

UNIT 16:

ADOLESCENTS WITH DISABILITIES

INTRODUCTION:

According to the global data currently available, there are over 1 billion persons with disabilities living in the world today, which account for about 15% to 20% of the world population. An estimated 80% live in a developing country and between 180 and 220 million are youth.


All young persons are entitled to the same basic human rights. However, children and adolescents with disabilities are far more likely than their peers without disabilities to be denied these rights. They experience poorer access to education, have limited access to employment and social protection, and more limited access to general health information and services, including those related to sexual and reproductive health.

Adolescents with disabilities are first of all adolescents, with the same SRH rights and needs of their peers without disabilities. Despite a real need for quality information, counseling and services, many adolescents with disabilities find it difficult to access information and services. Girls with disabilities often face multiple levels of discrimination based on their gender, youth, and disability and are often more disadvantaged by disability due to the intersection of gender norms and disability-related stigma.

Service providers play a critical role in ensuring that the SRH right and needs of all young people, including those with disabilities, are fulfilled. However, they often have limited understanding of the additional barriers adolescents with disabilities face when accessing SRH information and services. This unit is designed to raise service providers' awareness, strengthen their knowledge, and improve their skills for meeting the SRH rights and needs of adolescents with disabilities.

The present unit, however, is not designed to be taught as a standalone module and represents an appropriate tool to improve providers' skills and knowledge on disability-inclusive SRH only when is taught in combination with the other 14 units.

The information, guidance, principles and good practices included in the other 14 chapters are relevant to ensure better access to services for adolescents of all abilities. The present unit builds on the content of the other 14 units and provides additional guidance on how to better support young persons with different types of disabilities in need of SRH information and services. The inputs on service provider's attitudes, good communication, and the key principles of quality youth-friendly services introduced respectively in units 6 and 14, for example, represent an essential body of knowledge that trainees need to master before learning about the disability-inclusive communication techniques and service adaptations presented in this unit. Last but not least, each of the other 14 units includes additional disability inclusive components relevant to the specific subjects addressed in each unit that cannot be overlooked.


 **UNIT TRAINING OBJECTIVE:**

By the end of this unit, providers will have improved knowledge and skills for meeting the SRH rights and needs of adolescents with disabilities.




 **SPECIFIC LEARNING OBJECTIVES:**

By the end of the unit providers will be able to:

1. Define disability using the appropriate language and concepts.
2. Discuss how sexuality, gender, and disability intersect, and the barriers adolescents with disabilities face in accessing SRH information and services.
3. Describe the main characteristics of disability-inclusive SRH services and how they can contribute to promote change.
4. Demonstrate improved knowledge and skills on how to communicate with adolescents with different types of disabilities.

 **TOTAL TIME: 8 HOURS 40 MINUTES**

UNIT OVERVIEW:

Session	Methods 	Materials 	Time 
16.1	Trainer presentation Group discussion	Flipcharts and markers Post-its Handout 16a	45 minutes
16.2	Group discussion Trainer presentation	Flipcharts and markers Handouts 16b-g	2 hours
16.3	Trainer presentation Role play	Flipcharts and markers Handouts 16h-i	2.5 hours
16.4	Trainer presentation Role play	Flipcharts and markers Handout 16j	2 hours
Unit Summary	Individual reflection	Handout 16k	45 minutes
Training Evaluation	Post-test Individual evaluation worksheet	Participant Handouts 16l-m	40 minutes



WORK FOR TRAINERS TO DO IN ADVANCE:

- Search for data on young persons with disabilities in your country, including data on sexuality and disability, and summarize them in a handout to be shared with the participants (specific objective 2).
- Become familiar with the local policies/regulations concerning access to SRH services for adolescents and find out if and how these policies, regulations and laws refer to young persons with disabilities.
- Become familiar with how this particular country defines disability within legislation and what disability language (i.e., “person with a disability,” “disabled person,” etc.) is used in the country. Become aware of the differences, if any, between this country-specific terminology and the language used by the Convention on the Rights of Persons with Disabilities (CRPD).
- If not already aware, find out if the country where you are delivering the training has ratified the CRPD.
- Prepare copies of Handouts 16a-m



MAJOR REFERENCES AND TRAINING MATERIALS:

ACPF (African Child Policy Forum). (2010). *Breaking the silence: Violence against children with disabilities in Africa*. Addis Ababa: ACPF.

Center for Development and Justice. (2017). *Uncovered realities: Exploring experiences of child marriage among children with disabilities*. Plan International.

CREA. *The Nairobi principles on abortion, prenatal testing and disability*. (2018). CREA.
<https://nairobiprinciples.creaworld.org/>

De Beaudrap P. et al. (2017). *Prevalence of HIV infection among people with disabilities: A population-based observational study in Yaoundé, Cameroon (HandiVIH)*. *Lancet HIV*. April 4(4): e161-e168.

Goblet, D. (2011). *Handicap et homosexualité: Double tabou, double discrimination?* Namur: Université Notre-Dame de la Paix. <http://yagg.com/files/2011/08/TFE-HANDICAP-ET-HOMOSEXUALITEDOUBLE-TABOU-DOUBLE-DISCRIMINATION.pdf>

Groce, N. and Kett, M. (2014). *Youth with disabilities*. Working Paper 23. London: Leonard Cheshire Disability and Inclusive Development Centre, University College London.

Jones, L., Bellis, M.A., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C.,

- Shakespeare, T. and Officer, A. (2012). *Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies*. *Lancet* 380 (9845): 899–907.
- Jones, N., Presler-Marshall, E. and Stavropoulou, M. (2018). *Adolescents with disabilities: Enhancing resilience and delivering inclusive development*. London: Gender and Adolescence - Global Evidence.
- Kuper H. and Heydt P. (2019). *Access to health services for 1 billion people with disabilities*. London School of Hygiene and Tropical Medicine (LSHTM). <https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability/missing-billion>
- Leonard W. and Mann R. (2018). *The everyday experiences of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability*. La Trobe University.
- Management Sciences for Health & UNFPA. (2016). *We decide young persons with disabilities: Equal rights and a life free of violence*. https://www.msh.org/sites/msh.org/files/we_decide_infographic.pdf
- Msekele, S. (2018). *Being disabled, black and queer in South Africa: A personal journey*. P. Chappell and M. De Beer (eds.), *Diverse voices in disabled sexualities in the Global South*. New York: Palgrave Macmillan; 127-130.
- Office of the High Commissioner on Human Rights (OHCHR), et al. (2014). *Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement – OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO*. https://apps.who.int/iris/bitstream/handle/10665/112848/9789241507325_eng.pdf?sequence=1
- Office of the United Nations High Commissioner for Human Rights (OHCHR). (2012). *Thematic study on the Issue of violence against women and girls and disability, A/HRC/20/5* Geneva: OHCHR. <http://www2.ohchr.org/english/issues/women/docs/A.HRC.20.5.pdf>
- UNDESA. (2018). *Realization of the Sustainable Development Goals by, for and with persons with disabilities. UN flagship report on disability and development*. New York: UNDESA.
- UNFPA. (2018). *Young persons with disabilities: Global study on ending gender-based violence and realizing sexual and reproductive health and rights*. New York: UNFPA.
- UNFPA and Women Enable International. (2018). *Women and young persons with disabilities: Guidelines for providing rights-based and gender-responsive services to address gender-based violence and sexual and reproductive health and rights for women and young persons with disabilities*. New York: UNFPA
- United Nations Joint Programme on HIV/AIDS (UNAIDS). (2017). *Disability and HIV*. Geneva: UNAIDS. https://www.unaids.org/sites/default/files/media_asset/JC2905_disability-and-HIV_en.pdf

WHO and World Bank. (2011). World report on disability. Geneva: WHO.

Women's Refugee Commission. Reports on disability.

<https://www.womensrefugeecommission.org/populations/disabilities/research-and-resources?start=20>

- **Trainer's Note:** *This unit is intended to be delivered by trainers who have experience and knowledge on gender, age, and disability inclusive SRH (from now on, referred to as "inclusive SRH"). The trainers should be persons with disabilities. In many contexts, however, the number of trainers with disabilities with this profile is quite limited. If trainers with disabilities matching this profile cannot be identified, the inclusive SRH trainer should be accompanied by representatives of Organizations of Persons with Disabilities (DPOs) who have a background on gender, age, and disability. In both cases, the participation of young persons with different types of disabilities is essential.*

Refer to local DPOs that work with young persons with disabilities and/or on disability, gender, and sexuality-related issues to identify potential youth participants with disabilities.

