DISABILITY-INCLUSIVE HEALTH SERVICES TOOLKIT

A Resource for Health Facilities in the Western Pacific Region

World Health Organization
Western Pacific Region

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ISBN 978 92 9061 892 8
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Suggested citation. Disability-inclusive health services toolkit: a resource for health facilities in the Western Pacific Region. Manila, Philippines. World Health Organization Regional Office for the Western Pacific. 2020. Licence: CC BY-NC-SA 3.0 IGO.

Cataloguing-in-Publication (CIP) data. 1. Disabled persons. 2. Health facilities. 3. Health services for persons with disability. I. World Health Organization Regional Office for the Western Pacific (NLM Classification: WA300.1)

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ACKNOWLEDGEMENTS

This *Disability-inclusive Health Services Toolkit* was produced by a team of researchers and development practitioners from the Nossal Institute for Global Health and the Centre for Health Equity at the Melbourne School of Population and Global Health, University of Melbourne, Australia. It was authored primarily by Fleur Smith, Liz Gill-Atkinson and Cathy Vaughan. Alex Devine and Sally Baker were involved in designing the Toolkit structure, and provided feedback and revisions to draft written content. Liza Fitzgerald provided project management support and Alana Pirrone provided graphic design services for layout and formatting of the Toolkit.

We would like to express our gratitude to all the individuals whose contributions enabled us to produce this Toolkit. Stakeholders from the World Health Organization (WHO) Western Pacific Region who attended the WHO Meeting on Rehabilitation as Part of the Continuum of People-centred Health Care (2016) and the Meeting on Rehabilitation in Universal Health Coverage (2017) helped to prioritize the scope and purpose of the Toolkit, provided feedback on the draft Toolkit outline and module content, and shared examples of current practices that support disability-inclusive health services. Sam French from People with Disability Australia and their disabled people's organization partners in the Western Pacific Region contributed examples of case studies of disability-inclusive health services from the Region. Sally Baker worked with the Pacific Disability Forum to identify and develop case studies of disability-inclusive health services from the Pacific. Jerome Zayas from Inclusive Development and Empowerment Agenda (IDEA) also provided a case study on providing disability-inclusive health services during emergencies. We would particularly like to thank all representatives from disabled people's organizations who contributed to this work.

This resource was designed in consultation with WHO personnel from all levels of WHO. During its development it benefited from the input of Darryl Barrett, Mylene Rose Benigno-Escalante and Cheryl Ann Xavier from the WHO Regional Office for the Western Pacific, Lindsay Lee and Pauline Kleinitz from WHO headquarters and Vivath Chou from the WHO Cambodia Country Office.

The development of this Toolkit was supported by the Australian Government and WHO. The views expressed in this publication are the authors alone and are not necessarily the views of the Australian Government.

INTRODUCTION

HOW DID THE DISABILITY-INCLUSIVE HEALTH SERVICES TOOLKIT COME ABOUT?

A key objective of the *WHO Global Disability Action Plan 2014–2021* is to remove barriers and improve access to health services and programmes for people with disability. The *Disability-inclusive Health Services Toolkit* was commissioned by the World Health Organization (WHO) Regional Office for the Western Pacific as a resource to support greater inclusion of people with disability in health-care services across the Region.

Good health enables participation in a wide range of activities, including education and employment. However, it is well established that people with disability have unequal access to health-care services, have greater unmet health-care needs and experience poorer levels of health compared with the general population. Health systems frequently fail to respond adequately to both the general and specific health-care needs of people with disability. Health-care services can be made inclusive of people with disability if barriers are addressed and they and their representative organizations are explicitly included in health service planning, coordination, delivery and monitoring.

WHAT IS THE PURPOSE OF THE TOOLKIT?

The purpose of this Toolkit is to support the achievement of universal health coverage (UHC) by health-care service providers. This involves ensuring access to health information and services, best-quality outcomes and improved quality of life for all people with disability. This Toolkit has been specifically produced to strengthen efforts to provide disability-inclusive health services and information to people with disability in the Western Pacific Region. However, the materials will also have relevance to other settings.

HOW WAS THE TOOLKIT DEVELOPED?

A team from the Melbourne School of Population and Global Health at the University of Melbourne developed this Toolkit in consultation with staff and stakeholders of the WHO Regional Office, the Pacific Disability Forum, People with Disability Australia and their disabled people's organization (DPO) partners in the Western Pacific Region.

A desk review of existing literature and resources on disability-inclusive health services was conducted to inform the scope, structure and content of the Toolkit. The review focused on identifying peer-reviewed academic and grey literature publications from the Western Pacific Region. However, as a limited number of publications specific to the Region were available, these were complemented by publications from other settings, with a focus on lower-, middle- and high-income countries.

At two regional forums conducted by the WHO Regional Office, stakeholders from the Region shared examples of existing practices that support disability-inclusive health services, helped to prioritize what guidance is required to support disability inclusion within health services, and provided feedback on the draft Toolkit outline and module content. The Pacific Disability Forum, People with Disability Australia and Inclusive Development and Empowerment Agenda (IDEA) also helped to identify case examples of disability-inclusive health services from the perspectives of people with disability from the Western Pacific Region.

WHO IS THE TOOLKIT FOR?

This Toolkit has been primarily developed for managers and staff of health-care facilities and services (with a focus on primary health-care facilities, including local-level clinics and district hospitals), health policy-makers, and nongovernmental organizations (NGOs) providing health information and services to people with disability. This includes health-care workers and administrative and programme staff, as we recognize that those involved in designing and delivering health services are often in the best position to facilitate and support practical changes to service delivery. DPOs will also find this Toolkit useful in their efforts to strengthen the provision of disability-inclusive health information and services to people with disability.

WHAT IS THE SCOPE OF THE TOOLKIT?

This Toolkit provides practical guidance on how to identify and address barriers to health services experienced by people with different types of disability, so that everyone can access and benefit equally from these services.

This Toolkit has seven modules. Each module has a similar format and contains:

- a fact sheet of key messages;
- a short narrative overview of what is known about the key issues and identified solutions relevant to the module, with some case studies describing "good practice" examples;
- tools – samples of, and/or links to, checklists, audits and assessment tools that can be tailored for your health service; and
- resources and references for further information and guidance.

TOOLKIT OVERVIEW

MODULE 1. DISABILITY-INCLUSIVE HEALTH SERVICES – GETTING STARTED

FACT SHEET Key messages about disability-inclusive health services

NARRATIVE
1.1 What is disability?
1.2 Why is it important for your health service to be inclusive of people with disability?
1.3 People with disability face significant barriers to accessing health services
1.4 Providing accessible health services to people with disability benefits the whole community
1.5 Principles underpinning disability inclusion in health services
1.6 Case study: Promoting disability-inclusive health care, Cambodia

ACTIONS Where to begin when developing disability-inclusive health services

TOOLS Guidance note: Partnering with DPOs to strengthen disability-inclusive health services
Checklist: First steps in making your health service more inclusive

MODULE 2. PROMOTING DISABILITY-INCLUSIVE ATTITUDES

FACT SHEET Key messages about promoting inclusive attitudes

NARRATIVE
2.1 Attitudes as a barrier to health services
2.2 What are the most commonly reported attitudinal barriers at health facilities?
2.3 How can attitudinal barriers to health service provision be addressed?
2.4 Case study: Supply-side interventions to improve access to sexual and reproductive health services to women with disability in the Philippines: W-DARE programme

ACTIONS How to promote inclusive attitudes in your health service

TOOLS Checklist: Review of health service provision policies and practices for disability inclusion
Policy template: Disability access and inclusion policy

MODULE 3. ADDRESSING PHYSICAL BARRIERS – PROMOTING UNIVERSAL DESIGN AND REASONABLE ACCOMMODATIONS

FACT SHEET Key messages about addressing physical barriers

NARRATIVE
3.1 What are physical barriers to health service provision?
3.2 Universal design and reasonable accommodation
3.3 Making health services accessible: low-cost strategies
3.4 Case study: Accessible buildings improve access to eye health services for Fijians with disability

ACTIONS How to address physical barriers to health service access in your facility

TOOLS Checklist: Physical accessibility audit

MODULE 4. COMMUNICATION BARRIERS – PROVIDING DISABILITY-INCLUSIVE HEALTH INFORMATION

FACT SHEET Key messages about providing inclusive health information

NARRATIVE
4.1 What are communication barriers to health information and service provision?
4.2 What are some of the key strategies for providing disability-inclusive health information?
4.3 Case study: Inclusive communication in eye health care, Indonesia

ACTIONS How to provide disability-inclusive health information in your facility

TOOLS Checklist: Information accessibility audit for providing disability-inclusive health information
Practice note: Practical strategies for communicating inclusive health information to people with different types of impairment

MODULE 5. DISABILITY-INCLUSIVE HEALTH INFORMATION SYSTEMS FOR PLANNING, MONITORING AND EVALUATION

FACT SHEET Key messages about disability-inclusive information systems for health services

NARRATIVE
5.1 Disability-inclusive health management information systems
5.2 Disability inclusion in planning, monitoring and evaluation

ACTIONS How to implement disability-inclusive health information systems in your facility

TOOLS
Checklist: Assessment of current programming for disability inclusion
Practice note: Disability-sensitive indicators for health services including rehabilitation
Practice note: Information for disability-inclusive planning, monitoring and evaluation.

MODULE 6. REHABILITATION AND DISABILITY-INCLUSIVE HEALTH SERVICES

FACT SHEET Key messages about rehabilitation and disability-inclusive health services

NARRATIVE
6.1 Overview of rehabilitation
6.2 Relationship between rehabilitation services and health care
6.3 Needs and benefits of rehabilitation
6.4 Case study: Fiji's Mobile Rehabilitation Service – Elenoa's story

ACTIONS How to include rehabilitation services in your health facility

TOOLS Mapping rehabilitation services

MODULE 7. DISABILITY-INCLUSIVE HEALTH SERVICES IN EMERGENCIES

FACT SHEET Key messages about disability-inclusive health services in emergencies

NARRATIVE
7.1 Disability-inclusive health services during emergencies
7.2 Why focus on providing health services to people with disability during emergencies?
7.3 Key considerations for providing disability-inclusive health care during emergencies
7.4 Case study: Promoting safety and risk reduction over the radio, Philippines

ACTIONS How to provide health services to people with disability during emergencies

TOOLS
WHO Guidance Note on Disability and Emergency Risk Management for Health
WHO/UNFPA guidance note on promoting sexual and reproductive health for persons with disabilities
Age and Disability Capacity Programme (ADCAP) minimum standards for age and disability inclusion in humanitarian action

WHAT IS THE BEST WAY TO USE THIS TOOLKIT?

This Toolkit is intended as a guide that provides knowledge and resources to strengthen the provision of disability-inclusive health information and services. It is not intended to provide "one size fits all" solutions. Each health service will need to consider the recommended actions and tools and how they can best be adapted for implementation within the workplace.

Each module is intended as a stand-alone module, addressing a specific area of health information and service provision for people with disability. However, we do recommend that all readers start with Module 1.

Module 1 provides the foundation for the rest of the Toolkit. It outlines the rationale for including people with disability in health services, and introduces key concepts relating to disability and inclusion in health. It also includes two tools to get you started. The guidance note *Partnering with DPOs to strengthen disability-inclusive health services* provides practical advice on how to engage DPOs and people with disability in your efforts to improve health service access for people with disability.

The first checklist, *First steps in making your health service disability-inclusive,* is designed to help you think through and assess "where your health service is at" in providing inclusive health services and information to people with disability. In doing so, it will help you to identify and prioritize how you use the other modules in this Toolkit. All the modules are central to improving access to health services for people with disability. However, some modules might be more immediately important, or address more pressing issues, than others in your setting.

This Toolkit reflects current knowledge and understanding of good approaches to improving access to health services for people with disability and, as such, can be viewed as a work in progress. Your feedback is encouraged.

MODULE 1
DISABILITY-INCLUSIVE HEALTH SERVICES – GETTING STARTED

KEY MESSAGES

about disability-inclusive health services

Disability is present in all communities across **low-, middle-** and **high-income countries.**

15%

of the global population **(approximately 1 in 7 people worldwide)** have a disability

Women, older people and **poor people** are more likely to have a disability. Approximately 20% of the world's poorest people in developing countries have a disability.

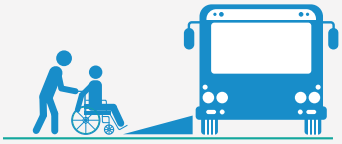
Everyone will experience conditions that contribute to disability at some point in their lives.

People with disability need to **access health services** for the **same reasons** as people without a disability.

People with disability may also need to **access health services** for **additional reasons** relating to disability.

However, people with disability report a **range of significant barriers** to health services.

Around the world, people with disability report that the **prejudiced attitudes** of health-care providers and **discriminatory behaviour** of health services are major barriers to health care. Health-care providers are often unaware of the rights and health needs of people with disability.



The United Nations Convention on the Rights of Persons with Disabilities (Article 25) upholds the rights of people with disabilities to access health services, as do other regional conventions and frameworks specific to the Western Pacific region.

There are many ways health services can address the access barriers experienced by people with disability, often for little expense.

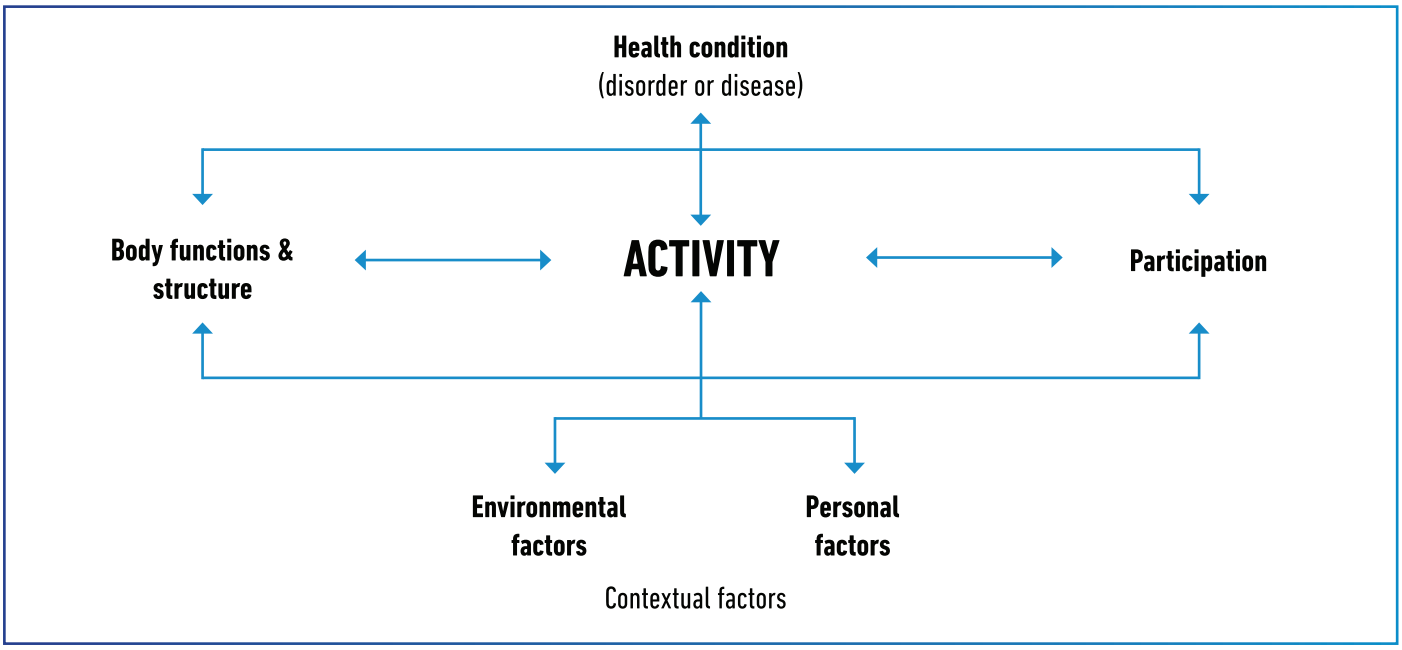
Providing disability-inclusive health services has substantial benefits for the whole community.

1.1 WHAT IS DISABILITY?

Disability is an evolving concept. The WHO International Classification of Functioning, Disability and Health (ICF) is used by regional and international organizations to classify disability. It is based on the idea that impairments can cause problems with a person's functioning, and that barriers in the environment can mean that functional limitations restrict a person's activities and participation in their community. All members of the community will experience impairments of varying severity at some point in their lives – disability is an issue for everyone.

The International Classification of Functioning, Disability and Health (ICF) helps us to understand this interaction.

Fig 1. The WHO ICF



The ICF considers disability to be an "umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)" *(1).*

ICF definitions:

Impairment = problems in body function or structure (e.g. physical, vision, hearing)

Activity limitations = difficulties in completing an everyday task or action (e.g. walking, eating)

Participation restrictions = problems an individual may experience during involvement in life situations (e.g. attending school, work, community activities)

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the first global legally binding instrument to uphold the rights of people with disability. It describes disability as resulting from "the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" *(2).*

As with the ICF, the CRPD recognizes that disability is not just a health condition; rather, it is caused by the interaction between the functional limitation arising from a person's impairment and their social and/or physical environment.

Both of these ways of thinking about disability emphasize that disability is not just because of a health condition or a problem in body function or structure, but that it is a person's interaction with the environment that limits activities and participation in the wider community. The idea that disability is the result of how an individual's impairment interacts with their environment represents a significant shift in how disability is understood and how people with disability are viewed by others.

1.2 WHY IS IT IMPORTANT FOR YOUR HEALTH SERVICE TO BE INCLUSIVE OF PEOPLE WITH DISABILITY?

Approximately ONE IN SEVEN people have a disability, and this number is higher in low-income countries

Disability is everybody's business. People with disability make up 15% of the world's population – approximately 1 billion people *(3).* People with disability can be found in every age group and in most countries. There are more women with disability than men with disability *(4).*

Approximately 20% of the world's poorest people have a disability, and there is a well-established relationship between poverty and disability *(3).* Poverty increases the likelihood of impairments through malnutrition, poor health care, and dangerous living, working and travelling conditions. People with disability are also less likely to attend school or access employment, which can lead to greater poverty and a lower standard of living for them and their families, and contribute to greater economic vulnerability and social exclusion and marginalization *(3).* Women with disability experience greater exclusion as a result of both disability discrimination and gender inequality than men with disability and women without disability in their communities, as a result of both disability discrimination and gender inequality.

It is estimated that two thirds of people with disability – approximately 650 million people – live in the Asia Pacific region *(5)*. The types of impairment and their causes vary substantially across and within countries, and individual experiences of disability differ due to age, gender, sexuality, ethnicity, geography and citizenship status.

The number of people with disability is growing

It is likely that all people will experience some form of impairment – whether temporary or permanent – at some stage in their lives. Global trends show that the number of people with disability is growing as a result of an ageing population, increasing prevalence of noncommunicable diseases (NCDs) and injuries as a result of road accidents or conflicts *(5)*. Health services need to be able to meet the needs of this growing population of people with disability.

National patterns of disability are influenced by trends in NCDs and some communicable diseases, and environmental and other factors, such as road traffic crashes, falls, burns, violence and humanitarian emergencies, including natural disasters and conflict *(3,5).* Intimate partner and sexual violence is also a significant contributor to disability for women in many countries *(6).*

In the Western Pacific Region, key contributors of disability include *(5,7)*:

- population ageing
- inadequate nutrition
- communicable and noncommunicable diseases, as well as chronic disease
- environmental factors (including natural disasters)
- road traffic accidents
- violence and conflict.

In the Pacific region in particular, the incidence of NCDs continues to rise *(8)*. These can result in disability from vision impairment, stroke and amputation.

While all of the above may cause a health condition with an associated impairment, disability is not related only to a health condition. Environmental and personal factors interact with a person's health condition, which affect their ability to participate fully in the society. The **impact on participation** is what concerns us when addressing disability.

People with disability have the same or greater health-care needs as others

People with disability have worse health outcomes, and greater unmet health needs, than people without disability.

People with disability need access to health information and services across the life course **for the same reasons as people without disability** (e.g. childhood vaccinations, contraception and family planning, disease prevention and treatment of illnesses, management of injuries, palliative care). People with disability may also need to access health services **for reasons related to their disability**. For example, research confirms that there is a strong relationship between NCDs and disability *(9)*. People with NCDs are more likely to acquire a disability because of their disease (for example, a person with cardiovascular disease who then has a stroke and loses the ability to perform some of the activities of daily living, or to walk around). Conversely, people with disability are more likely to be at risk of developing NCDs (for example, a person with a mobility impairment who finds it difficulty to exercise may become overweight and develop cardiovascular disease or have a stroke; because of prejudice, a woman with a disability may never be offered a pap smear, putting her at higher risk of developing cervical cancer). Depending on the nature of their disability and other factors such as their socioeconomic status, people with disability may be at greater risk of a range of secondary, co-morbid and age-related conditions that require health care.

Handicap International estimates that 80% of the health-care needs of people with disability is similar to those experienced by the rest of the population *(10)*. However, all too often, the health of people with disability has been overlooked by both those working in disability services and in primary health care, resulting in them being among the most marginalized populations when it comes to access to health services.

People with disability require health services over the life course and are more likely to have unmet health-care needs than people without disability. However, they are often excluded from efforts to promote health in the community. For example, studies have shown that:

- Women with disability are less likely to receive cancer screening services – for example, for breast and cervical cancer – than women without disability *(11–13)*.
- People with intellectual impairment are less likely to have health checks or to have their chronic health conditions monitored *(14,15)*.
- Adolescents and adults with disability are less likely to be included in sex education programmes *(16–19)*.
- People with disability – especially women and girls with disability – experience higher rates of violence but are often invisible in national responses to violence *(20–24)*.

What is universal health coverage?

Universal health coverage (UHC) means that everyone in the community receives the essential, quality health services they need without this causing financial hardship.

Inclusion is key to universal health coverage

To achieve UHC, health services must be disability-inclusive to ensure that all people receive the health services they need *(25)*. This means that all people, including people with disability, are able to use **the health services they need** (including prevention, health promotion, treatment, rehabilitation and palliative services); receive services of **sufficient quality** to be effective; and that services are **affordable** (that health-care costs do not cause financial hardship).

