



United Nations

Division for Social Policy Development (DSPD)
Department of Economic and Social Affairs (DESA)



Toolkit on
DISABILITY for **AFRICA**

**INCLUSIVE HEALTH SERVICES
FOR PERSONS WITH DISABILITIES**



Toolkit on disability for AFRICA



INCLUSIVE HEALTH SERVICES FOR PERSONS WITH DISABILITIES

TABLE OF CONTENTS

1. OVERVIEW	1
2. TECHNICAL CONTENT	3
2.A Background.....	3
2.B Legal Framework	4
2.C Access to Health for Persons with Disabilities: Areas of Concern	7
Country Checkpoint	8
2.D Measures to Ensure the Right of Persons with Disabilities to Health Services.....	12
Country Checkpoint	18
3. SUMMARY & KEY LEARNING POINTS	19
4. USEFUL RESOURCES	20
5. LEARNING ACTIVITIES	21
Session Sheet for the Trainer – The Right to Health, Session 1.....	22
Learning Activity 2.B.: The Inter-Connected Relation of Rights.....	23
Handout: CRPD Article 25	24
Session Sheet for the Trainer – The Right to Health, Session 2.....	25
Learning Activity 2.D. A Plan to Address Barriers to Health Care.....	26
Handout: Barriers to Health Care for Persons with Disabilities.....	27



Acknowledgements

The Division for Social Policy and Development (DSPD) would like to thank all those who contributed to the Toolkit on Disability for Africa, including the United Nations Office for the High Commissioner for Human Rights (OHCHR), the Economic Commission for Africa (ECA), the International Labour Office (ILO), the International Training Center - ILO (ITC-ILO), the World Health Organisation (WHO), the African Union and the governments of Kenya, South Africa and Zambia. DSPD also wishes to thank the Government of Italy for its financial support and the numerous African Disabled Peoples Organisations (DPOs) who contributed substantial input to the Toolkit.

List of acronyms

AT	Assistive Technology
CEDAW	Committee on the Elimination of Discrimination against Women
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CESCR	Committee on Economic, Social and Cultural Rights
CRPD	Convention on the Rights of Persons with Disabilities
CRPD	Committee on the Rights of Persons with Disabilities
CRC	Committee on the Rights of the Child
CRC	Convention on the Rights of the Child
CRC	Convention on the Rights of the Child
DFIs	Development Financing Institutions
DPOs	Disabled Persons Organizations
DSPD	Division for Social Policy and Development/UNDESA
EC	European Commission
G3ICT	Global Initiative for Inclusive ICTs
HIV/AIDS	Human Immunodeficiency virus / Acquired Immunodeficiency Syndrome
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic and Cultural Rights
ICF	International Classification of Function, The World Health Organization
ICT	Information and Communication Technology
ILO	International Labour Organization
ITCILO	International Training Centre of the ILO
IPU	Inter-Parliamentary Union
ITC	Information and Communication Technology
ITU	International Telecommunication Union
MDGs	Millennium Development Goals
MFI	Microfinance institutions
MSPs	Multi-stakeholder Partnerships
NAPs	National Action Plans
NGO	Non-Governmental Organization
NVDA	Non Visual Desktop Access
OHCHR	Office of the High Commissioner for Human Rights
OSISA	Open Society Initiative for Southern Africa

PCM	Project Cycle Management
PRP	Protracted Relief Programme
SABE	Self-Advocates Becoming Empowered
SDGs	Sustainable Development Goals
UDHR	Universal Declaration of Human Rights
UN	United Nations
UN DESA	United Nations Department of Economic and Social Affairs
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Fund
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VOCA	Voice Output Communication Aids
WHO	World Health Organization



1. OVERVIEW

The overview provides information on the objectives, the target audience, the module content, learning outcomes and the module map.

Module objectives

- ▶ To highlight the barriers to health services for persons with disabilities and to consider actions for removing them.

Who is this module for?

This module is relevant to everyone who has an interest or duty to protect and promote the human rights of persons with disabilities. The module is especially relevant for decision-makers in the context of health, health professionals, health care providers, and DPOs working on enhancing the access of persons with disabilities to health services.

What is this module about?

The content of this module:

- ▶ explains the linkages between health and disability generally;
- ▶ reviews provisions of the Convention on the Rights of Persons with Disabilities (CRPD) pertaining to health services;
- ▶ reviews specific areas of concern in relation to access to health services;
- ▶ sets out measures for overcoming barriers to the inclusion of persons with disabilities in health services;
- ▶ includes learning exercises to accompany the material;
- ▶ lists key resources for additional reference.

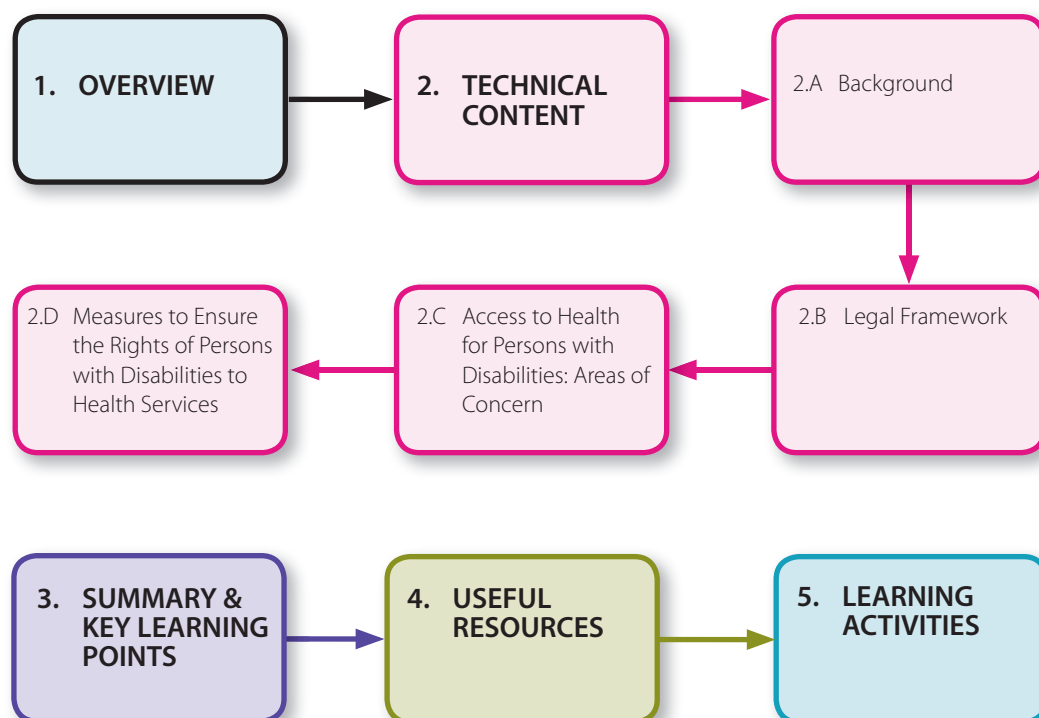


Learning objectives

On completion of this module, participants will have:

1. reviewed the main provisions of CRPD pertaining to health services;
2. identified specific areas of concern in relation to access to health services;
3. devised a number of strategies for overcoming barriers to the inclusion of persons with disabilities in health services.