The presence and meaningful participation of trainers and young persons with disabilities needs to be ensured by holding the meeting at an accessible venue and by offering accommodations as needed by the participants with different types of disabilities (i.e. sign language interpretation and/or Computer Aided Real-Time Transcription (CART)⁵, personal assistants, braille materials, large print materials, easy to read materials, etc.). Be aware that some trainees who will attend your session may also require special accommodations. Therefore, it is always important to ask and prepare in advance to ensure everybody is included.

⁵ CART is a method to provide access to spoken communication for people with hearing, cognitive or learning disabilities. CART refers to the instant translation of the spoken word into text using a stenotype machine, notebook computer and real-time software. The text produced by the CART service can be displayed on an individual's computer monitor, projected onto a screen, or made available using other display systems.

SPECIFIC OBJECTIVE 16.1: DEFINE DISABILITY USING THE APPROPRIATE LANGUAGE AND CONCEPTS



TIME

45 min



METHODS

- Trainer presentation
- Group discussion



MATERIALS NEEDED

- Flipcharts and markers
- Post-its
- Handout 16a



STEPS

Time: 10 minutes

Explore participants' understanding of disability

1. Ask each participant what disability means to them and to write their answers on a paper. It is important to stress that there are no right or wrong answers. This is about opinions and beliefs, and different people have different understandings and use different terms to describe disability.
2. Ask participants to share their answers with the group and discuss the different understandings of disability. Conclude by reminding participants there is not one definition of disability, and that over time, the understanding of disability has changed.
3. Introduce briefly the 3 major approaches that have been used in the last few decades to define, describe, and discuss disability: the charity, medical, and social models. Provide examples for clarification.

The charity model of disability:

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

Example:

“My daughter is deaf. She will not find a husband who takes care of her when I am gone. My husband and I need to put money aside for her future and provide for her”.

The medical model of disability:

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

Example:

“My son has cerebral palsy. He cannot walk and speak normally. He needs rehabilitation. Because of his impairment it is better if he does not have children, we want to prevent any risk of having grandchildren with physical problems”.

The social model of disability:

The social model sees disability as socially created and a relationship between the persons’ disabilities and the environment they live in. Adapting the environment by making all the modifications necessary for the meaningful participation and integration of persons with disabilities in all areas of life is considered a collective responsibility of society at large. Models such as universal design and reasonable accommodation are often used.

Examples:

“Yesterday, my younger brother went to the health clinic to ask about HIV prevention methods. He was very disappointed when the health worker gave him all the information on a regular printed leaflet and did not explain anything verbally. Accessible materials written in Braille were also unavailable. My brother is blind”.

“Last week, my younger sister Gloria, who has down syndrome, went to the health clinic to learn about contraceptive methods. She came home happy about the information she received. The health worker gave her all of the information in easy-to-read formats and spent time to explain its content, answering any questions she had.”

Show participants this short video to better illustrate the social model:
<https://www.youtube.com/watch?v=9s3NZaLhcc4>

4. Conclude the activity by asking participants:
 - If you have to choose the one(s) that best reflect(s) your understanding of disability, which model(s) would you choose?
 - If you have to choose the one(s) that are most widespread in the environment where you live and work, which model(s) would you choose?
 - If none of the models introduced above reflects your understanding of disability or the one widespread in the environment where you live and work, please share your thoughts with the other participants.

5. Allow time for a final discussion on differences and similarities in the answers provided by the participants, including time to reflect on their answers.

Time: 10 minutes

Disability and rights

6. Explain that in the last 2 decades, another very important perspective to discuss disability has emerged – the human rights perspective. This promotes the concept that persons with disabilities are entitled to the same rights as persons without disabilities, that disability rights are human rights and, as such, they need to be protected and promoted.
7. Ask the participants:
 - Do you think young persons with and without disabilities in your communities have rights to go to school, access health services, and access SRH information that are equally promoted and respected?
 - Do young persons with and without disabilities have the same access to school, health services, or SRH information?
 - If not, why?

Time: 10 minutes

Introduce the United Nations Convention on the Rights of Persons with Disabilities (CRPD)

8. Explain that the CRPD is a comprehensive human rights instrument which comprises 50 articles affirming the rights, freedoms and dignity of persons with disabilities, and calling upon states to take all appropriate measures to eliminate discrimination and ensure that persons with disabilities have equal enjoyment of rights in all spheres of life.
9. Explain that the CRPD was adopted in December 2006 and has so far been ratified by 177 states. This means that the Governments of these countries recognize that persons with disabilities should enjoy basic rights on an equal basis with others and commit their government to take all appropriate measures to protect these rights and transform discriminatory systems and practices.
10. Explain that the CRPD is legally binding for all signatory states.
11. Explain that the CRPD has introduced a new definition of “persons with disabilities” that appears below.

“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” (CRPD, Article 1).

12. Share the definition with the participants and explain that in this definition:

- Impairment refers to the biological factor, the medical condition. For instance, someone who cannot see properly or at all has a visual impairment.
- Impairments may be acquired through injury, illness, or congenital conditions and may have mild, moderate, or severe impacts on daily functioning depending on the nature of the impairment, as well as a wide range of personal, environmental, physical, social/cultural, and political factors.

These impairments—in interaction with various barriers—may make it difficult for people to participate equally in society thus leading to social exclusion.

Time: 10 minutes

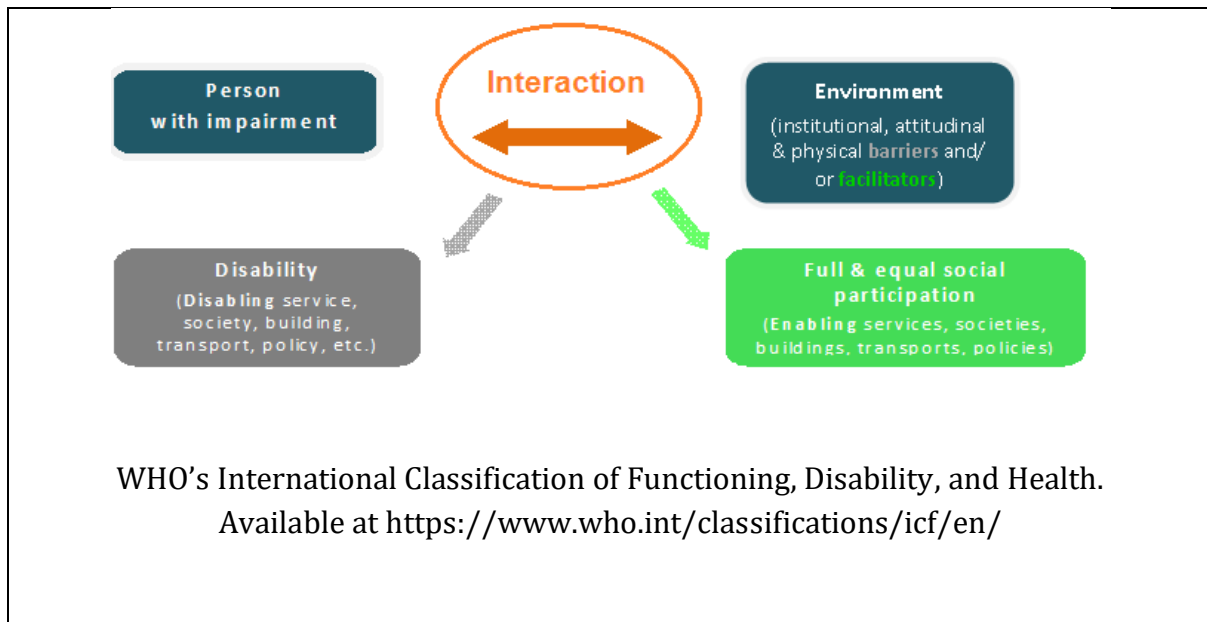
Then, what is a disability?

13. Explain that each country defines disability differently in its own laws and constitutions, and share the definition of disability you have identified for the country where you are providing the training.
14. Explain that this may be different from the one provided by the CRPD even in countries that have ratified the Convention.
15. Explain that there are many types of disabilities. Some disabilities can be seen, but others cannot. Types of disabilities might include:
 - Vision, hearing, or speech disabilities (sensory): people who experience difficulties to see (blind or low vision), to hear (deaf or hard of hearing), or to communicate.
 - Physical disabilities: people with mobility difficulties such as walking, going up/down stairs, standing for long periods of time, or limited use of their limbs.
 - Psychosocial disabilities - often referred to as mental health disabilities: depression, bipolar, and trauma.
 - Chronic health disabilities.
 - Intellectual, developmental, learning, neurological (i.e., epilepsy), and traumatic brain injuries.
 - Multiple disabilities including deaf, blind and Albinism.
16. Highlight that this list is not exhaustive of the many types of disabilities that exist.

➤ **Note to trainers:** *Among the different types of disabilities, intellectual and developmental disabilities are often the least well-known. Some additional information on the subject may*

help participants to better welcome young people with intellectual and developmental disabilities and meet their needs. Please refer to Handout 16a for additional information and distribute it to the participants who ask for more details.

