# 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<br><br>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)** |
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| Applying the ICF framework |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Small group discussion | 2 | Slides 18-23<br><br>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, as 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<br><br>Mod 01_ActivitySheet_Case Studies A<br><br>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)** |
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| Barriers along the MAMI care journey |

| **Activity Summary** | **Key messages** | **Slides & Materials** |
|---|---|---|
| Brainstorming activity | 1 | Slides 27-31<br><br>Flipchart, markers<br><br>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?

<u>Activity (30 minutes):</u>

- 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<br><br>Mod 01_Activity Sheet_Attitudinal Barriers<br><br>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).

<u>Activity (10 minutes):</u>

- 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<br><br>Mod 01_Activity Sheet_Disability-inclusive Attitudes |

| | | |
|---|---|---|
| | | Mod 01_Activity Sheet_Disability-inclusive Attitudes_Answers |

## 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<br><br>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.

# MODULE 2

## Disability, Feeding, and Nutrition in Infants

### 2.1 Common Disabilities and Conditions in Infants

**Time:** 60 minutes

**Preparation & materials required:** Slide Deck, markers, pens or dried beans, Bingo cards.

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

- Recall disabilities and conditions that may occur during infancy.
- Define cleft lip/palate, tongue tie, cerebral palsy, Down syndrome, hydrocephalus, spina bifida, and poliomyelitis.

### Key message(s) to take away for learners:

1. Some conditions and impairments in infants start from birth, such as cleft lip and palate, tongue tie, Down syndrome, and spina bifida, while others may develop soon after birth, such as cerebral palsy, hydrocephalus, and poliomyelitis.
2. Focus on an infant's functional abilities, such as the ability to feed well, rather than a specific diagnosis.

| **Activity 2.1.1 (60 minutes)** |
|---|
| Common conditions/disabilities in infants |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Interactive presentation & Bingo! | 1 & 2 | Slides 43-64<br><br>Markers/pens or dried beans for each participant<br><br>Mod 02_Activity Sheet Bingo cards |

#### Instructions

- Introduce the module:
    - There are many conditions and types of disabilities that may occur during infancy. In this module, we will explore common conditions and disabilities in infants and discuss how disability is linked to nutrition and feeding.
    - We may use terms like conditions, impairments, and disabilities interchangeably. But keep in mind that not every condition or impairment leads to disability, as disability is the result of an impairment interacting with the environment (e.g., barriers).

- Explain key terms and concepts related to infant conditions and disability:
    - *Developmental milestones*:
        - Developmental milestones are skills that most children should have by a certain age. Examples include rolling over, smiling, and sitting up. Although the timing can vary from child to child, meeting developmental milestones within the expected time frame means a child is developing typically.
    - *Developmental delays*:
        - Not all children develop at the same rate — some children naturally take longer to develop than others and attain developmental milestones.
        - Developmental delay is used to describe when a young child is learning skills slower than other children their age. But this does not mean they have disability.
        - If a child's developmental delay lasts until they are school age, it can then be described as a disability.
        - Risk factors for developmental delays include congenital anomalies or disorders (sometimes called birth defects), children born prematurely or are underweight, nutritional deficiencies, having certain infections (e.g., cytomegalovirus or toxoplasmosis) or being exposed to certain medications while pregnant, and environmental toxins such as lead.
    - *Developmental disabilities*:
        - Developmental disabilities include limitations in function that manifest during infancy or childhood as delays in reaching developmental milestones or as a lack of function in one or multiple domains, including cognition, motor, vision, hearing and speech, and behavior. Developmental disabilities are caused by health conditions affecting the developing nervous system.
    - *Congenital anomalies (disorders)*:
        - Congenital means present from birth. Congenital conditions can be inherited or caused by environmental factors.
- Lead an interactive presentation of each of the conditions/disabilities below. You may ask participants about what they know about the conditions and the standard of care in the country *(e.g., What can you tell me about tongue tie? What is it? How is it identified and addressed in your country?)*. Encourage discussion after each description to ensure understanding and reinforce learning. *[Note: This section can be adapted to focus on conditions that are common to a country/region.]*

- *Cleft lip/palate:*
- Cleft lip and cleft palate are openings in the upper lip, the roof of the mouth (palate), or both. Cleft lip/palate occurs when these mouth structures do not form properly during a pregnancy.
- A cleft lip is a visible condition and, as a result, the infant and mother may experience stigma.
- Infants with cleft lip/palate have impaired sucking and may experience difficulty feeding, resulting in poor growth and development.
- If not repaired, tooth development is impacted. When the palate is involved, speech and hearing are commonly impaired.
- Intervention:

- Surgical repair to close the cleft is recommended as early as possible and is very effective. The infant must be a certain weight to qualify for surgery.
- Additional reconstructive services are sometimes needed.
- Speech therapy services might be needed for infants with cleft palate.
- Several organizations including Smile Train, Operation Smile and Operation Rainbow, amongst others, provide cleft care services and training in low-resource settings.
- *Tongue tie:*
- Typically, the tongue attaches to the floor of the mouth with a web of tissue called a frenulum. Tongue tie is when the frenulum is short, thick, or tethered too close to the tip of the tongue, keeping the tongue from moving freely.
- Normally, the tongue can move out past the lower lip and reach up to the roof of the mouth and upper teeth.
- Tongue tie forms during pregnancy. It can range from mild (only a tiny fold of tissue holds the tip of the tongue) to severe (the entire bottom of the tongue connects to the floor of the mouth).
- Intervention:
- Most infants with tongue tie do not need treatment if they are able to feed well with proper attachment and breastfeeding position. As the child grows, the frenulum stretches and gives the tongue enough freedom to move normally.
- A procedure might be needed if an infant has difficulty feeding and is not receiving enough milk. The procedure involves making a small cut in the frenulum with a scalpel or scissors.
- It is important to note that the procedure is often contraindicated for infants with certain conditions like neuromuscular disorders, hypotonia, and micrognathia (a condition in which the lower jaw is very small) as it may increase the risk for airway obstruction and may complicate swallowing.
- *Cerebral palsy:*
- Cerebral palsy is a condition that affects muscle tone, movement, and coordination due to damage to the developing brain. It affects the brain's ability to properly send messages to muscles about how to move in smooth or well-coordinated ways. Cerebral palsy can also affect other body functions that involve motor skills and muscles, like breathing, bladder and bowel control, eating, and talking.
- Cerebral palsy may occur while an infant is in the womb, during birth, or in the first two years of life.
- Causes may include:
- Genetic disorders
- Birth complications (e.g., interruption in the flow of oxygen to the infant's brain)
- Infants who have a very low birth weight
- Infants born before 32 weeks of pregnancy
- Fever or infections during pregnancy, such as chicken pox or rubella
- Injury to the child's brain due to an accident
- Injury to the child's brain because of an infection of the brain, such as meningitis
- If cerebral palsy is severe, some signs and symptoms may be evident at birth. In many children, however, symptoms appear over time, as the child develops. Signs and symptoms in infants vary widely and may include the following:
- Inability to lift own head by the appropriate age of development
- Muscle tone that is too tight (stiffness) or too loose (heavy or floppy arms and legs) or an overlap of both types (e.g., high tone in the limbs, but low tone in the trunk)

- Difficulty coordinating body movements, including grasping and bringing both hands together to the middle of their body.
- Delay in meeting developmental milestones, such as sitting up without support and rolling over
- Difficulty swallowing or uncontrolled drooling
- Intervention:
- There is no cure for cerebral palsy. However, starting therapies (e.g., physical, speech, feeding) early on for various areas affected can help a child grow to their potential, develop functional skills, and prevent secondary impairments.
- *Down syndrome:*
- Also called trisomy 21, Down syndrome is a condition in which an infant is born with an extra chromosome number 21. The extra chromosome is associated with delays in the child's intellectual and physical development, as well as an increased risk for health problems.
- Down syndrome happens by chance, cannot be prevented, and is not caused by anything a mother did or did not do.
- Children with Down syndrome often have similar physical features, such as a flat facial profile, an upward slant to the eyes, small ears, and a tongue that tends to stick out.
- Low muscle tone is also common in infants with Down syndrome. Infants will reach developmental milestones, like sitting up, but generally later than other infants do. Low muscle tone may also contribute to sucking and feeding problems.
- At birth, infants with Down syndrome are often smaller than other newborns, and they tend to grow at a slower rate and remain shorter than their peers.
- All infants with Down syndrome should be checked with for congenital heart defect, which is common in infants with Down syndrome.
- Intervention:
- Health issues and therefore the care required vary. For infants, it is important to address feeding difficulties and treat a heart defect if present.
- *Hydrocephalus:*
- Hydrocephalus is the build-up of the fluid that normally bathes the brain, called cerebrospinal fluid. It may be present at birth, but more commonly occurs progressively during early infancy.
- It commonly follows brain infections in newborns (meningitis, encephalitis), which creates scars in the brain, blocking the flow of cerebrospinal fluid. This causes pressure on the brain tissue with progressive brain damage and impairment if not treated. *[Meningitis: inflammation of the tissues surrounding the brain and spinal cord; Encephalitis: inflammation of the brain].*
- The most obvious sign of hydrocephalus in infants is a rapid increase in head circumference or an unusually large head size. Other symptoms may include seizures, vomiting, sleepiness, irritability, poor feeding, visible scalp veins, or bulging eyes that gaze downward.
- Intervention:
- Urgent surgical referral to a specialized hospital unit is needed. Delay in referral results in permanent physical and intellectual disability.
- The goal of treatment is to reduce pressure inside the infant's head by draining the extra fluid. This can be done with a mechanical shunt (a special tube) from the brain to the abdomen, where it is absorbed.
- Community follow-up is very necessary because as the child grows the shunt may fail and need to be replaced.

- *Spina bifida:*
- Spina bifida is a condition in which the spine does not form properly before birth. It is the most common type of neural tube defect.
- It usually happens in the first month of pregnancy when the neural tube (structure that eventually forms the baby's back and spine) does not develop or close properly, leading to defects in the spinal cord and bones of the spine (vertebrae).
- There are different types of spina bifida that range from mild to severe, depending on factors such as the size of the opening and the location of the opening on the spine. In the severe form, an open sore or bulging soft tissue can be seen on the infant's back.
- Hydrocephalus often accompanies this condition.
- Prevention:
- Folic acid (folate) supplementation before conception and during the early weeks of pregnancy reduces the incidence and severity of spina bifida drastically. Taking folate during pregnancy might be too late to prevent this impairment.
- All women of childbearing age should be encouraged to receive folic acid supplements (often provided together with iron supplements). Health workers should encourage the intake of foods rich in folate (dark leafy green vegetables, peas, kidney beans, chickpeas) and food sources that are fortified with folate, if available.
- Intervention:
- Urgent referral for surgery is necessary for the severe form of spina bifida to close the opening the infant's back and treat hydrocephalus. Lack of urgent care results in a very high mortality rate.
- When severe, the condition cannot be cured and leads to permanent impairment that requires long-term rehabilitation.
- *Poliomyelitis (polio):*
- Polio is an infection caused by a virus called the poliovirus. It mainly affects children under 5 years of age.
- It causes mild or no symptoms in most people. Rarely, the virus affects the brain and spinal cord, causing meningitis, muscle weakness, and paralysis.
- Polio is very contagious. The virus enters the body through the mouth and grows in the throat and intestines. It then spreads to other people via saliva (e.g., coughing, sneezing, sharing utensils) or feces.
- Intervention:
- There is no cure for polio, only supportive care and therapies (e.g., physical, occupational) to alleviate the symptoms.
- The polio vaccine is the best way to prevent polio.

## Activity (15 minutes):

- Tell participants that they will now test their knowledge about common infant conditions/disabilities by playing a game called Bingo.
- Distribute bingo cards and markers or dried beans to each participant.
- Explain the rules of the game and give an example if needed:
- Each of you has a Bingo card that might be different than that of other participants.
- Your Bingo card has the names of some of the conditions/disabilities we discussed, one condition per square.
- I will read a statement describing a condition or disability.
- Listen to my statement carefully and mark the appropriate square if you have it on your Bingo card.

- The first participant to complete a row, column, or diagonal on their Bingo card shouts "Bingo!"
- Read each statement one by one *[answers are between brackets]*:
- This condition means the upper lip does not fully form, resulting in a gap. *[Cleft lip]*
- This condition affects movement and muscle coordination, often appearing in early childhood. *[Cerebral palsy]*
- This condition happens when too much fluid builds up in the brain, causing increased pressure and head size. *[Hydrocephalus]*
- This condition happens when the tissue under the tongue restricts movement, which could make feeding difficult. *[Tongue tie]*
- This condition means there is a gap in the roof of the mouth, which can make feeding, speech, and sometimes hearing more difficult. *[Cleft palate]*
- Infants with this condition have an extra chromosome 21, which can delay how they grow and develop. *[Down syndrome]*
- This condition happens when the spine does not form properly and can be prevented with folic acid supplementation before conception. *[Spina bifida]*
- This condition is caused by the poliovirus, which is transmitted through contaminated food, water, or contact with an infected person. *[Poliomyelitis]*
- Continue playing until multiple participants achieve Bingo or until all descriptions have been read out.

- Conclude this section:
- Ask participants:
- What is one new thing you learned today?
- What is one thing you found surprising?
- Some conditions and impairments in infants start from birth while others develop soon after birth. Some conditions can be easily identified by observation or basic physical examination while others may require specialized medical services.
- It is important to note that it can be difficult to identify disability in infants under six months old. A disability may not be identified until much later when developmental milestones are not met. This becomes even more difficult in humanitarian emergency situations. That is why, focusing on function, such as ability to feed well, rather than having a diagnosis, can be a strategy to support infants who may have a suspected 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. Some conditions and impairments in infants start from birth, such as cleft lip and palate, tongue tie, Down syndrome, and spina bifida, while others may develop soon after birth, such as cerebral palsy, hydrocephalus, and poliomyelitis.
2. Focus on an infant's functional abilities, such as the ability to feed well, rather than a specific diagnosis.

## 2.2 The Link between Disability, Nutrition, and Feeding

**Time:** 40 minutes

**Preparation & materials required:** Slide Deck, flipchart, markers, sticky notes.

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

- Explain how disability contributes to poor growth and development in infants.
- Explain how poor nutrition can lead to or worsen disability in infants.
- Explain how functional difficulties in mothers may impact feeding.
- Discuss growth expectations for infants with disabilities.

### Key message(s) to take away for learners:

1. Infants with disabilities are more likely to be malnourished as malnutrition can cause disabilities and disability can also lead to poor nutrition, growth and development, creating a cycle.
2. Mothers with disabilities often encounter inadequate support with breastfeeding and access to healthcare for themselves and their infants.
3. While infants with certain disabilities may have altered growth patterns due to the disability itself, most infants with disabilities have poor growth because appropriate care plans and support are not in place.

| Activity 2.2.1 (40 minutes) |
|---|
| The link between nutrition and disability |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Brainstorming activity | 1, 2, & 3 | Slides 65-71<br><br>Flipchart, markers, sticky notes |

#### Instructions

*Note: If time is limited, do this activity as a large group discussion.*

- On a flipchart, draw two large circles that overlap. Write "NUTRITION, GROWTH, & DEVELOPMENT" inside the circle on the left and "DISABILITY" inside the circle on the right. Draw an arrow on top that goes from the right to the left circle ("Nutrition" to "Disability"), and an arrow at the bottom that goes the opposite way ("Disability" to "Nutrition").
- Introduce the activity, pointing to the diagram on the flipchart:
- Disability and nutrition are closely linked. Poor nutrition can lead to disability or even make a disability worse. There are also aspects of disability that may contribute to malnutrition.
- In this activity, you are going to complete the diagram by brainstorming nutrition-related factors that can cause or worsen disability (point to the top arrow) and aspects of disability that may contribute to poor child nutrition, growth, and development

(point to the bottom arrow). These factors can be about the mother, the infant, the family, the community, health facility practices, national policies, etc.