Module map





2. TECHNICAL CONTENT

2.A Background

The World Health Organization defines health as “a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity.”¹ It has been said that, while “health is not everything, everything is nothing without health.” This is because good health is a prerequisite for the enjoyment of and participation in many fundamental aspects of life, including education, work and society.

Health is determined by a broad range of factors, most of which are outside the health sector. Social, economic and environmental factors are the main external determinants of health. Persons with disabilities who experience disproportionately high rates of poverty often face conditions that impact negatively on their health, including lack access to education, sanitary living conditions, clean water and food security, among others. At an individual level, factors such as age, sex, hereditary factors and lifestyle choices are important.

The number of persons living with disabilities is growing as a result of factors such as population increase, ageing, and medical advances that preserve and prolong life. This has increased the demand for health services. Some persons with disabilities are more susceptible than the general population to secondary health conditions. As a result, persons with disabilities may have greater needs than the general population. Health promotion services for the prevention of further disability and the promotion of health in general are important in determining the quality of life and health status of those with disabilities.

Persons with disabilities experience significant barriers to accessing health care. Barriers which can be particularly severe for those residing in rural areas, can include the following:

- ▶ physically inaccessible medical clinics and hospitals;
- ▶ lack of appropriate transport to enable them to seek medical care or rehabilitation services; lack of communications and accommodation in health care settings;
- ▶ untrained personnel and inadequate staffing;
- ▶ negative attitudes of health care providers;
- ▶ harmful practices, particularly in relation to persons with psychosocial disabilities;
- ▶ denial of treatment on grounds of disability.

As with all members of the general population, the health needs of persons with disabilities can vary broadly. The range of services available to the general population must also be accessible to persons with all types of disability. Care must also be taken to meet the health needs of those with invisible disabilities, particularly those with psychosocial disabilities and other mental health conditions. Ensuring optimal mental health is an integral part of health service provision, but has received inadequate attention by policy makers and also by society in general. As a result it imposes an enormous disease burden and an increasing obstacle to development in countries around the world.

While governments cannot offer guarantees against illness or disease, they are responsible for undertaking measures to advance human health, whether in the social, physical, legal or economic environments.

¹ Constitution of the World Health Organization. Geneva, World Health Organization, 1948

The Medical Model vs. The Social Model of Disability

The Medical Model of Disability:

Perhaps the most significant and widespread myth affecting human rights and disability is the idea that disability is simply a medical problem that needs to be solved or an illness that needs to be “cured.” This notion implies that a person with a disability is somehow “broken” or “sick” and requires fixing or healing. By defining disability as the problem and medical intervention as the solution, individuals, societies, and governments avoid the responsibility for addressing the barriers that exist in the social and physical environment. Instead they place the burden of addressing the “problem” in the person with the disability on the health profession. Many governments throughout the world have fuelled the medical model by funding extensive medical research that aims to find the “cure” for certain disabilities, while not providing any funding to remove the barriers that create disability in society.

The Social Model of Disability

The social model envisions disability as something that is created by the barriers and attitudes in society, not a trait or characteristic that is inherent in the person. Under the social model, society creates many of the social and physical barriers we consider “disabling,” and this model focuses on eliminating those barriers, not on “fixing” or “curing” disabilities. This includes modifying the created environment, providing information in accessible formats and ensuring that laws and policies support the exercise of full participation and non-discrimination.

Excerpted from Janet Lord and Allison deFranco, Human Rights Yes! The Convention on the Rights of Persons with Disabilities, The Right to Health, available at:

<http://www1.umn.edu/humanrts/edumat/hreduseries/HR-YES/chap-8.html>

2.B Legal Framework

The right to health is well established in international human rights law, including in the International Covenant on Economic, Social and Cultural Rights,² which recognizes the right of all persons to the highest attainable standard of health (Art. 12); and the Convention on the Rights of the Child, which requires State parties to recognize the rights of children with disabilities to specific assistance to ensure their effective access to health care services and rehabilitation services in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development (Art. 23).

The Constitution of the World Health Organization (WHO) also enshrines the highest attainable standard of health as a fundamental right of every human being. The right to health includes access to timely, acceptable, and affordable health care of appropriate quality. The right to health means that States must generate conditions in which everyone can be as healthy as possible. It does not mean the right to be healthy.

² The Universal Declaration of Human Rights, together with the International Covenant on Economic, Social and Cultural Rights, together with the International Covenant on Civil and Political Rights are known as the international bill of rights.

Health as a Resource for Everyday Life

To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is positive concept emphasizing social and personal resources, as well as physical capacities.' (WHO, 1998)

The Convention on the Rights of Persons with Disabilities reinforces and strengthens protection for persons with disabilities in relation to health and rehabilitation. It recognizes that persons with disabilities have the right to the highest attainable standard of health and that State parties must recognize that right without discrimination on the basis of disability (Art. 25) and further guarantees the right of persons with disabilities to access rehabilitation services of all kinds (Art. 26). Moreover, the Convention recognizes the right of persons with disabilities to access, within their communities, a range of in-home, residential and other support services (Art. 19.)

Important

- The right to health includes access to vital public health programmes as well as to rehabilitation services, including residential care, community-based care and support services.
- Services should be provided on an individual or “person-centered” basis, with due regard to the range of support services required (e.g., supportive devices, nursing, personal assistance, respite, rehabilitation, day activities and caring assistance).
- The right to health includes access to basic health services as well as specialized rehabilitation services.

