that laws addressing sexual assault encompass marital rape, acquaintance and date rape, and other scenarios where consent is not freely given.<sup>260</sup>
- Repealing “laws that prevent or deter women from reporting GBV, such as guardianship laws that deprive women of legal capacity or restrict the ability of women with disabilities to testify in court”.<sup>261</sup>

- Taking measures to prevent GBV, including, for example, by addressing the root causes of such violence (such as patriarchal stereotypes) and conducting awareness-raising campaigns.<sup>262</sup>
- Providing appropriate protection and support services to victims/survivors.<sup>263</sup>
- Taking all legal and other measures to provide effective protection against GBV, including legal, preventive, and protective measures.<sup>264</sup>

The Committee on the Rights of Persons with Disabilities has reiterated the obligation of

States to exercise due diligence with respect to the rights of women with disabilities to be free from exploitation, violence, and abuse, especially given their heightened risk of such violations.<sup>265</sup> The Committee on the Rights of the Child has explained that as part of the obligation to protect children from all forms of violence, States must “create more opportunities for scaling up institutional programmes on prevention and rehabilitation, and the social reintegration of adolescent victims”<sup>266</sup> and calls for participation of adolescents in the development of these programmes and strategies.<sup>267</sup>



A group of female police officers in Liberia work with members of the community. © UNFPA/Marcus Bleasdale/VII

## HUMANITARIAN EMERGENCIES

### Key Concept: GBV Standards

Ensure that minimum standards are followed for all services offered and provided to women and young persons with disabilities. International agencies have developed comprehensive gender equality<sup>268</sup> and minimum standards for GBV services during emergencies,<sup>269</sup> but these guidelines are not tailored for persons with disabilities. Service providers and support staff should work with women and young persons with disabilities to understand how to implement these standards with the adaptations and accommodations required by women and young persons with disabilities.

### Minimum Standards for Prevention and Response to Gender-Based Violence in Emergencies<sup>270</sup>

The following are minimum standards developed by UNFPA to address the heightened risk of GBV during emergency situations, such as natural disasters, or conflict situations, especially for women and girls:

1. Participation: Communities, including women and [young persons with disabilities], are engaged as active partners to end GBV and promote survivors' access to services.
2. National Systems: Actions to prevent, mitigate and respond to GBV in emergencies strengthen national systems and build local capacities.
3. Positive Gender & Social Norms: Emergency preparedness, prevention and response programming promotes positive social and gender norms to address GBV.
4. Collecting & Using Data: Quality, disaggregated, gender-sensitive data on the nature and scope of GBV and on the availability and accessibility of services informs programming, policy, and advocacy.
5. Healthcare: GBV survivors, including women [and young persons with disabilities] access quality, life-saving healthcare services, with an emphasis on clinical management of rape and [sexual violence].
6. Mental Health & Psychosocial Support: GBV survivors access quality mental health and psychosocial support focused on healing, empowerment, and recovery.
7. Safety & Security: Safety and security measures are in place to prevent and mitigate GBV and protect survivors.
8. Justice & Legal Aid: The legal and justice sectors protect survivors' rights and support their access to justice, consistent with international standards.
9. Dignity Kits: Culturally relevant dignity kits are distributed to affected populations to reduce vulnerability and connect women and [young persons with disabilities] to information and support services.
10. Socio-Economic Empowerment: Women and [young persons with disabilities] access livelihood support to mitigate the risk of GBV, and survivors access socio-economic support as part of a multisector response.
11. Referral Systems: Referral systems are established to connect women [and young persons with disabilities] to appropriate multisector GBV prevention and response services in a timely and safe manner.
12. Mainstreaming: GBV risk mitigation and survivor support are integrated across humanitarian sectors at every stage of the programme cycle.
13. Preparedness & Assessment: Potential GBV risks and vulnerable groups are identified

through quality gender- [and disability-] sensitive assessments, and risk-mitigation measures are put in place before the onset of an emergency.

14. Coordination: Coordination results in effective action to mitigate and prevent GBV and promote survivors' access to multisector services.
15. Advocacy & Communication: Coordinated advocacy and communication lead to increased funding and changes in policies and practices that mitigate the risk of GBV, promote resilience of women and [young persons with disabilities] and encourage a protective environment for all.
16. Monitoring & Evaluation: Objective information, collected ethically and safely, is used to improve the quality and accountability of GBV programmes.
17. Human Resources: Qualified, competent, skilled staff are rapidly recruited and deployed to design, coordinate and/or implement programmes to prevent and respond to GBV in emergencies, [and such recruitment efforts should include reaching out to applicants with disabilities].
18. Resource Mobilization: Dedicated financial resources are mobilized in a timely manner to prevent, mitigate and respond to GBV in emergencies.<sup>271</sup>

**Inter-Agency Standing Committee's 'Guidelines for Integrating Gender-Based Violence Interventions in Humanitarian Action': Protection.**<sup>272</sup>

The following is a sample of some of the Inter-Agency Standing Committee's (IASC) essential actions for GBV protection. Readers should refer to the Protection chapter of the IASC guidelines for further important details.

"Integrate GBV prevention and mitigation into protection-monitoring activities, and support the development of community-based production strategies.

- When conducting protection monitoring, consider the broad protection factors that may exacerbate the risks of GBV in the particular setting (e.g. displacement; closeness to armed forces or international borders; unsafe routes for firewood and water collection, to work, or to school; safety issues for those who remain in the home; distribution times and locations of food and non-food items; overcrowded camps, dwellings, shelters, apartments; family separation; placement of water and sanitation facilities; access to documentation; etc.).
- Wherever possible, include a GBV specialist or at least one protection staff member who has GBV expertise. This is especially important when undertaking any protection monitoring that specifically examines GBV issues or incidents. Ensure protection-monitoring processes adhere to guiding principles related to GBV.
- Support community-based strategies for monitoring high-risk areas. Combine a targeted, proactive presence around specific high-risk areas with a more widespread and mobile presence that gives protected people and potential violators a sense that someone is always around. Tactics might include:
  - Community watch programmes or security groups
  - Security patrols
  - Regular and frequent field visits by protection monitors to assess GBV-related concerns in communities (camps, villages, etc.), where security allows".<sup>273</sup>

### 3.3 GBV Prevention for Women and Young Persons with Disabilities

#### 3.3.1 Issue Overview

Preventing GBV before it happens is essential to combating GBV and is a core component of a State's due diligence obligation. GBV prevention requires both high-level policy and community-based interventions. GBV prevention programmes for women and young persons with disabilities include advocating for laws, policies, and awareness-raising campaigns aimed at preventing GBV against women and young persons with disabilities and dismantling harmful stereotypes and practices that contribute to such violence; educational programmes about the right to be free from GBV, how to recognize such violence, and how to report it; and identification of GBV victims/survivors.<sup>274</sup> Other measures include initiatives to strengthen economic independence, supported decision-making regimes, and other forms of autonomy for women and young persons with disabilities, as well as initiatives to support, educate, and provide respite care for their families and other caregivers. Effective prevention campaigns also address the root causes of GBV against women and young persons with disabilities, including gender inequality, discrimination on the basis of both gender and disability, and lack of adequate and disability- and gender- sensitive social protection and social support services for persons with disabilities and their families.

#### 3.3.2 Guidelines on Rights-Based GBV Prevention

The key considerations enumerated here identify common issues and barriers to preventing GBV violence against women and young persons with disabilities. The subsequent guidelines for action offer guidance for ensuring that GBV prevention programmes are available, accessible, acceptable and of good quality for women and young persons with disabilities. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

#### *Key Considerations*

- Due to prejudice, lack of knowledge about the nature of the violence experienced by persons with disabilities, and an absence of promising practices, awareness-raising campaigns around GBV seldom address violence against women and young persons with disabilities. Moreover, GBV campaigns are rarely designed and delivered in an accessible manner to reach women and young persons with disabilities.
- Women and young persons with disabilities are often excluded from educational programmes that address healthy relationships, GBV, and other fundamental aspects of prevention, denying them the opportunity to learn how to develop healthy relationships, understand what constitutes appropriate touch, and how to avoid, recognize, and report instances of exploitation, violence, and abuse. This exclusion places women and young persons with disabilities at greater risk of violence and enables perpetrators to target persons with disabilities with impunity.

- Lack of accessible prevention initiatives can keep women and young persons with disabilities from being screened for, recognizing, or reporting GBV. GBV prevention programmes for persons with disabilities are underfunded, limiting the efficacy of and access to critical programmes for women and young persons with disabilities who are at risk of GBV.
- Poverty and economic dependence can exacerbate the risk of violence for women and young persons with disabilities.
- Male survivors of sexual violence are less likely than women and girls to disclose assaults, with the result that such violence is “vastly under-represented” in official statistics.<sup>275</sup>

### Guidelines for Action:

#### ► **Availability**

1. Create effective GBV trainings about the rights of women and young persons with disabilities and how to report violence and abuse. These trainings and associated educational materials should be tailored for women and young persons with disabilities.<sup>276</sup>

#### ► **EXAMPLE:**

*Human Rights Watch produced an easy read guide to assist persons with intellectual and learning disabilities better understand what to do if they experience GBV. The guide is titled ‘What to Do if Someone Hurts You or Does Bad Things to You: Information about Gender-Based Violence for People with Disabilities’.*<sup>277</sup>

2. Produce SRHR programmes to help women and young persons with disabilities develop life skills and understand their SRHR. The right to health extends beyond healthcare to the underlying determinants of SRHR, which include effective protection from GBV.<sup>278</sup> For more information, see Comprehensive Sexuality Education for Women and Young Persons with Disabilities (Section 4.5).

#### ► **EXAMPLE:**

*The DisAbled Women’s Network (DAWN) and Canadian Association of Community Living (CACL) created a workshop series for persons with disabilities and their families titled ‘Our Right to be Safe! Building Safe Communities for People with Disabilities and Deaf People’.* The workshop series offers practical guidance through interactive workshops on violence prevention and services for persons with disabilities. The workshop for persons with disabilities covers forms of abuse and assists participants with developing a safety plan and identifying their accessibility needs. The workshop for service providers is about the nature, impact, and barriers to seeking assistance that persons with disabilities face to assist with dismantling these barriers.<sup>279</sup>

3. Develop programmes to reduce the isolation of women and young persons with disabilities, to connect them with services, and to make persons with disabilities more visible in their communities.<sup>280</sup>

► **EXAMPLES:**

*Some good practices include disability-sensitive GBV identification procedures; accessible women-, child-, adolescent-, and youth-friendly hotlines; text emergency services; a global hotline; inclusive education programmes; accessible housing programmes; a legal framework that allows children to access services without parental consent; and free or subsidized transportation.*

4. Create programmes to promote safe, stable and nurturing relationships between persons with disabilities and their family, romantic partners, community members, and caregivers.

► **EXAMPLE:**

*The Cambodian 'Challenging Discrimination Against Women with Disabilities: A Community Toolkit' offers a good example of a resource that service providers and support staff can use to promote inclusion and support of women with disabilities in their communities relating to GBV.<sup>281</sup>*

### Guidelines for Action:

► **Accessibility**

1. Ensure that prevention programmes target isolated settings to provide information about GBV rights and how to report violence to the most vulnerable women and young persons with disabilities (e.g. people in institutions and isolated group homes, indigenous women and young

persons, rural women and young persons, LGBTI individuals, and refugees and internally displaced persons).

2. Develop volunteer-led, community-based education and training programmes on preventing, recognizing, and responding to GBV as a low-cost alternative to more formalized education programmes.

### Guidelines for Action:

► **Acceptability**

1. Invest in educating and training service providers and support staff who encounter women and young persons with disabilities, especially healthcare workers, school officials, and social workers. Offer detailed guidance on how to detect and report violence against women and young persons with disabilities,<sup>282</sup> including sexual violence directed at males, as well as training on the rights of and risks for women and young persons with disabilities.<sup>283</sup>
2. Develop accessible public information campaigns that address the rights of children,<sup>284</sup> women,<sup>285</sup> and persons with disabilities,<sup>286</sup> as well as the vulnerability of women and young persons with disabilities to GBV,<sup>287</sup> women's role in society,<sup>288</sup> and information about available services.<sup>289</sup>
3. Create programmes for families of persons with disabilities that improve the care and support they provide for their family member with a disability. For example, assistance programmes such as caretaker trainings, counselling, financial assistance, and respite care.<sup>290</sup>

## Guidelines for Action:

### ► Quality

1. Ensure that public information and awareness-raising campaigns address the forms and manifestations of violence against women and young persons with disabilities, sexual harassment, and available services. Engage the health sector in developing these campaigns.<sup>291</sup>

### ► EXAMPLE:

*The 'Toolkit on Eliminating Violence Against Women and Girls with Disabilities in Fiji' was developed in partnership with multiple disabled persons organizations to provide detailed guidance on effective trainings designed to eliminate violence against women and girls with disabilities. The toolkit includes training sections on human rights generally, disability, gender, violence against women, and planning for inclusion. Useful appendixes include sample evaluation forms to a sample survey to assess gender bias.<sup>292</sup>*

2. Ensure that awareness-raising campaigns address GBV against boys and young men with disabilities to combat misperceptions that boys and men are not victims of GBV.
3. Develop identification procedures to determine whether service recipients qualify for poverty-reduction schemes or other support programmes or provide appropriate support or referrals to apply for such programmes.
4. Distribute information and develop programming aimed at reducing the available and harmful use and access to



A female judge in Nicaragua presides over a case involving a young woman © UNFPA Nicaragua/Joaquín Zuñiga

alcohol, guns, knives, and pesticides.<sup>293</sup> Each has been identified as a risk factor for GBV.

5. Design services and facilities for displaced populations and humanitarian emergency services to effectively prevent sexual and GBV during humanitarian emergencies.

### 3.3.3 Indicators

The following are illustrative of indicators useful to monitor and evaluate progress in the provision of GBV prevention programmes. This is not an exhaustive list, but rather lists examples that demonstrate the level of specificity, subjects, and form that indicators

should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- GBV public awareness campaigns include GBV against persons with disabilities.
- GBV information material is available in a variety of accessible formats to disseminate information about rights and prevention services.

### 3.4 Health Services for GBV Victims/Survivors with Disabilities

#### 3.4.1 Issue Overview

Health service providers and support staff are key to “secondary prevention—aimed at stopping or minimizing GBV —through screening for GBV, to identify women and [young persons] experiencing GBV and provide the needed support and referrals to prevent additional occurrences. Health services also undertake tertiary prevention: treatment and harm reduction for those women and [young persons] with severe injuries and health consequences from GBV. Many primary-prevention strategies are either community-based with direct face-to-face educational interventions or involve mass media campaigns”.<sup>294</sup> Women and young persons with disabilities who are victims/survivors of GBV have a right to access quality health services generally, including as an essential component of their physical and psychological recovery.

Important health services for GBV victims/survivors include: identification procedures for victims/survivors of GBV; first-line support to respond to the immediate emotional, physical, safety and support needs of victims/survivors of GBV with disabilities; care of injuries and urgent medical issues; sexual assault exam and care for victims/survivors of sexual violence (including access to emergency contraception to prevent unintended pregnancy, post-exposure prophylaxis to prevent HIV and other sexually transmitted infections, and abortion services where it is not against the law); mental health assessments and referrals for follow-up psychosocial care; and documentation of violence for medico-legal evidence.

#### 3.4.2 Providing Rights-Based Health Services for GBV Victims/Survivors with Disabilities

The key considerations enumerated here identify common barriers to accessing health services by women and young persons with disabilities who are victims/survivors of GBV. The guidelines for action offer guidance for ensuring that rights-based health services tailored to the specific needs and experiences of GBV victims/survivors with disabilities are available, accessible, acceptable, and of good quality. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

### Key Considerations

- Lack of clear and disability-sensitive laws, regulations, and protocols for accessing emergency contraception, abortion (where legal), and post-exposure prophylaxis for victims/survivors of sexual violence can result in unintended pregnancy and sexually transmitted infections going untested and untreated, resulting in further health problems.
- Provider misconception that persons with disabilities are not sexually active may result in the failure to identify GBV victims/survivors.<sup>295</sup>
- Ill-informed and disrespectful care in GBV health services can traumatize a victim/survivor.
- Failure to identify a need for or to respond to a request for GBV health services can result in GBV occurring for a prolonged period, expose victims/survivors to an increased risk of unintended pregnancy and sexually transmitted infections, and further traumatize a victim/survivor.
- Exclusion of women and young persons with disabilities from public health information campaigns about GBV and SRHR due to a variety of factors, including stereotypes, isolation, and the inaccessible formats.
- Denial of access to essential counselling for women and young persons with disabilities as needed to make decisions around urgent healthcare follow up, including emergency contraception, abortion (where legal), and STI testing and prophylactic treatment. This can lead some service providers and support staff to feel uncomfortable when treating women and girls with disabilities and limit the overall quality and effectiveness of care.<sup>296</sup>
- Inaccessible intake forms and other communication barriers that prevent service providers and support staff from accurately identifying sexual and GBV and assessing the health needs and risks for GBV victims/survivors with disabilities.
- During emergencies, some service providers and support staff may conclude that women and young persons with intellectual disabilities lack the capacity to benefit from services. Thus, services are not developed or offered to women and young persons with intellectual disabilities, despite their documented need.

### Guidelines for Action:

#### ► Availability

1. Create education programmes for family members, partners, and caregivers, who may act as gatekeepers to essential services, to help them better understand the importance of accessing GBV health services.
2. Ensure accessible emergency medical care is available for women and young persons with disabilities—including essential medicines (such as emergency contraception and STI prophylaxis), pregnancy and STI testing, and abortion services, where legal—for free or at a low cost to victims/survivors of GBV.<sup>297</sup>

### Guidelines for Action:

#### ► Accessibility

1. Picture guides and other accessible formats tailored for persons with different disabilities can be an especially useful resource to prepare women and young persons for medical exams and procedures.

► **EXAMPLE:**

*The Illinois Imagines' **SANE Picture Guides** are good examples of picture guides that can increase GBV health service accessibility. This collection of picture guides was developed to assist women with disabilities to better understand the sexual assault examination process. There are different guides depending on the needs of the woman and guides for medical staff and advocates to assist a woman with a disability.*<sup>298</sup>

## Guidelines for Action:

► **Acceptability**

1. Create—and train all service providers and support staff on—effective and trauma-informed GBV identification procedures and policies. Medical service providers must understand their responsibility to identify patients with disabilities experiencing or at risk of GBV and how to conduct appropriate and trauma-informed identification and referrals.<sup>299</sup> Stereotypes about women and young persons with disabilities not being GBV victims must be actively dispelled in training.<sup>300</sup> It is particularly important to include male service providers and support staff in gender sensitization programmes to improve their ability to identify women and young persons with and without disabilities who have experienced GBV.<sup>301</sup>
2. Tailor GBV identification policies to identify the unique types of violence that women and young persons with disabilities experience. Examples of identification questions include:
  - “Is there anything I need to know [about you] to be able to provide the best services possible?”
  - Now that I have described our program, (include path of travel to agency, physical layout of building, various services) do you have any concerns or hesitations about using our program’s services?
  - Does anyone control your communication with others or change what you are trying to say?
  - Has anyone taken or broken something that you need to be independent? For example, your cane, walker, wheelchair, respirator, or TTY [teletypewriter]?
  - Does anyone have legal control over your money or your decisions? What happens if you disagree with them about their decisions?
  - Does anyone prevent you from using resources and support you need to be independent? (For example, resources such as vocational services, personal care attendants, disability agency support person, specialized support personnel for Deaf-blind services, readers, or interpreters?)<sup>302</sup>
3. Ensure that service providers and support staff are equipped to provide disability- and gender-sensitive care as the first line of support for the physical, psychological, and emotional health consequences of GBV, where a person is identified as a victim/survivor. This includes the skills to provide or give robust referrals to appropriate medical care for injuries and health consequences of GBV, including STI prophylaxis and emergency contraception post-rape.<sup>303</sup>
4. Promulgate widespread accessible community information campaigns to increase knowledge about health needs for victims/survivors of GBV and the importance of timely health

interventions. Campaigns should feature women and young persons with disabilities and target them, their families, partners, caregivers, and healthcare practitioners. The contents of the campaigns must prioritize the forms of abuse most commonly experienced by persons with disabilities.

### Guidelines for Action:

#### ► Quality

1. Ensure that women and girls with disabilities who are victims/survivors of GBV have access to medically accurate information and unbiased counselling on the availability of emergency contraception; STI testing; post-exposure prophylaxis; and abortion services, where legal, in situations where pregnancy is a result of rape. Counselling should address the pros and cons of the service, the legal status of abortion for sexual violence victims/survivors, what to expect if an STI test result comes back positive, and the availability of STI treatment. Counselling must be accessible, respect patient privacy and confidentiality, and utilize supported decision-making tools.
2. Establish protocols and guidelines on—and train staff to implement—follow-up visits, delivery of test results, and referrals. Protocols and guidelines should also address follow-up procedures for people living in institutional settings.
3. Collect medico-legal evidence. Service providers should be trained on accurate documentation and reporting of medico-legal evidence; collection of forensic specimens; providing written evidence; the importance of attending court proceedings; and the legal process, including how to write a strong statement.<sup>304</sup> Challenges presented by a person's disability in collecting evidence is not a sufficient reason to not to collect evidence.

### 3.4.3 Indicators

The following is illustrative of the type of indicators that can be used to monitor and evaluate progress in the provision of GBV health services for women and young persons with disabilities. This is not an exhaustive list, but rather one example demonstrating the level of specificity, subject, and form that indicators for GBV health services should take. Service providers should tailor indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Percentage of facilities whose staff are trained to provide the following accommodations for GBV victims/survivors with disabilities and have essential resources to support these accommodations:
  - “A tip sheet on how to maximize exam accessibility when no accessible exam table is available.
  - A list of key considerations and guidelines to provide to sign language interpreters during sexual assault forensic exams.
  - A pictorial guide to explain the [sexual assault exam] in simple language.
  - An instruction guide on how to prioritize details when orienting a [victim/survivor] who is blind or visually impaired to the exam room”.<sup>305</sup>

## 3.5 Justice and Policing Services for GBV Victims/Survivors with Disabilities

### 3.5.1 Issue Overview

The concept of access to justice refers to the ability to make use of “the systems, procedures, information, and locations used in the administration of justice”.<sup>306</sup> As used in these Guidelines, the term ‘justice system’ refers to both formal and informal systems. Access to justice is a fundamental component of realizing and respecting the rights of women and young persons with disabilities.<sup>307</sup> For victims/survivors of GBV, this often means unencumbered access to a range of criminal and civil mechanisms to hold perpetrators accountable and to the justice and policing services necessary for these mechanisms. Justice and policing services include services that provide the information and support necessary to facilitate obtaining protection orders; participation in criminal investigation and prosecution of perpetrators; access to victim compensation funds and other forms of reparations; removal of guardianship designations; and access to divorce proceedings. Justice mechanisms can be formal state-sponsored mechanisms or informal mechanisms such as customary courts or local mediators that may or may not be connected to the government.