17. Use the below graphic to continue this introduction to disability and to emphasize that “Disability is not considered a static, fixed, and immutable trait of the person. It is the result of the interaction between the person and his/her environment” and consider the impact of an impairment on the social participation of the person.



18. Explain that this definition focuses on what creates a disabling situation and **do not provide strict and universal criteria to determine who persons with disabilities are**. Insist on this aspect as it may take time for an audience that is more familiar with the medical model to fully understand the implications of this concept. The aim is to overcome the idea that persons are labelled once and forever as disabled on the base of their impairment.
19. Explain that disability is an evolving concept and that the same impairment can lead to social exclusion or can have a very mild effect on a person's life depending on how inclusive the environment is.
20. To better explain the above concepts, ask the participants to think about a 25-year-old young woman who was born with only 1 lower limb. Consider how her life would differ if she lived in 3 different circumstances:
- In the center of Copenhagen.
 - In a slum in Nairobi with his family.
 - In the countryside in Greece.
21. Ask participants to discuss:

- Will the risk of social exclusion be the same?
- Will she have equal access to SRH information and services?
- What makes the difference in her opportunities for social inclusion and access to SRH services? The fact that she was born with one leg? The environment where she lives?
- How can we influence that environment to ensure that everybody can access SRH information and services according to the needs?

Time: 5 minutes

The language of disability

22. Explain that language is important when referring to persons with disabilities and continues to evolve.
23. This training we choose to use the person-first language utilized by the CRPD: Adolescent with disability. This is because adolescents with disabilities are first of all adolescents. Take this opportunity to highlight that the definition of “adolescent” and all the information related to adolescents’ SRH introduced in the other units applies to all, including adolescents with disabilities.
24. However, there can be some exceptions when people prefer to use identity-first language (e.g. autistic person, deaf person, disabled person).
25. Most importantly: Explain that a person’s preference for how they wish to be described or addressed must be respected at all times, and it is always best to ask the person what he/she prefers.
26. Highlight that terms you may have heard such as “handicapped”, “crippled” or “mentally retarded”, frequently used to refer to persons with different disabilities, are now perceived as disrespectful and offensive by many. These outdated terms should always be avoided.
27. Tell participants that it is better to avoid the use of the acronym PWD to refer to Person with Disability because this is often perceived as undignifying.
28. Leave time for questions and answers as needed.

PARTICIPANT HANDOUT 16A: INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

There are many kinds of intellectual disabilities—and many causes. Intellectual disability is the most common developmental disability. For a comprehensive list of intellectual and developmental disabilities, please see: <https://www.specialolympics.org/about/intellectual-disabilities/what-is-intellectual-disability>

What is an intellectual disability?

Intellectual disability (or ID) is a term used when a person has certain limitations in cognitive functioning and skills, including communication, social and self-care skills. These limitations can cause a child to develop and learn more slowly or differently than a typically developing child. An intellectual disability can develop at any time during childhood up until the age of 18 years old, even before birth.

Intellectual disability is the most common developmental disability.

According to the American Association of Intellectual and Developmental Disabilities, an individual has intellectual disability if he or she meets three criteria:

- IQ is below 70-75
- There are significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care)
- The condition manifests itself before the age of 18

What causes an intellectual disability?

Intellectual disability – formerly called mental retardation – can be caused by injury, disease, or a problem in the brain. For many children, the cause of their intellectual disability is unknown.

Some causes of intellectual disability—such as Down syndrome, Fetal Alcohol Syndrome, Fragile X syndrome, birth defects, and infections—can happen before birth while the fetus is still developing in the womb. Some happen while a baby is being born or soon after birth.

Other causes of intellectual disability do not occur until a child is older; these might include severe head injury (also known as “Traumatic Brain Injury -TBI), infections, or stroke.

What are the most common causes?

The most common causes of intellectual disabilities are:

- **Genetic conditions.** Sometimes an intellectual disability is caused by abnormal genes inherited from parents, errors when genes combine, or other reasons. Examples of genetic conditions are Down syndrome, Fragile X syndrome, and phenylketonuria (PKU).
- **Complications during pregnancy.** An intellectual disability can result when the baby does not develop inside the mother properly. For example, there may be a problem with the way the baby’s

cells divide. A woman who drinks alcohol or gets an infection like rubella during pregnancy may also have a baby with an intellectual disability.

- **Problems during birth.** If there are complications during labor and birth, such as a baby not getting enough oxygen, he or she may have an intellectual disability.

- **Diseases or toxic exposure.** Diseases like whooping cough, the measles, or meningitis can cause intellectual disabilities. They can also be caused by extreme malnutrition, not getting appropriate medical care, or by being exposed to poisons like lead or mercury.

We know that intellectual disability is not contagious. You cannot catch an intellectual disability from anyone else. We also know it's not a type of mental illness, like depression. There are no cures for intellectual disability. However, children with intellectual disabilities can learn to do many things. They may just need to take more time or learn differently than other children.

How common are intellectual disabilities?

Approximately 1-3% of the global population has an intellectual disability—as many as 200 million people.

Intellectual disability is significantly more common in low-income countries—it occurs at a rate of 16.4 out of every 1,000 people.

Source: Adapted from Special Olympics - <https://www.specialolympics.org/about/intellectual-disabilities/what-is-intellectual-disability>

SPECIFIC OBJECTIVE 16.2: DISCUSS HOW SEXUALITY, GENDER, AND DISABILITY INTERSECT AND THE BARRIERS ADOLESCENTS WITH DISABILITIES FACE IN ACCESSING SRH INFORMATION AND SERVICES



TIME

2 hours



METHODS

- Trainer presentation
- Group discussion



MATERIALS NEEDED

- Flipcharts and markers
- Handouts 16b-16g



STEPS

Time: 30 minutes

Disability, health, and young people

1. Start by asking participants to reflect on their current knowledge on adolescents and disability. Divide participants in subgroups, ask young co-trainers with disabilities to join the groups and invite them to discuss the local context where they live and work.
2. Support the subgroups' discussions by asking the following questions:
 - Are you familiar with the living conditions of adolescents with disabilities and their families in your country/local context?
 - Do adolescents with disabilities go to school? Do they work? Do they have access to health services? Are they treated equally to adolescents without disabilities? If not why? Are boys and girls with disabilities treated differently? If yes, in what way? Why?
 - Do you know any organization of persons with disabilities in your area? Which type of relation do you have with them?
3. Share Handout 16b with participants "Key facts and figures on young persons with disabilities" and present the relevant information.
4. Share Handout 16c with participants "Key facts and figures on health and disability" and present the relevant information.
5. Highlight that although global health data disaggregated by age, gender, and disability is rare, the available data clearly show that persons with disabilities face additional barriers in accessing health information and services and that young people are not an exception. Refer participants to additional readings included in the list of references and materials for more information.

6. Leave time for additional questions from participants as needed.

Time: 30 minutes

YOUNG PEOPLE, SEXUALITY AND DISABILITY

7. Start by asking participants to reflect on their current knowledge about adolescents, sexuality, and disability. Divide participants in subgroups, ask young co-trainers with disabilities to join the groups and invite them to discuss the local culture, beliefs, and understanding of adolescents, sexuality, and disability.
8. Support the subgroup discussions by asking the following questions:
 - What is your opinion about adolescents with disabilities expressing their sexuality, being in intimate relationships, getting married, and having children?
 - Do you know whether young persons with disabilities are encouraged to get married and have children in the same way as their peers without disabilities?
 - Do you know if adolescents with disabilities access SRH information and services in your country? If not, why?
 - Do you think adolescents with and without disabilities have the same need for SRHR? If not, why?
9. To conclude this activity, share the handout you have prepared with the young co-trainers on young persons with disabilities in your country, including data on sexuality and disability.
10. Reinsure the participants that data on SRH and adolescents are still very scattered but the information available confirms that globally the SRHR of young persons with disabilities are largely violated and that they face significant barriers to access SRH information and services.

Time: 30 minutes

The CRPD affirms the SRHR of persons with disabilities of any age

11. Highlight that the CRPD (art. 16, 23, and 25) affirms the SRHR of persons with disabilities of any age. More specifically, the CRPD:
 - Calls for the elimination of discrimination against persons with disabilities in all matters relating to relationships, reproduction, marriage, family, and parenthood on an equal basis with others.
 - Acknowledges that persons with disabilities have the same rights of persons without disabilities to access SRH information and services.
 - Calls for the protection of persons with disabilities from all forms of exploitation, violence, and abuse, including gender-based discrimination, both within and outside the home, and for their prevention.
12. Distribute Handouts 16d, 16e, and 16f and allow time for the participants to read them and to ask for clarifications if needed. Then ask:

- Why, does article 25 highlight SRH among all the health sectors?
- What is your experience of providing SRH information and services to adolescents with disabilities? If no experience is reported, invite the participants to discuss why, in their opinion, young persons with disabilities are not using their services and what the main consequences are.