Achieving UHC at the local and national level will require the input of people with disability into policies and strategies for improving access to health services. They are the most familiar with, and affected by, barriers to health services and are therefore an important resource that health services and health-care providers can draw on when developing strategies for achieving UHC.

People with disability have the right to access health services

The rights of people with disability to access health services are enshrined in multiple global and regional conventions and frameworks, including the WHO Constitution and frameworks specific to the Western Pacific Region.

The United Nations Convention on the Rights of Persons with Disabilities upholds the rights of people with disabilities to have the same access to health services as people without disabilities *(2).*

Specifically:

- Article 4 calls for administrative, legislative or other measures to implement the CRPD.
- Article 9 calls for accessibility, including to medical facilities and to information.
- Article 22 asserts the equal rights of people with disabilities to privacy, including privacy of personal health information.
- Article 25 requires that states ensure equal access to health services for people with disabilities, with specific mention of sexual and reproductive health services, population-based public health programmes, and disability-related health services. Health information and services should be of the same quality as those available to the rest of the community.
- Article 26 requires that states take measures to strengthen and extend habilitation and rehabilitation services, including promoting the use of assistive devices.

Many countries in the Western Pacific Region are signatories to the CRPD, and therefore have a legal obligation to provide accessible health services to people with disability in line with the relevant articles in the Convention. In addition to the CRPD, the right of people with disability in the Western Pacific Region to health services is referred to in the following:

- *The Biwako Millennium Framework* (BMF) of 2002 and the *Biwako Plus Five* (2007). These are the original and updated guidelines and actions adopted by governments in Asia and the Pacific to support disability-inclusive policy implementation.
- *Pacific Regional Strategy on Disability* 2010–2015 (2009).
- The *Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific* (2012) builds on the CRPD and the BMF and includes the first set of regionally agreed disability-inclusive development goals, focusing action on a set of targets from 2013 to 2022.
- The *WHO Global Disability Action Plan* 2014–2021 (2015) was agreed upon by all Member States at the 2014 World Health Assembly. One of its key objectives in the Global Disability Action Plan is "to remove barriers and improve access to health services and programmes for people with disabilities".
- The *WHO Regional Agenda for Implementing the Mental Health Action Plan 2013–2020 in the Western Pacific* provides guidance for Member States to improve health care and quality of life for those affected by mental health disorders.
- The 2017 *Tokyo Declaration on Universal Health Coverage* recognizes the integrated nature of the Sustainable Development Goals (SDGs) and the need for people-centred health services to leave no one behind.
- *Western Pacific Regional Framework on Rehabilitation* (2018).

Disability-Inclusive health services are essential to achieving the global Sustainable Development Goals

The Millennium Development Goals (MDGs) were widely criticized by disabled people's organizations (DPOs), disability advocates and researchers for failing to recognize the specific issues experienced by people with disability in efforts to address global poverty *(26).* It is well established that people with disability lack equitable access to resources such as education, employment and health care, and that this results in their being disproportionately likely to experience poverty. There is increasing recognition that the exclusion of people with disability from the MDGs made it harder for these global development targets to be met *(26).*

The current SDGs, the follow-up to the MDGs and current global development framework, are built on the principle of leaving no one behind and explicitly emphasize the importance of including people with disability in efforts to achieve sustainable development for all. SDG 3 (good health and well-being) emphasizes the importance of UHC and universal access to health-care services. Addressing the barriers to health services experienced by people with disability will be an essential part of achieving this goal.

1.3 PEOPLE WITH DISABILITY FACE SIGNIFICANT BARRIERS TO ACCESSING HEALTH SERVICES

Across low-, middle- and high-income countries, it is well established that people with disability face significant and multiple barriers that prevent them from accessing health services. Often, the difficulties that people with disability face when trying to access health services are not about their disability specifically, but are a reflection of wider prejudice in the community, the limited legal protections available to them and the lack of attention that has been given to disability in the past *(27)*.

There are barriers to health services for people with disability in relation to both the supply of health services by health workers, facilities and the state, and the demand for and uptake of health services by people with disability and their families. Barriers faced by people with disability to accessing health services can affect both the demand for, and the supply of, health information and services. Some of the major barriers to health services include:

ATTITUDINAL BARRIERS

- People with disability commonly report experiences of prejudice, stigma and discrimination by health service providers and other staff (including receptionists and security guards) at health facilities.
- Many service providers have limited knowledge and understanding of the rights of people with disability and their health needs, and have inadequate training and professional development about disability.
- Many health services do not have policies in place to accommodate the needs of people with disability. Such policies could include allowing longer and flexible appointment times, providing outreach services, and reducing costs for people with disability.
- Women with disability face particular barriers to sexual and reproductive health services and information. Health workers often make the inaccurate assumption that women with disability are asexual or are unfit to be mothers.
- People with disability are rarely asked for their opinion, or involved in decision-making, about the provision of health services to people with disability.

PHYSICAL BARRIERS

Health services are often physically inaccessible to people with disability. They may:

- be located far away from where most people live or in an area not serviced by accessible transport options;
- have stairs but no ramps at the entrance to buildings, or have key services located above the ground floor and not have accessible elevators;
- have inaccessible toilets, passages, doorways and rooms that do not accommodate wheelchairs or are difficult to navigate for people with mobility impairments;
- not have height-adjustable examination beds and chairs – fixed-height furniture can be difficult for people with disability to climb onto; and
- be poorly lit, not have clear signage that explains where key services are, or be laid out in a confusing way that makes it hard for people to find their way around.

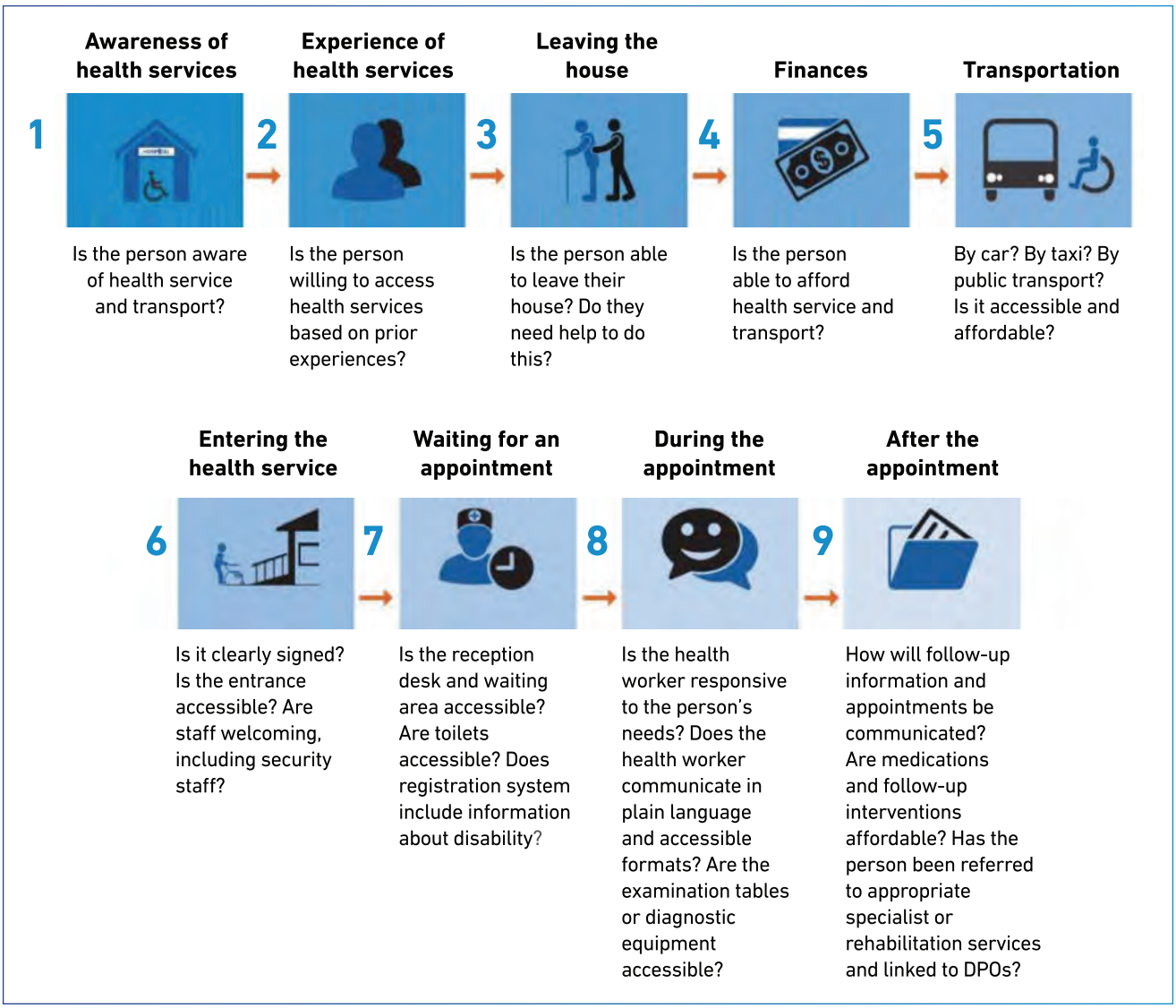
COMMUNICATION BARRIERS

- A key barrier to health services for people who have a hearing impairment is the limited availability of written material or sign language interpreters at health services.
- Health information and/or prescriptions may not be provided in accessible formats, including Braille or large print, which presents a barrier for people with vision impairment.
- Health information may be presented in complicated ways or use a lot of jargon. Making health information available in easy-to-follow formats – including plain language and pictures or other visual cues – can make it easier for people with cognitive impairments to follow.

FINANCIAL BARRIERS

- Over half of all people with disability in low-income countries cannot afford proper health care.
- Many people with disability also report being unable to afford the costs associated with travelling to a health service and paying for medicine, let alone the cost of paying to see a health service provider.

The flowchart below highlights barriers that people with disability may face at any stage of their journey when accessing health services.



1.4 PROVIDING ACCESSIBLE HEALTH SERVICES TO PEOPLE WITH DISABILITY BENEFITS THE WHOLE COMMUNITY

It is clear that access to appropriate and high-quality health services for a person with disability will benefit that individual, as it can ensure timely treatment of illness or injury and prevent the development of new health conditions or the deterioration of existing ones. In addition, the provision of disability-inclusive health services has significant benefits for the wider community.

Many disease prevention and health promotion programmes require the participation of as many people in the community as possible and for information to be widely disseminated – for example, vaccination programmes or health promotion campaigns to reduce transmission of infectious diseases. Being inclusive of people with disability will improve the community-wide effectiveness and efficiency of these programmes *(10).* Building the capacity of health service providers and health facilities to be more inclusive of people with disability will also mean that services are more accessible to people who face barriers for other reasons. These might include people who face access barriers because of a temporary injury or illness, or who experience communication barriers because they do not speak the local language.

Ensuring that people with disability can access health information and services is important for their wider participation in the community. A healthy individual has greater capacity to engage in education and employment, and to fully contribute to the social and cultural life of their community, which is of benefit to everyone.

1.5 PRINCIPLES UNDERPINNING DISABILITY INCLUSION IN HEALTH SERVICES

Article 4 of the CRPD states that people with disabilities, through their representative organizations, should be fully consulted and actively involved in all stages of formulating and implementing policies, laws and services that relate to them *(2).* Researchers, NGOs and United Nations (UN) agencies *(28)* have highlighted key principles that can underpin disability inclusion in health services. These include:

AWARENESS OF DISABILITY AND ITS IMPLICATIONS

Services can become more inclusive by raising awareness among all health service staff (including health workers, orderlies, receptionists and security guards) of the rights and needs of people with disability. This can be done by providing training for all staff and developing specific policies on disability inclusion.

PARTICIPATION AND ACTIVE INVOLVEMENT OF PEOPLE WITH DISABILITY

Services can become more inclusive by establishing partnerships with DPOs. DPOs are community organizations with members that include people with disability and those who work for the rights of people with disability. DPOs can play a representative role, undertake advocacy, provide services and peer support, and participate in research. Through collaborative partnerships with DPOs, health services can actively involve people with disability in awareness-raising activities, in identifying local barriers to health services and in developing strategies to improve access to health services for people with disability.

COMPREHENSIVE ACCESSIBILITY

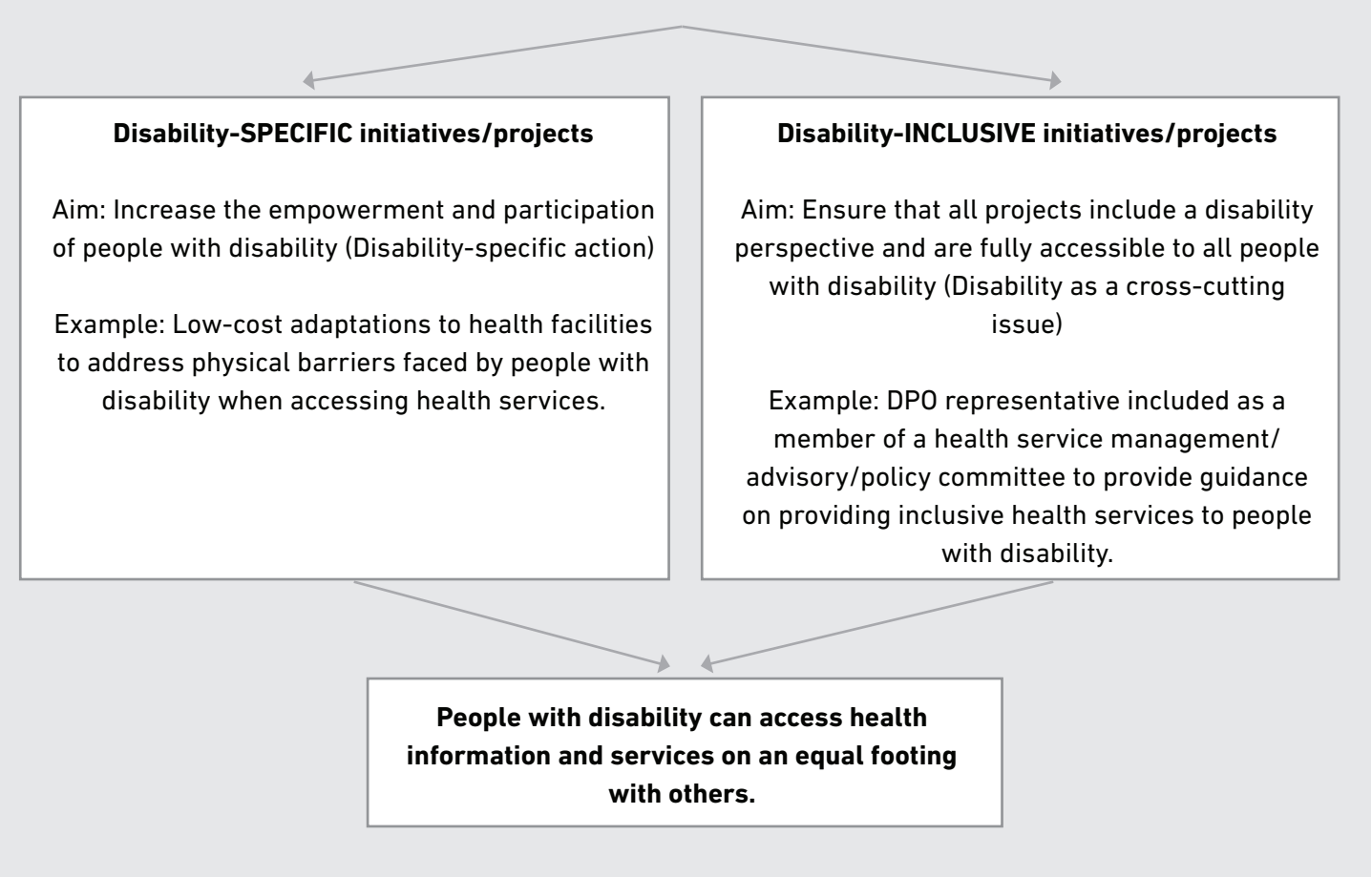
Increasing access to health services for people with disability is not just a matter of installing a ramp at the front door or some grab rails in the lavatory. It is important that health services address physical, communication, policy and attitudinal barriers to ensure accessibility. This also involves paying special attention to (11):

- *Gender and disability:* While many issues faced by people with disability apply equally to men and women, some issues are gender specific. Men and women with disability can have different health needs and have different experiences of marginalization and social exclusion. For example, women with disability often experience additional discrimination as a result of gender inequality.
- *Life-cycle approach:* Like everyone else, people with disability have health needs throughout their lives and these needs change over a lifetime. Ensuring age-appropriate health care is provided to people with disability is important.
- *Ethnic, minority and other marginalized communities:* There are people with disability in every ethnic and minority community and in other marginalized groups such as refugees, internally displaced persons and indigenous people. For these populations, health services must be doubly sure to remove barriers to care related to the status of these communities as well as to their disabilities.

TWIN TRACK – IDENTIFY DISABILITY-SPECIFIC ACTIONS COMBINED WITH MAINSTREAM APPROACHES

- *Disability inclusion within mainstream programmes:* Existing programmes can meet the health needs of most people with disability. Modest adaptations can accommodate a wide range of people with disability, and these adaptations can usually be identified easily with the help of people with disability.
- *Disability-specific programming when needed:* Disability-specific services are warranted when individuals or communities are difficult to reach through broad-based programmes.
- *Address disability in health policies, laws and budgets:* Strategies to increase inclusion in mainstream services and to provide disability-specific services need to be budgeted for to be effective.

TWIN-TRACK APPROACH TO PROVIDING INCLUSIVE HEALTH SERVICES



The above diagram was adapted from "Make development inclusive: how to include the perspectives of persons with disability in the project cycle management guidelines of the EC", cited in Inclusion Made Easy CBM (2012).

1.6 CASE STUDY: PROMOTING DISABILITY-INCLUSIVE HEALTH CARE, CAMBODIA

Studies in Cambodia have found that barriers to health care for people with disability include physically inaccessible health facilities, communication barriers, negative attitudes of health-care workers, and high direct and indirect costs.

The Cambodian–German Social Health Protection Programme (SHPP) has been implemented by GIZ, the German development agency, to support the Cambodian Ministry of Health to improve the inclusion of people with disability in the Cambodian health sector, with the aim of ensuring equitable access for poor and vulnerable people to quality health-care services.

The SHPP is implemented in the provinces of Kampong Thom, Kampot and Kep, and uses a twin-track approach of supporting specific activities to promote the rights of people with disability, while at the same time mainstreaming disability into health sector interventions.

Key project interventions to tackle the major barriers for people with disability in the health sector include:

- improving financial access to health care through a voucher system that covers some special services (e.g. cataract, clubfoot, cleft palate, transportation);
- improving physical access to health services through building ramps, accessible toilets and washrooms;
- conducting disability awareness training for health staff, including on disability rights;
- introducing early detection of impairments in infants and young children, and developing clinical pathways to facilitate referrals;
- developing signboards to improve communication between health workers and deaf and/or speech impaired patients;
- running health awareness training in collaboration with DPOs to develop health knowledge and health-seeking behaviours for people with disability; and
- encouraging DPOs and people with disability to participate in community forums and planning processes focused on the health system.

As a result of the SHPP, there is much greater awareness and understanding of the rights of people with disability in Cambodia. DPOs are more active in providing health- and rights-related information to their members, DPOs are participating in health planning and quality improvement workshops, and the physical disability checklist for newborns and young children has been integrated into clinical protocols for midwives and nurses working in public health facilities.

WHERE TO BEGIN WHEN DEVELOPING DISABILITY-INCLUSIVE HEALTH SERVICES

WHERE DO I BEGIN WHEN DEVELOPING AN INCLUSIVE HEALTH SERVICE?

Invite disabled people's organizations to be involved in improving access to health services for people with disability

Involving people with disability in your efforts to identify barriers to health information and services and to develop solutions is essential. Input from people with disability will ensure your efforts to increase access are relevant and practical. One way of doing this is by establishing partnerships with DPOs in your area (or DPOs that have connections to people with disability in your area). The guidance note: *Partnering with DPOs to strengthen disability-inclusive health services* contains practical advice on how to engage DPOs and people with disability in improving access to your health service for people with disability.

Review gaps and opportunities for providing inclusive health information and services to people with disability

The tool *First steps in making your health service more inclusive* is a checklist that is designed to help you to think through "where your health service is at" in providing inclusive health services and information to people with disability. Using this checklist will also help you to identify and prioritize how you use the other modules in this Toolkit. We recommend that you invite people with disability to be involved in completing this checklist with you.

LINKS AND RESOURCES

WHO global disability action plan 2014–2021: better health for all people with disability. Geneva: WHO; 2015 (http://www.who.int/disabilities/actionplan/en/).

World report on disability. Geneva: WHO and World Bank; 2011 (http://www.who.int/disabilities/world_report/2011/en/).

Inclusion made easy: a quick program guide to disability in development Part B. Disability inclusion: health. Bensheim: CBM International; 2012 (http://www.cbm.org/Inclusion-Made-Easy-329091.php).