### 3.5.2 Guidance on Justice and Policing Services

The key considerations in this section identify common barriers that women and young persons with disabilities face in accessing policing and justice mechanisms. The guidelines for

action provide guidance as to how service providers and support staff can promote greater access to justice for women and young persons with disabilities. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

#### *Key Considerations*

- Laws and policies, such as those that deny individuals with intellectual disabilities the ability to testify against their abuser, can directly prevent women and young persons with disabilities from accessing justice mechanisms.
- Many individuals involved in the administration of justice hold stereotypes about and lack awareness of the rights and experiences of women and young persons with disabilities. For example, because society generally fails to see women with disabilities as sexual, such stereotypes may lead judges, juries, law enforcement officers, and others to discount their testimony and experiences with violence.<sup>308</sup>
- Judicial systems systematically fail to acknowledge women with disabilities as competent witnesses or give sufficient credence to their testimony, which is particularly problematic in cases involving sexual assault or other forms of GBV where the victim/survivor’s testimony may provide the only evidence against the assailant.<sup>309</sup>
- Women with cognitive disabilities can have trouble remembering the sequence of events, which can make them seem less credible as witnesses.<sup>310</sup>

- Burdensome processes for removing someone as a legal guardian or obtaining a divorce and cumbersome evidentiary requirements act as barriers for GBV victims/survivors with disabilities to access justice.
- Women and young persons with disabilities, and their caregivers, often lack knowledge about their rights to and within the justice system.
- Information about legal rights is rarely available in accessible formats, which can prevent, for example, those with intellectual or visual disabilities, from knowing what rights they have, how to file a complaint or obtain a protective order or understand other justice and legal processes.
- Lack of interpretation or other communication aids throughout the justice system can prevent women and young persons with disabilities from reporting GBV or moving a complaint through the justice system. For instance, lack of sign language interpreters or communication technology may deny women and young persons with disabilities the ability to report GBV.
- Physically inaccessible courthouses, police departments, or legal aid offices and inaccessible transportation services can prevent women and young persons with disabilities from accessing justice mechanisms.
- Costs associated with hiring an attorney, transportation, filing fees, and medical services, as well as economic dependence on abusers, create financial barriers to accessing justice.
- Family members and caregivers can act as gatekeepers, either facilitating or hindering a woman or young person with a disability's

access to justice. In communities where there is considerable stigma around GBV, service providers may find that families and caregivers act as an even greater barrier.

### Guidelines for Action:

#### ► **Availability**

1. Develop programmes to build capacity of the legal profession, including attorneys, judges, and clerks, on representing and working with victims/survivors of violence with disabilities in a gender- and disability-sensitive manner and investigating GBV involving a woman or a young person with a disability. Educate staff at all levels of the justice system about the rights, experiences, and needs of women and young persons with disabilities to ensure that complaints made by women and young persons with disabilities are taken seriously.
2. Train law enforcement officers and other emergency personnel, such as emergency-line operators. Training and guidance for law enforcement is an important role that service providers can play in breaking down barriers in justice systems for women and young persons with disabilities. Consider implementing the recommendations in *'People with Mental Health and Cognitive Disabilities & Access to the Justice System'* by the Institute for Research and Development on Inclusion and Society.<sup>311</sup> This literature review identifies five strategic areas of focus for improving access to justice for people with mental health and cognitive disabilities:
  - Mental health policy framework;
  - Police training curriculum;
  - Police recruitment process;

- Collaborative programmes, protocols, and guidelines for cross-sectoral information sharing;
- Education and training for other key sectors, including healthcare, as well as for individuals and their families.<sup>312</sup>

► **EXAMPLE:**

*Safe Austin in the United States of America developed a training and manual that provides resources and tools for law enforcement: 'In My Jurisdiction: Responding to Crimes Against People with Disabilities, Deaf Individuals, and Older Adults.'*<sup>313</sup>

3. Recruit and maintain a list of legal services providers educated about the experiences of persons with disabilities whose services have low or no cost for women and young persons with disabilities.

## Guidelines for Action:

► **Accessibility**

1. Develop accessible and inclusive know your rights programmes for women and young persons with disabilities, including their rights during court proceedings and how to access justice and policing mechanisms.
2. Offer programmes that provide necessary supports for women and young persons with disabilities as they navigate the justice process. For instance, trained social workers can help women and young persons with disabilities navigate the justice system from the reporting of GBV through the remedy stages.<sup>314</sup> Ensure that support people or contextual advisers whom a woman or a young person wishes to join them before,

during, and after court proceedings are permitted.

► **EXAMPLE:**

*The National Union of Women with Disabilities of Uganda's paralegal programme uses well-trained paralegals to increase access to justice for women and young persons with disabilities. Thirty-two women with disabilities were trained about the rights of women and girls with disabilities relating to SRHR and GBV. These paralegals became community role models, offering peer-to-peer support in reporting violations and conducting the necessary follow-up to ensure justice was achieved and advocating for systemic change.*<sup>315</sup>

3. Develop programmes to increase the comfort of women and young persons with disabilities during court proceedings, assist victims/survivors in giving testimony, and address credibility concerns.

► **EXAMPLE:**

*The Sexual Abuse Victim Empowerment (SAVE) programme at Cape Mental Health in South Africa involves a psychological assessment; court preparation, comprehensive sexuality education, counselling, and support for the victim/survivor and their family; a cache of expert witnesses; a referral network within the justice and police departments; training and awareness-raising among the police and prosecutors; and training and ongoing support for other stakeholders.*<sup>316</sup>

4. Advocate for a comprehensive disability access plan for the justice system.<sup>317</sup> Ensure that any costs associated with

*Access to justice is a fundamental component of realizing and respecting the rights of women and young persons with disabilities.*

making the justice system accessible to women and young persons with disabilities are not passed on to them through formal or informal user fees. This could include costs associated with testifying, such as transportation costs and lost wages.

► **EXAMPLE:**

*The 'Brasilia Regulations Regarding Access to Justice for Vulnerable People' produced by the XIV Ibero-American Judicial Summit, provides guidance on how to improve access to justice for persons with disabilities and other intersectional vulnerabilities, such as women and indigenous communities. The document provides guiding rules and mechanisms for increasing the effectiveness of access to justice rules and regulations. Sample regulations address access to information, understanding judicial processes, appearing in court, and protection of privacy. For example, one sample regulation says: "All necessary measures will be adopted to reduce any difficulties in communication that affect the understanding of the judicial proceeding in which a vulnerable person is taking part, guaranteeing that they can understand its scope and significance".<sup>318</sup>*

5. Translate justice system forms, information material, and instructions into a range of accessible formats.
6. Lobby for women and young persons with disabilities to be included in access to justice initiatives in humanitarian emergency settings, particularly involving sexual and GBV and disabilities.<sup>319</sup>
7. Educate justice sector stakeholders about physical accessibility adaptations that increase the comfort and dignity of women and young persons with disabilities engaging with the justice system, such as ensuring that a witness box is accessible and that a person of short stature or sitting in a wheelchair can be clearly seen.
8. Advocate for government-funded legal services, fee waivers, and cost reductions for women and young persons with disabilities who are unable to afford legal representation or other fees associated with access to justice.<sup>320</sup>

## Putting into Practice

### The Leonard Cheshire Disability Zimbabwe Trust— ‘Access to Justice for Girls and Women with Disabilities Project’

After identifying significant gaps in reporting among girls and women with disabilities who were victims/survivors of sexual violence, Leonard Cheshire developed this project to help girls and women with disabilities realize full enjoyment of their rights and to stop violence against women. The project was successful in enhancing access to post-violence justice and related services for women and girls with disabilities, empowering them to access justice and other services, and increasing attention to their concerns. The following activities were identified as key to enhancing access:

- Provide logistical support to victims/survivors to access justice and other necessary post-violence services.
- Facilitate communication and provide technical advice in cases involving women and girls with disabilities who are victims/survivors.
- Train women and girls with disabilities on violence against women, GBV legal frameworks and how to report violence.
- Develop community awareness campaigns around access to justice targeting community leaders, community-based organizations, women and girls with disabilities, caregivers and the general community.
- Train police on sign language communication.
- Sensitize government stakeholders on disability and violence against women and girls with disabilities.
- Facilitate formation of support groups.
- Establish a national dialogue on violence against women and girls with disabilities and their access to services.
- Organize follow-up meetings with mainstream women’s organizations.<sup>321</sup>

## Guidelines for Action:

### ► **Acceptability**

1. Develop programmes to increase the capacity and representation of persons with disabilities in the justice system, including for example, by ensuring that law schools are accessible to persons with disabilities, incorporating disability law into law school curricula, and developing law school clinics that work with clients with disabilities.
2. Where sexual violence occurs, particularly in humanitarian emergency settings, develop programmes that support prompt and independent investigations to hold perpetrators accountable, along with appropriate compensation for the victim/survivor.<sup>323</sup>

Where security forces or public personnel are responsible for the sexual violence, advocate for such claims to be investigated and prosecuted and for perpetrators to be punished.<sup>324</sup>

### Guidelines for Action:

#### ► Quality

1. Conduct training sessions for members of the justice sector—including lawyers, paralegals, law enforcement officers, judges, court administrators, correctional facility staff—on the rights and experiences of women and young persons with disabilities relating to GBV. Service providers and support staff can offer themselves as resources for justice-sector professionals unclear on how to communicate with or better serve a woman or a young person with a disability.
2. Conduct regular evaluations of the extent to which GBV services promote access to justice for women and young persons with disabilities. When appraising access to justice services, particularly effective methods include violence safety audits, surveys, focus groups, key informant interviews, court monitoring, and human rights monitoring.

### 3.5.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based justice and policing services for women and young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators in the justice and policing service provision area

should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Number of prosecutions for crimes against a woman or young person with a disability.
- Number of prosecutions for crimes against a woman or young person with a disability in which the victim with a disability testified.
- Percentage of women or young persons with disabilities who know of an organization that provides legal assistance to GBV victims/survivors.<sup>325</sup>
- Number of service provider and support staff who are trained on the types of GBV and access-to-justice issues that women and young persons with disabilities experience.<sup>326</sup>
- Number of supports put in place for persons with disabilities in the justice system.

## 3.6 Social Services—Protection Services for GBV Victims/Survivors with Disabilities

### 3.6.1 Issue Overview

Access to protection services is an essential component of the right to be free from gender-based violence<sup>327</sup> and a core component of a State's due diligence obligations to prevent, protect against, investigate, punish, and provide redress for GBV.<sup>328</sup> Protection services are essential to help GBV victims/survivors to break the cycle of violence and to safeguard them from experiencing further violence. Essential protection services include: crisis information and counselling (including safety planning); crisis centres; help lines; emergency housing and other safe residences; material and financial

*Protection services must also include measures to strengthen economic independence, supported decision-making regimes, and other forms of autonomy for women and young persons both with and without disabilities.*

aid; and emergency protective orders.<sup>329</sup> Similar to prevention services, protection services must also include measures to strengthen economic independence, supported decision-making regimes, and other forms of autonomy for women and young persons both with and without disabilities.<sup>330</sup> Due to communication, information, physical, and other barriers, women and young persons with disabilities are often excluded from these essential protection services, undermining their right to be free from GBV.

### 3.6.2 Guidelines for Providing Rights-Based Protection Services for Victims/Survivors of GBV with Disabilities

The key considerations enumerated here identify common barriers to accessing protection services by women and young persons with disabilities who are victims/survivors of GBV. The guidelines for action offer guidance for ensuring that rights-based protection services are tailored to the specific needs and experiences of GBV victims/survivors with disabilities, and are available, accessible, acceptable, and of good quality for women and young persons with disabilities. These guidelines for action build on the Foundational Guidelines for Action

identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

This section addresses protection programmes and measures directed at immediate social services required by a woman or young person with a disability who has experienced GBV. Longer-term social services are addressed in **section 3.7**, which discusses rehabilitation services. This division has been made for organizational purposes with recognition that the need for many of these programmes and services will be overlapping.

#### **Key Considerations**

- Discriminatory laws, regulations, and policies that fail to protect the autonomy and legal capacity of women and young persons with disabilities can deter them from seeking GBV protection services. For example, women or young persons with disabilities may fear leaving their abuser or seeking protection services for fear of loss of custody of their children.<sup>331</sup>
- Economic dependence, dependence on caregiving, and fear of institutionalization can all deter women and young persons with disabilities from reporting violence

- by caregivers or intimate partners and can prevent them from seeking GBV protection services. They may fear losing necessary care if they lack funds to hire alternative care<sup>332</sup> or institutionalization in situations where the perpetrator owns the home.<sup>333</sup>
- Women and young persons with disabilities who leave violent or abusive situations may also lose access to assistive devices or supports, which can be prohibitively expensive to replace.
  - Women and young persons with disabilities encounter stereotypes and bias from service providers and support staff who do not recognize that they are at risk of violence or do not view them as rights-holders.<sup>334</sup>
  - Eligibility requirements for certain protection services, such as emergency shelters, may exclude women and young persons with disabilities. For instance, a shelter may not recognize certain forms of violence such as violence at the hands of a caregiver or not offer accommodations for victims/survivors with disabilities or women with children with disabilities.
  - Service providers and support staff — including social workers, medical providers, crisis centre or hotline staff — often lack necessary training on providing information about GBV and GBV services to women and young persons with disabilities. Isolation and lack of information in accessible formats further prevents women and young persons with disabilities from obtaining information about GBV services.<sup>335</sup>
  - Women and young persons with disabilities do not have access to information or education about their rights to be free from GBV, how to recognize forms of GBV, and how to access protective services.
  - Lack of data and information about the violence women and young persons with disabilities experience in their homes prevents the development of targeted services.
  - Communication barriers are often particularly acute for people with sensory and intellectual disabilities and present barriers to reporting violence and receiving crisis counselling, safety planning, and other protection services.<sup>336</sup>
  - Women and young persons with disabilities from indigenous, migrant, or linguistic minority communities face intersectional communication challenges and increased risk of violence.<sup>337</sup>
  - Physical barriers—such as lack of accessible transportation to services or inaccessible furniture or kitchen facilities in emergency shelters—can deny women and young persons with disabilities access to essential protection services.<sup>338</sup>
  - Shortages of accessible emergency GBV shelters and available beds for women and young persons with disabilities are widespread.<sup>339</sup> These challenges can be further exacerbated for certain groups of persons with disabilities:
    - GBV shelters and services for boys and young men with disabilities rarely exist, in part due to the misperceptions that men and boys are not victims/survivors of GBV or that funding for such services would reduce funding for female victim/survivors.
    - Women and young persons with psychosocial disabilities can face exclusion from GBV shelters and other services due to a perception that they may be dangerous or disruptive in a communal setting.

- Shelters sometimes fail to provide reasonable accommodations for a person’s mobility and sensory devices, medicines, and other necessary accommodations.

## Guidelines for Action:

### ► **Availability**

1. Evaluate the eligibility criteria to receive services or enter the shelter to ensure that services are available to women and young persons with disabilities and that the eligibility criteria are reflective of the forms of violence that women and young persons with disabilities experience. This includes ensuring that services are also available to women without disabilities who require services and have a child with a disability who will also use the services.

#### ► **EXAMPLE:**

*'More than Just a Ramp: A Guide for Women's Refuges to Develop Disability Discrimination Act Action Plans'* developed by Women with Disabilities Australia offers useful instructions to service providers and support staff on developing a plan for action to increase availability of services to women with disabilities. The process involves identification of barriers for women and children with disabilities seeking refuge and strategies for eliminating those barriers. The guide also includes instructions on how to conduct monitoring and evaluation following implementation of the plan. The guide offers the following ten steps for writing an action plan: (1) Develop a good working group; (2) Familiarize yourself with the barriers in your service; (3) Consult and involve women with

*disabilities; (4) Educate your organization about local disability rights legislation; (5) Ensure that you are well supported; (6) Develop strategies; (7) Resource the action plan; (8) Negotiate with the relevant government departments; (9) Determine responsibility; and (10) Evaluate.*<sup>340</sup>

2. Ensure that safety planning services are available from trained professionals.

#### ► **EXAMPLE:**

*Project CARE in the United States of America developed a guide for advocates on safety planning for persons with disabilities that includes questions and information about accommodations during the safety-planning process.*<sup>341</sup>

## Guidelines for Action:

### ► **Accessibility**

1. Develop crisis hotlines that allow for alternative forms of communication, including, for example, texting or other written formats for people with hearing related disabilities.
2. Develop initiatives to inform women and young persons with disabilities about how to report violence and access protection services. Resources should be available in various accessible formats and accompanied by training programmes.

#### ► **EXAMPLE:**

*In Croatia, the government and civil society published an SOS address book for women with disabilities with contact information for GBV service providers.*<sup>342</sup>

3. Ensure that shelters include accessible rooms for various disability-related needs and devices. Similarly, available recreational activities and resources such as phones and bathrooms must be accessible.
4. Where resources allow, offer free or low-cost assistive devices to reduce isolation and to replace devices lost in fleeing an abusive situation.

### Guidelines for Action:

#### ► **Acceptability**

1. Ensure that protection service staff are sensitive and educated about the intersectional and intercultural needs and experiences of women and young persons with disabilities from a variety of backgrounds. This is particularly important for shelter service providers and support staff.
2. Create information materials for all shelter residents that explains what personal care services are available, details available accommodations for persons with disabilities, lists persons with disabilities as part of any diversity statement, and limits the use of scents and fragrances to accommodate people with a chemical sensitivity.<sup>343</sup>

### Guidelines for Action:

#### ► **Quality**

1. Train service providers and support staff on how to recognize signs of GBV against women and young persons with disabilities, particularly relating to a caregiver. Training programmes should directly address power

dynamics between persons with disabilities and caregivers.

### 3.6.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based GBV protection services for women and young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators for GBV protection services should take.

Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Number of women and young persons with disabilities that can be accommodated in the shelter or other safe residence (disaggregated by gender, age, and type of disability).
- Agency provides a variety of accessible methods of communication, including:
  - An accessible website;
  - An in-house videophone that can be used for communication between staff and service recipients who are Deaf or hard of hearing;
  - A telephone for people who have low vision;
  - A dedicated line answered by a staff member for receiving text messages from service recipients.<sup>344</sup>
- Emergency shelter agency has a handbook for residents of its shelter that addresses use of scents and fragrances, clearly explains personal care services staff may

provide, offers flexibility for persons with disabilities, and lists persons with disabilities as part of any statement about respecting diversity.<sup>345</sup>

### 3.7 Social Services— Rehabilitation Services for GBV Victims/Survivors with Disabilities

#### 3.7.1 Issue Overview

The right of women and young persons with disabilities to be free from GBV encompasses a right to comprehensive rehabilitation services.<sup>346</sup> Rehabilitation services are essential to the psychological and social recovery of GBV victims/survivors. Important rehabilitation services include: mental healthcare; assessment for self-harm, suicide, and other severe consequences resulting from the experience of GBV; psychosocial support and counselling; necessary referrals, including to physical health services; and appropriate social reintegration services, such as assistance with recovering or replacing identity documents; women-centred support; children’s services for any child affected by violence; community information, education and outreach; and assistance towards economic independence, recovery and autonomy.<sup>347</sup>

*Rehabilitation services are fundamental to the recovery of any victim/survivor, as well as the right of that victim/survivor to be free from gender-based violence.*

#### Psychosocial Support

The term ‘psychosocial support’ refers to “the inter-connection between psychological and social processes and the fact that each continually interacts with and influences the other. ...The composite term mental health and psychosocial support (MHPSS) is used to describe any type of local or outside support that aims to protect or promote psychosocial well-being and/or prevent or treat mental disorder”.<sup>348</sup>

Rehabilitation services are fundamental to the recovery of any victim/survivor, as well as the right of that victim/survivor to be free from GBV.<sup>349</sup> This is especially so for women and young persons with disabilities given that they are more vulnerable to isolation and poverty and because the caregivers and intimate partners who act as gatekeepers to psychosocial services are often the perpetrators of GBV against women and young persons with disabilities. Victims/survivors of all forms of GBV — including intimate partner violence, sexual violence, psychological or financial abuse, and violence in institutional or medical settings — must have access to a range of psychosocial rehabilitation services.<sup>350</sup>

#### 3.7.2 Providing Rights-Based Rehabilitation Services for GBV Victims/Survivors with Disabilities

The key considerations enumerated here identify common barriers to comprehensive rehabilitation services faced by women and

young persons with disabilities who are victims/survivors of GBV. The guidelines for action offer guidance for ensuring that rights-based rehabilitation services tailored to the specific needs and experiences of GBV victims/survivors with disabilities are available, accessible, acceptable, and of good quality for women and young persons with disabilities. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

**Section 3.6** addressed immediate social services required by a woman or young person with a disability who is experiencing or has experienced GBV, while this section addresses long-term rehabilitation services. This division is for organizational purposes with recognition that many of these programmes and services overlap for those with both immediate and long-term needs.

### **Key Considerations**

- Laws and policies that mandate participation in psychosocial recovery programmes or that make benefits conditional, such as conditioning economic support on meeting job-seeking requirements or only providing immigration support to GBV victims/survivors who cooperate in prosecutions against their abuser, can deter women and young persons with disabilities from seeking or adhering to recovery programmes.
- While pursuing access to justice can have a rehabilitative effect for some GBV victims/survivors, navigating legal processes can potentially result in secondary trauma, particularly for victims/survivors with disabilities who may face additional barriers to justice.
- Rehabilitation services often do not offer the requisite sensitivity towards and understanding of the needs of victims/survivors with disabilities. Insensitive or discriminatory services can directly or indirectly result in additional trauma.
- Women and young persons with disabilities are often unable to access rehabilitative services, even where available, because information about such services is not accessible.
- Service providers, support staff, or family members are often unfamiliar with the rehabilitative needs of women and young persons with disabilities, thus key referrals are not made. For example, a doctor treating a woman with an intellectual disability who has been sexually assaulted may not refer that woman to counselling services because of a mistaken belief that she would not benefit from counselling.
- The trauma resulting from GBV can make navigating rehabilitative services a challenge for any victim/survivor. Disabilities increase already substantial barriers to services and can prevent women and young persons from accessing services at all.
- Psychological services are among the most critical rehabilitation services. Yet women and young persons with communication or intellectual disabilities are regularly excluded from such services due to communication barriers. There is also little guidance or training for mental healthcare service providers in this area.



Jamila Bako uses a cane while walking with two of her children through her village.

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- Effective rehabilitation services require multiple visits over a sustained period, and this can present a major barrier to women and young persons with disabilities, who often live in poverty and may live in an area without accessible transportation.
- Poverty and economic dependence can often keep women and young persons with disabilities in a violent situation or force their return. For example, if a woman is economically dependent on an abusive partner for insurance or funds to pay for vital medicines, she may feel she has no choice but to return to a violent situation.
- Victims/survivors of economic control, a form of GBV whereby an abuser controls the finances of a woman or young person with disabilities to coerce them into doing things against their will, may face additional barriers in securing adequate funds to obtain rehabilitation services.
- Victims/survivors with disabilities can often experience diagnostic overshadowing, where their trauma symptoms are attributed to an

already existing disability diagnosis and no further assessment is conducted to determine if there are issues or symptoms relating to trauma. Particularly for persons with intellectual and developmental disabilities, service providers may create a behaviour plan to stop the behaviour rather than exploring whether the behaviour reflects a trauma. Thus, the person with a disability is punished for their trauma responses.

### Guidelines for Action:

#### ► **Availability**

1. Develop community-based services, including peer-to-peer support groups, which can be particularly effective for making rehabilitation services available at a low cost and in the community. Handicraft-making groups, for example, can serve multiple purposes, providing both economic empowerment and peer support. When promoting these services, ensure that they are not classified as something for victims/survivors only, as this can be alienating.<sup>351</sup>
2. Conduct a review of social benefits to identify those that have mandatory or conditional components that can make them unavailable to women and young persons with disabilities. Advocate accordingly to make such services available to women and young persons with disabilities.
3. Where appropriate, offer individualized and group counselling led by professionals trained in working with women and young persons with disabilities who have experienced GBV.<sup>352</sup>

### Guidelines for Action:

#### ► **Accessibility**

1. Create one-stop spaces where women and young persons with disabilities can get information and receive rehabilitation services in a comfortable setting that feels safe and supportive.
2. Develop safe and effective ways to distribute accessible information about rehabilitation services to women and young persons with disabilities at risk of or experiencing gender-based violence. Identify specific entry points for young persons with disabilities to learn about and access rehabilitation services. Adult victims/survivors with and without disabilities can serve important roles as mentors and advocates for young victims/survivors.

