

## 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  Scissors, tape, flipcharts  Mod 03_ActivitySheet_Developmental Milestone Sorting (4)  Mod 03_ActivitySheet_Developmental Milestone Sorting Answers (1)  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.

### Activity (25 minutes):

- 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  Flipchart, markers  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.

#### Activity (15 minutes):

- 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:



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- 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 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.

#### Activity (20 minutes):

- 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**

<b>Activity Summary</b>	<b>Key message(s)</b>	<b>Slides &amp; Material(s)</b>
Small group brainstorm	3 & 4	Slides 101-106  Flipchart, markers  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?



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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 Flipchart, markers 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.

### **Activity (10 minutes):**

- 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"?

Optional activity note: 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  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.