In prohibiting all forms of discrimination the CRPD also requires that reasonable accommodation be provided. States are therefore required to take measures to:

- ▶ ensure that persons with disabilities are reasonably accommodated in the context of health care services, and
- ▶ ensure accessibility more generally to health care services.

Essential for many individuals with disabilities, the right to health includes access to health-related rehabilitation. The right to rehabilitation is more broadly set forth in Article 26 of the CRPD.

Health and Habilitation/Rehabilitation

“Habilitation refers to a process aimed at helping people gain certain new skills, abilities, and knowledge. Rehabilitation refers to re-gaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability, or due to a change in one’s disability or circumstances.”

“Closely related to the perception of disability in narrow terms as a health issue and reinforced by the medical model of disability is the notion that habilitation and rehabilitation are also medical subjects and therefore part of the health context. Habilitation and rehabilitation include a range of measures – physical, vocational, educational, training-related, and others – necessary to empower persons with disabilities to maximize independence and the ability to participate in society, not simply to achieve physical or mental health. For this reason, the right to health and the right to habilitation and rehabilitation are addressed separately in the CRPD. The exception, of course, is that health-related rehabilitation is recognized as part of the right to health. This would include, for example, physical therapy to strengthen muscles that are affected by an injury, illness, or disability.”

Excerpted from Janet Lord and Allison deFranco, Human Rights Yes! The Convention on the Rights of Persons with Disabilities, Chapters on the Right to Health and the Right to Habilitation and Rehabilitation, available at:

<http://www1.umn.edu/humanrts/edumat/hreduseries/HR-YES/contents.html>

As with other rights addressed in the present toolkit, the rights of persons with disabilities to health is indivisible, interdependent, and interconnected with the other rights enshrined in the CRPD. A bidirectional relationship often exists between one’s enjoyment or inability to enjoy one’s rights. For example, poor health negatively impacts on one’s ability to obtain an education or to work. At the same time lack of access to education or to work impacts on one’s ability to access appropriate health care. The present module focuses on the right to health. However the inter-connected relationships between the rights set out in the CRPD underscore the need for a holistic approach to its implementation.



See Learning Activity 2.B. titled titled *The Inter-Connected Relation of Rights*

The section that follows considers in more detail the application of these and other CRPD rights in the context of health services.

2.C Access to Health for Persons with Disabilities: Areas of Concern

Overarching Barriers Faced by Persons with Disabilities in Accessing Health

The health status of persons with disabilities is often poorer than that of the general population. Until relatively recently such differences were frequently viewed as an inevitable consequence of disability, but it is increasingly recognized that they may actually be the result of inequalities and inequities in access to healthcare.

Problems of disability are largely manifested in social contexts and social relations, rather than in an individual's medical condition. In the context of health, stigma and prejudice give rise to additional barriers that are then faced by persons with disabilities. These include physical barriers that prevent access for persons with disabilities to health clinics and hospitals; informational barriers that prevent access for persons with disabilities to health literacy and information brochures and leaflets on health promotion, prevention and protection; attitudinal barriers which give rise to discrimination that can have severe implications for the rights of persons with disabilities, particularly for those with psychosocial disabilities; and institutional barriers that include legislation, practices and processes that prohibit access to health services for persons with disabilities. Services for people with physical, sensory or intellectual disabilities have also been the subject of criticism in relation to communication and cultural barriers.

Access to healthcare for persons with disabilities extends well beyond the accessibility factors described above. Differences in access to health and social services may arise due to availability insofar as services may be scarce or simply not be provided to certain groups, quality may vary between groups, and not all groups may be aware of certain services owing to information deficiencies. It is important both to enhance the capacity of persons with disabilities to access the healthcare system and also to ensure that the system is able to respond in an appropriate and timely manner to their needs.

Specialist Services

While ensuring that persons with disabilities have access to general health services, some specialist services, such as rehabilitation services, may be needed. For example, in some cases persons require care or rehabilitation services specific to their impairment. Many countries have a National Rehabilitation Hospital or Centre which provides specialist services to patients from all over the country who, as a result of accident, illness or injury, have acquired a physical or cognitive disability and require specialist rehabilitation. The difficulty in many countries is that such facilities can only treat a limited number of patients, resulting in lengthy waiting periods or even denial of treatment.

Examples

- ▶ Where access to medical treatments is limited, persons with disabilities may not be prioritized for treatment. For example, in the case of HIV and AIDS persons with disabilities may not receive antiretroviral therapy and post-exposure prophylaxis on account of disability-related stigma and discrimination.

- ▶ Privacy and confidentiality may be compromised for persons with disabilities seeking medical treatment or counselling owing to the presence of personal assistants or sign language interpreters.
- ▶ Individuals who provide technical assistance to implement public health programmes often lack disability expertise and therefore leave disability out of their assessments and other work products (e.g. design of household surveys; outreach strategies).
- ▶ Written materials on health matters may not be accessible to persons who are blind. Radio messaging cannot be accessed by persons who are deaf.
- ▶ What, in your view, are the most important barriers to health and personal social services for persons with disabilities? How may these barriers be reduced?

Barriers to Health and Social Services for Persons with Disabilities

- lack of physical access, including transportation and/or proximity to clinics and, within clinics, lack of ramps, adapted examination tables, and similar facilities;
- lack of information and communication materials (e.g. lack of materials in braille, large print, simple language, and pictures; lack of sign language interpreters, lack of materials for the deaf and persons suffering from hearing loss);
- lack of private offices to discuss confidential health and social matters;
- lack of extra time, care and attention to meet the needs of the disabled person;
- lack of suitable water sources, toilets, washroom and restroom facilities;
- lack of awareness, knowledge and understanding of the needs of disabled persons;
- health-care and social service providers' negative attitudes, prejudice and imposed stigma;
- providers' lack of knowledge and skills as regards persons with disabilities;
- lack of coordination among health care providers;
- lack of training of health care personnel;
- lack of funding, including lack of health-care insurance.

Important

Too often, even well-intentioned policies treat disabled persons as a 'target', as a passive recipient of health and personal social services. Consultation with disabled persons and DPOs is essential to ensure that programmes meet needs effectively. The AAAQ framework (Availability, Accessibility, Acceptability and Quality) provides a useful framework for identifying obstacles to inclusive health care for persons with disabilities.

Country Checkpoint

What are obstacles to healthcare in your country in terms of the AAAQ Framework?