Time: 30 minutes

The SRHR of persons with disabilities, and especially young people, are largely violated

13. Highlight that although 177 countries have committed to the implementation of the CRPD, the SRHR of persons with disabilities, and especially young people, are largely violated.

14. Substantiate this statement by giving a short presentation on SRHR and disability following the script below. Before starting the presentation, share the “Young people, sexuality and disability” *handout* (Handout 16g) and refer to them for examples and additional information.

- Adolescents with disabilities are rarely regarded as subjects of sexual rights.
- Adolescents with disabilities are often assumed as asexual, not sexually active, or hypersexual.
- Adolescent with disabilities are often assumed as being unable to make decisions for themselves about their sexual life.
- Adolescent girls with disabilities are often denied the choice and autonomy/independence to make their own sexuality-related decisions on the basis of their disability.
- Adolescents with disabilities are often denied their reproductive autonomy.
- Adolescents with disabilities are particularly vulnerable to sexual harassment, violence, and abuse, but such incidents are rarely reported.
- In various countries, many persons with disabilities, particularly women with intellectual disabilities, have been subjected to forced abortion, involuntary sterilization, and long-term contraception which are often used as methods of fertility regulation on a precautionary basis.
- Reasons for higher rates of violence and abuse against persons with disabilities include but are not limited to stigma, discrimination, dependence, impunity, and negative cultural beliefs.
- Discrimination factors related to sexual orientation, gender identity, age, and disability intersect. As a result, LGBTQI adolescents with disabilities face more barriers in expressing their sexuality or gender identity. This is even more so for young persons with intellectual and developmental disabilities.
- Discrimination against and exclusion of people with disabilities, in particular women and girls with disabilities, increases their risk of HIV infection and limits their access to prevention, screening, and treatment services.

15. Ask participants how they feel about what they have just learned young people, sexuality, and disability, and allow time for questions and comments.
16. Conclude the presentation by highlighting that despite having equal needs and rights to access SRH services and being more exposed to the risk of HIV and SGBV, young people with disabilities continue to face higher barriers to accessing information and services. Types of barriers include but are not limited to:
 - **Attitudinal barriers:** Misconceptions and negative perceptions about disability and impairments such as stigma, prejudiced terminology, and behavior exhibited by family, society, cultural norms, and traditional beliefs.
 - **Communication barriers:** No accessible formats or easy to read/understand documents, no sign language interpreter.
 - **Institutional barriers:** Discriminative policies and programming tools, lack of disability inclusive implementation.
 - **Physical barriers:** Distance to services, stairs, inaccessible transportation, no lift, no ramps, no lighting, or no mobile services are available.
17. Explain that addressing and overcoming these barriers is at the core of what this curriculum refers to as “disability-inclusive SRH services”. This is discussed in the next section.

PARTICIPANT HANDOUT 16B: KEY FACTS AND FIGURES ON YOUNG PERSONS WITH DISABILITIES

According to the data currently available:

There are over 1 billion persons with disabilities living in the world today which account for about 15% to 20% of the world population. 80% of persons with disabilities live in a developing country.

According to the *World Health Organization (WHO) and World Bank's World Report on Disability*, the female disability prevalence rate worldwide is 19.2%. There are between 180 million and 220 million young persons with disabilities worldwide, predominantly in developing countries.

Children and adolescents with disabilities have little awareness of their rights and are far more likely than their peers without disabilities to be denied their basic human rights.

In most countries, boys are more likely to have disabilities than girls. Girls with disabilities, however, can face double discrimination based on their gender and disability and are often more disadvantaged by disability due to the intersection of gender norms and disability-related stigma.

Compared to their peers without disabilities, adolescents with disabilities:

- Experience higher rates of social isolation, stigma and exclusion.
- Experience poorer physical and psychosocial health.
- Have more limited access to general health information and services, including those related to sexual and reproductive health.
- Are three to four times more likely to experience violence. Girls with disabilities, especially those with intellectual and developmental disabilities and those living in conflict-affected areas, are particularly vulnerable to sexual violence.
- Experience more barriers in accessing protection mechanisms, report abuse, receive support services, and seek justice.
- Experience poorer access to education. It is estimated that 19 million out of the 58 million children who are out of school have a disability. Young people with intellectual and developmental disabilities are the most likely to be out of school.
- Have limited access to employment and social protection.

PARTICIPANT HANDOUT 16C: KEY FACTS AND FIGURES ON HEALTH AND DISABILITY

According to the *World Report on Disability*, persons with disabilities are:

- 2 times more likely to find health care providers' skills and facilities inadequate
- 3 times more likely to be denied health care
- 4 times more likely to be treated badly in health care facilities
- More than 50% of people with disabilities in the world cannot afford health care
- More than 50% of people with disabilities have an unmet need for rehabilitation

Source:

- Better Health for People with Disabilities. <https://www.who.int/disabilities/infographic/en/>
- WHO and World Bank. 2011. *World report on disability*. Geneva: WHO.

According to the *2018 United Nations Flagship Report on Disability and Development*

- Only 6 countries have explicit laws that guarantee access to healthcare to people with disabilities.
- 42% of people with disabilities perceive their health being poor versus 6% of people without disabilities. And the proportion of people with disabilities who perceive their health as poor goes up to 80% in countries with the lowest Gross Domestic Product (GDP) per capita and goes down to 20% in countries with high GDP.
- Women with disabilities are 3 times more likely to have unmet needs for health care than men without disabilities. Women with intellectual disabilities and those living in rural areas face additional barriers in accessing health services.

Source: UNDESA. 2018. *Realization of the Sustainable Development Goals by, for and with persons with disabilities*. *UN Flagship Report on Disability and Development*. New York: UNDESA.

*PARTICIPANT HANDOUT 16D: CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
(CRPD) ARTICLE 16 – FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE*

1. State Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
2. State Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. State Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, State Parties shall ensure that all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities.
4. State Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation, and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity, and autonomy of the person and takes into account gender- and age-specific needs.
5. State Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Source: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>

PARTICIPANT HANDOUT 16E: CRPD ARTICLE 23 – RESPECT FOR HOME AND THE FAMILY

1. State Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized.

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. State Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. State Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. State Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. State Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Source: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>

PARTICIPANT HANDOUT 16F: CRPD ARTICLE 25 – RIGHT TO HEALTH

State Parties recognize that persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability. They shall take all appropriate measures to ensure their access to gender-sensitive health services, including rehabilitation services. In particular, State Parties:

- (a) Provide persons with disabilities with free or affordable health services covering the same range and quality as those provided to other persons, including sexual and reproductive health services and community-based public health programs;
- (b) Provide persons with disabilities with the health services they need specifically because of their disability, including early identification and, where appropriate, early intervention services, and services to minimize or prevent new disabilities, especially among children and the elderly;
- (c) Provide these services to persons with disabilities as close as possible to their communities, including in rural areas;
- (d) Require health professionals to provide persons with disabilities with care of the same quality as that provided to others, including obtaining the free and informed consent of the persons with disabilities concerned;
- (e) Prohibit discrimination against persons with disabilities in the insurance sector, who must be able to obtain health insurance and, in countries where it is permitted by national law, life insurance on fair and reasonable terms; and
- (f) Prevent any discriminatory refusal to provide medical care or services or food or liquids because of a disability.

Source: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>

PARTICIPANT HANDOUT 16G: YOUNG PERSONS, SEXUALITY AND DISABILITY

Key Facts

Young persons with disabilities have equal needs and rights to access SRH information and services. However, their rights are largely violated.

- Adolescents with disabilities are rarely regarded as subjects of sexual rights
- Adolescents with disabilities are often assumed as asexual, not sexually active, or hypersexual
- Adolescent with disabilities are often assumed as not able to decide by themselves about their sexual life
- Adolescent girls with disabilities are often denied the choice and autonomy/independence to make their own sexuality-related decisions on the base of their disability
- Adolescents with disabilities are often denied their reproductive autonomy
- Adolescents with disabilities are particularly vulnerable to sexual harassment, violence and abuse but such incidents are rarely reported.
- In various countries, many persons with disabilities, particularly women and those with intellectual disabilities, have been subjected to forced abortion, involuntary sterilization and long-term contraception which are often used as methods of fertility regulation on a precautionary basis.

Reasons for higher rates of violence and abuse against persons with disabilities include but are not limited to stigma, discrimination, dependence, impunity, and negative traditional beliefs.