- Divide participants into four or six small groups (an even number). Give each group a set of sticky notes and markers.
- Ask half of the groups (two or three groups) to brainstorm "Nutrition à Disability" factors and the other half to brainstorm "Disability à Nutrition" factors. Encourage participants to include disability-nutrition linkages in a humanitarian context. Ask groups to write one factor per sticky note. Using the list below, provide an example for each to get the groups started (e.g., vitamin D deficiency causes rickets and infants with cleft lip/palate have feeding difficulties that may lead to poor growth).
- After 10 minutes, bring the large group back together.
- Ask the "Nutrition à Disability" group representatives to come up to the flipchart, place the sticky notes in the appropriate space, and share their responses.
- Invite the "Disability à Nutrition" groups to add to the list.
- Present information on the "Nutrition à Disability" link not shared by participants:
- *Maternal malnutrition*
- Low folate intake before conception and during early pregnancy may cause neural tube defects in children such as spina bifida
- Iodine deficiency during early pregnancy may lead to intellectual disability in children
- General maternal malnutrition contributes to physical and intellectual disability in children
- Poor maternal nutrition during pregnancy may cause adverse birth outcomes including low birth weight, premature birth, and congenital anomalies or disorders (sometimes called birth defects) (e.g., cleft lip and palate, heart defects), which are associated with an increased risk for disability
- Vitamin B12 deficiency in lactating mothers (such as in the case of untreated megaloblastic anemia) may cause developmental delays in infants
- *Child malnutrition*
- Vitamin D deficiency causes rickets
- Vitamin A deficiency causes blindness
- Protein deficiency may result in delayed physical growth or poor cognitive development
- Iron deficiency is associated with intellectual, learning and behavioral disability
- Iodine deficiency causes delayed cognitive development
- Ask the "Disability à Nutrition" group representatives to come up to the flipchart, place the sticky notes in the appropriate space, and share their responses.
- Invite the "Nutrition à Disability" groups to add to the list. Fill in gaps as needed by referring to the notes below.
- Present information on the "Disability à Nutrition" link not shared by participants:
- *Medical* (impairment is a direct cause of poor nutrition, growth and development)
- Conditions associated with oral motor difficulties (e.g., cleft lip and palate, cerebral palsy, Down syndrome) affect children's ability to eat safely and efficiently, leading to what are called feeding difficulties. They may limit the types and amounts of foods that children are able to consume.
- Certain conditions cause poor absorption of nutrients (e.g., cystic fibrosis, metabolic diseases).
- Certain conditions result in increased demands for energy and nutrients (e.g., cerebral palsy, congenital heart defect).

- Preterm infants commonly have reduced nutrient stores, immature digestive systems, feeding difficulties, and medical complications.
- Mothers with disabilities may have difficulty with breastfeeding:
- Mothers with cerebral palsy or physical disabilities (limited motion in arms or upper body; missing arms) may be unable to properly position and support their infant in order for them to latch properly.
- Mothers with learning or intellectual disabilities may have a difficult time understanding and following recommendations.
- Mothers with disabilities on certain medications may not be able to breastfeed.
- Breastfeeding may exacerbate symptoms of the disability (e.g., bone density) for mothers with certain disabilities.
- *Environmental* (educational, attitudinal, cultural, social):
- Inadequate knowledge among mothers on how to breastfeed an infant with difficulty feeding.
- Difficult feeding can lead to increased stress levels for the caregiver and the infant, which can result in insufficient food intake.
- Unsafe feeding practices that increase the risk for aspiration.
- Lack of training among healthcare providers on how to feed infants with certain conditions that impact feeding or how to support mothers with disabilities.
- Medical interventions that are not available (e.g., cleft repair, heart surgery).
- Lack of adaptive utensils like cups, bottles, and spoons when needed.
- Cultural norms that discourage mothers of newborns with a disability to breastfeed.
- Stigma and discrimination in the community and among healthcare providers that prevents mothers of infants with a disability or mothers with a disability to seek support.
- Lack of information on breastfeeding that is suitable for mothers with disabilities (e.g., breastfeeding positions for mothers with physical disabilities).
- Attitudinal barriers related to disability among healthcare providers, community members, program managers, and policy makers that hinder access to quality health services.
- Policies that are not inclusive of mothers with disabilities or infants with disabilities.
- Needs of mother-infant pairs impacted by disability might be overlooked in humanitarian contexts.
- Share with participants that studies have shown that children with disabilities are up to three times more likely to be malnourished, twice as likely to be stunted, twice as likely to be wasted, and twice as likely to die from malnutrition compared to children without disabilities.

- Present information on the impact of disability on physical growth of infants:
- Growth in infants with disabilities is not a product of a single, isolated factor. Genetic (e.g., family genetics, genetic disorders), biological (e.g., secondary medical conditions, impaired motor skills), and environmental (e.g., feeding practices, care practices) factors and their interaction can influence infants' growth. Determining which factors strongly influence an infant's growth can inform the design of an effective care plan for that infant.
- Infants with certain disabilities may have altered growth patterns as a direct result of the impairment. For example, cerebral palsy and Down syndrome may cause infants to grow differently than their typically developing peers. When compared to the World Health Organization growth standards, infants with these disabilities may appear to

be growing poorly. However, these growth patterns are influenced by many factors including medical conditions and the severity of the disability, as well as nutrition and feeding factors. A major challenge is to determine whether the factors contributing to this poor growth can be addressed directly or mitigated.

- In most cases, infants with disabilities have poor growth because appropriate care plans and support are not in place.
- Conclude this section:
- Poor nutrition in infants can lead to poor growth and health outcomes; missing or delays in reaching developmental milestones; acquiring avoidable secondary conditions; and, in extreme circumstances, death. At the same time, infants with disabilities may become malnourished due to feeding difficulties, frequent illness, difficulties absorbing nutrients, caregiver's lack of knowledge on feeding, and cultural and attitudinal barriers.
- This cycle is often exacerbated during humanitarian crises due to additional barriers.
- In the next module, we will discuss in more detail feeding difficulties and how certain disabilities may experience feeding difficulties.

**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 with disabilities are more likely to be malnourished as malnutrition can cause disabilities and disability can also lead to poor nutrition, growth and development, creating a cycle.
2. Mothers with disabilities often encounter inadequate support with breastfeeding and access to healthcare for themselves and their infants.
3. While infants with certain disabilities may have altered growth patterns due to the disability itself, most infants with disabilities have poor growth because appropriate care plans and support are not in place.

## 2.3 The intersection of Disability, Trauma, and Feeding

**Time:** 70 minutes

**Preparation & materials required:** Slide Deck, blank paper, markers (or crayons), stress connection scenario cards, stress level indicator sheets.

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

- Explore how the emotional state of both healthcare providers and mothers may affect each other.
- Recognize how stress, trauma, and disability may intersect and impact feeding practices.

**Key message(s) to take away for learners:**

1. Recognizing how stress affects healthcare providers and mothers and infant with disabilities enables the creation of better care strategies, resulting in healthier outcomes for both mothers and infants.
2. Disability-related stress is caused by stigmatization, lack of access to support, discrimination, and other abusive, violent, or exclusionary experiences or circumstances.
3. Maternal stress and trauma may impact the mother's ability to look after and bond with her infant, significantly influencing the infant's physical and emotional development.
4. When well supported, most mothers can begin or continue breastfeeding even in very challenging circumstances.

| **Activity 2.3.1 (20 minutes)** |
|---|
| Feelings Pie Chart |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Self-reflection activity | 1 | Slides 72-75<br><br>Blank paper and markers (or crayons) |

## Instructions

- Introduce this section:
- In this section, we are going explore the intersection of stress, trauma, and disability and how this combination of factors may impact feeding practices.
- In order to support mothers to deal with stressful situations, it would be helpful to understand different emotions that a mother might be going through.
- Let's start by first exploring our own emotions. It may be uncomfortable or unusual for some of you to think about your own feelings but understanding them is the first step towards providing compassionate and effective care for others.

### Activity (15 minutes):

*[Note: Activity is adapted from USAID Maternal and Child Survival Program (2019). Caregiver Psychosocial Support Session Guide: Helping Young Children with Disabilities Meet their Potential.]*

- Distribute the papers and markers/crayons to participants. Each participant needs one paper and a few markers/crayons. Participants sitting next to each other can share markers/crayons.
- Provide activity instructions to participants:
- Draw a large circle on your paper.
- Think of the different feelings that you have at this moment. It's okay if you are feeling many things at the same time. Sometimes we may feel happy and tired, or hopeful and angry.
- Make a list of those feelings with the corresponding color somewhere on the sheet of paper to create a "key" to understand how the pie is divided. *[Note: Show the slide with a list of feelings words and let participants know that they can refer to it if need support to describe their feelings].*

- Assign a color to each feeling. There is no right or wrong color to represent each feeling. Any color is okay.
- Then, divide the pie according to the size of each feeling you are experiencing at the moment. Some feelings will be stronger than others, so some pieces of the pie will be larger than others.
- Once you are done, share with the person sitting next to you if you feel comfortable doing so.
- After 10 minutes, bring the large group back together.
- Ask participants if anyone would like to talk about their drawing. *[Optional: Prepare your own feelings pie chart on a flipchart and share it with participants.]*
- Conclude this section:
- This activity is to help you recognize your feelings and realize that we all often have a mix of emotions at one time. This includes colleagues we work with, mothers we interact with, and family members we live with. These emotions may impact how we think, behave, work, treat others, and care for ourselves.
- In highly stressful or traumatic situations, negative emotions such as anger, worry, panic, irritability, fatigue, sadness, and helplessness may dominate feelings of joy, excitement, hope, and gratitude. Understanding how you and the mother-infant pairs in your care might be impacted by stress helps create better care strategies that support everyone, leading to healthier mothers and infants.

| **Activity 2.3.2 (50 minutes)** |
|---|
| Infant, mother, health worker stress connection and feeding |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Role-play & small group discussion | 1, 2, 3, & 4 | Slides 76-80<br><br>Mod 02_ActivitySheet_Stress Connection Scenario Cards |

## Instructions

- Introduce this section:
- The relationship between the mother, infant, and healthcare provider is crucial for ensuring the well-being and health of both the child and the mother. However, each of these individuals might be experiencing disability, trauma, and/or stress, leading to poor mental health and potentially impacting the infant's feeding, growth and development. This is exacerbated in traumatic and stressful situations including poverty, conflict, natural disasters, displacement, and other humanitarian/emergency contexts.
- *Mothers*:
- Pregnancy and the period after pregnancy are a psychologically distressing time for many women, particularly for those living in poverty, emergency situations, with violence, abuse, or an unintended pregnancy; those experiencing disability, and those who might be displaced from their homes and communities. Many women in low- and middle-income countries live in these circumstances.

- The birth of an infant with a disability is often perceived as the loss of a "perfect" infant and is typically an unanticipated event for the mother and family. Mothers may experience self-blame for the disability.
- Mothers with disabilities experience stress linked to their disability, stemming from stigmatization, limited access to support, discrimination, and encounters with abuse, violence, or exclusion. These challenges may arise from direct experiences related to their disability or from societal misconceptions about it.
- *Infants*:
- An infant's health and mental wellbeing are shaped by their relationship and interactions with their mother and other caregivers (e.g., whether they experience loving and nurturing interactions) and the level of stress in their environment.
- Maternal stress and trauma may impact the mother's ability to look after and bond with her infant. She may find it very difficult to soothe her infant, which may prolong her infant's experiences with stress.
- This dynamic becomes more complex when mother-infant pairs are impacted by disability without the presence of adequate care and support.
- *Healthcare providers*:
- Like everyone else, healthcare providers are influenced by their own experiences, families, communities and cultures. They have their own expectations and attitudes to the mothers they work with, no matter how professional and experienced they are.
- Factors that may affect healthcare providers range from external pressures (such as the work environment and personal relationships) to internal pressures (how they are feeling).
- Healthcare providers working in emergency contexts and in challenging circumstances may experience "secondary traumatic stress." This type of stress results from helping others who are suffering or who have been traumatized. It can have physical (headaches, heartburn), mental (difficulty concentrating), and emotional (feelings of grief, anxiety, or sadness) consequences in healthcare workers.
- In this section, we will explore how stress levels and mental health of the mother, infant, and healthcare provider are interconnected and how they impact each other.

## Activity (30 minutes):

*Note: If time is limited, skip the role-play. Ask participants to read their scenario and discuss the three questions listed below.*

- Divide participants into small groups of three. One group can have two or four participants if the class size cannot be divided equally into groups of three.
- Assign each participant in the group one of three roles: Mother, Infant, Healthcare Provider.
- Give each group a scenario card that describes a stressful situation. Tell participants that each scenario highlights potential stressors for all three roles.
- Participants will role-play a counseling session, during which the healthcare provider is counseling the mother, who brought her infant with her to the clinic, on breastfeeding and nurturing care.
- In their groups, participants role-play the scenario for 5 minutes, focusing on expressing and responding to stress in their assigned roles.
- After role-playing, each group then discusses the following questions:
- What are the specific stressors, traumas, and disabilities involved?

- How would the stress in one role affect the other roles?
- How may these stressors, traumas and disabilities intersect to impact breastfeeding and mother-infant interactions?
- Reconvene the entire group and invite small groups to share their experiences and insights from the role play and discussion.
- Use the flipchart to jot down key points shared by the groups, highlighting common themes.

- Present the following information on the impact of maternal stress on breastfeeding:
- When the infant suckles, two hormones are produced: the hormone "prolactin" stimulates milk production and the hormone "oxytocin" allows the milk to flow.
- The mothers' thoughts, feelings and sensations can affect the production of oxytocin.
- *Good feelings*, like thinking loving thoughts of her infant, touching, smelling or looking at her infant help the production of oxytocin.
- *Bad feelings*, like stress, worry, and pain can hinder the production of oxytocin and interfere with the flow of milk or even temporarily stop the flow of milk (not the production).
- Mothers experiencing insufficient milk flow might stop breastfeeding earlier. That is why it is crucial to support lactating mothers to cope with stress and improve their emotional state.
- Breastfeeding can be more problematic in emergency situations due to a higher chance of a mother having traumatic experiences, high stress levels and emotional difficulties. Breastfeeding can also be hindered by local myths and misconceptions, the mother's limited time, lack of space and privacy, insufficient support, and the unregulated distribution of breast milk substitutes. However, with proper technical and emotional support, enhanced coping skills for caregivers, and a supportive environment, most mothers can begin or continue breastfeeding even in challenging circumstances.
- Conclude this section:
- As healthcare providers, we should be aware of how our emotional state may influence the way we work and how our behaviors influence how a mother may feel.
- A mother experiencing stress and emotional difficulties is more likely to stop breastfeeding. However, with gentle and compassionate care, this can be improved. A mother who feels safe, understood, and well cared for is better able to bond with, breastfeed, and care for her infant. This highlights the crucial role of the healthcare provider.

**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. Recognizing how stress affects healthcare providers and mothers and infant with disabilities enables the creation of better care strategies, resulting in healthier outcomes for both mothers and infants.
2. Disability-related stress is caused by stigmatization, lack of access to support, discrimination, and other abusive, violent, or exclusionary experiences or circumstances.

3. Maternal stress and trauma may impact the mother's ability to look after and bond with her infant, significantly influencing the infant's physical and emotional development.
4. When well supported, most mothers can begin or continue breastfeeding even in very challenging circumstances.

## Optional Activity (5 minutes)

The topics in this session may bring up difficult emotions for some participants. Use the breathing exercise described below (or any meditation exercise you are familiar with) at the end or at any point during the session if you sense that the group needs calming.

[Note: Activity is adapted from *USAID Maternal and Child Survival Program (2019). Caregiver Psychosocial Support Session Guide: Helping Young Children with Disabilities Meet their Potential*.]

### Breathing Exercise Script

Show participants how to breathe.

*When you breathe in deeply, your belly should extend outward. When you breathe out, your belly moves in toward the spine. Explain that sometimes when we breathe, we take shallow breaths, filling the chest only a little. It is better to breathe deeply so the air fills your chest, expanding fully and pushing the belly outward. Then lead them through the following meditation.*

*Sit comfortably on the floor with legs crossed or on a chair with feet touching the floor; place one hand on your chest and one on your belly; keep your eyes closed. Slowly blow out through your mouth all the churned-up air from inside your body, as if you were blowing up a balloon (get it all out, blowing it into a make-believe balloon that you will then let fly away). Count one (to yourself). As you breathe in fresh, clean air through your nose, as slowly as you can, count two (to yourself). Blow the air out through your mouth, counting three (to yourself). Breathe in fresh air through your nose and count four (to yourself). Keep doing this until you count to 10. Watch those imaginary balloons filling with hot air and flying away!*

*Slowly return your attention to the room. Rub your hands together, and place them over your eyes. Then gently open your eyes.*

# MODULE 3

## Feeding Difficulties in Infants with Disabilities

### 3.1 Developmental Feeding Skills in Infants

**Time:** 50 minutes

**Preparation & materials required:** Slide Deck, flipchart, markers, scissors, 4 sets of developmental milestone sorting cards and the activity answer sheet, developmental milestones handout, Global Health Media video.

