PART I

DISABILITY-INCLUSIVE NUTRITION AND FEEDING FOR INFANTS AND CHILDREN

Facilitator Guide

SPOON

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INTRODUCTION

Disability-Inclusive Nutrition and Feeding for Infants and Children

Time: 30-45 minutes

Preparation & materials required: Slide Deck, flipchart, markers, training agenda, pre-test activity sheet and answer key.

Objectives: Give an overview of the training and what to expect (and what not to expect) and asses pre-training knowledge.

Activity Summary	Key messages	Slides & Materials
Presentation	n/a	Slides 1-5 Introduction_Handout_Disability-inclusive Nutrition & Feeding_Training Agenda Introduction_Activity Sheet_Disability-inclusive Nutrition & Feeding_Pre-post-test Introduction_Activity Sheet_Disability-inclusive Nutrition & Feeding_Pre-post-test_Answers

Instructions

- Introduce yourself and ask others to introduce themselves and share what they are looking forward to the most in the training.
- Conduct an icebreaker activity or ask local partner to lead activity.
- Introduce the training:
    - Children with disabilities are at increased risk of feeding difficulties and malnutrition. Conditions such as neurological disorders, congenital anomalies, genetic syndromes, and other health issues can further complicate feeding practices.
    - Mothers with disabilities also face significant barriers, including limited access to health information and services, communication challenges, and physical obstacles to reaching care. These factors heighten their vulnerability—particularly when their children are nutritionally at risk.
    - In humanitarian emergencies, delivering adequate services becomes even more challenging. Access to surgical interventions, screening, and diagnosis is often limited, while stigma and discrimination may increase.
    - This training aims to equip frontline health and nutrition workers in *[name of country]* with the knowledge, tools, and practical skills to provide disability-inclusive services for children under five and their mothers.

- Distribute a copy of the handout **agenda** to each participant and run through the agenda for each day of the training. Explain that the training is divided into several modules and topics and that learning objectives will be presented for each topic.
- Distribute the **pre-test** to participants and give them 15-20 minutes to complete the test. Explain that we will repeat the test after the training to be able to see the knowledge attainment, and that the scores will help us to improve the training content and delivery for next time.

Contextualization

- To ensure the training is relevant and meaningful, adapt content to reflect the local context of the country or community where the training is being conducted. This includes:
    - adjusting case studies to better align with local systems, services, and realities—for example, referencing existing referral pathways for children with disabilities, and
    - including national or community-specific support services such as hotlines or specialized care programs.
- When covering topics such as Breast-Milk Substitutes (BMS) or Infant and Young Child Feeding in Emergencies (IYCF-E), briefly mention any relevant national protocols, laws, or standard operating procedures.
- You are also encouraged to integrate common cultural beliefs and social myths related to disability and infant and young child feeding from the local context.
- Real-life barriers should be incorporated into discussions—particularly those affecting care-seeking behaviors, such as lack of accessible transportation in rural areas, limited access to health services, or stigma surrounding disability.
- Referencing national assessments or surveys (e.g., nutrition, health, or disability prevalence studies) can also help ground the training in locally relevant data and support more effective learning and discussion.

MODULE 1

Understanding Disability and Inclusion

(Total time: 245 minutes)

1.1 Understanding Disability

Time: 80 minutes

Preparation & materials required: Slide Deck, flipchart, markers, Understanding Disability handout, 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. A child 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 6-14 Flipchart, markers Mod 01_Handout_Understanding Disability

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 health and nutrition programs and services.

- In this module, we will discuss disability and common language to use when talking about disability, and think of the barriers that children 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. Two main approaches to understanding disability have been used throughout history:
    - *Charity model*:
      - Persons 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*:
      - Persons with disabilities are 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 persons 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*: loss or difference with anatomical parts of the body or physiological functions of body systems, resulting from a health condition
    - *Activity limitations*: difficulties in completing everyday tasks or actions (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 helps us understand a child's functioning at the level of the *body* (body structure and function), at the level of the *individual* (activity), and as a member of *society* (participation).
  - 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.

- 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.
  - Other international standards also reinforce a rights-based approach to disability:
    - The *World Declaration on Nutrition* affirms the right of *every* individual to nutritionally adequate and safe food.
    - The *United Nations Convention on the Rights of the Child (UNCRC)* upholds the rights of children with disabilities to adequate nutrition, access to quality healthcare services, and living conditions that support their independence and full participation in their communities.
  - Distribute handout to participants.

Activity 1.1.2 (30 minutes)
Applying the ICF framework

Activity Summary	**Key message(s)**	**Slides & Material(s)**
Small group discussion	2	Slides 15-21 Flipchart, markers

Instructions

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

- Introduce the activity:

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    - We will now practice using the ICF framework to increase our understanding of its components and 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.
- Tell participants that you will first demonstrate with an example.
- Draw an empty ICF framework (boxes and arrows) on a flipchart. *Note: Environmental and personal factors can be combined into one box.*
- Provide an example for the activity:
    - Let's take a look at how the ICF may apply for an infant girl with a cleft lip:
        - The *condition* 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.
- Ask group to draw an empty ICF framework (boxes and arrows) on their flipchart.
- 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. *Note: you can assign health conditions.*
    - Write a body *structures/functions* that might be impacted by this condition.
    - Write an *activity* or an everyday task/action that might be limited by this condition.
    - Write a social event or activity that a child may not *participate* in as a result of this condition and barriers.
    - Write two contextual factors (personal or environmental) that may create barriers to the child's participation.
- After 15 minutes, ask each group to present their ICF framework.
- Provide additional examples for each component of the ICF:
    - *Health conditions*:
        - Conditions commonly encountered may include cerebral palsy, Down syndrome, autism, cleft lip, cleft palate, spina bifida, intellectual disabilities, epilepsy/seizure disorder, learning disabilities, mobility or movement disorders, deaf or hard of hearing, and blind or partially sighted.
    - *Body structures/functions:*
        - Body structures include: nose, mouth, neck, brain, heart, nervous system, and limbs.
        - Body functions include: seeing, hearing, pain, sleep, attention, memory, language, emotional functions, digestion, muscle tone, mobility, immunity.
    - *Activities*:
        - Activities include: Self-care, eating, drinking, reading, writing, speaking, walking, grasping or lifting objects, using transportation, playing a sport, socializing.
    - *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
  - Services
  - Systems and policies
  - 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 22-24 Mod 01_ActivitySheet_Case Studies A Mod 01_ActivitySheet_Case Studies A_Answers

Instructions

Note: Adapt case studies to reflect the local context. This may include changing the names of children and towns, modifying details to align with the realities of the country or community where the training is taking place, and incorporating references to local systems, services, and programs.

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

- 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 two case studies. As you read:
    - *underline* any contextual factors that could negatively impact the infant's life
    - *circle* any contextual factors that could positively impact the infant's life
  - Then, discuss the following questions in your group:
    - What is the context in which each infant lives?
    - How might 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. A child 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: 50 minutes

Preparation & materials required: Slide Deck, flipchart, markers, Healthcare Journey Flowchart handout, Attitudinal Barriers activity sheet and answer key.

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

- Identify barriers faced by children and mothers with disabilities that exist in health and nutrition services.
- Describe common attitudes and social norms around disability among health workers and in communities where they work.

Key message(s) to take away for learners:

1. Children and mothers with disabilities commonly experience attitudinal, environmental, communication, financial, and institutional barriers in accessing a level of healthcare equal to that of children and mothers without disabilities.
2. Negative attitudes among health workers – such as avoidance, pity, or stereotyping of persons with disabilities – can create significant barriers to accessing quality health and nutrition services.

Activity 1.2.1 (30 minutes)
Barriers along the healthcare journey

Activity Summary	Key messages	Slides & Materials
Brainstorming activity	1	Slides 25-29 Flipchart, markers

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		Mod 01_Handout_Healthcare Journey Flowchart

Instructions

Note: When discussing barriers, include real-life examples from the country or community where the training is taking place—especially those faced in remote areas, those limiting access to health services, and those affecting care-seeking behaviors related to malnutrition screening and treatment. When addressing cultural beliefs, incorporate practical examples and common social myths around disability and infant and young child feeding relevant to the local context.

- Introduce this section:
  - Across the world, persons with disabilities face significant and multiple barriers that prevent them from accessing a level of healthcare and services equal to that of persons without disabilities.
  - These barriers can be placed in four categories:
    - *Attitudinal*: these include the negative perceptions, assumptions and beliefs about persons 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)
    - *Environmental*: these include the obstacles that prevent persons with disability from accessing 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 health workers (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 healthcare (e.g., cost of transport, cost of medicine, cost of special services)
    - *Institutional:* these include restrictions established through policy, legislation or formal structures that prevent persons with disabilities from fully participating in society on an equal basis with others (e.g., legislation that prevents right to enrollment in public school or access to social protection; policies that do not subsidize the cost of assistive devices or rehabilitation)
  - Barriers can occur at any point in accessing health services for a mother-child pair impacted by disability.

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

- Distribute the healthcare journey flowchart handout.
- Allow 5 minutes for participants to review it individually or in pairs, reflecting on each stage.
- Ask participants to consider:
  - What barriers might a child or mother with a disability face at each stage of this journey? Encourage them to think about attitudinal, environmental, communication, financial, and institutional barriers.
- Facilitate a group discussion by walking through the journey stage by stage. Invite participants to share the barriers they identified and discuss how these could impact access to care at each stage:
  1. *Awareness of health and nutrition services*: Is the mother aware of health and nutrition services? Is information about nutrition and feeding accessible and available in accessible formats?
  2. *Past experiences of health and nutrition services*: Is the mother willing to access health and nutrition services based on prior experiences with these services and health workers?

3. *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?
4. *Finances*: Can the mother afford healthcare and transport? Does she receive any financial support? Is she aware of existing social services?
5. *Transport*: Can the mother access and afford transport? How far is the clinic? Is public transport to the clinic available? Does the clinic offer transport services?
6. *Entering the health clinic*: Does the clinic have ramps? Is clinic signage accessible? Is staff, including reception and security, welcoming and respectful?
7. *Waiting for an appointment*: Is the waiting area accessible? Are toilets accessible? Do staff follow any discriminatory practices?
8. *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?
9. *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?

- 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 a child 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 30-33 Mod 01_Activity Sheet_Attitudinal Barriers Mod 01_Activity Sheet_Attitudinal Barriers_Answers

Instructions

- Introduce this section:
  - We will now delve deeper into attitudinal barriers as they often compound other types of barriers, such as environmental and communication barriers.
  - Attitudinal barriers are a major challenge for persons 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 persons 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.
  - Negative attitudes include:
    - *Stereotyping*: Assuming what persons 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 persons with disabilities are inferior because of their impairment.
- *Denial*: Not believing a person with disability or recognizing the impact of the impairment, or denying reasonable accommodation where needed. This is especially common when conditions may not be visible (e.g., intellectual disability).

Activity (10 minutes):

- Ask participants to pair up and distribute the activity sheet, one copy per participant.
- Ask pairs to match statements from healthcare 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 workers 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. Children and mothers with disabilities commonly experience attitudinal, environmental, communication, financial, and institutional barriers in accessing a level of healthcare equal to that of children and mothers without disabilities.
2. Negative attitudes among health workers – such as avoidance, pity, or stereotyping of persons with disabilities – can create significant barriers to accessing quality health and nutrition services.

1.3 Promoting Disability-inclusive Health and Nutrition Services

Time: 45 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 barriers to inclusive health and nutrition services.

Key message(s) to take away for learners:

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

Activity 1.3.1 (20 minutes)
Promoting disability-inclusive attitudes

Activity Summary	Key messages	Slides & Materials
Brainstorming activity	1	Slides 34-37 Mod 01_Activity Sheet_Disability-inclusive Attitudes Mod 01_Activity Sheet_Disability-inclusive Attitudes_Answers

Instructions

- Introduce this section:
  - Disability inclusion in health and nutrition services can be achieved through a twin-track approach:
    - *Disability inclusion within mainstream health and nutrition services*: The needs of many children and mothers with disability can be met through existing services with modest adaptations.
    - *Disability-specific health and nutrition services when needed*: Disability-specific services may be warranted when the needs of children 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 nutrition services.
  - To ensure nutrition services are inclusive, we need to remove or reduce the barriers for mother-child pairs impacted by disability. This starts by addressing negative attitudes.

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

- 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 this section:
  - 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 nutrition and health workers.

Activity 1.3.2 (25 minutes)
Addressing barriers along the healthcare care journey

Activity Summary	Key messages	Slides & Materials

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Brainstorming activity	2	Slides 38-39 Flipchart, markers

Instructions

Note: Incorporate in the discussion references to local systems, services, and programs that support disability-inclusive health and nutrition services.

Activity (25 minutes):

- Tell participants:
  - Earlier, you identified various barriers that mothers and child with disabilities face when accessing health and nutrition services.
  - Now, let's explore practical solutions to address or reduce these barriers.
  - You may share strategies you have personally used or would like to try. These can be general or linked to specific stages of the healthcare journey.
- Facilitate a group discussion, guiding participants through each type of barrier:
  - attitudinal
  - environmental
  - communication
  - financial
  - institutional
- Note participants' responses on a flipchart, creating a list under each barrier type.
- Provide additional solutions on each category if not shared by participants:
  - *Attitudinal*: Awareness training for all nutrition staff; community awareness-raising activities; monitoring of discriminatory practices; zero tolerance policy for discriminatory practices; integration of disability education into curriculum and accreditation for all health workers; longer and flexible appointment times; involving mothers in decision-making; assessment of the clinic policies for inclusion; collection of sex, age, and disability-disaggregated data; ensure health management information systems (HMIS) are inclusive.
  - *Environmental*: 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 nutrition 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 special services.
  - *Institutional*: disability mainstreamed in health and nutrition policies; disability-inclusive budgeting; advocacy activities; linking health and nutrition with other sectors like social protection and education; partnerships between government and OPDs; disability-disaggregated data; mandatory workforce training in disability inclusion; accountability mechanisms.

- 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.

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

1.4 Effective Communication with Mothers and Children with Disabilities

Time: 70 minutes

Preparation & materials required: Slide Deck, flipchart, markers, Mothers with Disabilities Scenario Cards activity sheet

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

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

Key message(s) to take away for learners:

1. Effective communication with mothers and children with disabilities requires empathy, patience, and the use of appropriate strategies tailored to their specific needs.
2. When children with disabilities have difficulty communicating, they may feel frustrated, scared, and isolated—affecting their emotional wellbeing, development, and bond with their caregiver.
3. When communicating with mothers and children who are deaf or hard of hearing, use clear written communication, gestures, visual aids, or sign language if possible.
4. When communicating with mothers and children who are blind or partially sighted, use detailed verbal descriptions and tactile aids or braille if available to convey information.
5. When communicating with mothers and children with intellectual disabilities, use simple, clear language and repeat key information.

Activity 1.4.1 (25 minutes)
Verbal and nonverbal communication

Activity Summary	Key message(s)	Slides & Material(s)
Game & group discussion	1	Slides 40-43

Instructions

Activity (20 minutes):

- Tell participants that in this section we will discuss strategies to remove communication barriers when interacting with mothers and children with disabilities. We will begin with a game.
- Ask for 8-10 volunteers 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. 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 his 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 make the 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 children and finding alternative ways of communicating, if required, is important.
    - Ask participants:
        - How else can we communicate nonverbally? *Note: share the following methods if not mentioned by participants: smiling, gesturing, nodding, maintaining eye contact, pointing, laughing, drawing, writing, sign language, facial expression, body language.*
    - Think back to this activity when you encounter mothers and children with disability as a reminder that it is more important to try to communicate and find out what their needs are than to always "get it right".

- Conclude this section:
  - Communicating effectively with mothers and children with disabilities involves understanding their communication needs, demonstrating empathy, practicing patience, and applying strategies tailored for their particular needs. Applying this approach is especially important during counseling to ensure that each mother receives the support and information she needs in a way that is accessible and respectful. This ultimately fosters a more inclusive and supportive environment.

