

MODULE 1

Understanding Disability and Inclusion

1.1 Understanding Disability

Time: 80 minutes

Preparation & materials required: Slide Deck, flipchart, markers, Case Studies A activity sheet and answer key

Objectives: At the end of this module, learners will be able to:

- Define disability using the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the WHO International Classification of Functioning, Disability and Health (ICF).
- Explain the differences between disability, condition, and impairment.

Key message(s) to take away for learners:

1. The ICF and UNCRPD recognize that disability is the interaction between impairments arising from a health condition and a person's social and physical environment.
2. While a condition refers to a health issue, impairment is the functional limitation resulting from the condition, and disability is the interaction between impairments and the individual's environment (e.g., barriers).
3. An infant or a mother's impairment may be more or less disabling depending on the context in which they live.

Activity 1.1.1 (30 minutes)

Defining disability

Activity Summary	Key message(s)	Slides & Material(s)
Group discussion	1	Slides 9-17 Flipchart, markers

Instructions

- Introduce the module:
 - Disability is an evolving concept and how we discuss it today might be new to some of you. The concept of disability can also be difficult to explain and may have a different meaning to different people or in different contexts. But developing a shared understanding of “disability” helps us to plan, monitor and evaluate inclusive programs and services, including those for the management of small and nutritionally at-risk infants and their mothers (MAMI).

- In this module, we will discuss disability and common language to use when talking about disability and think of the barriers that infants and mothers impacted by disability face and strategies to address some of these barriers.

Activity (10 minutes):

- Ask participants to provide their own definition of disability:
 - How would you define "disability" based on your own understanding and experiences?
- Write definitions provided by participants on a flipchart.
- Explain that in this training we will use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the WHO International Classification of Functioning, Disability and Health (ICF) to understand what is meant by "disability."
- Present ways in which disability has been framed throughout history:
 - When we talk about disability it is important to know about how disability has been viewed in the past and how it is seen today. How we think about the meaning of disability impacts the way people with disabilities are included or excluded from society. Two main approaches to understanding disability have been used throughout history:
 - *Charity model:*
 - People with disabilities are often seen as needing charity and pity.
 - *What this looks like if you have a disability:* People in your community assume you always need help and feel sorry for you. They see you as a burden that requires charity to get by. You may hear statements like: "I'm so sorry for what you're going through." "It's so inspiring to see you out and about." "You must be so strong to deal with your condition every day."
 - The charity model is an outdated approach to understanding disability.
 - *Medical model:*
 - The charity model later changed into the medical model, where people with disabilities were viewed as sick and in need of curing, fixing, and medical care. In this model, medical professionals like doctors, nurses, and therapists were seen as the experts on disability.
 - Children with disabilities are believed to be sick and are patients. In many communities today, they may still be seen this way.
 - *What this looks like if you have a disability:* People in your community see you as "sick" because of your disability. Most services aim to cure your disability or make you look non-disabled, rather than making the environment more accessible. You may hear statements like: "Your disability needs to be treated." "If you are disabled, you cannot make decisions concerning your life." "If you are disabled, you need specialists to serve you."
 - The medical model implies that the disability *comes from the person*.

- This model is also outdated.
 - These outdated approaches have been replaced by social and human rights-based models, which emphasizes that the challenges faced by people with disabilities stem from an inaccessible society, not from the disabilities themselves. This new perspective upholds the rights of persons with disabilities and will guide our work moving forward.
- Present the definition of disability by the UNCRPD highlighting similarities with definitions provided by participants:
 - The UNCRPD is a legally binding international agreement and human rights instrument that reaffirms that all persons with disabilities are entitled to fully enjoy all human rights and fundamental freedoms.
 - The UNCRPD defines persons with disabilities as: “...those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN 2006).
- Present the WHO ICF framework and talk through its components:
 - The WHO created the ICF to describe and organize information about disability. It integrates the many factors that can impact an individual's ability to function and participate.
 - The ICF components include:
 - *Condition*: a disease, disorder or injury
 - *Impairments in body structure and function*: problems with anatomical parts of the body or physiological functions of body systems, resulting from a health condition
 - *Activity limitations*: difficulties in completing an everyday task or action (e.g., eating)
 - *Participation restrictions*: limitations in engaging in everyday life or social activities (e.g., school, work, community activities)
 - *Environmental factors*: the physical, social and attitudinal environment in which the person lives
 - *Personal factors*: includes gender, age, coping styles, social background, education, and past experiences
 - The ICF components come together in this way: A child experiences a *condition* that leads to an *impairment* in function. The impairment leads to a *limitation* in their ability to do certain tasks. Those limitations can restrict their *participation* in daily life, with *environmental* and *personal* factors acting as barriers or facilitators.
 - Let's take a look at how the ICF may apply for a girl with a cleft lip:
 - The *condition* in this case is a “cleft lip,” which has resulted in impairments in the “structures of the nose and upper lip,” affecting the “function of sucking.”
 - Those impairments *limit* the infant's ability to “breastfeed well and receive adequate nutrition” and *restrict* her participation in a “bonding feeding experience with her mother.”
 - *Environmental* factors including negative attitudes towards the mother from her community lead to social isolation, causing her to hide her infant and hesitate to seek support.
 - *Personal* factors including the parents' “financial constraints” lead to delayed surgical repair for the cleft lip.