Water, Sanitation, and Hygiene

Access to water, sanitation and hygiene facilities is a precondition of good health for all persons. Article 28 of the Convention ensures 'equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs'. For many years the sanitation and hygiene needs of persons with disabilities have been treated as of low priority. Many persons with a disability live without access to basic sanitary services, which can exacerbate impairments and poverty.

Disabled persons are likely to experience increased health risks because of a lack of access to sanitation and hygiene services. The lack of inclusive facilities means that persons with disabilities sometimes must engage in unhygienic and dangerous practices. Access to safe and clean water and sanitation facilities is a basic right of all persons, including persons with disabilities, denial of which can have serious implications for their well-being. For example, inaccessible toilet and water facilities are major contributory factors to school dropouts among children with disabilities, especially girls.

Disability needs to be mainstreamed within sanitation and hygiene programmes and sanitation projects need to go beyond technical solutions and address attitudinal and institutional barriers to accessible sanitation. Better facilities reduce exposure to disease and illness, thereby increasing opportunities and life-chances for disabled persons. Participation by persons with disabilities in inclusive sanitation and hygiene programme design is crucial, including sharing of examples of successful policies and practices so that good practice can be applied more widely. The cost of improved access for all is far outweighed by the benefits.

Health and Persons with Psychosocial Disabilities

In some African countries, people who are perceived as having a psychosocial disability or a mental health condition often face particular challenges in accessing health care and, worse, often face severe abuses in the context of care or treatment. These can include arbitrary detention in prisons or involuntary commitment to institutions, where residents may experience forced treatments and medication, verbal and physical abuse, poor conditions and overcrowding, and are often chained up for long periods of time.³

Abuses have also been documented at community level where, due to false perceptions about persons with psychosocial disabilities, local health care providers - including traditional healers - sometimes also engage in abusive practices, often including shackling, even of children.⁴ Families and relatives are often the main support mechanisms available to individual patients with various psychosocial disabilities, but frequently struggle to provide effective support, given the lack of community-based support facilities such as out-patient medical and rehabilitation services and counselling based on free and informed consent.

³ Human Rights Watch has, for example, reported on instances of shackling in countries including Ghana, Somaliland and South Sudan. Reports available at: <https://www.hrw.org/topic/disability-rights>

⁴ Further information regarding the impacts of negative beliefs on persons with psychosocial disabilities can be found in the Module on "Culture, Beliefs and Disability" of the present Toolkit.

Sexual and Reproductive Health of Persons with Disabilities

Reproductive health goes beyond the absence of disease or infirmity. It is a state of complete physical, mental and social wellbeing in all matters relating to the reproductive system, and at all stages of life.

Persons with disabilities have the same sexual and reproductive health needs as other persons. However, although existing services and information can usually be adapted easily to accommodate persons with disabilities, there are often barriers to accessing them. In many cases barriers are created or sustained as a result of stigma, ignorance and negative attitudes of society and individuals, including health-care providers. For example it is often assumed that persons with disabilities are not sexually active and therefore do not need sexual and reproductive health services. In working to ensure that all sexual and reproductive health programs reach and serve persons with disabilities, increasing awareness regarding the needs and rights of persons with disabilities is critical.

The need for sexual and reproductive health services for women with disabilities is often heightened owing to their increased vulnerability to abuse. Women with disabilities experience higher rates of gender-based violence, sexual abuse, neglect, maltreatment and exploitation than women without disabilities.⁵ Persons with disabilities are sometimes placed in institutions, group homes, hospitals, and other group living situations, where they may not only be prevented from making informed and independent decisions about their sexual and reproductive health, but also face an increased risk of sexual abuse and violence. Persons with intellectual and mental disabilities are particularly vulnerable in this regard. Violence against women with disabilities can also take the form of forced medical treatment or procedures, including forced sterilization, the incidence of which has been documented in many countries and regions.

Women with disabilities have also often been denied the right to establish relationships and to decide whether, when, and with whom to have a family, in some cases being forced to marry.

As a result of the increased risk of sexual violence, women with disabilities are also at risk of becoming infected with HIV and other sexually transmitted diseases. In crisis situations, these risks are multiplied.

Disability Inclusion in HIV and AIDS Response

Evidence suggests that persons with disabilities are at equal, if not increased, risk of exposure to HIV. While data is scarce, a 2014 analysis of data from Sub-Saharan African countries showed that persons with disabilities are 1.3 times (1.48 for women) more at risk of contracting HIV than people without disabilities.⁶ In addition, evidence suggests that persons living with HIV or those with AIDS are also at risk of developing disabilities due to illness or related treatments.⁷

⁵ In his 2006 *In-Depth Study on All Forms of Violence against Women*, the Secretary-General observed that surveys conducted in Europe, North America and Australia have shown that over half of women with disabilities have experienced physical abuse, compared to one third of non-disabled women. A/61/122/Add.1, para. 152, citing to Human Rights Watch, "Women and girls with disabilities", available at: <http://hrw.org/women/disabled.html>

⁶ UN IRIN news, Heightened HIV risk for people with disabilities, available at: <http://www.irinnews.org/report/100414/heightened-hiv-risk-for-people-with-disabilities>

⁷ Dr. Jill Hanass-Hancock (HEARD, IDDC), Dr. Paul Chappell (University of Johannesburg, IDDC) and Leandri Pretorius (HEARD), Discussion Paper of UNAIDS Strategy Brief for Integrating Disability into AIDS Programming (2014).

Yet UNAIDS has found that persons with disabilities “represent one of the largest and most underserved populations” when it comes to health and HIV services.⁸ Barriers faced by persons with disabilities in this regard are similar to those faced in relation to access to health services generally, including lack of accessible information or education regarding HIV prevention, treatment, care and other matters and the inaccessibility of HIV testing and treatment centers due to physical barriers, poor coordination of health services and lack of accessible transport. For individuals with disabilities who are HIV-infected, poverty and barriers such as lack of transport to medical treatment centres hamper effective access to care and treatment, including antiretroviral and other medications for related infections. Persons with disabilities also experience disproportionately high levels of poverty, which further limits access to HIV prevention, treatment, care and support.

Obstacles to Inclusive HIV and AIDS Care

Lack of Availability: HIV-related facilities, goods, and services, including HIV prevention, treatment, care and support are often not available to persons with disabilities; health care providers are not qualified in sufficient numbers to provide disability-specific support and accommodation in HIV prevention, treatment, care and support services.