Activity 1.4.2 (15 minutes)
Communication strategies for children with disabilities

Activity Summary	Key message(s)	Slides & Material(s)
Group discussion	1 & 2	Slides 44-46

Instructions

Activity (15 minutes):

- Tell participants:
  - In your role, you may have interacted or will likely interact with children who have difficulty communicating. In this section, we will discuss some strategies for effective communication with children with disabilities.
- Ask participants:
  - Can you share examples of communication difficulties that children with disabilities experience? *[Answers may include unclear speech, delayed speech, limited vocabulary, difficulty expressing themselves, not following instructions, not responding appropriately to questions, no spoken language, difficulty maintaining eye contact, difficulty understanding social cues]*
  - What is one way a child with communication difficulties may communicate their needs to you? *[Answers may include crying, reaching, talking, yelling, pointing, body movements.]*
- Listen to responses, then say:
  - Some children with disabilities cannot communicate like other children their same age. A communication difficulty can impact a child's ability to send, receive, or process messages or to comprehend concepts, verbal or nonverbal communication and graphic symbol systems (like letters or words).
  - A child with an intellectual disability may have difficulty understanding or making sense of what they hear and difficulty thinking about ways to communicate or express messages.
  - A child with a physical disability, such as cerebral palsy, may have no difficulties thinking or learning, but may still have difficulty communicating, such as speech that is unclear. If a child's speech is unclear and it is difficult for them to express a message, people may think the child has an intellectual disability, even when they do not.
- Ask participants:
  - How do you think a child would feel when they are unable to communicate their wants and needs?
- Listen to responses, then say:
  - When a child has difficulty communicating, they may feel:
    - *Scared, anxious or insecure*, especially if their needs, like hunger, comfort, and attention, are not being met.
    - *Sad or isolated*, as communication is a key part of connecting with their mothers and other people.
    - *Frustrated*, because they know what they want but cannot make others understand.

        - *Angry or distressed*, especially if repeated attempts to communicate are misunderstood or ignored.
        - *Helpless*, because they may rely entirely on others to interpret their behaviors and cues.
    - Over time, these feeling can affect a child's emotional wellbeing and development. It may also negatively affect the mother-child relationship.
- Ask participants:
    - Can anyone share tips or strategies that are effective when communicating with children with disabilities?
- Listen to responses, then say:
    - Here are some additional tips for communicating with all children and especially those who have difficulty communicating:
        - First, LOOK!
            - Get down on the child's level to communicate and to watch for non-verbal cues. This includes watching facial expressions or eye gaze.
            - Make certain you have the child's attention before you talk to them.
              Call the child's name, when they look at you praise them by smiling, talking and using big facial expressions.
            - Make eye contact. Some children may have difficulty maintaining eye contact.
        - Second, TELL!
            - Tell the child what you are doing and what to expect. This may include saying, "I will now take your weight. Can you step on the scale for me?" By telling the child what to expect, the child is more likely to remain calm and respond. If a child doesn't know what to expect they may become startled or frightened.
            - Do not talk too fast or ask too many questions.
            - Do not use "baby talk" to an older child with a disability.
            - Use facial expressions and gestures.
        - Third, LISTEN!
            - Children with communication difficulties may take longer to respond. Give the child time to respond.
            - Children who cannot communicate verbally, may communicate with body language.
            - Praise and encourage (clap, cheer, smile).
            - Never force a child to speak, but encourage any attempt to communicate.
        - Finally, RESPOND!
            - Respond immediately to the child's verbal and non-verbal attempts to communicate.
            - Acknowledge the child's attempts to communicate.
            - Maintain a positive attitude towards the child.

- Conclude this section:
    - Mothers may feel guilt, shame, or defeat when they don't read their child's cues correctly. It is important allow them to share their struggles. You can let them know that mistakes happen, and you recognize they are doing their best. As we encourage mothers to communicate and connect with their children, remember the mother needs a meaningful connection as well.

Activity 1.4.3 (30 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 47-55 Flipchart, markers Mod 01_Activity Sheet_Mothers with Disabilities Scenario Cards

Instructions

Activity (20 minutes):

- Before the training, prepare the scenario cards by cutting along the dotted lines in the activity sheet.
- Introduce activity:
    - In this activity, we will role-play counselling sessions with mothers who have different types of disabilities. We will practice and reflect on communication strategies that can support effective counselling in each case. While the focus is on mothers, many of the strategies we will discuss can also be adapted for children, depending on their age.
- Divide participants into six groups.
- Give each group a scenario card. Each card includes a brief description of the mother's disability and the reason for her visit.
- Each group selects one person to play the mother and another to play the counselor. The remaining group members will observe the interaction.
- Each group will act out their scenario using communication strategies they believe are appropriate for the mother's specific disability. Observers may take notes on the communication techniques used. Group members may rotate roles if time allows. *Note: If participants have access to the Community IYCF Counseling Cards, they may use them if relevant to their scenario.*
- In the meantime, draw three columns labeled Hearing, Visual, and Intellectual on a flipchart.
- After 10 minutes, reconvene as a whole group.
- Each group briefly shares their experiences, challenges, and effective communication strategies they used.
- As participants share their strategies, write them in the corresponding column on the flipchart.
- 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 counseling sessions.
        - Use gestures or visual cues and body language.
        - Use visual aids.
        - Use 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, cup feeding, spoon feeding, and texture modification.
        - Braille and/or high contrast color 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 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 is the best way of communicating.
        - 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.
    - 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 and children with disabilities?
        - What is one new strategy you will implement in your practice?

- Conclude this 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 children (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. Effective communication with mothers and children with disabilities requires empathy, patience, and the use of appropriate strategies tailored to each type of disability.
2. When children with disabilities have difficulty communicating, they may feel frustrated, scared, and isolated—affecting their emotional wellbeing, development, and bond with their caregiver.
3. When communicating with mothers and children who are deaf or hard of hearing, use clear written communication, gestures, visual aids, or sign language if possible.
4. When communicating with mothers and children who are blind or partially sighted, use detailed verbal descriptions and tactile aids or braille if available to convey information.
5. When communicating with mothers and children with intellectual disabilities, use simple, clear language and repeat key information.

MODULE 2

Disability, Feeding, and Nutrition in Children

(Total time: 120 minutes)

2.1 Common Disabilities and Conditions in Children

Time: 40 minutes

Preparation & materials required: Slide Deck, markers, pens, Bingo cards.

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

- Recall disabilities and conditions that may occur during childhood.
- Define cleft lip/palate, cerebral palsy, Down syndrome, autism, hydrocephalus, and spina bifida.

Key message(s) to take away for learners:

1. Common childhood disabilities and conditions that may impact nutrition and feeding include cleft lip/palate, cerebral palsy, Down syndrome, autism, hydrocephalus, and spina bifida.
2. Some conditions and impairments in children start from birth while others develop soon after birth. Certain conditions can be identified through observation or basic physical examination, whereas others may require specialized medical evaluation.
3. Focus on a child's functional abilities, such as the ability to feed well, rather than a specific diagnosis.

Activity 2.1.1 (40 minutes)
Common conditions/disabilities in children

Activity Summary	Key message(s)	Slides & Material(s)
Interactive presentation & Bingo!	1, 2 & 3	Slides 56-76 Markers/pens Mod 02_Activity Sheet_Bingo cards

Instructions

- Introduce the module:
  - In this module, we will explore common conditions and disabilities in children 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 conditions and disability in children:
  - *Developmental milestones*:
    - Developmental milestones are skills that most children should have by a certain age. Examples include rolling over, smiling, sitting up, walking, running, and talking. 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 to attain developmental milestones.
    - Developmental delay is used to describe when a young child is slow to achieve expected skills compared to other children their same age. But this does not mean they have disability.
    - Many children with developmental delays can catch up with support and early intervention. If a child's developmental delays impact their abilities to learn and function long term, then it can be described as a disability.
    - Risk factors for developmental delays include genetic factors, birth defects, children born prematurely or are underweight, nutritional deficiencies, having certain infections (e.g., congenital cytomegalovirus or toxoplasmosis), birth complications, severe trauma, not enough oxygen at birth, or being exposed to certain medications, smoking, or alcohol 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 begin during a child's developmental period and typically last throughout their lifetime.
  - *Congenital anomalies (disorders)*:
    - Congenital means present from birth. Congenital conditions can be inherited or caused by environmental factors.

<u>Activity (15 minutes):</u>
Note: This section can be adapted to focus on conditions that are common to a country/region.

- 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 cerebral palsy? What is it? How is it identified and addressed in your country? What beliefs exist around cerebral palsy in your country?)*. Encourage discussion after each description to ensure understanding and reinforce learning.

  - *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 children with cleft palate.
        - Several organizations including Smile Train, Operation Smile and Operation Rainbow, Global Smile Foundation, amongst others, provide cleft care services and training in low-resource settings.
- *Cerebral palsy*
    - Cerebral palsy is a condition that affects 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:
        - Birth complications (e.g., interruption in the flow of oxygen to the infant's brain or bleeding in the 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
        - Genetic disorders
    - 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 children 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, bringing hands or spoon to mouth, sitting upright, and walking steadily
        - Delay in meeting developmental milestones, such as rolling over, sitting up without support, crawling, and walking
        - Difficulty swallowing, chewing, and 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*
    - Down syndrome, also known as trisomy 21, is a genetic condition in which a child is born with an extra copy of chromosome 21. This extra genetic

material affects the child's intellectual and physical development and increases the risk for certain health problems.
    - Down syndrome occurs by chance and cannot be prevented. It is not caused by anything a mother did or did not do before or during pregnancy.
    - Children with Down syndrome often share certain 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 common, particularly in infancy, but tends to improve with age. Children generally reach developmental milestones, like sitting up, crawling, and walking later than other children. Low muscle tone may also contribute to challenges with feeding (e.g., difficulty sucking, self-feeding), constipation, and gastroesophageal reflux (when food or acid flows back into the esophagus).
    - Children with Down syndrome usually grow more slowly and are shorter than their peers.
    - Most children have mild to moderate intellectual disability, meaning they learn new skills at a slower pace. With the right support, they can and do develop skills throughout their lives.
    - It is common for children with Down syndrome to have additional medical concerns, including congenital heart defect in infants, as well as hearing and vision problems.
    - Intervention:
        - Children with Down syndrome benefit significantly from early intervention services, including physical therapy, occupational therapy, and speech/feeding therapy. The care needs vary depending on their individual health challenges.
        - All newborns with Down syndrome should be screened for congenital heart defects, and any feeding issues or heart conditions should be addressed promptly.
        - Regular checkups are important to monitor and manage potential hearing and vision problems.
- *Autism*
    - Autism – also referred to as autism spectrum disorder – is a developmental disability involving a wide range of conditions related to brain development. Being autistic means the brain functions differently, which can influence how a child behaves, communicates, interacts with others, and learns. Children with autism may not appear physically different from their peers.
    - Autism can sometimes be identified at 18 months or younger, but is more commonly diagnosed between ages 3 to 5 years, or even later.
    - The causes of autism are not well understood. There is no evidence linking autism to poor parenting or vaccines.
    - Autism is typically characterized by:
        - some degree of difficulty with social interaction and communication, and
        - atypical activity and behavior patterns, such as:
            - Difficulty adapting to changes in routine or environment
            - Difficulty with transitions between activities
            - A strong focus on details
            - Unusual reactions to sounds, textures, and other sensations.

        - Repetitive behaviors
    - Feeding difficulties are also common among children with autism. These may include:
        - oral-motor and sensory feeding difficulties,
        - strong preference for certain foods, often carbohydrates, grains, and crunchy foods, and
        - resistance to changes in feeding routines, environments (e.g., unable to eat at school), tools (e.g., specific bowls, spoons, cups), and food presentation (e.g., texture, color, or temperature).
    - Intervention:
        - Autism exists on a spectrum, meaning that every child is unique. Some may require significant support in their daily lives, while others can be more independent.
        - Early identification and intervention can make a significant difference in identifying autism and helping children develop important skills such as communication and social interaction.
        - Caring for a child with autism can place considerable demands on families. Access to appropriate services, community support, and inclusive attitudes within society and from government institutions play a crucial role in ensuring the well-being and quality of life of both children and their families.
- *Hydrocephalus*
    - Hydrocephalus is the build-up of the fluid, called cerebrospinal fluid, that normally bathes and cushions the brain and spinal cord. It may be present at birth, but more commonly occurs progressively during early infancy.
    - A common cause in children is an infection in the brain (meningitis, encephalitis), which creates scars in the brain, blocking the flow of cerebrospinal fluid. This causes pressure on 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].*
    - Other causes include a brain tumor, bleeding in the brain due to brain injury, infection during pregnancy, spina bifida, and complications of prematurity.
    - Sign of hydrocephalus in children are more obvious in infants under 12 months old as their skull bones have not fully grown yet. The build-up of fluids causes a rapid increase in head circumference or an unusually large head size. Other signs and symptoms in children 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 child'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 the extra fluid is absorbed.
        - Community follow-up is 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:
    - Treatment for spina bifida varies depending on the severity of the condition. Many infants with the mildest form may not require any medical intervention.
    - In more severe cases, urgent referral for surgery is necessary to close the opening in the infant's back and treat hydrocephalus, if present. Delay in treatment results in a very high mortality rate.
    - While surgery can help prevent further complications, spina bifida cannot be cured and often results in permanent impairments that requires long-term rehabilitation. This can be extremely challenging for families, making emotional support, community resources, and access to specialized services critically important.

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

- Before the training, cut along the dotted lines on the Bingo card activity sheet to prepare enough cards for the entire class.
- Tell participants that they will now test their knowledge about common disabilities in children by playing a game called Bingo.
- Distribute bingo cards and markers 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 we discussed, one condition per square.
    - I will read a statement describing a condition.
    - Listen to my statement carefully and mark the appropriate square with your pen 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]*:

1. This condition means there is a gap in the upper lip and/or the roof of the mouth. *[Cleft lip or palate]*
2. This condition happens when the spine does not form properly and can be prevented with folic acid supplementation before conception. *[Spina bifida]*
3. This condition affects movement and muscle coordination, often appearing in early childhood. *[Cerebral palsy]*
4. This condition happens when too much fluid builds up in the brain, causing increased pressure and head size. *[Hydrocephalus]*
5. This condition is characterized by difficulty with social interaction and communication. *[Autism]*
6. This condition is common among children with Down syndrome. *[Congenital heart defect]*
7. This term refers to functional limitations in one or more developmental domains. *[Developmental disabilities]*
8. Infants with this condition have an extra chromosome 21, which can delay how they grow and develop. *[Down syndrome]*

- 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 in children 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 certain disabilities in infants and even young children. A disability may not be identified until later when certain 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 children 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. Common childhood disabilities and conditions that may impact nutrition and feeding include cleft lip/palate, cerebral palsy, Down syndrome, autism, hydrocephalus, and spina bifida.
2. Some conditions and impairments in children start from birth while others develop soon after birth. Certain conditions can be identified through observation or basic physical examination, whereas others may require specialized medical evaluation.
3. Focus on a child's functional abilities, such as the ability to feed well, rather than a specific diagnosis.

2.2 The Bidirectional Link between Disability and Nutrition

Time: 30 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 nutrition, growth, and development in children.
- Explain how poor nutrition can lead to or worsen disability in children.

Key message(s) to take away for learners:

1. Children 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 feeding and access to healthcare for themselves and their children.

Activity 2.2.1 (30 minutes)
The link between nutrition and disability

Activity Summary	Key message(s)	Slides & Material(s)
Brainstorming activity	1 & 2	Slides 77-82 Flipchart, markers, sticky notes

Instructions

<u>Activity (30 minutes):</u>
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 child, the family, the community, health facility practices, or national policies.
- 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 → Disability" factors and the other half to brainstorm "Disability → Nutrition" factors. Encourage participants to include disability-nutrition linkages in a humanitarian context. Ask groups to write one

factor per sticky note. If needed, provide an example for each to get the groups started (e.g., Nutrition → Disability: vitamin D deficiency causes rickets; Disability → Nutrition: feeding difficulties that may lead to poor growth).

- After 10 minutes, bring the large group back together.
- Ask the "Nutrition → Disability" group representatives to come up to the flipchart, place the sticky notes in the appropriate space, and share their responses. Invite others to add to the list.
- Present information on the "**Nutrition → 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
        - Poor maternal nutrition during pregnancy may cause adverse birth outcomes including low birth weight, premature birth, and birth defects (e.g., cleft lip and palate, heart defects), which are associated with an increased risk for disability
        - General maternal malnutrition contributes to physical and intellectual disability in children, perpetuating an intergenerational cycle of poor health and 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
        - Malnutrition weakens the immune system, increasing a child's susceptibility to infections such as meningitis and measles, which can cause permanent impairments like hearing or vision loss
        - Muscle wasting, seen in severe acute malnutrition, can cause physical disabilities
- Ask the "Disability → Nutrition" group representatives to come up to the flipchart, place the sticky notes in the appropriate space, and share their responses. Invite others to add to the list.
- Present information on the "**Disability → Nutrition**" link not shared by participants:
    - *Medical* (the 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) or sensory difficulties (e.g., autism) affect children's ability to eat safely and efficiently, leading to 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 feeding:
            - Without proper supper, mothers with cerebral palsy or physical disabilities (limited motion in arms or upper body; limb differences affecting the arms) may be unable to properly position and support their child to feed safely and efficiently (e.g., supporting an infant to latch properly for breastfeeding).
            - Mothers with learning or intellectual disabilities may have a difficult time understanding and following recommendations if the information is not communicated in an accessible and appropriate manner.
            - 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 feed a child with difficulty feeding.
        - Difficult feeding can lead to increased stress levels for the caregiver and the child, which can result in insufficient food intake.
        - Unsafe feeding practices that increase the risk for aspiration.
        - Lack of training among health workers on how to feed children with disabilities 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 health workers that prevents mothers of children with disabilities or mothers with disabilities to seek support.
        - Lack of information on feeding that is suitable for mothers with disabilities (e.g., breastfeeding positions for mothers with physical disabilities).
        - Attitudinal barriers related to disability among health workers, community members, program managers, and policy makers that hinder access to quality health services.
        - Policies that are not inclusive of mothers with disabilities or children with disabilities.
        - Needs of mother-child 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.