- Conclude this section:
 - Both the UNCRPD and ICF recognize that disability is not only a “diagnosis” or a “health condition” but rather, it stems from the interaction between a person’s impairments due to a health condition and their social and physical environment.

Activity 1.1.2 (30 minutes)

Applying the ICF framework

Activity Summary	Key message(s)	Slides & Material(s)
Small group discussion	2	Slides 18-23 Flipchart, markers

Instructions

- Introduce the activity:
 - We will now practice using the ICF to increase our understanding of its components and of the difference between a condition, an impairment, and a disability.
 - In this activity, you will create an ICF framework for a child health condition. You will think of the various ICF components impacted including body structures/functions, activity, and participation, as well as contextual factors that may interact with the child’s impairment, potentially leading to disability.
- Divide participants into small groups and give each group a flipchart and a marker.
- Ask group to draw an empty ICF framework (boxes and arrows) on the flipchart. *Note: Draw one yourself on a flipchart so they can follow your example. Environmental and personal factors can be combined into one box.*
- Ask groups to do the following, with a focus on children:
 - Select a *health condition* you commonly see in your local area or workplace that may lead to disability. Write it in the appropriate box on the flipchart.
 - Write a *body structures/functions* that might be impacted by this condition.
 - Write an *activity* or an everyday task/action that might be limited by this condition.
 - Write a social event or activity that a child may not *participate* in as a result of this condition and barriers.
 - Write two contextual factors (personal or environmental) that may create barriers to the child’s participation.
- After 15 minutes, ask each group to present their ICF framework.
- Provide additional examples for each component of the ICF:
 - *Health conditions:*
 - Conditions commonly encountered may include cerebral palsy, Down syndrome, autism, cleft lip, cleft palate, spina bifida, intellectual impairments, epilepsy/seizure disorder, learning disabilities, mobility or movement disorders, hearing impairment, and visual impairment.
 - *Body structures/functions:*
 - Body structures include: nose, mouth, neck, brain, heart, nervous system, and limbs.

- Body functions include: seeing, hearing, speaking, moving the body, eating, drinking, learning, communicating including understanding others and expressing oneself.
 - *Activities:*
 - Activities include: socializing, controlling behavior, self-care, taking public transport, grasping objects, going out alone.
 - *Participation:*
 - Participation in society and life events include: playing with friends, going to school, sharing meals with others, work and employment, accessing healthcare, community involvement.
 - *Contextual factors:*
 - Stigma
 - Discrimination
 - Cultural beliefs
 - Lack of services
 - Gender
 - Age
 - Coping styles
 - Social background
 - Level of education
 - Financial constraints
 - Past experiences
- Conclude this section:
 - Remember that conditions represent health issues, impairments are the resulting functional limitations, and disability is the interaction between impairments and the individual's environment (e.g., barriers). Understanding these distinctions helps us address diverse needs and ensures comprehensive support and inclusion.

Activity 1.1.3 (20 minutes)

ICF: Contextual factors

Activity Summary	Key messages	Slides & Materials
Case study discussion	3	Slides 24-26 Mod 01_ActivitySheet_Case Studies A Mod 01_ActivitySheet_Case Studies A_Answers

Instructions

- Ask participants to remain in their small groups.
- Hand out a copy of the case studies, one per participant.
- Explain the activity:
- We will now further explore contextual factors through case studies about two infants with same condition but living in different contexts.
- Read the case studies and then discuss with your group the following questions:
- What is the context in which each infant lives?