Violence, abuse and young persons with disabilities

State Parties recognize that persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability. They shall take all appropriate measure to ensure their access to gender-sensitive health services, including rehabilitation services. In particular, State Parties:

- Provide persons with disabilities with free or affordable health services covering the same range and quality as those provided to other persons, including sexual and reproductive health services and community-based public health programs;
- Provide persons with disabilities with the health services they need specifically because of their disability, including early identification and, where appropriate, early intervention services, and services to minimize or prevent new disabilities, especially among children and the elderly;
- Provide these services to persons with disabilities as close as possible to their communities, including in rural areas;

- Require health professionals to provide persons with disabilities with care of the same quality as that provided to others, including obtaining the free and informed consent of the persons with disabilities concerned;
- Prohibit discrimination against persons with disabilities in the insurance sector, who must be able to obtain health insurance and, in countries where it is permitted by national law, life insurance on fair and reasonable terms; and
- Prevent any discriminatory refusal to provide medical care or services or food or liquids because of a disability.

LGBTQI young persons with disabilities key facts

Discrimination factors related to sexual orientation, gender identity, age and disability intersect. As a result, LGBTQI adolescents with disabilities face more barriers in expressing their sexuality or gender identity. This is even more so for young persons with intellectual and developmental disabilities.

- LGBTQI persons with disabilities' experience of systemic discrimination and exclusion are associated with reduced health and wellbeing, reduced access to SRH services and increased risk of harassment when accessing the services.
- LGBTQI adolescents with disabilities often experience discrimination from within both LGBTQI and disability communities compounding their sense of social marginality and isolation and contributing to their increased risk of mental health
- Persons with disabilities who identify as LGBTQI are more likely to report having experienced harassment or violence than those without disabilities.

Example: On LGBTQI populations with disabilities and violence in Australia

One study published in Australia in 2018 reported that 46% of LGBT people with a disability versus 33% without reported having experienced at least one form of harassment or violence in the last 12 months prior to completing the survey. LGBT respondents with disabilities were more likely to have been subject to verbal abuse than respondents without disabilities (32% versus 24%); more likely to have 'received written threats of abuse including emails and graffiti' (11% versus 5%); more likely to have been subject to harassment (21% vs 14%); and more likely to have been subject to threats of physical violence or physical assault such as being punched, kicked, or beaten (13% vs 8%).

Sources:

Leonard W. and Mann R. 2018. *The everyday experiences of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability*. La Trobe University.

Msekele, S. 2018. "Being Disabled, Black and Queer in South Africa: A Personal Journey." P. Chappell and M. De Beer (eds.), *Diverse Voices in Disabled Sexualities in the Global South*.

New York: Palgrave Macmillan; 127-130.

Young persons with disabilities and HIV

Global HIV data disaggregated by age, gender and disability are not yet available. UNAIDS, however, highlight that persistent discrimination against and exclusion of people with disabilities, in particular women and girls with disabilities, increases their vulnerability, including their risk of HIV infection and limit their access to prevention, screening and treatment services.

According to UNAIDS, persons with disabilities may not benefit fully from HIV and related sexual and reproductive health services because:

- Service providers may lack knowledge about disability related issues, or have misinformed or stigmatizing attitudes towards persons with disabilities.
- Services offered at clinics, hospitals and in other locations may be inaccessible to persons with disabilities.

Recent studies conducted in sub-Saharan Africa:

- Highlight an increased risk of HIV infection of 1.48 times in men with disabilities and 2.21 times in women with disabilities compared with men without disabilities.
- Confirm that the higher prevalence of HIV infection in people with disabilities reflects a higher exposure to HIV infection as well as the presence of disability-associated HIV infection.
- Point out that the susceptibility of persons with disabilities to HIV infection seems to be shaped by social and environmental factors.
- Confirm that persons with disabilities living with HIV also face additional barriers in accessing SRH services, counselling and HIV treatment

Sources:

De Beudrap P. et al. 2017. Prevalence of HIV infection among people with disabilities: a population-based observational study in Yaoundé, Cameroon (HandiVIH). *Lancet HIV*. April 4(4): e161-e168.

United Nations Joint Programme on HIV/AIDS (UNAIDS). 2017. Disability and HIV. Geneva: UNAIDS. https://www.unaids.org/sites/default/files/media_asset/JC2905_disability-and-HIV_en.pdf

SPECIFIC OBJECTIVE 16.3: MAIN CHARACTERISTICS OF DISABILITY-INCLUSIVE SRH SERVICES AND HOW SERVICE PROVIDERS CAN CONTRIBUTE TO PROMOTE CHANGES



TIME

2.5 hours



METHODS

- Trainer presentation
- Role play



MATERIALS NEEDED

- Flipcharts and markers
- Handouts 16h-i



STEPS

Time: 30 minutes

3 Pillars of disability-inclusive health services

1. Ask participants to brainstorm on how services need to be adapted to ensure they meet the need of all young persons, including those living with HIV, LGBTQI youth, and young persons with disabilities.
2. Ask participants to think about the key characteristics that disability-inclusive SRH services should have and to share their thoughts with the group.
3. Highlight that disability-inclusive services are not “special services” developed for the exclusive benefit of young persons with disabilities, but rather services designed to meet the needs of all young people, including persons with disabilities.
4. Introduce the 3 pillars of disability-inclusive health services. More details are provided below.

Time: 30 minutes

Pillar 1: Accessibility

5. Start by explaining that:
 - Accessibility refers to an environment, product, or service that is made available to meet the needs of everyone, including persons with disabilities.
 - Accessibility makes it possible to reach, enter, circulate throughout, and fully use a physical space whatever its nature and function. Accessibility can also enable individuals to receive, understand, develop, modify, share and disseminate information.

- Accessibility, whether physical accessibility or access to information and communication in an appropriate form, is a prerequisite for the inclusion of persons with disabilities in all aspects of life.
6. Continue by explaining that:
 - To ensure meaningful access to services for the widest variety of clients, including adolescents with disabilities and vulnerable individuals, services should follow the principles of Universal Design.
 - Universal Design highlights how products (services, devices, environments, systems, and processes) should be created to maximize their usability for people across the full range of abilities.
 - The accessibility of facilities that were not developed following the principles of Universal Design can be improved through accommodations.
 - Accommodations include different modifications and adjustments that ensure persons with disabilities can enter the facilities and use the services on an equal basis with others. These include but are not limited to: ramps, sign language interpretation, braille, large print, and easy to read materials.
 7. Emphasize that health personnel can play a key role in advocating for accessibility at the health facility, community, and government levels. They can also serve as a great ally for DPOs in advocacy to make health policies and systems more accessible to persons with disabilities.

Time: 30 minutes

Pillar 2: Inclusive Policies

8. Start by highlighting that **inclusive policies in hospitals/clinics are in place to guarantee respect to all including persons with disabilities.** Having specific guidelines on how to offer quality services accessible to persons with disabilities is essential to create good inclusive practices or to institutionalize those that already exist in health facilities.

Distribute Handout 16h that provides an example related to the work conducted by Humanity & Inclusion in a health facility in South Sudan and its positive results. Ask participants to read the handout in preparation to the next activity.

9. Ask the participants to discuss disability-inclusive policies and how these policies, could help make their services more accessible to young persons with disabilities. Divide the participants into small groups (maximum 4 persons per group) and ask the young co-trainers to join the groups. Ask them to nominate a representative to take notes and give a summary at the end of the exercise.
10. Provide the following discussion points/questions to the groups:
 - Does your program/facility have a disability-inclusive policy?

- If yes, share with the other members of your group how this helps in providing quality SRH services to young persons with disabilities and provide inputs on how the policy could be further strengthened.
 - If not, come up with two recommendations that could make the services more accessible to young persons with disabilities.
 - Do you intend to take any steps toward promoting disability inclusive policies in your work place?
 - If yes, what are these steps?
11. Ask the group representatives to share the key recommendations identified and the steps the participants are thinking about taking.
 12. Ask the youth co-trainers to comment and share final inputs to guide the future actions of the participants.

Time: 60 minutes

Pillar 3: Positive Attitudes

13. Start by asking participants to think about how service providers' attitudes can affect adolescents' access to SRH services and their overall experience. Ask 3 volunteers to share their thoughts.
14. Highlight that attitudes play a key role in preventing or facilitating persons with disabilities to access health services. For this reason, it is important that all health workers and other staff in facilities including security guards, receptionists, and record keepers, have respectful and welcoming attitudes towards all clients including persons with disabilities and are trained on disability-inclusion accordingly.
15. Explain that persons with disabilities, just like everyone else, are less willing to go to a hospital or a clinic where they have experienced mistreatment/disrespectful behavior or where staff is perceived as unwelcoming towards persons with disabilities.
16. Ask participants to think about examples of negative and positive attitudes and to raise their hand to share them with the group. If necessary, stimulate the discussion by mentioning that discrimination in the form of ignoring, nicknaming, insulting, being disrespectful, mistreating, and abusing can often reflect service providers' negative attitudes toward young persons with disabilities.
17. Point out that negative attitudes can keep persons with disabilities from preventing or detecting certain problems at an early stage and obtaining the information they need related to their SRH.