- Conclude this section:
    - Poor nutrition in children 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, children with disabilities may become malnourished due to feeding difficulties, frequent illness,

difficulties absorbing nutrients, inappropriate feeding practices, and cultural and attitudinal barriers.
- This cycle is often exacerbated during humanitarian crises due to additional barriers.

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. Children 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 feeding and access to healthcare for themselves and their children.

2.3 How Stress and Trauma Affect Feeding in Children with Disabilities

Time: 50 minutes

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

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

- Explore how the emotional state of both health workers and caregivers 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 health workers, mothers and caregivers, and children with disabilities enables the creation of better care strategies, resulting in healthier outcomes for children and their caregivers.
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 child, significantly influencing the child's physical and emotional development.
4. When well supported, most mothers can practice responsive feeding and nurturing care even in very challenging circumstances.

Note: This topic offers an overview of how trauma, stress, and feeding intersect in the context of disability. For more in-depth training on stress and infant and young child feeding (IYCF) counseling in emergencies, refer to Save the Children's IYCF-E Curriculum for Frontline Workers: Addressing Stress in Emergencies.

Activity 2.3.1 (20 minutes)
Feelings Pie Chart

Activity Summary	Key message(s)	Slides & Material(s)

Self-reflection activity	1	Slides 83-86 Blank paper, 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 and other caregivers to deal with stressful situations, it would be helpful to understand different emotions that they 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.

<u>Activity (15 minutes):</u>
Note: This 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-child 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 (30 minutes)
Child, 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 87-92 Mod 02_Activity Sheet_Stress Connection Scenario Cards

Instructions

- Introduce this section:
  - The relationship between the mother, child, and health worker 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 child'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.
      - Having a child with a disability is often perceived as the loss of a "perfect" child 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.
    - *Children*:
      - A child'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 child. She may find it very difficult to soothe her child, which may prolong her child's experiences with stress.
      - This dynamic becomes more complex when mother-child pairs are impacted by disability without the presence of adequate care and support.
    - *Health workers*:

        - Like everyone else, health workers 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 health workers range from external pressures (such as the work environment and personal relationships) to internal pressures (how they are feeling).
        - Health workers 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 the mental health of the mother, the child, and the health worker are interconnected and how they impact each other.

<u>Activity (20 minutes):</u>
Note: If time is limited, skip the role-play. Ask participants to read their scenario and discuss the three questions listed below.

- Before the training, cut along the dotted lines on the stress connection scenario card activity sheet.
- Divide participants into small groups of three. If the total number of participants does not divide evenly, one or two groups can have two or four members.
- Give each group a scenario card describing a stressful situation. Explain that each scenario includes potential stressors relevant to three roles: Mother, Child, or Health Worker.
- Ask each person in the group to select one of three roles.
- Explain the activity:
    - In each scenario, the health worker is counseling the mother, who brought her young child with her to the clinic, on responsive feeding.
    - In your groups, role-play the counseling session for 5 minutes, focusing on expressing and responding to stress in your assigned roles.
    - After role-playing, discuss the following questions for another 5 minutes from the perspective of your assigned roles:
        - What specific stressors, traumas, or disabilities are present?
        - How might stress in one role affect the others?
        - In what ways could these stressors, traumas, and disabilities intersect to influence feeding and mother-child interactions?
    - You have 10 minutes total for role-play and discussion.
- After 10 minutes, reconvene the entire group and invite groups to share their insights from the discussion.
- Use the flipchart to jot down main points, highlighting common themes across the discussions.

- Present the following key points on the *impact of stress on feeding in children with disabilities*:
    - Stress, trauma, and disability often intersect in ways that deeply influence feeding practices for children with disabilities. Caregivers of children with disabilities may face heightened emotional and physical demands due to their child's complex needs, particularly when those needs involve feeding difficulties such as difficulty communicating needs, chewing or swallowing problems, food refusal, picky eating,

sensory sensitivities, or medical conditions requiring modified diets. These difficulties can make feeding a time-consuming, emotionally draining process and may disrupt the natural rhythms of responsive feeding.
    - Without adequate support, caregivers under high stress may feel overwhelmed, frustrated, or unsure of how to help their child. This can strain the feeding relationship, leading to tense or negative mealtimes, and can even contribute to poor growth in the child. In high-stress environments, even young children may lose their appetite or experience slowed digestion. For some, feeding becomes a source of distress rather than connection, which can reinforce feeding difficulties.
    - When trauma is also present—whether from birth complications, hospitalization, violence, conflict, displacement, or ongoing adversity—the impact on feeding is often intensified. Trauma can heighten the caregiver's stress response, making it harder to remain emotionally available or use nurturing feeding practices. For children with disabilities, who may already struggle with feeding, this creates a compounding effect: caregivers may become less responsive or give up on recommended feeding strategies due to burnout or hopelessness. On top of this, societal stigma and limited access to disability-inclusive health and nutrition services can lead to delayed identification of feeding difficulties and fewer opportunities for early intervention.
- Present the following key points 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).
    - For mothers of infants with disabilities, stress levels can be particularly high. They may experience increased emotional strain due to uncertainty around their infant's health, challenges with feeding, or difficulty accessing specialized support. Feeding difficulties are more common among infants with disabilities, which can contribute to a cycle where the stress of feeding challenges reduces milk flow.
    - It is critical to recognize that in such contexts, mothers may mistakenly believe their milk has "dried up" and stop breastfeeding earlier than intended. This highlights the importance of proactive support—both emotional and technical—for lactating mothers, especially those caring for infants with disabilities.
    - Breastfeeding in emergency situations or resource-limited settings can be further complicated by traumatic experiences by both the mother and infant, myths and misconceptions, the mother's limited time, lack of space and privacy, insufficient support, and the unregulated distribution of breast milk substitutes. For infants with disabilities, these challenges are often magnified. 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.
- Present the following information on *ways to manage stress in mothers*:
    - Health workers can play a key role in supporting and reducing stress in mothers (and other caregivers) of children with disabilities. Here are practical actions they can take:

- Listen and validate their feelings. Provide a safe space for mothers to share their worries and emotions without judgment. Acknowledge the challenges they face and validate their experiences ("*It makes sense that you feel overwhelmed.*").
- Offer clear, supportive information about the child's condition, needs, and available services.
- Set realistic expectations and goals to reduce uncertainty and fear.
- Connect them to available support systems (parent groups, community programs, mental health services).
- Encourage peer connections so they don't feel alone in their journey.
- Gently encourage rest, breaks, and small self-care practices—even a few minutes a day.
- Offer ideas for stress relief that fit their routine (e.g., breathing exercises, short walks, crafts).
- Assist with navigating health and social services, such as accessing nutrition programs, disability benefits, or cash transfers.
- Involve the whole family and offer family-centered support. When possible, encourage sharing caregiving roles with partners, relatives, or friends.

- Conclude this section:
  - Supporting feeding for children with disabilities, especially in the context of stress and trauma, requires a holistic, trauma-informed, and disability-inclusive approach—one that recognizes the emotional wellbeing of the caregiver as central to the child's nutritional and developmental outcomes.
  - As health workers, we must be aware of how our own emotional state influences the way we work and how our behaviors influence how a mother may feel.
  - A mother who feels safe, heard, and supported is more likely to bond with her child, engage in responsive feeding, and continue nurturing care practices even in the most stressful situations. This highlights the crucial role of health workers and the power of positive, empathetic counseling.
- Conclude this module:
  - This brings us to the end of the module. Remember, some disabilities begin at birth while others emerge later, and focusing on a child's functional abilities—like feeding—matters more than their specific diagnosis. It is also important to recognize the bidirectional link between malnutrition and disability, often creating a cycle of poor health. Mothers and children with disabilities may also face significant stress. Yet, with the right support, responsive feeding and nurturing care are possible—even in challenging situations.

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 health workers, mothers and caregivers, and children with disabilities enables the creation of better care strategies, resulting in healthier outcomes for children and their caregivers.
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 child, significantly influencing the child's physical and emotional development.
4. When well supported, most mothers can practice responsive feeding and nurturing care even in very challenging circumstances.

Optional Activity (5 minutes):
Note: This activity is adapted from USAID Maternal and Child Survival Program (2019). Caregiver Psychosocial Support Session Guide: Helping Young Children with Disabilities Meet their Potential.

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.

Breathing Exercise Script

Show participants how to breathe. (slide 93)

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

Nutrition Considerations for Children with Disabilities

(Total time: 175 minutes)

3.1 Common Nutritional Concerns in Children with Disabilities

Time: 80 minutes

Preparation & materials required: Slide Deck, flipchart, markers, sticky notes, Nutritional Concerns Matching Cards activity sheet and answer key, Common Nutritional Concerns in Children with Disabilities handout, Causes of Malnutrition Case Studies activity sheet and answer key.

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

- List nutritional concerns that are common in children with disabilities.
- Identify causes of malnutrition in children with disabilities.

Key message(s) to take away for learners:

1. Common nutrition-related concerns in children with disabilities include constipation, gastroesophageal reflux disease, celiac disease, poor oral health, micronutrient deficiencies, poor weight gain, and unintended weight gain.
2. The causes of malnutrition in children with disabilities often fall into three overlapping categories: what the child eats (the quality and diversity of their diet), how much the child eats (the quantity of food consumed relative to their needs), and how the child's body uses nutrients (how well their bodies absorb and utilize nutrients).

Activity 3.1.1 (40 minutes)
Nutritional concerns in children with disabilities

Activity Summary	Key messages	Slides & Materials
Interactive matching game	1	Slides 94-98 Mod 03_Activity Sheet_ Nutritional Concerns Matching Cards Mod 03_Activity Sheet_ Nutritional Concerns Matching_Answers Mod 03_Handout_Common Nutritional Concerns in Children with Disabilities Quick Guide

Instructions

- Introduce this section:

- Children with disabilities may experience health challenges that can affect their nutritional wellbeing and eating habits. These challenges, and how severe they are, can vary widely, even among children with the same diagnosis.
- One of the challenges is feeding difficulties. This will be covered in detail in upcoming modules. In this section, we will focus on nutrition-related concerns. There are many, but we will highlight the most common ones.

Activity (30 minutes):

- Before the training, prepare three sets of cards: "Condition" cards, "Symptom" cards, and "Risk factor" cards. Cut along the dotted lines in the nutritional concerns matching activity sheet to separate the cards. Adjust the total number of cards based on your group size, ensuring that each condition has at least one matching symptom and one matching risk factor. For example, if you are training 25 participants, you might include all 7 "Condition" cards, all 7 "Symptom" cards, and 11 "Risk factor" cards (with 1-2 risk factors per condition).
- Create an open space in the room for participants to move around.
- Tell participants that we are going to learn about common nutritional concerns in children with disabilities through a fun matching game.
- Shuffle each set of cards and distribute them randomly:
  - Give one "Condition" card to each of a number of participants (or facilitators if needed).
  - Everyone else gets a "Symptom" or "Risk factor" card.
- Explain the activity:
  - Some of you are holding a card labelled with a nutrition-related condition. The rest of you have cards with symptoms or risk factors linked to one of the conditions.
  - Your task is to walk around and find your matching group: each group will have one condition and at least two symptoms or risk factors related to it.
  - You have five minutes to move around, talk to each other, and figure out where your card belongs.
  - Once you think your group is complete, come to me for a check.
- As groups check in, use the answer key to confirm their matches.
  - If the group is correct, ask them to stay together and stand on one the side of the room.
  - If not, offer a hint and send them back to continue searching.
- Once all matches are made correctly, bring the groups back together.
- Ask each group to briefly present their condition and symptoms/risk factors they identified.
- Use the information below on common nutritional concerns to fill in any gaps:

Constipation

- Constipation is a gastrointestinal (GI) condition characterized by infrequent, hard, or difficult-to-pass bowel movements. It can cause discomfort, bloating, pain, irritability, and poor appetite.
- Children with disabilities may be at increased risk of constipation if they have:
  - *Low muscle tone*, which slows bowel movement
  - *High muscle tone*, which may make it difficult for muscles to relax and release bowel movements
  - *Limited physical activity*, which slows digestion and bowel movement
  - *Low fiber intake*, which makes stools harder and more difficult to pass
  - *Difficulty drinking enough fluids* (for example, due to difficulty swallowing), which can lead to dehydration and dry stools
  - *Chronic stress*, which can disrupt normal bowel patterns

Gastroesophageal reflux disease (GERD)

- GERD is a chronic GI condition in which stomach acid flows back up into the esophagus. It can cause heartburn, pain, vomiting, and ulcers, making eating

difficult. Over time, it can also lead to poor weight gain, difficulty swallowing, feeding refusal, and dental erosion.

- Children may be at increased risk of GERD if they have:
  - *Delayed gastric emptying* (slow digestion), which prolongs the presence of food in the stomach
  - *Low or high muscle tone*, affecting the muscles involved in digestion and swallowing
  - *Long periods of lying flat*, which can promote reflux due to gravity
  - *Difficulty swallowing*, increasing the likelihood of reflux or aspiration
  - *Constipation*, which puts extra pressure on the abdomen
  - *Skeletal abnormalities* (e.g., scoliosis), which may compress or displace the stomach
  - *Medication side effects* (e.g., epilepsy/seizure medications)

Celiac disease

- Celiac disease is an autoimmune disease (the immune system mistakenly damages healthy cells in the body) that primarily affects the small intestine. It is triggered by eating gluten, a protein found in wheat, rye, and barley. In children with celiac disease, gluten causes damage to the small intestine, impairing nutrient absorption. Symptoms vary based on the child's age and may include excessive gas, abdominal pain, irritability, constipation, diarrhea, vomiting, anemia, weight loss, and failure to thrive. Diagnosing celiac disease requires a blood test and often a biopsy of the small intestine.
- Children may be at increased risk of celiac disease if they have:
  - *Down syndrome*
  - *Other genetic disorders*

Poor oral health

- Poor oral health in children with disabilities may include tooth decay, gum inflammation, plaque buildup, and misaligned or missing teeth. These issues can cause pain, toothaches, and gum discomfort, leading to reduced appetite, difficulty feeding, vomiting, and overall decreased food intake. In more severe cases, poor oral health has been linked to aspiration, pneumonia, and other respiratory illnesses.
- Children may be at increased risk of poor oral health if they have:
  - *Sensory sensitivities*, which can make tooth brushing uncomfortable or distressing
  - *Motor impairments*, which can make tooth brushing difficult
  - *Communication barriers*, which may affect the ability to understand oral hygiene instructions or express oral discomfort or pain
  - *Behavioral difficulties*, which can interfere with establishing and maintaining oral hygiene routines
  - *Feeding difficulties*, which may lead to food being retained in the mouth, increasing tooth exposure to sugar and acids
  - *Chronic reflux*, causing dental erosion
  - *Medications* that cause dry mouth (e.g., seizure medications), contributing to buildup of bacteria

Micronutrient deficiencies

- Micronutrient deficiencies occur when the body lacks adequate levels of essential vitamins and minerals to grow, develop, and function properly. Micronutrient deficiencies weaken the immune system and increase the risk of infections. Common deficiencies in children with disabilities include iron, zinc, calcium, vitamin D, and vitamin C. For example, if a child does not eat enough iron-rich foods, their

body cannot make enough hemoglobin—the part of red blood cells that carries oxygen—which can lead to iron-deficiency anemia.