- How could this context impact their experiences of disability and participation in everyday life, in a positive or negative way?
- After 10 minutes, ask the groups to share their responses. Refer to the answer key and provide additional information as needed.
- Conclude this section:
- As demonstrated by the case studies, a person's impairment may be more or less disabling depending on the context in which they live. Therefore, it is important for healthcare workers to consider not only a child's treatment and outcomes but also their environment, family dynamic, and societal context.
- Ask participants to reflect on how their understanding of disability has changed:
- How does the definition of disability we discussed compare to what your understanding of disability was before this session? What are the similarities? What are the differences?



Check before proceeding.

These are the key messages for this module. Have these been explicitly addressed and learners appear to have a good understanding of them?

1. The ICF and UNCRPD recognize that disability is the interaction between impairments arising from a health condition and a person's social and physical environment.
2. While a condition refers to a health issue, impairment is the functional limitation resulting from the condition, and disability is the interaction between impairments and the individual's environment (e.g., barriers).
3. An infant or a mother's impairment may be more or less disabling depending on the context in which they live.

1.2 Barriers and Social Norms

Time: 60 minutes

Preparation & materials required: Slide Deck, flipchart, markers, MAMI Journey Flowchart handout, Attitudinal Barriers activity sheet.

Objectives: At the end of this module, learners will be able to:

- Identify barriers faced by infants and mothers with disabilities that exist in health and MAMI services.
- Know common attitudes and social norms around disability among healthcare providers and in communities where they work.

Key message(s) to take away for learners:



1. Infants and mothers with disabilities commonly experience attitudinal, physical, communication, and financial barriers in accessing a level of health care equal to that of infants and mothers without disabilities.
2. Negative attitudes by health workers about people with disability, including ignoring, judging, and stereotyping people with disability, can present barriers to accessing quality MAMI and other health services.

Activity 1.2.1 (40 minutes)

Barriers along the MAMI care journey

Activity Summary	Key messages	Slides & Materials
Brainstorming activity	1	Slides 27-31 Flipchart, markers Mod 01_Handout_MAMI Journey Flowchart

Instructions

- Introduce this section:
- Across the world, people with disability face significant and multiple barriers that prevent them from accessing a level of health care and services equal to that of people without disabilities.
- These barriers can be placed in four categories:
- *Attitudinal*: these include the negative perceptions, assumptions and beliefs about people with disability (e.g., stigma and discrimination; lack of knowledge and training of health workers; lack of inclusive policies; lack of inclusion in planning and decision-making)
- *Physical*: these include the obstacles that prevent people with disability from accessing good health services when they need them (e.g., location of health services; lack of accessible transport; poor access to buildings, toilets, consulting rooms and furniture)
- *Communication*: these include barriers to sharing and receiving information about health services and during interactions with healthcare providers (e.g., lack of alternative formats of health information; use of jargon; poor signage; unsuitable forms of communication during counseling)
- *Financial*: these include the direct and indirect costs of accessing health care (e.g., cost of transport, cost of medicine, cost of special services)
- Barriers can occur at any point in the MAMI care journey of a mother-infant pair impacted by disability.
- Distribute the MAMI journey flowchart handout and give participants a few minutes to go through it individually.
- Then, talk through the journey of a mother-infant pair through MAMI services:
- *Awareness of MAMI services*: Is the mother aware of MAMI services? Is information about MAMI accessible and available in accessible formats?
- *Past experiences of MAMI services*: Is the mother willing to access MAMI services based on prior experiences with health services and health workers?

- *Leaving the house:* Can the mother leave the house alone? What kind of support does she need to leave the house? Does she have child care? Does she experience stigma from the community?
- *Finances:* Can the mother afford health care and transport? Does she receive any financial support? Is she aware of existing social services?
- *Transport:* Can the mother access and afford transport? How far is the MAMI clinic? Is public transport to the clinic available? Does the clinic offer transport services?
- *Entering the MAMI clinic:* Does the clinic have ramps? Is clinic signage accessible? Is staff, including reception and security, welcoming and respectful?
- *Waiting for an appointment:* Is the waiting area accessible? Are toilets accessible? Do staff follow any discriminatory practices?
- *During the appointment:* Is the health worker responsive to the mother's needs? Does the health worker provide reasonable accommodation? Is the communication method appropriate?
- *After the appointment:* Is follow-up information communicated appropriately? Is the mother referred to the appropriate specialized services? Is she linked with a support group? Is the mother able to afford referral services?