#### ► **EXAMPLE:**

*The Illinois Imagines Project worked with self-advocates to develop the 'Our Rights, Right Now: Women with Disabilities and Sexual Violence Education Guide'. The guide offers a basic overview of sexual violence and rights related to sexuality with respect to women with disabilities, and then provides guidance, information, and handouts for facilitating education sessions for women with disabilities on healthy relationships, healthy sexuality, sexual violence risk reduction, and how to get help.*<sup>353</sup>

3. Facilitate access to social services programmes that provide independent caregiving. Prioritize access to programmes that promote economic independence and control. Also, assist with access to income

assistance and other social protection programmes where needed.<sup>354</sup>

### Guidelines for Action:

#### ► **Acceptability**

1. Train all service providers, support staff, and programme participants on preventing re-traumatization, from the receptionist to the peers in a peer-support group. In providing mental health services, the principle of 'do no harm' is paramount. Providers, staff, and participants must ensure they do not blame the victim/survivor, must listen with compassion, must not espouse harmful gender or disability norms that belittle the victim/survivor or normalize GBV, must assess danger, and must assist with safety planning.<sup>355</sup> Ensure that services are delivered in a way that is compassionate and non-judgmental and clearly conveys the message that violence is never deserved and that women and young persons with disabilities have the right to live free of violence.<sup>356</sup>

#### ► **EXAMPLE:**

*The Wisconsin's Violence Against Women with Disabilities and Deaf Women Project developed 'A Practical Guide for Creating Trauma-Informed Disability, Domestic Violence and Sexual Assault Organization'. The guide covers positive trauma-informed conditions and values that survivors/victims with disabilities prioritize for safety and healing.*<sup>357</sup>

2. Train mental health service providers on the specific skills required for counselling for women and young persons with various

## Putting into Practice

### Tools and resources for working with victims/survivors with disabilities.

The Women's Refugee Commission and the International Rescue Committee's *'Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings: A Toolkit for GBV Practitioners'*<sup>358</sup> offers important guidance and practical tools for GBV case coordinators working with victims/survivors with disabilities. Although these documents are written for the humanitarian context, they offer useful guidance for service providers and support staff in all settings, especially low-resource settings.

- Applying guiding principles when working with victims/survivors of disabilities—This tool has been developed to support GBV case coordinators to uphold a survivor-centred approach to working with GBV victims/survivors with disabilities. It summarizes guiding principles for working with GBV victims/survivors and highlights adaptations relating to communication and caregiver involvement that should be considered throughout the case-management process.
- Guidance on communicating with persons with disabilities—This tool provides simple tips and advice for GBV practitioners on interacting and communicating with people with different types of impairments.
- Informed consent process with adult victims/survivors with disabilities—This tool outlines steps to take in the informed consent process with adult victims/survivors and strategies to try when communication methods or understanding and comprehension are difficult to determine.
- Working with caregivers of victims/survivors with disabilities—This tool offers guidance on how to approach working with caregivers of victims/survivors with disabilities to ensure the rights of the victim/survivor are respected, and that positive relationships are strengthened.

disabilities, particularly persons with intellectual disabilities, communication difficulties, or acute mental health disabilities. Training should include services beyond talk therapy.

3. Create programmes and resources to help a woman or young person with a disability gain control over their financial assets and separate themselves financially from an abuser who previously held financial control.
4. Train case coordinators on unpacking specific considerations for women and young persons with disabilities and good management, advocacy, communication, and other soft skills. Case coordinators are crucial to helping victims/survivors navigate the different services available.

### Guidelines for Action:

#### ► Quality

1. Ensure that service providers are trained to identify the level and type of harm an incoming victim/survivor has experienced and assess their capacity to offer the appropriate rehabilitation services for the level and type of harm suffered. Effective referrals must be available where a provider cannot offer the level of services required. Develop robust referral networks to make appropriate referrals.
2. Facilitate and offer support needed to access justice mechanisms. Counsellors and psychologists should be knowledgeable



A group of community health workers being trained in Lao.  
© Chien-Chi Chang/Magnum Photos

- about these processes and prepared to offer expert opinions in any judicial proceedings, as needed. For more information, see Justice and Policing Services (Section 3.5).
3. Where resources allow, ensure that women and young persons with disabilities have access to a minimum number of support or counselling sessions, recognizing that people with communication or intellectual disabilities may require additional or extended sessions.<sup>359</sup>
4. Where possible, offer continued support for holistic recovery for a minimum of six months.<sup>360</sup>

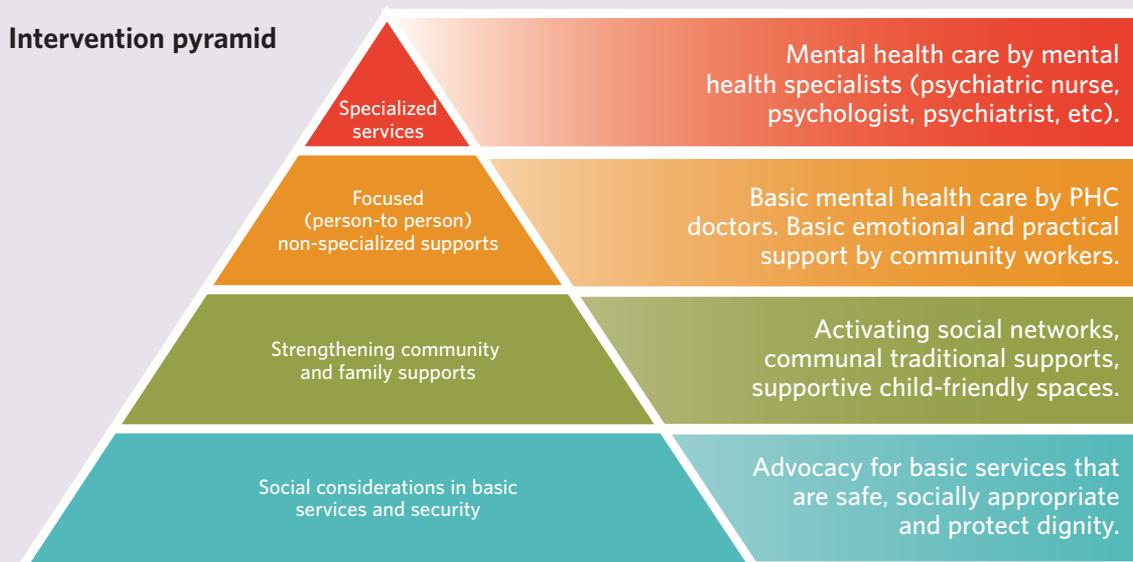
## Putting into Practice

### IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings.

This provides important guidance for both emergency and non-emergency settings on the provision of quality mental health and psychosocial support. The guidelines visually explain how service providers and support staff can understand the psychosocial needs of GBV victims/survivors when developing their programming.<sup>361</sup>

The image of a four-level pyramid identifies the service needs of GBV victims/survivors and provides examples. The base of the pyramid consists of “social considerations in basic services and security,” and includes the example of “advocacy for basic services that are safe, socially appropriate, and

protect dignity”. The second level consists of “strengthening community and family supports,” and provides the examples of “activating social networks,” “communal traditional supports,” and “supportive child-friendly spaces”. The third level consists of “focused (person-to-person) non-specialized supports,” and includes the examples of “basic mental health care by (primary health care) doctors”, and “basic emotional and practical support by community workers”. The fourth level at the point of the pyramid consists of “specialized services,” and provides the example of “mental health care by mental health specialists (psychiatric nurse, psychologist, psychiatrist, etc.)”.<sup>362</sup>



### 3.7.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based rehabilitation services for women and young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators for rehabilitation service provision should take. Service providers should tailor the indicators to appropriately fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Percentage of mental health service providers trained to provide mental health services to women and young persons with disabilities who have experienced violence.
- Service provider has a standard operating procedure that includes procedures for provision of rehabilitation services for women and young persons with disabilities.
- Agency's policies allow sufficient flexibility to promote full participation and meet needs of victims/survivors with disabilities (e.g., by allowing staff to meet victims/survivors at accessible locations, allowing non-offending personal assistants to accompany victims/survivors).<sup>363</sup>

## 3.8 GBV Services for Women and Young Persons with Disabilities Living in Institutional Settings

### 3.8.1 Issue Overview

Persons with disabilities receive care, services, and support from a variety of institutions. Women and young persons with disabilities,

particularly those with psychosocial or intellectual disabilities, regularly still live in large institutions, hospitals, or nursing homes. Children with disabilities are often placed in what are known as 'custodial facilities' such as orphanages and other institutional settings. Others may live in the community but reside in group homes, which are generally residences administered by a third party with multiple residents. Other institutions women and young persons with disabilities engage with include day programmes, youth programmes, and sometimes prisons and jails. This range of institutions share one or more of the following characteristics: they are certified by the State or a State agency; are subject to State rules and regulation; are subject to monitoring; are staffed by caregivers unrelated to the person with a disability; do not give the person with the disability the power to hire and terminate caregiving staff; and/or restrict the person with the disability's freedom of choice and independence while residing in the institution.

Women and young persons with disabilities living in institutions have the same right to be free from GBV as individuals with and without disabilities living outside of institutions. Yet, persons with disabilities living in institutions are frequently isolated, increasing their vulnerability to violence.<sup>364</sup> Women and young persons with intellectual disabilities are particularly at risk. One report from the European Parliament found that almost 80 per cent of woman with disabilities had been victims of violence, the majority of whom lived in institutions, and that women with disabilities were up to four times more at risk of sexual violence than their peers without disabilities.<sup>365</sup> The report also found that for

women living in institutions, violence was often perpetrated by staff and caregivers.<sup>366</sup> Given the unique power dynamics and special circumstances in institutional settings, there are additional human rights obligations to ensure independent and effective monitoring of these institutions.<sup>367</sup>

Children and young persons in alternative care, particularly those with disabilities, are especially vulnerable to violence.<sup>368</sup> Factors that increase this vulnerability include lack of legal protections, community prejudices against persons with disabilities, lack of research, and impunity for perpetrators. Increasingly, institutionalization of children with and without disabilities is being recognized as a human rights violation. UNICEF and other UN agencies have called for an end to institutionalization of children. The UN Special Rapporteur on Torture published a report documenting the torture and ill-treatment of children in institutions.<sup>369</sup>

### 3.8.2 Guidelines on Providing Rights-Based GBV Services for Women and Young Persons in Institutions

The key considerations enumerated here identify common issues encountered by women and young persons with disabilities residing in institutional settings. The guidelines for action offer guidance for ensuring that rights-based services tailored to the specific needs and experiences of women and young persons with disabilities living in institutions are available, accessible, acceptable, and of good quality. These guidelines for action build on the Foundational Guidelines

for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

#### **Key Considerations**

- Women and young persons with disabilities who experience violence in institutions may behave in violent or aggressive ways themselves as a result. Service providers and support staff who do not associate persons with disabilities as being victims/survivors of GBV may fail to recognize this as a sign of being a victim/survivor. Thus, violence may go undetected and institutionalized women and young persons with disabilities excluded from essential health, justice and policing, protective, and rehabilitative GBV services.
- Policies and certification requirements are not effectively enforced or monitored by independent bodies,<sup>370</sup> which means institutions are left to monitor themselves. Given that most violence in institutions is perpetrated by internal caregivers, inadequate external independent monitoring can lead to impunity and inaction.
- Monitoring visits and inspections of institutions are generally ineffective at identifying and responding to violence.<sup>371</sup> This contributes to perpetrator impunity and increases the isolation of women and young persons experiencing GBV.
- Laws and policies often promote or fail to prevent forced institutionalization of women and young persons with disabilities.

- Peer-to-peer violence can occur in institutional settings, particularly where there is overcrowding, or staff are ill-equipped to support a person's disability.<sup>372</sup> This violence can result in both people being traumatized, with neither person receiving the services they require.
- Institutional staff often lack the time or capacity to educate, recognize, or provide GBV services or information about gender-based violence to persons with disabilities in institutions. This is particularly so for young men with disabilities, because of the lack of awareness and understanding of GBV against men.
- Isolation in institutional settings increases the vulnerability of women and young persons with disabilities to violence and obstructs access to GBV services.<sup>373</sup>
- Certain institutional settings, such as prisons, schools, religious institutions, and armed services, can introduce young men with and without disabilities to violence, which perpetuate GBV.
- Women and young persons with disabilities in institutions face increased barriers to communicating the violence they are experiencing because they lack access to a private phone, do not have the opportunity to be alone or away from a perpetrator who is staff person at the facility, or are illiterate.<sup>374</sup>
- GBV services for women and young persons with disabilities in institutions can face barriers to funding, as service providers may be fearful of diverting general GBV resources to specialized services. This is particularly the case relating to services for men.

## Guidelines for Action:

### ► **Availability**

1. Develop training and support programmes to empower families and caregivers of women and young persons with disabilities to care for them in community-based homes or in their own home to reduce reliance on institutionalization. Diverting institutionalization of persons with disabilities should be a priority.
2. Create programmes that support women and young persons with disabilities to build relationships, friendships, and community-based support networks. In one survey in the UK of 1,004 people with a range of disabilities, 53 per cent reported feeling lonely, while 6 per cent reported feeling that they had no friends at all.<sup>375</sup> For the young persons surveyed, 77 per cent reported feeling lonely.<sup>376</sup> Unfortunately, many women and young persons with disabilities may not have a supportive family who can provide a foundation for their community-based living, but programmes like these can nurture a support circle of friends.

### ► **EXAMPLE:**

*The **Lao Disabled Women's Developmental Centre** is a non-profit organization run by and for Lao women with disabilities. Through practical vocational training and employment opportunities, the women create and sell handicraft products while continuing to train new students. The centre both empowers women with disabilities and fosters peer support networks that provide friendship and support.<sup>377</sup>*

3. Develop programmes to assist women and young persons with moving out of institutional settings and into community-based homes. Available services should include mechanisms to access community-based care and supports to live as independently as possible in the community and prevent return to institutionalization.<sup>378</sup>
4. Develop training programmes targeted at women and young persons in institutional settings to assist them with learning about their rights and about available GBV services. These trainings should:
  - Provide accessible information about the right to be free from GBV, SRHR, and other fundamental human rights.
  - Provide accessible information about alternatives to institutional settings and services available to assist a person with finding a community-based home.
  - Take place in institutions as much as possible to remove the barrier of transportation and to educate institutional staff about GBV.
  - Offer referral services.

### Guidelines for Action:

#### ► **Accessibility**

1. Offer free accessible hotlines available to women and young persons with disabilities living in institutions. Develop other creative strategies with the assistance of institutionalized or formerly institutionalized women and young persons with disabilities for how institutionalized women and young persons can report violence and access services.

2. As much as possible, offer GBV services that come to women and young persons with disabilities in institutional settings rather than external services requiring transport.<sup>379</sup>

### Guidelines for Action:

#### ► **Accessibility**

1. Schedule regular in-person visits to institutions with service providers trained in a variety of communication methods.
2. Incorporate services to prevent forced sterilization or contraception into GBV programmes. The sterilization of women with disabilities in institutions as a means of covering up sexual abuse—or preparing for what is viewed as inevitable sexual abuse—has been documented in institutions around the world.<sup>380</sup> GBV service providers and support staff must understand the scope of this problem and be prepared to provide appropriate services to institutionalized women with disabilities to screen for and protect against forced sterilization and forced contraception.
3. Establish mechanisms that assist women and young people with disabilities and their family members/advocates to meaningfully participate in placement decisions.<sup>381</sup> However, ensure that these programmes include and prioritize community based and independent living situations.
4. Advocate for an independent, confidential and accessible complaint mechanism to enable institutionalized women and young persons with disabilities to register complaints about GBV in institutions.<sup>382</sup>

## Guidelines for Action:

### ► **Quality**

1. Collect data on women and young persons receiving care in institutional settings.<sup>383</sup>  
This information is critical to improving and designing systems that minimize the risk of violence and ensure that GBV services reach those who need them.
2. Develop and administer programmes for institutional service providers and support staff designed to improve quality of care and reduce the risk of GBV for institutionalized women and young persons with disabilities. Quality of care is directly linked to the vulnerability of women and young persons with disabilities to violence.<sup>384</sup> Training should be conducted in whole or part by persons with disabilities. Specifically, training should address:
  - The intersectional needs and experiences of each individual.
  - The risks facing men.
  - Alternatives to institutionalization.
3. Build the capacity of independent monitoring bodies, such as an ombudsperson or a dedicated oversight agency or organization, to identify GBV among institutionalized women and young persons with disabilities and to provide services or referrals to GBV victims/survivors with disabilities. Advocate for quality and transparent State-sponsored monitoring, as appropriate. Service providers and support staff can look to guidelines such as the 'Guidelines for the Alternative Care of Children,' promulgated by the UN General Assembly for standards for residential care.<sup>385</sup>

### ► **EXAMPLE:**

*In Moldova, the UN Partnership to Promote the Rights of Persons with Disabilities (UNPRPD) led a project to support the creation of the Office of the Ombudsperson for Psychiatric Hospitals, an independent complaint mechanism. Tasked with visiting psychiatric institutions and long-stay mental hospitals to investigate allegations of mistreatment and forced detention, the ombudsperson received more than 12,000 complaints from 3,665 people over three years. The ombudsperson is mandated to carry out regular monitoring visits and has unhindered access to all patients who want to approach the ombudsperson for a confidential discussion. The ombudsperson has significantly enhanced access to justice for Moldovans with mental and intellectual disabilities living in institutions.<sup>386</sup>*

4. Advocate for behavioural health courts and other specialized courts. Offer training for officials involved in the justice system to educate officials about alternatives to institutionalization and incarceration of women and young persons with disabilities.
5. Engage family members of people in institutions (unless the person with the disability opposes the involvement of their family member). Services providers and support staff should offer or refer family members to services to assist them with helping their family member with a disability navigate the GBV system, as needed and requested.

6. Assess the laws and policies that contribute to institutionalization and develop strategies to advocate for legal and policy changes, including advocating as necessary against forced institutionalization.<sup>387</sup>

### 3.8.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based GBV services for women and young persons with disabilities living in institutions. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators should take for GBV services in institutional settings. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Percentage of women or young persons with disabilities living in community-based homes.
- Percentage of institutional service providers offering accessible training on the rights of institutionalized persons every six months. The training includes information about SRHR, the right to be free from GBV (including explanation of different forms of violence), and education on healthy sexuality and relationships.
- Percentage of institutional service providers and support staff with resources to help them provide crisis intervention services when they learn of sexual violence against women and young persons with disabilities living in the institution.

- Percentage of GBV incidents investigated by a facility-monitoring body and found to be unsubstantiated and the percentage of GBV incidents investigated and found to be substantiated.

## 3.9 Access to GBV Services for Adolescents and Youth with Disabilities

### 3.9.1 Issue Overview

The period between ages 10 and 24 is a pivotal time of development for any person, and no less so for those with disabilities. During that period, girls and boys experience puberty and go through significant physical, mental, and emotional changes. Throughout this development period, young persons with disabilities are just as likely to become sexually active as their peers without disabilities and to form intimate relationships. Yet, young persons with disabilities are often excluded from comprehensive sexuality education or other educational programmes that can empower them to develop healthy relationships or to recognize and report GBV. Moreover, young persons with disabilities are more likely to be isolated in homes or institutions than adults with disabilities. These factors make young persons with disabilities uniquely vulnerable to violence.

It is essential to tailor GBV prevention strategies to the specific vulnerabilities that young persons with disabilities face and to ensure that young persons with disabilities, both those living in the community and those in institutional settings, have access to essential GBV services, including health services, justice and policing services, protection services, and rehabilitation services.

### 3.9.2 Guidelines on Providing Adolescent- and Youth-Friendly Rights-Based GBV Services to Young Persons with Disabilities

The key considerations enumerated here identify common barriers that young persons with disabilities encounter in accessing essential GBV services. The guidelines for action offer guidance for ensuring that rights-based GBV services tailored to the specific needs and considerations of young persons with disabilities are available, accessible, acceptable, and of good quality. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

#### **Key Considerations**

- Lack of participation by young persons with disabilities in the development of national plans, policies, and programmes on GBV services result in plans, policies, and programmes that effectively exclude young persons with disabilities.
- Young persons with disabilities are at heightened risk for harmful practices, such as child marriage and virgin rape.<sup>388</sup> Inadequate laws and policies aimed at preventing GBV, protecting young persons with disabilities from sexual and GBV, and punishing perpetrators contribute to impunity and exacerbate these risks.
- Parents, guardians, or other caregivers can be overprotective and may not want young persons with disabilities who are in their care to participate in comprehensive sexuality education programmes for fear it will increase their sexual activity. This type of gatekeeping denies young persons with disabilities the opportunity to learn how to develop healthy relationships, understand what constitutes appropriate touch, and learn to avoid, recognize, and report instances of exploitation, violence, and abuse.
- Stereotypes or misperceptions that young persons with disabilities are asexual or that they do not have intimate relationships can prevent service providers and support staff from identifying them as having needs relating to GBV.
- Young persons with disabilities are often isolated in their homes or in institutions, where families or caregivers can act as gatekeepers to services, including opportunities to be screened for GBV.
- Inadequate training, counselling, financial support, and respite care for families and caregivers of young persons with disabilities can exacerbate risks of violence.
- Young persons with disabilities may fear institutionalization if they report abuse by family members or caregivers, which can deter them from reporting violence.
- Young persons with disabilities often lack a way to communicate privately with GBV service providers and support staff and may have concerns about the confidentiality of their conversations.
- Adolescents, especially marginalized adolescents like those with disabilities, are at increased risk of GBV during humanitarian emergencies due to the increased risk of sexual exploitation and abuse, lack of SRHR services, and disruption of SRHR services during humanitarian emergencies.<sup>389</sup>

## Guidelines for Action:

### ► **Availability**

1. Advocate for and implement GBV laws and policies that specifically address and incorporate young persons with disabilities and their experiences.<sup>390</sup>
2. Offer programmes to support, educate, and provide respite care for parents, families and other caregivers of young persons with disabilities.<sup>391</sup>
3. Develop programmes to train teachers, school officials, police, and other figures of authority who encounter young persons with disabilities to understand the risk of violence they face and to recognize and report GBV where it occurs.
4. Advocate for the appointment of a public official specializing in harmful practices.<sup>392</sup> Educate public officials about harmful practices and how they affect young persons with disabilities.
5. Make community services and leaders available to intervene and provide mediation, education, and support to young persons with disabilities and their families when a young person with a disability is at risk of a harmful practice.<sup>393</sup>
6. Develop protection services that specifically cater to young persons with disabilities experiencing GBV.<sup>394</sup> For example, ensure that emergency shelters and other safe housing are designed to accommodate young persons with disabilities and their educational and developmental needs.
7. Prioritize programmes aimed at securing the safety of children with disabilities during

humanitarian emergencies, particularly those living in institutions.<sup>395</sup>

## Guidelines for Action:

### ► **Accessibility**

1. Distribute accessible GBV information for young persons with disabilities through social media platforms and other forms of technology.

### ► **EXAMPLE:**

*UNICEF has successfully utilized technology to spread information and empower young persons using **U-Report** in Uganda. U-Report is a free SMS social monitoring tool designed to engage users in issues they care about. For example, one female user in Uganda reported that she used the platform to share her experience of being raped with other U-Reporters, which allowed the girl and her peers on the platform to encourage one another and offer support. U-Report has also been used to improve access for girls with disabilities to education, to promote self-acceptance, and to create peer networks between young persons with and without disabilities.<sup>396</sup>*

2. Actively engage young persons with disabilities in the design, implementation and evaluation of GBV programmes to ensure accessibility.<sup>397</sup> For example, ensure that easy read versions are available and understandable to young persons with intellectual disabilities.
3. Offer services in the home or another safe, accessible space within the community, rather than depending on families or caregivers to bring a young person with a disability to a facility or clinic to receive services.