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

- Describe typical development of feeding skills in infants from birth to 6 months old.

### Key message(s) to take away for learners:

1. Developmental milestones progress in a predictable manner during certain windows of time, but all children learn and develop at different rates.
2. Feeding skills are developmental skills that develop over time and with opportunity to practice. Proper attachment, effective sucking, and safe swallowing are important components of efficient feeding in infancy. The skills and coordination developed in infancy lay the foundation for lifelong feeding skills.

| **Activity 3.1.1 (25 minutes)** |
|---|
| Developmental milestones |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Group sorting/matching activity | 1 | Slides 81-86<br><br>Scissors, tape, flipcharts<br><br>Mod 03_ActivitySheet_Developmental Milestone Sorting (4)<br><br>Mod 03_ActivitySheet_Developmental Milestone Sorting Answers (1)<br><br>Mod 03_Handout_Developmental Milestones up to 6 Months |

**Instructions**

- Introduce the module:
    - Developmental milestones are the behaviors or skills that mark a transition in a child's development such as learning to walk. Typical development is how those skills or behaviors are expected to be acquired over time.
    - Certain skills are expected to develop around certain ages and with opportunities to practice, but the exact time may be a little different for every child.
    - Each area of development continually interacts with the others and development in one area supports the development of other areas.
    - Understanding typical development and milestones related to feeding and nutrition is important because it will equip you to identify potential delays, know when to seek help, and support children to learn lifelong skills.

<u>Activity (25 minutes):</u>

- Prior to training, cut out and prepare four sets of milestone activity cards.
- Prepare four flipcharts, each with three columns labeled "2 months," "4 months," and "6 months." *Note: Flipcharts can be prepared with double-sided tape (5 pieces of tape under each column) ahead of time.*
- Divide participants into four teams. Give each team one set of 15 milestone activity cards and tape.
- Explain to participants that each team has 15 cards showing various developmental milestones. The task is to correctly sort developmental milestones by age in 5 minutes. Each team will work together to review the developmental milestones on the cards and decide together at which age a child might typically achieve each milestone: "2 months," "4 months," and "6 months." When ready, teams should tape the milestone activity cards in the appropriate column on the flipchart. Offer teams a tip that there are five milestones per age.
- After 5 minutes, use the Developmental Milestones Sorting Answers activity sheet to reveal the correct answers. Teams get a point for each correct answer; tally the points on their flipchart. The team with the highest points wins.
- Conclude this section by providing a summary of some key developmental milestones, highlighting feeding and nutrition-related milestones, from the handout by presenting this information:
    - *0 to 2 months*: Infants are typically learning to control their body against gravity, suck reflexively (automatically) to feed and should be consuming breast milk exclusively.
    - *4 months*: Infants are typically rolling actively from tummy to back and improving head and trunk control. For feeding, the tongue moves mostly forward/back. Infants at this age should be consuming breast milk exclusively.
    - *6 months*: Infants typically are now sitting with minimal or no support. When feeding, the tongue is able to move forward/back and up/down. The jaw moves up/down and the lips move together to gather food from a spoon. At this age, children should continue consuming breast milk and complementary foods can be introduced.
- Distribute the 0-6 Months Development Chart Handout and allow participants a few minutes to review it individually.

| Activity 3.1.2 (25 minutes) |
|---|
| Developmental feeding skills in infants |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Facilitated discussion | 2 | Slides 87-92<br><br>Flipchart, markers<br><br>Global Health Media video: Attaching Your Baby to the Breast (0:00 to 2:30 of 10:27) |

**Instructions**

- Introduce this section about developmental feeding skills:
- Lifelong feeding skills begin at birth, so it is important to support safe and efficient feeding from the beginning. Feeding skills are the abilities required to consume a developmentally appropriate diet safely and efficiently, ensuring children get the nutrition they need to grow and thrive.
- While healthy infants are born with some instinctual feeding skills, a child must go from drinking only breastmilk in infancy to eating the wide variety of foods that adults eat. In order to do that, a child must develop skills such as moving the parts of the mouth (e.g., lips, tongue, and jaw) to prepare and swallow food safely and easily.
- As with other areas of development, feeding skills develop over time and with the opportunity to practice. A child's ability to move the parts of their mouth changes as they grow, and this allows them to eat a wider variety of foods and textures.

<u>Activity (15 minutes):</u>

- Introduce the activity:
- You will view a short video clip of an infant breastfeeding. Watch the infant carefully and take note of what you observe about the infant's feeding skills.
- Show the "Attaching Your Baby at the Breast" video (from the beginning until 2:30).
- Ask participants to share some key observations about the infant's feeding during the video. Write down observations shared on a flip chart.
- To expand, ask participants questions to help identify specific aspects of the infant's feeding:
- What did you observe about the infant's jaw during feeding?
- What can you tell me about the infant's tongue during feeding?
- What did you observe about the infant's lips during feeding?

- Present information about some key aspects of feeding skills to expand on what participants shared:
- Well-coordinated feeding has a regular, rhythmic pattern of sucking, swallowing, and breathing:
- *Sucking* involves rhythmic movement of the tongue and jaw to extract liquid from the breast.
- *Swallowing* involves moving the liquid from the mouth to the stomach.

- *Breathing* involves coordinating breaths to avoid aspiration or prolonged periods of not breathing, also called apnea.
- A feeding typically begins with consistent bursts of the suck-swallow-breathe pattern and then the infant pauses to just breathe. The length of the burst depends on the age and development of the infant. Over the course of a feeding, the infant may start to feel full (or satiated) and the pattern may become more intermittent with longer or more frequent pauses.
- During breastfeeding, the tongue both compresses the breast tissue by pressing it toward the top or roof of the mouth and moves to help create suction which, together, efficiently extracts milk from the breast.
- The jaw moves only up and down. (As children advance their skills, they will be able to move it in a more diagonal/rotary pattern). When infants are sucking, you will notice their jaw moving, but they should not pull off the breast frequently or have wide, open mouth movements while latched.
- A proper attachment, or latch, is important for infants. A proper latch helps the infant get the most breast milk efficiently. And infants must have good lip closure with their lips around the breast with the lower lip flared outward, like a fish. A good latch helps the infant create the suction we just talked about, too. Most infants, especially after the first few weeks of life, should be able to maintain a proper latch independently throughout each feeding.
- Young infants have limited ability to control their body movement and posture. It is important for caregivers to provide support to the infant so they can maintain a safe position for feeding.
- Conclude this section:
- Check for evidence of learning by asking participants to share in their own words what they learned about feeding skills or how they understand feeding skills differently.

**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. Developmental milestones progress in a predictable manner during certain windows of time, but all children learn and develop at different rates.
2. Feeding skills are developmental skills that develop over time and with opportunity to practice. Proper attachment, effective sucking, and safe swallowing are important components of efficient feeding in infancy. The skills and coordination developed in infancy lay the foundation for lifelong feeding skills.

## 3.2 Types of Feeding Difficulties

**Time:** 45 minutes

**Preparation & materials required:** Slide Deck, flipchart, markers, Global Health Media video.

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

- Describe the types of feeding difficulties that are common in infants with disabilities.
- Define aspiration and recognize its signs and symptoms in infants.

## Key message(s) to take away for learners:

1. Any infant can have difficulty with feeding and up to 80% of children with developmental disabilities have feeding difficulties.
2. Reasons for feeding difficulties may include immature feeding skills, lack of responsive feeding practices, interruptions in typical development, poor nutrition, untreated illnesses, or other medical conditions or complications.
3. Aspiration can be very serious because it may lead to respiratory problems like pneumonia, dehydration, malnutrition, weight loss, or increased risk for illness.
4. Signs and symptoms of aspiration, like a wet-sounding voice or watering eyes, may happen during or right after feeding.

| **Activity 3.2.1 (25 minutes)** |
|---|
| Types of feeding difficulties |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Group discussion | 1 & 2 | Slides 93-100<br><br>Flipchart, markers |

**Instructions**

- Introduce this section by defining and discussing feeding difficulties:
- **Feeding difficulties** are a wide range of delays or issues that lead to oral intake that is not age appropriate.
- Safe and efficient feeding in infancy should have minimal risk for aspiration, provide sufficient nutrition for healthy growth and development, and be pleasurable.
- The severity and complexity of specific feeding difficulties in infancy can vary widely. Up to 80% of children with disabilities have feeding difficulties.
- You are familiar with the MAMI Feeding Assessment Form, which is used to assess feeding issues after a feeding risk has been identified. This step in the MAMI Care Pathway will begin the process of identifying feeding issues for the infant-mother pairs that you work with.
- In this section, we will take a closer look at feeding difficulties and aspiration and then identify issues that are common among infants with disabilities.

<u>Activity (20 minutes):</u>

- Prepare flipcharts with the following headings: Examples, Signs, Causes, Consequences.
- Introduce the activity by telling participants that we will discuss their experiences and understanding of feeding difficulties.

***Examples***

- Ask participants to describe the feeding difficulties that you have observed in your work. Write down the examples shared on the flipchart under "**Examples**."

- Provide additional examples of feeding difficulties that are common for infants with disabilities using this list:
- Difficulty latching
- Difficulty sucking or weak suck
- Poor lip closure around the breast
- Difficulty swallowing
- Using wide-open jaw movements or inconsistent jaw movements while feeding
- Difficulty coordinating sucking, swallowing, and breathing
- Poor endurance, prolonged feedings, or requiring more breaks while feeding
- Increased effort during feeding causing tiredness
- Difficulty finishing an adequate amount
- Breast milk spilling from the mouth while feeding

***Signs***

- Ask participants:
- What are some **signs**, or things that you or a mother may observe, that might indicate an infant is having difficulty feeding? Think about any signs that you have observed before, during, or after the infant is feeding that have made you think that the infant is having issues.
- Write down the signs and symptoms share under "Signs."
- Provide additional examples of signs that an infant is having feeding difficulties using this list:
- Frequent nasal congestion
- Loss of milk from the mouth or nose
- Fatigue or falling asleep while feeding
- Difficulty finishing an adequate amount
- Prolonged feeding
- Arching back during feeding
- Frequent gagging
- Coughing or choking
- Frequent or repeated vomiting
- Low number of wet diapers
- Poor weight gain

***Causes***

- Ask participants to explain the reason or **causes** for some of the feeding difficulties that they named. Write down key words describing the causes of feeding difficulties that they encounter in their work on the flipchart under "Causes." *Note: Participants may share examples of beliefs about the causes of feeding difficulties, as well. If it is appropriate, you can try to discuss some of those further, especially if there are myths that could contribute to harm or stigma.*
- Present information about the causes to expand the conversation:
- There are many reasons that any infant may have feeding difficulties such as limited opportunities to practice feeding skills, poor nutrition, or a lack of responsive feeding and care practices.
- Issues with body function or body structure, like a palate that has a cleft for example, can limit an infant's ability or efficiency, interrupt their skill development, or put them at risk for aspiration.
- Certain aspects of disability can disrupt the typical progression of development, including developing the skills needed for feeding (e.g., when stigmatization (attitudinal barriers) leads to isolation or limited interaction from caregivers or family,

then an infant may miss out on critical stimulation that supports development of skills).
- Issues within the infant's gut, intestines, or throughout the gastrointestinal (GI) tract can also contribute to feeding difficulties (e.g., an infant who has severe reflux or frequent constipation may feel pain and discomfort during or after eating and begin to avoid feeding or limit the amount they consume.).
- Other complex medical needs can contribute to delays in developing skills due to the nature of the condition or due to secondary impacts such as illness, hospitalizations, procedures, or long recovery times.

***Consequences***

- Ask participants: what are the possible **consequences** of feeding difficulties?
- Write down key words mentioned by participants on the flipchart under "Consequences."
- Explain
- Poor feeding in infancy can lead to serious issues with growth and development. It is important to avoid dismissing feeding difficulties as something that will improve on their own over time. The consequences of unaddressed feeding difficulties can include choking, frequent illness, malnutrition, and even death.

- Conclude this section:
- Many factors can contribute to feeding difficulties, such as: medical, nutritional, feeding skill, and/or psychosocial issues.
- Ask participants to reflect on how their understanding of feeding difficulties has changed or improved after this discussion. Invite 1-2 participants to share their reflection.

| **Activity 3.2.2 (20 minutes)** |
|---|
| Understanding aspiration |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Small group brainstorm | 3 & 4 | Slides 101-106<br><br>Flipchart, markers<br><br>Global Health Media video: A small baby's feeding journey (1:13 to 1:23) |

**Instructions**

- Introduce this section:
- Feeding is a complex task, but we all need to do it every day. In fact, swallowing involves the coordination of more than 30 muscles and nerves.
- **Safe swallowing** is the timely and coordinated movement of food or liquid from the mouth to the stomach.
- Define aspiration:
- **Aspiration** is when food or liquid enters the airway or lungs instead of the tube leading to the stomach (esophagus). Food and liquid should never be in the airway.

- You cannot know for certain if someone is aspirating just by looking at them. However, there are often signs that you can observe that may suggest that the infant is aspirating. Coughing and choking during feeding, for example, are often a sign that the body is trying to protect the airway and lungs from food, liquid, or saliva.
- Signs or symptoms of aspiration may happen during feeding or right after. The signs may depend on the age of the infant, how often, and how much they aspirate. Infants and children may show one or many signs. Some who aspirate may not show any outward signs. This is called **silent aspiration**. In fact, research has shown that most aspiration in young infants is silent aspiration.
- Many infants with disabilities may be at higher risk for frequent aspiration.
- If aspiration occurs frequently, in large amounts, or the child is not able to cough sufficiently, it can be very serious and lead to respiratory problems such as pneumonia, dehydration, malnutrition, weight loss, and increased risk of illness.

Activity (15 minutes):

- Introduce the activity:
- You will view a short video clip of an infant having difficulty swallowing. Watch carefully for signs that the infant is having difficulty swallowing. Afterwards, you will brainstorm a list of signs of aspiration. Use what you observed during the video and think about your own experiences with infants to make a list of signs of aspiration. *Note: It may be helpful to show the short clip more than once.*
- Show the brief clip from the "A Small Baby's Feeding Journey" video (from 1:13 to 1:23).
- Once participants have had a few minutes to make a list of the signs of aspiration, invite participants to share 1-2 examples.
- Record the signs and symptoms shared on a flipchart.
- Use this list of signs and symptoms of aspiration in infants to add to or clarify the list:
- Signs or symptoms of aspiration may include:
- coughing or choking
- wet-sounding or rattling voice
- facial grimacing
- change in color of face (e.g., redness or blue)
- watering eyes
- redness around the eyes during or after feeding
- runny nose
- gulping
- difficulty breathing (e.g., fast breathing, wheezing)
- frequent respiratory illness
- poor weight gain
- Conclude this section:
- Remember that aspiration can be very serious, can be silent, and can happen during or right after feeding.

**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. Any infant can have difficulty with feeding, and up to 80% of children with developmental disabilities have feeding difficulties.
2. Reasons for feeding difficulties may include immature feeding skills, lack of responsive feeding practices, interruptions in typical development, poor nutrition, untreated illnesses, or other medical conditions or complications.
3. Aspiration can be very serious because it may lead to respiratory problems like pneumonia, dehydration, malnutrition, weight loss, or increased risk for illness.
4. Signs and symptoms of aspiration, like a wet-sounding voice or watering eyes, may happen during or right after feeding.

## 3.3 Identifying Feeding Difficulties

**Time:** 120 minutes

**Preparation & materials required:** Slide Deck, flipchart, infant feeding difficulties checklist.

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

- Recognize when mother-infant pairs impacted by disability are experiencing feeding difficulties.
- Know specific feeding difficulties for infants associated with cleft lip/palate, cerebral palsy, Down syndrome, hydrocephalus, and spina bifida.