- Children may be at increased risk of micronutrient deficiencies if they have:
  - *Feeding difficulties* that limit their food intake
  - *Diets low in nutrient-dense foods*
  - *Restricted diets* due to food allergies, intolerances, or medical conditions
  - *GI conditions* that lower the absorption of nutrients
  - *Medications side effects* that interfere with the absorption and utilization of nutrients (how nutrients are used in the body)
  - *A feeding tube* and are unable to tolerate the full volume required for their age and needs

Poor weight gain

- Poor weight gain is when a child is not meeting expected growth patterns due to insufficient intake, increased nutrient losses, poor nutrient absorption, or an underlying genetic or medical condition that affects growth.
- Children may be at increased risk of poor weight gain if they have:
  - *Diets low in energy and protein*, which do not meet the child's nutritional needs for growth
  - *Feeding difficulties* that limit their food intake
  - *Communication difficulties*, which can make it hard for the child to signal hunger, leading to underfeeding
  - *High muscle tone*, which makes the child's body work harder and use more energy
  - *Low muscle tone*, which can make feeding inefficient
  - *GI conditions* that lower nutrient absorption
  - *GERD*, which can make eating painful or uncomfortable, reducing food intake
  - *Medication side effects* that reduce appetite or alter taste
  - Had *recent surgery* (e.g., for a heart defect), which increases caloric and protein needs
  - *Genetic conditions* that inherently affect growth and metabolism
  - *Chronic stress*, which disrupts nutrient absorption and utilization
  - Experienced *neglect or inadequate care*, which may result in insufficient feeding and stimulation needed for growth

Unintended weight gain

- Unintended weight gain occurs when caloric intake consistently exceeds energy needs, potentially leading to overweight and obesity. This can negatively affect a child's physical health, mobility, and overall wellbeing.
- Children may be at increased risk of unintended weight gain if they have:
  - *Low mobility or activity levels*, which means the body uses less energy
  - *Social or communication difficulties*, which may limit participation in physical activities
  - *Low muscle tone*, which contributes to reduced energy needs
  - *Short stature*, resulting in reduced energy needs
  - *Hypothyroidism*, a condition that slows metabolism
  - *Altered body composition* (higher fat percentage)
  - *Difficulty signaling fullness*, which may lead to overfeeding
  - *Sensory sensitivities or picky eating*, often resulting in diets high in energy-dense foods but low in nutrient-dense foods
  - *Medication side effects*, which can slow metabolism or increase appetite (e.g., medications for mental health conditions)
  - *Some genetic disorders* (e.g., Prader-Willi Syndrome), which often causes hyperphagia or wanting to eat all the time without feeling full

- Conclude this section:
  - Distribute the quick guide handout on common nutritional concerns in children with disabilities.
  - Tell participants:
    - Keep in mind that many of the risk factors for these nutritional concerns are similar to those seen in typically developing children. However, children with certain disabilities may experience additional challenges that increase their vulnerability to these common risks, and may also experience a unique set of risk factors not shared by their peers without disabilities.

Activity 3.1.2 (40 minutes)
Causes of malnutrition in children with disabilities

Activity Summary	Key messages	Slides & Materials
Case studies	2	Slides 99-105 Flipchart, markers, sticky notes Mod 03_Activity Sheet_Causes of Malnutrition Case Studies Mod 03_Activity Sheet_Causes of Malnutrition Case Studies_Answers

Instructions

Note: Adapt case studies to reflect the local context. This may include changing the names of children and types of foods, and modifying details to align with the realities of the country or community where the training is taking place.

- Introduce this section:
  - In the previous section, we explored three types of malnutrition: micronutrient deficiencies, poor weight gain, and unintended weight gain. We also looked at a variety of risk factors that can contribute to these conditions.
  - In this next section, we'll learn how to systematically identify these risk factors so we can address them in a timely and effective way.
- Present the causes of malnutrition:
  - Malnutrition in children often results from a combination of factors, which can be grouped into three overlapping categories:
    - *What children eat*: A diet that lacks diversity, relies on highly processed foods, or excludes certain foods due to allergies can leave out key nutrients. Without these essential nutrients, malnutrition can develop.
    - *How much children eat*: Feeding difficulties, poor appetite, or limited availability of food impact how much a child eats compared to what they need. If children do not get enough food to meet their body's nutritional needs, malnutrition can develop.
    - *How children use nutrients*: Frequent illnesses, infections, chronic stress, or neglect can prevent a child's body from properly absorbing or using the nutrients from their food. If children do not get the full benefit of those nutrients, malnutrition can develop.
- Tell participants:

- When counseling caregivers about nutrition and feeding, it's important to ask open-ended questions that help you gather information across all the three categories.
- For example, I might ask a caregiver: "What did your child eat yesterday?" "What does your child usually have for snacks?" These questions help me understand whether the child's diet is diverse, contains highly processed foods, and if it's missing essential nutrients due to food allergies.
- What are some other questions you could ask to learn more about *what* a child eats? *[Listen to answers and contribute more questions if needed.]*
  - *Answers may include:*
    - *What does your child usually eat for breakfast/lunch/dinner?*
    - *How many different fruits and vegetables does your child eat in a typical week?*
    - *Are there any foods your child refuses to eat or avoids?*
    - *Does your child follow any special diet (e.g., gluten-free, dairy-free)?*
    - *Is your child able to eat the same food as the rest of the family?*
    - *Does your child have difficulty chewing or swallowing certain foods?*
    - *Do you have any challenges finding or affording certain foods?*
- What are some questions you could ask to learn more about *how much* a child eats? *[Listen to answers and contribute more questions if needed.]*
  - *Answers may include:*
    - *How many meals and snacks does your child usually eat in a day?*
    - *Does your child finish most of their meals or leave a lot of food on the plate?*
    - *Do you feel your child eats enough for their age and activity level?*
    - *Does your child ever skip meals? If so, why?*
    - *Has your child's appetite changed since our last session?*
    - *Do you have any challenges serving enough food for the entire family?*
- What are some questions you could ask to learn more about *how a child's body uses nutrients? [Listen to answers and contribute more questions if needed.]*
  - *Answers may include:*
    - *Has your child had any recent illnesses or infections?*
    - *Does your child have any conditions that affect the stomach or intestines?*
    - *Has your child had any diarrhea, constipation, or vomiting since our last session?*
    - *Is your child currently taking any medications?*
    - *Has your child had any recent surgeries?*
    - *Can you walk me through what a typical day looks like for your child—including who they spend time with and what kind of activities they do?*
    - *Do you notice any changes in your child's eating or sleeping when they are upset?*
- Be sure to tailor your questions to the child's individual needs, their disability, and any background information you have about the family.

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

- Prepare a flipchart with three large overlapping circles labeled:
  - "WHAT" (What the child eats),
  - "HOW MUCH" (How much the child eats), and
  - "USE" (How the child uses nutrients)
- Tell participants that we will now apply this approach to some case studies.
- Divide participants into five groups.
- Give each group copies of the causes of malnutrition case studies (one per participant), sticky notes, and markers.
- Assign each group a case scenario.

- Explain the activity:
  - Each group has a case scenario involving a child with disability who might be malnourished or at risk for malnutrition.
  - Based on your assigned case study, identify the potential causes of malnutrition. These causes can relate to what the child eats, how much they eat, or how their body uses the nutrients they consume.
  - Write each cause on a separate sticky note. If a cause fits in more than one category, write it on separate sticky notes for each.
  - Label your sticky notes with your case study number.
  - When your group is ready, come up to the flipchart and place each sticky note in the appropriate circle.
- Allow 5-7 minutes for group discussion and posting.
- Bring everyone back together.
  - Review the sticky notes by case study.
  - Ask groups to share their reasoning.
  - Make corrections as needed by referring to the answer key.

- Conclude this section:
  - Malnutrition can lead to poor health outcomes, delays in growth and development, new or worsened disabilities or impairments, and premature death. That's why it's so important to understand not just *what* and *how much* a child eats, but also how their body *uses* those nutrients—so we can identify the root causes and respond early.
  - Ask participants:
    - In your current work, which of these three areas —WHAT, HOW MUCH, or USE—do you think is most often overlooked when assessing a child's nutrition?
    - Which of these three areas do you feel most confident assessing? Which one do you find more challenging?

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. Common nutrition-related concerns in children with disabilities include constipation, gastroesophageal reflux disease, celiac disease, poor oral health, micronutrient deficiencies, poor weight gain, and unintended weight gain.
2. The causes of malnutrition in children with disabilities often fall into three overlapping categories: what the child eats (the quality and diversity of their diet), how much the child eats (the quantity of food consumed relative to their needs), and how the child's body uses nutrients (how well their bodies absorb and utilize nutrients).

3.2 Growth in Children with Disabilities

Time: 65 minutes

Preparation & materials required: Slide Deck, flipchart, markers – green, orange, red, and black (optional), Growth Assessment Flashcards activity

sheet and answer key, Growth Expectations Case Studies activity sheet and answer key.

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

- Describe how disability can affect growth.
- Discuss growth expectations for children with disabilities.
- Discuss key considerations when measuring and interpreting growth for children with disabilities.

Key message(s) to take away for learners:

1. When assessing the growth of children with physical impairments, it is important to select only the measurements that can be taken safely and accurately.
2. Growth assessment for children with disabilities follows the same steps as for any child: weigh and measure, compare results to standards, determine risk, design a care plan, counsel caregiver, and follow-up.
3. While existing WHO growth charts may not always reflect realistic expectations for children with certain disabilities, they are still useful tools when interpreted with care and the child's situation in mind.
4. Children with certain disabilities like Down syndrome, cerebral palsy, and spina bifida, may have altered growth patterns due to the disability itself.
5. All children with disabilities can reach their own growth potential if they receive proper nutrition and feeding, adequate health services, and nurturing care.

Activity 3.2.1 (25 minutes)
Growth assessment – a review

Activity Summary	Key messages	Slides & Materials
Quiz game	1, 2, & 3	Slides 106-113 Optional: Flipchart, markers (green, orange, red, black) Mod 03_LB_Activity Sheet_Growth Assessment Flashcards Mod 03_LB_Activity Sheet_Growth Assessment Flashcards_Answers

Instructions

- Introduce this section:
  - A key step in assessing a child's growth is to compare the child's measurements, like weight and height, to growth standards to determine how well the child is growing.
  - The World Health Organization (WHO) Growth Standards are recommended for use worldwide, regardless of a child's ethnicity, socioeconomic background, or geographic location. The WHO growth charts allow us to visually track a child's growth and identify whether, and to what extent, a child may be malnourished.
  - In this section, we will discuss how to use WHO growth charts to interpret growth patterns for children with disabilities.

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

Note: You may skip this activity if all participants regularly conduct growth assessment using WHO growth charts and a review is not necessary.

- Prior to the sessions, prepare the flash cards (20 in total) by cutting along the dotted lines in the growth assessment flashcards activity sheet. Shuffle the cards.
- Project the PowerPoint slide that contains a WHO growth chart to refer to during the game if needed. Alternatively, on a flipchart, draw a large growth chart including the x-axis, y-axis, median (in green), +1 and -1 z-scores lines (in orange), +2 and -2 z-scores lines (in red), and +3 and -3 z-scores lines (in black).
- Introduce the activity:
    - Many of you already have experience with weighing and measuring children and plotting their growth on WHO growth charts. Today, we will be reviewing these essential steps with a fun and competitive quiz 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 growth assessment. Some are easier than others.
    - The team will have 20 seconds 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 when applicable.
- Refer to the answer key to provide the correct answer and additional information.
- After the first round, play three 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 (or a small prize if available).

- Conclude this section:
    - Growth assessment for children with disabilities is a key aspect of their care. However, when working with children with disabilities we are faced with two major challenges.
        - First, accurate and reliable weight, length, and height measurements may be difficult to obtain for some children due to impairments such as scoliosis or joint contractures.
        - Second, children with certain disabilities may have different growth patterns than their typically developing peers. The WHO growth charts, which are based on data from typically developing children, may not always reflect realistic expectations for children with certain disabilities. While alternative growth charts exist for certain disabilities, they have limitations and may not be widely applicable. Therefore, it is still recommended to use the WHO growth charts for children with disabilities.
    - In the next section, we will discuss how to interpret these charts appropriately when assessing growth in children with disabilities.

Activity 3.2.2 (40 minutes)
Growth expectations in children with disabilities

Activity Summary	Key messages	Slides & Materials
Case studies	3, 4, & 5	Slides 114-124

		Mod 03_LB_Activity Sheet_Growth Expectations Case Studies Mod 03_LB_Activity Sheet_Growth Expectations Case Studies_Answers

Instructions

Note: Adapt case studies to reflect the local context. This may include changing the names of children and types of foods, and modifying details to align with the realities of the country or community where the training is taking place.

- Present information on the factors that impact growth in children with disabilities:
  - Growth in children with disabilities is not a product of a single, isolated factor. **Genetic** (e.g., family genetics, genetic disorders), **medical** (e.g., severity of the disability, secondary medical conditions, impaired motor skills), and **environmental** (e.g., feeding practices, care practices) factors and their interaction can influence children's growth. Determining which of these factors play the biggest role in a child's growth can inform the design of an effective and individualized care plan.
  - Children with certain disabilities may grow differently than their typically developing peers due to the nature of their disability. For example:
    - Down syndrome is a genetic condition that directly affects height. As a result, children with Down syndrome are typically shorter than other children of the same age.
    - Cerebral palsy can influence both height and body composition. Children with cerebral palsy often have higher body fat and lower lean body mass (muscles, organs, and bones). Because of this, they may be shorter and weigh less than typically developing children – not necessarily because they are undernourished, but because of the way their condition affects their bodies.
    - Children with spina bifida may have disproportionate growth of the lower body resulting in short stature. In some cases, they may also have a deficiency in growth hormones, which stimulate growth, help build bones and muscles, and regulate metabolism. Because of this, children with spina bifida may be shorter than their typically developing peers. If a growth hormone deficiency is not identified and managed, it can lead to slower metabolism, increasing the risk for unintended weight gain.
  - When we use WHO growth charts to assess these children, they may appear to be growing poorly. However, these growth patterns can be an expected part of their condition. At the same time, we know that children with disabilities are more likely to have nutrition and feeding concerns. If these issues go unaddressed, they can contribute to true growth faltering.
  - The key challenge is to determine whether a child's poor growth is a natural part of their disability – which cannot be changed – or a sign that something can and should be improved.
  - While a child's disability may help explain unusual growth patterns, it's important to remember that children with disabilities can still reach their own growth potential – especially when they receive proper nutrition and feeding support, access to health services, and nurturing care. In many cases, poor growth in children with disabilities is the result of inadequate care plans and support.

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

- Introduce activity:

    - We will now work with four case studies to practice how to assess growth in children with disabilities and think through what factors to consider.
- Divide participants into four groups.
- Give each participant a copy of the growth expectations activity sheet.
- Assign one case study to each group.
- Explain the activity:
    - Each case study includes some background information about the child and their growth chart.
    - Read the case study and examine the growth chart.
    - Discuss the following questions within your group:
        - Do you expect this child to grow differently as part of their condition? If yes, how might the disability alter the child's growth?
        - Are you concerned about the child's growth? Why or why not?
        - What other information should you consider when interpreting this child's growth?
    - Be sure to incorporate the three key factors in your discussion: what the child eats, how much, and how their body uses the nutrients they consume.
    - Prepare to present your case and your group's answers to the larger group.
- While groups work, walk around the room to answer questions and provide support as needed.
- After 10 minutes, bring the entire group back together.
- Each group will present their case and discuss their responses.
- Display the corresponding growth chart slide for everyone to see.
- Refer to the answers in the activity sheet to highlight any important points that were missed or to clarify key ideas.
- Wrap up the activity by highlighting the following points:
    - Always interpret growth in context, considering the child's growth trend, diet and feeding history, health status, care practices, overall wellbeing, functional ability, and growth expectations. When evaluating poor growth in children with disabilities, consider these two questions:
        - Is poor growth expected or typical for a child with that disability and, therefore, cannot be modified?
        - Is poor growth impacted by factors that can be improved, such as nutrition and feeding?

- Conclude this section:
    - Ask participants:
        - How has your understanding of growth assessment in children with disabilities changed?
        - What will you do differently when interpreting growth or speaking with caregivers as a result? *[Note: Encourage participants to have a discussion with the caregiver about their child's expected growth. However, emphasize the importance of avoiding assumptions or reinforcing the belief that all children with disabilities will experience poor growth.]*

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. When assessing the growth of children with physical impairments, it is important to select only the measurements that can be taken safely and accurately.

2. Growth assessment for children with disabilities follows the same steps as for any child: weigh and measure, compare results to standards, determine risk, design a care plan, counsel caregiver, and follow-up.
3. While existing WHO growth charts may not always reflect realistic expectations for children with certain disabilities, they are still useful tools when interpreted with care and the child's situation in mind.
4. Children with certain disabilities like Down syndrome, cerebral palsy, and spina bifida, may have altered growth patterns due to the disability itself.
5. All children with disabilities can reach their own growth potential if they receive proper nutrition and feeding, adequate health services, and nurturing care.

3.3 Dietary Considerations for Children with Disabilities

Time: 30 minutes

Preparation & materials required: Slide Deck, flipchart, markers.