Barriers to Accessibility: Accessibility requires attention to discriminatory attitudes as well as to physical, economic and informational barriers.

- **Discrimination:** Stigma and discrimination create barriers to HIV prevention, treatment, care and support for persons with disabilities.
- **Physical inaccessibility:** HIV and AIDS prevention, treatment, care and support are often inaccessible to persons with disabilities, including HIV testing and treatment centers, because of physical barriers, poor coordination of health services or lack of accessible transport.
- **Economic inaccessibility:** Consumers with disabilities often live in poverty which limits their access to HIV prevention, treatment, care and support; persons with disabilities may not enjoy equal access to health facilities, goods and services, including medicines and supportive devices.
- **Information inaccessibility:** Information relating to HIV prevention, treatment, care and other matters, is inaccessible to persons with disabilities; and persons with disabilities are often wrongly judged to lack the capacity to make or participate in decisions about their treatment and care.

Unacceptable HIV and AIDS facilities, goods, and services: Persons with disabilities often experience disrespectful treatment in the context of HIV and AIDS; informed consent procedures are often not respected for persons with disabilities; confidentiality and privacy of persons with disabilities is often breached.

Poor quality HIV and AIDS facilities, goods and services: Persons with disabilities are entitled to quality facilities, goods and services.

Source: One Billion Strong, HIV/AIDS, Disability and Discrimination: A Thematic Guide to Law, Policy and Programming (2012).

Important

Just as disability should be mainstreamed across health services generally, the rights and needs of persons with disabilities should be mainstreamed in national responses to HIV and AIDS, including national strategic plans. In many countries, this has not been done.

⁸ UNAIDS, The Gap Report: People with Disabilities (2014)

Good Practice Examples

Persons with disabilities – and the organizations they form – can meaningfully and fully engage in HIV and AIDS programming. The forms of engagement include the following types of intervention:

- ▶ educating persons about HIV;
- ▶ providing HIV prevention commodities, services, and treatment;
- ▶ providing protection from discrimination and sexual violence; and
- ▶ empowering persons to participate in the HIV response.

DHAT

The Disability, HIV and AIDS Trust (DHAT) promotes the rights and capacity-building of Persons with Disabilities with cervical cancer, TB, HIV- and AIDS-related infections; and aims at achieving inclusion and full participation of Persons with Disabilities in the context of disability rights, cervical cancer, tuberculosis, sexual reproductive health rights (SRHR), HIV and AIDS interventions.

The Disability HIV and AIDS Trust (DHAT) is a non-profit regional organization, registered in Harare, Zimbabwe. Website: www.DHATRegional.org

2.D Measures to Ensure the Right of Persons with Disabilities to Health Services

The present section explores approaches to ensuring the right to health services for persons with disabilities. As with the implementation of other rights enshrined in the CRPD, there are a range of measures that can be taken by countries and other stakeholders to ensure the right to health services for persons with disabilities. These include the following:

See Learning Activity 2.D. titled *A Plan to Address Barriers to Health Care*

Legislative and Policy Frameworks

Countries have specific obligations under international law to respect, protect and ensure the right to health for persons with disabilities. States, in cooperation with persons with disabilities and their representative organizations, should conduct a review or scoping of all relevant legislation and policy that touches on the right of persons with disabilities to health care. Through this process, State parties can identify areas in need of reform or development which can provide a foundation for establishing a comprehensive legislative and policy framework for the right to health for persons with disabilities. In developing new legislation and policy frameworks, it is essential that an implementation plan⁹ be established and that monitoring and evaluation processes are included.

In evaluating legislative and policy frameworks the following areas, among others, should be considered:

⁹ See Module on National Action Plans of the Present Toolkit.



The role of doctors, nurses and administrators

As members of the caring professions, health professionals have a particularly important role. Awareness among health service professionals of the needs of persons with disabilities in health care settings is, therefore, of paramount importance. Beyond understanding of the rights and concerns of persons with disabilities, organizations representing persons with disabilities have reiterated the continuing attitudinal barriers in health care, including patronizing and ignorant front-line staff. Negative attitudes and harmful beliefs create significant barriers to the provision of health services for persons with disabilities. Measures to achieve genuinely inclusive health services must address attitudinal barriers including the education of health care professionals on the rights of persons with disabilities. Attitudinal barriers can have a devastating impact on the quality of health care particularly for people with learning and mental health disabilities who have a long history of misunderstanding, fear and stigma.

In the area of health services it is of utmost importance to involve frontline healthcare providers in daily contact with persons with disabilities in awareness-raising. Awareness-raising is essential to the building of organizational and individual capacity to deliver the range of health services that will enable persons with disabilities to live fully inclusive lives in their communities.

Physical accessibility

Persons with disabilities with health problems cannot visit hospitals or health clinics if buildings are physically inaccessible to them. To ensure enjoyment of the right of persons with disabilities to health services, accessibility must therefore be addressed broadly, for example in relation to entrances to buildings and healthcare facilities, appropriate equipment, restroom facilities, and to transportation to the health care facility. Accessibility should be focused mainly on the difficulties of orientation to the health care setting, including completion of registration forms, location of a seat in the waiting area, and realization of when to enter the examination room.

Informational barriers

Health service information is rarely available in formats that are accessible to persons with disabilities. This limits people's understanding of what services are available and of how to access them and it raises questions about:

1. whether the uptake of disability, mental health and general services by persons with disabilities is an accurate reflection of real need; and
2. the quality of informed consent to treatment that is being secured.

Health outreach and health promotion efforts also often fail to reach persons with disabilities.

Economic Barriers

Economic and financial factors are real barriers in relation to health service for persons with disabilities. While financial barriers within the health care system can affect members of the general population in accessing health care, persons with disabilities may experience additional disadvantages in their health and well-being. Low-income persons with disabilities are more likely to experience financial barriers to care. There are significant differences in the availability of services between those who are able to pay for services and those who do not have the resources to do so. In many countries, only those who can afford to pay for supportive devices such as crutches, hearing aids and reading glasses are able to receive them.

Ensuring DPOs' Participation

Health and social services support should be provided, organised and designed around what is important to service users from their own perspectives. User involvement and participation remains limited in the health sector, although there is now a greater awareness of the importance of developing effective forms of participation. This is consistent with the CRPD, which provides that persons with disabilities and their representative organizations should be consulted in law, policy and programming decisions (Art. 4(3)).