Activity (30 minutes):

- Ahead of the session, prepare four flipcharts with a mother-infant pair's journey through MAMI services. Use the handout as a template for how to prepare the flipcharts. Write the nine stages of the flowchart (e.g., 1. Awareness of MAMI services; 2. Past experiences of MAMI services; etc.), leaving enough space under each stage for participants to add their responses.
- Tell participants that in this activity they will identify common barriers related to disability in their community and challenges that infants and mothers with disabilities may have in their MAMI care journey.
- Divide participants into four groups and give each group a prepared flipchart.
- Assign each group one of the four barrier categories:
 - Attitudinal
 - Physical
 - Communication
 - Financial
- Tell participants:
 - A mother who is deaf or hard of hearing is struggling to breastfeed her little girl with a cleft lip and is seeking support. Think of barriers under your assigned category that the mother-infant pair may face at any point of their journey of accessing MAMI services. Make sure the barrier is relevant to the mother's hearing impairment and/or the infant's health condition. Refer to the handout if needed.
- After 15 minutes, ask each group to share their responses and invite other groups to contribute more barriers.
- Ask participants to save the flipchart. They will use it again in another activity.
- Conclude this section:
 - It is essential for us to have a good understanding of what the experience of accessing health services is like from the perspective of a mother with disability or a mother of an infant with disability. It is this understanding that will allow us to adapt our practices to become more disability inclusive, and to influence and educate our colleagues to do the same.

Activity 1.2.2 (20 minutes)

Attitudinal barriers

Activity Summary	Key messages	Slides & Materials
Matching activity	2	Slides 32-35 Mod 01_Activity Sheet_Attitudinal Barriers Mod 01_Activity Sheet_Attitudinal Barriers_Answers

Instructions

- Introduce this section:
- We will now delve deeper into attitudinal barriers as they often compound other types of barriers, such as physical and communication barriers.
- Attitudinal barriers are a major challenge for people with disabilities when accessing healthcare services. Many of these barriers come from lack of knowledge and awareness about disability and disability rights or understanding what people with disabilities require in terms of support.
- As we talk about attitudinal barriers, you might realize that you also have gaps in your knowledge or negative attitudes about disabilities. Do not worry if this happens. It is a normal part of learning. Recognizing our own attitudes and beliefs is crucial for identifying and dealing with attitudinal barriers in healthcare.
- The types of negative attitudes include:
- *Stereotyping*: Assuming what people with disabilities need or do not need and can and cannot do.
- *Pity*: Feeling sorry for a person with disability, leading to patronizing behavior.
- *Fear and avoidance*: Avoiding a person with disability because of fear of saying or doing the “wrong” thing.
- *Inferiority*: Believing people with disability are inferior because of their impairment.
- *Denial*: Not believing a person with disability or recognizing the impact of the impairment, or denying reasonable accommodation where needed. This is especially common when conditions may not be visible (e.g., intellectual disability).

Activity (10 minutes):

- Ask participants to pair up and distribute the activity sheet, one copy per participant.
- Ask pairs to match statements from health care workers to the type of negative attitude.
- After 5 minutes, ask participants to share their responses. Refer to the answer key for the correct responses and additional notes.
- If time allows, give participants 2-3 minutes to individually reflect on their own beliefs and attitudes towards disability. Participants may note their reflections in their notebooks. Let participants know that this is a self-reflection activity and they will not be asked to share with the group.
- Conclude this section:

- Attitudinal barriers can come from health service providers themselves. They often include no, little, or inaccurate knowledge and awareness about disability, discrimination and inferior treatment, and health service policies and practices that are not inclusive.



Check before proceeding.

These are the key messages for this module. Have these been explicitly addressed and learners appear to have a good understanding of them?

1. Infants and mothers with disabilities commonly experience attitudinal, physical, communication, and financial barriers in accessing a level of health care equal to that of infants and mothers without disabilities.
2. Negative attitudes by health service providers about people with disability, including ignoring, judging, and stereotyping people with disability, can present barriers to accessing quality MAMI services.

1.3 Promoting Disability-inclusive MAMI Services

Time: 60 minutes

Preparation & materials required: Slide Deck, flipchart, markers, Disability-inclusive Attitudes activity sheet and answer key.

Objectives: At the end of this module, learners will be able to:

- Discuss key strategies to address attitudinal, physical, and communication barriers to inclusive MAMI services.

Key message(s) to take away for learners:

1. The needs of many infants and mothers with disabilities can be met by making mainstream MAMI services more inclusive.
2. Promoting disability-inclusive attitudes through awareness raising and capacity building is key to providing disability-inclusive health services.

