

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 Markers/pens or dried beans for each participant 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.
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- 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 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:



Save the Children

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 Blank paper and markers (or crayons)

Instructions

- Introduce this section:
- In this section, we are going to 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 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.
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- 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.