18. Share Handout 16i with the participants. Then ask them to divide into 3 groups and assign 1 case study to each group. Ask youth co-trainers to join the groups and have each group nominate a representative to take notes and give a summary at the end of the exercise.
19. Provide the following discussion points to the groups:
 - What do you think about the provider's attitude in your case study?
 - What are the benefits or potential consequences for the young person with disability?
 - What can we learn from the positive/negative attitudes described in the different case studies?
20. Ask the 3 representatives to provide a summary of the discussion.
21. Provide three additional discussion points for the entire group to discuss:
 - What are the roots of service providers' negative attitudes? Point out that negative attitudes towards young persons with disabilities are often based on prejudice, lack of knowledge of the rights of persons with disabilities, and limited understanding of disability. Ask participants' to share their opinion on the subject.
 - What do you think is needed to improve service providers' attitudes towards young persons with disabilities?
 - Has your attitude towards young persons with disabilities changed at all after this training? If yes, how?
22. Conclude by explaining to participants that:
 - Even when service providers have positive or supportive attitudes towards persons with disabilities, they may feel disempowered if the overall social environment is hostile or unfriendly. Some of them may go along with dominant social norms because it's easier or because they are afraid to go against the organizational culture or leadership of the facility. This is one of the reasons why policies are important.
 - With the right support, guidance, and training, health workers are in the position to create a positive and welcoming environment for persons with disabilities and to influence their colleagues and working environment.

Case Study from South Sudan – Humanity & Inclusion

Humanity & Inclusion carried out a full participatory accessibility audit in a South Sudanese hospital. This encompassed a baseline on attitudinal barriers from services provider, physical accessibility of the health facility, and accessibility to health information. The subsequent report and its recommendations were shared with local stakeholders, and an action plan for the monitoring of the relevant implementation was agreed upon. A steering committee with participants from local and international NGOs, DPOs, and persons with disabilities was created, and its role and responsibilities outlined and enforced. A series of hospital protocols were proposed to improve quality of services and accountability.

As a result of this initiative, the Hospital developed a policy to ensure that all members of the Hospital Community are aware of their rights and responsibilities to benefit all patients, visitors, employees, associates and volunteers by achieving accessibility for people with disabilities. According to the policy, this will be done by developing, implementing and enforcing accessibility standards concerning goods, services, accommodation, facilities, buildings and employment. The policy was designed to bring about systemic and organizational changes to foster the conditions that create a healthy, respectful and positive hospital and work environment. More specifically, this policy was designed to accomplish the following outcomes:

- Foster a positive hospital environment through proactive measures, barrier free systems analysis and enforcement;
- Ensure that all members of the hospital community are treated equitably and with dignity and respect;
- Address breaches of this policy and settle disputes quickly, fairly and as close to the source as possible;
- Ensure that all members of the hospital community are aware of their rights and responsibilities under this policy
- Provide proactive education, organizational training and development at the Hospital is aimed at providing an environment that is accessible.



HANDOUT 16I: CASE STUDIES-SERVICE PROVIDERS' ATTITUDE

Case Study 1

Aisatu is a 19-year-old girl. She suffers from epilepsy and has frequent seizures. She has been living with her boyfriend in the streets of a big city since she turned 17 and was diagnosed with epilepsy. Her father said that she was possessed by a demon and that she will never be a bride. Aisatu doesn't want to get pregnant by her boyfriend who is the same age and lives in the streets, so they use condoms. As they struggle to buy condoms, Aisatu and her boyfriend heard of a form of long-acting, reversible form of contraception (implants). When Aisatu went to the dispensary to get her medicines for epilepsy, she asked the usual nurse if she could get the implant. The nurse told her that the medicines that she is taking "are not good" if she wants an implant and did not offer any alternative. Aisatu went back to the street with a dilemma: either she keeps taking her epilepsy medicines and risks having a baby or stops taking her medicines, gets the implant but risks having life-threatening seizures.

Case Study 2

Giorgina is 14 years old and she has Down Syndrome. She wants to be a mother one day. She has been studying sexuality education at school and is well informed about puberty and the related physical and psychosexual development. She is also well informed about pregnancy. One evening, Giorgina overhears part of a conversation between her parents. They are concerned about Giorgina's desire to become a mother in the future, her risk having a child with a disability and the related consequences. Giorgina only heard the last part of the conversation when they concluded that "It is better for Giorgina to never be a mum!". Giorgina is very confused and the day after, she decides to go to the school nurse to ask about her ability to have children and why her parents do not want her to become a mum when she grows up. The nurse is taken completely unprepared by Giorgina's question and feels the need to learn more about the experience of girls with Down Syndrome becoming mothers before providing an answer. She also wants to consult with Giorgina's parents. She recognizes that Giorgina is a bit agitated, so she takes the time to talk to her in a kind and relaxed way to calm her down before giving her an appointment for the following day.

Case Study 3

John is 16 and has a physical disability due to polio. John has a boyfriend, Brian, with whom he has unprotected sex. He does not have a disability. John enjoys being with Brian but suspects he has been unfaithful. His friends say he should be careful because promiscuity brings HIV but he does not know what 'being careful' really means. John starts being worried and decides to go to the clinic near his school to ask for support. Initially, the receptionist did not pay attention to him and asked "are you sure you are in the right place? This is an SRH clinic". When finally John manages to tell the nurse that he has a boyfriend and he is afraid of contracting HIV, the nurse turned to his colleague and said loudly: "how can he be disabled and gay?" John felt bad and ended up leaving without obtaining the information he was looking for.

SPECIFIC OBJECTIVE 16.4: SKILLS ON HOW TO COMMUNICATE WITH ADOLESCENTS WITH DIFFERENT TYPES OF DISABILITIES



TIME

2 hours



METHODS

- Trainer presentation
- Group discussion
- Role play



MATERIALS NEEDED

- Flipcharts and markers
- Handout 16j



STEPS

Time: 30 minutes

1. Start by asking participants to share why, in their opinion, good communication is a key component that can affect adolescents' access to SRH services and their overall experience.
2. Remind participants that health care providers who use good communication skills ensure adolescents obtain accurate and unbiased SRH information, which can both educate young people and facilitate their ability to make responsible decisions.
3. Point out that marginalized young people face additional barriers to accessing accurate and quality information and that young persons with disabilities face additional communication barriers that could vary according to the type of disability.
4. Explain that service providers should consider the following good practices and principles for good communication when attending to young persons with disabilities:
 - Accommodation is needed to ensure good communication:
 - Sign language interpretation or subtitles in video materials for young persons with hearing disabilities.
 - Braille, large print. or audio materials for young persons with low vision or visual disabilities.
 - Easy to read/simplified materials and pictures for young persons with intellectual and developmental disabilities.
 - In low-resource settings, the use of other simple methods is recommended to ensure good communication:

- Lip reading or exchange of written messages and images with persons with hearing disabilities.
 - Reading aloud the information included in written materials that is inaccessible for persons with visual disabilities.
 - The use of simplified language and images to communicate with persons with intellectual and developmental disabilities.
- In all circumstances the most important resource for providers is time, patience, and willingness to establish good communication with persons with disabilities.
5. Explain that service providers should not make assumptions about young persons' sexuality based on their disability. He/she should listen to what the young person has to say in relation to their sexuality and experience.
 6. Remind participants that service providers should avoid focusing on the disability of the client. Instead they should stay focused on the SRH experience/problem the young person is interested in discussing.
 7. Point out that since many services are not accessible, young persons with disabilities are often accompanied by a family member or caregiver to help them overcome physical or communication barriers. In these circumstances, service providers should find out if the young client with disabilities would like the accompanying person to stay or to wait outside the consultation room. If the adolescent client asks for the accompanying person to stay, service providers should make sure the young person remains the main interlocutor and prevent the accompanying person from speaking or making decisions on behalf of the person with disability.
 8. Conclude the session by sharing Handout 16j that summarizes some key points on "disability etiquette". Explain that in addition to the general principles introduced so far, it is important to learn more about the specificities of communicating with young persons with different types of disabilities.

Time: 30 minutes

Communicating with young persons with hearing disabilities

9. Explain that one of the biggest barriers for young persons with hearing disabilities to access SRH services independently is communicating with the relevant staff including receptionists and nurses as well as doctors.
10. Explain that the expression "communicating with persons with hearing disabilities" is often automatically associated with sign language. However, not all persons with hearing disabilities know sign language and most persons without a hearing disability do not know sign language.