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

- Share key dietary recommendations for children with disabilities.
- Describe strategies to manage common nutritional concerns in children with disabilities.
- Explain when to refer children with disabilities for further evaluation of nutritional concerns.

Key message(s) to take away for learners:

1. Energy, protein, and micronutrient needs for children with disabilities should be personalized based on their activity level, muscle tone, nutritional status, and overall health – similar to children without developmental delay or disabilities.
2. Effectively managing nutrition-related concerns such as constipation, GERD, celiac disease, oral health, and weight issues requires tailored dietary strategies.
3. Refer children for further evaluation of nutritional concerns if they are under 6 months, show faltering growth, have feeding difficulties or poor nutrition, are not improving, or if caregivers or you have concerns about their health or wellbeing.

Activity 3.3.1 (30 minutes)
Dietary strategies to address nutrition-related concerns

Activity Summary	Key messages	Slides & Materials
Large group discussion	1, 2 & 3	Slides 125-139 Flipchart, markers

Instructions

Note: Contextualize examples of foods to what is available in the country or community where you are training. Where appropriate, incorporate references to national health and nutrition guidelines and local services and programs. If relevant to the context, include a brief discussion following this session on food insecurity and referrals to locally-available cash transfers and other social protection services.

- Present information on key dietary recommendations for children with disabilities:

Energy and protein requirements:

- Children with disabilities might need more or fewer calories depending on their activity level and muscle tone. For example, a child with high muscle tone and a high activity level will use more energy and need to eat more than a child with low muscle tone and a low activity level.
- The best way to estimate caloric needs of children with disabilities is to individualize them, taking into account mobility, muscle tone, and activity level. This is the same approach that is used for typically developing children.
- No evidence currently exists to suggest that protein requirements of children with disabilities differ from those of typically developing children.
- For severely undernourished children with disabilities, additional protein and energy may be required to promote 'catch up' growth.
- Ongoing monitoring of whether children are meeting their energy and protein requirements is important to avoid overfeeding or underfeeding. This should be done through a combination of asking the caregiver about their child's dietary intake and monitoring changes in weight and length/height (if able to measure).

Micronutrient requirements:

- Children with disabilities need a variety of vitamins and minerals, similar to their peers, and in most cases, the recommended amounts are the same. However, there are certain situations where supplemental vitamins and minerals may be needed:
  - Children with limited mobility or who have trouble getting enough nutrients in their diet due to feeding difficulties are more likely to have weak bones (low bone density). This makes their bones more likely to fracture, or break. A doctor may recommend calcium and vitamin D supplements to keep bones strong.
  - Some medications can interfere with the body's ability to absorb or use certain nutrients. For example, anti-seizure medications interfere with how vitamin D is processed in the body, making supplementation necessary to maintain healthy levels.
  - Children with celiac disease are more likely to have deficiencies in key micronutrients, including iron, folic acid, and vitamin B12, which can lead to anemia. In such cases, supplements may be needed to treat or prevent anemia and other deficiencies.
- Referring children with disabilities who might be at risk to a health facility for micronutrient status testing is recommended.

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

- Facilitate a group discussion on dietary strategies for managing common nutrition-related concerns by inviting participants to share their tips and experiences for each concern:
  - Nausea and vomiting
  - Diarrhea
  - Constipation
  - GERD
  - Celiac disease
  - Poor oral health
  - Micronutrient deficiencies
  - Poor weight gain
  - Unintended weight gain
- Record responses on a flipchart.
- Use the content provided below to supplement the discussion with additional strategies:

Nausea and vomiting

- Offer small sips of clean fluids (water, fresh juice, rice drink) often

- Give small, frequent meals every 2–3 hours
- Choose plain, soft foods (bread, rice, boiled potatoes)
- Include favorite nutrient-rich foods if tolerated
- Avoid greasy, fried foods and foods with strong smells

Diarrhea

- Offer small, frequent sips of fluids (clean water, rice drink) to prevent dehydration
- Use Oral Rehydration Solution (ORS) if possible
- Provide small meals every 2–3 hours
- Offer soft, low-fat foods (plain rice, bananas, bread, boiled potatoes or chicken)
- Avoid milk if it makes diarrhea worse

Constipation

- Increase fiber-rich foods (fruits, vegetables, whole grains, legumes)
- Encourage adequate fluid intake
- Encourage physical activity
- Limit highly processed, low-fiber foods

GERD

- Offer smaller, more frequent meals
- Position child upright or in an inclined position after meals
- Avoid trigger foods (fried, citrus, chocolate)
- Manage feeding difficulties to improve swallowing

Celiac disease

- Follow a strict gluten-free diet (no wheat, barley, or rye)
- Ensure alternatives provide enough fiber and nutrients
- Monitor for hidden sources of gluten
- Reduce cross-contamination (ingesting small amounts of gluten, like crumbs from a cutting board or toaster, can trigger small intestinal damage).

Poor oral health

- Offer soft, easy-to-chew, nutrient-rich foods
- Avoid sticky or sugary snacks and drinks
- Encourage water after meals
- Work on gentle, sensory-friendly approaches to improve daily oral care (e.g., use soft bristle brushes, toothpaste with tolerated flavors, a soft cloth to wipe teeth and gums while working towards using a toothbrush, visual timers, songs and playful routines)
- Encourage regular dental care from a professional

Micronutrient deficiencies

- Provide a variety of nutrient-dense foods (fruits and vegetables, eggs, dairy, fortified cereals)
- Consider fortified foods or supplements (e.g., micronutrient powder) if needed
- Monitor with a health provider for specific deficiencies

Poor weight gain

- Increase energy intake with energy- and nutrient-dense foods (avocado, peanut butter, full-fat dairy)
- Modify traditional recipes to increase their nutritional value by adding nutrient-dense foods (nuts, seeds, avocado, starchy vegetables, eggs, dairy, legumes, animal protein).
- Offer frequent meals and snacks
- Manage feeding difficulties to improve intake

Unintended weight gain

- Focus on balanced meals with fruits, vegetables, proteins, and whole grains
- Limit sugary, high-fat, and highly processed foods
- Encourage active play or movement as able

- Share key red flags that indicate the need for referral for further evaluation:

- Always follow the referral protocols and guidelines established by your country and workplace.
- Refer children with nutritional concerns for further evaluation if:
  - The child is under 6 months of age
  - There is evidence of faltering growth
  - The concern is affecting the child's feeding or ability to get enough nutrition
  - The child's condition is not improving despite intervention
  - The concern is negatively affecting the well-being or quality of life of the child or caregiver
  - The caregiver expresses concern about the child's growth, development, or health
  - You have concerns about the child's growth, development, or health

- Conclude this section:
  - To support healthy growth in children, provide practical strategies to manage common nutrition-related concerns and encourage caregivers to make every bite count – meaning each bite should be as nourishing as possible to support the child's growth and development.
  - When applying dietary strategies, always consider:
    - The food textures the child can safely eat
    - Any feeding difficulties the child may have
    - Food allergies or intolerances
    - The child's appetite and ability to manage larger meals
    - The family's access to food and overall food security
- Conclude this module:
  - Children with certain disabilities have unique but manageable nutritional needs. With careful growth monitoring and tailored support, we can help every child reach their full growth and health potential. Always refer when concerns arise – early action makes a difference.

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. Energy, protein, and micronutrient needs for children with disabilities should be personalized based on their activity level, muscle tone, nutritional status, and overall health – similar to children without developmental delay or disabilities.
2. Effectively managing nutrition-related concerns such as constipation, GERD, celiac disease, oral health, and weight issues requires tailored dietary strategies.
3. Refer children for further evaluation of nutritional concerns if they are under 6 months, show faltering growth, have feeding difficulties or poor nutrition, are not improving, or if caregivers or you have concerns about their health or wellbeing.

MODULE 4

Feeding Difficulties in Infants and Children with Disabilities

(Total time: 185 minutes)

4.1 Developmental Feeding Skills in Infants and Children

Time: 55 minutes

Preparation & materials required: Slide Deck, flipchart, markers, scissors, food that requires chewing, 4 sets of Developmental Milestone Sorting Cards activity sheet and answer key, Developmental Milestones handout.

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

- Describe typical development of feeding skills in children from birth to five years.
- Discuss the relationship between physical development, feeding skills, and appropriate food textures during development.
- List four factors that could limit or delay the development of skills in children.

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. There is a relationship between a child's physical development, feeding skills development, and food texture.

Activity 4.1.1 (25 minutes)
Developmental milestones

Activity Summary	Key message(s)	Slides & Material(s)
Group sorting/matching activity	1	Slides 140-145 Scissors, flipchart, markers, food that requires chewing (e.g., biscuits, bread) Mod 04_Activity Sheet_Developmental Milestone Sorting (4) Mod 04_Activity Sheet_Developmental Milestone Sorting Answers (1) Mod 04_Handout_Developmental Milestones up to 2 Years

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.
    - 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 (20 minutes):</u>

- Prior to training, cut out and prepare four sets of developmental milestone activity cards.
- Introduce the activity:
    - It can be helpful to think of development in different areas or domains. One area or domain is physical development. Physical development involves learning to move the body such as learning to walk.
- Ask participants to name other areas or domains of development.
- Reveal the domains on the PowerPoint slides or write them on a flipchart as participants share.
    - *Physical/Movement*: learning to move the body; this includes fine motor, or small muscle movements like in the hands and fingers, and gross motor, or whole body or larger muscle movements like crawling, walking or running.
    - *Self-Care*: learning skills for everyday tasks and independence such as self-feeding, dressing, bathing, and cleaning teeth.
    - *Social and Emotional*: learning skills to understand who you are, how you feel, and how to interact with others.
    - *Communication or Language*: learning skills to understand communication and to express words, thoughts, or feelings.
    - *Cognitive or Brain*: learning how to think, explore and figure things out.
    - *Feeding Skills*: learning the ability to eat and drink safely and efficiently.
    - *Sensory:* learning skills related to the senses including vision, hearing, touch, smell and taste.
- If it is helpful, use the physical/movement domain to demonstrate how to place the developmental skills in chronological order according to how the skills typically develop.
- *Note: Each card has a label with the domain, so they can be easily sorted before participants place them in chronological order.*
- Divide participants into four groups. Distribute a set of developmental milestone cards to each group.
- Explain to participants that each team has a set of cards for three developmental domains. The task is to correctly place the milestones in each of the three remaining domains in chronological order the fastest.
- Use the Developmental Milestones Sorting Answers activity sheet to reveal the correct answers. Teams get a point for each correct answer and bonus points for completing the task the fastest; tally the points for each team. The team with the highest points wins.
- Distribute the Developmental Milestone Handout and allow participants a few minutes to review it individually.

- Conclude this section:
    - Each area of development continually interacts with the others and development in one area supports the development of other areas.

- Early development is critical for each child's future health, well-being, and participation in their community.

Activity 4.1.2 (30 minutes)
Developmental feeding skills

Activity Summary	Key message(s)	Slides & Material(s)
Facilitated discussion & feeding skills simulation activity	2	Slides 146-153 Flipchart, markers

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 breast milk 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 (5 minutes):</u>

- Introduce the activity:
  - Understanding the typical development of feeding skills will help you to better know how to feed children and support them to acquire lifelong feeding skills in support of healthy growth and development.
  - Feeding skills generally develop during about the first 18 months of life and continue to get better and more efficient until around 3-5 years of age.
- Ask participants: what do you think are the most important parts of the mouth for feeding?
  - All of the parts of the mouth play a role in eating and drinking. Each part works together to prepare and move food and liquids for swallowing.
  - Understanding each part's job and how those skills develop over time helps us to better understand how to feed children safely and efficiently and to identify when children are having trouble.
  - The tongue, lips, and jaw have key roles and are important parts of the mouth for eating and drinking.
    - *Tongue:* The tongue gathers food or liquid together to prepare to swallow. The tongue moves the food or liquid in the mouth.
    - *Lips*: Lips pull the food into the mouth from a spoon, from the fingers, or the liquid from a cup. Lips help to keep the food in the mouth.
    - *Jaw*: The jaw provides stability to allow the other parts of the mouth to do their jobs. The jaw moves to chew the food.
  - *Note: Teeth are very useful for tearing foods like meats and raw vegetables that are difficult to chew, but they are <u>not</u> <u>required</u> for safe and efficient feeding for many foods.*

- Present information about feeding skills development:
    - There is a relationship between a child's physical development, feeding skills development, and food texture. Acquiring feeding skills and the ability to move the key parts of the mouth is linked directly to the food textures the child is able to eat.
    - As the child develops and acquires skills to move the body, notice how the ability to move the mouth changes.
    - As the movement of the parts of the mouth changes, the child is able to eat a larger variety of food textures. (*Note: food texture is a food's consistency, or how the food feels in the mouth.*)

0 to 3 months
- Infants are typically learning to control their body against gravity, suck reflexively to feed and should be consuming breast milk exclusively. Well-coordinated feeding has a regular, rhythmic pattern of sucking, swallowing, and breathing.

4 to 5 months
- Infants are typically rolling actively and improving head and trunk control. For feeding, the tongue moves mostly forward/back. If you were to try to offer complementary foods now, the tongue will eject the food involuntarily. 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. Based on the child's skill and stage of development, smooth, pureed food textures are the most appropriate.

7 to 9 months
- Children typically have full trunk control and are beginning to crawl. During feeding, the child's tongue is starting to move side to side and follow the food, the jaw moves up/down, and the lips close easily on a spoon or cup. Breast milk, thicker purees, and mashed foods are appropriate for the child's age and stage of development.

10 to 12 months
- Children typically are standing and learning to walk. During feeding, the tongue is becoming coordinated, the jaw moves in a circular/diagonal pattern, and the lips actively help pull food into the mouth. Breast milk, liquids from a cup, and soft and bite-sized foods that require chewing are appropriate for the child's age and stage of development.
- After 12 months of age, children are typically able to consume most regular foods safely. They will become more and more efficient as skills continue to develop and will be able to manage more difficult-to-chew foods and mixed textures or foods that contain more than one food texture like soups with small pieces of vegetables or soft meats.

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

- Introduce activity by explaining that they will experience how the ability to move the tongue, lips, and jaw impacts the food we are able to eat. This activity will help you understand the potential challenges children can face when they are given foods they do not yet have the skills to eat and this will help you to more fully understand the importance of matching the textures of foods to a child's skills.
- Pass out food items for this activity.

- Explain the activity to participants:
  - You are going to try to eat as if you have the feeding skills of a 6-month-old infant.
  - Break off a piece of food and place it on the center of the tongue and try to eat it using only the skills of a 6-month-old.
  - Remember, your tongue can *only* move forward/back and up/down; your tongue is not able to move the food to the side of the mouth to chew it, but it can only mash the food against the top of the mouth.
  - Give feedback if people are using more advanced chewing skills.
  - Encourage participants to eat the food as usual after they have sufficiently tried the simulation.
- Ask participants:
  - What did it feel like to be offered a food that was too challenging to eat?
  - What is a more appropriate food texture for the feeding skills you have? *Explain that a puree texture, like yogurt or smooth porridge would be easier and more enjoyable when they can only move their tongue up/down and forward/back.*

- 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. There is a relationship between a child's physical development, feeding skills development, and food texture.

4.2 Types of Feeding Difficulties

Time: 50 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 types of feeding difficulties that are common in infants and children with disabilities.
- Define aspiration and recognize its signs and symptoms.

Key message(s) to take away for learners:

1. Any infant or child can have difficulty with feeding and up to 80% of children with developmental disabilities have feeding difficulties.