4. Foster participation of young persons with disabilities in community-based programme development.

► **EXAMPLE:**

*The Women's Refugee Commission and ChildFund's 'Toolkit for Child Protection Actors' was designed for humanitarian and development staff to strengthen capacity in disability inclusion, identify GBV needs, and engage children with and without disabilities in programme planning, implementation, and monitoring. It includes a participatory process, which facilitates informed consent and risk mitigation, and a Communication Toolbox which children and youth can use, combine, and adapt to collect and convey information about GBV risks and programming strategies to decision-makers.*<sup>398</sup>

5. Raise awareness among young persons with disabilities, along with their families, caregivers and health personnel, about the rights of young persons to be free from GBV, including harmful practices, and the availability of essential services.<sup>399</sup>

### Guidelines for Action:

► **Acceptability**

1. Offer training about young persons with disabilities to GBV service providers and support staff and the community in general.<sup>400</sup> Include young persons with disabilities as presenters as much as possible.
2. Treat young persons with disabilities who are seeking services with respect and protect their confidentiality. Young persons worldwide have identified this treatment as essential to making services adolescent and youth friendly.<sup>401</sup>
3. Mentor and develop young persons with disabilities to become peer educators to share GBV information with other young persons with disabilities.
4. Train service providers and support staff on how to identify and recognize signs of GBV against young persons with disabilities, particularly relating to potential GBV from a caregiver. Programmes should directly address the power dynamics between young persons with disabilities and caregivers.
5. Develop relationships with comprehensive sexuality education service providers. Train educators on teaching students with disabilities about healthy relationships and GBV, including how to give and receive consent for sexual contact. GBV service providers can also play an important role in helping to teach young persons with disabilities about how to develop healthy relationships, understand what an appropriate touch is, understand consent, recognize and report GBV, and understand and access available GBV services. For more information, see Comprehensive Sexuality Education for Women and Young Persons with Disabilities (Section 4.5).
6. Create campaigns and programmes that improve understanding and visibility of GBV against young persons with disabilities. These should address misconceptions about sexuality and disabilities, such as the myth that persons with disabilities are asexual or cannot develop intimate relationships.<sup>402</sup> Incorporate young

persons with disabilities into campaigns for adolescents and youth with and without disabilities.

### Guidelines for Action:

#### ► **Quality**

1. Ensure that adolescent- and youth-friendly GBV services include age-appropriate social services, counselling, information, and referrals to help young persons with disabilities cope with the violence and break the cycle of violence.<sup>403</sup>
2. Develop, support, and engage organizations led by young persons with disabilities and peer support groups. Programmes like these are critical partners for disseminating information about GBV and connecting young persons with disabilities with services. Members with and without disabilities should be encouraged to join and develop peer networks. Engagement should focus on understanding and addressing the social and structural discrimination young persons with disabilities face in accessing services.<sup>404</sup>
3. Develop safeguards with medical service providers to ensure that children with disabilities are registered at birth. Young persons without birth certificates are more vulnerable to harmful practices, and children with disabilities are often not registered.<sup>405</sup>
4. Offer accessible GBV crisis hotlines tailored for young persons with disabilities to receive effective referrals, including options for callers who are Deaf, have communication difficulties, or have an intellectual disability.
5. Advocate for mandatory training about harmful practices and the rights of young persons with disabilities for health care service providers and religious, customary, community and traditional leaders.<sup>406</sup>
6. Conduct further research and collect data about GBV experienced by young persons with disabilities.<sup>407</sup>

### 3.9.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based services for young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that should be taken for indicators around youth-friendly GBV services should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Percentage of girls, boys, young women, and young men with disabilities (ages 10-24) who know their rights and entitlements.<sup>408</sup>
- Percentage of available places for young persons with disabilities (ages 10-24) in shelters and refuges per 1,000 population (urban and rural).<sup>409</sup>
- Percentage of young persons with disabilities (ages 10-24) who participate in comprehensive sexuality education or life skills programmes that address healthy relationships and GBV.<sup>410</sup>
- Legislation prohibits harmful practices (e.g. female genital mutilation and cutting; child and forced marriage).





## Sexual and Reproductive Health and Rights Services for Women and Young Persons with Disabilities

### 4.1 Background

Women and young persons with disabilities have the same right to reproductive and sexual health as persons without disabilities, but they are regularly excluded from services necessary to achieve their reproductive and sexual health because of a variety of factors. Reproductive health refers to the “state of complete physical, mental and social well-being, not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capacity to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are: the rights of men and women

to be informed, have access to safe, effective, affordable, and acceptable methods of family planning, including methods for regulation of fertility, which are not against the law, and the right of access to appropriate healthcare services to enable women to have a safe pregnancy and childbirth and provide couples with the best chance of having a healthy infant”.<sup>411</sup> Sexual health, which is also a component of reproductive rights, comprises of “the enhancement of life and personal relations, not merely counselling and care related to reproduction and sexually transmitted infections. It refers to the integration of the somatic, emotional, intellectual and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love”.<sup>412</sup>

## Key SRHR Guidance

These Guidelines should be read in tandem with and complimentary to the influential 2018 Guttmacher–Lancet Commission report, *'Accelerate Progress - Sexual and Reproductive Health and Rights for All: Report of the Guttmacher–Lancet Commission'*.<sup>413</sup> The report from the Commission — a commission made up of global health, development and human rights experts from around the world — lays out an agenda for national governments, international agencies, donors, civil society groups and other key stakeholders to achieve universal access to SRHR, explicitly including persons with disabilities. The report highlights the importance of considering the particular SRHR needs of persons with disabilities and the dearth of substantive research and data

on the SRHR of persons with disabilities.<sup>414</sup> For example: “People living with disabilities are another underserved population subjected to harmful stereotypes and myths. They have similar SRHR needs as able-bodied people; however, they are much more likely to be victims of physical and sexual abuse and rape, even by their caretakers in some situations. They are also more likely to be subjected to forced or coerced procedures, such as sterilisation, abortion, and contraception. Inadequate information and a paucity of targeted resources contribute to this group’s vulnerability; these disadvantages begin early in life and continue in adulthood”.<sup>415</sup>

## Barriers

Women and young persons worldwide, both with and without disabilities, encounter legal and practical barriers to SRHR information and services. These barriers are exacerbated for women and young persons with disabilities. Common barriers include: lack of training or awareness raising among service providers and support staff on how to serve persons with disabilities<sup>416</sup> (for instance, one study in the United States found that 40–50 per cent of gynecologists felt somewhat to completely unprepared to treat adolescents with disabilities<sup>417</sup>); failure to consider disability-related accessibility in developing programmes or building facilities<sup>418</sup>; poverty/socio-economic marginalization; isolation of

women and young persons with disabilities living in institutions, camps, family homes, group homes<sup>419</sup> or who are homeless; and stereotypes about women and young persons with disabilities that lead service providers and support staff to assume women and young persons with disabilities are unable to make their own decisions, are asexual or hypersexual, cannot become pregnant, or are incapable of parenting.

Humanitarian emergencies increase these exclusionary factors and exacerbate their impact. Additional demands on the system result in de-prioritization or failure to develop disability-inclusive services, more

pronounced accessibility barriers, and increased isolation and vulnerability. The cultural, political, and security climate of the country where the humanitarian aid is taking place can also increase barriers to essential services.

### **Increased Risk**

Lack of access to essential SRHR information and services increases the vulnerability of women and young persons with disabilities to sexual abuse, sexually transmitted infections (STIs), unintended pregnancy,<sup>420</sup> and adverse birth outcomes (for mother and baby); it also denies them their right to the highest attainable standard of sexual and reproductive health. In addition to being excluded from these critical health services, women and young persons with disabilities are often subject to coercive healthcare practices and medical procedures, such as forced sterilization, forced abortion, and forced contraception,<sup>421</sup> as well as disrespectful and abusive treatment. Substituted decision-making systems, in particular, have been associated with heightened rates of abuse of persons with disabilities, allowing parents or guardians to subject women and young persons with disabilities to medical procedures against their will.<sup>422</sup> Adolescent girls with disabilities are especially at risk of forced sterilizations and forced abortions,<sup>423</sup> and women and adolescent girls with disabilities are more likely to have hysterectomies at a younger age and for a non-medically necessary reason, including by request of a parent or guardian.<sup>424</sup>



A young couple embracing at night in the city.  
© LWA/Dann Tardif/Getty Images

The guidelines in this section are organized according to different SRHR services that women and young persons with disabilities may require. While not exhaustive, the below subsections address key service areas from which women and young persons with disabilities are regularly excluded. To ensure a continuum of care across all areas of SRHR services for women and young persons with disabilities, each of these service-area subsections should be read in conjunction with the other subsections.

## HUMANITARIAN EMERGENCIES

### Key Concept: SRHR Minimum Standards

Ensure that minimum standards are followed for all services offered and provided to women and young persons with disabilities. The Inter-Agency Working Group on Reproductive Health in Crises, of which UNFPA is a member, developed a comprehensive Minimum Initial Service Package to respond to reproductive health needs at the onset of a humanitarian crisis.<sup>425</sup> These standards are not tailored for persons with disabilities, so service providers should work with women and young persons with disabilities to understand how to implement these standards with the adaptations and accommodations required by women and young persons with disabilities.

### UNFPA Minimum Initial Service Package (MISP):<sup>426</sup>

#### 1. Identify an agency to lead the implementation of the MISP

- a. Appoint a reproductive health officer
- b. Coordination of reproductive health services
- c. Reproductive health officer reports back to health cluster or sector
- d. Reproductive kits and supplies are made available

#### 2. Prevent and manage the consequence of sexual violence

- a. Protection system in place, especially for women and adolescent girls
- b. Medical services and psychological support available for survivors
- c. Community aware of services

#### 3. Reduce transmission of HIV

- a. Safe blood transfusion available
- b. Standard precautions practiced
- c. Free condoms available

#### 4. Prevent maternal and infant mortality

- a. Emergency obstetric and newborn care services available.
- b. 24/7 referral system established
- c. Clean delivery kits provided to skilled birth attendants and visibly pregnant women
- d. Community aware of services

#### 5. Plan for comprehensive reproductive health services integrated into primary healthcare

- a. Background data collected
- b. Sites identified for future delivery of comprehensive reproductive health
- c. Staff capacity assessed and trainings planned
- d. Reproductive health equipment and supplies ordered

## 4.2 SRHR Human Rights Framework

Sexual and reproductive health and rights encompass both freedoms, such as the freedom to make decisions about whether and when to reproduce free from coercion or violence, and entitlements, such as access to the full range of essential SRHR services. These rights are underpinned by the following fundamental human rights:

- The rights to life and health, including sexual and reproductive health, protected in the International Covenant on Civil and Political Rights (ICCPR),<sup>427</sup> the International Covenant on Economic, Social, and Cultural Rights (ICESCR),<sup>428</sup> Convention on the Rights of Persons with Disabilities (CRPD),<sup>429</sup> Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),<sup>430</sup> and the Convention on the Rights of the Child (CRC).<sup>431</sup>
- The rights to privacy, liberty and security of the person, and to decide the number and spacing of children, protected in the ICCPR,<sup>432</sup> CRPD,<sup>433</sup> CEDAW,<sup>434</sup> and the CRC.<sup>435</sup>
- The rights to information and education, including information and education on sexual and reproductive health, protected in the ICESCR,<sup>436</sup> CRPD,<sup>437</sup> CEDAW,<sup>438</sup> and the CRC.<sup>439</sup>
- The right to equality and non-discrimination, protected in the ICCPR,<sup>440</sup> the ICESCR,<sup>441</sup> CRPD,<sup>442</sup> CEDAW,<sup>443</sup> and the CRC.<sup>444</sup>
- The right to enjoy the benefit of scientific progress, protected in the ICESCR.<sup>445</sup>
- The right to be free from torture or cruel, inhuman or degrading treatment or

punishment which is protected in the ICCPR,<sup>446</sup> the Convention against Torture and other Cruel, Inhuman, and Degrading Treatment or Punishment (CAT),<sup>447</sup> the CRPD,<sup>448</sup> and the CRC.<sup>449</sup>

- The right to consent to marriage and to equal rights within marriage, protected in the ICCPR,<sup>450</sup> the ICESCR,<sup>451</sup> CEDAW,<sup>452</sup> and the CRPD.<sup>453</sup>
- The right to accessibility, protected in the CRPD.<sup>454</sup>
- The right to protection and safety for persons with disabilities in situations of risk, including humanitarian emergencies, protected in the CRPD.<sup>455</sup>
- The right to reasonable accommodation where needed, enumerated in the CRPD.<sup>456</sup>

A key underpinning of the right to health—and accordingly, the right to sexual and reproductive health—is the obligation that health-related information, goods, and services be available; accessible; acceptable; and of good quality, collectively known as the AAAQ framework.<sup>457</sup>

The AAAQ framework describes the requirements for services that States must abide to fulfil their obligations to respect, protect, and fulfil SRHR.<sup>458</sup>

The AAAQ framework requires information, goods and services to be:<sup>459</sup>

- **Available**, meaning that information, goods, and services exist in sufficient quantity across a country. This includes having enough trained service providers and appropriate healthcare facilities equitably distributed.

- **Accessible**, meaning the information, goods, and services can be used by all persons with disabilities. The requirement of accessibility includes physical accessibility, economic accessibility, and information accessibility.
- **Acceptable**, meaning that health information, goods and services conform to ethical standards, are culturally respectful, sensitive to the gender and disability needs of the individual, and respectful of a person's privacy and confidentiality.
- **Quality**, meaning that health information, goods and services are scientifically and medically appropriate and delivered by trained personnel in a respectful and rights-based manner.
- To enact and enforce the legal prohibition of harmful practices and gender-based violence—including female genital mutilation, child marriage and forced marriage, and domestic and sexual violence, including marital rape—while ensuring privacy, confidentiality, and free, informed, and responsible decision-making, without coercion, discrimination, or fear of violence, in relation to the sexual and reproductive needs and behaviours of individuals.
- To take measures to prevent unsafe abortions and to provide post-abortion care and counselling for those in need.
- To ensure all individuals and groups have access to comprehensive sexuality education and information on sexual and reproductive health that are non-discriminatory, non-biased, and evidence-based, and that take into account the evolving capacities of children and adolescents.

Furthermore, the Committee on Economic, Social, and Cultural Rights has identified the following minimum core obligations:

- "To repeal or eliminate laws, policies and practices that criminalize, obstruct, or undermine access by individuals or a particular group to sexual and reproductive health facilities, services, goods, and information.
- To adopt and implement a national strategy and action plan, with adequate budget allocation, on sexual and reproductive health, which is devised, periodically reviewed, and monitored through a participatory and transparent process, disaggregated by prohibited grounds of discrimination.
- To guarantee universal and equitable access to affordable, acceptable and quality sexual and reproductive health services, goods and facilities, in particular for women and disadvantaged and marginalized groups.
- To provide medicines, equipment and technologies essential to sexual and reproductive health, including those based on the WHO Model List of Essential Medicines.<sup>[460]</sup>
- To ensure access to effective and transparent remedies and redress, including administrative and judicial ones, for violations of the right to sexual and reproductive health".<sup>461</sup>

The UN Committee on the Rights of Persons with Disabilities has emphasized that States must ensure that women with disabilities can exercise their legal capacity particularly in regard to decisions relating to their SRHR,<sup>462</sup> including their right to found a family and raise their children.<sup>463</sup>



Judith, a young woman laughs and waits for customers at her mandazi (doughnut stand) in Uganda.

© 2013 d'Arcy Lunn, Courtesy of Photoshare

With regard to the SRHR of adolescents in particular, the UN Committee on the Rights of the Child urges States to:

- Adopt “comprehensive gender and sexuality-sensitive sexual and reproductive health policies for adolescents,” particularly for adolescent girls.<sup>464</sup>
- Provide all adolescents “access to free, confidential, adolescent-responsive, and non-discriminatory sexual and reproductive health services, information, and education, available both online and in person, including on family planning, contraception, including emergency contraception; prevention; care and treatment of sexually transmitted infections; counselling; pre-conception care; maternal health services; and menstrual hygiene”.<sup>465</sup>
- Ensure that adolescents, particularly adolescent girls with disabilities, do not face barriers to “commodities, information and counselling on SRHR, such as requirements for third-party consent or authorization”.<sup>466</sup>
- “Review legislation with a view to guaranteeing the best interests of pregnant adolescents and ensure that their views are always heard and respected”.<sup>467</sup>
- Offer “[a]ge-appropriate, comprehensive and inclusive sexual and reproductive health education, based on scientific evidence and human rights standards and developed with adolescents...[as] part of the mandatory school curriculum and [should] reach out-of-school adolescents”. Special attention should be given to topics such as gender equality and preventing early pregnancy and sexually transmitted infections. The UN Committee on the Rights of the Child explicitly notes that, “information should be available in alternative formats to ensure accessibility to all adolescents, especially adolescents with disabilities”.<sup>468</sup>

## HUMANITARIAN EMERGENCIES

### Disability and Emergency Risk Management for Health

The WHO and partners' *'Guidance Note on Disability and Emergency Risk Management for Health'*,<sup>469</sup> enumerates the following principles for designing and implementing all disability-inclusive emergency risk management measures:

- Equality and non-discrimination: All measures must be inclusive, particularly for those whose disabilities makes them especially vulnerable.
- Accessibility: Ensure equal access to all physical sites, information, communications, and systems in all areas including urban and rural.
- Participation and dignity: Engage persons with disabilities in the assessment, design, implementation, and monitoring of emergency programmes and enable and respect the participation of persons with disabilities before, during, and after an emergency situation.
- Resourcefulness and capacity: "Many persons with disabilities have existing resources and capacities to make meaningful contributions to emergency risk management. They also have the right to receive support and assistance to develop the skills, knowledge and capacities required to prepare and protect themselves from hazards, and to maximize their ability for survival and recovery following an emergency".<sup>470</sup>

For additional detailed guidance on practical implementation, refer to the Guidance Note's annexed guides such as *'How to make services in health-related sectors inclusive of people with disabilities'*<sup>471</sup> and *'Disability and emergency risk management: checklist of minimum actions required by the health sector'*.<sup>472</sup>

### 4.3. Contraceptive Information, Goods, and Services for Women and Young Persons with Disabilities

#### 4.3.1 Issue Overview

Access to contraceptive information, goods, and services is one of the fundamental pillars of SRHR services. Contraceptive access helps women and young persons with disabilities decide whether and when to have children, prevent unintended pregnancies (and the attendant risks of maternal/newborn mortality or morbidity), and protect against STIs, including HIV. Women and young persons with disabilities have a right to equal access to voluntary family planning and modern contraceptive methods, as well as counselling on how to safely and effectively use them. This includes access and training on how to use emergency contraceptives. The full range of modern contraceptive methods to which persons with disabilities should have access includes: barrier methods (male and female

condoms, diaphragms), short-acting hormonal methods (the pill, injectables, the vaginal ring), long acting reversible methods (implants, intrauterine devices), permanent methods (male and female voluntary sterilization), and emergency contraception.<sup>473</sup> Women and young persons with disabilities must also have access to accurate, evidence-based information about family planning methods, including the basal temperature method, two day method, and standard day method.<sup>474</sup> Women and young persons with disabilities must be allowed and supported to make their own decisions around whether to use contraceptives and which method is best for them. No individual with a disability should undergo sterilization or be given contraception without their voluntary and fully informed consent. Safeguarding women and young persons with disabilities from forced contraception, including forced sterilization, is essential to preserving their right to be free from torture or cruel, inhuman or degrading treatment or punishment.

*Women and young persons with disabilities have a right to equal access to voluntary family planning and modern contraceptive methods, as well as counselling on how to safely and effectively use them.*

## SPOTLIGHT ISSUE

### Engaging Men in Family Planning

Engaging men as partners and to address their own SRHR needs is a critical part of improving SRHR. With respect to contraceptive information, goods, and services, it is essential that men, including young men and boys with disabilities, be informed about a range of contraceptive methods and how to use them, the importance of condoms to prevent transmission of sexually transmitted infections and unintended pregnancy, and the importance of consistent contraceptive use. Young men and boys with disabilities need to be able to discuss a range of issues around contraceptive use with their sexual partners, including contraceptive

methods and cost-sharing to ensure that the economic burden of contraceptive use does not always fall on female sexual partners. Service providers must also be conscious of the form their programming takes and ensure that it is not reliant on harmful gender stereotypes. Rather, programmes should be gender-sensitive or, better yet, gender-transformative. A gender-transformative programme promotes equitable gender-norms, such as a “condom campaign which promotes gender-equal relationships with shared decision-making and respect along with discussion around sexual and reproductive health and fertility intentions”.<sup>475</sup>

### 4.3.2 Guidelines for Providing Rights-Based Contraceptive Information, Goods, and Services for Women and Young Persons with Disabilities

The key considerations enumerated here identify common barriers that women and young persons with disabilities face in accessing contraceptive services. The guidelines for action offer guidance for ensuring that rights-based contraceptive services are available, are tailored to the specific needs of women and young persons with disabilities, are accessible, are acceptable, and are of good quality. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

The UNFPA and WHO *'Ensuring Human Rights within Contraceptive Service Delivery: Implementation Guide'*<sup>476</sup> and a companion checklist from WHO, *'Quality of Care in Contraceptive Information and Services, Based on Human Rights Standards: A Checklist for Health Care Providers,'*<sup>477</sup> offer important guidance on implementation of rights-based contraceptive service delivery. Service providers should engage the expertise of women and young persons with various disabilities to develop and monitor programmes to implement the guidance in an accessible and disability-sensitive manner. The action points in the following section are drawn from the generalized action points contained in the Guide.

#### Key Considerations

- Laws and policies that allow parents, guardians, courts, and others to substitute their decision for that of a woman or young person with a disability regarding surgical sterilization, contraceptive use, or use of hormone therapies to regulate fertility, growth, or menstruation, violate the rights of women and young persons with disabilities and carry harmful physical, psychological, and emotional consequences. Forced sterilization is widely considered to be a form of torture or ill-treatment.<sup>478</sup>
- Substituted decision-making, paternalism, biased counselling, power dynamics, and lack of confidentiality in the provision of care can lead to forced contraception, including forced sterilization, of women and young persons with disabilities, with attendant consequences to their physical and mental health and well-being. Complaints about violations are regularly not taken seriously,<sup>479</sup> and there are rarely safe mechanisms for individuals to register a complaint.
- Laws and policies that limit access to contraception, such as laws requiring parental or spousal notification or authorization or laws prohibiting the distribution of emergency contraception, create enormous barriers to contraceptive access for women and young persons, and such restrictions can exacerbate the barriers that women and young persons with disabilities face in accessing contraceptive information, goods, and services.
- Negative attitudes and stereotypes about the sexuality of women and young persons with disabilities, including stereotypes

that individuals with disabilities are either hypersexual or asexual, can prevent persons with disabilities from receiving quality and appropriate contraceptive information, goods, and services. Service providers may neglect to share information about contraceptive use and methods with women and young persons with disabilities.

- Protocols and guidelines for emergency contraception seldom include provisions for ensuring availability to women and adolescent girls with disabilities, which can place them at increased risk of unintended pregnancy.
- Caregivers and family members may have negative views about women and young

persons with disabilities using contraceptives and can act as gatekeepers.

- Service providers are often unable to explain the various methods of contraception in an accessible way to women and young persons with disabilities. Not only does this prevent women and young persons from providing their informed consent, but it also deprives a person of the chance to understand and weigh the various pros and cons for different forms of contraceptives.
- Poverty, the physical environment of healthcare facilities, and isolation can prevent women and young persons with disabilities from accessing contraceptive information, goods, and services.



A mother and child from Benin sitting in a chair together. © UNFPA/Olivier Girard

## SPOTLIGHT ISSUE

### Sterilization

Forced sterilization of women and young persons with disabilities has been widely documented.<sup>480</sup> Sterilization is the irreversible “process or act that renders an individual incapable of sexual reproduction”.<sup>481</sup> Forced or coerced sterilization occurs when the surgery is performed without the free and informed consent of the person upon whom the procedure is performed. Forced sterilization also occurs when the procedure is performed without a person’s knowledge or situations where consent is provided by someone other than the person being sterilized. Coerced sterilization can occur whenever consent is obtained by intimidation, misinformation, or coercion. All individuals with disabilities—both female and male—are vulnerable to forced sterilization. Forced sterilization has been widely decried as a human rights abuse that amounts to torture<sup>482</sup> and a particularly pernicious form of GBV.<sup>483</sup>

Research demonstrates that persons with disabilities generally are sterilized for two principle reasons:

- Paternalistic and eugenics-based reasons grounded in the prejudiced belief that persons with disabilities cannot and should not have and raise children<sup>484</sup> and, relatedly, the belief that persons with disabilities cannot make decisions for themselves.