11. Explain that if communication is supported by a sign language interpreter, it remains important to talk directly to the adolescent client, not the interpreter.
12. Explain that persons with hearing disabilities may use hearing aids. This will certainly help communication, but it doesn't mean they can hear everything.

Explain that regardless of whether the communication is facilitated through sign language interpretation or hearing aids, it is always important to understand the techniques that can enhance communication with a person with hearing disabilities listed below:

- When talking to a group that includes young persons with and without hearing disabilities, don't just focus on the hearing youth.
- Don't shout. It can be uncomfortable for hearing aid users and it looks aggressive.
- Take the time to find out what the best way is to communicate with each client and to adjust the communication style to what she/he is most comfortable with as every person with hearing disabilities is different.
- Be imaginative and use all the available resources such as written messages, text, WhatsApp messages, gestures, pictures, and lip-reading. Keep in mind that young persons with disabilities may be illiterate and this would eliminate the utility of written messages.
- If using lip-reading⁶:
 - Find a suitable place to talk, with good lighting and away from noise and distractions. Make sure to have face-to-face contact with the person.
 - Get the listener's attention before starting speaking, maybe by waving or tapping them on the arm.
 - Don't cover your mouth with your hands or clothing while talking.
 - Speak clearly but not too slowly, and don't exaggerate your lip movements – this can make it harder to lip-read.
 - Use natural facial expressions and gestures.
 - If someone doesn't understand what you've said, don't keep repeating it. Try saying it in a different way instead.
 - Check that the person you're talking to is following you during the conversation. Use clear, plain language. Avoid jargon and unfamiliar abbreviations.

Let's practice:

13. Ask the youth trainers with hearing disabilities in the room to play the role of the client and ask for volunteers who are willing to go through a mock counseling session and play the role

⁶ Adapted from version of Action on Hearing Loss, 2016.

of the health worker. If no youth trainers with hearing disabilities are available, ask for volunteers to engage in a sensitization activity and attempt to learn about the lived experience of having a hearing disability in this setting. Have the volunteer ensure she/he cannot hear the voice of his/her partner by using earplugs, wadded up cotton wool, fingers in the ears, or any other safe tool available.

14. Assuming that sign language interpretation is not available and that the person with a hearing disability is not wearing hearing aids, ask the participants who play the role of the health workers to use all the resources they can think of to communicate with the client.
15. At the end of the role play, ask the participants to share their experience.
16. Ask for comments and observations from the rest of the group.
17. Ask if any additional inputs should be added to the above list of tips.

Time: 30 minutes

Communicating with persons with visual disabilities

18. Explain that when communicating with persons with visual disabilities, it is important to pay attention to some details to ensure mutual understanding⁷:
 - Identify yourself – don't assume the person will recognize you by your voice.
 - Speak naturally and clearly. Loss of eyesight does not mean loss of hearing.
 - Continue to use body language. This will affect the tone of your voice and give a lot of extra information to the person with a visual disability.
 - Use everyday language. Don't worry about avoiding words like "see" or "look" or talking about everyday activities such as watching TV or videos.
 - Introduce and describe what the consultation will include and the different actions before putting them in place. For example: I am going to take your blood pressure, I am going to collect a sample of blood, etc.
 - Name the person when introducing yourself or when directing conversation to them in a group situation.
 - Never channel conversation through a third person.
 - In a group situation, introduce the other people present.
 - Never leave a conversation with a person without saying so and always announce if you are leaving the room.
 - Use accurate and specific language when giving directions. For example, "the door is on your left", rather than "the door is over there".

⁷ Adapted from Vision Australia, 2016.

- Avoid situations where there is competing noise.

Let's practice:

19. Ask the youth trainers with visual disabilities in the room to play the role of the client and ask for volunteers who are willing to go through a mock counseling session and play the role of the health worker. If no youth trainers with visual disabilities are in the room, engage in a similar sensitization activity as the hearing disability listed above and ask for volunteers to be blindfolded. Ask the other participants to observe the role play.
20. Conclude the exercise by asking those involved in the role play to share their experience with the rest of the group.
21. Ask for comments and observations from the rest of the group.
22. Ask if any additional inputs should be added to the above list of tips.

Time: 30 minutes

Communicating with young persons with intellectual and developmental disabilities

23. Highlight that all adolescents with disabilities, including adolescents with intellectual and developmental disabilities, have the right to access information about their health status and to make decisions about their own health, including sexual and reproductive health.
24. Explain that it may be necessary to spend more time with adolescent clients with intellectual and developmental disabilities to ensure information is well understood and clients have the opportunity to ask all the relevant questions. This is because young persons with intellectual and developmental disabilities may find it difficult to interact with service providers and may need extra time to read, write, understand, learn, focus, or memorize information.
25. Clarify that every person is different and the time and style of communication may require some adaptation according to the level and severity of the impairment. But in general, the following actions are always recommended:
 - Speak slowly without acting like you are speaking with a child. Try to be as clear as possible without being offensive.
 - Use short sentences and simple words prioritizing key information.
 - Repeat multiple times using different words if necessary.
 - Ask short questions that require short answers or a nod of the head. Complex questions might trouble the person to finding the right answer.
 - Integrate pictures with key words if needed.

- Instead of asking the client if she/he understood, ask them to tell you what they have learned in their own words.
- Listen attentively and do not interrupt. Wait for the clients to finish. Giving them more time will allow you to gather more information and show that you respect them.
- Never pretend to understand. Instead repeat what you have understood and allow the person to respond.
- Speak directly to the client rather than to their companion who may be present.
- Address the person by their first names only if you would extend that same familiarity to all others.
- Walk them through the different choices and decisions to make. Do not decide for them, but do help them to make their own informed decisions.
- When possible, provide any materials in advance so the individual can review and become familiar them beforehand.

Let's discuss:

26. If youth with intellectual and developmental disabilities are in the room, ask them to share experiences on accessing SRH information and services. Ask participants how they feel about what they have heard and to react to their inputs.
27. Ask participants how they personally have interacted with persons with intellectual and developmental disabilities or what they have observed in terms of good or poor practices.
28. Discuss any additional communication tips that could be included in the list above.



HANDOUT 16J: DISABILITY ETIQUETTE SNAPSHOT

Person-first language	
DON'T SAY	DO SAY
A handicapped person, the disabled, PWD, PwD	Person with a disability, people with disabilities
A normal person, people living normal lives	A person without a disability
A crippled, physically challenged, infirm	A person with a physical disability
Wheelchair bound	A wheelchair user
The blind	A person with low vision / A person who is blind/ A person with a visual impairment
The deaf, the hard of hearing	A person who is hard of hearing / A deaf (Deaf) person
Mentally retarded, mentally challenged	A person with an intellectual disability
Insane, lunatic, mentally sick, mentally imbalanced, mad person, mentally ill person, psycho, crazy people	A person with a mental condition A person living with Schizophrenia A person living with bipolar disorder

Interactions with Persons with Disabilities

DON'T	DO
Talk only to family, and ask them to tell you how the person with a disability feels, what they think	Talk directly to the person, rather than through their support staff or other caregiver
Refer to the person as a 'patient' or 'disabled'	Refer to the person by their name
Display impatience	Be understanding of other people's needs
Ask negative questions like "What's wrong with you?" or "Have you always been like that?"	Ask positive questions such as "Do you face any difficulties with different activities?" or "How long have you faced these difficulties?"
Assume all persons with disabilities cannot shake hands	Shake hands. You can ask first if it is okay, or to inform someone with low vision that cannot see your hand
Assume all persons with disabilities need help, and that you know how to help	Ask if a person needs assistance with something, and how you can help

UNIT 16 SUMMARY



TIME

20 minutes



METHODS

- Reflection



MATERIALS NEEDED

- Handout 16k



STEPS

1. Conclude this section by emphasizing that:
 - DPOs working at the local level can be strategic allies when it comes to learning about persons with disabilities and their living conditions. Although not all of them have experience in working with adolescents and their SRH, joining forces with these organizations can optimize your ability to raise the awareness of adolescents with disabilities on SRHR, identify adolescents with disabilities who are in need of SRHR services, better address their needs, and promote both their SRHR as well as disability-inclusive services.
 - More data disaggregated by age, gender and disability is needed to better understand and address the SRH needs of young persons with disabilities. Highlight that collecting data at the service provision level is an essential step. This can be done by the health information systems by integrating a short set of questions developed by the Washington Group available in Handout 16k. It is important to ensure that staff responsible for administering this questionnaire are trained on how to use this tool. Direct the participants to the website <http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/> for more information.
 - With the right support, guidance, and training, health workers are in the position to create a positive and welcoming environment for persons with disabilities and to influence their colleagues and working environment. They can also be great allies of DPOs in advocacy actions aiming at making health policies and systems more disability inclusive.
2. Give space for final questions if needed.
3. As a conclusion, ask participants:
 - Do you feel better-equipped to welcome young persons with disabilities in their facilities then when they started this training?
 - What did you find most useful in this module?
 - What would you like to know more about?