GUIDANCE NOTE: PARTNERING WITH DPOs TO STRENGTHEN DISABILITY-INCLUSIVE HEALTH SERVICES

ACTIONS	
• Consider identifying a local person with a disability who has accessed the service, or establishing a "user group" of patients who are people with disability to provide feedback and identify barriers and solutions to health service access. • Search for and contact DPOs in your local area with a view to establishing partnerships. • Consider whether DPOs are representative of men and women with different types of impairment – for example, some DPOs only represent people with specific impairment types (e.g. people who are deaf or people who are blind). If not, consider engaging several DPOs to make sure there is representation of people with different types of disability. • Allocate budget to cover travel and participation expenses along with attendance time for people with disability and DPOs to be actively involved in consultations. • Ensure people with disability and DPOs are paid appropriately for their time and expertise. • Consider employing a person with a disability within the health service. • Promote people with disability as health workers to demonstrate their skills and capacities and improve representation and visibility of people with disability. Work with DPOs to consider specific opportunities (in addition to those listed below) for involving people with disability in decision-making about health service provision.	
RECOMMENDED ACTIVITIES:	
Module 1 – Getting started	Invite DPOs and people with disability to be involved in identifying barriers and solutions to inclusive health service provision, including completing the *First steps in making your health service more accessible.*
Module 2 – Attitudinal barriers	Involve DPOs and people with disability in developing and delivering training and awareness-raising activities and to review service provision policies for disability inclusion.
Module 3 – Physical barriers	Involve people with different types of disability in an accessibility audit of your health service to identify any physical barriers to access.
Module 4 – Communication barriers	Involve different people or people with different disability in identifying health information that is not accessible, developing new health promotion materials and disseminating health promotion materials to people with disability. Engage people with a variety of impairments (vision, hearing, mobility) in developing and delivering training on respectful communication strategies for all staff, including reception and security staff.
Module 5 – Health information systems for planning, monitoring and evaluation	Involve people with disability in the planning, design and implementation of data collection processes for planning, monitoring and evaluation activities.
Module 6 – Rehabilitation services	Involve DPOs in service mapping for referral pathways drawing on their knowledge of disability-specific services. Seek input from DPOs/people with disability to assist in training on basic rehabilitation approaches.
Module 7 – Inclusive health in emergencies	Involve people with disability in disaster preparedness planning and in anticipating access barriers to health services during emergencies

CHECKLIST: FIRST STEPS IN MAKING YOUR HEALTH SERVICE MORE INCLUSIVE

Partnering with DPOs to strengthen disability-inclusive health services

This checklist summarizes key elements of a disability-inclusive health service. Each module in this Toolkit focuses on one or more of these factors and is designed to equip health services with the knowledge and tools to make changes that can improve access to health services for people with disability. An important first step is assessing "where you are at" by reviewing the different elements of a disability-inclusive health service and thinking about what has already been done and what is yet to begin. You can use the checklist to map the different areas that may need specific attention in your health service, or areas where you have positive foundations to build on.

Elements of a disability-inclusive health service	Current situation	Ideas for improvements
Relationships are established with local DPOs. DPO members are actively involved in raising awareness of disability among health service staff. DPO members are actively involved in identifying barriers to health services and strategies to improve health service provision.	*If you are currently working with DPOs, you could list them here and describe when and how you are engaging with them.*	
Staff are disability aware. All staff at the health service (including health-care workers and other staff, such as security and administrative staff) have undergone training on disability and disability inclusion, and are aware of the rights of people with disability and their health needs (for more information see Module 2).	*List who has received training and when, and who has not yet had any disability awareness or sensitization training.*	
Policies are disability inclusive. Health service policies are disability inclusive, and policies and programmes are regularly reviewed to ensure that people with disability are not being specifically excluded in any way (see Module 2).	*Have you reviewed policies to identify whether they are disability inclusive and to identify any aspects of policy that may unintentionally exclude people with disability? This may include policies around wait times, costs, transport, outreach services and so on.*	

Elements of a disability-inclusive health service	Current situation	Ideas for improvements
Service is physically accessible. An accessibility audit has been conducted, together with people with different types of impairments, and strategies to address barriers to health services for people with disability have been put in place (Module 3).	*If an accessibility audit has been done, you could list key barriers identified here and then what has been done to rectify them.*	
Communication strategies are in place. All staff are aware of the different communication barriers that may be experienced by people with disability and are equipped with strategies to address these (Module 4).	*List specific steps that have been taken to address communication barriers (e.g. availability of sign language interpreters, adaptation of information sheets, use of visual or physical communication tools).*	
Disability data available. Health information systems include information on disability and data that are disaggregated by disability to assess the health needs of people with disability and whether services are reaching people with disability (Module 5).	*Is disability recorded by the health service? If so, how, where and when? How is disaggregated data used in planning and evaluation of services?*	
Strong links with rehabilitation. Health service providers are aware of the relationship between rehabilitation and primary health-care services and strong referral pathways exist in both directions (Module 6).	*Is there communication and coordination with rehabilitation services? Are basic assistive devices available through health services?*	

Elements of a disability-inclusive health service	Current situation	Ideas for improvements
Inclusive emergency health responses. Health services have strategies for ensuring people with disability are included in health responses to emergencies, including conflict, disasters and epidemics (Module 7).	*Have emergency response policies been reviewed? Are specific strategies in place to ensure that people with disability are reached during emergencies?*	
Referrals are made to other relevant services. Health service providers are aware of the range of other services that people with disability may require (including across sectors and within the health sector) and have the capacity to make relevant referrals.	*Are relevant local services (including legal, welfare, education, protection, etc.) available, and do health workers have the ability to make referrals?*	
Disability inclusion is continuously monitored. Strategies to increase disability inclusion are part of routine monitoring systems and they are periodically evaluated for effectiveness and revised accordingly (Module 5).	*How is disability inclusion incorporated into monitoring and evaluation (M&E) systems? How does M&E include the perspectives of people with disability?*	

MODULE 2
PROMOTING DISABILITY-INCLUSIVE ATTITUDES

KEY MESSAGES

about promoting inclusive attitudes

One of the most common **barriers** to health services is the **negative and limiting attitude and knowledge** some health workers and other health facility staff have towards people **with disability.**

Health workers' **negative and limiting attitudes** often compound other types of barriers, such as **physical and communication barriers.**

In comparison to people without disability, **people with disability are:**

2X as likely to find health-care providers' skills and facilities inadequate

3X more likely to be denied health care

4X more likely to be treated badly in the health-care system

Negative perceptions, assumptions and beliefs about people with disability...

- can lead to health workers practising discriminatory behaviouor.

- can also lead to health facilities having discriminatory policies and practices.

Barriers to health services that arise because of negative perceptions, assumptions and beliefs about people with disability are known as **ATTITUDINAL BARRIERS**.

Many attitudinal barriers are the result of a lack of knowledge and awareness about disability, the rights and needs of people with disability, and how to provide disability-inclusive health information and services.

The most effective way to **address attitudinal barriers** is to **raise awareness** and build capacity for **disability inclusion** among all health service staff *(3).*

Involve people with disability in efforts to change attitudes, including in:

- designing and **delivering training** for staff on how to provide disability-inclusive health services;
- reviewing of **health service policies** and practices to see how they support inclusion of people with disability; and
- advocating for training on disability to be integrated into **curriculum and accreditation requirements** for doctors, nurses, midwives and community health workers *(3).*

Publicly available training materials on disability inclusion can be adapted to buil knowledge and capacity of health service staff to provide inclusive health services to people with disability.

2.1 ATTITUDES AS A BARRIER TO HEALTH SERVICES

Across all settings, people with disability commonly report experiencing attitudinal barriers to accessing health information and services *(1).* Attitudinal barriers include negative beliefs, perceptions and assumptions about people with disability. Negative attitudes can lead to discrimination against people with disability. These barriers are often caused by limited knowledge about disability, which can lead people to ignore, judge, have misconceptions about and/or to stereotype people with disability.

Examples of negative attitudes about people with disability that can present barriers to health services include *(2)*:

Stereotyping:
assuming that their quality of life is poor, or that they are unhealthy or not sexually active because of their impairments.

Perception of inferiority:
thinking that people with disability are inferior because of their impairment.

Pity:
feeling sorry for people with disability, which can lead to patronizing behaviour.

Hero worship:
having a perception that people with disability who live independently, manage everyday tasks or pursue a profession are brave or "special" for overcoming a disability.

Ignorance:
assuming that people with disability are incapable of accomplishing something – for example, working in an office or taking care of children – because of their impairment.

Spread effect:
having a misconception that a person's disability negatively affects their other senses or abilities, leading to behaviours such as shouting at a person who is blind or not expecting a person who is a wheelchair user to be able to speak for themselves.

Backlash or resentment:
believing that people with disability are given unfair advantages, such as easier work requirements.

Denial:
not recognizing that certain conditions or impairments which may not be visible (such as cognitive impairment, bipolar disorder, depression, epilepsy, multiple sclerosis, etc.) can contribute to disability and therefore require reasonable accommodation, i.e. necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with disability the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Fear and avoidance:
being afraid of saying or doing the "wrong" thing around people with disability and therefore managing their own discomfort by avoiding the person.

Attitudinal barriers result in behaviours that limit opportunities for people with disability to participate in society in the same ways as people without disability. Attitudinal barriers are also often the cause of other types of barriers experienced by people with disability. For example, the misconception that people with different types of impairment do not have the same health-care needs as people without impairments can lead to health facilities being built in ways that contribute to disability, for example, when health facilities are physically inaccessible to people with mobility impairments (physical barriers) or when information about health issues is not provided in formats accessible to people with sensory or communication impairments (communication barriers) *(3).*

2.2 WHAT ARE THE MOST COMMONLY REPORTED ATTITUDINAL BARRIERS AT HEALTH FACILITIES?

People with disability commonly report that health service providers have no, little or inaccurate knowledge and awareness about disability and the health rights and needs of people with disability. People with disability also commonly report experiencing discrimination and inferior treatment when accessing health services, and that many health service policies and practices are not inclusive of their needs. There are attitudinal barriers to health services across low-, middle- and high-income countries, and when accessing different types of health care, including primary health care, preventive health care, cancer screening and community health services *(4).*

Disability knowledge and awareness among health service staff

People with disability commonly report that health-care providers (including doctors, nurses and community health workers) have limited knowledge about disability and about the rights and health needs of people with disability, and have limited capacity to provide disability-inclusive health services to people with disability *(1).*

In many places, education and training on disability and disability-inclusive health is not a compulsory part of training and curriculum for medical and nursing students, nor is it mandatory in accreditation and qualification processes for health-care workers. Because health-care providers have had limited, inadequate or no formal training on disability and disability inclusion, they start their working lives without the knowledge and skills required to provide appropriate health care to people with disability. Health-care services rarely offer professional development or additional training and capacity-building about disability-inclusive health to health service staff, further undermining their capacity to provide inclusive health information and services to people with disability.

This can result in:

- Health-care providers underestimating the quality of life of people with disability and providing biased health information.
- Health-care workers focusing on the individual's disability (assuming that their disability was the reason for their visit), rather than listening to people with disability and/or providing health promotion information.
- Health-care providers having limited capacity to provide early detection of, and screening for, disability – resulting in inaccurate diagnoses.
- Limited understanding of the specific factors that can undermine the health of people with disability, including violence and abuse (for example, many health workers do not know that people with disability are more likely to experience violence than people without disability, and fail to detect signs of abuse during health visits).

Disability prejudice and discrimination

Many people with disability report experiencing prejudiced attitudes and discrimination from health service staff (including staff not directly involved in providing health services, such as receptionists and security personnel) when accessing health services *(5,6)*.

However, not all people with disability experience the same attitudinal barriers to health services. Attitudinal barriers experienced by people with disability can be influenced by their age, gender, health condition and the nature of their disability *(1)*. For example, in many settings, women and girls with disability experience greater barriers to health services than women without disability or men with disability in their communities *(3, 7–10)*. This is because gender inequality combines with disability discrimination to further undermine the ability of women with disability to access health services.

People with disability report many examples of inappropriate and unprofessional behaviour by health professionals, including:

- Assumptions that people with disability are "not whole persons", that they are "incapable", "not quite normal" or "not quite human".
- Perceptions that disability is an illness; therefore, the general health needs of the individual are not met and instead, the focus is on diagnosis and cure related to disability.
- Discriminatory attitudes linked to the ability, or perceived ability, of people with disability to pay for their services.
- Health service staff feeling it is not their responsibility to deliver adequate and appropriate treatment to people with disability – that disability is someone else's problem.

Prejudicial and discriminatory attitudes towards people with disability are, in many cases, caused by limited knowledge and awareness about disability and the rights, needs and capacities of people with disability. This further demonstrates the need for health service staff to be trained in disability and disability inclusion.

Health service policies and practices

At many health-care centres, policies around the cost, duration and timing of health appointments (including processes for rescheduling appointments) can further undermine access to health services for people with disability *(9)*. For example:

- People with disability often report that standard appointment durations are insufficient to address their full range of health needs. Standard appointment times may not be enough when people communicate, think or move slowly, but accommodations are not made *(3).*
- Appointment fees and the costs of medicine can be too high for many people with disability *(6,11).*
- Many health services do not provide outreach services, even though costs associated with travelling to and from health services, and limited accessible transport options, further undermine health service access for people with disability *(12).*

2.3 HOW CAN ATTITUDINAL BARRIERS TO HEALTH SERVICE PROVISION BE ADDRESSED?

Addressing attitudinal barriers to health services for people with disability will improve their health care, health outcomes and well-being *(13)*. When people with disability have positive interactions with health service providers, they are more likely to return to the service for follow-up appointments and care, increasing their demand for health services *(9)*. Addressing attitudinal barriers also provides an opportunity to build the values, attitudes, skills and knowledge of health service providers essential for providing high-quality health care to all people in the community, including people with disability. This is essential for achieving UHC *(14)*.

Research suggests three main strategies can successfully address attitudinal barriers to health services for people with disability:

- Integration of training on disability issues into curriculum and accreditation for all health professionals *(11)*.
- Provision of in-house disability inclusion training and capacity-building for all health service staff (including health-care providers, reception and administrative staff, and security personnel) *(15)*.
- Review of service provider policies and processes for disability inclusion *(9)*.

Integrate disability education into curriculum and accreditation for all health professionals

To bring about changes in disability inclusion across all aspects of health service provision, information about the needs and rights of people with disability needs to be incorporated into the training curriculum for all health-care workers (including doctors, nurses, midwives and community health workers) *(9)*. Some researchers have recommended making accreditation of medical, nursing and midwifery programmes contingent on completion of disability-specific curriculum components *(16)*.

However, compulsory education and training on disability and disability inclusion in health and medical curricula are not common practice. Research suggests that when appropriate training on disability does occur, it is often the result of actions by "champions" – individuals within institutions and professional bodies who advocate for the integration of disability into health-care provider education and curricula *(17)*. The integration of disability education as a mandatory part of the training curriculum for health professionals will increase understanding of disability and disability inclusion among health service providers, and better equip them to provide inclusive health services.

The responsibility for curriculum in health and medical training courses often lies with academic and professional bodies *(17)*. Advocating to these bodies for the mandatory inclusion of training and capacity development on disability and disability inclusion as part of qualification and accreditation requirements for all health professionals is a practical action that health services can take to promote disability-inclusive health care.

Provide in-house training and capacity development on disability and disability inclusion

To address the generally low rates of disability and disability inclusion knowledge, awareness and skills to provide disability-inclusive health services among health service staff, it is widely recommended that health facilities implement in-house awareness-raising and capacity-building activities to contribute to achieving UHC *(11).*

Training on disability and disability inclusion could be integrated into existing staff training activities or be conducted as a separate activity *(1).* Wherever possible, people with disability and DPOs should conduct this training, or work with and advise health service staff responsible for designing and delivering the training *(18).* Studies show that health service providers are more likely to be better equipped to communicate and work with people with disability if they learn directly from them *(19,20).*

While training can take many different forms and be delivered in various ways *(20)*, disability awareness-raising activities should aim to do the following:

Address prejudicial attitudes towards people with disability

Increase knowledge and awareness:

- of the issues surrounding disability and health and the importance of disability inclusion across all policies and programmes;
- of relevant legal and ethical frameworks and how these relate to the health-care needs of people with disability;
- to appreciate current inequities and discrimination in health-care access and provision, and their contribution to physical and mental health outcomes;
- that people with disability are diverse and service providers cannot assume to know everything about a person because of their disability; and
- of the role that DPOs can play, including their capacity to build disability management skills and facilitate empowerment of people with disability in community participation.

Build capacity required to provide high-quality comprehensive health care to people with disability, including:

- to communicate health information to a range of people with disability;
- to meet the basic health requirements of early identification and diagnosis of impairment, with appropriate referrals; and
- to build awareness of the benefits and uses of available tools and information to improve care, such as health-care guidelines, structured comprehensive health assessments and health checks with people with disability.

Assess service-level policies for disability inclusion

An assessment of health service policies can indicate the extent to which an "attitude of inclusion" is present in existing service provider policies and practices. For example, people with disability report that the costs associated with travelling to health services, as well as paying for an appointment and for medication, undermine their ability to access health services *(1)*. Standard opening hours can undermine access to services for people with disability, as sometimes it is not possible for people with disability to attend a health service during work hours (if either they or their companion has to work, or accessible transport is not available). Often, the time allocated for an appointment is not adequate for a person with disability to receive the health care they need.

A review of health service policies for disability inclusion should involve a review of all policies, including those that relate to child protection/gender, health facility budgeting and planning, service costs and fees, models of service provision (including outreach, and flexibility around appointment times and duration), and human resources *(20).*

2.4 CASE STUDY: SUPPLY-SIDE INTERVENTIONS TO IMPROVE ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH SERVICES TO WOMEN WITH DISABILITY IN THE PHILIPPINES: W-DARE PROGRAMME

The W-DARE research programme (2013–2016) aimed to improve access to sexual and reproductive health (SRH) information and services for women and girls with disability in the Philippines. The programme was conducted in Quezon City in Metro Manila and in Ligao City in Albay Province. During in-depth interviews conducted in the first phase of the programme, health service providers identified the following factors as impacting the provision of quality SRH services for women with disability *(12)*:

- limited awareness of the sexual and reproductive health needs of women with disability;
- inadequate understanding of the rights of women with disability to SRH;
- very limited training in relation to disability;
- limited access to resources to enable disability-inclusive service provision;
- prejudiced attitudes of service providers towards women with disability seeking SRH care; and
- lack of awareness of other factors undermining the health of women with disability, such as violence and abuse.

PILOT INTERVENTIONS

The W-DARE researchers worked with partner organizations, including DPOs and women's health service providers, to pilot a range of interventions to address these factors. Interventions prioritized by the W-DARE team included:

Disability and gender sensitization workshops

Workshops were held with local government policy-makers, health facility managers and clinicians. These workshops aimed to raise participants' awareness of the rights of women with disability, the strengths of and contributions made by women with disability, and the challenges they face in accessing SRH services and information. Workshops were co-facilitated by women with different types of disability. Participants developed action plans to improve access to services.

Accessibility audits of selected facilities

This process involved health facility managers working with women with different kinds of disability to use a checklist when "walking through" a health facility, in order to assess all forms of accessibility at different points in a client's use of a facility, including entrance, reception, finding a service, passages and transit areas, waiting rooms, toilets and consulting suites (detailed information about conducting an accessibility audit is included in Module 4).

Disability and SRH training

Training sessions were conducted for doctors, nurses, midwives, neighbourhood officers, and workers in the justice arena such as police and personnel from the women's and children's protection units. Women with disability were resource persons throughout these training sessions, working with participants to develop strategies for improving communication with women with disability (including basic sign language skills) and for adapting examination and other procedures (the W-DARE SRH and disability training toolkit is available in Module 4).

OUTCOMES OF INTERVENTIONS

In order to assess the efficacy of the sensitization workshops and service provider training, participants completed pre- and post-training questionnaires to assess changes in knowledge and attitudes and were interviewed six to nine months following the training to assess changes in practices or services offered. Key outcomes identified included:

- Strengthened relationships between DPOs and women's health service providers, with DPO representatives now included in policy and practice consultations and advocacy efforts.
- Service providers having increased knowledge about the SRH needs of women with disability, and increased skills and strategies to communicate with and provide services to women with disability.
- Concrete changes in services and service provider practice, including:
    1. staff from physically inaccessible facilities conducting mobile outreach clinics;
    2. successful advocacy efforts to ensure that a new facility constructed in Quezon City is fully accessible;
    3. budgeting for adaptive equipment (e.g. height-adjustable examination couches); and
    4. establishing referral pathways from general health services to community-based rehabilitation and other disability-specific services.

REFLECTIONS ON EFFORTS TO INCREASE SUPPLY OF SRH SERVICES TO WOMEN WITH DISABILITIES

Women with disability co-facilitating training for doctors and other clinicians (April 2015)

Based on the experiences of implementing the above supply-side interventions, the W-DARE team has the following reflections about working with health service providers to improve access to SRH services for women with disability:

- When service providers have had minimal exposure to people with disability and little training in the area, basic disability sensitization can have a substantial impact on their attitudes and practices.
- Disability sensitization activities are most effective when (trained) people with disability lead these activities themselves.
- The resources required to increase the accessibility of physical facilities and equipment have to be included in local government budgeting and therefore will take time to mobilize.
- In the meantime, strategies for increasing accessibility must prioritize expanding disability sensitization efforts to include engineers and other personnel responsible for health facility standards, construction and accreditation, thereby strengthening efforts to ensure that health facilities (current and planned) are fully accessible.
- Health facilities and service providers require ongoing support to develop strategies for monitoring the uptake and use of SRH and other services by people with disability.
- Extensive collaboration between national, provincial and local government health offices are required to ensure that strategies are feasible and generate data that are useful for improving practice.
- Forums that bring together service providers working in health and violence with women with disability can generate innovative solutions to practical service barriers.

HOW TO PROMOTE DISABILITY-INCLUSIVE ATTITUDES IN YOUR HEALTH SERVICE

Training on disability and disability inclusion for all staff

One practical way to address attitudinal barriers to health services is to develop and implement a training programme to build staff capacity and awareness of disability and disability inclusion.

Described below are key steps in developing and implementing an in-house training programme.

Conduct a training needs assessment of disability knowledge, expertise and skills among staff:

- Identify and acknowledge prevailing attitudes, as well as actions.
- Assess existing capacity and awareness of good practice for disability inclusion.
- Review prior disability education and training experiences or qualifications.

Create a plan for addressing gaps in disability knowledge and awareness:

- Ensure that disability training and the new workplace practices are included in induction processes for all new staff.
- Implement annual training and capacity-building activities to consolidate and update disability inclusion knowledge and skills among all staff.

Develop disability inclusion training to meet staff needs:

- Check with DPOs in your local area to see whether they have their own training resources and whether they are interested in being involved in designing and delivering training and awareness-raising activities for staff at your health service.
- Identify a local person with a disability who has accessed the service to also be involved in developing the training materials.
- Review existing training materials and guidelines for disability inclusion in health services, such as those listed below, and tailor for your workplace.

Undertake and evaluate disability inclusion training with all staff:

- Undertake whole-of-staff training in disability awareness-raising and sensitization so that staff can interact appropriately with people with different types of impairment.