- For the convenience of caregivers and, in some cases, as a precaution to avoid unintended pregnancies because of the perceived inevitable sexual abuse that persons with disabilities are expected to experience.<sup>485</sup>

Service providers and support staff must take the risk of forced sterilization seriously and work with women and young persons, medical providers, families, and caregivers to educate them about the fertility rights of persons with disabilities. Service providers should ensure that women and young persons with disabilities who are seeking sterilization have been fully informed in a manner that they can understand about the risks and benefits of the procedure and alternative long-acting and reversible forms of contraception and that they are provided with the necessary supports to make such a decision. This is necessary for anyone to be able to grant their free and informed consent for such a procedure. At the same time, service providers and support staff must not let safeguards for preventing forced sterilization infringe on the rights of a woman or a young person with disability to provide her or his free and informed consent for voluntary sterilization.

To learn more about free and informed consent, see *Equal Recognition Before the Law* (Section 1.2).

## Guidelines for Action:

### ► **Availability**

1. Establish disability-sensitive protocols and guidelines on follow-up visits, management of side effects, and referrals and train service providers to implement the protocols and guidelines effectively. Protocols and guidelines should clearly establish a woman or young person's right to remove long-acting contraceptives and should also address follow-up procedures for persons living in institutional and isolated settings.

#### ► **EXAMPLE:**

*USAID and Handicap International's guide, 'Disability-Inclusive Sexual and Reproductive Health Component: Training of Trainers Manual on Disability—Inclusive HIV and Sexual and Reproductive Health for Health Workers',<sup>486</sup> offers a good example of how to train service providers about disability-inclusive family planning, including various contraception methods. The family planning component of this training teaches participants about the benefits and methods of family planning, why women and men with disabilities need family planning, family planning counselling applied to persons with disabilities, and specific considerations for patients with various disabilities. For example, the training teaches participants to better understand the factors influencing a woman's choice of family planning methods: "Physical disabilities may affect acceptability, safety, and appropriateness of certain methods. Intellectual disabilities may have an effect on informed consent for contraception. Some medications interact with hormonal methods of contraception. ... For example, women with*

*circulation or hypertension problems will not be prescribed contraceptive pills".<sup>487</sup>*

#### ► **EXAMPLE:**

*IPAS's guide, 'Access for Everybody: Disability Inclusion in Abortion and Contraceptive Care',<sup>488</sup> provides practical guidance for contraceptive programme implementers, managers, and trainers on disability-inclusive policies and service delivery.*

2. Particularly in humanitarian emergency settings, establish easy to navigate mechanisms for replacement of essential medicines and devices. Integrate replacement of contraceptives with the mechanisms to replace other necessary devices and medicines.
3. Ensure at least five modern contraceptive methods are available and in sufficient supplies.<sup>489</sup> Service providers must offer contraceptive methods in a range of formats, since some disabilities will preclude certain contraception options. For example, a woman without the use of her hands may not be able to utilize a female condom.

## Guidelines for Action:

### ► **Accessibility**

1. Create accessible informational materials tailored for women and young persons with different types of disabilities that address the range of contraceptive methods available.
2. Offer contraceptive information, goods, and services for women and young persons with disabilities in different models of service delivery to reach a wider population, including through health facilities,

community-based clinics, mobile clinics, community-health-worker programmes, referrals, and through other disability-related service providers.<sup>490</sup> Ensure that services are offered in isolated areas where women and young persons with disabilities reside, which do not require regular doctor visits. For example, train community health workers, especially community health workers with disabilities, to provide home-based contraceptive information and services or to accompany a woman or young person to referral services.

3. Where resources allow, subsidize contraceptive goods and services, including condoms, so they are free or at a low-cost for all low-income women and young persons, regardless of age, marital status, or disability.

### Guidelines for Action:

#### ► **Acceptability**

1. Establish protocols and guidelines to respond to GBV for women and young persons with disabilities seeking contraceptive services. Train service providers and support staff to implement these protocols and to understand and recognize the unique forms of GBV that women and young persons with disabilities can experience. For more information, see Guidelines for Gender-Based Violence Service Provision (Chapter 3).
2. Train female community health workers, midwives, nurses, and other women's health promoters — especially those with disabilities — to educate about contraceptive use in a manner that is gender-, disability-, age-, and sexual orientation-appropriate and culturally sensitive.
3. Train service providers to explain the pros and cons of various methods of contraceptives to women and young persons with disabilities, particularly people with intellectual disabilities. Service providers should be trained on the WHO's '**Medical Eligibility Criteria for Contraceptive Use**,<sup>491</sup> to ensure that service providers manage contraceptive methods based on evidence and help women and young persons with disabilities to make a free and informed choice about their contraceptive method.
4. Develop awareness-raising campaigns and educational materials for caregivers and family members of persons with disabilities, who often serve as gatekeepers to services, to assist them with better understanding the importance of contraceptive use and to generate support for the provision of contraceptive information, goods, and services.
5. Ensure that contraceptive information, goods, and services are offered to young men and boys with disabilities. Men and boys should also receive information to help them understand the rights of women and adolescent girls with disabilities to use contraceptives. Train service providers to recognize that young men and boys with disabilities also need access to contraceptive information, goods, and services.



A young couple in Mexico, who have decided to get married once the young woman finishes her studies.  
© UNFPA/Ricardo Ramirez

## Guidelines for Action:

### ► **Quality**

1. Utilize the WHO, *'Quality of Care in Contraceptive Information and Services, Based on Human Rights Standards: A Checklist for Health Care Providers'*<sup>492</sup> to ensure that the provision of services meets quality of care standards.
2. Recognize the variety of forms that forced contraception can take, including incentives, disincentives, pressure, biased counselling, and scolding or admonishing women or young persons with disabilities who are or wish to become sexually active or who wish to become parents. Train service providers on the various types of force so they can understand how their actions, words, and power imbalances can affect informed decision-making for service recipients with disabilities.
3. Develop service provision evidence-based protocols, along with safeguards, to ensure women and young persons with disabilities can provide informed consent for any contraceptive method, following informed counselling about risks and benefits of each method, including potential side effects and alternative contraceptive methods, and information on their use.<sup>493</sup>
4. Translate accurate, evidence-based information about contraceptives into languages and formats that women and young persons with a range of disabilities can access and understand. Safeguard their right to access this information in an accessible and comfortable way.<sup>494</sup>
5. Ensure women and young persons with disabilities have information and access to a range of contraceptive methods and that providers are trained to counsel persons with disabilities about the pros and cons of different methods, including as they may relate to the person's disability.<sup>495</sup>
6. Offer continuity of care and follow-up for women and young persons with disabilities by prioritizing follow-up of the management of potential side effects or efficacy of the chosen method, maintaining an ongoing relationship, integrated

and coordinated services, and sharing information between providers. Ensure that service recipients understand how to follow-up after their appointment, if needed.<sup>496</sup> For example, if a woman with a disability lives in a nursing home, her provider should identify the best way to follow up with her to determine if the method chosen works for her lifestyle, share information with her consent with other providers both at the nursing home and outside of the home, and identify sources of follow-up care close to the home or who can come to the home.<sup>497</sup>

### 4.3.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based contraceptive services for women and young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators around contraceptive information, goods, and services should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- At least five modern contraceptive methods are available, and information about their use is available in accessible formats.<sup>498</sup>
- Emergency contraception and condoms are available to women and young persons with disabilities (disaggregated by number of new users, by method and age).
- Percentage of clients who are women with disabilities in need of and receiving

contraceptive services (disaggregated by disability, age, and method being used).

- All service providers and support staff receive training on working with women with disabilities.
- All service providers and support staff receive training on working with young persons with disabilities.
- Compliance with quality standards for the delivery of contraceptive services to adolescents and youth that include young persons with disabilities.

## 4.4 Maternal and Newborn Health Services for Women and Adolescent Girls with Disabilities

### 4.4.1 Issue Overview

Women and adolescent girls with disabilities have a right to access the full range of maternal and newborn health services during the perinatal period, including information, goods, and services to prevent unintended pregnancy; post-abortion care; antenatal care; skilled birth attendance; emergency obstetric care; post-partum care; and newborn care. 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 disability.<sup>499</sup> Women and adolescent girls with disabilities must also have access to the components of a healthy pregnancy (e.g. potable water, education, sufficient nutrition, diagnosis and treatment of STIs (including HIV & AIDS, syphilis, HPV, and non-communicable diseases) to promote safe pregnancy and reduce the risk of pregnancy-related death and disability.

#### 4.4.2 Guidelines on Providing Rights-Based Maternal and Newborn Health Services for Women and Adolescent Girls with Disabilities

The key considerations enumerated here identify common barriers that women, including adolescent girls, with disabilities face in accessing the full array of maternal and newborn health services. The guidelines for action offer guidance for ensuring that rights-based maternal and newborn health services to women and adolescent girls with disabilities are available, accessible, acceptable, and of good quality. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

##### **Key Considerations**

- Laws and policies that restrict the parental rights of women with disabilities can deter them from accessing maternal and newborn health services. For instance, if women with disabilities fear that they may lose custody of their children, they may refrain from seeking prenatal care or skilled attendance during birth.
- Women with disabilities frequently encounter substandard care, including discrimination and abusive treatment, when accessing maternal and newborn health services.<sup>500</sup> Negative attitudes about women with disabilities having and raising children can deter them from utilizing these vital services.
- Women with physical disabilities are often told they must give birth by caesarean

section, despite the fact that this is not always necessary,<sup>501</sup> leading to overuse of surgical procedures.

- Women with disabilities often lack access to information about maternal and newborn healthcare and services. For example, stereotypes that women with disabilities are asexual or that they should not become parents can lead service providers and support staff to overlook their need for counselling on safe pregnancy and on preventing unintended pregnancy.
- Materials about maternal and newborn health are regularly unavailable in alternative formats that are accessible to women with certain disabilities.
- Several factors, including disability, gender, language, culture, age, sexuality, and negative attitudes held by service providers and support staff, can contribute to communication barriers.<sup>502</sup> Because of these conscious or unconscious biases, a woman may not receive important information for her maternal health or newborn care.
- Formal and informal user fees in health facilities, as well as indirect costs for transportation and accommodation, can make accessing quality maternal and newborn health services prohibitively expensive for women with disabilities.
- The costs associated with underlying determinants of healthy pregnancy, including good nutrition, clean water, habitation, and sanitation, can also jeopardize the ability of women with disabilities to have safe pregnancies.

## SPOTLIGHT ISSUE

### Obstetric Fistula

An obstetric fistula is “a hole between the birth canal and bladder or rectum caused by prolonged, obstructed labour, without access to timely, high-quality medical treatment [e.g. a Caesarean section]”.<sup>503</sup> Obstetric fistula is one of the most serious injuries that can occur during childbirth. Women and adolescent girls with disabilities are equally vulnerable to obstetric fistula as women without disabilities. In fact, they may often be more vulnerable due to poverty, physical complications relating to their disability, or structural impediments or complications resulting from their disability, including impaired ability to access health services. While the majority of obstetric fistula cases can be treated through surgery, research suggests that there is a very significant unmet need for fistula treatment. Currently, few healthcare facilities are able to provide high-quality fistula surgery, due to a lack of healthcare professionals with the necessary skills, essential equipment, and life-saving medical supplies. When services are available, many women are not aware of, cannot afford, or are unable to reach these services due to barriers such as transportation costs. Most women who develop fistula will never receive treatment, given the current rate of

progress. Additionally, there are some women and adolescent girls with fistula whose cases are deemed inoperable and incurable.

A woman with fistula is not only left incontinent but may also experience neurological disorders, orthopaedic injury, bladder infections, painful sores, kidney failure, or infertility. Their isolation may affect their mental health, resulting in depression, low self-esteem and even suicide. The condition can also recur in women whose fistula has been surgically treated but who receive little or no medical follow-up and become pregnant again.

It should be noted that whether women and adolescent girls with fistula choose to classify themselves as a person with a disability is a personal choice and this choice must be respected accordingly. Service providers and support staff should educate themselves about obstetric fistula to better serve women and adolescent girls with disabilities. The Report of the UN Secretary-General on *‘Intensifying Efforts to End Obstetric Fistula’* provides a comprehensive overview.<sup>504</sup> Other important reference documents are WHO’s *‘Obstetric Fistula: Guiding Principles for Clinical Management and Programme Development’*<sup>505</sup> and FIGO and partners’ *‘Global Competency-Based Fistula Surgery Training Manual’*.<sup>506</sup>

## Guidelines for Action:

### ► **Availability**

1. Ensure that essential maternal and newborn services are available to women and girls with disabilities during pregnancy, childbirth, and the time immediately after birth, as quality care during this period is critical for reducing maternal, fetal, and neonatal death and injuries, and maintaining well-being.<sup>507</sup> Services should be in accordance with the following key recommendations tailored to the circumstances of the woman or adolescent and her specific disability:
  - **'WHO Recommendations on Maternal Health'**<sup>508</sup>
  - **'WHO Recommendations on Newborn Health'**<sup>509</sup>
2. Advocate for comprehensive health insurance and other social protection programmes that ensure women and young person's SRHR, including maternal and newborn health services, and budget accordingly.<sup>510</sup>
3. Ensure maternity waiting homes (residential facilities located near medical facilities where women with high-risk pregnancies can reside until their delivery) are available and accessible to women and adolescent girls with disabilities. Maternity waiting homes can help minimize the risk of complications for rural women and adolescent girls with disabilities, especially where accessible transportation is an issue.

## Guidelines for Action:

### ► **Accessibility**

1. Develop programmes to educate, counsel and empower women and adolescent girls

with disabilities about their rights to make informed and voluntary choices around pregnancy and motherhood, as well as how to access and navigate maternal health services throughout the perinatal period.<sup>511</sup> This is especially needed for women and adolescent girls with cognitive disabilities.<sup>512</sup>

### ► **EXAMPLE:**

***The Disabled Woman's Guide to Pregnancy and Birth*** by Judith Rogers is a comprehensive and practical resource for women with disabilities on how to plan for and have a child. The guide was developed based on interviews with ninety women with a wide range of disabilities who chose to have children. It is also a useful resource for service providers and support staff to better understand the experience of women with disabilities and maternal and newborn healthcare and how to better serve them.<sup>513</sup>

2. Develop culturally-, disability-, and gender-sensitive antenatal classes that can be taught by a range of service providers (e.g. midwives, community health workers, doctors, nurses) in all settings (e.g. rural communities, group homes) to address questions and considerations around pregnancy, labour, delivery, and the post-partum period for women and adolescent girls with disabilities. Classes should cover possible adaptations to assist during labour and delivery and adaptive technologies that can support women and adolescent girls with disabilities through pregnancy, delivery, and parenting and help make these positive experiences.<sup>514</sup>

3. Create and implement a birth plan that accounts for any necessary accommodations for the woman or girl's disability.
4. Allow for a woman or girl's partner, spouse, parent, personal assistant, or other support person of choice to accompany the woman or girl as a support throughout the process, both during and after labour and her stay in the health facility/hospital. Ask the woman or girl if she desires such support.
5. Offer alternative birthing positions and supports for women with physical disabilities.

► **EXAMPLE:**

*Hesperian's 'A Health Handbook for Women with Disabilities' offers a range of practical suggestions for home delivery and low resource settings on how women with a range of disabilities can make the birth process easier. Such as:*

- "If you have little or no leg or arm control, you can sit on a lap. Or you can rest on cushions in a half-sitting position.
- If you have good arm and hand control, you can use a birthing chair [or] you can use a birthing chair with arm and back support[.]
- With help, a woman with some leg control can squat or stand. The person or object that supports you must be strong and balanced. You can also hold onto the back of a chair. The squatting or standing positions can help bring the baby down when the birth is slow, or if the mother is having trouble with pushing.
- If you have some leg and arm control, you may want to try the hands-and-knees

position. This position sometimes also helps prevent and control muscle spasms.

- If you have little or no leg control, you can lie on your side while someone holds your top leg, with your legs bent or straight".<sup>515</sup>
6. Ensure that all guidelines regarding skin to skin promotion and breast feeding are adapted to the woman and her disability-related needs and capabilities.<sup>516</sup>
  7. Provide mothers with disabilities with any necessary assistance to register the birth of their child, as well as to access any financial, medical, or other post-partum support mechanisms to which new mothers may be entitled.<sup>517</sup>
  8. Develop parenting programmes tailored for persons with disabilities to train new parents on how to care for their newborns with any necessary adaptations or assistance.

### Guidelines for Action:

► **Acceptability**

1. Utilize strategies for long-term community engagement through education, partnerships with local religious, traditional or opinion leaders, institutional strengthening, community partnerships, and local advocacy involving persons with disabilities,<sup>518</sup> to raise awareness about the rights of women with disabilities to become parents and to change attitudes about their ability to raise children.
2. Create programmes and campaigns to increase awareness about men's role in facilitating access to maternal and newborn

health services, as well as care and support during the perinatal period.<sup>519</sup>

3. Ensure that users find programme services to be respectful of their rights to become parents, including the right of women and adolescent girls with disabilities to retain their fertility and raise children.<sup>520</sup> Train all individuals involved in providing maternal and newborn health services—including administrative staff, doctors, nurses, midwives, community health workers, and any other individuals who engage with a patient, about the rights of persons with disabilities to have and raise children. Trainings should address and combat underlying biases. It is critical that service providers and support staff have mechanisms to assess their biases to ensure that they are not excluding important pieces of information based on assumptions or biases against women and adolescent girls with disabilities as mothers.

► **EXAMPLE:**

*The Disabled Women's Network and Resource Organization (DWNRO) in Uganda developed a programme to target discrimination and barriers pregnant women with disabilities faced in accessing healthcare. Through workshops with doctors and midwives, DWNRO succeeded in making hospital wards more accessible through physical modifications, attitudinal changes, and training midwives in sign language. DWNRO followed up the project with a campaign to educate women with disabilities about the services.<sup>521</sup>*

4. Offer and foster emotional support during pregnancy tailored for women and adolescent

girls with disabilities. Community groups, peer support groups, or community counsellors can be a valuable source of support to women and adolescent girls with disabilities throughout their pregnancies. Service providers and support staff can also provide emotional support by creating a comfortable environment, guaranteeing confidentiality and privacy, conveying respect, giving simple and direct answers in plain language, providing comprehensive information for making decisions, practicing good listening skills, and offering follow-up visits as needed.<sup>522</sup>

5. Promote and use intercultural approaches.

► **EXAMPLE:**

*The UNFPA led project 'Reducing Maternal Mortality Indicators' in Mexico aimed to improve maternal health among indigenous people in the State of San Luis Potosi of the Huasteca region. The project utilized the following key strategies for combating maternal mortality: "To promote an intercultural approach through the integration of traditional and institutional medicine; To promote community participation; and, To enhance organizational development in support of the initiative".<sup>523</sup> The project successfully increased health coverage for indigenous people in the project area along with knowledge or use of family planning and reduction of maternal health deaths to zero in the area. Upon evaluation, the following factors were identified as contributing to the success of the project: "Enhanced political will and commitment from local authorities; sustained involvement of mass media; participation, coordination*



A classroom of youth who are receiving comprehensive sexuality education. © UNFPA/Turkmenistan Country Office

*and exchange among local authorities and traditional physicians and birth attendants' organizations; support from the Commission for the Development of Indigenous Peoples (CDI) and the involvement of indigenous authorities; coordination, monitoring and facilitation from COESPO, the State's population committee; clear agreements for community participation that defined the role of each community agent; and, a social audit mechanism aimed at ensuring transparency in the follow-up process".<sup>524</sup>*

6. Ensure that women with disabilities can be accompanied by a companion of their choice at birth.<sup>525</sup>

### Guidelines for Action:

#### ► Quality

1. Align services with components of quality of care, which "for pregnant women and newborns in facilities requires competent and motivated human resources [that can provide standardized midwifery care] and the availability of essential physical resources. Also, evidence-based practices for routine and emergency care, actionable information systems where record-keeping enables review and audit mechanisms, and functional referral systems between levels of care should be in place. Experience of care includes, firstly, effective communication—a woman (or her family if required)

should feel that she understands what is happening, what to expect, and knows her rights. Secondly, she should receive care with respect and dignity. Thirdly, she should have access to the social and emotional support of her choice".<sup>526</sup>

Services should be in accordance with the following key recommendations tailored to the circumstances of the woman or girl and her specific disability:

- *'Quality of Care for Pregnant Women and Newborns—the WHO Vision';*<sup>527</sup>
  - *'WHO Recommendations on Antenatal Care for a Positive Pregnancy Experience';*<sup>528</sup>
  - *'WHO Recommendations Intrapartum Care for a Positive Childbirth Experience';*<sup>529</sup>
2. Ensure that women and girls with disabilities have access to a skilled birth attendant that can provide standardised midwifery care. Develop programmes to sensitize and train skilled birth attendants on working with women and girls with disabilities.
  3. Strengthen linkages between women, families, communities, health delivery services, disabled persons and women's organizations, and other service providers to bolster available social support for better maternal health outcomes.<sup>530</sup>
  4. Assess whether women and adolescent girls with disabilities are subject to unnecessary and excessive dependence on caesarean sections at health facilities. Train service providers on alternatives to

caesarean sections and help service providers to understand when a caesarean section is medically indicated to minimize overuse of caesarean sections for women and adolescent girls with disabilities.<sup>531</sup>

5. Where resources allow, utilize multidisciplinary teams to improve communication between maternal and newborn service practitioners and mental health practitioners. For example, designate a multidisciplinary perinatal team that include psychologists and social workers in addition to skilled birth attendants.<sup>532</sup>
6. Ensure that feedback mechanisms are in place to collect feedback on the quality of maternity and newborn health services from the end users themselves to inform future programming. There should also be a system in place to analyse and act upon this feedback.

#### 4.4.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based maternal and newborn health services for women and adolescent girls with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that maternal and newborn health services indicators should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Maternal mortality ratio, disaggregated by disability.<sup>533</sup>

- Proportion of women with disabilities who receive skilled care (or attendance) at birth.
- Proportion of pregnant women with disabilities who receive antenatal care (ANC) per the 2016 WHO ANC Model.<sup>534</sup>
- Proportion of women with disabilities who receive at least one postpartum care visit.
- Proportion of pregnant women having a planned caesarean section who have the procedure carried out at or after 39 weeks 0 days, disaggregated by disability.<sup>535</sup>
- Number of skilled birth attendants who speak sign language.

## 4.5 Comprehensive Sexuality Education and Information for Women and Young Persons with Disabilities

### 4.5.1 Issue Overview

Comprehensive sexuality education (CSE) and information is fundamental to empowering all women and young persons, including those with disabilities, to understand their bodies and sexual development, SRHR, protect themselves against sexually transmitted infections and unintended pregnancies, form healthy and pleasurable relationships, and make informed choices about their sexuality and reproduction.<sup>536</sup>

Comprehensive sexuality education is defined as “a curriculum-based process of teaching and learning about the cognitive, emotional, physical and social aspects of sexuality. It aims to equip children and young persons with knowledge, skills, attitudes and values that will empower them to: realize their health, well-being and dignity; develop respectful social and sexual

relationships; consider how their choices affect their own well-being and that of others; and, understand and ensure the protection of their rights throughout their lives”.<sup>537</sup> Comprehensive sexuality education and information materials and programmes for adults outside the school setting have the same scope and purpose. All comprehensive sexuality education programmes and materials should be scientifically accurate, incremental, age- and developmentally-appropriate, curriculum based, comprehensive, based on a human-rights approach, based on gender equality, culturally relevant and context appropriate, transformative, and assistive in the development of life skills needed to support healthy choices.<sup>538</sup> Information that should be covered in a comprehensive sexuality education programme and adapted for persons with disabilities includes, but is not limited to, “sexual and reproductive anatomy and physiology; puberty and menstruation; reproduction, modern contraception, pregnancy and childbirth; and STIs, including HIV and AIDS. [Comprehensive sexuality education] covers the full range of topics that are important for all learners to know, including those that may be challenging in some social and cultural contexts”.<sup>539</sup>

Comprehensive sexuality education generally refers to education that students receive in school. Women and young persons with disabilities have the same right to participate in sexuality programmes, yet students with disabilities often do not receive comprehensive sexuality education in school or are excluded from such programmes. Accordingly, it is essential that CSE be made available to both adults and young persons with disabilities, including outside of school settings. Consequently, this

section addresses provision of traditionally formatted CSE in school settings but also CSE for adults and young persons outside of school settings and education through information sharing rather than traditional education formats. The term comprehensive sexuality education (CSE) is thus used throughout these Guidelines to capture this broader scope. The guidelines detailed below are focused primarily on the content of both education programmes or information materials for women and young persons with disabilities.