Activity 1.3.1 (20 minutes)

Promoting disability-inclusive attitudes

Activity Summary	Key messages	Slides & Materials
Brainstorming activity	2	Slides 36-39 Mod 01_Activity Sheet_Disability-inclusive Attitudes



		Mod 01_Activity Sheet_Disability-inclusive Attitudes_Answers
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Instructions

- Introduce this section:
- Disability inclusion in MAMI services can be achieved through a twin-track approach:
- *Disability inclusion within mainstream MAMI services:* The needs of many infants and mothers with disability can be met through existing MAMI services with modest adaptations.
- *Disability-specific health services when needed:* Disability-specific services may be warranted when the needs of infants and mothers with disabilities cannot be met through existing services.
- In this training, we will focus on how we can achieve disability inclusion within mainstream MAMI services.
- To ensure MAMI services are inclusive, we need to remove or reduce the barriers for mother-infant pairs impacted by disability. This starts by addressing negative attitudes.

Activity (15 minutes):

- Distribute the activity sheet, one copy per participant.
- Introduce activity:
- In the activity sheet, you can see the various types of negative attitudes and example statements from health workers from the previous activity.
- Working in pairs, come up with a more disability-inclusive statement that the health worker can say instead for each type of negative attitude. Write your statements in the space provided. *Note: Give an example if participants ask for clarification.*
- After 10 minutes, ask participants to share their responses. Refer to the answer key and share more examples of statements if needed. Provide additional information on inclusive approaches to counter each type of negative attitude.
- Conclude the session:
- Replacing approaches that are based on negative attitudes with disability-inclusive approaches is a key strategy to addressing attitudinal barriers in your health service. To do that, recognize your own bias and take action, and help raise awareness and build capacity for disability inclusion among all MAMI and health workers.

Activity 1.3.2 (40 minutes)

Addressing barriers along the MAMI care journey

Activity Summary	Key messages	Slides & Materials
Brainstorming activity	1	Slides 40-42 Flipchart, markers

Instructions

Activity (30 minutes):

Note: If time is limited, do this activity as a large group discussion. Ask participants for ideas on what they can do to address each of the types of barriers (attitudinal, physical, communication, and financial) and note responses on a flipchart.

- Ask participants to divide into the same four groups from Activity 1.2.1 (Barriers along the MAMI care journey).
- Explain the activity:
- You previously identified several attitudinal, physical, communication, and financial barriers that mother-infant pairs impacted by disability may face at each stage of their MAMI journey.
- You will now think of possible solutions that MAMI clinic staff or you could provide to address or mitigate these barriers and improve access to quality MAMI care for mothers and infants with disabilities.
- Include practices that you have used yourselves or have seen others use.
- Solutions can apply to any stage along the MAMI journey or can be linked to a specific stage.
- After 15 minutes, ask each group to share their responses and invite other groups to contribute more solutions.
- Provide additional solutions on each category if not shared by participants:
- *Attitudinal:* Awareness training for all MAMI staff; community awareness-raising activities; monitoring of discriminatory practices; zero policy for discriminatory practices; integration of disability education into curriculum and accreditation for all health service providers; longer and flexible appointment times; involving mothers in decision-making; assessment of the MAMI clinic policies for inclusion; collection of sex, age, and disability-disaggregated data; ensure health management information systems (HMIS) are inclusive.
- *Physical:* Outreach services; home visits; support with transport difficulties; ramp at health facility entrance; facility entrances clear of hazards and obstacles; accessible doorways, bathrooms, handwashing facilities, and examination rooms; accessibility audit of the health facility; adaptive equipment.
- *Communication:* Information available in a range of formats (i.e., radio, SMS messaging, TV, newspaper); health services engage local Organizations of Persons with Disabilities (OPDs) to distribute information to their members; involve OPDs in MAMI services; appointment reminders in accessible formats; available sign language interpreters; use of plain language, pictures, and other visual cues; use of signboards.
- *Financial:* Referral to social services for families with financial constraints; mapping of free-of-charge services available in the community; transportation assistance; home visits to lower transportation costs; voucher system that covers some special services.
- Conclude this section:
- This is just a beginning activity to get us starting to think about how we can provide solutions to barriers. As we move through the rest of the modules in this training, we will be exploring various solutions to some barriers in more detail.
- Conclude the module:

- This brings us to the end of this module. Now that you have a stronger understanding of disability and inclusion, what is one thing you will do differently when you work and interact with mothers and infants (or other persons) with disability?



Check before proceeding.

These are the key messages for this module. Have these been explicitly addressed and learners appear to have a good understanding of them?

1. The needs of many infants and mothers with disabilities can be met by making mainstream MAMI services more inclusive.
2. Promoting disability-inclusive attitudes through awareness raising and capacity building is key to providing disability-inclusive health services.