Key topics for consideration when developing disability training for health-care providers include:

- Introduction to disability (concepts of disability, impairment, functioning and participation).
- The experience of disability (learning about the experiences of people with disability in your country and promotion of positive attitudes towards people with disability).
- Rights of people with disability (policy and legal frameworks protecting the rights of people with disability).
- Access to health services (why people with disability need access to health services).
- Introduction to disability inclusion (key concepts and principles of disability inclusion).
- Identifying disability (how to screen patients for impairments).
- Ethical practices (informed consent, privacy and confidentiality when providing services to people with disability).
- Communicating with a range of people with different types of impairment.
- Personal reflections on work practices (how to adapt work practices based on training).

Review health service provision policies and practices for disability inclusion

STEPS

1. Nominate a group of people who will review service processes for disability inclusion. Ideally, this group would include members of the leadership team, other staff members (including health-care providers), and people with disability/DPO representatives.
2. Complete review of policies and practices for disability inclusion using the list of considerations listed in the *Checklist: Review of health service provision policies and practices for disability inclusion.*
3. Develop a disability inclusion policy based on the outcomes of the review – ensure that the policy is linked with other policies (such as those on gender and child protection). Please refer to the *Policy template: Disability access and inclusion policy* at the end of this module.
4. Appoint a disability inclusion officer (who could be an existing staff member) or identify staff and community members to form a committee with responsibilities for implementing and updating the disability inclusion policy.

LINKS AND RESOURCES

W-DARE service providers session guide. Women with Disability taking Action on Reproductive and Sexual Health; 2014 (https://wdare.file.wordpress.com/2018/09/w-dare-service-provider-trainingpackage1.pdf).

Disability-inclusive sexual and reproductive health component. Training of trainers manual on disability-inclusive HIV and sexual and reproductive health for health workers. USAID and Handicap International; 2011 (http://www.asksource.info/resources/training-trainers-manual-disabilityinclusive-hiv-services-and-disability-inclusive-sexual).

CHECKLIST: REVIEW OF HEALTH SERVICE PROVISION POLICIES AND PRACTICES FOR DISABILITY INCLUSION

THINGS TO CONSIDER	YES/NO	NOTES
Child protection policy • Does the health service have a child protection policy that is inclusive of children with disability?		
Health service budget and planning • Is there a budget line for reasonable accommodation (adjustments for accessibility and inclusion), including staff training, accessible communication formats and accessible infrastructure? • Have costs for disability inclusion been accounted for in the overall health service budget? • Are there additional funds available to your health service to support disability inclusion?		
Service affordability • Affordability of the service – is it possible to reduce service fees (or scale fees) for people with disability and their families/households? • Are people with disability entitled to a concession/ discount/rebate due to their disability? If so, are health service providers aware of this, and is it being promoted?		
Transport options • Does the service provide transport options to support people with disability to reach the health service (e.g. organize a pick-up and drop-off service, or an established patient transfer process)? • Do staff provide outreach services to people with disability (e.g. house visits, or through a fortnightly/ monthly visit to a DPO or rehabilitation centre)?		
Health appointments • Are flexible/extended appointment durations available for people with disability? • Do you have flexible/extended opening hours (once weekly or fortnightly)?		
Human resources • Is demonstration of disability-inclusive practices included in job descriptions and performance evaluations? • Have you considered employing people with disability as health service staff?		

POLICY TEMPLATE: DISABILITY ACCESS AND INCLUSION POLICY

Insert your logo here

Scope

This policy applies to all persons employed within *{insert name of your organization}* and supersedes all previous policies related to disability access and inclusion.

Policy statement

{Insert name of your organization} is committed to ensuring that people with disability, their families and carers are able to fully access the range of health services, facilities and health information available in this health service. The intention of *{insert name of your organization}* is to provide people with disability the same opportunities, rights and responsibilities enjoyed by other people in the community.

{Insert name of your organization} will also ensure that access for people with disability is a primary concern when health services and/or facilities are developed or modified.

To ensure this commitment, *{insert name of your organization}* will:

- Create and actively promote an environment where information, services and facilities are readily accessible to all people and do not directly or indirectly discriminate against people with disability.
- Consult people with disability, their families and carers, and DPOs to ensure that barriers to access and inclusion are addressed appropriately.
- Work in partnership with community groups and other public authorities to facilitate the inclusion of people with disability in consultation and planning forums.
- Ensure that any services contracted by *{insert name of your organization}* are provided in a manner that promotes access and inclusion for people with disability.
- Develop a disability access and inclusion plan that outlines the steps we will take to ensure a disability-inclusive health service, and review this plan annually.

The disability access and inclusion plan will achieve these outcomes:

1. People with disability have the same opportunities as other people to access the services of *{insert name of your organization}.*
2. People with disability have the same opportunities as other people to access the buildings and other facilities of *{insert name of your organization}.*
3. People with disability receive information from *{insert name of your organization}* in a format that will enable them to access the information as readily as other people are able to access it.
4. People with disability receive the same level and quality of service from the staff of *{insert name of your organization}.*
5. People with disability have the same opportunities as other people to provide feedback and make choices about their health care.
6. People with disability have the same opportunities as other people to participate in any public consultation by *{insert name of your organization}.*

Disability access and inclusion plans are developed in consultation with the community and employees of *{insert name of your organization}* and are intrinsic in meeting the overall objective of ensuring a quality health service.

Supporting documents

List any relevant documents, including guidelines, procedures and plans, that address disability inclusion.

Relevant legislation

List all relevant local acts and regulations – for example, those relating to disability, accessibility, discrimination and human rights.

Authority

Endorsed by:	
Date:	
Date for review:	

MODULE 3
ADDRESSING PHYSICAL BARRIERS – PROMOTING UNIVERSAL DESIGN AND REASONABLE ACCOMMODATIONS

KEY MESSAGES

about addressing physical barriers

Addressing **physical barriers** is key to providing **disability-inclusive health care**.

Everyone will experience impairment at some time in his or her life. Having **health facilities** that are **physically accessible** benefits everyone.

Health service infrastructure, the **equipment used** in health facilities, and **transport to and from health services** can all pose a barrier to health care if they are inaccessible for people with disability.

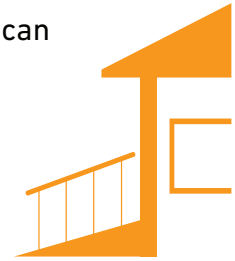
Inaccessible services cannot provide universal health coverage or high-quality care.

Article 9 of the **Convention on the Rights of Persons with Disabilities** requires that measures are taken to ensure **people with disabilities can access health-care facilities on an equal basis with others.**

Universal design principles promote the design of products, environments, programmes and services that are usable by people of all ages and abilities.

For existing facilities, **reasonable accommodations** can be made to overcome physical barriers.

Improving the **accessibility of health-care facilities** does not have to be expensive.



The first step to improving physical accessibility is to conduct an audit to identify physical barriers and strategies for improvement.

3.1 WHAT ARE PHYSICAL BARRIERS TO HEALTH SERVICE PROVISION?

Physical accessibility to health care is defined as "the availability of good health services within reasonable reach of those who need them and of the opening hours, appointment systems and other aspects of service organization and delivery that allow people to obtain the services when they need them" *(1)*.

Addressing physical barriers to health care is a key aspect to ensuring the accessibility and availability of quality health services for all people. Whether due to injury, illness, surgical interventions, pregnancy, ageing or disability, most people experience impairment at some point in their lives; therefore, the need for accessible and inclusive design when accessing health services applies to everyone.

Health infrastructure is often physically inaccessible to people with disability. This means that even if people with disability are able to overcome the geographic, distance and cost barriers to reach a health service, they may not be able to get inside the building or be able to use the facilities safely and with dignity *(2)*.

In addition to the infrastructure of health facilities, physical barriers relate to the equipment used within health facilities and transportation to and from health facilities. A study of barriers and facilitators to health services for people with disability in Cambodia *(3)* found that physically inaccessible facilities, transport and distance to health facilities were all barriers to access, while a study in the United States of America, barriers to preventive health services for people with a physical disability similarly identified structural barriers related to the facility itself, the equipment used (e.g. height of examination tables, whether diagnostic equipment was accessible), and transportation *(4)*. In a Cameroon study of reproductive health services for women with disability, physically inaccessible health centres led to some women feeling shame and embarrassment if they were not able to access the facilities independently and needed to rely on others to lift or carry them *(5)*. Other research has found that physically accessible buildings and equipment contribute to quality health services, such as services for sexual and reproductive health care *(6)*.

Community members without disability, including health practitioners, can easily underestimate the impact of physical barriers for people with disability. A study in the United States of America found that 86–90% of physicians believed that their premises and examination rooms were wheelchair accessible. However, many people with disability report that they cannot access their general practitioners' rooms or examination equipment *(7)*.

Physical access to health service buildings and clinics, as well as the indoor and outdoor facilities of health services, including toilets, is crucial to people with disability. Accessibility needs to be considered in all places in which health services occur, which include not only clinics and hospitals, but also anywhere that health promotion, prevention or treatment activities occur.

COMMON PHYSICAL BARRIERS AT HEALTH FACILITIES *(7)*

- **Uneven or rough pathways to entrances or between buildings.**
- **Steps/stairs at entrances and lack of ramp access.**
- **Shoes, rugs or other hazards at doorways.**
- **Stairs within buildings to access different floors.**
- **Narrow door openings that do not fit a wheelchair.**
- **Doors that are heavy or door handles that are too high.**
- **Inaccessible toilets – insufficient space for wheelchairs or a carer to assist, lack of grab rails, inward-opening doors.**
- **Lack of height-adjustable or low examination tables that are easier to transfer on and off from.**
- **Inaccessible diagnostic equipment such as x-ray or mammography equipment that cannot be moved into different positions.**
- **Reception desks that are too high for wheelchair users.**
- **Furniture in hallways.**
- **Inaccessible drinking-water and handwashing facilities.**

Source: Mobilituk wheelchair-accessible tuk-tuk with its ramp extended out onto the ground. Sourced from: https:// wheelchairtravel.org/mobilituk-wheelchair-accessible-tuktuk/mobilituk-feature-onsite/

Transportation

Transportation to and from health-care facilities is a barrier for many people with disability. This is especially the case in rural areas where distances may be greater or terrain more difficult – many people with disability are unable to easily get to clinics, community centres or other places where health services are available. Many are unable to afford buses, taxis or other forms of public transportation that could take them to services. Where transportation is available and affordable, the vehicles are often inaccessible, unsuitable or inappropriate for those with physical impairments. Thus, people with disability may need mobility equipment such as tricycles or prostheses, personal assistance services, or financial support to be able to reach health services. Transportation schemes to improve health service access that consider the needs of people with disability are an important aspect of removing physical barriers and enabling access to health care for all *(8)*.

3.2 UNIVERSAL DESIGN & REASONABLE ACCOMMODATION

Universal design

Although the concept originally emerged with people with disability in mind, universal design refers to the design of products, environments, programmes and services to be usable by people of all ages and abilities, to the greatest extent possible, without the need for adaptation or specialized design *(9)*. The benefits of universal design therefore are of value to the whole population and not only to people with disability.

Article 9 (Accessibility) of the CRPD requires that State Parties take appropriate measures to ensure that people with disability have access, on an equal basis with others, to the physical environment, transport, information and communications, and other facilities and services open or provided to the public in both urban and rural areas *(9)*. This includes health facilities. The measures to be taken include the identification and elimination of obstacles and barriers to accessibility in relation to buildings, transportation, and other indoor and outdoor facilities. Applying the principles of universal design to health facility infrastructure will go some way to achieving this; therefore, universal design principles should be integrated into all standards relating to health infrastructure *(2)*.

PRINCIPLES OF UNIVERSAL DESIGN *(10)*

- **Design that is useful and marketable to people with diverse abilities.**
- **Design that accommodates a wide range of individual preferences and abilities.**
- **Design that is easy to understand, regardless of the user's experience, knowledge, language skills or concentration level.**
- **Design that communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.**
- **Design that minimizes hazards and the adverse consequences of accidental or unintended actions.**
- **Design that can be used efficiently and comfortably and with a minimum of fatigue.**
- **Design that provides appropriate size and space for approach, reach, manipulation and use, regardless of the user's body size, posture or mobility.**
- **It is important to also take into account cultural, economic, engineering, environmental, gender and social contexts when applying these principles.**

Reasonable accommodations

"Reasonable accommodations" refers to the provision of necessary and appropriate modifications and/or adjustments, where these do not impose a disproportionate or undue burden, to ensure that people with disability enjoy the same fundamental freedoms and human rights on an equal basis with others *(9)*. Reasonable accommodations are a requirement under the CRPD and apply to all aspects of society to promote equality and eliminate discrimination for people with disability, including employment, education and health care.

Reasonable accommodations may include modifying equipment or facilities, but may include simply moving furniture, changing the location of an activity or service to a more accessible location, using technology to communicate, being mindful of placing information or objects at heights accessible to all, or thinking flexibly about how, when and where to provide interventions and services.

3.3 MAKING HEALTH SERVICES ACCESSIBLE: LOW-COST STRATEGIES

The cost of incorporating universal design principles is not as great as many people assume. This is particularly true if it is addressed during the planning and design phase wherever possible. It is estimated that providing accessible facilities increases building costs by as little as 0.5–1% if planned, designed and implemented from the outset *(11)*. The cost of retrofitting for accessibility after construction is complete may be far greater.

However, it is acknowledged that many health services have existing facilities that are too costly to retrofit on limited resources. Therefore, in these instances health services should consider what reasonable accommodations can be made to improve accessibility and ensure equitable health services for people with disability. Many of these can be done at low cost.

Examples of low-cost strategies and reasonable accommodations to remove physical barriers and improve the physical accessibility of health facilities are:

☐ **Clear hallways and clinic rooms of obstructions and excess furniture.**

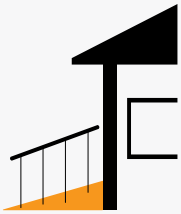
☐ **Provide accessible toilets with a wide doorway, outward-opening door and appropriately positioned grab rails.**

☐ **Make available an over-toilet frame/seat if only squat toilets are available.**

☐ **Ensure reception desk height is low enough to be seen over if seated in a wheelchair.**

☐ **Provide clear signage so that people know where to go.**

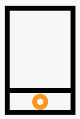
☐ **Have a ramped entrance into the facility.**



☐ **Ensure drinking-water and hand hygiene materials are placed at heights accessible to wheelchair users.**

☐ **Designate accessible car parking spaces close to the facility entrance.**

☐ **Consider alternative models of service delivery**
- **Home visits**
- **Telemedicine – for example, via Skype**
- **Mobile health clinics**
- **Outreach programmes.**



☐ **Have a foldable cot available in examination rooms, which can be set up quickly for patients who are unable to climb on to an examination table.**

☐ **Ensure health education/ prevention activities are held on the ground floor of buildings or in community spaces that are accessible.**

3.4 CASE STUDY: ACCESSIBLE BUILDINGS IMPROVE ACCESS TO EYE HEALTH SERVICES FOR FIJIANS WITH DISABILITY

Located in Suva, Fiji, the Pacific Eye Institute is the Pacific region's first training facility for eye health professionals. Incorporating training and clinical services that focus on eye health, the Pacific Eye Institute's programmes are delivered in a state-of-the-art building which houses a fully equipped eye clinic, theatres, classrooms and resource centre.

With support from the Government of Australia, the Pacific Eye Institute's custom-built premises were constructed within the grounds of Suva's Colonial War Memorial Hospital in 2010. A high priority was to ensure that its services could be accessed by people with disability – whether as students, staff, patients or family members.

As a result, the Institute has a covered mobility ramp connecting the ground floor to the first floor, with wheelchair rest areas and turning spaces. Tactile indicators are installed on the covered ramp and throughout the buildings to assist those with low vision, and handrails also assist those with mobility disabilities. A covered external walkway connects the Institute to the Colonial War Memorial Eye Clinic and hospital grounds. These changes have allowed students, staff, patients and family members with disability to access health services easily.

Overcoming barriers in the built environment requires early consideration of accessible features and their costs. Barriers to accessibility and localized solutions should be identified in conjunction with local people with disability. The cost of accessible design is reduced when incorporated early into initial planning and design phases rather than being negotiated later as add-on expenses.

In addition to considering the voices of people with disability, making health infrastructure appropriately accessible may also require standards and guidelines to assist the incorporation of inclusive design in planning and at construction stages. However, many countries lack agreed technical standards. *The Accessibility Design Guide: Universal principles for Australia's aid program* is a resource that describes the principles which development practitioners can consider when applying universal design to facilitate the rights of people with disability to access infrastructure such as the Pacific Eye Institute.

HOW TO ADDRESS PHYSICAL BARRIERS TO HEALTH SERVICE ACCESS IN YOUR FACILITY

Accessibility audits

Conducting an accessibility audit within the health facility is a practical way to identify physical barriers that may influence access to services and programmes, thereby allowing you to address these and improve disability inclusion.

An accessibility audit involves moving through the facility to gain an understanding of the physical accessibility of all areas of the health facility and the surrounding environment. Ideally, this will be undertaken with a member of a local DPO, a member of the service provider leadership team and, where possible, with people with different types of impairment (for example, a person with a mobility impairment and a person with visual impairment). It should start from outside the facility, from transport access points, and then through the service, including reception/triage and all relevant clinics or areas that may be accessed by members of the public.

Areas that should be considered in terms of their accessibility include:

- ☐ Transport and parking facilities
- ☐ Access from transport to the health facility buildings
- ☐ Entry and exit in and out of the buildings
- ☐ Presence of ramps and their suitability in terms of width and gradient
- ☐ Reception and waiting areas
- ☐ Pathways within and between buildings
- ☐ Examination and treatment rooms
- ☐ Dispensaries
- ☐ Toilet and hygiene facilities
- ☐ Emergency evacuation routes and procedures

Use a checklist or "audit tool" that outlines the elements throughout the health facility to observe and record your observations and take note of areas for improvement. An example is available at the end of this module.

LINKS AND RESOURCES

Accessibility design guide: universal principles for Australia's aid program. Australian Agency for International Development (AusAID); 2013 (http://dfat.gov.au/about-us/publications/Pages/accessibility-design-guide-universal-design-principles-for-australia-s-aid-program.aspx).

Accessibility for the disabled: a design manual for a barrier free environment. New York: United Nations Enable; 2003–2004 (http://www.un.org/esa/socdev/enable/designm/index.html).

Access strategies in eye health. Inclusion made easy in eye health programs: disability-inclusive practices for strengthening comprehensive eye care. Bensheim: CBM International; 2012, p29–30 (https://www.cbm.org/article/downloads/54741/Inclusion_in_Eye_Health_Guide.pdf).

How to build an accessible environment in developing countries: based on the Cambodia Program's experience. Manual #1 – introduction & accessibility standards. Phnom Penh: Handicap International France, Cambodia Program; 2008 (www.hiproweb.org/uploads/tx_hidrtdocs/Manual1.pdf).

A health handbook for women with disabilities. Berkeley: Hesperian Foundation; 2007 (https://hesperian.org/wp-content/uploads/pdf/en_wwd_2008/en_WWD_2008_fm.pdf).

CHECKLIST: PHYSICAL ACCESSIBILITY AUDIT

This checklist provides a guide of accessibility elements to observe. There is space for comments about listed items and additional observations on accessibility.

ITEM	ELEMENT TO OBSERVE	✓	✕	COMMENTS
Parking facilities	Are there parking spaces strictly observed for people with disability?			
	If YES – Are reserved parking spaces close to the building entrance?			
Route to service	Are kerb ramps built into the footpath, especially for access from parking area/road to public transport?			
	Are road crossings clearly signed and safe for passage?			
	Is the pathway to building entrance clear of steps?			
	Is the pathway to the building clear of obstacles? (e.g. vehicles, plants, electrical wiring)			
	Are pathways level with minimal breaks?			
Entrance to service	Is the building entrance accessible for people with mobility impairments?			
	Does the building have a ramp at the entrance?			
	If YES – • Is ramp at least 1.2 metres wide? • Is ramp gentle enough for wheelchair users to self-propel or be pushed easily by a carer? • Is the ramp surface non-slippery? • Is there a landing at least every 9 metres? • Are there handrails on either side of the ramp?			
	Is the door width wide enough to fit a wheelchair?			
	Is door handle at a height that can be reached from a wheelchair?			
	Can the door be opened easily without much effort?			
	Is service signage readable, e.g. in Braille or large print, understandable symbols (for accessible entrances, toilets)?			
	Are door staff/security staff aware of any policies regarding priority of treatment for people with disability?			

ITEM	ELEMENT TO OBSERVE	✓	✕	COMMENTS
Reception and waiting areas	Is the pathway from entrance to reception/ triage clearly signed?			
	Is pathway from entrance to reception/triage clear of obstacles?			
	Is there space for wheelchairs in the waiting area?			
	Is drinking-water available at a height/location accessible for all people?			
Service buildings – internal environment	Is there level access to all relevant areas where health service provision takes place?			
	Are there any steps inside the service buildings? If YES – • Is there a ramp or lift that can be used as an alternative? • Do steps have contrast strips for people with vision impairment? • Are there handrails beside steps and ramps?			
	Are there handrails along corridor walls?			
	Are corridors free from obstacles?			
	Are floor coverings non-slip?			
	Are service areas well-lit to support people with low vision to see visual cues and people who are hard of hearing to lip read?			
Examination rooms	Are doorways to examination/treatment rooms wide enough to fit a wheelchair?			
	Are examination tables height adjustable or of a height that allow a person from a wheelchair to transfer easily?			
	Is floor covering non-slip?			
Toilet & hygiene facilities	Are toilets accessible? • Is there signage indicating toilet is accessible? • Is doorway wide enough to fit wheelchair? • Do doorways slide or swing outwards? • Is there turning space inside the toilet cubicle for a wheelchair? • Are there grab rails near the toilet? • Are bins available for disposal of menstrual hygiene products? • Are hand basins, taps and soap at a height that can be reached from a wheelchair? • If toilet is a squat style toilet is there any adaptive seating device?			
Service provider information	Is health information available in accessible formats, e.g. large print, Braille, sign language interpreters, simplified for people with intellectual disability?			
	Are people with communication difficulties requiring assistance able to access support and/or interpreters?			

ITEM	ELEMENT TO OBSERVE	✓	✕	COMMENTS
Emergency evacuation	Have emergency evacuation plans been designed in consultation with people with disability?			
	Is information about what to do in an emergency accessible to all?			
	Are emergency evacuation routes clearly signed and in Braille for people with vision impairments?			
	Are emergency warning systems implemented using a number of formats, e.g. flags or lights, sirens, large print for people with vision and hearing impairments?			
	Have people responsible for emergency responses had training in providing additional assistance for people with disability during an emergency?			
	Are emergency exits clear from obstacles?			
	Are escape routes accessible for people with a mobility impairment or vision impairment?			
	Are assembly points accessible for people with mobility impairments?			