### Key message(s) to take away for learners:

1. It is important to take a systematic approach to look at various aspects of feeding before, during, and after the process to identify feeding difficulties and provide the information needed to select targeted interventions.
2. Some conditions may contribute to delays in skill development. Some may affect the structure or function of an infant's body. Many of these factors may make it difficult for the infant to safely and effectively feed and to get an adequate amount of nutrition for healthy growth and development.
3. Knowing common symptoms for specific conditions can equip you to anticipate some of the feeding difficulties that an infant with that condition may face. When you know what to look for, you will be able to better support mothers and caregivers to recognize and address feeding difficulties early.

| Activity 3.3.1 (80 minutes) |
|---|
| Identifying feeding difficulties |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Infant Feeding Difficulties Checklist overview | 1 | Slides 107-133<br><br>Flipchart, markers<br><br>Mod 03_Handout_Infant Feeding Difficulties Checklist |

**Instructions**

- Introduce this section by asking one participant to summarize the feeding assessment that they typically complete as part of the MAMI Care Pathway. Provide additional information if not shared by participants:
- Establish how the infant is fed.
- Ask the mother to describe the feeding concerns and how often the infant is fed.
- Observe breastfeeding (if possible and with permission) to determine if the infant is well-attached, sucking effectively, and identify any breast conditions.
- Identify/investigate if the infant is receiving anything other than breast milk or more details about infant formula.
- Explain how identifying feeding difficulties for some infants may require a closer look at the infant's feeding:
- For infants with disabilities and more significant feeding difficulties, a closer look at their feeding skills will provide insight and guide you to select targeted support for the mother-infant pair to ensure that feeding is adequate (i.e., enough nutrition) and safe (i.e., reducing risks of aspiration).
- The severity and complexity of specific feeding difficulties in infancy can vary widely. In order to identify feeding difficulties, you must take a systematic approach, looking at various aspects of feeding to identify the issues that can be addressed.
- Today, we will look at how to further investigate feeding difficulties by looking at key aspects of feeding during three parts: *before* feeding, *during* feeding, and *after* feeding.
- Introduce the Infant Feeding Difficulties Checklist handout and explain that it can be used as a job aid to systematically look at key aspects of an infant's feeding in order to identify feeding difficulties and provide the information needed to select targeted interventions to address the issues identified.
- Distribute a copy of the Infant Feeding Difficulties Checklist to each participant.
- Ask participants to spend around 5 minutes reading through the form.
- Bring the group back together. Present each section of the Feeding Difficulties Checklist using the slides and the information below.

***Before feeding***

- Ask participants: how do you know an infant is ready to feed?
- Listen to responses and then present information about what to look for before feeding:
- Readiness to feed can be assessed by looking at three things:
- an infant's alertness,
- muscle tone, and
- non-feeding suck.
- A number of conditions or complications can impact an infant's readiness to feed. For infants that need additional support for safe and adequate feeding, careful attention to these factors prior to feeding can help you support improved feeding.
- It can be helpful to recognize the ways an infant may communicate readiness to feed. When mothers recognize the different moods, behaviors, and expressions of their infant, they are better able to respond to the infant. You are familiar with infant feeding cues and the support actions you can take to help a mother understand early hunger cues.

- Let's take a closer look at each of the three factors and how we can use the checklist to support the mother and her infant:

1) *Alertness:*

- It is helpful to understand an infant's state of alertness to better anticipate their needs. Infants transition between states of alertness multiple times per day. Mothers can help their infant learn the skills to eat well by feeding them when they are in the appropriate state of alertness. Here are four key states for infants:
- *Drowsy*: The infant's eyes start to close and may doze.
- *Quiet, alert*: The infant's eyes are open wide, and face is bright, but their body is quiet.
- *Active, alert*: The infant's face and body are actively moving.
- *Crying*: The infant cries, or perhaps, screams. The infant's body moves in irregular ways.
- The most ideal state for feeding is a **quiet, alert state** when the infant is calm and attentive to their environment.
- *Checklist instructions*: Observe the infant's state before feeding to determine if they need support to transition to a better state for feeding, which will allow the infant to engage in feeding and build important skills.

2) *Muscle tone:*

- Muscle tone is the tension in a muscle at rest. It is important for balance, posture, and preparing muscles to move. Certain conditions can impact an infant's muscle tone, which may have an impact on feeding. Understanding an infant's muscle tone can help you prepare the infant better for feeding.
- *High tone (hypertonia)*: when there is too much tension at rest. High tone can make feeding difficult. An infant with high tone appears stiff with muscles that feel "tight." The infant's tongue may be bunched up or pulled to the back of the mouth and their jaw may be clenched. The infant may have difficulty controlling jaw and tongue movements for sucking and swallowing, difficulty maintaining positioning, and tends to burn a lot of calories requiring more feeding to meet their nutritional needs.
- *Low tone (hypotonia)*: when there is not enough tension at rest. Low tone can make feeding difficult. A child with a low tone appears floppy and muscles seem flexible. The infant's arms may fall to the side or appear limp. Their mouth may be mostly open, and the tongue may be sticking out or touching the roof of the mouth. Infants with low tone may have difficulty swallowing and digesting, have muscles that tire easily, and have difficulty maintaining positioning.
- *Checklist instructions*: Observe the infant and, if possible, hold or touch the infant to assess muscle tone. Pay attention to how easy the infant is to handle, their head control, the symmetry of their movements, if the infant's body curls up or falls to the side, and if the body feels stiff to determine if the infant has high tone, low tone, or no concerns.

3) *Non-feeding suck:*

- This is the sucking that infants do when there is no breast milk to swallow and is usually done for comfort. This kind of sucking is typically more rapid than the pattern used for feeding. It also does not require as much coordination because there is nothing to swallow. While it is different from the sucking used to feed, it can provide some important information about the infant's feeding skills.

- *Checklist instructions*: Assess the infant's non-feeding suck by gently placing the tip of a clean and gloved finger into the infant's mouth. A gentle touch to their palate should elicit automatic sucking (reflex) for young infants. As the infant sucks, you can feel the movement of the tongue, strength of suction, and assess how long the infant is able to suck. If the infant has well-coordinated and rhythmic sucking, you can continue to observe feeding. If the infant has weak sucking or is biting/munching, this may be a sign of potential feeding difficulties. If the sucking reflex is completely absent or you notice any change in the infant's breathing or heart rate and non-feeding sucking is too effortful or stressful, the infant may not be ready to feed at this time. Referral for additional assessment may be necessary.
- Check for questions and clarify understanding before continuing to the next section of the checklist.

### *During feeding*

- Similar to the aspects of feeding that you already are familiar with observing, for infants with feeding difficulties, careful attention to latch, sucking, and swallowing are critical to identifying feeding difficulties:

#### *1) Latch:*

- A proper latch, or how the infant attaches to the breast, is important for infants to feed safely and adequately. A proper latch helps the infant get the most breast milk efficiently. This is a component of feeding that you are familiar with assessing.
- Ask participants: what four things do you look for when assessing attachment?
- Listen to participants responses. Use these key points from the MAMI Counseling Cards (A1) if not shared by participants:
- Infant's mouth wide open when breastfeeding.
- Infant's lower lip turned outwards.
- Infant's chin touching breast.
- You can see more darker skin (areola) above than below the infant's mouth.
- These observations describe well-coordinated and effective suckling. Remember that well-coordinated feeding has a regular, rhythmic pattern of sucking, swallowing, and breathing. To identify feeding difficulties, we will look at both sucking and swallowing.
- *Checklist instructions*: Observe the infant feeding to determine if the infant has a wide latch with a complete seal of the lips around the breast, if the seal is adequate, and if the infant is able to maintain the attachment throughout the feeding. If the latch is shallow, the lip seal is poor, or there is frequent loss of latch, these may be indicators of feeding difficulties.

#### *2) Sucking:*

- Sucking involves rhythmic movement of the tongue and jaw to extract liquid from the breast. Sucking is a reflex. Infants are born automatically knowing how to suck, but as they grow, it will not be automatic, and they will need to have the skills to continue to effectively feed. This is part of why successful early feeding builds a foundation for lifelong feeding skills. During breastfeeding, an infant's sucking pattern may change depending on the flow of milk throughout a feeding. Typically, infants are able to cope with changes in flow and maintain rhythmic, coordinated sucking throughout. If an infant struggles to establish or maintain rhythmic, coordinated sucking, they may use

immature or disorganized patterns that are less efficient or that may put them at risk for aspiration.
- *Checklist instructions*: Observe the infant sucking to determine if it is well coordinated and rhythmic or disorganized, weak, with long pauses, wide-open jaw movement, or poor endurance.

*3) Swallowing:*

- Recall that a safe swallow involves the timely and coordinated movement of breast milk from the mouth to the stomach. A delayed or uncoordinated swallow may lead to aspiration.
- *Checklist instructions*: Observe the infant feeding and take note of any signs or symptoms of aspiration or other difficulties swallowing. Signs of aspiration suggest difficulty feeding.
- Check for questions and clarify understanding before continuing to the next section of the checklist.

***After feeding***

- Observing an infant's state after feeding and for signs of discomfort are a key component for identifying feeding difficulties.

*1) State:*

- It is helpful to understand an infant's state of alertness at the end of feeding, too. Infants will communicate when they are full or satisfied and they may also display signs of stress, fatigue, or discomfort. Stopping a feeding when an infant communicates fullness reinforces their communication skills and may help reduce discomfort from overfeeding or reflux.
- *Checklist instructions*: Observe the infant at the end of the feeding. Note if the infant appears settled and content, more tired than expected, or crying/fussing. These observations will help you determine if the infant has received adequate milk, is getting very tired, or experiencing any discomfort.

*2) Signs of discomfort:*

- Infants may communicate discomfort in a number of ways including crying, agitation, fussing, and vomiting. Spitting up a small amount within the first hour after a feeding is common among young infants. However, vomiting frequently or in large amounts could mean the infant has had too much milk, they are not tolerating the milk or the amount, or the infant swallowed too much air while feeding. Infants with feeding difficulties may experience vomiting more often.
- *Checklist instructions*: Observe the infant at the end of feeding or ask the mother to report any signs of discomfort after feeding.
- Check for questions and understanding before concluding this section.

<u>Activity (10 minutes):</u>

- Tell participants that they will now test their knowledge about identifying feeding difficulties by playing a game.
- Explain the rules of the game and give an example if needed:
- Each of you, if you are able, will stand up.

- I will read a true/false statement about identifying feeding difficulties.
- If you think the statement is true, place your hands on your head.
- If you think the statement is false, place your hands on your hips.
- *Note: if participants are not comfortable or able to stand, you can select different gestures for each answer. For example, place your hands on your head for true and your hands on the table for false.*
- Listen to my statement carefully before making the gesture to indicate your answer.
- Read each statement one by one *[answers are between brackets]*:
- The most ideal state for feeding is a quiet, alert state. *[True]*
- During breastfeeding, an infant's sucking pattern may change depending on the flow of milk. *[True]*
- For infants, non-feeding sucking is the same rate and pattern as the sucking used for feeding. *[False, non-feeding sucking is more rapid than the pattern used for feeding.]*
- A delayed or uncoordinated swallow may lead to aspiration. *[True]*
- High tone is when muscles appear floppy or flexible. *[False, high tone is when muscles appear tight or stiff.]*
- It is only important to pay attention to an infant's state before feeding. *[False, the infant's state after feeding can provide critical information about the infant's skills and challenges.]*
- Proper attachment requires a wide latch and complete seal of the lips around the breast. *[True]*
- Infants may communicate discomfort or pain by crying or fussing. *[True]*
- Continue playing until all statements have been read out.

- Conclude this section:
- Ask participants about their own experiences of observing infants breastfeeding:
- Are there any other signs you consider as an indication that breastfeeding is 'going well'?
- Are there any other observations you typically recognize as signs of possible feeding difficulties?
- Are there any other signs you recognize as "red flags"?

*<u>Optional activity note:</u> Ahead of training, if country staff are able to collect video clips of infants with disabilities breastfeeding, these can be used for participants to practice completing the Infant Feeding Difficulties Checklist. Prepare for this activity by viewing the clips ahead of the training and preparing a completed checklist to provide answers and expand understanding.*

| **Activity 3.3.2 (40 minutes)** |
|---|
| Feeding Difficulties Associated with Specific Conditions |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Small group brainstorm | 2, 3 | Slides 134-142<br><br>Flipchart, markers |

**Instructions**

- Introduce this section by explaining that each infant is unique and many factors may contribute to their individual feeding needs and challenges. However, with certain conditions, we may be able to anticipate some of the feeding difficulties that an infant with that condition may face. Knowing what to look for can help you support mothers to watch for signs of feeding difficulties so that they can be identified early and provided with the support the infant needs.
- Provide an example of how understanding a specific condition may help you anticipate possible feeding challenges.
- *Prematurity*: Infants born prematurely, that is before 37 weeks of gestation, commonly have reduced nutrient stores, immature digestive systems, immature or absent skills required for feeding, and other medical complications that can impact feeding. Using the Infant Feeding Checklist, I would expect to see signs of possible difficulty *before* feeding, *during* feeding, and *after* feeding.
- Before feeding, I might expect an infant born prematurely to have difficulties with alertness and non-feeding sucking.
- During feeding, I might expect to see reduced intake of breast milk, immature sucking, and difficulty coordinating sucking, swallowing, and breathing.
- After feeding, I might expect possible issues with frequent vomiting.

Activity (30 minutes):

- Divide participants into at least four small groups.
- Assign each group a specific condition (Cleft lip/palate, cerebral palsy, Down syndrome, and hydrocephalus/spina bifida).
- Provide each group with a blank piece of flipchart paper and markers.
- Explain the activity:
- Based on your experience and today's discussion about feeding skills and feeding difficulties, brainstorm potential feeding difficulties that you might anticipate for your assigned condition. Use the Infant Feeding Difficulties Checklist to help you systematically consider which aspects of feeding an infant with the condition may experience. Use the flipchart paper to write down some of the key challenges you anticipate for the assigned condition.
- After 15 minutes, ask each group to share and invite other groups to contribute to the lists of anticipated challenges.
- Provide additional detail or expand on each condition if not shared by participants:
*Cleft lip/palate:*
- Infants born with an opening in the lip, palate, or both may face a variety of feeding challenges, depending on the size and/or location of the cleft. Sometimes, clefts are associated with syndromes, which could contribute to further complications. I would expect to see signs before, during, and after feeding.
- Before feeding, the infant may have difficulty with non-feeding sucking. The gap in the lip or palate can cause an inadequate or weak lip seal, making it more difficult.
- During feeding, an infant with a cleft lip or palate may have difficulty achieving a good latch with a complete seal around the breast. The opening in the lip causes air to escape and feeding can be inefficient. With a cleft palate, the opening in the mouth affects the amount of suction and eliminates the surface against which to compress the breast which both make extracting milk from the breast more difficult and inefficient. With an opening in the lip or palate, milk can also escape into the nose.
- After feeding, the infant may be more likely to experience discomfort due to the large amount of air that infants with cleft lip/palate may swallow during feeding. In addition,

the infant's state may be more tired than expected due to the inefficient feeding which may mean the infant consumes less breast milk and/or takes a very long time to feed.

*Cerebral palsy:*

- Infants with cerebral palsy are likely to have issues with their muscle tone. If the infant has high tone, the stiffness of the muscles may impact how they move their tongue, jaw, and lips and the infant may require support to achieve a stable and safe position for feeding.
- Before feeding, the high tone may impact sucking both for comfort and for feeding. The infant may bite down or "chomp" instead of sucking.
- During feeding, the high tone may make it difficult to open the mouth wide enough or may open it too wide, making it difficult to achieve and maintain a good latch. Some infants with cerebral palsy may be at higher risk for aspiration, as well.
- After feeding, the infant's state may be more tired than expected due to the inefficient feeding which may mean the infant consumes less breast milk and/or takes a very long time to feed. In addition, Infants with high tone tend to burn more calories and may need more milk. Often, infants with high tone are more likely to vomit after feeding, as well.

*Down syndrome:*

- Infants with Down syndrome tend to have low muscle tone. Infants with low tone may not be alert enough to feed or may get tired quickly and not have enough stamina for a full feed.
- Before feeding, I would expect to see potential challenges with alertness. Some infants with lower tone may require support to achieve and maintain an ideal state for feeding. Low tone may impact the infant's success with non-feeding sucking, as well. A weak seal or uncoordinated sucking may be observed for some infants with low tone.
- During feeding, infants with low tone may require support for positioning in order to breastfeed or to maintain good attachment. With lower tone, the infant will require increased effort to maintain a complete seal. Low tone is associated with reduced sensation in the body, too, which includes within the mouth and throat. This may make it difficult for the infant to feel the milk in their mouth and impact their ability to swallow at the right time, which can increase the risk for aspiration.
- After feeding, infants with low tone may be more tired than expected due to inefficient feeding and are more likely to vomit after feeding, as well.