In order to ensure a fully inclusive health sector, it is essential for government officials to consult with and ensure the participation - at all stages of health-related policy development, implementation, monitoring and evaluation - of persons with disabilities across the full range of disability, along with their representative organizations. It is recognized in relation to health services that there is no 'one size fits all', and that the services and situations in each community and country are unique and different.

DPOs may have valuable contributions to make in areas including the following:

- ▶ training of doctors, nurses and health professionals;
- ▶ design of accessible health services;
- ▶ advice on accessibility to the created environment;
- ▶ advice on communication access;
- ▶ identification of strategies for inclusion;
- ▶ provision of support to families of persons and patients with disabilities.

A disability access focal point could be designated within each hospital or health clinic to serve as a resource and to interface with the disability community, with the families of patients with disabilities, and with others. DPOs should be included in all outreach to civil society organizations in relation to health service utilization.

Supporting DPOs

Many disabled persons' organizations have managed to develop without any consistent support for the development of their staff and organizational structures. Health and social ministries, and agencies working in partnership with disabled persons' organizations, can support DPOs in ensuring that management processes such as strategic planning, governance and financial accounting are put in place for each organization and collectively.

Institutional Structures to Support Access to Health Services

Persons with disabilities should be able to access health services within the general health system. Institutional structures at national level must work to ensure the adequate provision of health services for persons with disabilities.

In many cases disability issues are addressed primarily by a focal ministry, often a ministry for social affairs. The Health Ministry in many countries has responsibility for mainstreaming disability across all relevant parts of the health services and for rolling out the latest medical and surgical advances to help persons with disabilities lead fuller and more active lives.

Mainstreaming in the context of health promotes inclusion and addresses the barriers that exclude persons with disabilities from accessing health services open to the general population. Mainstreaming is about making appropriate adjustments to healthcare services, policies, practice, facilities and delivery so that persons with disabilities can achieve full inclusion and active, barrier-free participation in health care and enjoy the benefits of advances in medical science and technology. Moreover, as disability is present throughout the entire life cycle, so health services must be available and accessible to persons with disabilities at all stages of life.

The CRPD calls for the establishment of (i) a national framework for its implementation and monitoring (Art. 33), consisting of one or more 'focal points' within government, (ii) the possible establishment of a 'coordination mechanism' to promote, protect and monitor implementation, and (iii) the designation or establishment of an independent monitoring mechanism. This framework, which must also include the participation of persons with disabilities and their representative organizations, should be harnessed to advance implementation of health rights, and to ensure that efforts in this regard are harmonized across the government.

Budgeting

The non-affordability of health services and transport accounts for two of the main reasons why persons with disabilities do not receive needed health care in low-income countries. Many governments around the world have difficulty providing adequate resources for the health services. There is often very severe competing pressure within health budgets for limited resources, and services such as those provided by general hospitals do not cover the needs of persons with disabilities. In many countries current budgetary allocations are not enough to make significant impacts in the field of services for persons with disabilities. Nonetheless, governments can improve health outcomes for persons with disabilities by making health services affordable, within the best use of the available resources.

In Africa, as in many other continents, there has been a significant increase in the range and diversity of health and personal social services provided by private health care providers. Where private health insurance dominates private health markets and care financing, governments should ensure that persons with disabilities are covered and consider measures to make health premiums affordable. Governments should use financial incentives to encourage health care providers to make services accessible and provide comprehensive assessments, treatment, and follow-up. Governments should also consider options for reducing or removing out-of-pocket payments for people with disabilities who do not have other means of financing their need for health care services.

Collecting Data on the Provision of Health Care Services for Persons with Disabilities

Data on the rate at which persons with disabilities use health services is often not readily available in many countries. The uptake of health services by persons with disabilities is rarely measured in African countries. General surveys do not fully or consistently disaggregate data on disability in such a way that a distinct analysis of the social, economic and demographic factors relating to disability in health services can be made. The CRPD requires States to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to inclusive health services and other rights guaranteed in the treaty.

Advances in Medical Science and Technology: Gaining Access to Supportive Devices and Technologies

In accordance with the CRPD, State parties are to promote the availability, knowledge and use of supportive devices and technologies designed for persons with disabilities, as they relate to habilitation and rehabilitation. In recent years there have been significant improvements in supportive technologies available for persons with disabilities:

- ▶ People with physical disabilities that affect movement can use mobility aids such as wheelchairs, scooters, walkers, canes, crutches, prosthetic devices, and orthotic devices to enhance their mobility.
- ▶ Hearing aids can improve hearing ability in persons with hearing impairments.
- ▶ Cognitive assistance, including computer or electrical supportive devices, can help people function following brain injury.
- ▶ Computer software and hardware, such as voice recognition programmes, screen readers, and screen enlargement applications, help people with mobility and sensory impairments to use computer technology¹⁰.
- ▶ In the classroom and elsewhere, supportive devices, such as automatic page-turners, book holders, and adapted pencil grips, allow learners with disabilities to participate in educational activities.
- ▶ Closed captioning allows people with hearing impairments to enjoy movies and television programmes.
- ▶ Barriers in community buildings, businesses, and workplaces can be removed or modified to improve accessibility. Such modifications include ramps, automatic door openers, grab bars and wider doorways.
- ▶ Adaptive switches make it possible for a child with limited motor skills to play with toys and games.
- ▶ Many types of devices help people with disabilities perform such tasks as cooking, dressing and grooming. Kitchen implements are available with large, cushioned grips to help people with weaknesses or arthritis in their hands. Medication dispensers with alarms can help people remember to take their medicine on time. People who use wheelchairs for mobility can use extendable reaching devices to reach items on shelves.
- ▶ When afforded access to such supportive technologies, persons with disabilities may be better able to live independently and participate in their societies. It has been estimated, however, that in many low-income and middle-income countries only 5%-15% of people who require assistive devices and technologies have access to them.¹¹