Date Completed: _____

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MODULE 4
COMMUNICATION BARRIERS – PROVIDING DISABILITY-INCLUSIVE HEALTH INFORMATION

KEY MESSAGES

about providing inclusive health information

People with **disability** have less access to health information and **lower levels of knowledge** about their health and the health services available to them, compared with other people.

Addressing **communication barriers** and providing **inclusive health information** are key to improving access to health services for people with disability.

People who have disabilities that affect their hearing, speaking, reading, writing or understanding, and who communicate differently from people who do not have these disabilities, commonly report communication barriers to accessing health information.

However, **all people with disability** can experience **barriers to accessing health information** when others have **negative attitudes** about their health and disability and limited awareness of their health needs and rights.

People with disability experience barriers to information provided during interactions with health service staff, including when making an appointment, waiting to be seen by a health worker and during a health appointment.

Health promotion materials are rarely inclusive of people with disability. They rarely include positive images of, or information specific to, people with disability, and are often provided in formats inaccessible to people with different types of disability.

Article 9 of the Convention on the Rights of Persons with Disabilities requires that appropriate and high-quality health information be provided in accessible formats for people with disability.

People with different types of impairment may require different materials to be adapted in different ways. Many adaptations cost nothing or very little to put in place. Practice notes provide advice for communicating health information to people with different types of impairment.

People with disability can help to identify barriers to health information at your health service, and can help to develop accessible health information materials for people with disability.

The **"Information accessibility audit for providing inclusive health information to people with disability" checklist** can also assist you to identify and address communication barriers to accessing health information at your health service.

4.1 WHAT ARE COMMUNICATION BARRIERS TO HEALTH INFORMATION AND SERVICE PROVISION?

Communication barriers are commonly experienced by people who have disabilities that affect their hearing, speaking, reading, writing or understanding, and who use different ways to communicate than people who do not have these disabilities *(1).* For example, people with impairments in vision, hearing, intellect and cognition commonly report experiencing communication barriers to accessing a range of services, including health services.

People with disability have the same rights to access health information and services as people without disability. Article 9 of the CRPD requires that appropriate and high-quality health information is provided in accessible formats to people with disability *(2).* Promoting health literacy is also important for empowering people with disability to improve health outcomes *(3).* However, it is well established that people with disability across all settings have less access to information about health, health services and their health rights and needs, than people without disability *(4–8).*

Communication barriers experienced by people with disability can reduce demand for health services, and result in greater unmet health needs, among people with disability *(9,10)*. However, many barriers to health information and to communicating with health service providers can be addressed at little or no cost, especially if people with disability are involved in identifying communication barriers and developing solutions to provide accessible and inclusive health information.

What contributes to communication barriers?

A range of factors contributes to communication barriers experienced by people with disability when accessing health information and services. When health workers have inaccurate ideas about the health needs and rights of people with disability, such as the false belief that people with disability are not sexually active or do not have the same health needs as people without disability, they tend not to offer important health information. Many people with disability have had limited opportunities to attend school and therefore have not had access to health education programmes provided by schools, and may not be able to read written health information provided at health facilities. Low levels of health knowledge among the family members and carers of people with disability can result in people with disability not receiving any health information, or being provided with health information in inaccessible formats *(4,6,7,11–13).*

People with disability are also often excluded (whether intentionally or unintentionally) from research that provides the evidence base for health promotion campaigns *(14).* Consequently, health promotion materials are rarely provided in accessible formats to people with disability. Around the world, there are many examples of health promotion campaigns that have excluded people with disability (including campaigns that aim to reduce rates of HIV, sexually transmitted infections and NCDs).

What are common communication barriers experienced by people with disability?

People with different types of impairment frequently experience communication barriers to receiving information about their health, the health services available to them and preventive health programmes. People with disability report experiencing communication barriers during one-on-one interactions with health service staff (including health workers and administrative staff) and not being able to access information provided in health promotion materials.

Communication barriers experienced by people with disability during one-on-one interactions with health service staff include:

- Being talked down to or patronized by staff at the reception area when arriving at the health service, and by health workers during health appointments *(15).*
- Not being listened to by health-care providers *(15).*
- Being ignored by health workers, who do not talk directly to the person with disability but only talk to the person accompanying them *(15).*
- Being given inadequate explanations of either their health condition or of upcoming procedures *(15).* Women with disability report not knowing what was being done to them during physical examinations by health workers *(7).*
- Written information not being provided in accessible formats. People who are blind or vision impaired report not being able to receive information about appointment times, prescriptions and instructions for medications, labels on medication bottles, and packaging not made available in accessible formats (for example, in Braille or large print) *(13).*
- Verbal information not being provided in accessible formats. People with hearing impairment report limited availability of sign language interpreters during appointments and verbal information not being provided in alternative formats. For example, a Kenyan study found that most HIV testing and counselling services do not offer counselling using sign language *(8).*

Barriers to information provided during health promotion campaigns include:

- *Inaccessible formats:* Many health promotion campaigns provide information in either one or a limited number of formats – for example, only through posters and brochures or only through television and radio campaigns. While posters and brochures might be accessible to people with some types of impairment (e.g. people who are deaf or hard of hearing, people with mobility impairments), people who are blind or have a vision impairment cannot read written health information unless it is provided in Braille or large print *(8).* People with a hearing impairment cannot pick up information broadcast via radio campaigns. Complex health promotion messages can be confusing to people with intellectual disabilities or to people with disability who have not attended school *(6).*
- *Exclusion of people with disability from health promotion materials:* Health information usually does not include information specifically relevant to people with disability. Images of people with disability are rarely included on posters or brochures aimed at the general community. An Australian study found that women with disability were not targeted adequately by community organizations or health services providing health promotion information about breast and cervical cancer screening *(16).*

4.2 WHAT ARE SOME OF THE KEY STRATEGIES FOR PROVIDING DISABILITY-INCLUSIVE HEALTH INFORMATION?

Involve people with disability in identifying and addressing communication barriers to health information and services

Involve people with different types of impairment in auditing how your health service communicates information to people with disability. This could involve reviewing health information materials to ensure that they are provided in a range of **accessible formats**; that they include **images and content** inclusive of, and relevant to, people with disability; and that health information is reaching people with disability. People with disability can also pilot or test health information resources for accessibility once developed, distribute health information resources to other people with disability, and provide advice about strategies to increase demand for health services by people with disability and their partners and carers *(16)*.

Communicate health information to partners, families and carers of people with disability

Family members and carers of people with disability play a key role in influencing access to health information for people with disability. Family members and carers are often the primary source of health information for people with disability, act as "gatekeepers" between people with disability and health services, interpret for or communicate with people with disability, and make decisions on behalf of people with disability who struggle (or who are perceived to struggle) to communicate with health service providers *(4,6,7,17)*. However, studies show that the partners, families and carers of people with disability also often have low rates of health literacy and limited knowledge about the health needs and rights of people with disability (including the right to access health services).

Ensuring that health information also reaches the carers and family members of people with disability can help increase demand for health services and improve health outcomes among people with disability.

Provide "patient-centred care" during one-on-one interactions with people with disability

Many people with disability report negative interactions with health service staff when accessing health services. Providing patient-centred care for people with disability by focusing on the person – not their disability – can help to improve communication of health information to people with disability.

Key principles for providing patient-centred care for people with disability include:

Establishing rapport with the person with a disability:

- Listen to the person, ask them why they have come and how you can help (do not assume the reason for their visit is because of their disability – focus on the information and issue they present with rather than their disability) *(18,19).*
- Check with the person and their support person about how they would like information to be presented *(20).*
- Communicate directly with the person, not their carer (e.g. look at the person with disability when speaking, even when using an interpreter).
- Acknowledge the person's expertise in managing their own disability. People with disability often understand their own health problems better than anyone else and can make decisions about their own treatment *(18).*

Ensuring that the person with a disability understands the information being communicated:

- Ask the person or their companion to explain their understanding of what you have said to check it is clear and understood *(20).*
- Be patient. Sometimes communication is slower when you are not familiar with communicating with someone with a disability.

Obtaining informed consent from person with disability:

- Assume that the person with a disability can provide consent, unless there is evidence to indicate otherwise (this includes people with intellectual disability who are sometimes assumed to be unable to provide consent, even when they can) *(19).*
- Use an adapted consent process to check whether a person with intellectual/cognitive impairment understands the information provided and can retain and use it to make decisions. This may involve asking the person about different elements of the information provided to assess their capacity to provide informed consent to a treatment or procedure.
- Ensure that the person with disability has all the necessary information (in an accessible format) to voluntarily consent to a specific health treatment or procedure, including an explanation of the treatment; information about alternatives, benefits and risks of the treatment; and knowledge about the consequences of no treatment *(19).*

Before, during and after physical examinations health workers should:

- Explain accurately, directly and in everyday language exactly what is being done *(7,21)*.
- Undertake a comprehensive assessment *(16)*.
- Describe the examination, ensure the safety of the person with disability during the examination and give immediate feedback about the examination *(16)*.

Include people with disability in health promotion campaigns

- Health promotion campaigns that aim to prevent further disability and promote good health and well-being are important to improve the quality of life and health of people with disability *(22)*. However, people with disability are generally excluded from health promotion campaigns, which can have a negative impact on their health. For example, an increasing number of studies from around the world highlight the relationship between the lack of HIV information provided to people with disability and increasing rates of HIV among this population *(23–25)*.
- All health promotion campaigns should be reviewed to ensure that materials are provided in accessible formats for people with different types of impairment (including Braille, large print, radio, television, posters, etc.), include positive images of and/or references to people with disability, and are disseminated through channels that reach people with disability. For example, peer education has been found to be an effective tool for communicating health information to people with disability in many settings *(26,27)*.

4.3 CASE STUDY: INCLUSIVE COMMUNICATION IN EYE HEALTH CARE, INDONESIA

Eye health care is a critical area of health services where disability inclusion is important because eye conditions may lead to disability. Many people with disability also require eye health care unrelated to their primary impairment or disability.

The Cicendo National Eye Hospital in Bandung, Indonesia, has been participating as a major partner in a pilot programme for disability inclusion in eye health care – the Inclusive System for Eye-care (I-SEE) launched in 2014 by the Australian Government's aid programme in partnership with the District Health Office of Bandung and CBM Indonesia.

As part of the pilot, staff of Cicendo National Eye Hospital received disability awareness training from CBM staff and representatives of local DPOs, and building facilities were made more accessible for people with disability. Besides addressing physical accessibility through the use of ramps, low registration desks for wheelchair users, tactile markers to guide the path from the entry to the registration desk and handrails were installed in the facility, Cicendo Hospital has introduced measures to ensure communication is more inclusive of people with disability.

These inclusive communication measures include the use of large-format signage throughout the hospital – for example, numbering of floors, entries, exits and evacuation routes. Written signage is supplemented by signage that uses symbols or diagrams for those who are unable to read written language. There are Braille markings on lift buttons and on signs indicating the different floors of the hospital. At the hospital registration area, patients are called up by number using both visual digital signage and auditory announcements to accommodate those with hearing and vision impairments, respectively. In addition, all staff have been trained to introduce themselves and what they are doing when approaching all patients, but particularly those with vision impairment, so that the patients understand what is happening and are actively involved in their health care.

As a result of these inclusive communication strategies, patients with disability attending Cicendo National Eye Hospital report feeling welcome and having a positive experience in seeking eye health care.

HOW TO PROVIDE DISABILITY-INCLUSIVE HEALTH INFORMATION IN YOUR FACILITY

Information accessibility audit

Auditing how information is provided to people with disability within your health facility is a practical way to identify communication barriers that may undermine access to health information, services and programmes. This allows you to begin to address these barriers and provide inclusive health information to people with disability.

An audit would assess how information about the health service is provided to people with disability. For example, it would determine what people with disability know about the health service, including how to make an appointment and what to expect. It also would look at what people face upon arrival at the health service. Are the signs for the health service clearly marked and easily identifiable? The audit would also determine how information is provided during interactions with health service staff, including reception staff and health-care providers. In addition, it would examine how information is presented in health promotion materials.

Ideally, this audit will be jointly conducted by a member of the service provider leadership team, a member of a local DPO and people with different types of impairment (who may experience different communication barriers). An information accessibility audit can be conducted alongside the physical accessibility audit to assess physical barriers (see Module 3) or as a separate exercise.

Use a checklist or "audit tool" that outlines the elements to observe during the audit of the facility, and that allows you to record your observations and take note of areas for improvement.

A sample checklist is available in the Tools section at the end of this module.

This checklist can be used to audit how your health service provides information to people with different types of impairment. It includes a list of key considerations and recommended actions relating to information provided about the health service during one-on-one interactions before and during health appointments, and those through health promotion materials.

Invite people with different types of impairment and DPO representatives to complete the audit along with health service staff.

Put in place practical strategies for communicating inclusive health information to people with disability

Once an information accessibility audit has been completed and potential barriers to providing inclusive health information to people with different types of impairment have been identified, practical actions and strategies can be implemented to ensure that health information is provided to people with disability in inclusive formats.

At the end of this module, practice notes with practical strategies for communicating health information for people with different types of impairment are provided.

This resource was developed by adapting and combining information from several other resources (listed in the Links and Resources section below). We suggest you also review these resources for additional guidance around identifying communication barriers for people with disability and practical advice on communicating inclusive health information to people with different types of impairment.

Discuss these resources with a local DPO representative to determine the best approaches to providing health information to people with disability in your local community.

LINKS AND RESOURCES

- Inclusion made easy: a quick program guide to disability in development. Part B. Bensheim: CBM International; 2012 (https://www.cbm.org/article/downloads/78851/CBM_Inclusion_Made_Easy_-_complete_guide.pdf).
- Inclusion made easy in eye health programs: disability-inclusive practices for strengthening comprehensive eye care. Bensheim: CBM International; 2012 (https://www.cbm.org/article/downloads/54741/Inclusion_in_Eye_Health_Guide.pdf).
- Maxwell J, Belser JW, David D. A health handbook for women with disabilities. Berkeley: Hesperian Foundation; 2007 (https://www.cds.hawaii.edu/sites/default/files/downloads/resources/womenshealth/HealthHandbookforWomen.pdf).
- Fiduccia BM. Multiplying choices: improving access to reproductive health services for women with disabilities. Berkeley: Berkeley Planning Associates; 1997 (https://wdare.files.wordpress.com/2018/12/report-multiplying-choices-improving-access-to-srh-for-wwd.pdf).
- NSW Cervical Screening Program, Preventative women's health care for women with disabilities. Ryde: Centre for Developmental Disability Studies; 2013 (http://wwda.org.au/wp-content/uploads/2013/12/nswguidelines3.pdf.

CHECKLIST: INFORMATION ACCESSIBILITY AUDIT FOR PROVIDING DISABILITY-INCLUSIVE HEALTH INFORMATION

CONSIDERATIONS	RECOMMENDED ACTIONS	RESPONSES
INFORMATION TO BUILD DEMAND FOR HEALTH SERVICES		
Are people with disability in your community aware of your health services? **Consider whether people with disability are aware of:** **1. Services on offer.** **2. How much an appointment costs and how they can pay (as well as any insurance/concessions available).** **3. How to make an appointment.** **4. What to bring to a health service appointment (identification, medical history, referral letters).** **5. How to contact and find the health service.** **Are people with disability in your community happy to attend your health service? Some people with disability may be afraid or distrustful of health services due to previous negative experiences.**	Contact local DPOs and rehabilitation services to promote your health service to people with disability in your community. Develop materials for distribution that promote your health service to people with disability for distribution: • Use a variety of formats (e.g. written posters, pamphlets, large print and Braille; verbal – radio and TV announcements, word of mouth). • Include positive representations of people with disability as part of the general community. • Consider a range of dissemination channels – DPOs, schools, religious leaders, families, carers and rehabilitation workers.	
ARRIVAL AT THE HEALTH SERVICE		
Can people with disability find your health service? Is the location of the health service clearly signposted? **Can reception staff provide appropriate information about the appointment fee/wait time/required paperwork to be completed to people with different types of impairment?**	As part of an accessibility walk-through, review whether all signs relating to the location of your health service can be understood by people with different types of impairment. Use clear images with good colour contrast on signs. Organize training for reception staff on: • How to communicate with people with different types of impairment (consider including as part of disability inclusion awareness training for all staff). • Using basic local sign language.	

CONSIDERATIONS	RECOMMENDED ACTIONS	RESPONSES
DURING HEALTH APPOINTMENTS		
Consider whether people with different types of impairment can understand information about: • **What the health appointment involves.** • **Providing informed consent.** • **Their own health needs and issues.** • **Relevant health promotion and preventive health information.** • **What a treatment or physical examination involves.** • **How to stop any treatment or physical examination if they are uncomfortable.** • **Providing immediate feedback on the treatment or examination.** • **What the follow-up course of action is/any next steps in managing health issues.** • **Instructions/prescriptions for any medications/ongoing treatment.** • **Requirements for any follow-up appointments.**	Review how health information is communicated to people with disability during appointments (consider written and verbal information). For example, can people with vision impairment access all health information that is normally written down? Can people who are deaf access all health information that is normally communicated verbally? Based on this review, consider and be prepared to source alternative communication options. Discuss options and gaps in provision of information with DPOs. Organize training for health workers on: • How to identify preferred methods of communication for people with disability. • Using different methods to communicate health information to people with different types of impairment.	
HEALTH PROMOTION CAMPAIGNS		
Is information provided during health promotion campaigns inclusive of people with disability? **Consider:** • **Can people with disability access health promotion materials (are they provided in a range of accessible formats)?** • **Do health promotion materials feature positive representations of people with disability as part of the general community?**	Review health promotion materials for the following: • Positive visual representation and inclusion of people with disability (e.g. are positive images of, and language regarding, people with disability included?) • Accessibility of materials to people with different types of impairment (e.g. people who are blind and vision impaired, people who are deaf and hard of hearing, people with intellectual disability). • Channels of distribution for health promotion materials – are they reaching people with disability? (e.g. are health promotion materials disseminated by DPOs, outreach health workers, rehabilitation centres, churches, schools attended by children with disability, through peer education programmes?)	

CONSIDERATIONS	RECOMMENDED ACTIONS	RESPONSES
HEALTH PROMOTION CAMPAIGNS (CON'T)		
	Review all health promotion campaigns addressing health issues across the life course, for example: • Vaccinations and early child health • Adolescent health and SRH (including access to contraception) • Maternal and neonatal health • Prevention of NCDs • Nutrition.	

PRACTICE NOTE: PRACTICAL STRATEGIES FOR COMMUNICATING INCLUSIVE HEALTH INFORMATION TO PEOPLE WITH DIFFERENT TYPES OF IMPAIRMENT

Practical strategies for communicating inclusive health information: PEOPLE WITH HEARING IMPAIRMENT

Deafness and other hearing impairments can vary greatly in the extent to which they affect a person's health-care needs. People who are deaf or hard of hearing may rely on professional sign language interpreters, an interpreter who is a family member or friend, written notes, real-time transcriptions or TDDs (telecommunication devices for the deaf) and hearing aids.

Facility-level policies and practices *(20)*	• Engage a professional sign language interpreter. Consider nominating a day each month where consultations are scheduled for people who are deaf. • Where sign language interpreting is not available, provide notepaper and a pen for the person to communicate through writing. • Use gestures to supplement communication. • Ensure that at least one staff member knows the sign language used among the local deaf community (ask local DPOs for advice on training). • Obtain a local sign language dictionary if one is available; ensure health service staff are familiar with the dictionary and key words.
During one-on-one interactions *(18)*	• Ask the person (through their interpreter/assistant if necessary) to indicate their preferred form of communication. • Make sure you have the individual's attention before speaking. If he or she is not facing you, touch them gently on the shoulder. • Do not shout or exaggerate your speech. • Look directly at the person, and do not cover your mouth with anything. • Offer explanations via an oral or sign language interpreter or through lip-reading, depending on the person's preference and abilities. • Allow for adequate time for interpretation to take place and speak slowly. • Universal signs for many medical terms are limited and words may need to be spelled out by the interpreter for the person to understand. Have a list of terminology with definitions available for the person and their interpreter so they can become familiar with the terms. • Use diagrams or three-dimensional models to explain health issues.
During a physical examination *(19)*	• Supply the person with a mirror so that they can see what is happening. • Raise the head of the examination table (in particular, during gynaecological examinations with women who are deaf or hard of hearing). • Make sure the person can always see the health practitioner's face. • When demonstrating the use of various examination methods, different procedures or health issues, allow time for the person to focus on the speaker or interpreter to understand the words first, then on the demonstration of how particular methods are used (e.g. do not talk and demonstrate at the same time).
Health promotion campaigns *(25)*	• Use sign language interpreters to communicate health promotion messages. • Use visual images and real photographs of people who are deaf signing to each other.

Practical strategies for communicating inclusive health information: PEOPLE WHO ARE BLIND OR VISION IMPAIRED

People with vision impairments vary in their degree of vision. People who are blind or vision impaired may use auxiliary aids and services such as information written in Braille or large print, or a text-to-speech converter on their computer or mobile phone.

During one-on-one interactions *(28)*	• Say your name when introducing yourself. • Use the name of the person with low vision to ensure they are aware that you are talking to them. • Face and talk to the person with the vision impairment and not just to a family member or carer who may be with them. • Identify the room where the person is if they cannot see sufficiently to recognize surroundings. State whether they are in a waiting room or a small consultation room. Offer to describe the environment. • Identify others that are involved in the consultation. • Read any written information that is not accessible, including the risks and rights related to treatment. • Be specific in giving directions. • Do not leave the person alone in the centre of a room. Make sure they can touch a table, chair or wall to maintain orientation to their surroundings. **When guiding a person who is vision impaired:** • Always ask the person if they would like to be guided and where they would like to go. • Offer your arm for the person to hold just above the elbow. This will allow them to walk slightly behind you, following you as you turn or step up or down. • Walk at an average pace. • Mention when you are arriving at a turn, step or obstacle.
During a physical examination *(19)*	• Provide verbal descriptions of actions and visual information to the person during the examination. • Use three-dimensional models and make sure that the person is correctly oriented to the model. • Orient the person to the examination room so they know where furniture and equipment are located, where to place their belongings and sit, and how to position themselves on the examination table. • During examinations, talk to the person throughout and explain each procedure before touching any part of their body. • Make sure that written information (in particular, consent forms, medication labelling and instructions) is available in accessible formats, including Braille and large print.
Health promotion campaigns *(25)*	• Formats preferred by people with vision impairments include: large, clear print; Braille; audio recordings; spoken announcements; electronic versions of documents; accessible websites; and telephone services. • Use tactile-oriented approaches in peer education sessions during health promotion for people with vision impairment. For example, during condom demonstrations, allow blind people to feel a condom and put it on a model of a penis.