2. Reasons for feeding difficulties may include medical, nutritional, feeding skill, and psychosocial issues. These may involve immature feeding skills, lack of responsive feeding practices, interruptions in typical development, poor nutrition, untreated illnesses, or other co-occurring complex medical needs 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 4.2.1 (25 minutes)
Types of feeding difficulties

Activity Summary	Key message(s)	Slides & Material(s)
Group discussion	1 & 2	Slides 154-161 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 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 can vary widely. Up to 80% of children with disabilities have feeding difficulties.
  - In this section, we will take a closer look at feeding difficulties and aspiration and then identify issues that are common among infants and children 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.
- *Note: Alternatively, you can divide participants into four groups and assign one heading to each group. Groups can brainstorm examples for their topic from their own experience and knowledge. After time to brainstorm, bring the groups back together to share their ideas. Use notes below to add to each group as needed.*

Examples

- Ask participants:
  - What are 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 and children with disabilities using this list:
  - Difficulty latching during breastfeeding
  - Difficulty sucking or weak suck
  - Poor lip closure
  - Difficulty swallowing
  - Difficulty biting or chewing
  - Using wide-open jaw movements or inconsistent jaw movements while feeding
  - Difficulty coordinating sucking, swallowing, and breathing

    - Difficulty advancing food textures
    - Poor endurance, prolonged feedings, or requiring more breaks while feeding
    - Increased effort during feeding causing tiredness
    - Difficulty finishing an adequate amount
    - Difficulty drinking from a cup
    - Difficulty with self-feeding
    - Food refusal or selective eating
    - Limited variety of types or textures of food
    - Food or liquid 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 or child is having difficulty feeding? Think about any signs that you have observed feeding that have made you think that the child is having issues.
- Write down the signs and symptoms shared under "**Signs**."
- Provide additional examples of signs that infants or children are having feeding difficulties using this list:
    - Frequent nasal congestion
    - Loss of milk from the mouth or nose
    - Loss of food from the mouth or nose
    - Fatigue or falling asleep while feeding
    - Difficulty finishing an adequate amount
    - Long feeding times
    - Arching back during feeding
    - Frequent gagging
    - Coughing or choking
    - Frequent or repeated vomiting
    - Low number of wet diapers or other signs of dehydration
    - Poor weight gain
    - Refusal or avoidance behaviors
    - Grimace or finger splay *(spreading the fingers wide apart)*

Causes

- Ask participants:
    - What might be reasons or causes for some of the feeding difficulties that you 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 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 child's gut, intestines, or throughout the gastrointestinal (GI) tract can also contribute to feeding difficulties (e.g., a child 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.
- Sensory-based sensitivities often related to taste, touch, sound, texture, smell, and/or appearance that the brain has to process during feeding experiences can contribute to feeding difficulties. This can typically manifest in strong preferences or avoidance behaviors.

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 and early childhood 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 about their reflection.

Activity 4.2.2 (25 minutes)
Understanding aspiration

Activity Summary	Key message(s)	Slides & Material(s)
Small group brainstorm	3 & 4	Slides 162-167 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 or child 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 child, 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 and children 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.

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

- 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. The clip has sound, but can still be used if audio is not available.*
- Show the brief clip from the "A Small Baby's Feeding Journey" video (from 1:13 to 1:23).
- Explain that the video will show a small infant. You will observe some possible signs of aspiration. Signs or symptoms of aspiration may look different depending on the child and the age of the child.
- 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 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 or child can have difficulty with feeding and up to 80% of children with developmental disabilities have feeding difficulties.
2. Reasons for feeding difficulties may include medical, nutritional, feeding skill, and psychosocial issues. These may involve immature feeding skills, lack of responsive feeding practices, interruptions in typical development, poor nutrition, untreated illnesses, or other co-occurring complex medical needs 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.

4.3 Identifying Feeding Difficulties

Time: 80 minutes

Preparation & materials required: Slide Deck, flipchart, markers, Feeding Scenarios activity sheet and answer key, Feeding Difficulties Screening Checklist handout.

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

- Recognize when infants and children are experiencing feeding difficulties.
- Describe key components of feeding that can be used to screen children for feeding difficulties.

Key message(s) to take away for learners:

1. It is important to take a systematic approach to look at various aspects of feeding to identify feeding difficulties and provide the information needed to take the next steps to address them.
2. Some conditions may contribute to delays in skill development. Some may affect the structure or function of a child's body. Many of these factors may make it difficult for the child to safely and effectively feed and to get adequate nutrition for healthy growth and development.
3. Knowing common symptoms for specific conditions can equip you to anticipate some of the feeding difficulties that a child 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 4.3.1 (40 minutes)
Identifying feeding difficulties

Activity Summary	Key message(s)	Slides & Material(s)
Feeding scenarios activity Feeding Difficulties Screening Checklist overview	1	Slides 168-175 Flipchart, markers Mod 04_Activity Sheet_Feeding Scenarios Mod 04_Activity Sheet_Feeding Scenarios_Answers (1) Mod 04_Handout_ Feeding Difficulties Screening Checklist

Instructions

Note: You may adapt scenarios to reflect the local context. This may include changing the names of children, modifying details to align with the realities of the country or community where the training is taking place, and incorporating references to local systems, services, and programs.

- Introduce this section by asking participants to share any strategies or tools they currently use to identify when a child has feeding difficulties.
- Present information on identifying feeding difficulties:
  - Many caregivers can identify when feeding is difficult or different than expected, but there are times they may not know exactly what the challenge is. Taking a systematic approach to screen for feeding difficulties at appropriate developmental stages helps you to intervene early for better outcomes and support for families.
  - Screening is a necessary step in the process of appropriately identifying and managing feeding difficulties for infants and children. It involves examining key aspects of feeding to inform next steps, such as how to counsel caregivers or the need for further assessment.

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

- Introduce the activity:
  - It is important to practice applying what you have learned about development and feeding skills to help you identify feeding difficulties. This includes determining if the feeding described or observed is appropriate for the child's age and stage of development.
  - Remember that some children with disabilities may be at a developmental stage that does not match their age.
- Ask participants to pair up or work in small groups.
- Distribute the Feeding Scenarios activity sheets to participants.
- Explain the activity:
  - Read each feeding scenario and determine if it is appropriate for the child's age and stage of development. Use your knowledge of developmental feeding skills to consider:
    - What is appropriate for the child's age?
    - What is appropriate for the child's stage of development?
    - Does this affect the child's safety during feeding?
  - Be prepared to give your rationale.

- After 5-10 minutes, bring the group back together to review each scenario. Invite participants to share their answers and explain their reasoning.

Activity (15 minutes):

- Explain that the severity and complexity of specific feeding difficulties can vary widely. Research has shown that some key aspects of feeding can help us screen a child for risk of feeding difficulties.
- Introduce the Feeding Difficulties Screening Checklist handout and explain that it can be used as a job aid to systematically ask mothers about key aspects of feeding in order to identify children birth to five years of age at risk for feeding difficulties.
- Remind participants that caregivers are reliable reporters of their children's feeding behavior and know their children best. If they answer a question in a way that seems to conflict with information they have already provided, it may be helpful to explain what is meant by the aspect of feeding or the question to ensure they have understood what you are asking.
- Distribute a copy of the Feeding Difficulties Screening Checklist to each participant.
- Ask participants to spend around 5 minutes reading through the handout.
- Bring the group back together. Present each section of the Feeding Difficulties Checklist using the slides and the information below, pausing after each section to check for understanding. Use information below to clarify each aspect as needed.

1) *Hunger and fullness cues:*

- This refers to if the child is able to let the caregiver know about hunger and fullness.
    - Children communicate in many ways, even before they are able to talk.
    - Infants will give cues that they are hungry or full:
        - Early hunger cues say "I'm hungry." This includes stirring, mouth opening, and turning head seeking/rooting.
        - Mid hunger cues say "I'm really hungry." This includes stretching, increasing movement, and bringing hands to mouth
        - Late hunger cues say "Calm me, then feed me." This includes crying, lots of movement, and skin color turning red
        - Fullness cues say "I'm done." This includes the infant opening fists, arms lying low across the body, and falling asleep with body relaxed.
    - Ask:
        - How do children give you cues that they're hungry and full? (*Hunger: reaching for food, pointing to food, getting excited at the sight of food, pointing to mouth; Fullness: playing with food, closing mouth, turning away, pushing food away, falling asleep)*
    - It's important to watch and listen to children to communicate when they are hungry. It is also important to stop when a child communicates that they do not want to eat. The child may be full, uncomfortable, or even fearful. Responding to this communication allows a child to feel safe and makes the feeding experience more positive.

2) *Enough food:*

- This refers to, when there is adequate food available, if the child is consuming enough quantity of nutrient-dense foods to meet their needs for healthy growth and development.

3) *Duration:*

- This refers to how long it takes for the child to complete a meal. It is important for infants and children to eat the right amount of food in an appropriate amount of time.

- Most infants and children should be able to eat a meal in about 20-30 minutes.
- In places where duration is not monitored, you may still be able to identify if the child's rate is typical, too fast, or too slow compared to others of the same age.

4) *Respiratory problems:*

- This refers to if there are frequent signs of airway or respiratory problems.
  - Frequent respiratory problems, such as coughing and choking during feeding, are often a sign that the body is trying to protect the airway and lungs from food, liquid, or saliva. It's also important to note recurrent respiratory illnesses without a clear cause, like an infection, as these may be signs of aspiration.
  - Remember that you cannot know for certain if someone is aspirating just by looking at them. And there isn't necessarily a known amount of aspiration that leads to respiratory illness. For that reason, children with frequent airway or respiratory problems may benefit from a referral for further medical evaluation.

5) *Effort:*

- This refers to how much effort it usually takes the caregiver to get the child to eat, especially compared to other children the same age.
  - Level of effort is determined by the primary caregiver. If caregivers believe they have to do something special or additional to get children to eat, then it may be more effort than is typically required for children the same age. This may include making accommodations to the timing, environment, or the menu to meet the needs of the child. It may include the mother providing more support than is typically required at the child's age in order for the child to be fed.

6) *Growth:*

- This refers to if the caregiver perceives that the child's growth over the past month is concerning.
  - If a caregiver believes that the child has lost weight or not gained enough weight over the course of the previous month, this is important information.

7) *Mealtime stress:*

- This refers to if the mealtime is stressful for the child and/or the caregiver.
  - Mealtime can be stressful for many caregivers. However, if feeding the child is often bringing additional stress for the caregiver or mealtime is distressing for the child, this is important information.

8) *Caregiver concerns:*

- This refers to any concerns the caregiver may have about the child's feeding, especially after having responded to the previous questions.
  - Research has shown that caregivers are generally reliable reporters of their children's feeding difficulties. If the caregiver is feeling concerned about feeding their child, this is important information.
- Check for questions and clarify understanding before concluding.

- Conclude this section:
  - Using a systematic screening tool like this checklist can help you decide when to observe a child during feeding to better understand their specific challenges or when to refer the child to a health professional for further assessment. Screening is an important first step that provides critical information to identify and address feeding difficulties early.

Note: Some questions included in the Feeding Difficulties Screening Checklist were adapted from existing tools and literature including the ICFQ tool developed by Silverman et al (2020). References:

- *Arvedson, J. (2017, October 27). Evaluation Feeding and Swallowing Disorders in Infants and Children. Lecture.*
- *Silverman et al (2020). (Silverman AH, Kristoffer BS, Linn C, et al. Psychometric Properties of the Infant and Child Feeding Questionnaire. Journal of Pediatrics. 2020 August; 223:81-86.e2. DOI: 10.1016/j.jpeds.2020.04.040.)*

Activity 4.3.2 (40 minutes)
Feeding Difficulties Associated with Specific Conditions

Activity Summary	Key message(s)	Slides & Material(s)
Small group brainstorm	2, 3	Slides 176-183 Flipchart, markers

Instructions

- Introduce this section by explaining that each child 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 or child 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. Often, infants born prematurely are at higher risk for sensory processing difficulties due to immature nervous systems and exposure to heightened sensory stimuli in NICU settings.
        - I might expect an infant born prematurely to have difficulties with alertness, readiness to feed and sucking for comfort.
        - I might expect to see reduced intake of breast milk, immature sucking, and difficulty coordinating sucking, swallowing, and breathing.
        - I might expect possible issues with frequent vomiting.
        - I might expect a child with a history of prematurity to be at higher risk of sensory-related sensitivities.

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

- Divide participants into at least four small groups.
- Assign each group a specific condition (cerebral palsy, Down syndrome, autism, and blind or partially sighted).
- Provide each group with a blank piece of flipchart paper and markers.
- Explain the activity:
    - Based on your experience and discussions throughout this training about feeding skills and feeding difficulties, brainstorm potential feeding difficulties that you might anticipate for your assigned condition. You can use the Feeding Difficulties Screening Checklist to systematically consider which aspects of feeding are impacted by the condition.

  - Use the flipchart paper to write down some of the key feeding-related challenges you anticipate for the assigned condition.
- After 15 minutes, ask each group to share and invite others to contribute to the lists of anticipated challenges. *Note: You can do this like a round robin, with the flipcharts posted on the wall and have everyone move from one to the next like a gallery. Or a group representative can bring their flipchart to the front of the class to present.*
- Provide additional detail or expand on each condition if not shared by participants:

  Cerebral palsy:
  - Children with cerebral palsy are likely to have issues with their muscle tone. If the child has high tone, the stiffness of the muscles may impact how they move their tongue, jaw, and lips and the child may require support to achieve a stable and safe position for feeding.
  - For infants, the high tone may impact sucking both for comfort and for feeding.
  - During feeding, the child may bite down instead of sucking, sipping, or taking a bite.
  - With high tone, it may be difficult for the child to open the mouth wide enough or may open it too wide, making it difficult to achieve and maintain a good latch in infancy or to accept a bite of food from a spoon during complementary feeding. Some children with cerebral palsy may be at higher risk for aspiration, as well.
  - Infants and children with cerebral palsy may be more tired than expected after feeding due to the inefficient feeding, which may mean they consume less and/or take a very long time to feed.
  - In addition, children with high tone tend to burn more calories and may need more food to meet their needs. Often, infants and children with high tone can be more likely to vomit after feeding, as well.

  Down syndrome:
  - Children with Down syndrome tend to have low muscle tone. Children with low tone may not be alert enough to feed as infants, and may get tired quickly or not have enough stamina to complete an entire meal.
  - 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.
  - Infants with low tone may require additional support for positioning in order to breastfeed or to maintain good attachment. Children with low tone may also require additional support for safe and upright positioning for feeding.
  - 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 child to feel food or liquids in their mouth and impact their ability to swallow at the right time, which can increase the risk for aspiration. Many children with low tone may also overfill their mouth, taking bites that are too large and difficult to manage, which puts them at risk for choking.
  - Children with low tone may be more tired than expected due to inefficient feeding and are more likely to vomit after feeding.
  - Children with Down syndrome experience some degree of intellectual disability, which can lead to difficulty with learning to chew and developing skills for self-feeding.

  Autism:

- Some children with autism experience sensory-related feeding difficulties. Some children with autism may experience oral motor feeding difficulties such as difficulties learning to bite or chew foods.
- A child with autism may gag, shudder, or vomit at the sight, smell, or taste of certain foods. Or a child may become emotionally upset when encouraged to interact with non-preferred foods. These sensory-related feeding difficulties can contribute to picky or selective eating or even feeding aversion where the child consumes a limited variety of foods or food textures.
- Extremely limited diets can impact the child's growth and nutritional status. Poor diet can also contribute to GI problems such as constipation, which can lead to discomfort, pain, and can further limit the amount of food a child is willing to eat.

Blind or partially sighted:

- The severity of this condition can range widely from one child to the next.
- Infants who are blind or partially sighted are capable of successful breastfeeding. Some may need additional support or tactile cues when establishing breastfeeding. Mothers should be encouraged to exclusively breastfeed and build connection with their child who is blind or partially sighted.
- Low or no vision may make it difficult for a child to locate food on a plate, to introduce or transition to new textures or types of food, or to build skills for self-feeding. During self-feeding, it can be difficult to regulate the size of a bite of food on a utensil, which could lead to bites that are too small or too large. Beyond just the potential frustration, bites that are too large can be difficult for young children to manage and may increase their risk of choking.
- Some children who are blind or partially sighted may not experience feeding difficulties at all, especially with proper support and access to adaptive equipment.

- Conclude this section:
  - Check for questions and clarify.
  - Certain conditions and developmental disabilities can limit or interfere with an infant or child'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 or increase the child'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.

- Conclude this module:
  - This brings us the end of this module. Remember that the first step of managing feeding difficulties is to identify them. Following a systematic approach and knowing common symptoms for various conditions and disabilities can help you in that process. In the next modules, we will discuss how we can intervene to address feeding difficulties in infants and children and support their caregivers.
  - Ask participants:
    - What is a new understanding you gained today that changed how you think about feeding infants and children and how might you apply this in your work or daily 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. It is important to take a systematic approach to look at various aspects of feeding to identify feeding difficulties and provide the information needed to take the next steps to address them.
2. Some conditions may contribute to delays in skill development. Some may affect the structure or function of a child's body. Many of these factors may make it difficult for the child 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 a child 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 5

Strategies to Address Feeding Difficulties for Infants with Disabilities

(Total time: 175 minutes)

5.1 Addressing Feeding Difficulties in Infants with Disabilities

Time: 130 minutes

Preparation & materials required: Slide Deck, flipchart, markers, dolls, blankets/cloths/scarves, C-IYCF Counseling Cards, Applying Strategies during Feeding activity sheet and answer key, Breastfeeding Positions handout.

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

- Apply IYCF breastfeeding support actions for infants with disabilities.
- Describe strategies to address feeding difficulties for infants with disabilities to support safe and successful feeding.