Community-Based Rehabilitation

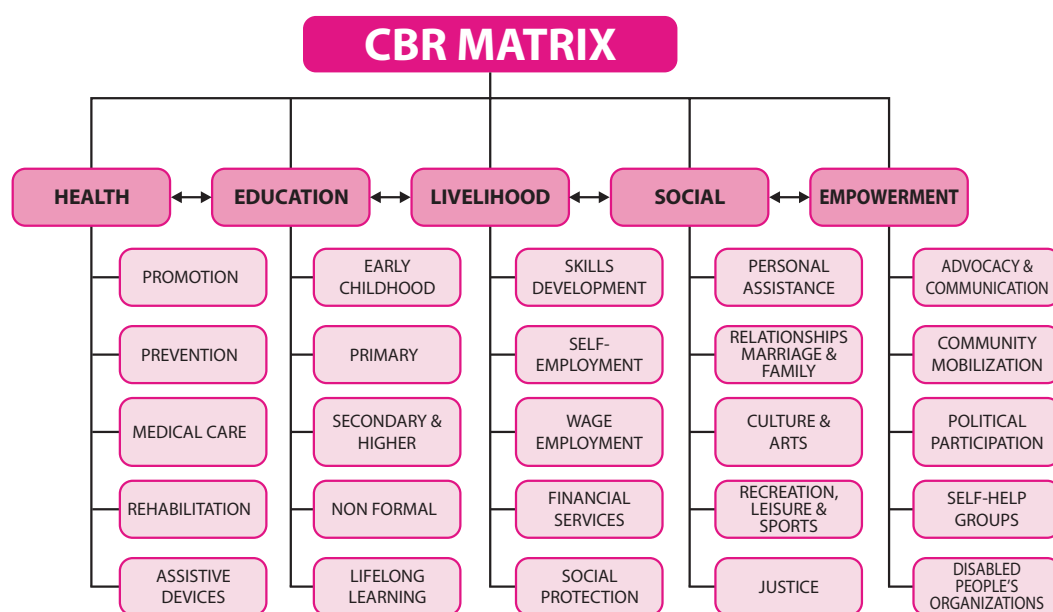
The CRPD specifies the right of persons with disabilities to live within their communities (Art. 19). Community Based Rehabilitation (CBR) focuses on enhancing the quality of life for people with disabilities and their families; meeting basic needs; and ensuring inclusion and participation. It is a multi-sectoral strategy that empowers persons with disabilities to

¹⁰ For more examples on supportive IT see the Module on Information and Communication Technology (ICT) and Disability

¹¹ WHO (2012). (2)Assistive devices/technologies: what WHO is doing; World Health Organization; 2012 [19 June 2012]. Available from: <http://www.who.int/disabilities/technology/activities/en/#>

access and benefit from education, employment, health and social services. It is a strategy within general community development targeted on rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities.

CBR is implemented through the combined efforts of persons with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.¹² CBR has developed from a medical approach to one based on the human rights of persons with disabilities. Thus the focus of CBR has evolved from medical rehabilitation towards more comprehensive multi-sector approaches such as access to health care, education, vocational training, income generation programmes and community participation and inclusion. Again it is essential to have (i) the direct participation of persons with disabilities in planning and implementation of community-based rehabilitation programmes, (ii) increased collaboration between sectors providing services, and (iii) government support in development of national policies. However, as all communities differ in their socio-economic conditions, terrain, cultures and political systems, no single model of CBR is appropriate for all countries or for all parts of an individual country. CBR is an essential component of community development.¹³



¹² ILO, UNESCO, WHO, CBR: A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of Persons with Disabilities, Joint Position Paper (2004), p. 2, available at: http://apps.who.int/iris/bitstream/10665/43060/1/9241592389_eng.pdf

¹³ See WHO, UNESCO, ILO, IDDC, Community-Based Rehabilitation Guidelines, available at: www.who.int/disabilities

Key Community-Based Rehabilitation (CBR) Elements for Africa

CBR must:

1. adopt a rights-based approach, empowering persons with disabilities and their families;
2. involve persons with disabilities, parents and their organizations from the start;
3. enable key stakeholders to access information on all issues, including HIV and AIDS;
4. look at persons with disabilities holistically;
5. advocate for appropriate legislation and policies;
6. enhance self-advocacy of disabled persons;
7. develop long-term and short-term plans together with all stakeholders, i.e. it must 'be strategic';
8. ensure inclusion of disability issues in all development programmes, collaborating in all sectors;
9. take into consideration local cultures, resources and practices;
10. address issues of poverty among persons with disabilities and their families.

Source: *Community-Based Rehabilitation (CBR) as a Participatory Strategy in Africa*, Cornell University ILR School, 2002, available at: <http://digitalcommons.ilr.cornell.edu/gladnetcollect/60>.

Community care and personal social services can be broadly defined as those designed to enable people to remain living in their communities, especially when they have difficulties doing so because of illness, disability or age. The key to ensuring non-discrimination and equal access to health and personal social services is raising the level of awareness of the needs and rights of persons with disabilities. This requires consultation and participation with persons with disabilities at all stages of policy development, programme planning and implementation. Policies and programmes at all levels are consistently better when organizations of persons with disabilities take part in planning from the outset.



Country Checkpoint

Thinking about your own local context, what could be alternative models to the following practices?

- Placing in orphanages children with disabilities or orphaned as a result of infectious diseases such as malaria and HIV/AIDS; what is a community-based alternative?
- Keeping children with disabilities at home and out of schools because of fears of abuse or inaccessible schools; what options exist for tackling isolation from the community and schooling?
- Separating adults with mental disabilities in isolated camps or psychiatric hospitals with little or no support; what is a community-based alternative?



3. SUMMARY & KEY LEARNING POINTS

The emphasis now placed on the full inclusion of persons with disabilities and on anti-discrimination has provided an important backdrop to the development of more inclusive health services for persons with disabilities. The demands of persons with disabilities, disabled persons' organisations, their advocates and families for better quality and more accessible and appropriate services has challenged service providers to consider how services can be mainstreamed and how the integration and inclusion of persons with disabilities in all areas of society can be promoted and supported. This also reflects a greater understanding and awareness of the experience of persons with disabilities in accessing health services and of the impact of disabling barriers on their independence, autonomy, health and well-being. As a result, health service providers have had to address the issues of consultation with and participation of persons with disability in planning and service delivery.

Substantial action needs to be taken by all stakeholders in order to realize the mainstreaming of health service provision, the reorientation of health services towards a social model of disability, and the inclusion of people with disabilities not only as active participants in their health care but in strategic decisions regarding the funding and planning of health services.