HANDOUT 16K: THE WASHINGTON GROUP SHORT SET OF QUESTIONS ON DISABILITY

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
 - a. No – no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?
 - a. No – no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

3. Do you have difficulty walking or climbing steps?
 - a. No – no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

4. Do you have difficulty remembering or concentrating?
 - a. No – no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing?
 - a. No – no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
 - a. No – no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

Source: <http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/>

TRAINING COURSE POST-TEST AND EVALUATION



TIME

40 minutes



METHODS

- Quiz
- Individual worksheet



MATERIALS NEEDED

- Participant Handout 16l: SRH Services for Adolescents Post-Test
- Participant Handout 16m: Participant Evaluation Form



STEPS

1. Distribute **Participant Handout 16l: SRH Services for Adolescents Post-Test**.
2. Remind participants that the purpose of the post-test is to evaluate the training, not the participants, so there is no need to put their names on the test forms. Allow **30 minutes** for participants to complete the test.
3. Instruct participants that when they finish the test, they should bring it to you and collect **Participant Handout 16m: Participant Evaluation Form**. They should then return to their seats and fill out the evaluation.
4. Tell participants that they can take as much or as little time as they want to fill in the evaluation form: their responses will help improve future trainings.
5. **Thank participants for bringing their time and their energy over the course of the training.**



PARTICIPANT HANDOUT 16L: SRH SERVICES FOR ADOLESCENTS POST-TEST

Instructions: Write in “V” for very young adolescents (10-14) “O” for older adolescents, or “B” for both.

1. Identify which of the following more commonly occur near the beginning or end of adolescence:

- ___ reaches physical and sexual maturity
- ___ focused on the present with little future-planning
- ___ growth in capacity for abstract thought
- ___ concern about being “normal” and comparison of self to others in peer group
- ___ rapidly changing sense of sexuality and gender

Instructions: Circle all answers that apply. Some questions have more than one correct answer

2. Specially trained providers serving adolescents are important because:

- a. Communicating with adolescents can require special care with regards to language, tone, and establishing trust.
- b. Understanding the sociocultural pressures on adolescents can help providers address adolescent risk-taking.
- c. Adolescents need different services from adults.
- d. Life-long health habits are established during adolescence.
- e. Adolescent clients may ask to see a training certificate.

3. Which of the following occur more in adolescents than adults:

- a. Heart conditions.
- b. Anemia.
- c. Depression and self-harm.
- d. Injuries.
- e. Low birth-weight babies.

4. Adolescents can be vulnerable to illness or health problems because:

- a. This period of rapid growth has greater nutritional requirements.
- b. Adolescents face sociocultural barriers to health information and services.
- c. Young people have less power to make decisions about their sexual behavior.
- d. Adolescents are more susceptible to colds, flu, and other infections.
- e. Services for adolescents are too expensive.
- f. Services are not accessible

5. Among the most important conditions a provider can ensure for the adolescent client are:

- a. Privacy.
- b. Popular music playing.
- c. Respect.
- d. Fun atmosphere.

6. Some appropriate prevention strategies for adolescents to reduce risk of STI transmission include:

- a. Only abstinence from all sexual activity.
- b. Vaccination for HPV.
- c. Consistent and correct use of male and female condoms.
- d. Regular testing between partners.

7. The contraceptive methods that are appropriate for breast-feeding women who are more than 6 weeks post-partum are:

- a. IUD
- b. Combined oral contraceptives
- c. Progestin-only contraceptive (progestin-only pills, implants, injectables)
- d. Lactational amenorrhea method

8. You can assess the capacity of an adolescent client to make health decisions by:

- a. Watching for signs that the client is nervous or refusing to provide information.
- b. Looking for decisions the adolescent has made independently about their health care.
- c. Allowing the adolescent to express their opinion about their health care and considering that opinion in your advice.
- d. Their age alone.
- e. Their disability alone

9. Which of the following complications of pregnancy are more likely to occur in adolescents under the age of 15 compared with older women?

- a. Giving birth to very large babies.
- b. Premature labour.
- c. Spontaneous abortion.
- d. Still birth.
- e. Anemia.
- f. Delivery complications

10. Which rights do adolescents have?

- a. The right to information and education about sexual and reproductive health.
- b. The right own, control, and protect ones' own body.
- c. The right to sexual pleasure.
- d. The right to privacy and confidentiality when accessing health services.
- e. The right to choose one's sexual and romantic partners.
- f. The right to make decisions about their sexual and reproductive health.

11. What responsibilities does a provider have to disclose an adolescent client's HIV status?

- a. To disclose to the adolescent's parent/guardian.
- b. To disclose to the adolescent.
- c. To disclose to the adolescent's sexual or romantic partners.
- d. To disclose to the parent/guardian of the adolescent with disability.

12. Which methods of contraception may not be suitable to the adolescent client?

- a. Emergency contraception
- b. Combined oral contraceptives
- c. Sterilization
- d. Condoms
- e. IUDs

13. Which of the following reactions are appropriate when an adolescent client is struggling with sexual orientation or gender identity?

- a. Suggesting counseling to help "fix" the problem or make it go away.
- b. Offering non-judgmental counseling and support.
- c. Electro-shock or invasive sexual treatments.
- d. Providing SRH counseling and services with an open clinical manner.

14. Which of the following methods are appropriate for counteracting rumors and misconceptions about contraceptives?

- a. Using strong scientific facts to counteract misinformation.
- b. Giving less information so the client is not confused.
- c. Finding where the rumors came from and checking to see if there is any basis for the rumor.
- d. Not telling the client about side effects because it might make them frightened.
- e. Dismissing the rumor as "stupid" or "obviously wrong."

15. Which of the following reactions are appropriate when dealing with adolescent clients with visual disabilities?

- a. Raising the tone of your voice
- b. Offering non-judgmental counseling and support.
- c. Focusing on the origin of their impairment
- d. Providing accessible information and materials

Instructions: Write in the correct answers.

16. Name two common sources of sexual and reproductive health information for adolescents.

17. Name a model of youth-friendly service delivery that is accessible for out-of-school adolescents.

18. What does dual protection mean?

19. Name the major barriers to SRH information and services youth with disabilities face

20. What does universal design mean?

Instructions: Write "T" for true and "F" for false.

21. ___ International policies agreed to by a majority of the world's countries call for sexual and reproductive health information and services to be available to adolescents.

22. ___ Rape only happens to women.

23. ___ International conventions signed by a majority of the world's countries call for sexual and reproductive health information and services to be available to persons with disabilities.

24. ___ STIs cannot be transmitted through oral sex.

25. ___ Rape does not happen to youth with disabilities.

26. ___ Young persons with and without disabilities have equal rights to access sexual and reproductive health information and services

27. ___ Young persons with disabilities are asexual

28. ___ Young persons with disabilities are more vulnerable to contract HIV

PARTICIPANT HANDOUT 16M: PARTICIPANT EVALUATION FORM

Rate each of the following statements as to whether or not you agree with them, using the following key:

- 5 Strongly agree
- 4 Somewhat agree
- 3 Neither agree nor disagree
- 2 Somewhat disagree
- 1 Strongly disagree

Course Materials

I feel that:

- The objectives of the course were clearly defined. 5 4 3 2 1
- The material was presented clearly and in an organized fashion. 5 4 3 2 1
- The pre-/post-tests accurately assessed my in-course learning. 5 4 3 2 1
- The role plays and case study practices were useful. 5 4 3 2 1

Technical Information

I learned new information in this course. 5 4 3 2 1

I will now be able to:

- Provide youth-friendly services to adolescent clients. 5 4 3 2 1
- Adapt the counseling process to the needs of adolescents. 5 4 3 2 1
- Dispel rumors and misconceptions about SRH. 5 4 3 2 1
- Dispel rumors and misconceptions about sexuality and disability 5 4 3 2 1

Training Methodology

The trainers' presentations were clear and organized. 5 4 3 2 1

Class discussion contributed to my learning. 5 4 3 2 1

I learned practical skills in the role plays and case studies. 5 4 3 2 1

The trainers encouraged my questions and input. 5 4 3 2 1

Training Location and Schedule

The training site and schedule were convenient.

5 4 3 2 1

The necessary materials were available.

5 4 3 2 1

Suggestions

What was the most useful part of this training?

What was the least useful part of this training?

What suggestions do you have to improve the module?

Do you feel that the disability-related information provided was helpful for you to learn how to better support youth with disabilities? What would you have liked to learn more?