Practical strategies for communicating inclusive health information: PEOPLE WITH COGNITIVE OR INTELLECTUAL IMPAIRMENTS

Many people with intellectual/cognitive impairments are very capable of participating in health decision-making; however, some people will need additional support or reasonable accommodations to ensure informed consent and effective service delivery.

Aids and auxiliaries *(19)*	• Tools might include scheduling extra time during the appointment and working with communication assistants/ advocates. Health information can also be presented using models, pictures and/or videos.
Key actions *(16)*	• Where there is uncertainty about a person's communication ability, proceed on the assumption of competence – speak directly to the person and adjust the communication level as necessary.
During one-on-one interactions *(16)*	• Be patient and polite – communication may take more time than usual. Wait 10 seconds before expecting a response. • Be aware that the person may have difficulty speaking, but they may still understand what you say. • Take time to get to know how the person communicates – find out if they can indicate yes or no before asking questions. • Let the person know that you have understood them; ask them to repeat words that you have not understood. Never pretend to understand. • Make use of the person's communication aids. • If the person is having difficulty, talk about one idea at a time using simple words and short sentences. • Supplement communication with signs, gestures and facial expressions. • Be prepared for silences and pauses in the conversation. • Use repetition to reinforce a message when necessary and to check that the person has understood. • Begin with simple language while exploring comprehension and the need for explanation. • Repeat information as many times as is necessary. • Use plain language, but accurate terms, for body parts – if the person uses their own terms, it might be helpful to clarify meaning and match their language.
During a physical examination *(19)*	• People with cognitive impairments may have vastly different communication needs – some might be comfortable and need very little extra explanation, while others might be anxious or need more time. If you are aware that the person is very anxious or has had a previous negative experience, non-threatening physical contact may ease tension and establish communication.
Health promotion campaigns	• Invest in the development of communication materials for people with intellectual disabilities that use key words and visual supports (or contextualize and reproduce those already available). • Drawings and illustrations that focus on health issues should be provided for people with intellectually disability.

Practical strategies for communicating inclusive health information: PEOPLE WITH MOBILITY IMPAIRMENTS

Do not assume that a person with a physical impairment has difficulties in learning or understanding. However, because of reduced access to schools and the outside community, be aware that the person may have a lower level of health knowledge and awareness.

Key actions *(18)*	• If possible, sit so that you are at eye level with the person. • Do not move any crutches, sticks, walkers or wheelchairs without the person's permission or without arranging for their return. • If the person is a wheelchair user, do not lean on or touch their wheelchair without permission.
During a physical examination	• Ask if the person needs assistance with positioning or transfers during physical examinations.
Health promotion campaigns	• People with mobility impairments may have trouble attending meetings, workshops or information sessions due to physical barriers associated with the venue. • Ensure that venues are physically accessible to people with mobility impairments.

Practical strategies for communicating inclusive health information: PEOPLE WHO HAVE TROUBLE SPEAKING

Even though their speech may be slow or difficult to understand, this does not mean a person with a communication impairment has any difficulties learning or understanding.

Key actions *(18)*	• Ask the person to repeat something you do not understand. • Ask questions the person can answer by indicating yes or no. • Let the person take as much time as they need to explain their health problem. Be patient. • Train health workers to communicate with people who have problems speaking clearly. • It might be helpful to provide pen and paper, or gadgets to write or type on (tablet/phone/computer). • Communication aids or boards with letters, words or images may also be helpful.

WHO

MODULE 5
DISABILITY-INCLUSIVE HEALTH INFORMATION SYSTEMS FOR PLANNING, MONITORING AND EVALUATION

KEY MESSAGES

about disability-inclusive health information systems for planning, monitoring and evaluation

Health information systems must include collection of information about disability. A lack of data about people with disability results in their health needs being overlooked.

Collecting data on disability allows the data to be disaggregated about disability.

Collection of disability data can be integrated into existing systems.

Ensure all staff understand the importance of collecting disability data

DATA THAT CAN BE DISAGGREGATED BY DISABILITY IS NECESSARY:

- to understand the **health needs** of people with disability;
- to **compare** the health needs of people with disability to those without disability to understand how they may be the same or different; and
- to learn how to **better plan for and address** the health needs of people with disability.

Identification of disability is best done by asking questions about function and participation.

Disability data enable monitoring and evaluation of disability inclusion with health services.

There are different tools and methods available for collecting data, depending on what the data are needed for.

Actively involve people with disability in data collection, planning, monitoring and evaluation activities.

5.1 DISABILITY-INCLUSIVE HEALTH MANAGEMENT INFORMATION SYSTEMS

Accurate, timely and accessible health-care data – including data that relate to the needs and experiences of people with disability – play a vital role in the planning, development and maintenance of a quality health-care service. As such, health services must take actions to mainstream disability-inclusive data collection into their health management information systems.

What is a health management information system (HMIS)?

An HMIS – sometimes called a routine health information system (RHIS) – is a facility-based data collection system that collects routine health information used to support the planning, management and decision-making of health facilities. The data collected provide a picture of the health status of the patient/client population, the health services provided, and the resources needed to provide services, and may include the number, type and age of patients, types of conditions treated, treatments provided, and referrals made. Sources of this data include individual patient health or medical records, records of services delivered and human resources, and equipment and supply records, and are usually collected by health-care providers in the course of their work and through routine health facility surveys or audits *(1).*

Why include disability data in HMIS?

Data about disability are often lacking and result in people with disability being excluded from health services and activities, and their health needs being overlooked. The planning, running and monitoring of a disability-inclusive health service require intentionally collecting data relating to people with disability within the HMIS. Collecting data on disability allows the data to be "disaggregated by disability", or broken down into subgroups, to compare data among these subgroups. If data are collected on the age, gender and disability of people attending a health facility, for example, then it is possible to make comparisons between men, women, boys and girls with and without disability, and identify similarities and differences in patterns of these groups in accessing health care at that facility.

Data that can be disaggregated by disability are necessary in order:

- to understand the health needs of people with disability;
- to compare the health needs of people with disability to those without disability to understand how they may be the same or different; and
- to learn how to better address the health needs of people with disability.

How to ensure a disability-inclusive HMIS

1. An effective HMIS

All health-care facilities collect information for a range of internal and external reporting purposes; therefore, disability data collection should be integrated within existing health service data and information collection processes. These data can also be combined with data collected through other mechanisms (e.g. national survey data, national census data, ministry of health service-provision assessment tools, registers held by DPOs).

Developing effective and efficient data collection processes is vital for ensuring quality data that will be useful for monitoring, evaluation and reporting purposes. Whether collecting data using a paper-based or electronic computer-based system, data must be accurate, reliable and organized in such a way that they are easily understood and accessible to those who need them *(2).*

Data collected should at a minimum include:

Demographic data – age, gender, place of residence
Clinical data – presenting health condition, previous/ongoing health conditions, tests/treatments/services received, any referrals made
Financial data – sources of payment, e.g. health insurance, direct payment.

General tips for ensuring quality data collection *(2)*

REVIEW OF DATA COLLECTION FORMS

- Review data collection forms to ensure minimum data are being collected, and to assess whether information that is not useful is being collected; redesign forms as required.
- Design forms to collect data in a logical sequence.
- Maintain simplicity of design.

STAFF REQUIREMENTS AND TRAINING

- Identify staff responsible for data collection.
- Train staff on the requirements and importance of accurate data collection. This should include educating them about why data quality is important and the consequences of poor-quality data collection.
- Train staff in processes of data collection and recording for your HMIS.
- Train staff in inclusive communication strategies (see Module 4).

2. Collection of disability-specific information is included in the HMIS

Questions about disability must be included in the HMIS, such as in the patient registration system; however, there are considerations about how to do this.

IDENTIFYING PEOPLE WITH DISABILITY

Identification of disability is usually based on self-reporting. In order to break down the data you collect about the people using your service into a group of people reporting that they experience disability and a group of people reporting that they do not, you need a way to record whether people report having a disability.

IDENTIFYING DISABILITY

- Identifies people who might have a disability or are at risk of experiencing disability.
- Typically takes a few quick questions based on the most common types of impairment.
- Can be undertaken by administrative or project staff with basic training.
- Allows data for monitoring and evaluation to be disaggregated by disability.
- Identifies people with disability to ensure inclusion in health activities and referral to services.

HOW TO ASK ABOUT DISABILITY

It is best to avoid simply asking "Do you have a disability?"

Asking in this way can lead to inaccurate and unreliable responses due to a varied understanding of what "disability" means, potential stigma associated with disability and therefore a reluctance to disclose this information, or people with impairments not identifying as having a "disability" *(3).*

In her review of access to health and rehabilitation services for people with disability in Timor-Leste, McCoy *(4)* states that having a clear definition of disability is a key factor in determining what and how disability-inclusive information is collected and its reliability. She recommends WHO's ICF as the best available tool to help understand disability and inform classification systems.

RECAP FROM MODULE 1:

The ICF considers disability to be an "umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)"*(5).*

Disability = health condition + environmental and contextual factors

Therefore, rather than asking about "disability", ask questions about difficulties with functioning (e.g. walking, seeing, communicating, remembering, etc.) and functional limitations in everyday activities (e.g. eating, bathing, using transport, working). This has been found to be a more effective and sensitive way of identifying disability.

Questions may include *(6)*:

Do you have any difficulty walking or moving any part of your body?
Do you have any difficulty seeing?
Do you have any difficulty hearing?
Do you have any difficulty speaking or communicating with others?
Do you have any difficulty remembering or concentrating?
Do you have any difficulty doing any of your usual activities because of your difficulty with (moving/seeing/hearing/communicating/remembering/concentrating)?

It may also be useful to include a question about the use of assistive products to identify functional impairments. For example:

"Do you use any equipment to assist you with daily activities – such as walking, bathing, seeing?"

Questions about functioning are different from a clinical assessment and diagnosis, and are designed simply to identify those who have or are at risk of disability, and to ensure that this is included in data recording.

5.2 DISABILITY INCLUSION IN PLANNING, MONITORING AND EVALUATION

Implementing a disability-inclusive health service requires careful planning, monitoring and evaluation. Ideally, disability inclusion occurs within the planning of all mainstream health services and activities, but planning for specific activities to target and improve disability inclusion within the health service may also be necessary.

Disability inclusion must also be incorporated into health service monitoring and evaluation systems to monitor the inclusivity of mainstream activities and also to monitor and evaluate those strategies and activities specifically designed to increase disability inclusion.

Planning in a disability-inclusive health service

Planning for a disability-inclusive health service involves first collecting data and information to understand the current situation. Audit tools and checklists as outlined in the previous modules and other sources of information can be used to conduct a baseline or situation analysis of your health service that will help to identify priority areas for improvement and facilitate planning.

All areas of health services should be considered when conducting a situation analysis of disability inclusion, including:

- demand for services and the health needs of people with disability
- the collection and integration of disability disaggregated data into HMIS
- service-provider capacity to provide inclusive health services (see Module 2)
- physical accessibility of health services (see Module 3)
- inclusive health messaging and communication (see Module 4)
- inclusive health within rehabilitation (see Module 6)
- disability-inclusive health in emergencies (see Module 7).

Using the information from the situation analysis, it is possible to begin planning what is required to deliver a more disability-inclusive health service, and to identify relevant objectives and strategies to achieve this. Activities and resources, including budgets, are then decided upon and allocated in order to achieve the objectives outlined in the planning.

CONSIDERATIONS FOR DISABILITY-INCLUSIVE PLANNING:

- Ensure the participation of people with disability in leadership and decision-making when planning for health services.
- Apply principles of universal design for any infrastructure planning (see Module 3).
- Ensure that any planned services, activities or facilities are accessible and appropriate for people with disability and other vulnerable groups – for example, pregnant women, older people.
- Ensure disability inclusion is specifically budgeted for within service budgets.

Monitoring in a disability-inclusive health service

Monitoring keeps track of your activities and ensures that the strategies designed to increase disability-inclusive health care are achieving what they set out to do. This is done through regularly collecting and analysing information about those activities or strategies. Monitoring requires effective systems for the collection of information or data, including HMIS as described above or other more in-depth methods as described below.

COLLECTING MORE IN-DEPTH DATA ON PEOPLE WITH DISABILITY

It may be useful at times to collect more in-depth data about the experiences of people with disability in utilizing your health services to examine a particular issue or trend more closely. There are many different tools and methods available to do this – both qualitative and quantitative – depending on what you wish to find out.

These sources can help:

EXISTING DATA SOURCES – existing data about disability may be useful in understanding your local context and population. These include, for example, census data, government survey results, nongovernmental organization surveys or reports, education department records and DPO registers. Care should be taken with regard to estimates of disability prevalence from existing data sources, as disability is frequently under-reported in mainstream data collection.

HOUSEHOLD SURVEYS – surveys allow the opportunity to measure key aspects of inclusion, such as equitable access to services both among households and among individuals within a household. The Model Disability Survey (MDS) is a general population survey designed by WHO to provide detailed information about how people with and without disability conduct their lives, and the difficulties they encounter, regardless of any underlying health condition or impairment. The Rapid Assessment of Disability (RAD) is a different survey tool that has questions designed to measure and compare individuals' inclusion and participation across different domains, including health care. The Washington Group Short Set of Questions is another tool that may be used in surveys (e.g. of service utilization) to identify people with functional limitation and to compare the outcomes for people with and without functional limitation.

KEY INFORMANT INTERVIEWS & FOCUS GROUP DISCUSSIONS – interviews and focus group discussions provide an opportunity to obtain detailed information about the experiences and opinions of people with and without disability. These may be used to gain an understanding of patterns that you have found from analysis of other data, and to identify barriers or enablers to accessing health-care services. Be mindful of ensuring that key informant interviews and focus groups are inclusive of people with different types of impairment, and take into consideration physical accessibility and the use of inclusive communication strategies.

PARTICIPATORY METHODS – participatory approaches involve local community members playing an active role by sharing their experiences, knowledge and opinions to inform decision-making. These approaches include a range of tools, methods, attitudes and behaviour, and use accessible visual and verbal techniques with the aim of bringing together diverse perspectives to promote discussion, reflection and learning. They may be particularly useful in monitoring and evaluating services from the perspective of people with disability, their families and their carers.

COLLECTING DATA ABOUT CHILDREN WITH DISABILITY

Identifying children with disability and collecting data about them presents some added complexities. Impairments may not be evident early in a child's development, and questions are often directed to parents who may mediate responses or may not identify, or wish to identify, that their child has an impairment. Children with disability are a particularly vulnerable group, and at risk of prejudice and discrimination. It is therefore vital that efforts are made to include them in data collection. Staff may require training on how to ask about childhood disability sensitively – for example, by asking about any concerns for a child's functioning and development rather than asking about "disability".

Some tools and methods have been developed to collect data about the experiences of boys and girls with disability. The Washington Group and the United Nations Children's Fund (UNICEF) have developed the *Module on Child Functioning and Disability* for use with children 0–17 years. In addition, a *Guide to Inclusive Practice for Research with Children with Disability (6)* presents a set of resources specifically for supporting the involvement of children with disability in research as well as service development and monitoring and evaluation activities.

STEPS OF MONITORING – ADAPTED FROM JENKIN ET AL., 2015 *(7)*:

1. *Setting indicators:* Indicators should have been set during the planning phase. For each activity that you identify to ensure disability inclusion, develop some indicators to measure progress in these activities (see Practice Note on page 82).
2. *Deciding how to collect information:* Decide how you will collect information to monitor your activities. These may be from existing data sources such as health information system (HIS) or may require you to set up new systems for that particular activity.
3. *Collecting and recording information:* Once you have decided how you will collect information, systems should be put in place to collect and record information. It is important that these systems are as simple as possible. All relevant staff should receive training on how to follow and use these systems, e.g. staff will need to be trained on how to use data collection forms correctly. Decide on a schedule for information collection – these may be more or less frequent depending on the needs of the programme or activity.
4. *Analysing information:* Health service managers should look closely at the information to observe the progress of the programme activities and identify any potential problems.
5. *Reporting and sharing information:* Reporting and sharing the results of monitoring with key stakeholders show that the programme is transparent and accountable. A monitoring report should include information on the activity or work area being reported on, activities planned for the period and completed, progress towards the programme outcomes, budgeted versus actual expenditure, achievements, constraints/problems and action taken or recommended, and lessons learned. Reporting requirements will vary depending on your service's requirements.

Evaluation in a disability-inclusive health service

Strategies to improve disability-inclusive health care should be periodically evaluated for effectiveness and revised accordingly. Information and data collected through the monitoring activities are used to evaluate the success and impact of strategies against the original objectives identified during planning. It is important to find out both what did and did not work well so that this can be learned from and used for future planning. While monitoring occurs continuously, evaluation occurs at specific points in time (e.g. at the end of an activity, after six months of implementation of a strategy).

STEPS OF EVALUATION – ADAPTED FROM WHO COMMUNITY-BASED REHABILITATION GUIDELINES *(8)*

1. *Determine the purpose of the evaluation:* Decide on what you want to know from the evaluation and the questions you want to answer. For example, has access to services for people with disability improved? What has contributed to this? What have been the barriers?
2. *Collect information:* Determine where, how and when to obtain information to answer the questions identified in the purpose of the evaluation. Information may come from a variety of sources – for example, HIS data, surveys, focus group discussions.
3. *Analyse the information:* Analyse the information to identify trends and patterns and to attempt to answer the evaluation questions. Different types of information are analysed in different ways. Quantitative data are analysed using statistical methods, whereas qualitative data (e.g. from interviews or focus group discussions) are analysed by organizing the information into key themes or categories.
4. *Make recommendations:* After analysing the information, it is possible to draw conclusions and make recommendations based on these. These findings and recommendations should be shared with relevant stakeholders and used to influence decision-making and future planning for the ongoing process of ensuring disability inclusion.

CONSIDERATIONS FOR MONITORING & EVALUATION IN A DISABILITY-INCLUSIVE HEALTH SERVICE:

- Ensure data collected are disaggregated by disability type, age and gender.
- Ensure staff understand the importance of collecting data and adhere to protocols for collecting data for all people attending the service.
- Involve people with disability or a DPO representative to participate in monitoring and evaluation activities – ensure the perspectives of people with disability are included.
- Engage people with disability and/or local DPOs for input to overcome any barriers to inclusion in monitoring activities – seek their input for training in disability-inclusive data collection.
- Monitor whether disability-specific budget lines being spent are according to those outlined in the plan.

HOW TO IMPLEMENT DISABILITY-INCLUSIVE HEALTH INFORMATION SYSTEMS IN YOUR FACILITY

1. Review existing HMIS within your health facility to understand what data are already being collected and how.

- Is there an HMIS in place for collecting information?
- Is disability recorded in the HMIS?
- If so, how, where and when?
- Are disaggregated data used? If so, how? For example, how are disaggregated data used in planning and evaluation of services?

2. For guidance on establishing quality data collection systems, refer to the WHO Guide on Improving Data Quality in the list of resources below.

3. Making data collection disability inclusive

- Integrate with existing data collection mechanisms (where available).
- Decide on questions to be included in registration systems that ask about functioning and use of/access to assistive technology.
- Collect data on the specific needs and issues impacting people with disabilities.
- Align data collection with Ministry of Health disability data where applicable so that information can be integrated into national health information systems.
- Involve people with disabilities as active participants:
  - At all stages of data collection – designing, adapting and implementing.
  - Include people with disabilities (or DPO representatives) on advisory committees.
  - Ensure representation of men and women with disabilities, and people with various impairments.
- Adapt data collection methods and tools to ensure they are accessible for all:
  - Use inclusive communication strategies (see Module 4).
  - Be mindful of ensuring confidentiality when collecting data – if using a family member to assist be sure to gain the consent first of the person with disability.
- Raise awareness among staff of the need for accurate data on disability.
  - Address any attitudinal barriers (see Module 2).

4. Use data collected for responding to the needs of people with disability

- Analyse data, disaggregated by disability, age and gender.
- Look for any differences in outcomes and health services provision for people with disability compared to people without disability.
- Use data for reporting on patterns of service provision and outcomes.

5. Key steps to disability inclusion in planning, monitoring and evaluation

- Conduct a **situation analysis** of the current inclusivity of your health service.
  - Start with a quick overview using a checklist that examines all areas of the health service. See Checklist on the following pages as an example.
  - Conduct a more thorough assessment using tools from earlier modules of those areas identified as not yet achieving disability inclusion.
- Develop an inclusive **action plan** targeting priority areas as identified from your situation analysis. List down these areas and identify objectives for each and key activities to improve disability inclusion.
- **Budget** for disability inclusion.
- Develop monitoring and evaluation plans for activities to improve disability inclusion.
- Ensure disability inclusion aspects are also embedded in monitoring and evaluation of all general health programmes and activities at your health service.

TOOLS

Some tools are provided on the following pages that may be helpful to ensure disability inclusion in planning, monitoring and evaluation in your health service.

- **Checklist:** Assessment of current programming for disability inclusion
- **Practice note:** Disability-sensitive indicators for the health services, including rehabilitation
- **Practice note:** Information for disability-inclusive planning, monitoring and evaluation.

LINKS AND RESOURCES

- Jenkin E, Wilson E, Murfitt K, Clarke M, Campain R, Stockman L. Inclusive practice for research with children with disability: a guide. Melbourne: Deakin University; 2015 (http://www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice- Research_ACCESSIBLE.pdf).
- Improving data quality: a guide for developing countries. Manila: WHO Regional Office for the Western Pacific; 2003 (http://iris.wpro.who.int/bitstream/handle/10665.1/5421/9290610506_eng.pdf).
- Information and guidance on using the WHO Model Disability Survey (MDS) can be found at http://www.who.int/disabilities/data/mds/en/.
- For the Rapid Assessment of Disability (RAD), please contact the Nossal Institute for Global Health at RAD-enquiries@unimelb.edu.au.
- The Washington Group Short Set of Questions can be found at www.cdc.gov/nchs/washington_group/wg_questions.htm.