4. USEFUL RESOURCES

- 📖 One Billion Strong, HIV/AIDS, *Disability and Discrimination: A Thematic Guide to Law, Policy and Programming* (2012).
- 📖 UNAIDS, World Health Organization and Office of the High Commissioner for Human Rights, *Policy Brief: Disability and HIV* (2009).
- 📖 United Nations, *Declaration on the Rights of Disabled Persons, Proclaimed by General Assembly resolution 3447 of 9 December 1975*
- 📖 United Nations, *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, Adopted by General Assembly Resolution A/46/119 of 17 December 1991
- 📖 United Nations, *Substantive Issues arising in the implementation of the International Covenant on Economic, Social and Cultural Rights*, Committee on Economic, Social and Cultural Rights, Twenty-second session, General Comment No. (2000).The right to the highest attainable standard of health, 11/08/2000. E/C.12/2000/4, CESCR, 22nd Session. Geneva: United Nations
- 📖 WHO, *Ottawa Charter for Health Promotion*. Geneva: (1998) WHO
- 📖 WHO, *Health 21 - the health for all policy framework for the WHO European Region*. Europe Health for All Series, No 6. Copenhagen: WHO Regional Office for Europe. Copenhagen: (1999), WHO
- 📖 WHO *Reducing Inequalities in Health - proposals for health promotion policy and action, Consensus Statement*, European Committee for Health Promotion Development, WHO Regional Office for Europe. Copenhagen: (1999) WHO
- 📖 WHO, *Rethinking Care from the Perspective of Disabled People, Conference and Report and Recommendations*, WHO Disability and Rehabilitation Team, WHO: (2001) Geneva
- 📖 WHO, *Mental Health: New Understanding, New Hope*, WHO: (2001) Geneva.
- 📖 WHO, *Government responses to the implementation of the UN Standard Rules on medical care, rehabilitation, support services and personnel training: Main Report*, WHO: (2001) Geneva.
- 📖 WHO, *Rethinking Care from the Perspective of Disabled People, Conference and Report and Recommendations*, WHO Disability and Rehabilitation Team, WHO: (2001) Geneva.
- 📖 WHO and USAID, *Joint Position Paper on the Provision of Mobility Devices in Less-Resourced Settings*, (2011)
- 📖 World Bank, "Disability and HIV/AIDS at a Glance – A World Bank Factsheet" (Nov. 2004).
- 📖 World Bank, *Global Survey on HIV/AIDS and Disability* (April 2004).
- 📖 World Bank and World Health Organization: *The World Report on Disability* (2011).



5. LEARNING ACTIVITIES

Session Sheet for the Trainer – The Right to Health, Session 1

Technical Content 2.B.: Legal Framework

Learning Activity 2.B. The Inter-Connected Relation of Rights

Handout: CRPD Article 25









Session Sheet for the Trainer – The Right to Health, Session 2

Session Sheet for the Trainer – The Right to Health, Session 2

Learning Activity 2.D. A Plan to Address Barriers to Health Care

Handout: Barriers to Health Care for Persons with Disabilities

Session Sheet for the Trainer – The Right to Health, Session 1

	Key Messages	See the summary and key learning points.
	Objectives	By the end of this session, participants will have reviewed the main provisions of CRPD pertaining to health services.
	Room Arrangement	Tables for small groups of 4 Round table/chair circle for plenary discussion
	Activity	30 mins – Introduction to topic and technical input. 30 mins – Group work around Learning Activity 2.B. 30 mins – Plenary feedback and discussion.
	Duration	90 minutes
	Notes for a Training Team	Make sure to use the follow-up conversation to group work to draw out country- and context-specific examples to encourage learning from each other.
	Task Sheets	Learning Activity 2.B.: The Inter-Connected Relation of Rights
	Handouts	Handout: CRPD Article 25











Handout: CRPD Article 25

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

- a. provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the areas of sexual and reproductive health and population-based public health programmes;
- b. provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, along with services designed to minimize and prevent further disabilities, including among children and older persons;
- c. provide these health services as close as possible to people's own communities, including in rural areas;
- d. require health professionals to provide care to persons with disabilities of the same quality as that provided to others, including on the basis of free and informed consent by *inter alia* raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards in public and private health care;
- e. prohibit discrimination against persons with disabilities in the provision of health insurance, and also of life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f. prevent discriminatory denial of health care, health services; or food and fluids on the basis of disability.

Session Sheet for the Trainer – The Right to Health, Session 2

	Key Messages	See the summary and key learning points.
	Objectives	By the end of this session, participants will have devised a number of strategies to overcome barriers to the inclusion of persons with disabilities in health services.
	Room Arrangement	Flipcharts and markers Tables for small groups of 4. Round table/chair circle for presentations and discussion.
	Activity	40 mins – Group work around LA 2.D. 20 mins – Presentations (4 x 5mins) 30 mins – Q&A and discussion.
	Duration	90 minutes
	Notes for a Training Team	On the handout, there are four listed barriers to health services for persons with disabilities. Assign one to each group. After the group presentation, use the final 30 minutes to discuss each group's work and fill in any learning gaps you have identified. Use: http://www.who.int/mediacentre/factsheets/fs352/en/ for further support.
	Task Sheets	Learning Activity 2.D: A Plan to Address Barriers to Health Care
	Handouts	Handout: Barriers to Health Care for Persons with Disabilities



Handout: Barriers to Health Care for Persons with Disabilities

For further reading, see: Fact Sheet 352, WHO:

<http://www.who.int/mediacentre/factsheets/fs352/en/>

Prohibitive costs

Affordability of health services and transportation are two main reasons why people with disabilities do not receive the required health care in low-income countries; 32-33% of non-disabled people are unable to afford health care as compared to 51-53% of people with disabilities.

Limited availability of services

The lack of appropriate services for people with disabilities is a significant barrier to health care. For example, research in India's Uttar Pradesh and Tamil Nadu States found that, the lack of services in the area was the second most significant barrier to using health facilities after cost considerations.

Physical barriers

Uneven access to buildings (hospitals, health centres), inaccessible medical equipment, poor signage, narrow doorways and internal steps, inadequate bathroom facilities, and inaccessible parking areas create barriers to health care facilities. For example, women with mobility difficulties are often unable to access breast and cervical cancer screening because examination tables are not height-adjustable and mammography equipment only accommodates women who are able to stand.

Inadequate skills and knowledge of health workers

People with disabilities were more than twice as likely to report finding health care providers' skills inadequate to meet their needs; four times more likely to report being treated badly; and nearly three times more likely to report being denied care.