*Hydrocephalus:*

- The impact of hydrocephalus can vary widely depending on any co-occurring conditions or the amount of pressure within the infant's brain. Hydrocephalus can cause certain symptoms soon after birth, such as irritability, seizures, drowsiness, and poor feeding. This could impact the infant's alertness and readiness to feed.
- Before feeding, some children with hydrocephalus may have difficulty achieving and maintaining an ideal state for feeding.
- During feeding, untreated hydrocephalus can also impact an infant's movement skills. This may impact the infant's ability to achieve and maintain good attachment and to suck effectively. The infant may require support for good positioning.

- After feeding, careful attention to the infant's state would be important for infants with hydrocephalus, too. With inefficient feeding, the infant may be more tired than expected.

*Spina bifida:*

- The severity of this condition can range widely from one child to the next. Some infants with spina bifida may not experience feeding difficulties in infancy at all. Some infants with spina bifida also have hydrocephalus. When this is not well-managed, it can cause seizures and other neurological challenges that can contribute to or cause feeding difficulties. There may not be obvious feeding concerns before or during feeding based on this condition alone.
- After feeding, infants with spina bifida may demonstrate signs of discomfort. Many children with spina bifida experience bowel problems. Problems within the GI tract can contribute to feeding difficulties for some infants.

- Conclude this section:
- Check for questions and clarify.
- Certain conditions and developmental disabilities can limit or interfere with an infant's ability to feed properly. A number of conditions can contribute to delays in skill development. Some may affect the structures or functions of the body. Others may limit/ increase the infant's risk for aspiration. Many of these factors may make it difficult for them to get an adequate amount of nutrition for healthy growth and development.

**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. It is important to take a systematic approach to look at various aspects of feeding before, during, and after the process to identify feeding difficulties and provide the information needed to select targeted interventions.
2. Some conditions may contribute to delays in skill development. Some may affect the structure or function of an infant's body. Many of these factors may make it difficult for the infant to safely and effectively feed and to get an adequate amount of nutrition for healthy growth and development.
3. Knowing common symptoms for specific conditions can equip you to anticipate some of the feeding difficulties that an infant with that condition may face. When you know what to look for, you will be able to better support mothers and caregivers to recognize and address feeding difficulties early.

# MODULE 4

## Strategies to Address Feeding Difficulties for Infants with Disabilities

### 4.1 Addressing Feeding Difficulties Before, During, and After Feeding

**Time:** 145 minutes

**Preparation & materials required:** Slide Deck, flipchart, markers, dolls, blanket/cloth/scarf, MAMI Counseling Cards (generic or country-specific), applying strategies during feeding activity sheet & answer key.

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

- Apply MAMI breastfeeding support actions for infants with disabilities.
- Learn strategies for supporting infants with disabilities to breastfeed successfully.

### Key message(s) to take away for learners:

1. Managing alertness and tone are important ways to support an infant before feeding.
2. A variety of breastfeeding positions may support an infant with disabilities to achieve and maintain good attachment during feeding.
3. MAMI breastfeeding support actions can be applied to support infants with disabilities and their mothers.
4. Infant feeding recommendations should aim to improve safe and effective feeding for both the infant and mother, always prioritizing the principle of "do no harm."
5. Understanding an infant's communication and cues equips mothers to provide responsive care and discern if their infant is getting enough or experiencing any discomfort after feeding.

| Activity 4.1.1 (45 minutes) |
|---|
| Strategies to prepare infants with disabilities before feeding |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Swaddling activity | 1 | Slides 143-151<br><br>Dolls, blanket, cloth or scarf for each doll |

**Instructions**

- Introduce the module:
    - Once you have systematically looked at an infant's feeding and identified the issues, then you will have important information to help you select targeted interventions to address the feeding difficulties identified.

- We discussed how to investigate feeding difficulties by looking at key aspects of feeding during three parts: before feeding, during feeding, and after feeding. We will look at some key strategies to address challenges during each of these key parts.

***Managing alertness***

- Explain managing alertness:
  - Before feeding, one of the first areas of intervention is managing the infant's alertness.
- Facilitate a conversation about strategies to manage an infant's alertness using the following questions as prompts and then referring to the notes below to offer additional suggestions:
  - What kind of strategies do you use/recommend to alert a drowsy or sleepy infant?
  - What kind of strategies do you use/recommend to calm an agitated or crying infant?
  - What do you think would happen if infants with feeding difficulties are fed while sleepy/asleep? Why could this be a problem?
- Present the following strategies to help manage an infant's alertness:
  - You can help an infant transition to a better state for feeding by changing the environment or amount of stimulation the infant is given.
  - If the infant is drowsy or sleepy, then they may need to be alerted.
    - Try changing the environment, for instance, by turning on a light or moving to a space that is brighter. Or you can offer something to see, hear, or suck to help rouse the infant to a more alert state.
    - Other strategies to alert a drowsy or sleepy infant include removing layers of blankets, holding the infant upright and rocking gently side-to-side, and using firm but gentle pressure/damp cloth to touch the baby on the face, extremities or chest.
  - If the infant is very active, agitated, or crying, then they may need to be calmed.
    - Try dimming the lights, moving to a space that is more dark or shaded and not so bright, or removing distractions (e.g., visual and sounds) to promote a calm, quiet state.
    - Other strategies to help calm an infant include wrapping the infant in a cloth (swaddle), skin to skin, or gently patting the infant's back rhythmically (avoid bouncing).
  - Many infants, especially in the first few months, will still suck on the breast in a drowsy state. For infants with feeding difficulties, however, feeding when drowsy or sleepy may make it difficult to achieve good attachment and increase risk for aspiration. In addition, the infant is not actively engaged and learning feeding skills when feeding in this state.

***Managing tone***

- Explain managing tone:
  - Managing tone is an important strategy to support safe and effective breastfeeding for infants with high or low muscle tone.

- Present information about good positioning and managing tone:
    - A developmentally supportive position for young infants with disabilities is a flexed position with the arms at midline.
    - All infants need support for good positioning during feeding, but infants with high or low muscle tone may need extra support to maintain a good body position for feeding.
    - Unlike older children, infants' body structures for feeding and breathing support feeding in a semi-reclined position. However, feeding an infant lying flat on their back can lead to increased risk for ear infections, choking, and aspiration.
    - During feeding, infants with high and low tone should be held with the body fully supported. The infant needs to focus on breastfeeding and use energy for this, rather than for maintaining their position. A good position will help the infant to achieve a good latch and feed effectively. The key parts of the body for positioning infants during feeding are the head, shoulders, and trunk:
        - *Head*: Supported in a neutral position with chin slightly tucked towards the chest and resting in the middle, not turned to one side or the other.
        - *Shoulders*: Relaxed and symmetrical, the same on both sides.
        - *Trunk*: Elongated, not leaning to one side, curved forward or arching back, and in a straight line from the hips.
    - **Swaddling** (with one cloth) can be an effective way to provide stability and additional support during feeding for infants with low and high tone. Swaddling is often recommended for young infants, especially in the first few weeks of life, to help calm and soothe them. Because swaddling is often used to soothe infants, this strategy may not be helpful for some infants who tend to be very sleepy during feeding.

Activity (25 minutes):

- Ask for a volunteer to demonstrate to the group how to swaddle an infant.
- Present the following steps to support proper swaddling:
    - Spread a blanket out flat with one corner folded toward the center of the blanket.
    - Lay the infant, face up, on the blanket with their head above the folded corner.
    - Use the blanket to snuggly wrap the infant. Bring the infant's arms toward the middle of the chest. Fold one side of the blanket over the infant's body and tuck it under the other side.
    - Bring the bottom corner up over the infant's feet. Make sure the hips and feet can move and that the blanket is snug, but not too tight.
    - Wrap the remaining corner across the body and tuck it under the infant's body. You want to be able to get at least two to three fingers between the infant's chest and the swaddle.
- Divide participants into groups and provide each group with a doll and a blanket or cloth.
- Provide these key reminders:
    - Do not swaddle too tightly around the infant's chest, legs, or hips.
    - Do not swaddle with a heavy blanket.
    - Do not swaddle once the infant can roll over.
    - Do not swaddle during infants who are already drowsy while feeding.

- Ask participants to take turns swaddling the doll until everyone in each group has had a chance to try it. Walk around the room offering support as needed.

***Non-feeding suck***

- Explain non-feeding suck:
    - The final aspect that we looked at with the Feeding Difficulties Checklist before feeding was the non-feeding suck.
- Present information about one possible strategy to support non-feeding suck:
    - Infants with feeding difficulties may need support to initiate sucking or to maintain rhythmical sucking. Sucking can improve with practice. In fact, research has shown that practicing non-feeding sucking can support an infant to improve sucking for feeding, too.
    - Introducing sucking on a clean, gloved finger or a gloved finger dipped in breast milk, can help the infant to practice sucking skills. *(Note: proper hygiene is critical for this strategy)*
    - Begin with a gloved finger. Gently stroke the infant's tongue or palate to initiate a suck. Some infants may benefit from dipping the gloved finger into breast milk to elicit a stronger suck. *Please note: if you are unable to elicit a suck at all despite multiple attempts, referral to a medical provider for additional assessment may be necessary.*
    - Once the infant is active and continuously sucking on the finger with organized and coordinated sucking, try breastfeeding.
    - Some infants may benefit from this "practice" for several feeds.
- Conclude this section:
    - Ask a few participants to share a brief summary of something new they learned or something they understand differently.

| **Activity 4.1.2 (60 minutes)** |
|---|
| Strategies to support infants with disabilities during feeding |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Demonstrating/describing breastfeeding positions<br><br>Applying Strategies During Feeding Brainstorm (option 1 & 2) | 2, 3, & 4 | Slides 152-162<br><br>Dolls<br><br>MAMI Counselling cards: A1-Good positioning & attachment (Kaarkas A1 & A2), A2-Effective suckling (Kaarkas A3)<br><br>Mod04_Handout_Breastfeeding Positions<br><br>Mod04_ActivitySheet_Applying Strategies During Feeding |

| | | |
|---|---|---|
| | | Mod04_ActivitySheet_Applying Strategies During Feeding Answers |

**Instructions**

- Introduce this section by reminding participants that during feeding, there are three key areas that we will focus on: latch, sucking, and swallowing.

***Latch***

- During feeding, the first aspect we will discuss is latch or attachment.
- Present information about good attachment:
- A good latch is necessary for effective extraction of milk from the breast. A poor latch can increase the amount of air the infant swallows and can cause pain and damage to the mother's nipples.
- Positioning can be an effective way to support improved latch. Some breastfeeding positions may work better for specific conditions or circumstances. However, different mothers and infants may have different experiences depending on breast size, milk flow, and the infant's skills, so it is good to encourage mothers to try different positions to identify their most successful option.

Activity (10 minutes):

- Show each position named below using the images in the PowerPoint slides.
- Invite a participant to volunteer to demonstrate the position that is pictured on the slide. Then use the content below to name and discuss each position:
- *Note: For reference, the following positions are included on the MAMI counselling card for Good Attachment-A1 (MAMI Kaarkas A2): cradle hold, under arm, cross cradle, reclined, or side lying.*
    - *Cradle hold*: this may be the most familiar position, but it gives the mother less control of the infant's head. It works better when the infant is bigger and easy to handle or has already learned to breastfeed effectively. It does not work as well for small infants, infants that need additional positioning support, or if the mother's breasts are large.
    - *Underarm:* this position gives the mother a good view of the infant's attachment. It works well with infants with very low tone (floppy) or infants with tight or small jaws. This position gives the mother good control of the infant's head to help achieve and maintain a good latch.
    - *Cross cradle:* this position supports the infant's body well and gives the mother more control of the infant's head position. It often works well for infants that are small or in need of additional support for body position. The mother is able to provide support along the infant's body to help promote and maintain a good latch.
    - *Reclined:* this position is good for skin to skin and closeness that can help calm the infant. In addition, gravity may help the infant to attach deeply in this position.
    - *Side lying*: this position helps mother to rest while breastfeeding. The infant's nose should be level with mother's nipple, so that they do not need to bend their neck to reach the nipple. This position works well for infants who are larger.

  - *Upright (not shown in counseling card)*: The mother holds the infant upright, facing toward her breast. The mother should provide plenty of support to the infant's body. She places the infant on her lap or with legs straddling the mother's thigh. This position works well for older infants, but when provided with adequate support, it can also be helpful for smaller and younger infants with difficulty coordinating sucking and swallowing, frequent reflux, tongue tie, or low tone.

- Distribute handout on breastfeeding positions to participants.
- Check for questions and clarify understanding before continuing to the next section.

***Sucking***

- The next aspect we will look at during feeding is *sucking*. You are familiar with the supports and key messages to support effective sucking from the MAMI counselling cards (*A2-Effective suckling or MAMI Kaarkas A3)*.
- Explain:
  - When you complete an Infant Feeding Difficulties Checklist, and you identify additional concerns with sucking, such as weak suck, disorganized suck, long pauses, poor endurance, or wide-open jaw movements, then some additional strategies may be helpful to support effective feeding.
- Today, we will discuss two strategies to address some of these concerns with sucking: breast compression/massage and the dancer hold. Present information about each of the strategies:
  - *Breast compressions/massage*: If the infant has a weak suck or uses long pauses, try using breast compressions or massage to stimulate milk flow. Breast compressions should be tested before the infant is on the breast to know how much milk flow it may generate. Too much milk flow for an infant that cannot coordinate sucking and swallowing could increase the risk for aspiration.
  - For breast compression, instruct the mother to use one hand to gently squeeze the breast.
  - For breast massage, instruct the mother to massage her breast with downward and inward strokes. For some infants, alternating massage at the base of the breast with the infant's bursts of sucking can increase efficiency.
  - *Dancer hold*: *(Note: this position is also called "Dancer hand" or "Dancer position")* This position can help an infant to achieve and maintain a complete seal. If the infant is using wide-open jaw movements, use the dancer position to support the infant's jaw and cheeks.
  - Instruct the mother to use one hand to support the breast with four fingers on one side and her thumb on the other. Have her slide the hand that is under the breast forward, so the hand is supporting the breast with three fingers rather than four. Tell her to form a U-shape with the thumb and forefinger to cradle the infant's chin and support the jaw and cheeks.
- Check for questions and clarify understanding before continuing to the activity.

Activity (25 minutes):

- Divide participants into at least four small groups. Assign each group one of the following conditions:

- Down syndrome
- Cleft lip (*Note: we will discuss cleft lip and cleft palate at length in the next session)*
- Cerebral palsy
- Spina bifida/hydrocephalus

Option 1:

- Distribute the Applying Strategies During Feeding Answer Key. *Note: In this option, you will only use the answer key and not the activity sheet.*
- Instruct participants to review the answer key and discuss the anticipated challenges during feeding, recommended positions & strategies, and the reasons for the recommendations. Each group will then have the opportunity to present what they learned to the large group and demonstrate the recommended techniques.
- Move about the room to answer questions as needed.
- Once groups have had the opportunity to discuss, invite each group to present about their assigned condition.
- Use the Answer Key to clarify or expand on the participant's answers.

Option 2:

- Instruct each group to recall together some of the challenges during feeding that they might anticipate for an infant with the assigned condition. Based on their discussion, the group should agree on (1) which position(s) or strategy they would recommend a mother to try and (2) be ready to explain the reason for their recommendation.
- Distribute the Applying Strategies During Feeding activity sheet so groups can take notes about their discussions and what other participants share.
- Move about the room to answer questions as needed.
- Once groups have had the opportunity to discuss, invite each of the groups to share about their discussion including the strategies they would recommend and the reason they made that decision.
- There may not be a single correct answer for each condition. Use the Answer Key to clarify or expand on the participant's answers.
- Distribute the Answer Key as a handout.

***Swallowing***

- The final aspect during feeding we will discuss is swallowing.
- Present information about safety and swallowing:
  - Recall that a safe swallow involves the timely and coordinated movement of breast milk from the mouth to the stomach. A delayed or uncoordinated swallow may lead to aspiration.
  - It is important to note that when we recommend changes, we are aiming to improve safe and effective feeding for the infant and the mother. To do this well, we must always remember to **do no harm**. That is, do not accidentally make a situation worse with the changes you are recommending. Always be responsive to the infant's communication to ensure that the strategies or support actions are helping.
  - Here are a few tips to ensure that you support safe swallowing:
    - If the infant is not swallowing, do not feed orally and refer for further evaluation.