CHECKLIST: ASSESSMENT OF CURRENT PROGRAMMING FOR DISABILITY INCLUSION

CHECKLIST TO ASSESS CURRENT PROGRAMMING FOR DISABILITY INCLUSION	YES	NO
Is awareness of disability inclusion promoted within your health service?		
Have all staff undergone training on disability inclusion?		
Are you and your staff familiar with the Convention on the Rights of Persons with Disabilities?		
Are people with disabilities accessing the full range of health services available? • Prevention, health promotion, and treatment services • Inpatient, outpatient and outreach services		
Are people with disability being referred to the appropriate services and organizations for follow-up of specific needs relating to disability?		
Have you and your staff established a relationship with local organizations of and for persons with disabilities, and have you set up a system with them for ongoing dialogue and exchange of knowledge about health and the needs of persons with disabilities?		
Have you and your staff reviewed all ongoing internal policies and programmes to ensure that the needs of persons with disabilities are addressed?		
Are all areas of the health service accessible for people with disabilities?		
Is communication, including signage and health promotion materials, accessible for people with disability?		
Do you and your staff review all proposed new activities and programmes to ensure optimal inclusion and participation of people with disability?		
Have you and your staff established clear benchmarks for inclusion, and are monitoring and evaluation systems in place to ensure that these benchmarks are being reached?		
Have you and your staff reviewed all local and national legislation and regulation affecting health and health care to identify where people with disabilities should be included?		
Have you and your staff looked at whether and how these laws are actually being implemented?		
Is information on implementation of laws within your policies available to organizations of and for people with disability and other concerned members of civil society?		
Is information available on how to seek redress in case of violation of the rights of persons with disability?		
Have you and your staff reviewed budgeting to ensure that inclusion of people with disabilities is funded?		
Have you included disability issues in surveys and research?		

Adapted from: Promoting sexual and reproductive health for persons with disabilities (WHO/UNFPA, 2009) *(9)*.

PRACTICE NOTE: DISABILITY-SENSITIVE INDICATORS FOR HEALTH SERVICES, INCLUDING REHABILITATION

IN GENERAL

If our goal is to include disability in development cooperation, we need to establish disability-sensitive indicators. Disability-sensitive indicators will be used in combination with:

- disability-sensitive targets
- disability-disaggregated data/sources of information that are disability sensitive *(10).*

This tool gives a selection of possible indicators that could be adapted for individual situations depending on the sector and the context. The authors are aware of the crucial nature of indicators, the need to harmonize with other countries, not to increase the burden of work for governments, among other issues.

These indicators are presented as a list of options to be used or adapted as and when necessary as disability components and targets are introduced to various projects and sectors.

Source: www.make-development-inclusive.org

SAMPLE DISABILITY-SENSITIVE INDICATORS FOR HEALTH, INCLUDING REHABILITATION

Note that these indicators do not take health insurance issues into consideration

TYPE/LEVEL OF INDICATOR	SAMPLE DISABILITY-SENSITIVE INDICATORS
Input	• Expenditure on making health services inclusive of people with disabilities. • Expenditure on disability-specific health services. • Expenditure on training for health professionals at all levels in disability-related health care and rehabilitation. • Expenditure on disability-inclusive health information systems.
Output	• Percentage of health facility that is physically accessible to a person with disability. • Health information systems are inclusive of disability data. • Rehabilitation is integrated into the health system at all levels. • Systems for provision of assistive products designed for people with disability in place. • Number of staff trained (both initial and continuous training) in rehabilitation. • Number of health professionals trained in disability awareness and ethical standards of care for people with disability.
Outcome	• Health information collected, analysed and reported is disability disaggregated. • Number of people with disabilities accessing health services and programmes. • Percentage of women with disabilities accessing health care and services for sexual and reproductive health. • Percentage of people who require it and are accessing rehabilitation services. • Percentage of people who require them are accessing assistive products. • Percentage of people with disability with access to population-based health programmes. • Number of children with/at risk of disability with access to early identification and intervention services. • Health and rehabilitation services are reachable to all population groups (including people living in rural areas). • Health and rehabilitation services are affordable to all population groups (including people living in rural areas). • Health and rehabilitation services are physically accessible to all population groups (including people living in rural areas).
Impact	• Information is available on access for people with disability to the health sector, enabling better planning of inclusive health services. • Persons with disabilities have the same health status as others in the population.

Source: www.make-development-inclusive.org

INDICATORS

While different classifications for indicators exist, we use here the typology suggested by the European Commission *(11)*.

INPUT → OUTPUT → OUTCOME → IMPACT

INPUT INDICATORS refer to the financial, administrative and regulatory resources provided by government and donors, dedicated to achieving our disability-sensitive targets (within the overall goal of disability-inclusive project management). For example, investment in disability-inclusive health information systems.

OUTPUT INDICATORS measure the immediate and concrete consequences of the measures taken and the resources used. For example, a national health-related rehabilitation service in place.

OUTCOME INDICATORS measure the results at the level of beneficiaries' access to, use of and satisfaction with the above outputs; this is not an actual measurement of quality of life as such, but gives a strong indication. For example, percentage of people with disability with access to population-based health programmes.

IMPACT INDICATORS are the consequences of the outcomes, or the measurement of key dimensions of well-being. For example, good health, literacy, etc.

Source: www.make-development-inclusive.org

PRACTICE NOTE: INFORMATION FOR DISABILITY–INCLUSIVE PLANNING, MONITORING AND EVALUATION

	WHY COLLECT INFORMATION?	WHAT DO WE WANT TO KNOW?	HOW/WHERE TO COLLECT INFORMATION?
Situation analysis & planning	• To better understand the local situation. • To target activities where they are most needed. • To plan and budget for disability inclusion.	• Are people with disability accessing health services? • What are the barriers? • What are the experiences/ opinions of people with disability in accessing health services? • Are staff trained in and/or do they have knowledge about disability inclusion? • What are the current policies for disability inclusion? • Are buildings physically accessible? • Is health information accessible? • What disability-specific services and organizations exist locally?	• Data from health information system disaggregated by disability. • Qualitative information from people with disability – key informant interviews, focus group discussions. • Staff surveys. • Document review of current policies. • Accessibility audit. • Mapping of local DPOs and disability service providers.
Monitoring	• To monitor who is participating/benefiting and who is not – and why. • To make adaptations and improvements to activities to make them disability inclusive.	• Who is accessing health services and who is not? • How are activities that target inclusion working? • What changes are needed to make health care more disability inclusive?	• Who is accessing health services and who is not? • How are activities that target inclusion working? • What changes are needed to make health care more disability inclusive?
Evaluation	• To evaluate what changes have taken place. • To capture learning about inclusive practice.	• What changes have occurred in terms of disability inclusion? • Compare to baseline data. • What factors enabled or hindered inclusion?	• Data from health information system disaggregated by disability. • End-line surveys. • Key informant interviews/ focus group discussions with people with disability. • Follow-up accessibility audit.

Adapted from: Practice note: Collecting and using data on disability to inform inclusive development (Plan International Australia, CBM Australia & Nossal Institute for Global Health, 2015) *(3)*.

Dengar sini, abang.
Tengok sini.
SONY
CAGNESTON

MODULE 6
REHABILITATION AND DISABILITY-INCLUSIVE HEALTH SERVICES

KEY MESSAGES

about rehabilitation and disability-inclusive health services

Rehabilitation is an important part of health-care service provision.

Rehabilitation is a set of interventions designed to **optimize functioning and reduce disability** in individuals with health conditions, in interaction with their environment.

Health condition refers to disease (acute or chronic), disorder, injury or trauma. A health condition may also include circumstances such as pregnancy, ageing, stress, congenital anomaly or genetic predisposition.

The need for rehabilitation is growing with the changing health needs of the global population.

People of **all ages** may benefit from rehabilitation.

Rehabilitation is for **all people** experiencing or at risk of **functional impairment**, not only people with disabilities.

Rehabilitation services may be based in:

- hospitals
- primary health-care settings
- outreach based in people's homes and communities

Rehabilitation includes **therapy** (exercises, activities and advice), **providing assistive products**, and **modifying the environment** to improve function, independence and participation in everyday activities.

Health-care providers have an important role to play in identifying the need for rehabilitation and making timely and appropriate referrals.

Health-care providers may be able to provide some basic advice and rehabilitation strategies.

6.1 OVERVIEW OF REHABILITATION

What is rehabilitation?

Rehabilitation is an important part of the continuum of health care that helps people to live, work, learn and play to their greatest potential. Rehabilitation is a set of interventions that seeks to enable optimal functioning and minimize disability for those who have experienced impairment as a consequence of a health condition or injury, in interaction with their environments *(1).* There is a growing need for rehabilitation as the world's population and health needs change with increased ageing, NCDs and the number of people living with the consequences of injury or illness *(2).*

Rehabilitation may involve working with an individual to improve their functioning (e.g. walking, eating), and may also involve making changes or adaptations in their environment to facilitate functioning, independence and participation (e.g. a grab rail or chair in the shower to allow a person to shower themselves safely). Rehabilitation can also involve health promotion and prevention activities to provide early interventions that prevent and minimize the impact of disability, in addition to providing interventions where impairment has already occurred *(3).*

A distinction is sometimes made between "habilitation", which aims to assist those who are born with impairments or acquire them early in life, and "rehabilitation" for those who acquire impairments later. For the purpose of this Toolkit, we will use the term *rehabilitation* to refer to both conditions.

The availability of rehabilitation services is part of achieving UHC *(4)* and meeting the needs of people with disability. Article 26 (Habilitation and Rehabilitation) of the CRPD outlines the need for States Parties to undertake "effective and appropriate measures... to enable persons with disabilities to attain and maintain maximum independence, full inclusion and participation in all aspects of life"*(5).*

Strengthening rehabilitation was identified as a key objective in the *WHO Global Disability Action Plan (2014–2021) (6)*. Measures to strengthen rehabilitation and uphold the requirements of Article 26 include strengthening and extending rehabilitation and support services, training rehabilitation professionals, and promoting the availability of assistive devices and technology.

6.2 RELATIONSHIP BETWEEN REHABILITATION SERVICES AND HEALTH CARE

Generally, the earlier rehabilitation begins, the better the functional outcomes for individuals. Therefore, health-care workers who are the first point of contact when responding to a person's health condition have an important role to play by identifying the need for rehabilitation and making timely and appropriate referrals.

In a study of the rehabilitation workforce in the Pacific, DPO key informants stressed the need for health workers to not only look at an individual's health condition but to consider the broader family, social and economic issues facing people with disability or impairments. They reported that this could contribute to better referral systems from primary health services to rehabilitation. This also applied to village health workers having an understanding of frequently encountered impairments and health conditions, and the benefits to be gained from rehabilitation intervention *(3).* Health-care workers with some basic training in rehabilitation principles may also be able to provide some simple strategies to help facilitate functioning and independence *(1).*

Health-care providers may be able:

- to identify people with impairments or who are at risk of impairment (e.g. due to illness, injury, surgery);
- to provide some basic rehabilitation strategies that are accessible and affordable;
- to facilitate referrals to specialist rehabilitation providers;
- to provide information about basic assistive devices; and
- to encourage continued participation of people with impairments in all aspects of daily life, including family and community activities.

6.3 NEEDS AND BENEFITS OF REHABILITATION

Rehabilitation is of benefit to people of all ages who experience, or are at risk of, a functional impairment. This includes, but is not limited to, people with a disability. **For example, older people often benefit from rehabilitation services to maintain healthy ageing.** Access to rehabilitation can improve functioning and independence for those with health conditions that result in short- or long-term limitations in functioning, and that may be associated with injuries, illnesses, NCDs, ageing, surgery, mental illness, developmental delays and disabilities.

The benefits of rehabilitation are broad, and are at the individual, family and community level. Benefits of rehabilitation include:

- reducing the impact of a range of health conditions by preventing loss of function
- improving health and quality of life by increasing or restoring lost function
- increasing independence in daily activities
- increasing participation in family and community life
- reducing caregiving demands on family members
- increasing ability to participate in school or work
- reducing costs to health system in the longer term.

Some examples of rehabilitation interventions are:

For a man who has diabetes and recently had both legs amputated below the knee, rehabilitation could include provision of secondary and tertiary prevention, residual limb care advice, prostheses and mobility aids, and functional training to teach mobility and daily living skills.

For a 3-year-old boy with vision and hearing impairment, rehabilitation may include working with his parents to provide appropriate opportunities for play and stimulation, mobility training to help him move around his home and community, and developing communication strategies.

How rehabilitation is delivered

Where?

The availability of rehabilitation services varies greatly and may be delivered by a range of people and in a variety of settings. Rehabilitation services may be hospital based, where they can be inpatient and/or outpatient services; they may be clinic based in community health settings; or they may be provided in the community in people's homes or villages through outreach programmes. People may receive rehabilitation as a short-term intervention or may require it over a longer period for more long-term or chronic conditions.

Rehabilitation services can be provided by the government or nongovernmental organizations, or be privately run. Ministries of health often manage rehabilitation services, but they may also be under other ministries such as social affairs, social welfare or even education. Best practice delivery of community and hospital rehabilitation services occurs when they are well integrated with mainstream health and primary health-care services to ensure availability of locally based rehabilitation to people in both urban and rural communities *(3)*, rather than being only available as hospital-based services in capital cities and larger urban areas.

Who provides rehabilitation?

Rehabilitation services are provided by a broad range of personnel, including medical professionals (e.g. rehabilitation physicians, nurses), allied health professionals (e.g. physiotherapists, occupational therapists, speech pathologists, psychologists, prosthetists and orthotists) and rehabilitation workers (e.g. rehabilitation/allied health assistants, community rehabilitation workers) *(7).*

BOX 1. OVERVIEW OF REHABILITATION PERSONNEL

REHABILITATION DOCTORS/PHYSIATRISTS
These are medical doctors who have completed specialist training in physical medicine and rehabilitation. They are able to diagnose health conditions, provide comprehensive health management plans, and prescribe medical and other interventions to treat the health condition, optimize function and prevent further complications.

PHYSIOTHERAPIST/PHYSICAL THERAPIST
These therapists provide services to develop, maintain and maximize movement potential and functional ability. They can also provide assistance with managing pain, problems with breathing and early recovery after surgery.

OCCUPATIONAL THERAPIST
These therapists aim to enable people to participate in the activities of everyday life, which include self-care, work, school, domestic, community and social activities. They can help modify the task or the environment to enable participation, and provide adaptive equipment, strategies and advice, especially when there are limitations in the use of arms/hands that affect everyday activities. They can also provide cognitive and behavioural therapy.

SPEECH PATHOLOGIST/SPEECH THERAPIST/SPEECH AND LANGUAGE THERAPIST
These professionals assist people to communicate effectively and to swallow and eat safely and efficiently. They may provide therapy and strategies to assist people to express correctly, articulate appropriately, communicate through spoken and written words, and understand written, oral and augmentative language.

PSYCHOLOGIST
Psychologists provide assessment and intervention to address difficulties with learning, behaviour, social skills and emotional disturbance.

PROSTHETIST/ORTHOTIST
These individuals provide prosthetic and orthotic care and other mobility devices aimed at improving functioning in people with physical impairments. Orthoses are external devices used to protect, support, strengthen or improve the functioning of a body part. Prostheses are an artificial replacement for a body part.

SOCIAL WORKER
Social workers work with individuals or groups (e.g. a household, communities) to enhance or restore their well-being or address societal issues that may impact on well-being or create inequality. Social workers undertake roles in casework, counselling, advocacy, community engagement, and social action to address issues at both the individual and societal levels.

What can be provided?

Rehabilitation services encompass evaluation and diagnostics, therapeutic interventions, advice and provision of assistive products, and environmental modifications.

1. Evaluations and diagnostics

Assessments through evaluations (e.g. functional baseline and outcome measures, neurologic or postural) and diagnostic examinations (e.g. gait and motion analysis, electromyogram and nerve-conduction studies, musculoskeletal ultrasound) provide objective findings for a directed plan of intervention.

2. Therapeutic interventions

The goal of therapeutic interventions is to improve, encourage or develop functional independence. Therapy is concerned with restoring and compensating for the loss of function and preventing or slowing deterioration in functioning in any area of a person's life *(1)* – for example, mobility, communication, bathing, toileting, dressing, eating, learning or working.

For children with developmental delays or disabilities, therapy may be described as an "early intervention" and aims to promote development in all areas (movement, communication, cognition, social skills) and prevent long-term impairment or disability.

Therapy measures, generally provided by the professionals listed in Box 1, include the following:

- exercises and activities to address impairments and improve function;
- training and advice on modified, corrective or compensatory strategies (different ways to carry out activities);
- education and support for families and carers;
- support and counselling;
- advice regarding environmental modifications; and
- support for the provision and use of assistive products.

3. Assistive products

Assistive products include items or equipment that are designed or adapted to assist a person with an impairment to perform a particular task safely and as independently as possible and improve participation in everyday activities. They may be used for people experiencing either temporary health conditions (e.g. following hip replacement surgery) or long-term health conditions (e.g. limb loss).

There are many different types of assistive products to help people with a range of activities.

MOBILITY PRODUCTS
Assist people to walk or move.

POSITIONING PRODUCTS
Support people in lying down, sitting or standing positions to enable functional activity or prevent deformity.

DAILY LIVING PRODUCTS
Assist people to perform self-care activities – for example, toileting, bathing, dressing and eating.

VISION DEVICES
Assist people to see or reduce the functional impact of vision impairment.

COMMUNICATION TOOLS
Provide an alternative means of communication for people who have difficulty in speech and language.

HEARING DEVICES
Assist people with a hearing impairment to communicate and interact.

4. Environmental modifications

Environmental modifications in the home, school, community or work environment may be necessary to improve the functional independence and safety of a person with a long-term impairment or disability. Often, these are made under the guidance of an occupational therapist.

Environmental modifications are many and varied, and depend on the needs of the individual and their particular environment. These could include installing ramps or a lift in place of stairs, fitting handrails, widening doorways, making toilet or bathroom adaptations, and installing tactile strips to guide people who are vision impaired. They may also involve the need for management to be flexible in considering where daily activities are carried out to optimize independence.

6.4 CASE STUDY: FIJI'S MOBILE REHABILITATION SERVICE – ELENOA'S STORY

Unique in the Pacific region, the Government of Fiji offers a multidisciplinary Mobile Rehabilitation Service, which services people with physical impairments in many communities across the country. A rehabilitation physician leads the team, which includes a nurse, community rehabilitation assistant (CRA), and prosthetist and orthotist (P&O). These staff are based at Suva's National Rehabilitation Hospital (NRH) – one of five tertiary referral hospitals in Fiji, and the only one providing rehabilitation service.

For several decades, the NRH has offered rehabilitation services, including rehabilitation medicine, physiotherapy, and prosthetics and orthotics to inpatients and outpatients with physical and neurological disabilities. These include people with spinal cord injuries, stroke patients and amputees, as well as orthopaedic, neurological and geriatric cases.

However, several issues impede access to the NRH. Fiji is an archipelago, and its population is distributed across more than 200 islands; travel to the NRH can be difficult and costly. Furthermore, the NRH has a limited number of beds.

In 2012, NRH staff started actively identifying previous spinal cord injury inpatients who required continued rehabilitation assistance in their homes. In response, the Mobile Rehabilitation Service was established. A team that initially comprised the rehabilitation physician, nurse and CRA undertook half-day clinics at health facilities for clients with spinal cord injuries, spending the remainder of the day making home visits to clients who were unable to get to the clinic. In 2014, the NRH's P&O joined the outreach team, which then began visiting people who had amputations.

Today, the Mobile Rehabilitation Service draws upon staff at the NRH to form a mobile outreach team. The team generally is comprised of:

- The rehabilitation physician, who leads outreach visits and monitors health conditions such as diabetes, and prescribes and supplies medications.
- The P&O, who assesses patients requiring prosthetic and orthotic devices in their homes, and visits later with devices that can be adjusted during the visit. The P&O brings tools to make adjustments to existing devices that may need modification.
- A nurse, who is responsible for checking blood sugar and blood pressure, administering medications, and writing case notes.
- A technician, who attends follow-up visits in order to support wheelchair fitting.
- The CRA, who provides advice and support on the fitting and use of assistive devices, including wheelchairs, crutches and walking sticks, and gives advice regarding rehabilitation exercises and the management of daily living activities.

When available, the team is joined by a zone nurse (district/community nurse), physiotherapist and/or CRA from the local health facility.

Outreach visits allow follow-up with former patients from the NRH, follow-up with existing outreach clients, and the provision of rehabilitation service to clients who have never received such services before. Sometimes new clients will be referred to the NRH for inpatient care, but in most cases they are provided with services at home. The Mobile Rehabilitation Service identifies clients who require assistive devices, such as a wheelchair, crutches, walking frame or stick, and works closely with Fiji's Spinal Injuries Association (SIA) – a DPO located in Suva – to source appropriate equipment through the store of assistive devices that they manage. The team then visits the client with the equipment, and a technician who has been trained in wheelchair fitting by Motivation Australia assembles and fits the device. Outreach visits are not complete until a follow-up visit by the Mobile Rehabilitation Service has occurred, to monitor the effectiveness of the equipment and/or advice provided and make adjustments as necessary.

Local CRAs are an important decentralized operational arm of the Mobile Rehabilitation Service, undertaking outreach visits in their prescribed geographical areas to provide follow-up support to past clients, and identifying, supporting and referring new clients to the Mobile Rehabilitation Service as required. Where they exist, CRAs are an important rehabilitation referral and support mechanism. When the Mobile Rehabilitation Service visits their areas, they generally accompany the team and provide logistical support.

The Mobile Rehabilitation Service seeks to extend its role within Fiji's health services by consolidating referral pathways and expanding its reach.

LINKS AND RESOURCES

- Rehabilitation in health systems: guide for action (https://www.who.int/rehabilitation/rehabilitation-guide-for-action/en/).
- Priority Assistive Products list (https://www.who.int/phi/implementation/assistive_technology/EMP_PHI_2016.01/en/).