Key message(s) to take away for learners:

1. Managing alertness and tone are important ways to support an infant for feeding.
2. A variety of breastfeeding positions may support an infant with disabilities to achieve and maintain good attachment during feeding.
3. 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 5.1.1 (35 minutes)
Strategies to prepare infants with disabilities before feeding

Activity Summary	Key message(s)	Slides & Material(s)
Swaddling activity	1	Slides 184-198 Dolls, blanket, cloth or scarf for each doll

Instructions

- *Note: Prior to training, prepare a flipchart to help you and participants keep track of the various feeding aspects and strategies within this section. On the flipchart, ready three columns with Before, During, and After. As you go through each section, add the aspects you are discussing and then after discussing them, briefly list the strategies discussed. This will be helpful throughout this session and can be referred back to during activities later in the training, as well.*
- Introduce the module:
    - Once you have identified that an infant with disabilities is at risk for feeding difficulties, you may need to closely observe the infant during breastfeeding to understand more about specifically where the issues are. By paying close attention to the infant before, during and after feeding, you can gather important information to help you select targeted interventions to address the feeding difficulties identified.
    - We will discuss some key strategies to address feeding challenges for infants with disabilities before, during and after feeding.
    - In this section, we're going to begin by talking about some things you can do even *before* feeding begins to support an infant for successful breastfeeding including managing the infant's alertness, addressing muscle tone, and strategies to support comfort or non-feeding sucking.

Managing alertness

- Explain managing alertness:
    - 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 the infant 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.
    - 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 the following strategies:
        - Change the environment. For example, turn on a light or move to a brighter space.

        - Offer the infant something to see, hear, or suck to help rouse the infant to a more alert state.
        - Remove layers of blankets.
        - Hold the infant upright and rock gently side-to-side.
        - Use 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 the following strategies:
        - Dim the lights or move to a space that is darker or shaded and not so bright.
        - Remove distractions (e.g., visual and sounds) to promote a calm, quiet state.
        - Wrap the infant in a cloth (swaddle).
        - Apply skin-to-skin contact.
        - Gently pat the infants 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, when feeding in this state, the infant is not actively engaged and learning feeding skills.

Managing tone

- Explain managing 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.
        - *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 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.
        - Tone that is too high or too low may also impact the infant's ability to signal hunger with cues such as difficulty bringing hands to mouth.
    - 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:
    - Unlike older children, infants' body structures for feeding and breathing allow them to feed 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.
    - A developmentally supportive position for young infants with disabilities is a flexed, or more curled-up, 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.
- 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 better 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. This neutral head position is especially important for some infants with disabilities, for whom too much turning of the head to one side (*cervical rotation)* can lead to high tone.
  - *Shoulders*: Relaxed and symmetrical, the same on both sides.
  - *Trunk*: Elongated, not leaning to one side, arching back, and in a straight line from the hips.
- **Swaddling** with a 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.

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

- 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 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 (*comfort suck*):
  - This is the sucking that infants do without the intake of nutrients. That is, when there is no breast milk to swallow. It 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.

- *Note: Non-feeding suck, also called non-nutritive sucking, can be especially helpful for infants in the NICU or born pre-term. Research has shown that it can help improve feeding skills, help physiological stability, may support digestion, and potentially supports pain management for minor discomfort.*

- 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 *(if the infant can safely swallow)*, 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, especially for infants under 4 months of age.*
  - 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 explain in their own words one strategy they can do *before* feeding to prepare infants with disabilities to breastfeed successfully?

Activity 5.1.2 (60 minutes)
Strategies to support infants with disabilities during feeding

Activity Summary	Key message(s)	Slides & Material(s)
Demonstrating/describing breastfeeding positions Applying strategies during feeding brainstorm (options 1 & 2)	2, 3, & 4	Slides 199-212 Dolls C-IYCF Counselling Cards for Breastfeeding Positions (Card 6) and Good Attachment (Card 7) Mod 05_Handout_Breastfeeding Positions Mod 05_Activity Sheet_Applying Strategies During Feeding *(option 1only)* Mod 05_Activity Sheet_Applying Strategies During Feeding_Answers *Note: C-IYCF Counseling Card numbers may differ by country and the version used. Update prior to training.*

Instructions

- Introduce this section by telling participants that in this section, we're going to talk about some things you can do *during* feeding to support an infant for successful breastfeeding including supporting proper latch, facilitating more effective sucking, and ensuring you support safe swallowing.

Latch

- During feeding, the first aspect we will discuss is latch or attachment.
- Present information about good attachment:
    - A proper latch, or how the infant attaches to the breast, is important for infants to feed safely and adequately. A good latch helps the infant extract the most breast milk efficiently.
    - A poor latch can increase the amount of air the infant swallows and can cause pain and damage to the mother's nipples.
    - This is a component of feeding that you may be familiar with assessing.
    - Ask:
        - Can you name 4 signs of a good latch? (*Refer to C-IYCF counseling card for Good Attachment*
            - The infant's mouth is wide open.
            - You can see more darker skin (areola) above the infant's mouth than below.
            - The infant's lower lip is turned outward.
            - The infant's chin is touching mother's breast.
    - Positioning can be an effective way to support improved latch. Some breastfeeding positions may work better for specific circumstances or conditions. 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.

<u>Activity (10 minutes):</u>
Note: Positions described in this activity, except for reclined and upright, are included on the C-IYCF counselling card for Breastfeeding Positions: cradle hold, cross cradle, under arm, and side lying.

- 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 using the dolls.
- Use the content below to name and discuss each position:
    - *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.
    - *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.
    - *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.

  - *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.
  - *Reclined (not shown in C-IYCF counseling card):* 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.
  - *Upright (not shown in C-IYCF 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 C-IYCF counselling cards.
- To review, ask: What are signs of effective sucking? (*Refer to C-IYCF counseling card for Good Attachment)*
  - Slow, deep suckles; sometimes pausing
  - You can see or hear the infant swallow, after 1-2 suckles
  - Suckling is comfortable and pain free for the mother
  - The infant finishes the feed, releases the breast, and looks contented and relaxed
  - The breast is softer after the feed
- Explain:
  - When you observe an infant breastfeeding and notice concerns with sucking, such as weak suck, disorganized suck, long pauses, poor endurance, or wide-open jaw movements, then additional strategies may be helpful to support effective feeding.
- Today, we will discuss two strategies to address 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 takes 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
    - Cerebral palsy
    - Spina bifida/hydrocephalus

Option 1:

- Distribute the Applying Strategies During Feeding Activity Sheet, which includes each of the conditions listed above and a list of potential challenges during feeding.
- Instruct each group to review the challenges during feeding that they might anticipate for an infant with the assigned condition. Based on their discussion, the group should:
    - discuss which position(s) or strategy they would recommend a mother to try, and
    - be ready to explain the reason for their recommendation.
- Move about the room to answer questions as needed.
- After 10 minutes, invite each of the groups to share their answers. 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.

Option 2:

- 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 and 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.
- After 10 minutes, invite each group to present about their assigned condition.
- Use the Answer Key to clarify or expand on the participant's answers.

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 an 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 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 5.1.3 (35 minutes)
Strategies to support infants with disabilities after feeding

Activity Summary	Key message(s)	Slides & Material(s)
Group discussion Review game	5	Slides 213-227 Flipchart, markers

Instructions

- Introduce this section:
    - We will now consider strategies to address challenges *after* feeding.
    - Observing an infant's state and for signs of discomfort after feeding are an important part of the process of addressing feeding difficulties.
        - An infant's state after feeding can provide critical information about the infant's skills and challenges. Infants will communicate when they are full or satisfied and they will communicate if they are experiencing stress, fatigue, or discomfort.
        - Supporting a mother to recognize her infant's cues is a key strategy to foster responsive care and improved feeding. This is especially important for infants with disabilities, some of whom may communicate their needs differently than their peers.

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

- 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.

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

- Tell participants that they will now test their knowledge about addressing feeding difficulties by playing a game.
- Explain the rules of the game and give an example if needed:
  - Stand up if you are able to.
  - 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]*:
  1. The most ideal state for feeding an infant is a quiet, alert state. *[True]*

2. An infant with a stable body position can achieve a better latch and feed effectively *[True]*
3. The cradle hold is the most common breastfeeding position because it is effective for most infants and gives the mother control of the infant's head. *[False, the cradle hold is a familiar hold, but it gives the mother less control of the infant's head and may be more effective for bigger infants or infants who have already learned to effectively breastfeed.]*
4. A delayed or uncoordinated swallow may lead to aspiration. *[True]*
5. High tone is when muscles appear floppy or flexible. *[False, high tone is when muscles appear tight or stiff.]*
6. 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.]*
7. Breast compressions or massage can be used to support an infant with a weak suck or who takes long pauses. *[True]*
8. Infants may communicate discomfort or pain by crying or fussing. *[True]*

- Continue playing until all statements have been read out. If all participants are seated before all the statements have been read, invite everyone to stand up again and continue the game.
- The last person or group standing wins a round of applause – or a small prize if available.

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. 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.

5.2 Other Feeding Considerations for Infants with Disabilities

Time: 45 minutes

Preparation & materials required: Slide Deck, flipchart, markers, dolls, small cups, drinking water, Counseling Cards, Global Health Media video

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

- Explore alternatives to breastfeeding 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.

Activity 5.2.1 (40 minutes)
Alternative methods for feeding

Activity Summary	Key message(s)	Slides & Material(s)
Cup feeding simulation	1, 2, & 3	Slides 228-244 Flipchart, markers, small cups, water, dolls C-IYCF counselling card for how to hand express breast milk and cup feed (Card 9) "Cup Feeding Your Small Baby" video from Global Health Media (0:00-5:06)

Instructions

- Introduce this section by telling participants If the infant is unable to breastfeed or unable to fully breastfeed, alternative feeding methods may be necessary.
- In this section, we 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

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

- 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.
- 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.
- After the video has concluded, ask participants the questions listed below. Reference the notes provided below each question to provide additional information:
    - 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 movement or 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 C-IYCF Counselling cards outline some steps and tips for successful cup feeding, as well. Explain that these steps 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 suckle. Never cup or spoon feed a sleeping infant.
    - Use a small cup, such as a medicine cup (30 ml).

- Instruct the mother to hold the infant close to her body. Position the infant upright with adequate support for a good body position. 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. It is best to keep the cup at the infant's mouth, however, if the infant is having difficulty coordinating suckling 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.

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

- 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 at health facilities in communities where you work?
  - Raise your hand if you are familiar with the protocols of using tube feeding in children?
  - If the group is not familiar, present information about tube feeding.
  - If some participants are familiar, ask: What can you tell me about how decisions are made to start or stop tube feeding?
- 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
  - consistently unable to consume an adequate amount for healthy growth by breast/cup
  - showing signs of aspiration or respiratory distress while/after feeding
  - not gaining weight
  - not passing urine
- If an infant is safe and able to breastfeed, but still needs tube or cup feeding, try the following sequence:

  - First, breastfeed.
  - Then, cup feed.
  - Lastly, tube feed.

- Present briefly about specialized feeders used in certain contexts:
  - 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. These specialized feeders were originally designed to meet the needs of infants with cleft lip and/or palate, but in some contexts may be used with other infants with disabilities who have difficulty achieving adequate suction for efficient breastfeeding. 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:
  - 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.

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.

MODULE 6

Strategies to Address Feeding Difficulties for Children with Disabilities (6 months and older)

(Total time: 180 minutes)

6.1 Applying Responsive Feeding for Children with Feeding Difficulties

Time: 45 minutes

Preparation & materials required: Slide Deck, flipchart, markers, scissors, tape, C-IYCF Counseling Cards (generic or country-specific), communication for feeding sorting cards.

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

- Discuss considerations for introducing complementary feeding for children with disabilities.
- Describe responsive feeding strategies to use while feeding children with disabilities.

Key message(s) to take away for learners:

1. At about 6 months, infants need foods beyond breast milk. For infants with disabilities, timely introduction of complementary feeding and developmental considerations are crucial.
2. For children with disabilities, successful introduction of complementary foods requires careful consideration of their readiness, proper positioning and appropriate food textures.
3. When applied consistently, responsive feeding supports healthy growth and makes feeding positive, enjoyable, and a safe opportunity to build new skills.
4. Understanding the communication and cues of children with disabilities equips caregivers to provide responsive feeding and nurturing care.

Activity 6.1.1 (20 minutes)
Considerations for introducing complementary feeding

Activity Summary	Key message(s)	Slides & Material(s)
Simulation game	1&2	Slides 245-252 C-IYCF Counseling card: Starting Complementary Feeding When Baby Reaches 6 Months (Card 12) *Note: C-IYCF Counseling Card numbers may differ by country and the version used. Update prior to training.*

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 children with disabilities, too. For some children with disabilities, additional considerations may be necessary when introducing complementary foods.
    - The complementary feeding period represents an important window of opportunity to meet nutritional needs and support a child's development. This is also a critical time of learning and transition for children as they develop their feeding skills. Difficulties in this period can contribute to ongoing feeding difficulties.
- Ask participants to name some key messages around introduction of complementary feeding. 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 C-IYCF counselling card – "Starting complementary feeding when baby reaches 6 months" 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 breast milk 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.

<u>Activity (2 minutes):</u>

- 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:
    - Three key factors to consider when supporting mothers to introduce complementary feeding for children with disabilities are readiness, positioning, and food textures. We will come back to some of these concepts in more detail as we continue to discuss strategies to address feeding difficulties.

  Readiness
    - A child'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 child'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 children with disabilities. The child 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 child 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 child eat and drink safely and learn skills for more independence during mealtime.
- To introduce complementary foods, the child should be able to sit with minimal support. When feeding first foods, make sure the child 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. We will talk more in detail about positioning a bit later.
- Provide additional support if needed. Some children are not able to maintain proper positioning on their own. Children with disabilities that affect their body movement or posture may need additional support to make feeding 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
- As you experienced when we discussed developmental feeding skills, 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 child a diet that includes a variety of nutrient-dense foods.
- Mothers can prepare the foods in a texture that is appropriate for the child's feeding abilities.

- Conclude this section:
  - For children 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.

Activity 6.1.2 (25 minutes)
Responsive feeding for children with disabilities

Activity Summary	Key message(s)	Slides & Material(s)
Communication for feeding sorting activity	3 & 4	Slides 253-259 Flipchart, markers, scissors, tape Mod 06_Activity Sheet_ Communication for Feeding Sorting Cards (1 set)

Save the Children

Instructions

- Introduce this section by explaining that a key strategy to support successful introduction of complementary foods and ongoing positive feeding experiences for children with disabilities is to encourage responsive feeding. Responsive mealtime practices help to make feeding positive, enjoyable, and a safe time for learning new skills.
- Ask: what does the term "responsive feeding" mean?
- Present information about responsive feeding:
    - Responsive feeding is when a child communicates hunger, fullness, discomfort, or readiness to eat and the adult responds appropriately.
    - The WHO states that infants and young children need assistance that is appropriate for their age and developmental needs to support adequate nutrition. The WHO definition includes:
        - feeding with a balance between giving assistance and encouraging self-feeding, as appropriate for the child's abilities
        - feeding with positive verbal encouragement without coercion or forcing
        - feeding with age-appropriate and culturally-appropriate eating utensils
        - responding to early hunger cues
        - feeding within a safe and comfortable environment
        - feeding by someone with whom the child has a positive emotional relationship and is aware of the child's needs.
- Present steps for applying responsive feeding:
    - When applied consistently, responsive feeding practices support skill development, communication, and healthy growth. Here are a few simple steps to help caregivers apply responsive feeding practices:
        - Pay attention to the child's communication.
        - Respond warmly and promptly.
        - Feed the right food for the child's age and stage.
        - Let the child stop when they are full.
        - Focus on being affectionate and nurturing.

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

- Prior to training, cut out and prepare one set of communication for feeding activity cards. Place the cards into a bag, bowl, or other container from which they can be drawn.
- Introduce the activity:
    - Children communicate in many ways, even before they are able to talk. Adults also communicate with children during feeding to offer support, comfort, and encouragement.
    - Some children with disabilities may have delays in the development of their language or communication skills, but they still communicate in a variety of other ways. Responsive feeding can play an important role in reinforcing and supporting the development of a child's communication skills.
- Tell participants that they are going to do an activity to explore the ways a young child may communicate during mealtime.
- On a flipchart, draw a vertical line down the center to divide the page in half.
- Draw a happy face on one side of flipchart. Explain:
    - This happy face represents a child who is ready to eat. This child is hungry and ready for the next bite.
- Draw a sad face on the other side of the flipchart. Explain:
    - This sad face represents a child who is not ready to eat. This child may be full, uncomfortable, or just not ready to take another bite.
- One at a time, have a participant draw one of the cards and read the phrase out loud. Instruct the participant to place the card on the correct side of the flipchart.