#### 4.5.2 Guidelines on Providing CSE for Women and Young Persons with Disabilities

The key considerations enumerated here identify common barriers that women and young persons with disabilities face in accessing CSE. The guidelines for action offer guidance for ensuring that CSE programmes that are inclusive of women and young persons with disabilities are available, accessible, acceptable, and of good quality. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

##### **Key Considerations**

- All women and young persons have the right to education, but that right is particularly undermined for those with disabilities who are regularly excluded from receiving any form of education and especially sexuality education. Young persons are very likely to be excluded from in-school CSE because the programmes are inaccessible or considered to be unnecessary for students with disabilities.
- Stigma and harmful stereotypes that persons with disabilities should not be sexually active or that they do not need the type of information covered in CSE can lead to the denial of a woman or a young person with a disability's right to health, including their right to know about and control their own bodies, along with critical life skills.
- Failure to establish laws and policies that guarantee access to inclusive education can effectively exclude young persons with disabilities from participating in established CSE programmes.
- Taboos that prevent people from discussing sex, sexuality, and reproduction in general can exacerbate the barriers that women and young persons with disabilities face in accessing the information offered in CSE, as they are more likely to be isolated and have fewer opportunities to receive CSE in informal settings.
- There is generally little investment in CSE for young persons, and especially for those with disabilities, because of a misperception that educating young persons about human sexuality will encourage promiscuous or risky sexual behaviour, or sexual activity generally, which is often considered especially inappropriate for persons with disabilities.
- Low level of enrollment and participation of persons with disabilities in school, isolation in institutions and homes, and lack of accessible information about formal and informal CSE programmes prevents persons with disabilities accessing CSE even where available.
- Several factors can make the environments where CSE is provided inaccessible,

including the locations of and layout of rooms where CSE programmes are held, the hours when courses take place, and the availability of affordable and accessible transportation.

- When available, CSE programmes and materials offered to students with disabilities are often ineffective. Programmes and educational materials lack relevant content for persons with disabilities, are presented in inaccessible ways, or lack value for students with disabilities. Because of this, students with disabilities can miss out on critical information and experience.
- During humanitarian emergencies, the exclusion that women and young persons with disabilities experienced prior to the emergency can prevent them from accessing services available to them as part of the humanitarian emergency services. For example, if a young person with a disability has never participated in integrated education, when that young person learns of a CSE programme they may assume they are not invited to join, no matter how inclusive the programme is intended to be.

### Guidelines for Action:

#### ► **Availability**

1. Advocate as necessary for laws, policies and protocols to guarantee inclusive education, which includes CSE programmes.
2. Lobby for CSE to be made available at all grade levels in schools, both integrated and segregated schools for students with disabilities.
3. Design and offer CSE programmes for women and young persons with disabilities in accordance with the United Nations Educational, Scientific and Cultural Organization (UNESCO), '*Revised Edition International Technical Guidance on Sexuality Education: An Evidence-Informed Approach*'.<sup>540</sup>
4. Use accessible techniques and activities to teach persons with disabilities about key sexual health topics.
  - **EXAMPLE:**  
*The Inter-American Institute for Disability and Inclusive Development, Uruguay's National Public Education Administration, UNFPA and UNICEF developed 'Es Parte de la Vida: Material de apoyo sobre educación sexual y discapacidad para compartir en familia [It is Part of Life: Support materials on sexuality education and disability to share with family] to offer families in the Latin American and Caribbean region a variety of practical tips for providing comprehensive sexuality education to their children with disabilities.*<sup>541</sup>
5. Ensure a safe and healthy learning environment free from bullying, discrimination, harassment and violence from peers, educators, family, and caregivers.<sup>542</sup>
6. Create sexual health programmes tailored to women and young persons with disabilities that provide a forum, along with practical tools, to better understand and explore their sexual health and how their disability may or may not affect their sexual life.

► **EXAMPLE:**

*The following talking points are a starting point for women and young persons with disabilities to begin a conversation with their partners about sex:<sup>543</sup>*

- The easiest location to have sex.
  - The most comfortable position or positions that can cause pain.
  - How your disability affects your body and how it functions.
  - How you and your partner can give pleasure to one another.
  - If your disability affects your energy levels, when is the best time for you to have sex.
  - What feels good to you and what does not.
  - If your partner is also your caregiver, boundaries between time spent together for care and for sexual relations.
7. Utilize or adapt existing programmes for CSE for students with disabilities.

► **EXAMPLE:**

*The **Circles: Intimacy & Relationship Education**<sup>544</sup> curriculum was developed in the United States of America to teach students with disabilities to understand social and relationship boundaries and skills.*

## Guidelines for Action:

► **Accessibility**

1. Create spaces where women and young persons with disabilities can learn about and discuss their sexual health in a safe, supportive, and educational way.

► **EXAMPLE:**

*The **Sexuality and Disability Blog**<sup>545</sup> is great example of increasing visibility around sexuality and disability while providing an important resource and community for women with and without disabilities. Created by Point of View and CREA based in Mumbai, Delhi, and New York, the blog covers a range of topics surrounding gender identity, sexual health, and reproductive health for persons with disabilities. The free blog is structured as a series of questions, promoting easy access, and is offered in an accessible format. The blog was created by and with women with disabilities, as well as disability rights advocates and other stakeholders.*

2. Create programmes tailored to the learning and accessibility needs of the women and young persons and their disabilities. Because SRHR can be particularly sensitive topics, it is important to create smaller supportive and accessible spaces that will allow women and young persons to ask questions they may be shy about asking and that can be tailored to different learning styles.

► **EXAMPLE:**

*Point of View organized and hosted a workshop in India through its Sexuality and Disability Project to teach women and girls with visual impairments about their bodies, menstruation, menstrual health, hygiene, female genitalia, sex, and contraception use. The organization used physical female anatomy charts with raised diagrams of female genitalia and secondary sex characteristics to allow participants to have a tactile method of understanding what the parts of their bodies were called and*

*the function of each part. Verbal methods were used to explain menstruation and menstruation care, accompanied by clay charts of reproductive organs and explanations of different types of reproductive concepts. Additionally, a sexual education activity with rubber models of the male reproductive system was used for tactile pairing with verbal explanations and an activity to teach participants how to put on a condom.<sup>546</sup>*

3. Develop accessible CSE materials that can be taken home and distributed widely for women and young persons with disabilities to review in private. Social media and digital media are excellent ways of providing CSE materials and information in a form that is highly adaptable for accessibility needs.

► **EXAMPLE:**

*The “Decímelo a mi!” phone application in Uruguay is an example of the effective use of technology to more widely distribute SRHR information to women and young persons with disabilities. The application was created to make information about sexual and reproductive health rights in Latin American more accessible to women from the Deaf and hard of hearing community. The programme included the adding of barcodes to flyers and posters, which could be scanned by the application, giving the user access to videos in sign language on sexual health, reproductive health, diversity, and gender equality, as well as videos dispelling myths and false information on those subjects and others. This type of technology makes public information more accessible, user friendly, and inclusive for persons with disabilities.<sup>547</sup>*

## Guidelines for Action:

► **Acceptability**

1. Promote national plans and policies on CSE to require development of inclusive CSE curricula, accessible and inclusive CSE materials that do not perpetuate harmful stereotypes on the basis of gender, disability, sexual orientation, or gender identity, and trainings for teachers to provide quality CSE to young persons with and without disabilities.
2. Integrate women and young persons with disabilities into mainstream CSE programmes as much as possible. Learning about sexuality in an integrated setting can help dismantle prejudices and harmful stereotypes about persons with disabilities and sexuality.
3. Develop disability-inclusive and sensitive CSE programmes and trainings for CSE educators or to supplement established programmes. Use images of individuals with disabilities in all CSE curriculum materials, as mainstreaming such images can help dismantle discrimination about persons with disabilities and sexuality and it can be empowering for persons with disabilities to see such images.
4. Ensure that young men with and without disabilities are included in CSE programmes.<sup>548</sup> Adolescence is an especially key time for services to reach young men and boys with disabilities. Dismantling harmful stereotypes about gender roles can help foster healthy relationships for young men and boys with disabilities.

5. Build capacity of women and young persons with disabilities to be peer educators and develop self-empowerment groups for women and young persons with disabilities that can address CSE topics.

► **EXAMPLE:**

*In Pakistan, the National Forum for Women with Disabilities (NFWWD) trains women with disabilities to become peer educators for women with and without disabilities in their communities.<sup>549</sup> More information on NFWWD and other organizations doing effective SRHR work for women with disabilities in the Asia-Pacific region are documented in The Asian-Pacific Resource and Research Centre for Women (ARROW) and CREA publication, 'ARROW for Change – Women with Disabilities: Disabled, Sexual, Reproductive'.<sup>550</sup>*

6. Engage family members and caregivers of young persons with disabilities in advocacy and information campaigns and educate them about the importance of young persons participating in CSE programmes. Family members can be encouraged to provide sexuality education to young persons with disabilities or enroll their children in programmes by framing involvement as 'risk reduction' (e.g. to reduce the risk of abuse or STIs).

► **EXAMPLE:**

*There are a number of resources to assist parents of children with disabilities to provide comprehensive sexuality education to their children. Some useful resources include the Vanderbilt Kennedy Center's 'The Healthy*

*Bodies Toolkit for Boys and Girls,'<sup>551</sup> guides for parents of boys and girls with disabilities to guide boys and girls through puberty, which includes visual aids and tools. Or DiAnn L. Baxley and Anna L. Zendell's 'Sexuality Across the Lifespan—Sexuality Education for Children and Adolescents with Developmental Disabilities,' a manual for educators about CSE for students with developmental disabilities, which includes topics on sexual and physical abuse.<sup>552</sup>*

7. Offer training for teachers and service providers about accessible and inclusive CSE.

► **EXAMPLE:**

*Service providers must create opportunities to learn from women and young persons with disabilities about their experiences, concerns, and needs relating to sexuality. One research project entitled (S)exploring Disability: Intimacies, Sexualities, and Disabilities,<sup>553</sup> looked at the experiences of women and men with disabilities and their sexuality and resulted in the following findings:*

*"Disabled men and women were significantly disempowered by sexual norms; disabled men could exercise more sexual power, and had better sexual access and opportunity, than disabled women; disabled men and women had to carry out forms of work within a variety of spaces in their private and intimate lives; impairment was important; disabled participants experienced substantial sexual oppression and psycho-emotional disablism as routine within their sexual and intimate lives".<sup>554</sup>*

*Providing CSE to young persons with disabilities is fundamental to helping them understand their changing bodies and develop healthy habits.*

8. Develop separate sexuality education depending on the life stage of the target audience, as the needs, sensitivities, and experiences of adult women with disabilities will differ from those of young persons with disabilities.
  - **Young persons:** Providing CSE to young persons with disabilities is fundamental to helping them understand their changing bodies and develop healthy habits. Key sexual and reproductive health topics for young persons include, puberty, pregnancy, access to modern contraception, unsafe abortion, violence (including GBV), HIV and AIDS, and STIs.<sup>555</sup> Other important issues include, the influence of technology (e.g. online images, cyberbullying, sexting); poor mental/emotional health; and alcohol, tobacco and drugs.<sup>556</sup>
  - **Adults:** Many women with disabilities will have missed out on the opportunity to participate in CSE programmes as a girl or received inaccurate information. CSE programmes targeted towards women with disabilities who were excluded from CSE as young persons can empower them to understand and exercise their sexual and reproductive health rights and to foster healthy sexuality and healthy relationships in a way that respects their life experiences.
9. Ensure that persons with disabilities are included in information campaigns on CSE topics and that disability-specific issues are also addressed in public education campaigns.
10. Develop programmes that reach across formal and informal sectors, across age groupings, and across disabilities to ensure CSE programmes serve a large population of young persons and women with disabilities, including those who are not in school and persons with severe disabilities.<sup>557</sup> Do not exclude students from participating in CSE programmes based on stereotypes or perceptions about who needs CSE and who does not.

### Guidelines for Action:

#### ► Quality

1. Adhere to the core principles developed by UNFPA of quality sexuality education when developing sexuality programmes and information materials, which are: "Respect for human rights and diversity, with sexuality education affirmed as a right; critical thinking skills, promotion of young persons's participation in decision-making, and strengthening of their capacities for citizenship; fostering of norms and attitudes that promote gender equality and inclusion; addressing vulnerabilities and exclusion; local ownership and cultural relevance; a positive life-cycle approach to sexuality".<sup>558</sup>

2. Make sure that CSE programmes tailored for women and young persons with disabilities are 'gender-focused'.<sup>559</sup> This can be done by ensuring comprehensive coverage of gender either as a solo topic or integrated throughout the curriculum, promoting gender equality and dismantling stereotyped gender roles, and fostering a foundation of communication and relationship building.<sup>560</sup>
3. Ensure that CSE programmes contain unbiased and scientifically accurate information.<sup>561</sup> This includes correcting inaccurate information that has been taught or discerned by women and young persons with disabilities.
4. Use participatory teaching methods for personalization of information and strengthened skills in communication, decision-making and critical thinking. Skills should include communication, negotiation, and decision-making.<sup>564</sup>
5. Where possible, engage GBV service providers in providing CSE to women and young persons with disabilities to reduce the risk of exploitation, particularly during humanitarian emergencies. During emergencies, it is especially effective to have education services take place in non-education settings to better reach persons with disabilities.

► **EXAMPLE:**

*There is extensive UN technical guidance on sexuality education which can be used to develop and assess the quality of a CSE programme. The 2018 UNESCO, 'Revised Edition International Technical Guidance on Sexuality Education: An Evidence-Informed Approach'<sup>562</sup> provides essential guidance to "assist education, health and other relevant authorities in the development and implementation of school-based and out-of-school comprehensive sexuality education programmes and materials".<sup>563</sup> While the Guidance is not tailored to women and young persons with disabilities, it serves as a guide on the quality and necessary content of any comprehensive sexuality education programmes tailored to women and young persons with disabilities.*

6. Service providers should review and understand the WHO's '**Consolidated Guideline on Sexual and Reproductive Health and Rights of Women Living with HIV**'.<sup>565</sup> In 2017, WHO issued a new guideline consolidating existing recommendations to strengthen the realization of SRHR for women living with HIV. The Guideline offers a women-centred approach to improved services that positions women living with HIV as active participants in, and beneficiaries of, a responsive and holistic health system that is respectful of their autonomy. When providing services to women and young persons with disabilities living with HIV, service providers and support staff should adhere to the WHO recommendations contained in the Guideline.

## SPOTLIGHT ISSUE

# Comprehensive Sexuality Education for Students with Intellectual Disabilities

Examples of models and strategies for providing sexuality education for adolescents with intellectual disabilities include:

- *Information, Motivation, and Behavioural Skills (IMB) Model* – From the Canadian Guideline for Sexual Health Education, this model utilizes the following three elements: “Information that is directly relevant to sexual health and is easy to apply in the individual’s own life; Motivation to use the knowledge to avoid negative sexual health outcomes and to promote their sexual health; Behavioural skills to carry out the healthy behaviours; practice and role-play are seen as necessary”.
- *Direct Instruction Model* – Utilizing lessons “designed around small learning increments and clearly defined and prescribed teaching tasks”.
- *Using Technology* - Computer-based interactive multimedia programmes have been found to be particularly effective in helping people with intellectual disabilities increase their knowledge of SRHR-related topics.
- “Going through *information slowly* to ensure that the individuals can process the information, ask questions, and have discussions.
- Practicing the material through *role-play, modelling, and rehearsal*.
- Starting with *basic information* and moving to more complex issues.
- Teaching *refusal skills*.
- Practicing *appropriate affection*.
- Discussing *masturbation* (i.e., what it is, when it is and is not appropriate)”.<sup>566</sup>

Note, these suggested models and strategies are drawn from a literature review and have thus not necessarily been widely evaluated or used. Service providers should engage in further research as needed.

*Stereotypes ... and barriers to accessing STI services can result in women and young persons with disabilities being excluded from such services.*

### 4.5.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based CSE services for women and young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form for indicators for CSE service provision. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Percentage of young women and men with disabilities aged 15–24 who correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission (female and male).
- Sexuality education materials are available in disability-accessible formats.
- CSE curriculum includes reference to and images of persons with disabilities and address their SRHR.
- Students with disabilities receive CSE, regardless of whether they receive their education in special education programmes or in inclusive education settings.

## 4.6 Information, Testing, and Treatment Services for Sexually Transmitted Infection, including HIV/AIDS for Women and Young Persons with Disabilities

### 4.6.1 Issue Overview

Information, testing, and treatment services for sexually transmitted infection (STI), including HIV, are fundamental to protecting SRHR for women and young persons both with and without disabilities.<sup>567</sup> Women and young persons with disabilities have the same right to these services as individuals without disabilities. Essential STI services include: access to accurate information regarding STI and how to prevent them; access to voluntary methods for prevention, treatment, and care; vaccination against human papillomavirus (HPV) and hepatitis B; access to prophylactic treatment for individuals who may have been exposed to STIs, including survivors of sexual violence; voluntary and confidential testing for STIs with timely dissemination of test results; counselling and psychosocial support; and access to affordable antiretroviral medicines for people living with HIV. Common STIs that women and young persons should be informed about and tested for include HIV, trichomoniasis, gonorrhoea and chlamydia infection, syphilis, chancroid, genital herpes and warts, and hepatitis B.<sup>568</sup> Access to both male and female condoms and information on how to properly use condoms are central components of STI information and prevention services.

Stereotypes that women and young persons with disabilities are not at risk for STI and barriers to accessing STI services can result in women and young persons with disabilities being excluded from such services. Individuals living with HIV, who may or may not self-identify as a person with a disability, are also at risk of violations of their SRHR, including their right to become parents, their right to be free from forced or coerced abortion or sterilization, and their right to access sexual and reproductive health services.

#### 4.6.2 Guideline on Providing Rights-Based STI Services for Women and Young Persons with Disabilities

The key considerations enumerated here identify common barriers that women and young persons with disabilities encounter with respect to accessing STI information, testing, and treatment. The guidelines for action offer guidance for ensuring that rights-based service delivery of the full array of information, testing, and treatment services for STIs are available, accessible, acceptable, and of good quality. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

##### **Key Considerations**

- Women and young persons with disabilities are often excluded from information campaigns about STIs due to a variety of factors, including stereotypes, isolation, and the inaccessible nature of some public education campaigns. The lack of accessible and inclusive CSE similarly prevents women and young persons with disabilities from knowing how to protect themselves from STIs.
- Stereotypes around the sexuality of women and young persons with disabilities, including stereotypes that they are asexual, not sexually active, or not sexually desirable, can lead service providers and support staff to assume that they are not at risk of contracting STIs. As a result, service providers often fail to provide women and young persons with disabilities with information about STI prevention methods (such as HPV vaccines or use of condoms) or to inform them about or offer them tests for STIs as part of routine healthcare visits.
- Some family members or caregivers of women and young persons with disabilities do not want them to learn about sexual and reproductive health, including STIs, for fear it will increase their sexual activity.
- Lack of disability-sensitive regulations and protocols for pre-and post-exposure for victims/survivors of rape can exclude women and young persons with disabilities from prophylactic treatment or STI testing, increasing their vulnerability to contracting STIs and resulting in STIs going undetected and untreated.
- Women and young persons with disabilities are at heightened risk for harmful practices, such as child marriage and ‘virgin rape’ that can significantly increase their vulnerability to STIs.<sup>569</sup> Inadequate laws and policies aimed at preventing and protecting women and young persons with disabilities from GBV

and punishing perpetrators contribute to impunity and exacerbate these risks.

- Women living with HIV are at particular risk of forced sterilization and forced abortion, which is only further exacerbated for women with disabilities with HIV.
- When a woman or a young person with a disability is found to have an STI, service providers often fail to counsel that woman or young person on how the diagnosis affects other areas of their SRHR, such as how to have sex safely or how to plan for pregnancy.
- Communication barriers can deny women and young persons with disabilities access to essential counselling and psychological support when making decisions to undergo STI testing, treatment, and prevention.
- Poverty, physical barriers to STI testing facilities, and isolation can prevent women and young persons with disabilities from accessing STI testing, treatment, and other related services.

#### STARTING POINT

### UNAIDS: Zero-Discrimination in Healthcare

UNAIDS has developed the following minimum standards for discrimination-free healthcare settings based on lessons from the AIDs response:

- “Provide timely and quality health care regardless of gender, nationality, age, disability, ethnic origin, sexual orientation, religion, language, socioeconomic status, or HIV or other health status, or because of selling sex, using drugs and/or living in prison.
- Prohibit mandatory testing or treatment, or coercive practices.
- Respect patient privacy and confidentiality.
- Link marginalized and most affected populations to additional service providers, peer support networks or community-based organizations, or legal services when necessary.
- Employ clinical providers who ask health questions or perform health intakes to actively inform people of their rights and provide quality non-judgmental care.
- Put in place grievance mechanisms and mechanisms of redress and accountability for discrimination and violation of the rights of clients.
- Ensure participation of affected communities in the development of policies and programmes promoting equality and non-discrimination in healthcare”.<sup>570</sup>

### Guidelines for Action:

#### ► **Availability**

1. Guarantee that accessible services are available for women and young persons with all different forms of disabilities at each stage in the continuum of STI services (prevention, testing, link to care, treatment, chronic care).<sup>571</sup> To learn more about strategic implementation of the continuum of care and priority action areas for combating STIs, review the WHO's *'Global Health Sector Strategy on Sexually Transmitted Infections, 2016-2021: Towards Ending STIs'*.<sup>572</sup>
2. Create programmes tailored to women and young persons with disabilities on STI education, support, and counselling services.<sup>573</sup> Improve access to CSE for women and young persons with disabilities. For more information, see Comprehensive Sexuality Education for Women and Young Persons with Disabilities (Section 4.5).
3. Ensure that women and young persons with disabilities have access to accessible counselling and testing for HIV.

### Guidelines for Action:

#### ► **Accessibility**

1. Offer consultations for women and young persons with disabilities that present accessible opportunities to learn how STIs are transmitted and how to prevent them. The woman or young person should also be shown how to use a male and female condom and how to negotiate its use with a partner. As part of this consultation, service providers should also enquire about potential problems some women and young persons with disabilities may have with taking certain medicines to treat STIs. If the patient is a young person, service providers can explain to the person's parents that children who learn about STIs, including HIV, will make safer choices later in life.<sup>574</sup>
2. Promote peer-to-peer and community health worker education programmes to provide free, disability-sensitive education and information around STIs based in the community.
3. Develop accessible, targeted, and non-stigmatizing information and testing campaigns around STIs.<sup>575</sup> For instance, create radio bulletins or accessible informational leaflets. Integrate women and young persons with disabilities into public information campaigns.
4. Ensure that testing facilities and machines are physically accessible to women and young persons with any type of disability, including women and young persons who may experience difficulties with needles or sitting still for periods of time.
5. Offer free or low-cost access to the HPV and Hepatitis B vaccines for low-income women and young persons with disabilities or those living in poverty.
6. Where resources allow, advocate for subsidized antiretroviral treatment and antibiotics for individuals who are unable to afford necessary medicines.
7. Where resources allow, offer male and female condoms for free or at a low cost along with accessible information and training on how to use both types of condoms. Condoms should be available in health service provider settings as well as other disability-related service settings.