        - If and infant is not pausing from sucking and swallowing to occasionally just breathe, instruct the mother to insert a clean finger in the corner of the infant's mouth to break the seal. This will make the infant pause and breathe.
        - If the infant is often fatigued and having difficulty consistently when they are tired (e.g., always starts coughing as they get tired), try feeding the infant more frequently and for shorter durations.
        - If the infant has persistent coughing or respiratory problems, referral for additional assessment may be necessary.
- Check for questions and clarify understanding before concluding this section.

- Conclude this section:
    - There are certain positions that may be well suited for particular feeding challenges. A good position is both comfortable for the mother and helps the infant attach well. However, there is no single correct way to position an infant for breastfeeding, so it may require trials to figure out what works best for each mother and infant pair.
    - Applying MAMI breastfeeding support actions for infants with disabilities can support mothers to address challenges during feeding.
    - Always be responsive to an infant's communication to ensure that the strategies or support actions are helping and being well-tolerated by the infant.

| **Activity 4.1.3 (40 minutes)** |
|---|
| Strategies to support infants with disabilities after feeding |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Group Discussion<br><br>Round Robin Review | 5 | Slides 163-169<br><br>Flipchart, markers |

## Instructions

- Introduce this section:

    - Observing an infant's state after feeding and for signs of discomfort are an important part of the process of identifying feeding difficulties. We will now consider strategies to address challenges after feeding:
    - Supporting a mother to recognize her infant's cues is a key strategy to foster responsive care and improved feeding.
    - State: Infants will communicate when they are full or satisfied and they will communicate if they are experiencing stress, fatigue, or discomfort.

### Activity (20 minutes):

- Facilitate a group discussion about signs that an infant is getting enough to eat, signs of fullness, signs of dehydration, and signs of discomfort.
- Use information below as needed to clarify or expand the conversation:
    - *Signs of getting enough:*

        - Soiled diapers: Several bowel movements per day; yellow stools by day 4
        - Wet diapers: 5-7 wet diapers per day by day 5 until about 6 months of age *(Note: Dark yellow or strong-smelling urine may be sign of dehydration)*
        - Weight gain: Gaining ½-1 oz. (14-28 grams) per day
        - Mood and appearance: Calm/active when awake and satisfied after a feeding (not lethargic)
    - *Signs of fullness:*
        - Encourage mothers to stop a feeding when the infant indicates fullness. This will reinforce the infant's communication skills and may help reduce discomfort from overfeeding.
            - Fullness cues say, "I'm done."
            - A relaxed body shows us the infant is calm and satisfied. This can include fists opening, arms lying low across the body, falling asleep with the body relaxed (not lethargic or fatigued).
    - *Signs of dehydration:* A dehydrated infant needs urgent referral to a hospital for clinical care.
        - Infant has not urinated for over 6 hours
        - No tears when infant cries
        - Mouth feels dry and sticky
        - "Soft spot" on top of head is flat or sunken
        - Infant is acting confused
    - *Signs of discomfort & Vomiting:* Infants may communicate discomfort in a number of ways including crying, agitation, and fussing. Vomiting frequently or in large amounts could mean the infant has had too much milk, they are not tolerating the milk or the amount, their gut is immature, they have reflux, or the infant swallowed too much air while feeding. Infants with feeding difficulties may experience vomiting more often. Frequent vomiting can cause infants to become sensitive to touch in and around the mouth and gag easily, leading to refusal to feed and dehydration.
        - For infants that vomit frequently:
            - Try increasing the frequency of feeds but feeding for shorter durations so the infant is likely to take a smaller volume each feed.
            - Position the infant upright after feeding for at least 10-15 minutes.
            - Avoid wrapping the infant tightly in a cloth or securing diapers too tightly, especially right after feeding.
            - Position the infant on the left side after feeding. (*Do not leave unattended*)
            - For some infants, referral for additional assessment may be necessary.
- Conclude this section with a review activity.

Activity (15 minutes):

- Tell participants, you will now play a game to review the strategies we have discussed to address feeding difficulties *before*, *during*, and *after* feeding.
- Instruct participants on how to play a Round Robin Review:

    - Each one of you will need to recall one key message, fact, or point of interest about strategies to address feeding difficulties *before*, *during* or *after* feeding.
    - I will select a participant to begin the round and then each of you will present their comment one after the other.
    - Try to avoid repeating what someone else has shared before you.
    - If you present something that is inaccurate, we will take a moment to refine or correct your comment.

- Have participants stand in a circle or participate from their seats, depending on time and space available.
- Allow participants 2-3 minutes first to think about their response. After a few minutes, begin the round robin by selecting a person to start the round.
- *Note: If the group enjoys competition or is very large, you can divide participants into 2 groups and see who can complete a round first. Timing the game to see how fast they can complete the round may be a fun adaptation for some groups, too.*

**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. Managing alertness and tone are important ways to support an infant before feeding.
2. A variety of breastfeeding positions may support an infant with disabilities to achieve and maintain good attachment during feeding.
3. MAMI breastfeeding support actions can be applied to support infants with disabilities and their mothers.
4. Infant feeding recommendations should aim to improve safe and effective feeding for both the infant and mother, always prioritizing the principle of "do no harm."
5. Understanding an infant's communication and cues equips mothers to provide responsive care and discern if their infant is getting enough or experiencing any discomfort after feeding.

## 4.2 Strategies for Feeding Infants with Cleft Lip/Palate

### Time: 30 minutes

**Preparation & materials required:** Slide Deck, flipchart, markers, straws (or small pieces of paper).

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

- Learn strategies for supporting infants with cleft lip and palate.

### Key message(s) to take away for learners:

1. Infants with cleft lip/palate may have difficulties with breastfeeding due to gaps in their oral structure(s) affecting suction and compression needed for efficient feeding.

2. There are a number of strategies before, during, and after feeding that you can use to support a mother to feed her infant with cleft lip/palate safely and effectively.

| **Activity 4.2.1 (30 minutes)** |
|---|
| Understanding suction and compression |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Simulation activity | 1 & 2 | Slides 170-177<br><br>Straws or small pieces of paper that can be rolled into a straw-like tube<br>Mod 04_Handout_Feeding Infants with Cleft Lip and Palate |

**Instructions**

- Introduce this section by explaining that there are some feeding challenges that are unique to infants with cleft lip/palate. This section will focus on some key strategies to optimize breastfeeding for infants with cleft lip, cleft palate, or both.

Activity (10 minutes)

- Provide these key reminders:
    - Recall that during breastfeeding, both compression and suction are important for an infant to efficiently extract milk from the breast. The lips form a complete seal and the movement of the tongue help to create suction. At the same time, the tongue compresses the breast tissue by pressing it toward the top of the mouth.
- Provide instructions for participation in the simulation activity:
    - Today we are going to attempt to simulate the difference a complete seal can make. *Note: this exercise is only a simulation to build understanding of the concepts of suction and the impact an opening or gap can have on creating that suction. Breastfeeding and straw drinking are not comparable.*
    - Distribute straws (or small pieces of paper that can be rolled into a small tube or straw).
    - Provide instructions and demonstration:
        - Place the straw between your lips. Make sure to round your lips and make a complete seal around the straw.
        - Suck air into your mouth through the straw.
        - Place a finger on the opposite end of the straw while sucking to feel the suction created. Tell participants to take note of the suction.
        - Once everyone has felt the suction, instruct the participants to part their lips, so that they do not have a complete seal around the straw.
        - Suck air into your mouth without a complete seal of the lips.
        - Place a finger on the opposite end of the straw while attempting to draw air in and feel the difference in the suction created.
    - Ask participants to reflect on the difference between the two experiences.
    - Invite a few people to describe the experience and their reflections.
    - Tell participants that you would like them to try one more thing.

        - Instruct participants to make a sucking motion with their mouth closed. If it is helpful, you can imagine you have a mint or hard piece of candy in your mouth.
        - Ask participants to describe the movement of their tongue during that sucking action.
        - Highlight how the tongue moves not only back and forth, but pushes against the top of the mouth/palate.
        - Explain that this should highlight the importance of the palate during breastfeeding.
    - Conclude this activity by saying:
        - For infants with cleft lip/palate, an opening or gap in the oral cavity (e.g., lip or palate) reduces the strength of suction, making the extraction of milk from the breast more difficult.
        - Infants with a cleft palate do not have a surface against which to compress the breast.
        - So, you can see that when there is an opening or gap in structure, that is the lip or the palate, this could have a significant impact on an infant's ability to effectively and efficiently breastfeeding.

- Briefly remind participants of some of the feeding challenges that infants with a cleft lip/palate may experience:
    - Weak suck
    - Non-rhythmic suck
    - Swallowing too much air
    - Trouble maintaining a good seal
    - Gagging and choking
    - Milk leaking out of the nose. Sometimes milk can escape into the nose because of the opening in the palate, or if the palate muscle is weak.
    - May tire more easily and not nurse long enough; the intake of milk may be limited.
    - The feeding process can take a long time
    - May prefer the side without the cleft
- Present strategies to address feeding difficulties for infants with cleft lip/palate:
    - General cleft lip/palate recommendations:
        - Have mother apply a warm compress *before* breastfeeding using a warm, damp towel or a hot water bottle to help stimulate milk flow.
        - Stimulate flow of milk by using breast compressions or massage initially. Some infants may need continued breast compressions to increase the efficiency of feeding and reduce fatigue throughout.
        - Have the mother try breastfeeding in an upright position.
        - If the infant has a small jaw, they may benefit from feeding in reclined position (prone).
        - Burp the infant frequently. Keep the infant upright about 10 mins after a feed.
        - Increase the frequency of feeds and decrease the duration.
        - Instruct the mother to press the infant into the breast to support the latch and create a better seal.
    - Unilateral cleft lip:
        - Orient the cleft towards the top of the breast.

        - Use the breast to fill the gap in the lip. This helps to create a better lip seal and an air-tight oral cavity.
        - Give the infant cheek support to decrease the width of the cleft lip (e.g., Dancer hold), or instruct the mother to occlude the gap with her thumb.
    - Bilateral cleft lip:
        - Position the infant "face on," or directly facing the breast (not to one side or the other), using an upright position.
    - Cleft palate:
        - Position breast away from the cleft to have surface for compression.
- Present briefly about specialized feeders used in certain contexts:
    - If the infant is unable to breastfeed, alternative feeding methods such as cups, spoons, or tube feeding may be necessary.
    - In some contexts, where proper hygiene is possible and access to specialized equipment is available, specialized infant feeders or bottles may be used to feed infants before resorting to tube feeding. The slide contains images of specialized feeders. It is recommended to try several feeding strategies and cup feeding before using specialized bottles.
- Conclude this section:
    - Check for questions and clarify understanding.
    - Distribute Mod 04_Handout_Feeding Infants with Cleft Lip and Palate

**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 with cleft lip/palate may have difficulties with breastfeeding due to gaps in their oral structure(s) affecting suction and compression needed for efficient feeding.
2. There are a number of strategies before, during, and after feeding that you can use to support a mother to feed her infant with cleft lip/palate safely and effectively.

## 4.3 Other Feeding Considerations

**Time:** 90 minutes

**Preparation & materials required:** Slide Deck, flipchart, markers, dolls, small cups, drinking water, MAMI Counseling Cards, Global Health Media video, food that requires chewing (biscuit, bread).

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

- Explore alternatives to breastfeeding for infants with disabilities.
- Discuss considerations for complementary feeding for infants with disabilities.

**Key message(s) to take away for learners:**

1. Cup and spoon feeding may be appropriate alternative methods to feed infants with disabilities and require careful observation for readiness, skills, and any signs of difficulty or aspiration.
2. Tube feeding may be necessary for infants who are medically unstable, consistently not alert during feeding, show aspiration signs, or have poor weight gain and urine output.
3. If Infants can safely feed by mouth, follow this order: first breastfeed, then cup feed, and lastly tube feed.
4. At about 6 months, infants need foods beyond breast milk. For infants with disabilities, timely introduction of complementary feeding and developmental considerations are crucial.

| **Activity 4.3.1 (50 minutes)** |
|---|
| Alternative methods for feeding |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Cup feeding Simulation | 1, 2, & 3 | Slides 178-191<br><br>Flipchart, markers, small cups, water, dolls<br><br>MAMI counselling card: A 22 (Counselling Kaarkas A24) cup feeding<br><br>"Cup Feeding Your Small Baby" video from Global Health Media (0:00-5:06) |

## Instructions

- Introduce this section by telling participants that you will discuss alternative methods for feeding, like spoon, cup or tube feeding for infants with disabilities.
- Facilitate a conversation about participants' current practices around cup feeding:
    - Do you use cup feeding for some infants?
    - Describe some of the circumstances where you recommend cup feeding.
    - What guidelines do you have, if any?
    - If necessary, prompt additional details with questions like: Are all the infants cup fed? Is this before or after trying to breastfeed? When is it used instead of breastfeeding? How are the volumes determined?
- Listen to responses and note words or phrases to summarize the circumstances on a flipchart.
- Expand or clarify the conversation by explaining when to use cup feeding:
    - Cup feeding may be used when:
    - An infant's mother is unavailable
    - An infant is alert and can suck but is unable to latch onto the breast
    - An infant is not able to effectively breastfeed or is only able to partially breastfeed

Activity (10 minutes):

- Tell participants:
    - You will watch a video clip that demonstrates cup and spoon feeding. (*Note: You can show the video and ask all the questions OR show the cup feeding first (0:00-4:32) and ask questions then show the spoon feeding (4:33-5:06) and ask the last question*)

- Explain the activity:
    - During the video, I want you to watch and listen carefully. Pay attention to what happens before and during feeding. Listen for information about signs that the infant is ready for cup feeding, the steps the mother should take, how the infant feeds from the cup, and how the infant signals they are done with feeding. After each part, I will ask you some questions.

- Write these key words/phrases on a flipchart as a reminder about the topics you will ask questions about: readiness, mother's steps before, how infant feeds, stopping signs, and spoon feeding.
- After the video has concluded, go through the questions and use the notes provided to support participants to answer each question:
    - When is the infant ready to cup feed?
    - If he can swallow milk without coughing, choking or turning blue.
    - What are some key steps the mother must take before feeding?
    - Practice first with guidance from a trained health worker.
    - Recognize the infant's feeding signals.
    - Wash hands
    - Pour milk into a small cup
    - Wrap the infant and position nearly upright.
    - During the first example, what do you notice in the video about the small infant's pace of cup feeding?
    - The infant pauses, sometimes for longer periods of time.
    - The infant laps the milk from the cup.
    - The infant controls moving the liquid into their mouth
    - During the first example, what signs did the small infant give that it was done feeding?
    - The infant held his hand up
    - The infant starts to fall asleep
    - Why does cup feeding help prepare the infant for breastfeeding?
    - It uses a similar tongue action.
    - When is spoon feeding a good alternative method to cup feeding?
    - According to the video, especially in the first few days when the infant only needs a very small amount of milk.
    - Spoon feeding is an alternative to cup feeding that can give the infant more time to swallow, as they can more easily take breaks between sips. This method could be used as an introduction to cup feeding to help the infant and feeder learn the rhythm of feeding and giving breaks.

- Explain that the MAMI Counselling cards out line key steps and tips for successful cup feeding, as well. Explain that these same steps and key messages are important when cup feeding an infant with disabilities. Additional consideration may be necessary depending on the infant's positioning, tone, feeding skills, and risk for aspiration.

- Present these key tips for successful cup feeding for all infants including infants with disabilities:
    - The infant should be alert and able to suck. Never cup or spoon feed a sleeping infant.
    - Use a small cup, such as a medicine cup (10 ml).
    - Position the infant upright. Never feed the infant lying flat on their back.
    - Present the cup to the infant's lips and bring the liquid to the rim of the cup.
    - Do not pour milk into the mouth!
    - Avoid applying too much pressure on the infant's lip.
    - Avoid putting the cup too far inside the infant's mouth.
    - Observe the infant closely for swallowing. If the infant is having difficulty coordinating sucking and swallowing, try offering single sips and moving the cup away from the mouth to observe for a swallow. As the infant can manage it, you can allow the infant to suck and swallow for 3 or 4 sips and then provide a short break.
    - *Cup feeding may be risky if not done correctly*, especially if the infant cannot control the milk in their mouth. Watch the infant closely for signs of aspiration and discontinue cup or spoon-feeding trials if signs increase or persist.
    - *Stop cup feeding immediately if*:
    - the infant is not responsive (e.g., no lips or jaw movement),
    - milk remains in the mouth then pours out (i.e., not swallowing), or
    - the infant is coughing, gasping, change in color.