Elenoa's story

Elenoa, a 64-year-old single mother to three adult children, lives in a peri-urban area an hour away from Suva. Elenoa was diagnosed with diabetes in 2009 and had a below-knee amputation in 2010 at Colonial War Hospital, following which she returned home with a wheelchair.

In 2013, Elenoa's local CRA met her and began visiting her at home. In 2014, she was referred to the NRH, where she learned to use crutches as an outpatient. At home, however, she continued to use the wheelchair. Due to the inaccessible built environment in her community – for example, pathways, shops and buses with steps and narrow doorways – Elenoa found she could not visit the various places she wanted to go. As a result, she found herself spending a lot of time at home and dependent on her children.

The Mobile Rehabilitation Service visited Elenoa at her home and helped her to practise using her crutches, until one day they visited and she was no longer there. They made phone calls to her children but were unable to locate her. One weekend, the CRA from the Mobile Rehabilitation Service team saw Elenoa's son at the market. She approached him and found out where Elenoa was living now.

In 2015, the Mobile Rehabilitation Service team resumed their visits to Elenoa at her new home. She was now living at the top of a flight of narrow and rickety stairs, and spent most of her time indoors. She was now using a walking frame to move around inside her home; however, her stump had developed a flexion contracture. She was referred to the Mobile Rehabilitation Service's P&O.

The P&O visited, along with the rest of the Mobile Rehabilitation Service team, and measured Elenoa for a prosthetic leg. The team taught Elenoa some exercises to do which would address the contracture and increase mobility in her knee joint. The Mobile Rehabilitation Service team provided Elenoa with a prosthetic leg in July 2015, along with mobility training and advice in stump care. In February 2016, the team visited again and made adjustments to the prosthesis. They found that the contracture had diminished, and joint mobility had improved.

In July 2017, the Mobile Rehabilitation Service team visited again. The P&O checked the prosthesis and made adjustments to the socket, which was loose as the stump had shrunk. The nurse identified pressure sores and provided wound management advice and bandages.

Elenoa now experiences a degree of independence that she previously did not think was possible. Using her prosthesis and a walking frame, she walks everywhere independently – including navigating the steps in her house. Elenoa says, "I do everything for myself now. I go everywhere – even to parties – everywhere".

HOW TO INCLUDE REHABILITATION SERVICES IN YOUR HEALTH FACILITY

1. Consider what basic rehabilitation services can be provided at your health-care facility with existing resources.
   These could include:
   - identifying any unmet functional needs relating to impairment of patients attending your health service; and
   - facilitating referrals to specialist rehabilitation providers.

2. Consider training for staff in basic rehabilitation approaches.
   a. Early identification:
      - identify individuals who are at high risk for developing the different impairments; and
      - know red flag-signs denoting delay in the development or regression of motor skills, language skills, visual responses and psychosocial skills.
   b. Initial medical assessment.
   c. Patient, caregiver and family education:
      - basic advice, health tips, home and environmental modifications.
   d. Referral and coordination mechanism to specialized professionals, facilities, services, suppliers, and organizations or associations for people with different impairments.
   e. Monitoring of high-risk individuals.
   f. Provision of financial and transportation assistance.

Possible providers of this include:
- any existing staff members with rehabilitation training
- external specialist rehabilitation providers
- DPOs.

3. Perform a mapping activity to develop a list of rehabilitation service providers in the local area and contact these providers to establish referral pathways. Refer to the tool on the next page: Mapping Rehabilitation Services.

MAPPING REHABILITATION SERVICES

See sample below.

NAME OF SERVICE & KEY CONTACT PERSON	SERVICES PROVIDED	COST	HOW TO REFER
Pacific Rehabilitation Clinic	• Physical therapy • Prosthetics and orthotics	**No cost**	**No referral required. Call 123 456 for an appointment.**

MODULE 7
DISABILITY-INCLUSIVE HEALTH SERVICES IN EMERGENCIES

KEY MESSAGES

about disability-inclusive health services in emergencies

People with **disability** have an **increased need for health information** and services during **emergencies.**

Emergencies can include natural disasters (such as **earthquakes, floods** and **cyclones**) as well as **food insecurity, armed conflict** and other situations where people are forced to **evacuate** or **flee their homes.**

Emergencies can **increase** the number of people with **disability** due to **injuries sustained during an emergency**, or exacerbated during an emergency because they are left untreated.

People with disability are also disproportionately impacted by emergencies, experiencing a range of outcomes that can increase demand for health services, including:

Higher fatality rates than people without disabilities.
Increased risk of violence and abuse.
Worsened disability because of additional injury, or the interruption of medication and health services.

Reduced access to caregivers and assistive devices.
Receiving less warning about the onset of an emergency (and therefore, increased vulnerability to being left behind during an evacuation).

However, despite the increased need for health services, **people with disability face significant barriers to access of health services during emergencies** (some of which existed before an emergency, others which are **the result** of the emergency).

People with disability are generally **excluded from the planning and delivery of emergency response measures**, including the planning and delivery of health services.

Article 11 of the Convention on the Rights of Persons with Disabilities states that people with disabilities have the right to access health (and other basic services, including water and sanitation, housing and settlement) during emergencies.

Many DPOs are involved in delivering services to people with disabilities during emergencies and can **work with health services to strengthen planning and delivery** of inclusive health services to people with disability before, during and after an emergency.

There are several excellent tools available to guide health service planning and delivery of health services to people with disability during emergencies, including the **WHO Guidance Note on Disability and Emergency Risk Management for Health.**

7.1 DISABILITY-INCLUSIVE HEALTH SERVICES DURING EMERGENCIES

People with disability have traditionally been excluded during the planning and delivery of disaster responses and disaster preparedness measures, including the planning and delivery of health services *(1,2).* People with disability are often not counted or identified before, during or after emergencies, and are rarely consulted or represented in emergency risk management. The carers and families of people with disability may also lack knowledge and information about what they can do in emergency contexts to support people with disability *(2,3).* Consequently, the basic and specific needs of people with disability – including their need to access health information and services – are often overlooked or ignored during an emergency *(3).*

During disasters and other emergencies, there are often limited resources available to provide disability-inclusive health care. Emergencies often occur in low- and middle-income countries where health service provision is already constrained by a lack of resources *(4).* There are also often limited resources available during emergencies to take additional actions to support the inclusion of people with disability in health services *(4)*; therefore, preparedness is key.

In addition, in many emergency settings, there is limited health and rehabilitation infrastructure available, which can exacerbate challenges in providing disability-inclusive health services *(3).* Where health service infrastructure and health information are available, people with disability experience additional attitudinal, physical and communication barriers to accessing health information and services.

However, as this module will demonstrate, many strategies can be implemented at little or no additional cost before, during and after emergencies, and there are several excellent tools available to guide and strengthen the provision of disability-inclusive health care during emergencies.

Across the literature, the terms *emergencies* and *humanitarian contexts/settings* are used interchangeably. This module uses the WHO definition of "emergencies" provided in the *WHO Global Disability Action Plan* (see Box 2).

BOX 2. WHO DEFINITION OF "EMERGENCIES" *(5)*:

Emergencies are a type of event or incident that requires action, usually urgent and often non-routine.
Emergencies are due to natural hazards (such as earthquakes, cyclones, forest fires, floods, heatwaves and droughts); epidemic and pandemic diseases; transport crashes; building fires; chemical, radiological and other technological hazards; food insecurity; conflicts; and situations such as mass-gathering events.
Disasters can be considered large-scale emergencies that result in "a serious disruption of the functioning of a community or a society involving widespread human, material, economic or environmental losses and impacts, which exceeds the ability of the affected community or society to cope using its own resources".

7.2 WHY FOCUS ON PROVIDING HEALTH SERVICES TO PEOPLE WITH DISABILITY DURING EMERGENCIES?

While people with disability are often excluded from the planning and delivery of health information and services during emergencies, it is important that they can access health information and services for the following reasons:

People with disability have the right to access health services during emergencies

Article 11 of the CRPD (regarding situations of risk and humanitarian emergencies) states that countries take "all necessary measures to ensure the protection and safety of persons with disability in all situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters" *(6)*. This includes the provision of health services to people with disability.

Emergencies can increase the number of people with disability

During emergencies, the number of people with disability in a community can grow *(2, 3, 7, 8)* because of injuries sustained due to collapse of buildings and other structures, flooding, dust, broken glass, electrocution and flying debris, and (during conflict situations in particular) rape, torture and armed violence. In addition, many injuries sustained during emergencies are left untreated or are inadequately treated (due to the failure of essential services), which can result in further increasing the number of people with severe and long-term impairments *(2,9)*.

People with disability are disproportionately impacted by emergencies

People with disability (and especially) people with intellectual or psychosocial disability, and women and children with disability, are disproportionately affected by the impacts of emergencies *(9).*

People with disability can experience higher fatality rates during emergencies than people without disability. After the tsunami and earthquake in Japan in 2011, the fatality rate for people with disability registered with the Government was 2.06% compared to 1.03% for the rest of the population *(2).* People (especially women *(9,10)* with disability also face increased risk of violence and abuse during emergencies, due to a particularly difficult physical environment (including dislocation, unsafe and inaccessible temporary accommodation and services) and the breakdown of social and other support networks *(7).*

The severity and/or nature of an individual's impairment can be made worse through additional injury acquired during an emergency, as well as the interruption or lack of provision of medication and health-care services *(11)*. People with disability may also have reduced access to essential assistive devices and/or medications, or may be left behind when a community is forced to evacuate. In addition, emergencies may result in the loss of, or reduced capacity of, caregivers to support people with disability, increasing the vulnerability of people with disability to abuse, isolation or neglect during emergencies *(1–3,11).* People with disability are often also inadequately prepared for emergencies. People who are blind or have vision impairment or who are deaf or hard of hearing may not receive early warning messages or may not understand what is happening due to the communication of critical information about emergencies in inaccessible formats.

The increased likelihood of fatalities or exacerbated disability, abuse and violence; reduced access to assistive devices; the loss or reduced capacity of caregivers; and inadequate preparation for emergencies can all contribute to an increased need for people with disability to access health information and services during emergencies.

However, an increasing number of studies demonstrate that people with disability face significant barriers to accessing health services during emergencies. In some instances, barriers to health services existed before the emergency took place, whereas other barriers (e.g. collapsed or damaged health facilities) were the direct result of the emergency. Handicap International conducted a key study in this area in 2015 *(1)*, the findings of which are summarized in the box on the following page.

BOX 3. HANDICAP INTERNATIONAL "DISABILITY IN THE HUMANITARIAN CONTEXT GLOBAL CONSULTATION" – FINDINGS ON THE IMPORTANCE OF ACCESS TO HEALTH SERVICES FOR PEOPLE WITH DISABILITY *(1)*

This research project aimed to identify the changes needed to strengthen disability-inclusive humanitarian responses. A total of **769 responses** were collected from **484 people** with disability (including 400 directly impacted by an emergency), **118 DPOs** and **167 humanitarian organizations** around the world.

Key research findings about the need for, and provision of, health services to people with disability during an emergency include:

- **ACCESS TO BASIC SERVICES: 75%** of people with disability reported inadequate access to basic assistance such as water, shelter, food or health services.
- **PHYSICAL IMPACT: 54%** of people with disability reported a loss of mobility and increased dependence on others; **45%** of people with disability reported acquiring a new disability during emergencies.
- **PSYCHOLOGICAL EFFECTS: 38%** of people with disability reported psychological stress and/or disorientation.
- **ABUSE AND VIOLENCE: 27%** of people with disability reported experiencing physical, psychological, sexual or other types of abuse; **33%** of women with disability reported psychological, physical or sexual abuse.
- **LOSS OF MEDICAL TREATMENT: 21%** of people with disability reported an absence or lack of appropriate medication during emergencies (which can exacerbate disability, lead to complications or increase levels of mortality and morbidity).
- **ACCESS TO HEALTH SERVICES: 70%** of people with disability (including people with new impairments acquired during the emergency and people who had a disability before the emergency) reported this as a significant primary concern.
- **MAIN BARRIERS TO SERVICES: 30%** of people with disability did not know where to find available services; **32%** did not know what types of services existed; **22%** reported physical barriers to accessibility of services.
- **EXCLUSION OF PEOPLE WITH DISABILITY FROM EMERGENCY RESPONSES: 92%** of all respondents estimate that people with disability are not properly considered in current humanitarian responses.
- **DPO INVOLVEMENT DURING EMERGENCIES: 81%** of DPOs report having continued to run activities during the crisis; **36%** adapted their activities to respond to evolving situations; **29%** developed new activities in response to the crisis.

7.3 KEY CONSIDERATIONS FOR PROVIDING DISABILITY-INCLUSIVE HEALTH SERVICES DURING EMERGENCIES

A range of tools to guide the provision of health services to people with disability during emergencies have been developed by international organizations, including WHO and United Nations agencies. A short summary of each tool, including the relevant checklists and assessment audits that each contains, is available in the Actions section at the end of this module. While the format, language and intended audiences for each tool vary, across the tools there are several common key considerations and areas of action considered necessary to the provision of health services to people with disability during emergencies. These include:

Engagement of people with disability and DPOs

Although the importance of including people with disability in developing health-care and emergency responses is well established, they are routinely excluded from emergency planning and preparation decision-making *(1,3,7)*. However, many DPOs are already involved in providing services to people with disability during emergencies *(1)*. As such, it is important to engage DPOs in efforts to identify people with disability and provide appropriate health services during emergencies.

Physical accessibility

Physical barriers to health services that are experienced by people with disability before an emergency are often exacerbated during an emergency. Health service facilities may be damaged or may have collapsed, and in a humanitarian crisis, health services may be provided from within a camp or settlement. The physical layout and structure of evacuation and refugee camps and settlements are often inaccessible to people with disability, making it difficult or impossible for people with disability to access essential health services *(5,7)*. When there is flooding, landslides, mud, debris, and damaged roads and footpaths, the terrain may become particularly difficult for people with disability to navigate. Therefore, health services should attempt to reach people with disability where they reside during an emergency – in camps, shelters, houses and other institutions. After an emergency, the rebuilding and replacement of health service facilities provide an opportunity to "build back better" and address physical barriers that existed before the emergency to facilitate access for people with disability *(5)*. It is important to make the most of this opportunity.

Communication

Low levels of awareness among people with disability about health service availability can also be exacerbated during emergencies. People with disability often do not receive early warning information about the onset of an emergency, about evacuation procedures, or where and how to access essential services (including health services) during an emergency. Putting in place mechanisms to provide information about available health services before, during and after an emergency, in accessible formats, can help to improve awareness and uptake of these services by people with disability *(5)*.

Human resources

Many health service providers have limited knowledge about how emergency situations affect people with disability, and limited capacity to respond to the health needs of people with disability before, during and after an emergency *(3)*. In addition, DPO representatives may lack experience in emergency risk management, and emergency teams might lack knowledge about the rights of people with disability and have limited staff with the expertise to respond to their needs *(12)*. Training with health service providers to provide health services to people with disability during emergencies can be conducted during routine emergency preparedness and response training, or as a component of disability-inclusion training. However, even during an emergency, health service staff and health workers can be briefly oriented and sensitized to prioritize disability issues and needs *(3)*.

Health information systems

Before, during and after an emergency, it is important that people with disability can be identified to ensure that they can be reached for early warning about an emergency, and with information on how to access health services during an emergency. To identify people with disability, HMIS should be disability inclusive and include data on people with disability, disaggregated by age, gender and the nature of their disability and details of their location. Injury surveillance systems should allow people with disability to be readily identified; there should be mechanisms for sharing non-confidential data about people with disability in an accessible format to DPOs, relevant government bodies and emergency coordination groups. Information regarding the type and quantity of treatment, equipment (including assistive devices) and support that has been or is currently provided to people with disability, and referral pathways to other services required by people with disability will also assist in the planning and delivery of health services to people with disability during emergencies *(3)*.

7.4 CASE STUDY: PROMOTING SAFETY AND RISK REDUCTION OVER THE RADIO, PHILIPPINES

Handicap International *(1)* reported that during emergencies, up to 81% of DPOs reported having to continue to run activities during the crisis, 36% adapted their activities to respond to evolving situations, and 29% developed new activities in response to the crisis. The *Empowerment and Participation* report *(13)* provides a range of good practice examples where people with disability and DPOs have been included in disaster preparedness responses. The case study from the Philippines described below (adapted from the report for the purposes of this Toolkit) demonstrates how radio programmes can be an effective tool to disseminate key messages to people with disability about disasters.

Health facilities can work with DPOs and people with disability to determine and implement communication strategies to ensure that they are prepared for emergencies and have access to inclusive health information and services during and after emergencies.

A Philippine civil society organization, Simon of Cyrene, trained men and women with disability to anchor a weekly radio programme in the rural areas of central Philippines. Through the programme, they disseminate key messages on disaster risk reduction and disability inclusion to villagers. Vicente Vic Balonso is one of the Bicol region radio announcers.

Vic is 61 years old and a field officer for the Municipal Agriculture Office in Santo Domingo. He is also the president of the Association of Persons with Disabilities in Santo Domingo, and last year he was elected president of their federation, a DPO that promotes inclusive disaster risk management and the rights of people with disability, providing assistance across 23 barangays (subdistricts) in the Philippines.

Living with hazards

Vic explains that his community faces several risks. “In our municipality of Santo Domingo, there are many risks. We are just under the gaze of the Mayon volcano and we also get a lot of typhoons in this area. Through my work with the farmers I know that the upland farmers sit at the foot of the Mayon volcano that regularly has ash fall and sometimes eruptions, and the lowland farmers are on the coast and face typhoons. All across our region people face landslides.”

Radio broadcasting

Through Vic's association with Simon of Cyrene, he picked up the extra job of radio broadcaster, delivering information about people with disability and connected issues in Santo Domingo. "My passion is helping farmers not to use chemicals on their crops and to use organic methods. My other passion is helping to prevent illnesses and accidents so we don't get any more unnecessary members of our PWD (persons with disability) club," he laughs. "We started to broadcast to our area about different topics concerning people with disabilities. Simon of Cyrene helped prepare the information to present each week. We broadcast every Friday for one hour... On the radio programme we discussed a number of topics related to disasters. We spoke about climate change, about the role of the barangay officials during a disaster and advised what people with disabilities should do in an emergency."

Radio programmes: a model for inclusive disaster risk management

Vic recommends radio programming to other areas in the Philippines and beyond. "With radio you reach a wide audience, people should do it – it is good", he says. "I have seen that people are more aware in my community since the radio programme started."

HOW TO PROVIDE HEALTH SERVICES TO PEOPLE WITH DISABILITY DURING EMERGENCIES

Using a checklist to identify potential barriers that people with disability may experience in seeking health service provision during an emergency, and to plan and deliver disability-inclusive health services during an emergency, is an effective approach for ensuring that the health needs of people with disability immediately before, during and after emergencies are addressed.

LINKS AND RESOURCES

- Emergency medical teams: minimum technical standards and recommendations for rehabilitation. Geneva: World Health Organization; 2016 (http://apps.who.int/iris/handle/10665/252809).
- Minimum standard commitments to gender and diversity in emergency programming. Pilot version. Geneva: International Federation of Red Cross and Red Crescent Societies; 2015 (http://www.ifrc.org/Global/Photos/Secretariat/201505/Gender%20Diversity%20MSCs% 20Emergency%20Programming%20HR3.pdf).

TOOLS

There are several tools that can be adapted by your health service to ensure that the health needs of people with disability are met immediately before, during and after an emergency.

WHO Guidance Note on Disability and Emergency Risk Management for Health

This Guidance Note is designed for health service providers working in emergency risk management at local, national or international levels, and in government or nongovernmental agencies. It is a short, practical guide that covers actions across emergency risk management, such as risk assessment, prevention (including hazard and vulnerability reduction), preparedness, response, recovery and reconstruction. It outlines the minimum steps that health service providers can take to ensure that appropriate health support and services are available for people with disability during emergencies.

It is divided into two sections.

Section 1 provides an overview of the impact of emergencies on people with disability and describes the principles that should underpin practical action related to emergencies. This section also includes useful information and strategies to build capacity of health service staff to provide disability-inclusive health services during an emergency.

Section 2 of the Guidance Note provides a series of tools to equip health services to provide disability-inclusive health services during an emergency. Some examples include:

Annex 3. Emergency assessment tools and how they can be used to assess disability

- These consist of a series of questions within different domains that can be used to identify the unmet needs of people with disability during an emergency.

Annex 4. Health services to support people with disability

- This is a checklist that identifies core health services (e.g. general health care, child health, communicable diseases, injury prevention, NCDs and SRH) and recommended actions to provide these services to people with disability.

Annex 5. How to make services in health-related sectors inclusive of people with disability

- This includes key actions by sector (e.g. nutrition and food security; water, sanitation and hygiene; housing and shelter) to ensure that the health needs of people with disability are being met.

Annex 6. Disability and emergency risk management: checklist of minimum actions required by the health sector

- This includes a checklist of minimum actions required by the health sector for different functions (e.g. policies, budgeting, human resources, planning and coordination, and service delivery). While this checklist is primarily designed for those coordinating health services at a sectoral level, it is also a useful tool for health service facilities.

WHO/UNFPA guidance note on promoting the sexual and reproductive health for persons with disability

While this resource focuses on implementing strategies to improve the SRH of people with disability, Appendix C. *Key recommendations to all humanitarian actors concerning persons with disabilities in emergency situations* provides guidance on how to ensure the general health needs of people with disabilities are met during emergency situations.

Age and Disability Capacity Programme (ADCAP) minimum standards for age and disability inclusion in humanitarian action

This resource provides a set of standards that are intended to guide the design, implementation, monitoring and evaluation of humanitarian programmes and to build capacity to conduct disability-inclusive humanitarian programmes, including the provision of disability-inclusive health services during emergencies. These standards include *Key Inclusion Standards* (p.7) that outline underlying principles for responding to the needs of people with disability during emergencies. There are also sector-specific standards to guide the provision of services to people with disability across different sectors. To guide the provision of health services to people with disability during an emergency, the resource includes a list of health standards (p.46), as well as a series of practical actions that can be implemented to ensure that each standard is implemented.

REFERENCES

MODULE 1. DISABILITY-INCLUSIVE HEALTH SERVICES – GETTING STARTED

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World Health Organization
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PUBLICATION

ISBN-13 978 92 9061 892 8