## SPOTLIGHT ISSUE

### HPV and Cervical Cancer

Cervical cancer is one of the greatest threats worldwide to women's lives. The primary cause of cervical cancer is persistent or chronic infection with one or more of the high-risk types of human papillomavirus (HPV). Preventing HPV through vaccination is fundamental to curbing cervical cancer. Service providers must ensure that women and adolescent girls with disabilities have access to the vaccine. All adolescent girls should receive the vaccine before initiating

sexual activity. Service providers must also be sure to offer the vaccine to women with disabilities who may have missed out on receiving the vaccine as an adolescent. Since the vaccine does not protect against all types of HPV, and many women with disabilities may not have received the vaccine before the onset of sexual activity, service providers should screen all adolescent girls and women with disabilities for cervical cancer.<sup>576</sup>

#### Guidelines for Action:

##### ► **Acceptability**

1. Ensure that programmes are tailored to serve populations of women and young persons with disabilities who may be even more vulnerable to STIs due to isolation or intersecting forms of discrimination, including women and young persons with disabilities living in poverty, those living in institutions, women and young persons with disabilities from indigenous or the LGBTI communities, sex workers, and refugees or internally displaced persons.
2. Train women and young persons with disabilities to become peer or community health educators and foster the development of support groups.<sup>577</sup> Look for opportunities to engage with already existing groups of women and young persons with disabilities. Community leaders can also work with service providers to ensure STI information, testing, and treatment services are reaching communities of women and young persons with different types of disabilities.<sup>578</sup>
3. Train service providers and support staff and implement safeguards to guarantee privacy and confidentiality of STI counselling and test results, including for those younger than 18 years old. Ensure results are given in private, unless the patient has privately and voluntarily given their informed consent to allow a companion, family member, or caregiver to stay.<sup>579</sup>
4. Develop education programmes for family members and caregivers to understand the importance of STI information, testing, and prevention. Train and assist supportive community leaders, family members, and caregivers on how to conduct outreach to other families and caregivers of women

and young persons with disabilities on the importance of STI education and testing.<sup>580</sup> Framing such information and education as risk reduction can help foster support.

### Guidelines for Action:

#### ► Quality

1. Provide accessible, confidential pre-testing counselling to support a woman or young person with a disability to make her or his own voluntary decision around STI testing and prevention. Counselling should address the pros and cons of STI testing, what to expect if a test result comes back positive, and the availability of STI treatment and psychosocial support.
2. Provide accessible, confidential post-testing counselling. Refer to the WHO's *'Consolidated Guidelines on HIV Testing Services'*<sup>581</sup> for guidance on the contents of this counselling depending on the results of the test.
3. Provide accessible, tailored, and appropriate counselling, support, and contraceptives to HIV-positive women and young persons with disabilities to address their unmet needs relating to HIV care, treatment, and support.<sup>582</sup>
4. Establish coordination and referral systems for women and young persons with disabilities identified as suffering consequences of violence or abuse. Refer to the WHO's *'Strengthening Health Systems to Respond to Women Subjected to Intimate Partner Violence or Sexual Violence: A Manual for Health Managers'*<sup>583</sup> for practical guidance, in addition to local legal requirements.

### SPOTLIGHT ISSUE

## HIV and Sexual Violence against Women and Young Persons with Disabilities

Some individuals believe the dangerous and false myth that a person living with HIV can be cured by having sex with a virgin, also known as 'virgin rape'. Due to stereotypes that persons with disabilities are asexual, and therefore presumed to be virgins, women and young persons with disabilities can be particularly vulnerable to this form of sexual violence. In

addition to referring such crimes to the criminal justice system, it is important to actively dispel this harmful myth through awareness-raising and public education campaigns and to educate women and young persons with disabilities about this risk as well as the importance of seeking timely health services for prophylactic care if they experience sexual violence.<sup>584</sup>

### 4.6.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based STI services for women and young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators on STI service provision should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Percentage of women and young persons with disabilities who know their HIV status.
- Percentage of women and young persons with disabilities receiving an STI test on their first visit to a health provider.
- Percentage of adolescent girls with disabilities immunized against HPV
- Percentage of women and young persons with disabilities who received an STI test and the results within the past year.
- Percentage of women and young persons with disabilities who report using a condom the last time they had sex.

## 4.7 Access to Other Women's Health Information and Services for Women and Adolescent Girls with Disabilities

### 4.7.1 Issue Overview

Women and adolescent girls with disabilities have a right to access quality essential health services on an equal basis with men and women without disabilities.<sup>585</sup> In addition to the

range of services addressed in the previous sections of these Guidelines, women and adolescent girls with disabilities require routine access to a range of healthcare services related to their sexual and reproductive health, including abortion (where legal), pelvic exams, Pap smear tests, mammograms, and cancer screenings. Lack of access to care and delays in receiving these important services or diagnosing potentially terminal illnesses can have serious consequences for a woman or girl's health and life.<sup>586</sup>

Where abortion is legal, it is critical to ensure that all women and adolescent girls have ready access to safe, good-quality abortion services<sup>587</sup>. Unsafe abortions account for approximately 13 per cent of all maternal deaths.<sup>588</sup> The WHO estimates that there are roughly 22 million unsafe abortions each year leading to 5 million complications that result in hospital admissions,<sup>589</sup> which in some circumstances can lead to a woman becoming permanently disabled.<sup>590</sup> Women and adolescent girls with disabilities have a right to safe and accessible abortion services, where legal.<sup>591</sup> They also have a right to access post-abortion care regardless of the legal status of abortion. Women and adolescent girls with disabilities can be subjected to forced abortion, a form of GBV. For more information about the GBV women and young persons with disabilities experience, see Guidelines for Gender-Based Violence Service Provision (Chapter 3).

### 4.7.2 Guidelines on Providing Rights-Based Health Services to Women and Adolescent Girls with Disabilities

The fundamental principle for providing quality healthcare services is that women and adolescent girls with disabilities must always be treated with respect and dignity and encouraged to communicate their opinions about their own health.<sup>592</sup> The following key considerations explain the barriers that women and girls with disabilities face in accessing quality health services. The guidelines for action provide guidance on ensuring that quality, rights-based services are available, accessible, acceptable, and of good quality for women and girls with disabilities. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

#### Key Considerations

- Exclusion of women and adolescent girls with disabilities from public health promotion and prevention campaigns and lack of inclusive and accessible information about women's health services and needs prevent women and adolescent girls with disabilities from accessing necessary services and limit their understanding of how such services contribute to their overall health.
- Lack of clarity about the legal status of abortion and lack of understanding that post-abortion care must be accessible irrespective of the legal status of abortion can lead service providers to refrain from providing safe abortion services, where legal, and post-abortion care, even where necessary to safeguard a woman or girl's life or health.
- Low education and literacy levels can prevent women and adolescent girls with disabilities from understanding information about important health services.<sup>593</sup> For example, women and adolescent girls with disabilities often lack information about pregnancy, abortion, where legal, and associated services.<sup>594</sup> They may therefore lack the necessary information to recognize the signs of pregnancy or about services to access in the first trimester, which can exacerbate legal, financial, and other barriers if an unplanned pregnancy occurs. For more information on accessible CSE, see *Comprehensive Sexuality Education for Women and Young Persons with Disabilities* (Section 4.5).
- Stigma around abortion (where legal), can lead to abuse and mistreatment for women and adolescent girls with disabilities when they are seeking post-abortion care for complications.
- Women and adolescent girls with disabilities often do not receive cancer screenings and other essential SRHR services due to a variety of factors, including a lack of competencies at the service level, lack of disability- and gender-sensitive procedural guidelines, inaccessible equipment, and insufficient educational resources.<sup>595</sup>
- Lack of standardized training for all healthcare service providers and support staff on adapting and providing services to women and girls with disabilities can exclude women and girls from essential health services and contributes to provider discomfort.
- Medical appointments can often require complex coordination for persons with

disabilities to acquire the necessary transportation and support. However, service providers and support staff are often not prepared with the accommodations which the person requires, which results in a woman or girl being turned away or asked to return another day when services can be made accessible. Not only can this be expensive and time-consuming for the person with the disability, but it is also discriminatory and can deter use of important health services.

- Inaccessible intake forms and other communication barriers can prevent women and adolescent girls with disabilities from being able to inform service providers and support staff about their symptoms, personal and family health history, and experiences, thus preventing accurate assessment of their health needs and risks. Communication barriers can similarly prevent service providers and support staff from being able to effectively communicate about necessary medical exams, diagnoses, and treatment plans with patients.<sup>596</sup>
- Communication barriers can deny women and adolescent girls with disabilities access to essential counselling and psychological support when making decisions about health-related matters, such as whether to proceed with chemotherapy.
- Physical barriers to both healthcare facilities and medical equipment, such as mammogram machines, effectively deny women and adolescent girls with disabilities access to essential and life-saving SRHR services.
- Formal and informal user fees for healthcare facilities and the cost of transportation, can make preventive healthcare financially

inaccessible for women and adolescent girls with disabilities, deterring them from obtaining essential routine healthcare.

- Women and adolescent girls with disabilities are often less able to escape in humanitarian emergency situations and may lose critical medicines or devices in the process.

## Guidelines for Action:

### ► **Availability**

1. Create programmes to improve women and adolescent girls with disabilities access to available health services and increase their understanding of their health needs and rights.

### ► **EXAMPLE:**

*The Canadian Association for Community Living and the DisAbled Women's Network (DAWN) Canada developed the 'Our Health Matters! Improving Access to Cancer Identification & General Healthcare for People with Disabilities & Deaf People Toolkit' to address the knowledge gap about healthcare for persons with disabilities and Deaf people. One module of the Toolkit is aimed at persons with disabilities and addresses their right to be healthy and various aspects of health, including SRHR. The other is for healthcare service providers to help them learn about issues affecting access to healthcare for persons with disabilities and how to proactively address these issues.<sup>597</sup>*

2. Include women and adolescent girls with disabilities in menstrual hygiene management programmes and when distributing resources. For example, distribution of dignity kits during humanitarian emergencies. Develop

programmes specifically for adult women with intellectual and learning disabilities to give them the opportunity to understand and ask questions about menstrual hygiene management, about which they may have never received accessible information.

► **EXAMPLE:**

*The Centre for Developmental Disability Health in Australia produced a useful guide titled ‘Supporting Women: Information and Resources for Carers Supporting Women with Intellectual Disabilities to Manage their Menstruation’.<sup>598</sup> The guide contains comprehensive guidance for caretakers about addressing menstruation for women with intellectual disabilities and potential issues they may encounter ranging from medical management to legal issues.*

3. Advocate for clarity in laws and policies around access to abortion, where legal, for victims/survivors of sexual violence and ensure that such laws and policies are inclusive of women and adolescent girls with disabilities.
4. Advocate, as necessary, for national laws and policies to state clearly that access to safe abortion, where legal, cannot require the consent of a parent, guardian, or spouse.<sup>599</sup>
5. Prioritize and integrate into SRHR services psychological first-aid and other mental health services for women and young persons with disabilities, especially during



Two sisters sitting on chairs at home by windows.  
© kali9/Getty Images

emergencies. This can be done directly or through referrals. According to the **‘Inter-Agency Standing Committee’s Guidelines on Mental Health and Psychosocial Support in Emergency Settings’**, the fundamental principles of emergency mental health and psychosocial interventions are: (1) Promote respect for human rights and equity; (2) promote community participation; (3) do no harm; (4) build on available resources and capacities; (5) integrate activities and programming into wider systems (such as health programmes, education programmes, etc.); and (6) develop a multi-layered response.<sup>600</sup>

## Guidelines for Action:

### ► **Accessibility**

1. Provide accessible information, education, and counselling for women and adolescent girls with disabilities on their SRHR, including on contraceptive use to prevent unintended pregnancy and the availability of safe, abortion services, where it is not against the law.<sup>601</sup> Ensure that accessible counselling on a range of contraceptive methods and access to a contraceptive method of choice is available to women with disabilities who seek an abortion, where legal, or post-abortion care.<sup>602</sup>

#### ► **EXAMPLE:**

*In Nigeria, the **Deaf Woman's Association of Nigeria (DWAN) and Ipas Nigeria** implemented a twin-track disability SRHR programme to strengthen the capacity of sign language interpreters.<sup>603</sup> Through sensitization workshops focused on information, communication, and financial barriers and advocacy meetings, the project identified three key lessons learned for dismantling barriers faced by Deaf women in accessing SRHR services: "[1] Access to sign language interpreters at sexual and reproductive health service sites is imperative to promote access to quality services for deaf women and ultimately reduce maternal morbidity and mortality amongst this population. [2] Provision of free sign language interpretation services to support deaf women in accessing health care must be accompanied by advocacy with health facility leadership to secure buy-in and facilitate policies—including waiving certain costs—that optimize service use by people with disabilities. [3] Engaging the leadership of various community*

*members and institutions is crucial to ensure ownership of the project".<sup>604</sup>*

2. Adapt services, such as exams, procedures and equipment, to accommodate women and adolescent girl's disability-related needs. Where possible, design services utilizing universal design principles for everything from the service delivery location to gynecological chairs. Doing so allows for a wider range of usage and not just for persons with disabilities.

#### ► **EXAMPLE:**

*The **Keela Cup** is an accessible menstrual cup designed by a woman with a disability to be accessible for women with disabilities.<sup>605</sup>*

#### ► **EXAMPLE:**

*The manual '**Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations,**' offers practical guidance for service providers and support staff on how to improve the experience of a gynecological exam for women with disabilities. The manual covers guidance for assessing the accommodations required; conducting exams, including alternative positions and accommodations for various disabilities; and follow-up steps after the exam.<sup>606</sup>*

3. Create alternative and creative ways to help women with disabilities better understand their bodies and procedures through the creation of models or picture guides.

#### ► **EXAMPLE:**

*The '**Kahani Her Mahine Ki**' kit was created in India and contains a tactile model and booklet*



Members of the blind women's orchestra Al Nour wal Amal (Light and Hope) Basma and Dina at the hotel after a rehearsal before their concert in Segre on the orchestra's European tour. © Fernando Moleres/Panos Pictures

*that helps visually impaired girls learn about their bodies and menstruation.*<sup>607</sup>

► **EXAMPLE:**

*The Centre for Developmental Disability Health in Australia has produced a simplified guide on Pap smear tests that service providers can use to help patients with disabilities called 'Pap Tests: The Plain Facts'. The guide explains in plain language what women with disabilities can expect as part of a Pap smear test and uses drawings to explain the procedure.*<sup>608</sup>

4. Train mid-level service providers to provide early safe abortion services, where legal, to ensure affordability of services and to facilitate access in rural or isolated areas.<sup>609</sup>
5. Ensure abortion services are accessible and quality, where it is not against the law, at the community level, primary-care facility level, and through referral hospitals.<sup>610</sup>

6. Ensure that toilets and latrines are accessible, gender-sensitive, and safe, particularly during humanitarian emergency situations. This is critical for both the dignity, privacy, and safety of women and adolescent girls with disabilities and their SRHR and health needs generally.

► **EXAMPLE:**

*Hesperian's 'A Health Handbook for Women with Disabilities' offers the following suggestions for adapting toilets and latrines to make them easier for women with disabilities, particularly in low-resource settings:*

- "If a person has difficulty squatting, make a simple hand support or a raised seat. Or, if the toilet is set in the ground, make a hole in the seat of a stool or chair and place it over the toilet.
- If a person has difficulty controlling her body, make supports for her back, sides, and legs, and a seat belt or bar.

- Use a rope or fence to guide blind people from the house to the toilet.
  - If a person has difficulty adjusting or removing her clothes, adapt her clothing to make it loose or elastic. Make a clean, dry place to sit or lie down and dress.
  - If a person has difficulty sitting, make moveable handrails and steps”.<sup>611</sup>
7. Ensure that any additional costs associated with making essential healthcare services accessible to women and adolescent girls with disabilities are not passed on to them through formal or informal user fees.

### Guidelines for Action:

#### ► **Acceptability**

1. Develop mentoring and experiential training programmes that help service providers and support staff build confidence and overcome concerns about serving women and adolescent girls with disabilities.
2. Create model programmes to help providers better serve women and adolescent girls with disabilities and understand what inclusive programming looks like.
3. Develop orientation procedures that address a woman or adolescent girl’s apprehension or lack of understanding about an upcoming exam. Examples might include:<sup>612</sup>
  - Communicate the importance of the exam and the steps involved with the process.
  - Create illustration guides for exam procedures, particularly gynecological exams, using pictures, models, or videos.
  - Offer the patient a tour of a clinic and the equipment prior to an exam to help increase their comfort levels.
  - Provide a description of the procedure for the exam and the test results.
  - Allow the patient to role play the exam with models or dolls.
4. Develop widespread community information campaigns to increase knowledge about women’s health needs and the rights of women and adolescent girls with disabilities. Campaigns should feature persons with disabilities and target healthcare practitioners, traditional healers, community and religious leaders, women and adolescent girls with disabilities, and families and caregivers who may act as gatekeepers to essential health services.
5. Develop programmes to combat harmful stereotypes and provider bias, including fear of complications for women and adolescent girls with disabilities.
6. Ensure that information is in a format that the patient can understand about surgical and medical abortion, where legal, and the risks and benefits of each procedure given the circumstances of her pregnancy and ensure that the patient’s choice of method is respected.<sup>613</sup>
7. Provide accessible, confidential pre-abortion counselling, where legal, to support a woman with a disability to make her own voluntary decision.<sup>614</sup>

## Guidelines for Action:

### ► Quality

1. Develop integrated medical school programmes and basic course materials to train all medical service providers on the needs and available adaptations to serve women and adolescent girls with disabilities. These should not be specialized programmes but integrated into the curriculum to underscore that serving persons with disabilities is the responsibility of every service provider.
2. Increase healthcare service provider capacities to screen women and adolescent girls with disabilities for cancer and other diseases with any necessary accommodations.
3. Train service providers and input robust safeguards to ensure that women and adolescent girls with disabilities are not coerced into abortions and that informed consent is always received.<sup>615</sup> Providers must ensure that all service providers and support staff are trained accordingly to ensure women and adolescent girls with disabilities are making a free and informed choice. Women and adolescent girls with disabilities can be pressured to undergo a procedure or the procedure can be performed without the person's free and informed consent. This can take place for a variety of reasons, including misconceptions that women with disabilities cannot raise children, concern that a woman with a disability may give birth to a child with a disability, substituted decision-making by the woman's parents or guardian, or to cover up sexual abuse. Conversely, women or adolescent girls with disabilities may be prevented from accessing a desired abortion, where it is not against the law, due to the prejudiced belief that a woman with a disability cannot make such a decision herself, substituted decision-making by the woman's parents or guardian.
4. Ensure the following minimum required services, as identified by WHO, are met when women and adolescent girls with disabilities seek abortion services, where it is not against the law:
  - “[M]edically accurate information about abortion [where it is not against the law] in a form the woman can understand and recall, and non-directive counselling if requested by the woman to facilitate informed decision-making;
  - abortion services delivered without delay [where it is not against the law];
  - timely treatment for abortion complications, including complications from unsafe abortion;
  - contraception information, services and referrals, to help prevent repeat unintended pregnancy”.<sup>616</sup>
5. Provide immediate and unconditional treatment of emergency medical care, including post-abortion care, when needed, irrespective of the legal status of abortion and without regard as to the patient's ability to pay for such services.<sup>617</sup>

## *Putting into Practice*

### **Improving Breast Cancer Identification**

DisAbleD Women's Network (DAWN) Canada and the Canadian Breast Cancer Network conducted a review of the research and guidance on breast cancer and women with disabilities, resulting in recommendations around:

1. Adapting the physical environment—buildings and equipment.
2. Adapting or proposing new procedural and practices. For example, patient advocates, support groups, checklists of healthcare providers.
3. Developing women-centred disability sensitivity training for healthcare providers.
4. Conducting outreach and health/breast cancer awareness and promotion to women with disabilities.
5. Establishing policy recommendations and reforms. For example, making accessibility a requirement for accreditation for healthcare facilities or adopting national guidelines for cancer screenings that address access for persons with disabilities.

The review also identified useful resources and training materials to advance reforms in breast cancer screenings for women with disabilities.<sup>618</sup>

#### **4.7.3 Indicators**

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based health services for women and adolescent girls with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators for women's health services should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Sexual and reproductive health services for women and adolescent girls with disabilities are included in the curriculum for pre-service and in-service training of healthcare service providers and social service providers.
- Breast, uterine, pelvic, and cervical cancer identification protocols explicitly include women and adolescent girls with disabilities.
- Healthcare facility has accessible mammogram and ultrasound machines or access to them.
- Healthcare facility has an accessibility needs identification protocol to establish patient's

*To fully realize the sexual and reproductive health and rights of young persons with disabilities on an equal basis with young persons without disabilities, services must be tailored to their health and developmental needs.*

accessibility needs and inform the provider of these needs before the patient arrives at the appointment.

- Women and adolescent girls with disabilities have correct knowledge of the legal status of abortion.<sup>619</sup>

## 4.8 Adolescent and Youth with Disabilities' Access to Health Information and Services

### 4.8.1 Issue Overview

The period between ages 10 and 24 is a pivotal time of development for any person, and no less so for those with disabilities. During that period, adolescent girls and boys experience puberty and go through significant physical, mental, and emotional changes. To fully realize the SRHR of young persons with disabilities on an equal basis with young persons without disabilities, services must be tailored to their health and developmental needs. This requires adolescents and youth with and without disabilities to have access to age- and developmentally-appropriate gender- and disability-sensitive education and information and youth-friendly services. Essential information and services include CSE; contraceptive information, counselling, goods, and services; STI information, counselling, testing, and treatment; maternal and newborn health services; and access to safe abortion services (where legal); and post-abortion care.

Adolescents and youth with disabilities are just as likely to be sexually active as their peers without disabilities, yet they face significant barriers to accessing these essential services. Not only does this deny adolescents and youth with disabilities the information necessary to keep themselves healthy and to foster the development of safe and healthy relationships, but it also communicates to persons with disabilities at a young age that their community does not prioritize investing in them.

### 4.8.2 Guidelines on Providing Adolescent- and Youth-Friendly Rights-Based SRHR Services to Young Persons with Disabilities

The key considerations enumerated here identify common barriers that young persons with disabilities encounter in accessing essential SRHR services. The guidelines for action offer guidance for ensuring that rights-based services tailored to the specific needs and considerations of young persons with disabilities are available, accessible, acceptable and of good quality. These guidelines for action build on the Foundational Guidelines for Action identified in **Chapter 2** and are not exhaustive but provide a starting point for developing disability-inclusive services and programmes.