Activity (15 minutes):

- Introduce activity by telling participants that they will now practice cup feeding together.
- Divide participants into pairs or small groups.
- Provide each participant with their own small cup.
- Instruct participants to practice cup feeding:
    - Use dolls to practice positioning an infant for cup feeding.
    - Use water to practice bringing water to the edge of the cup.
    - If comfortable, practice presenting water to each other by bringing water to the edge of the cup without pouring the liquid into their partner's mouth.
- After groups have had time to practice, bring the large group back together to discuss the experience.

### *Tube feeding*

- Tell participants that another alternative method of feeding is tube feeding.
- Facilitate a conversation about tube feeding practices that participants are familiar with:
    - Is tube feeding available in your health facilities?
    - When do you use tube feeding in your facilities?
    - How is the decision made to start or stop tube feeding?
    - What are the criteria?
- Listen to responses and, if appropriate, make notes or summarize on a flipchart.
- Present information about tube feeding:
- An infant needs tube feeding if they are:
    - medically unstable

  - consistently not alert at breast/cup, even after trial on gloved finger
  - showing signs of aspiration or respiratory distress while/after feeding
  - not gaining weight
  - not passing urine

- If an infant is safe to feed by mouth, but still needs tube or cup feeding, try the following sequence:
  - First, breastfeed.
  - Then, cup feed.
  - Lastly, tube feed.

- Conclude this section:
  - Ask participants to reflect on their experiences with alternative methods of feeding in the past and how these methods may also be used to support infants with disabilities.
  - Invite participants to share about their own reflections or remaining questions.

| **Activity 4.3.2 (40 minutes)** |
|---|
| Considerations for Complementary feeding |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Feeding Skill Experience | 4 | Slides 192-198<br><br>Biscuit, bread or other food that requires chewing |

## Instructions

- Introduce this section:
  - Starting at about 6 months, infants need other foods in addition to breast milk. The timely introduction of complementary feeding at 6 months is important for infants with disabilities, too. For some infants with disabilities, additional considerations may be necessary when introducing complementary foods.

- Ask participants to name some key messages around introduction of complementary foods. Listen to responses and write briefly on flipchart.
- Use information below to expand or clarify the statements that participants share:
  - Refer to key messages from MAMI counselling card C7 – "Start complementary feeding at 6 months of age" (Kaarkas C8), which focuses on frequency, amount, thickness, variety, active/responsive feeding, and hygiene.
  - The World Health Organization (WHO) recommends timely, adequate, and appropriate introduction of complementary foods beginning at 6 months of age.
  - *Timely:* Refers to introducing foods when an infant needs more energy and nutrients than they can get from breastmilk or formula alone. When introducing new foods, it is also important to recognize a child's readiness and skill level to eat and drink safely.
  - *Adequate:* Refers to offering foods that provide sufficient energy, protein, and micronutrients to meet the child's nutritional needs.

- *Appropriate:* Refers to offering foods that are both safe and properly fed.
- *Safe* means foods are hygienically stored and prepared.
- *Properly fed* means that the child is fed appropriately for their age. That includes providing the appropriate texture and meal frequency, and using responsive feeding techniques. **Responsive feeding** is when the adult acknowledges and responds warmly to the infant's or child's communication of hunger, fullness, discomfort, or readiness.

Activity (5 minutes):

- Ask participants to stand up.
- Instruct participants to begin by rubbing their stomach.
- Then, while continuing to rub their stomachs, instruct participants to close their eyes, then balance on one leg, and pat their head.
- Ask participants to share their experience with the activity.
- Explain that while this was mostly just a silly task, hopefully it also reminds us how difficult it can be when we have many demands placed on us and how difficult it can be for an infant who is required to learn many new skills.

- Present additional considerations for infants with disabilities:

***Readiness***

- An infant's readiness has to do with being equipped to learn and grow. This includes their willingness and confidence to advance to a new skill and a caregiver's responsiveness to the child.
- For feeding skills, this may include the infant's readiness to begin first foods or to advance food textures, that is to progress from easy-to-eat foods to food textures that require more skills.
- Readiness is an important factor in developing feeding skills and an important consideration when introducing complementary foods for infants with disabilities. The infant must be able to move their lips, tongue, and jaw to prepare the food to be swallowed safely and easily.
- Advancing a diet when a child does not yet have the necessary feeding skills can lead to gagging, choking, coughing, fear, and refusal to eat.
- It is important to look closely at the skills the infant has, and not just the skills we expect them to have at a certain age.

***Positioning***

- How the child sits can have a big impact on safe feeding. Proper positioning helps the infant eat and drink safely and learn skills for more independence during mealtime.
- To introduce complementary foods, the infant should be able to sit with minimal support. When feeding first foods, make sure the infant is seated as upright as possible. Check that hips are steady and balanced, body is straight, head is upright, and feet are resting on a flat, firm surface.
- Provide additional support if needed. Some children are not able to maintain proper positioning on their own. Infants with disabilities that affect their body movement or posture may need additional support to make mealtime safer.

***Food textures***

- Select appropriate food textures when introducing complementary foods.
- *Puree*: smooth, without lumps and no chewing is required
- *Mashed: soft, lumpy, and thick*. May need to mash before swallowing
- *Soft and bite-sized*: soft and tender pieces, must be chewed before swallowing.
- A child who does not yet have the necessary skills to manage the texture provided may gag, choke, cough, become fearful, and refuse to eat.
- Select food high in energy and nutrients. Encourage mothers to offer their infant a diverse diet that includes a variety of foods.
- Mothers can prepare the foods in a texture that is appropriate for the infant's feeding abilities.

Activity (15 minutes):

- Introduce activity:
  - We will experience and better understand the challenges a child may face if they are given food they do not yet have the skills to eat.

- Pass out food items for this activity.
- Tell participants that for this activity, they are going to try to eat as if they have the feeding skills of a typical 6-month-old infant.
- Remind participants of the skills they should have:
  - They can only move their tongue forward/back and up/down.
  - The tongue is not able to move the food to the side of the mouth to chew it, but it can only push the food against the top of the mouth.
  - The lips can come together, but do not form a strong seal so the tongue may push past the lips.
- Instruct participants to place a piece of food that requires some chewing (e.g., bread, biscuit) on the center of your tongue and try to eat it only with the skills of a 6-month-old infant.
- Give feedback if people are using more advanced feeding skills than you instructed them to.
  Facilitate a discussion about what it felt like to be offered a food that was too challenging to eat.

- Conclude this section:
  - For infants with disabilities who may have delays in their feeding skills, consideration of their developmental skills and the textures of the foods being introduced are especially important for successful introduction of complementary foods.
  - Check for questions and clarify understanding.

**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. Cup and spoon feeding may be appropriate alternative methods to feed infants with disabilities and require careful observation for readiness, skills, and any signs of difficulty or aspiration.
2. Tube feeding may be necessary for infants who are medically unstable, consistently not alert during feeding, show aspiration signs, or have poor weight gain and urine output.
3. If infants can safely feed by mouth, follow this order: first breastfeed, then cup feed, and lastly tube feed.
4. Starting at about 6 months, infants need other foods in addition to breast milk. Timely introduction of complementary feeding is important for infants with disabilities. Additional consideration for the infant's stage of development can help guide strategies for positive and support introduction of complementary feeding.

# MODULE 5

## Supporting Mothers with Disabilities and Mothers of Infants with Disabilities

### 5.1 Effective Communication with Mothers with Disabilities

**Time:** 60 minutes

**Preparation & materials required:** Slide Deck, flipchart, markers, MAMI Counseling Cards (generic or country-specific).

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

- Apply communication strategies for mothers who are deaf or hard of hearing.
- Apply communication strategies for mothers who are blind or partially sighted.
- Apply communication strategies for mothers who have intellectual disabilities.

### Key message(s) to take away for learners:

1. Effective communication with mothers with disabilities requires empathy, patience, and the use of appropriate strategies tailored to their specific needs.
2. When communicating with mothers who are deaf or hard of hearing, use clear written communication, gestures, visual aids, or sign language if possible.
3. When communicating with mothers who are blind or partially sighted, use detailed verbal descriptions and tactile aids or braille if available to convey information.
4. When communicating with mothers with intellectual disabilities, use simple, clear language and repeat key information.

| Activity 5.1.1 (25 minutes) |
|---|
| Verbal and nonverbal communication |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Game & group discussion | 1 | Slides 199-203 |

#### Instructions

- Tell participants that we are going to start this section about communication with mothers with disabilities by playing a game.
- Ask for 8-10 volunteers to participate in the game and to come stand at the front of the room. Make sure it is an even number of participants.
- Have the participants stand in a line at the front of the room. Ask the first person in line to face towards you. Everyone else turns away with their backs towards the first person in line.

- Explain the rules of the game:
    - I will whisper to you a sentence or phrase that will then be communicated down the line to the last person, who will share the message with all of us.
    - The first person will communicate the phrase without using words or speaking. You may act it out any way you choose. When you are ready, the next person in line will turn around to receive the message.
    - Then the second person will whisper quietly the phrase or sentence that they understood to the next person in line.
    - The message will continue down the line, alternating between acting out the phrase and whispering it until it reaches the last person, who will speak the message out loud to the group.
    - Remember that you will only turn around when it is your turn to receive the message.
- Select one of the following phrases for the first message:
    - A bird is sewing a dress.
    - A cat is washing the dishes.
    - A dog is riding a bicycle.
    - A snake is brushing its teeth.
    - A chicken is playing a piano.
- When the message makes it to the end of the line and is shared out loud, ask the first person to share the message that they received at the very beginning to compare it with the original message.
- If time allows, you can repeat the activity a second and third time with 8-10 new participants.
- Reconvene as a large group and ask participants:
    - In what ways did communication happen during this game?
    - What helped to make communication more successful?
- Listen to responses then say:
    - In this game, some of you were required to use nonverbal communication like gestures or facial expressions, while others were able to communicate using words. It was important for you to be creative and use whatever method you can think of to communicate the message as clearly and accurately as possible. You didn't worry much about saying the "wrong" thing and you tried your best explaining the message without words. This approach is important to counter a common type of attitudinal barrier. *[Ask participants to guess which one]*. That is "fear and avoidance" – avoiding a person with disability because of fear of saying or doing the "wrong" thing. Trying our best to communicate with all mothers and finding alternative ways of communicating, if required, is important. Think back to this activity when you encounter a mother with a disability as a reminder that it is more important to try to communicate and find out what the mother's needs are than to always "get it right".
    - Also, for the message to successfully pass down the line, it was very important for the person receiving the message to focus and pay close attention to the person communicating. This is true when working with all mothers, especially mothers who have disabilities resulting in difficulties in functioning (speech, hearing, communication, and comprehension). When we focus on understanding each mother's communication needs and style, we are better able to support them and their infants.
- Conclude this section:
    - Communicating effectively with mothers with disabilities involves demonstrating empathy, practicing patience, and applying strategies tailored for their particular type of disability. This approach ensures that each mother

receives the support and information she needs in a way that is accessible and respectful, ultimately fostering a more inclusive and supportive environment for both the mothers and their infants.

| **Activity 5.1.2 (35 minutes)** |
|---|
| Communication strategies for mothers with disabilities |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Role-play/Scenario & group discussion | 1, 2, 3, & 4 | Slides 204-211<br><br>Flipchart, markers<br><br>MAMI Counseling Cards Kaarkas [Somalia/Somaliland]: A4, A8, A18, A19, A24, C1, C2, C4, C5, C6, C7, C8, C9, C10<br><br>Mod 05_ActivitySheet_Mothers with Disabilities Scenario Cards_Somalia/Somaliland<br><br>*Note: MAMI Counseling Cards numbers may differ by the version used. If using the generic package, use the following materials*:<br><br>*Mod 05_ActivitySheet_Mothers with Disabilities Scenario Cards_Generic*<br><br>*MAMI Counseling Cards [Generic]: A3, A6, A16, A17, A22, C1, C2, C4, C5, C6, C7, C8, C9, C10* |

**Instructions**

- Introduce activity:
  - In this activity, we will imagine that we are counselling mothers with a variety of types of disabilities and we will practice communication strategies for these mothers.
- Divide participants into small groups of 3-4.
- Each group receives a set of scenario cards which mentions the mother's type of disability and the purpose of her visit and a set of MAMI Counselling Cards. You may give each group the entire set or only the ones listed on the activity sheet. *[Note: Participants may bring their own set of MAMI Counseling Cards to the training if they have one.]*
- Groups will decide on a mother, counselor and observer(s). The roles can rotate for each scenario.
- Groups act out the scenario cards, including the appropriate communication strategies they think are effective depending on their mothers' disabilities. Observers take notes on the effectiveness of the communication techniques used.

- Several scenario cards list one or more MAMI Counseling Cards that the "counselor" can use during the role-play; other scenarios do not require counseling cards. Inform participants that using the MAMI Counseling Cards is optional and should only be done if it is appropriate for the mother's disability.
- After 15 minutes, reconvene as a whole group.
- Each small group shares their experiences, challenges, and successful strategies from the role-plays.
- On a flipchart, create three columns and label them with Hearing, Visual, and Intellectual. Write the communication techniques as they are shared by participants for each type of disability.
- Present the key strategies below if not shared by participants:
    - When communicating with mothers who are deaf or hard of hearing:
        - If the mother uses sign language, you can use it if you know it or book a qualified sign language interpreter for counselling sessions.
        - Use gestures or visual cues and body language.
        - Use visual aids.
        - Use writing, written notes and instructions.
        - Use facial expressions to convey understanding and empathy.
        - Check for understanding.
    - When communicating with mothers who are blind and partially sighted:
        - Use clear, descriptive language.
        - With permission from the mother, use physical guidance and tactile demonstrations when explaining different techniques such as breastfeeding positions, latch techniques, and cup feeding.
        - Braille and/or high contrast colour and large print for written materials
        - Design communication materials in an audio format.
        - Use props to increase tactile input.
    - When communicating with mothers with intellectual disability:
        - Break down instructions into simple steps.
        - Use simple language.
        - Use repetition (e.g., repeat instructions).
        - Demonstrate techniques and have the mother show you.
        - Check for understanding.
        - Use visual aids and props.
        - Give take home pamphlets/visuals.
        - Send SMS text reminders.
        - Conduct home visits.

- Present additional tips on how to respectfully and effectively interact with mothers with disabilities *[adapted from Hesperian (2007) a health handbook for Women with Disabilities]*:
    - A mother who is deaf or hard of hearing:
        - Ask her what is the best way of communicating.
        - Make sure you have her attention before speaking. If she is not facing you, touch her gently on the shoulder.
        - Do not shout or exaggerate your speech.
        - Look directly at her, and do not cover your mouth with anything.
        - If the mother uses a sign language interpreter, look at her and not her interpreter or at the family member who interprets her home signs.
    - A mother who is blind or partially sighted:
        - Ask her what the best way of communicating is.

        - Unless it is an emergency, do not touch the woman before telling her who you are and requesting permission.
        - Do not think she cannot see you at all.
        - Explain to her where she is and guide her to a chair or exam table. Do not leave her in the middle of a room.
        - Speak in your normal voice.
        - If she has a walking cane, do not take it away from her at any time.
        - Say goodbye before walking away or leaving.
        - Provide written educational materials in high-contrast colors and large-print or braille
    - A mother who has a physical disability (difficulty moving or different anatomy):
        - Act as you would with any other mother.
        - Do not assume she has an associated intellectual disability.
        - If there is a difference between you and her in eye level, try to adjust so you sit at the same level.
        - Speak directly with her and not to her family member or caregiver.
        - Do not touch or move any crutches, sticks, walkers, or wheelchairs without the mother's permission or without arranging for their return.
        - If she is a wheelchair user, do not lean on or touch her wheelchair without her permission.
        - Ensure that your recommendations are anatomically appropriate or make necessary adjustments and show how.
    - A mother who has difficulty being understood (speech difficulty):
        - Even though her speech may be slow or difficult to understand, this does not mean she has any difficulties learning or understanding.
        - Ask her to repeat anything you do not understand. Do not pretend you understand her if you do not.
        - Ask questions she can answer by "yes" or "no."
        - Let her take as much time as she needs to explain her problem. Be patient. Do not interrupt.
    - A mother who has an intellectual disability (difficulty learning or understanding):
        - Find out how she learns best.
        - Give clear instructions.
        - Use simple words and short sentences.
        - Be polite and patient, and do not treat her like a child.
        - Give her one piece of information at a time and repeat it if necessary.
- Conclude this section:
    - Ask participants:
        - How has this scenario/activity changed your understanding of communicating with mothers with disabilities?
        - What is one new strategy you will implement in your practice?