## Understanding Adolescence and Youth

Different stages of adolescence and youth development raise specific vulnerabilities for adolescent girls and boys, both with and without disabilities. Service providers and support staff must be cognizant of these age- and development-specific vulnerabilities and ensure that young persons with disabilities are included in programming addressing these issues. The following list of vulnerabilities is drawn from UNFPA's *'Adolescent Boys and Young Men'* publication.<sup>620</sup>

### Early Adolescence: Ages 10-14

- Gender-based violence and bullying (girls and boys)
- Unintended and unplanned pregnancy (girls)
- Unsafe abortion (girls)
- Harmful practices (girls)
- Peer pressure to become sexually active or abstain from condoms (boys)
- Taboos in seeking health services (boys)
- Recruitment in violent male peer groups (boys)
- No access to SRHR information and service (girls and boys)
- Depression and suicide (girls and boys)
- Body image anxiety (girls and boys)
- Taboos in seeking health services (boys)
- Exposure to violence in relationships (girls and boys, but girls disproportionately affected)
- No or limited access to SRHR information and service (girls and boys)
- Sexually transmitted infection (girls and boys, but generally higher for girls)

### Mid-Adolescence: Ages 15-19

- Pressure to embody stereotypical gender roles (submissive for female, dominant for males) (girls and boys)
- Gender-based violence (girls and boys)
- Unintended and unplanned pregnancy (girls and boys)
- Unsafe abortion (girls)
- Harmful practices (girls)
- Risk-taking behaviour (boys and girls)
- Transactional sex and sex work (girls)
- Tobacco, alcohol, and substance abuse (boys and girls, but generally higher for boys)
- Early Adulthood: Ages 20-24
- Gender-based violence (girls and boys)
- Transactional sex and sex work (girls)
- Harmful practices (girls)
- Unintended and unplanned pregnancy (girls)
- Unsafe abortion (girls)
- Taboos in seeking health services (boys)
- Gang involvement (boys)
- Poor mental health (boys and girls)
- Unemployment (boys)
- Limited access to SRHR information and service (girls and boys)
- Sexually transmitted infection (girls and boys, but generally higher for girls in some settings)
- Tobacco, alcohol, substance abuse (boys and girls, but generally higher for boys)

### Key Considerations

- Lack of participation by, and consideration of the needs of, young persons with disabilities in the development of national plans, policies, and programmes on SRHR services result in plans, policies, and programmes that effectively exclude young persons with disabilities from these essential services.
- Policies or laws requiring third-party authorization or notification, such as policies that require parental consent or notification for young persons to participate in CSE programmes or to obtain contraception, can effectively deny young persons access to essential SRHR information and services.<sup>621</sup> Barriers that are only further exacerbated for young persons with disabilities.
- Young persons with disabilities are at heightened risk for harmful practices, which has serious consequences for their SRHR.<sup>622</sup>
- Service providers do not receive adequate training on and are not confident with providing SRHR services to young persons with disabilities.
- Adolescent and youth sexuality, especially for persons with disabilities, is often considered a taboo subject, leading to an environment where sexuality is viewed as something negative that must be suppressed.
- Parents, guardians, or other caregivers can be overprotective and may not want young persons with disabilities who are in their care to learn about their sexual and reproductive health for fear it will increase their sexual activity. This type of gatekeeping can prevent adolescents and youth with disabilities from accessing the SRHR services they need and may also lead them to hide health conditions.<sup>623</sup> Moreover, adolescents and youth with disabilities generally lack funds to access or receive healthcare services independent of their families or caregivers.
- Adolescents and youth with disabilities fear accessing services because of a perception that service providers or support staff will scold them, put them through painful procedures, or violate their confidentiality.<sup>624</sup>
- Lack of discretion or privacy in accessing SRHR services, such as the inability to seek services without being seen publicly, can deter adolescents and youth with disabilities from seeking such services.<sup>625</sup>
- Adolescents and youth with and without disabilities often lack a way to confidentially communicate with SRHR service providers and to ask questions. Lack of trust and communication can lead to proliferation of misinformation about SRHR with attending consequences to their health.
- Negative experiences as a young person with medical service providers can lead persons with disabilities to avoid important medical care later in life.<sup>626</sup>

### Guidelines for Action:

#### ► Availability

1. Assess the needs of young persons with disabilities in your community and develop programmes tailored to improve and address their health needs. The WHO's *'Global Accelerated Action for the Health of Adolescents (AA-HA!): Guidance to Support Country Implementation'*<sup>627</sup> document for policy makers and programme developers offers important guidance for understanding the needs of adolescents in a country, analysing the current scope of what is being

done, conducting a consultative process to set priorities, and planning, implementing, monitoring, and evaluating national health programmes. The document lays out the following systematic approach that can offer service providers both big and small guidance on how to begin developing effective programmes to serve young persons with disabilities or assess current programmes for how they serve or do not serve young persons with disabilities:

- “Section 1: Understanding what is special about young persons and why investing in them results in long-term societal benefits.
  - Section 2: Understanding global and regional young person health profiles.
  - Section 3: Understanding what works—the AA-HA! Package of evidence-based interventions.
  - Section 4: Understanding the country’s young person health profile. Undertaking landscape analysis. Conducting a consultative process for setting priorities based on explicit criteria.
  - Section 5: Planning and implementing national programmes.
  - Section 6: Strengthening accountability for young persons’s health: monitoring and evaluating young person health programmes and priorities for young person health research”.
  - Each of these sections are underpinned by “Leadership and participation of adolescents and young persons” and “Addressing adolescent health needs in humanitarian and fragile settings”.<sup>628</sup>
2. Ensure that evidence-based youth-friendly services are available. Train educators

on implementing SRHR guidance for adolescents and youth with disabilities. The WHO promulgated the following guidance for adolescent-friendly services in *‘Global Standards for Quality Health-Care Services for Adolescents: A Guide to Implement a Standards-Driven Approach to Improve the Quality of Healthcare Services for Adolescents’*.<sup>629</sup> Service providers and support staff should use this document to better understand the standards for the development and provision of youth-friendly services. Although not explicitly tailored for young persons with disabilities, these standards equally apply, and service providers and support staff must ensure the following standards are met to ensure that health services are available. The document lays out eight criteria that inform the required level of quality in the delivery of services:

- “Adolescents’ health literacy.
- Community support.
- Appropriate package of services.
- Providers’ competencies.
- Facility characteristics.
- Equity and non-discrimination.
- Data and quality improvement.
- Adolescents’ participation”.<sup>630</sup>

### Guidelines for Action:

#### ► **Accessibility**

1. Develop, support, or engage young persons with disability-led organizations and peer support groups. Programmes like these are critical partners for disseminating SRHR information and connecting young persons

with disabilities with services. These organizations should be integrated to encourage the development of peer networks and understanding between young persons with and without disabilities.

► **EXAMPLE:**

*In Israel, the Israel Family Planning Association (IFPA), developed a peer education programme for young persons with physical and sensory disabilities.<sup>631</sup> Following a comprehensive sexuality education and training course, the young persons partnered with peer educators without disabilities to deliver over fifty workshops and lectures along with counselling and media interviews to other young persons, parents and professionals.<sup>632</sup> More information about this programme and other good practices for inclusion of adults and young persons with disabilities in sexual and reproductive health and rights programmes, is available in the Dutch Coalition on Disability and Development (DCDD) and Share-Net International's publication **'Everybody Matters'**.<sup>633</sup>*

2. Offer accessible hotlines tailored for young persons to receive SRHR information and effective referrals.
3. Offer services in the home or another safe or accessible space within the community, rather than depending on families or caregivers to bring a young person with a disability to a facility or clinic to receive services.
4. Create programmes and materials that assist young women with intellectual disabilities

or learning disabilities with understanding menstruation and how to take care of monthly bleeding. Programmes should use plain language and/or easy read documents and allow young women the time to understand menstrual hygiene. Picture guides can be a particularly useful tool where available.

► **EXAMPLE:**

*Down's Syndrome Scotland has produced a free booklet titled **'Let's Talk about Periods'** to help girls with disabilities learn about their periods. The booklet is written in plain language and uses visual aids.<sup>634</sup>*

► **EXAMPLE:**

*Hesperian's **'A Health Handbook for Women with Disabilities'** suggests that a trusted family member or friend take the following steps to help a young woman who has trouble understanding or learning to better understand her menstrual cycle:*

- Use the same kinds of pads or cloth as are commonly used.
- Show the young woman where the supply of pads is kept.
- Show the young woman where the cloths or pads are thrown out or washed.
- Show the young woman how to place the pad or cloth in her underwear so that she can practice using and wearing it.
- Suggest that she may want to consider wearing dark clothing, if she has any, to avoid stains showing. But explain that getting blood on your clothing during your period is normal.<sup>635</sup>

## Guidelines for Action:

### ► **Acceptability**

1. Invest in developing targeted programmes and conducting outreach services for adolescent girls and boys with disabilities during the early adolescence period (ages 10-14). This is the period during which adolescents are most excluded from receiving SRHR information and services
2. Develop programmes for young persons with disabilities to learn about menstruation with information presented in a clear, direct manner and with opportunities to practice new skills.<sup>636</sup> Concurrently, include young women with disabilities in mainstream menstrual hygiene management programmes and when distributing resources.

#### ► **EXAMPLE:**

*In Tanzania, Femme International (FI) and Youth with Disabilities Community Program developed a project in Tanga, a region of Tanzania, to bring FI's 'Feminine Health Empowerment Program' to girls with disabilities in the community. Tanga girls with disabilities, particularly those with intellectual disabilities, face difficulties in understanding the menstruation process especially given the Tanga tradition of learning about menstruation from a female elder. The programme aims to teach girls and boys with and without disabilities about how their bodies work, the menstrual cycle, and how to make safe and healthy SRHR choices.<sup>637</sup>*

3. Develop programmes aimed at engaging young persons with disabilities to promote

expression and involvement in programme development.

#### ► **EXAMPLE:**

*UNICEF developed the 'Adolescent Kit for Expression and Innovation,' along with associated guidance, to assist service providers and support staff with engaging young persons in emergencies. The Kit includes guidance, tools, and supplies "to support country programmes to reach and engage adolescents ages 10-18 affected by conflict and other crises through education, child protection, youth development and/or peacebuilding initiative".<sup>638</sup> To learn more and order the kit, visit <http://adolescentkit.org/>*

4. Work with adolescents and youth with disabilities to create creative tools for sharing information about SRHR and how to integrate these tools into people's lives. UNICEF has identified the following standards to ensure high-quality participation of young persons with disabilities in the development of youth-friendly health services:

- "Participation of young persons with disabilities is embedded in the culture and practices of the organization.
- There is a wide range of opportunities for young persons with disabilities to participate within the organization.
- Participation opportunities are inclusive.
- Participation activities are accessible.
- Young persons with disabilities set the agenda.
- Participation is a positive and meaningful experience for young persons with disabilities.

- Staff have appropriate attitudes, understanding and skills.
  - Participation is monitored and evaluated.
  - Participation of disabled young persons brings about change.
  - The organization shows that it values young persons with disabilities' participation".<sup>639</sup>
5. Treat young persons with disabilities who are seeking services with respect and protect their confidentiality. This is a key issue that adolescents and youth worldwide have identified as essential to making services youth-friendly.<sup>640</sup> Advocate as necessary for laws, policies, and ethical guidelines that protect the confidentiality of adolescent and youth patients receiving SRHR services.
  6. Mentor and develop young persons with disabilities to become peer educators to share SRHR information with other young persons with disabilities.
  7. Create campaigns and programmes that improve understanding and visibility about sexuality among young persons, including those with disabilities. These should address discrimination and misconceptions about sexuality and disabilities, such as the myth that persons with disabilities cannot have fulfilling relationships or an active sex life. Raise awareness among adolescents and youth with disabilities, along with their families, caregivers and health personnel, about the rights of young persons with disabilities and the importance of access to SRHR services.<sup>641</sup>
  8. Use technology to share information with young persons with and without disabilities. Incorporate young persons with disabilities into social media campaigns. Use text messaging and other messaging services to encourage information and experience sharing among peer groups; this has proven particularly effective among Deaf youth. Include mechanisms for accessing more information through links and codes to encourage deeper learning.<sup>642</sup>

### Guidelines for Action:

#### ► Quality

1. Adapt the WHO's '**Core Competencies in Adolescent Health and Development for Primary Care Providers**'<sup>643</sup> guidance, in conjunction with young persons with disabilities, to train healthcare service providers on service provision for adolescents with disabilities.
2. Collect and disaggregate data by age, sex, and disability to assess health services for young persons with disabilities. The Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health published a report on the rights of adolescents that details the mental health and SRHR needs of adolescents. The Special Rapporteur identifies the lack of data disaggregated by age, sex, and disability as one of the biggest challenges to promoting adolescent's rights.<sup>644</sup> The report also emphasizes the need for disability- and age-appropriate services.<sup>645</sup> The standards laid out in the report provide additional guidance on how to realize the right to health for young persons with disabilities.<sup>646</sup>

## HUMANITARIAN EMERGENCIES

### Young Person's Access to Health Information and Services

Ensure that minimum standards are followed for all services offered and provided to young persons with disabilities during humanitarian emergencies. UNFPA and Save the Children USA have developed comprehensive minimum standards and services for adolescent SRHR services during emergencies, as a companion to the *'Inter-Agency Field Manual on Reproductive Health in Humanitarian Settings'*.<sup>647</sup> These guidelines are not tailored to persons with disabilities, thus service providers should work with young persons with disabilities to understand how to implement these standards with the adaptations and accommodations required by young persons with disabilities.

*'Adolescent Sexual and Reproductive Health Toolkit for Humanitarian Settings: A Companion to the Inter-Agency Field Manual on Reproductive Health in Humanitarian Settings'*<sup>648</sup> – Minimum Initial Service Package:

- “Adolescent-friendly clinical services;
- Clinical management of survivors of sexual violence;
- Treatment and referral of clients with obstetric emergencies;
- Standard precautions;
- Condom distribution”.<sup>649</sup>

Utilize the following techniques to improve service delivery to young persons with disabilities during humanitarian emergencies:

- Establish or identify safe spaces for adolescents.<sup>650</sup>
- Twenty-four seven availability of clinical services.
- Private triage areas.
- Same-sex service providers and support staff.
- Limited vaginal speculum examinations to pre-pubertal girls.
- Non-judgmental service providers and support staff trained to ensure privacy and respect young victim/survivor's dignity.
- Confidential services that do not require parental consent.
- Service providers and support staff trained to identify sexual assault in males.<sup>651</sup>

### 4.8.3 Indicators

The following are illustrative of indicators that can be used to monitor and evaluate progress in the provision of rights-based SRHR services for young persons with disabilities. This is not an exhaustive list, but rather a few examples demonstrating the level of specificity, subjects, and form that indicators around youth-friendly SRHR services should take. Service providers should tailor the indicators to fit their programme settings and levels, including by specifying at which level and by whom indicator data should be collected.

- Percentage of young persons with disabilities aged 15-19 with comprehensive knowledge of HIV/AIDS.<sup>652</sup>
- “Number and distribution of health facilities with basic adolescent-friendly service capacity per 10,000 adolescents”.<sup>653</sup>
- Percentage of adolescent girls with disabilities between the ages of 9 and 13 years who have received the HPV vaccine.<sup>654</sup>
- Percentage of contraceptives and condoms distributed by age.
- Satisfaction and perception of the service by young persons with disabilities.
- Percentage of service providers trained on providing adolescent-friendly health services to adolescents with disabilities.







## Glossary and Resources

### 5.1 Glossary

**Adolescents** are boys and girls between the ages of 10 and 19 years old. The period is defined by the physical, cognitive, behavioural and psychosocial changes taking place during the period and illustrated by increased sense of self, confidence, and independence.<sup>655</sup>

**Capacity** generally refers to “a patient’s ability to understand the significant benefits, risks, and alternatives to proposed healthcare and to make and communicate a healthcare decision. It is question- and decision-specific and should be documented relative to each decision. Capacity to consent should be assessed and documented for each treatment or plan of treatment. An individual is presumed to have capacity to

make a healthcare decision, to give or revoke an advance directive, and to designate or disqualify a surrogate”.<sup>656</sup> However, service providers and support staff must look to their national and local legal systems and professional standards for the definition applicable to their practice.

**Comprehensive sexuality education (CSE)** refers to sexuality education that is rights-based and assists people with obtaining accurate and age-appropriate information about all aspects of SRHR; healthy exploration of sexuality; empowerment; and positive thinking about sexuality and SRHR. CSE also supports the development of positive life skills and relationships.<sup>657</sup>

**Child marriage**, also known as early or forced marriage, occurs when one or both spouses are below the age of 18, and as such, not yet physically, physiologically, or psychologically ready for marriage. Nor can the child consent to be formally bound.<sup>658</sup>

**Economic violence** involves denying a person access to and control over basic financial resources.<sup>659</sup> Since many persons with disabilities are not given responsibility over their finances, persons with disabilities can be at risk of this form of violence.

**Female genital mutilation**, or female genital cutting, “comprises all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons”.<sup>660</sup> Female genital mutilation is broadly recognized as a human rights violation.<sup>661</sup>

**Justice system** refers to both formal and informal justice systems. Formal justice systems involve the State and its agents administering justice through the enforcement and application of laws. Mechanisms include law enforcement, criminal justice systems, and courts and judges.<sup>662</sup> Informal justice systems refer to the range of mechanisms varying in formality involved in access to justice and rule of law but that exist outside of the traditional State justice structure. Informal justice systems may or may not be connected or recognized by the State. Mechanisms include, systems involved in the “resolution of disputes and the regulation of conduct by adjudication or the assistance of a neutral third party that [] is not a part of the judiciary as established by law and/or whose

substantive, procedural or structural foundation is not primarily based on statutory law”.<sup>663</sup>

**Forced marriage** occurs when one or both spouses have not consented to be formally bound in marriage. Child or early marriage is a form of forced marriage, but young persons and women with disabilities over the age of 18 may also be subjected to forced marriage.

**Gender-based violence (GBV)** are acts of violence “perpetrated against a person’s will and that is based on socially ascribed (i.e. gender) differences between males and females. The term ‘gender-based violence’ is primarily used to underscore the fact that structural, gender-based power differentials between males and females around the world place females at risk for multiple forms of violence. As agreed in the *Declaration on the Elimination of Violence against Women* (1993), this includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty, whether occurring in public or in private life. The term is also used by some to describe some forms of sexual violence against males or targeted violence against LGBTI populations”.<sup>664</sup>

**Harmful practices** refers to practices, behaviours and attitudes—often grounded in culture, religion, or superstition—that negatively affect the human rights and fundamental freedoms of women and young persons with disabilities.<sup>665</sup> Examples of harmful practices include child or forced marriage, female genital mutilation, and honour killings.

**Healthcare service providers** offer healthcare services in a systemic way. Examples include doctors, midwives, nurses, community health

workers, and other individuals trained to provide health services.<sup>666</sup>

**Health system** is defined by the WHO as “all the activities whose primary purpose is to promote, restore and/or maintain health” and “the people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve”.<sup>667</sup>

**Humanitarian emergencies** are situations of armed conflict, natural disasters, and other situations of risk resulting in a need for humanitarian services and often involving internal displacement or refugee populations.<sup>668</sup> States are required to fulfil their international legal obligations during emergencies, which includes taking all necessary measures to ensure the protection and safety of persons with disabilities.<sup>669</sup>

**Informed consent** is the process of communication between a service provider and a service recipient that results in the service recipient providing consent voluntarily and without threats, intimidation, or inducements, for a service, referral, or dissemination of the person’s private information. The service recipient must receive counselling about the services available and potential alternatives in a language and form that is understandable to the service recipient.

**Legal capacity** refers to the right of persons with disabilities to recognition everywhere as people before the law. Under international human rights law, persons with disabilities have a right to legal capacity—which is distinct

and independent from mental capacity—on an equal basis with individuals without disabilities. Supported decision-making mechanisms may be necessary to empower persons with disabilities to exercise their right to legal capacity.<sup>670</sup>

**Medico-legal evidence** is medical evidence for use in legal proceedings, particularly relating to sexual violence. The WHO defines it as “documented extra and ano-genital injuries ... and emotional state ... as well as those ‘samples and specimens that are taken [from the victim’s body or clothing] solely for legal purposes.’ Such evidence includes saliva, seminal fluid ..., head hair, pubic hair ..., blood, urine ..., fibre, debris and soil ...”.<sup>671</sup>

**Person with a disability** is the person-first language used by the Convention on the Rights of Persons with Disabilities and “include[s] 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.”<sup>672</sup>

**Psychological violence** refers to behaviour that is controlling, isolating, humiliating or embarrassing and which causes the person upon who it is perpetrated psychological distress.<sup>673</sup>

**Psychosocial disability** is the term used to refer to people with what is otherwise known as a “mental impairment”. The term psychosocial disability is defined by the World Network of Users and Survivors of Psychiatry as “the interaction between psychological and social/cultural components of our disability. The psychological component refers to ways of

thinking and processing our experiences and our perception of the world around us. The social/cultural component refers to societal and cultural limits for behaviour that interact with those psychological differences/madness as well as the stigma that the society attaches to labelling us as disabled".<sup>674</sup> Although the term "mental impairment" is used in the CRPD to refer to persons with psychiatric disabilities, the preferred term among persons with psychiatric disabilities is psychosocial disability.<sup>675</sup> The term has no association with the psychosocial rehabilitation movement.

**Reasonable accommodation** is defined by the CRPD 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".<sup>676</sup>

**Reproductive health** refers to a person's complete physical, mental and social well-being, not only the absence of disease or illness, in all matters relating to the reproductive system and to its functions and processes. Reproductive health includes the ability to enjoy a satisfying and safe sex life and the freedom and legal capacity to decide if, when, and how often to do so. For women and young persons with disabilities, this means the right to be free from forced sterilization, contraceptives and abortion; access to accessible information about reproductive health and safe, effective, affordable, and acceptable methods of family planning; and the right to access quality accessible maternal and newborn health services.

**Reproductive rights** are human rights recognized in national laws, international laws, and international human rights documents that uphold the rights of all people to decide freely and responsibly on the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. Women and young persons with disabilities, as with all rights-holders, must be free to make these decisions free of discrimination, coercion, or violence.<sup>677</sup>

**Sexual health** is defined as "a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled".<sup>678</sup>

**Sexual violence** refers to abusive sexual contact, making a person engage in a sexual act without consent, and attempted or completed sex acts with a person who is unable to consent to sexual contact. It can take many forms, including any unintended or non-consensual sexual act, sexual harassment, and violent acts. A person may be unable to consent due to their disability (however, having a disability does not mean a person is automatically unable to consent to voluntary sexual conduct). Other reasons a person may be unable to consent include that the person is asleep, unconscious, ill, under pressure, or under the influence of drugs or alcohol.<sup>679</sup>

**Supported-decision making** refers to regimes that replace substitute decision-making models, such as guardianship. Supported decision-making “comprises various support options which give primacy to a person’s will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.)”.<sup>680</sup> Substituted decision-making models perpetuate power imbalances, which can make women and young persons with disabilities especially vulnerable to gender-based violence and other forms of abuse and ill-treatment.<sup>681</sup>

**Survivor-centred** services are those that “prioritize the rights, needs, dignity and choices of the survivor—including the survivor’s choice as to whether or not to access legal and judicial services”.<sup>682</sup>

**Twin-track approach** has been defined by the Committee on the Rights of Persons with Disabilities as: “systematically mainstreaming the interests and rights of women and girls with disabilities across all national action plans, strategies and policies concerning women, childhood and disability, as well as in sectoral plans concerning, for example, gender equality, health, violence, education, political participation, employment, access to justice and social protection” and “targeted and monitored action aimed specifically at women with disabilities”.<sup>683</sup>

**Victim/survivor** is a person who has experienced or is currently experiencing GBV. There has been debate about the use of the terms victim and survivor. The UN Secretary-General’s *‘In-Depth Study on Violence Against Women’* explains that for some, “the term ‘victim’ should be avoided because it implies passivity, weakness and inherent vulnerability and fails to recognize the reality of women’s resilience and agency. For others, the term ‘survivor’ is problematic because it denies the sense of victimization experienced by women who have been the target of violent crime”.<sup>684</sup>

**Virgin rape**, also known as virgin cleansing, is the “the belief that people who have a sexually transmitted infection can rid themselves of the condition by transferring the infective organism by having sexual intercourse with a virgin”.<sup>685</sup> A more recent iteration of the practice has been documented in the targeting of individuals with disabilities by people who believe themselves to be infected with HIV.<sup>686</sup> It is believed that individuals with disabilities are targeted because of the misperception that they are likely to be virgins and are easy targets.

**Violence against women** is defined as “any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life”.<sup>687</sup> This definition includes the many forms violence against women with disabilities can take, including intimate partner violence, caregiver violence, medical violence (e.g. forced sterilizations and other procedures, forced medication or overmedication), sexual

violence, psychological violence, economic violence, institutional violence, and violence during emergencies.

**Violence, non-partner** is violence committed by a caregiver (non-partner), family member, friend, acquaintance, neighbour, work colleague or stranger. Frequently, non-partner violence is committed by a person familiar to the victim/survivor. For persons with disabilities, offenders can serve in a caregiver role for the person either in the person's home or in an institutional setting.

**Violence, intimate partner** refers to the range of sexual, psychological and physical acts that can be used against women and young persons with disabilities by a current or former intimate partner, without that person's consent. For persons with disabilities, intimate partner violence is regularly perpetrated by partners who are also caregivers for that person, which can often prevent such violence being identified.

**Young persons** refers to girls, boys, young women, and young men from age 10 to 24 years old, encompassing the globally accepted definitions of adolescents (an age range of 10 to 19) and youth (an age range of 15 to 24).<sup>688</sup>

**Youth** refers to young women and men from age 15 to 24.<sup>689</sup>

## 5.2 Resources

Ann M. Starrs et. al., *Accelerate Progress - Sexual and Reproductive Health and Rights for All: Report of the Guttmacher-Lancet Commission*, *The Lancet* 7-57 (May. 9, 2018), [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)30293-9/fulltext?code=lancet-site](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)30293-9/fulltext?code=lancet-site)

The Adolescent Kit For Expression and Innovation, <http://adolescentkit.org/>  
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