**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. Effective communication with mothers with disabilities requires empathy, patience, and the use of appropriate strategies tailored to each type of disability.

2. When communicating with mothers who are deaf or hard of hearing, use clear written communication, gestures, visual aids, or sign language if possible.
3. When communicating with mothers who are blind or partially sighted, use detailed verbal descriptions and tactile aids or braille if available to convey information.
4. When communicating with mothers with intellectual disabilities, use simple, clear language and repeat key information.

## 5.2 Counseling Mothers Impacted by Disability

**Time:** 80 minutes

**Preparation & materials required:** Slide Deck, positive counseling skills flashcards and answer key, MAMI Counseling Cards (generic or country-specific), MAMI Counseling Cards activity sheet and answer key.

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

- Apply positive communication skills when counseling mothers impacted by disability.
- Discuss considerations for supporting mothers with disabilities to breastfeed and address feeding difficulties.

### Key message(s) to take away for learners:

1. Counseling of mothers impacted by disability is most effective if mothers receive accessible and relevant information, if they are listened to, have their difficulties acknowledged, have their questions answered, and if there is a caring and supportive environment.
2. When supporting mothers with disabilities in addressing infant feeding difficulties, it is important to collaborate with them to identify practical, tailored solutions. This can include trying different breastfeeding positions, receiving physical assistance from others, and connecting with peers.

| Activity 5.2.1 (30 minutes) |
|---|
| Positive counseling skills: a review |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Quiz game | 1 | Slides 212-217<br><br>Mod 05_ActivitySheet_Positive Counseling Skills Flashcards<br><br>Mod 05_ActivitySheet_Positive Counseling Skills Flashcards_Answers |

**Instructions**

- Introduce the activity:

    - Almost all of you have participated in a training on positive counseling skills and have experience counseling mothers on nutrition and breastfeeding. Today, we will be reviewing these essential counseling skills with a fun and competitive game.
- Divide participants into five teams.
- Explain the rules of the game:
    - Each team will take turns drawing a flashcard.
    - Each card will have a question or scenario related to positive counseling skills. Some are easier than others.
    - The team will have 1 minute to discuss and respond to the question or scenario.
    - If you answer correctly, you earn 10 points.
    - The team with the most points at the end wins.
- Start the game, having each team draw a flashcard and respond.
- Use a flipchart to keep track of points.
- Encourage teams to explain their reasoning or demonstrate their skills when applicable.
- Refer to the answer key to offer additional suggestions.
- After the first round, play two more rounds if time allows. Rotate turns quickly to maintain engagement.
- Tally the points on the flipchart. The winning team gets a round of applause.
- Summarize the key points reviewed during the game and fill gaps as needed by sharing the following about positive counseling skills:
    - The three steps in counseling are:
        - Step 1: Assess – ask, listen and observe
        - Step 2: Analyze – identify difficulty and, if there is more than one, prioritize difficulties
        - Step 3: Act: discuss, suggest a small amount of relevant information, agree on doable action
    - Basic counselling skills include listening and learning, building confidence, and giving support. For all mothers, but especially those with mental health concerns, it is important to also create a safe environment.
    - The MAMI Counseling Cards and Support Action booklet lists positive counseling and communication skills (pages 4-5). Some key ones are:
        - Be welcoming and conduct introductions.
        - Treat the mother with kindness and respect.
        - Sit at same level.
        - Make eye contact.
        - Use authentic communication to establish trust.
        - Ask open-ended questions.
        - Listen carefully to the mother without interruptions.
        - Give mother time to talk and ask questions.
        - Summarize what the mother says.
        - Use simple and clear language.
        - Avoid judging words and scolding gestures.
        - Accept how the mother feels. Do not rush into correcting wrong ideas.
        - Recognize and praise what a mother and child are doing right.
        - Identify small, 'doable' (achievable) actions, which mothers can easily integrate.
        - Make one or two practical suggestions, not commands.
        - Be mindful of considerations for mothers with mental health concerns.
    - Present additional considerations for mothers impacted by disability or emergency contexts:

- Do not force mothers to talk about their disabilities or their infants' disabilities. Some mothers may talk about their disability or infants' disability on their own while others may need more time. It is also possible that in some counseling sessions, mothers will want to discuss other issues they are facing.
- Suggest additional bonding and stimulation activities for infants with disabilities and their mothers.
- If you are working in emergency settings:
    - Recognize that the ongoing disruption, violence, and limited access to quality services affects a mother's ability to care for the child.
    - Identify and acknowledge the stress and possible trauma caused by the crisis and understand how these factors might influence the mother's infant feeding and care practices.
    - Ensure a strong focus on psychosocial and mental health support, including listening to, reassuring, and supporting the mother.

- Conclude this section:
    - Just like with any mother, we should use positive counselling and communication skills with mothers who have disabilities or who have infants with disabilities. Considering the extra stress associated with these circumstances, it is crucial to create a safe and supportive environment for both the mother and her child.

| **Activity 5.2.2 (50 minutes)** |
|---|
| Considerations for supporting mothers with disabilities |

| **Activity Summary** | **Key message(s)** | **Slides & Material(s)** |
|---|---|---|
| Brainstorming in small groups | 2 | Slides 218-224<br><br>MAMI Counseling Cards/Kaarkas [Somalia/Somaliland]: A1, A2, A4, A8, A24, C9, C10<br><br>Mod05_ActivitySheet_MAMI Counseling Card Adaptations<br><br>Mod05_ActivitySheet_MAMI Counseling Card Adaptations_Answers<br><br>*Note: MAMI Counseling Cards numbers may differ by the version used. If using the generic package, use the following cards: A1, A3, A6, A22, C8* |

**Instructions**

- Introduce this section:
    - All new mothers, including those with disabilities, can face challenges with breastfeeding and appreciate help with taking care of their infants.

- Most mothers with disabilities can breastfeed, but some might need help with positioning, may not produce enough milk, have difficulty with latching, or feel too weak and tired.
  - A mother with a physical disability may not have the physical strength to hold, position and burp her infant.
  - A mother with limb length difference, one-sided weakness, or only one arm, may need to consider other ways to support her breast while holding her infant.
  - A mother with a spinal cord injury may have reduced or absent sensation, which can impact milk production.
  - A mother who is deaf or hard of hearing may have difficulty hearing and responding promptly to her infant's crying.
  - A mother who is blind or partially sighted may have difficulty knowing if her infant has a good latch.
- These mothers also face additional barriers such as insufficient support, limited access to information, stigma and misconceptions about their ability to breastfeed. By using positive counselling skills, we can empower mothers to decide for themselves if they can breastfeed and collaborate with them to find practical solutions that work for their unique situations.
- The MAMI Counseling Cards and Support Action booklet are excellent job aids for counseling mothers with disabilities and mothers of infants with disabilities. For some mothers, you may need to adapt information on certain cards to provide targeted, individualized counselling.
- *Note: An updated version of the Community IYCF Counseling Package was launched in April 2024. It includes improved and increased focus on counseling, the needs of children with disabilities and with feeding difficulties, and consideration for emergency contexts.*

<u>Activity (40 minutes):</u>

*Note: If time is limited, do this activity as a large group discussion. Select three counselling cards and ask the group how they would adapt them for mothers with various impairments. For example: 1) Adapting "Good positioning" (Kaarkas A2) for a mother with limited use of one arm; 2) Adapting "Good attachment" (Kaarkas A1) for a mother who is blind or partially sighted; 3) Adapting "Crying a lot & not sleeping" (Kaarkas A8) for a mother who is deaf or hard of hearing. Refer to the answer key for suggestions to add to the discussion.*

- Divide participants into six small groups.
- Give each group an activity sheet and a counseling card (kaarkas):
  - Card A1: Good Attachment
  - Card A2: Good Positioning
  - Card A4: How often to breastfeed
  - Card A8: Crying a lot and not sleeping
  - Card A24: Cup feeding
  - Card C9: Nurturing care for early childhood development: recommendations

  *Note: If using the generic package, use card numbers listed in Slides & Materials.*
- Share activity instructions:
  - Indicate your assigned MAMI Counseling Card number on the activity sheet.
  - Brainstorm suggestions on how you would adapt the card to meet the needs of a mother
    - with a physical disability (limited use of arms and/or upper body; limited mobility)
    - who is deaf or hard of hearing (partial or total hearing loss)

        - who is blind or partially sighted (partial or total vision loss)
    - Adaptations can include tailoring the "Key messages," the information under "Check," and "Counseling and support actions" to the mother's needs. For example, how should the "Good Positioning" counseling card be adapted for a mother with limited use of her arms? What strategies, techniques, or support actions can you suggest to support this mother? You may think about equipment or materials that might be helpful, receiving physical assistance from others, and peer support, among other strategies.
    - Write your specific suggestions on the activity sheet for each type of disability.
    - If you do not think your card requires adaptation, indicate so on the activity sheet.
- After 10 minutes, reconvene as a large group. Ask each group to share some of their suggestions.
- Share additional suggestions by referring to the answer key.

- Present information on general considerations when supporting mothers with disabilities:
    - The experiences of mothers with disabilities vary widely so it is important to collaborate with the mother to identify strategies that are most useful for her and customize your suggestions accordingly.
    - Depending on the mother and her needs, you may consider partial breastfeeding (supplement with cup feeding or other supports).
    - Identify practical solutions (e.g., use of pillows, cushions, and towels) that work within the financial constraints of the family.
    - Ongoing support is key. Conduct home visits and provide resources on community and peer support.
    - Consider the following three key strategies:
        - *Positioning during breastfeeding*: This may require mothers to modify traditional positions and try various positions before they are successful. This is particularly important for mothers with physical disabilities.
        - *Physical help from others*: It may be necessary for mothers to receive physical help from others, such as the father, a family member, or a close neighbor or friend. Collaborate with the mother to identify people in her family/community that can assist her with breastfeeding, breast milk expression, and/or infant care. This is particularly important for mothers with physical disabilities and mothers who are blind or partially sighted.
        - *Peer support*: Women with disabilities may find value in receiving breastfeeding information from peers, particularly those who share similar disabilities. This allows for the exchange of advice on adaptation and positioning during breastfeeding.
- Conclude this section:
    - Mothers with disabilities are more likely to initiate and continue breastfeeding when provided with accessible information, practical guidance, and emotional support tailored to their specific needs. Using your positive communication and counseling skills and strategies from this training to ensuring a supportive environment that promotes both the mother's and the infant's wellbeing.

**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. Counseling of mothers impacted by disability is most effective if mothers receive accessible and relevant information, if they are listened to, have their difficulties acknowledged, have their questions answered, and if there is a caring and supportive environment.
2. When supporting mothers with disabilities in addressing infant feeding difficulties, it is important to collaborate with them to identify practical, tailored solutions. This can include trying different breastfeeding positions, receiving physical assistance from others, and connecting with peers.

# MODULE 6

## Disability-Inclusive MAMI Scenario Role Play

**Time:** 2.5 hours

**Preparation & materials required:** Slide Deck, MAMI Counseling Cards (generic or country-specific), scenario documents, activity sheet, and answer key.

**Preparation and materials required for option 1:** Organize for trainees to be able to visit health clinic/ local community space with mothers and infants less than 6-months and carry out real-life MAMI assessments and counselling. Alternatively, can use family and friends of colleagues who attend the training venue.

**Preparation and materials required for option 2:** Contextualize scenarios A, B, C, and D.

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

- Apply the MAMI Care Pathway steps (assess, analyze, act) for infants and mothers with disabilities.

### Key message(s) to take away for learners:

1. Implement the MAMI Care Pathway in a safe environment to identify areas of strengths and work through priority challenges to support infants and mothers with disabilities.

| Activity 6.1 |
|---|
| Disability-inclusive MAMI scenarios |

| Activity Summary | Key message(s) | Slides & Material(s) |
|---|---|---|
| Practical | 1 | Slides 225-227<br><br>**Option 1**: MAMI Assessment forms, thermometer, Child and adult MUAC tape, stopwatch, weighing scales, length board & MAMI Counselling Cards<br><br>**Option 2**: contextualised Scenarios A, B, C, and D – all relevant documents:<br>• *Scenario A*: 6-week male; cleft lip<br>*Scenario B*: 4-month male; suspected disability, high tone |

| | | |
|---|---|---|
| | | • *Scenario C*: 2-month female; feeding difficulties related to positioning; mother with physical disability<br>• *Scenario D*: 1-month female; Down syndrome<br><br>MAMI Counselling Cards (generic or country-specific)<br><br>Mod 03_Handouts_Infant Feeding Difficulties Checklist<br><br>Mod 06_ActivitySheet_Addressing Scenarios<br><br>Mod 06_ActivitySheet_Addressing Scenarios A-D_Answers |

**Option 1 Instructions:**

- If possible, this should take place within a health clinic, the local community space with mothers and infants from the community who have volunteered to be part of the training, or friends and families who have infants. [*Note: Ideally, infants and/or mothers would have disabilities covered in the training.]*
- It is really important that the mothers and infants have appropriate information shared in advance of the role-play with aims and objectives, and a clear understanding that learners will be supervised and written consent from the mother must be given.
- Have the space set up as it would be normally, with any safety measures needed to mitigate the risk of infections. Please make sure you as a facilitator are aware of any adjustments that may be needed to be put in place ahead of the role-play.
- Whichever approach you as a facilitator feel is appropriate, it is really important that you keep a close eye on learners as they practice using the MAMI Care Pathway Package and apply it to infants/mothers with disabilities.
- Depending on the size of the group, it is advisable to split them into smaller groups so that you can support learners more. Recommended group size is 6-10 learners.
- Depending on the number of mother-infant pairs that have volunteered or are able to act, the group can be split into pairs. One person will be practicing using the Care Pathway, whilst the other observes and supports them. They can then swap round to ensure that both learners can practice.

**Option 2 Instructions:**

- Explain that we are going to use some scenarios to get familiar with the MAMI assessments & counselling cards.

<u>Activity (60 minutes + 75 minutes for role play & discussion):</u>

- Split participants in to four groups and assign each group a Scenario from A, B, C, and D. *Note: If time allows, groups can work on additional scenarios.*
- Handout all the relevant documents for each of the assigned scenarios, 1 full set of forms per person in the group.

- Participants are to go through the scenarios and take the following steps for the group scenario:
    - Look at the information provided in the completed forms (ASSESS).
    - Look at the results of the assessment and complete an Infant Feeding Difficulties Checklist for the infant (ANALYZE).
    - Summarise the assessments, and classify the risk as low, moderate or severe (ANALYZE).
    - Identify the two priority problems from the assessment (ANALYZE).
    - Review the information and decide on the actions needed for these priority problems at the support visit with the caregiver and infant.
    - Decide which of the MAMI Counselling Cards, strategies, or adaptations would be useful to provide support to this caregiver and infant, according to the challenges identified (ACT).
    - Prepare a short role play of the 1st counselling session, targeting the priority problem(s), for your assigned scenario to present to the group, using the identified counselling card(s).
- Walk around the room and answer questions as needed.
- After 60 minutes, ask each group to present 1-2 scenario(s), describing briefly the case of the infant-mother pair (e.g., infant's age, sex, health condition, nutritional status, feeding status, etc.).
- Each group will then role-play their Scenario, 1 person as the counsellor and 1 person as the mother/ caregiver, making clear which counselling card(s) they have identified to us.
- Ask the rest of the group for reflections:
    - What positive counselling skills did you observe?
    - Is there any constructive feedback to give?
    - Did you agree with the selected counselling cards and information given?

**At the end of the role-plays**

- A thorough debrief is really important after the simulation. Ask the group how they found the experience, what their successes were, and understand where there may have been challenges. It is also important for you as a facilitator to give feedback on your observations and what the mothers fed-back to you and the group.
- When closing the session, make sure that participants are confident in their ability to apply the MAMI Care Pathway Package to infants and mothers with disabilities. Consider arranging follow up 1-to-1 support with individuals who have concerns, or you feel could potentially use some additional training or encouragement. On-the-job coaching and regular supportive supervision is essential for all staff.

**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. Implement the MAMI Care Pathway in a safe environment to identify areas of strengths and work through priority challenges to support infants and mothers with disabilities.