- If you have tape or adhesive, participants can stick the cards to the flipchart. If not, they can use a marker to copy the words from their card to the flipchart.
- Invite the other participants to provide feedback by sharing if they agree or disagree.
- Use answers below to discuss each of the examples and what the child is communicating.
    - *Happy face answers:* When feeding children, it is important to watch for them to communicate that they are ready for another bite.
        - *Mouth open*: When a child's mouth is open, they are telling you they are ready for the next bite.
        - *Looking at feeder*: When a child is looking at you as you feed them, they are telling you they are ready for the next bite.
        - *Leaning forward*: When a child is leaning forward, they are telling you they are ready for the next bite.
        - *Mouth empty*: When a child's mouth is empty after taking a bite, that means they have swallowed and are ready for the next bite.
        - *Awake and alert*: A child should be awake and alert to be ready for eating and drinking.
        - *Bringing hands to mouth*: Many infants will bring their hands to their mouth to communicate that they are ready for feeding.
    - *Sad face answers*: It is important to stop when a child communicates that they do not want to eat. The child may be full, uncomfortable, or even fearful. When caregivers respond to this communication, it helps the child feel safe and makes mealtime more positive
        - *Falling asleep*: When a child is falling asleep, they are telling you they are not ready to eat. Putting food in the mouth of a very sleepy child may increase the risk of choking or aspiration.
        - *Crying*: When a child is crying, they are telling you they are not ready to eat. Putting food in the mouth of a crying child may increase the risk of choking or aspiration. If the child is hungry, calm the child before feeding.
        - *Mouth closed*: When a child keeps their mouth closed when offered food or asked to open their mouth, they are telling you they are not ready to eat.
        - *Turning or leaning away*: When a child is leaning away or turning their head when offered a bite, they are telling you they are not ready to eat.
        - *Spitting out or pushing food away*: When a child is spitting out food or pushing it away, they are telling you they are not ready to eat.
        - *Mouth full of food*: When a child's mouth is still full of food, they are telling you they not ready for the next bite. If more food is placed in the child's mouth before they have finished, it can become more difficult to chew or move the food in the mouth. This is not safe and may increase the child's risk for choking, too. Encourage caregivers to wait for an empty mouth or signs that the child has swallowed, like watching the child's throat for movement. This allows the child to set the pace of feeding for eating that is safe and more efficient.
- Here are some simple ways that you can recommend to encourage mothers and fathers to communicate with their child during feeding:
    - Make eye contact.
    - Gently touch the child.
    - Hold or soothe the child.
    - Describe the food – *"This food is soft and easy to chew."*
    - Describe what you are doing – *"I am drinking from a cup."*

- Conclude this section:

- Inappropriate feeding practices can have a large impact on the health and development of children.
- Research has shown that caregivers need skilled support for appropriate and responsive feeding. This is also true in contexts with additional stress or trauma.
- Supporting a mother to recognize and respond to her child's communication during feeding is an important way to support pleasant and safe feeding for children with disabilities.

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. At about 6 months, infants need foods beyond breast milk. For infants with disabilities, timely introduction of complementary feeding and developmental considerations are crucial.
2. For children with disabilities, successful introduction of complementary foods requires careful consideration of their readiness, proper positioning and appropriate food textures.
3. When applied consistently, responsive feeding supports healthy growth and makes feeding positive, enjoyable, and a safe opportunity to build new skills.
4. Understanding the communication and cues of children with disabilities equips caregivers to provide responsive feeding and nurturing care.

6.2 Addressing Feeding Difficulties for Children with Disabilities

Time: 90 minutes

Preparation & materials required: Slide Deck, flipchart, markers, scarf, towel/blanket, small box or foot stool, food items (soft mashable food and crunchy dissolvable food), utensils, plates or bowls, observing positioning activity cards, and strategies to address positioning handout.

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

- Discuss strategies for supporting children with disabilities to feed safely.
- Describe the impact positioning has on safe and efficient feeding and how to facilitate improved positioning.
- Summarize strategies to avoid harm when addressing feeding difficulties.
- Differentiate various food textures and the feeding skills required to eat each food texture.

Key message(s) to take away for learners:

1. Proper positioning provides a stable foundation for children to develop feeding skills, learn to eat and drink safely and efficiently, and become more independent during feeding.
2. The hips are the foundation of stability while seated, so it is important to begin there when observing and improving positioning for feeding.
3. While changing a child's position can improve their safety for feeding, making sudden changes to their typical position can also put some children at risk for more difficulties.
4. Work systematically to help children sit as upright as possible. While ideal positioning may not always be possible, small changes and using available objects for support can help the child feel more stable and safer during feeding.

5. We can modify food textures to match the feeding skills of a child. As a child is able, we can gradually change the texture to offer opportunities to practice and develop more feeding skills.

Activity 6.2.1 (30 minutes)
Positioning for safe and efficient feeding

Activity Summary	Key message(s)	Slides & Material(s)
Brainstorm activity Observing positioning simulation activity	1 & 2	Slides 260-273 Flipchart, markers Mod 06_Activity Sheet_Observing Positioning Cards (4 sets)

Instructions

- Introduce this section:
  - Once you have identified that a child with disabilities is at risk for feeding difficulties, you may need to closely observe the child during feeding to better understand where the issues are.
  - The severity of feeding difficulties can range widely from one child to the next. As children grow and develop, there are a number of new skills developing for feeding, and a wide variety of factors that can contribute to feeding difficulties. Some feeding challenges can be quite complex and may need more specialized care and support. In these cases, referrals for targeted services will be necessary.
  - This module will focus on some strategies to support overall safe and efficient feeding for children with disabilities.
    - *Safety* refers to decreasing the risk of coughing, choking, or aspiration during mealtime.
    - *Efficiency* means that a child is able to take in the appropriate number of calories, in the right amount of time, without burning too many calories.
  - By counseling caregivers on practices that prioritize safety and efficiency, you can support children with disabilities to have more successful, safe, and positive feeding.
  - Two key strategies that support safe and efficient feeding are proper positioning and food textures that match the child's feeding skills. We will begin with proper positioning.
  - The position of a child's body during mealtime is critical for safe eating and drinking, feeding efficiency, and learning new skills and independence during mealtime.
  - The risk for feeding difficulties increases when a child is not in a safe and stable position for feeding, especially for some children with disabilities, who may have challenges achieving and maintaining a proper position.
  - Often the simplest and most effective way to improve safe feeding is by changing a child's position.

<u>Activity (5 minutes):</u>

- Introduce activity by defining some key terms:
  - *Positioning*, in the context of feeding children, is how the parts of the child's body are arranged, especially with the help of an adult.
  - *Posture* is defined as the position in which the child holds their body while standing or sitting.
  - *Postural control* is the ability to maintain posture for a period of time.

    - *Stability* refers to the ability to remain balanced.
- Make two columns on a flip chart. Label one "Proper" and the other "Poor."
- Ask participants:
    - Why is proper positioning important during feeding?
    - What happens if a child has poor positioning during feeding?
- Use the information below to fill in both columns and build understanding of the impact of positioning:
    - Proper positioning during feeding:
        - Supports breathing
        - Provides stability, or balance and support
        - Allows the child to enjoy and focus on eating
        - Helps the child to more easily chew and swallow
        - Supports development of lifelong feeding skills
    - Poor positioning during feeding may lead to the following:
        - Coughing and choking
        - Increased risk for aspiration–when food or liquid enters the airway/lungs instead of the stomach
        - Difficulty moving food in the mouth and chewing
        - Losing food out of the mouth
        - Difficulty advancing feeding skills and learning self-feeding
        - Reduced efficiency
- Present information:
    - Muscle tone plays an important role in a child's posture. Children with a disability, such as cerebral palsy, that alters their muscle tone may have challenges with postural control. This is important because it can compromise a child's ability to do daily activities and increases the risk for complications like contractures or pressure sores. Children with disabilities that affect their postural control may need additional support for proper positioning to make mealtime safer, to develop more effective ways of moving, and to help prevent secondary complications.
    - Now that you understand the impact of positioning, it is important to talk about ideal positioning and the key parts of the body for proper positioning during mealtime.
        - The ideal position for a child during eating and drinking is as upright as possible.
        - The key body parts are the head, shoulders, trunk, hips, knees and feet.
        - Ask: When observing a child's position, which of those key body parts should be the first one you look at?
            - You might think to begin at the top and look from head to toe, but the hips are the foundation of stability while seated, so start there. Poor stability can lead to difficulty moving food or chewing and increased risk for choking and aspiration.
- Describe the ideal position during feeding for each of the key parts:
    - **Hips:** The ideal position for the hips is when the child is seated upright with the hips at about a 90-degree angle. They should be stable, symmetrical with weight evenly on both sides of the buttocks.
    - **Trunk:** The trunk, or torso, is supported by stable hips. They ideal position for the trunk is a straight line up from the hips. The trunk should not be leaning to one side or the other, curved forward, or arching backwards.
    - **Shoulders:** Shoulders are supported by a trunk that is in a straight line. The ideal position for the shoulders is relaxed and symmetrical, the same on both sides. When at rest or being fed by a caregiver, arms and hands should rest in front of the body on the lap or a table. The shoulders should not be one higher than the other, both pulled up near the child's ears, nor rounded forward.
    - **Head:** Properly positioned shoulders support the head and neck. The ideal position of the head is an upright, neutral position. This means the head rests over the spine,

between the shoulders with the chin level and the gaze of the eyes forward. The head should not be extended back, falling to one side, or all the way forward with the chin resting on the chest.
    - **Knees:** Supported and well-positioned knees help a child remain stable at the hips. When a child is seated in a chair or on an adult's lap, the ideal position for the knees is resting comfortably over the edge of the chair or lap with the thighs supported. When seated on the floor, the ideal position can be straight with legs out in front, bent with legs crossed and one foot in front of the other, or bent with feet facing each other.
    - **Feet:** Supported and properly positioned feet help a child remain stable at the hips. The ideal position for feet is resting flat on a firm surface like the floor or a foot rest. For a child seated in a caregiver's lap, if the adult is providing total support for the hips, trunk, and head, then foot support is optional. For a child seated on the floor, no additional support for the feet is needed.

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

- Prior to training, prepare four sets of observing positioning activity cards by cutting along the dotted lines. Each set should include five cards.
- Introduce the activity by telling participants:
    - In order to improve positioning for feeding, we must first recognize when positioning is not ideal and needs adjustment. You will practice today by observing the key parts of the body to determine if the position is ideal for feeding.
- Divide participants into four groups.
- Give each group one set of cards.
- Explain the activity:
    - Each set includes five illustrated cards, each showing a different feeding position.
    - Within your group, you will each take turns acting out the positions shown on the card.
    - While one person demonstrates a position, the others will observe and assess whether each key part of the body is *ideal* for feeding or *in need of improvement*.
    - After discussing the first position, another group member will demonstrate a new position shown on the card, and the process repeats until all five positions have been practiced.
- Walk around the room to provide feedback and answer questions as needed.
- After 10 minutes, bring everyone back together.
- Review each position as a large group, discussing whether it was identified as *ideal* or *in need of improvement*.
    - *Position 1*: child seated on the floor leaning forward
        - The child's position needs improvement.
        - In this position, it may be difficult to keep food inside the mouth and move food in the mouth for chewing and swallowing.
    - *Position 2:* child seated in a chair
        - The child's position is as upright as possible and well-supported for mealtime.
        - Stable positioning supports safe swallowing and opportunities to develop feeding skills.
    - *Position 3:* child seated in reclined position with chin up and shoulders raised
        - The child's position needs improvement.
        - In this position, it may be difficult to swallow safely, control or move food in the mouth, and interact with the caregiver or peers
    - *Position 4:* child seated leaning to one side
        - The child's position needs improvement.
        - In this position, it may be difficult to move the food in the mouth for chewing and swallowing.
    - *Position 5:* child lying flat on the ground

        - The child's position needs improvement.
        - In this position, the child is at high risk for aspiration and choking. The child cannot engage in interactions with others and has little active involvement in the feeding process.
    - Ask participants to save the cards to use for another activity.

- Conclude this section:
    - It takes time and practice to strengthen observation skills. In order to improve positioning, you must first recognize when positioning is not ideal for safe and efficient feeding.
    - With practice, your observation skills will continue to improve. Knowing the importance of stable positioning during feeding and having good observation skills will allow you to identify poor positioning and to help a child achieve improved positioning that supports safe and efficient feeding.

Activity 6.2.2 (30 minutes)
Improving positioning for safe feeding

Activity Summary	Key message(s)	Slides & Material(s)
Improving positioning role play Brainstorm activity	2, 3 & 4	Slides 274-281 Flipchart, markers Scarf, towel/blanket, small box or footstool Mod 06_Activity Sheet_Observing Positioning Activity Cards *(use the same cards from Activity 6.2.1)* Mod 06_Handout_Strategies to Address Positioning

Instructions

- Introduce this section by explaining that once you have identified a need for improvement in a child's position, it is important to work toward a position that is as upright as possible to support safe and efficient feeding.
- Present information on avoiding harm:
    - Before you attempt to change a child's position, it is important to remember to first, and always, **do no harm**. That is, do not accidentally make a situation worse with your changes.
    - While changing a child's position can improve their safety for feeding, making sudden changes to their typical position can also put some children at risk for more difficulties.
    - Sometimes children are unable to move or help with movement, and you must physically move them to improve positioning. When that is the case:
        - Use firm, but gentle, and flat hands (not finger tips) when moving the child.
        - Do not pull or drag a child into position using the child's limbs. Place hands on the trunk to facilitate movement and provide head and neck support when necessary.
        - Do not force a child into any position. Some children with disabilities have altered muscle tone or may be at risk for secondary complications like

contractures or pressure sores. Forcing a child into an "ideal" position could cause serious pain or injury.
        - Sitting upright can be difficult or even scary for children who are not accustomed to this position, and it may take time and repeated opportunities for the child to tolerate it.
- Present information on improving position for feeding:
    - Ideal positioning may not be possible for all children with disabilities. You may still be able to improve positioning so they are more upright, stable, and safe for feeding. Aim to establish symmetry and alignment as much as possible.
    - The child and caregiver should both feel comfortable when positioned for mealtime. At first, the child may not tolerate the new position and may require time to adjust to a new position. This may mean partially compromising what is ideal. Do not ask caregivers to assume a position that cannot be comfortably maintained for the duration of feeding.
    - A child should be stable, but never stuck. Good positioning supports better posture and movement. While additional support may be necessary for a child who cannot maintain a position on their own, the child should be stable and able to experience movement, but not be restricted or stuck.
    - When working on improving positioning for children with disabilities, remember these four principles to ensure that you do no harm:
        - *Be responsive:* Pay close attention to what the child is communicating and respond promptly and warmly. Remember that communication is more than words. Watch for signs of distress like arching, crying, or fussing. If you see signs of distress, adjust the child's position so they feel safe and more comfortable.
        - *Take it slow:* Make changes slowly to determine what is most helpful for each child and what the child is able to tolerate. Make sure that the physical movement to transition from the child's typical position to a more ideal position is slow and not too sudden. Allow enough time for the child to adjust and experience each change. Watch for signs that the child is tolerating the change in positioning.
        - *Make small changes:* Some children may be able to tolerate small changes, but not all of the changes required to achieve ideal positioning. Instead of changing all of the key body parts to the ideal position immediately, make smaller changes to start. For example, if a child is accustomed to lying flat and is not yet able to tolerate his hips positioned at 90 degrees, try propping the child more and more upright as he is able to tolerate it.
        - *Practice outside of mealtime:* Start by practicing more upright positioning for 5-10 minutes during play or other activities. As the child increases their ability to tolerate the new position, increase the amount of time in that position to work toward the 20-30 minutes required for a typical mealtime. Practice moving more and more upright outside of mealtime and then gradually begin practicing during mealtime, as tolerated.

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

- Invite two people to come to the front of the room who are willing to participate in a role play about how to improve positioning. *Note: This will require one person to physically assist the other one to move their body into a more ideal position.*
    - One person will be the child. Using the observing positioning activity cards from the last section, have the participant assume one of the positions on a card (Position 1, 3, 4, and 5).
    - The other person will work to improve the "child's" position so they are as upright as possible.
    - Participants observing can offer guidance as needed.

    - Provide support as needed to help those doing the role play to facilitate a functional, upright position.
- If time allows, repeat the role play with new volunteers for each of the "not ideal" positions (Position 1, 3, 4, and 5)
- Invite participants who participated in the role play to reflect on the experience and share about how it felt in each role.

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

- Introduce the activity:
    - Ask participants: What would you do if the child is not able to maintain that improved or more ideal position?
    - In some places, specialized seating equipment or other assistive technology may be available to provide customized support and to meet the positioning needs of a child with disabilities for feeding and other activities. However, this kind of specialized equipment is often expensive and not always available locally.
    - You can still try to provide additional support for children using objects that are easy to find such as blankets, towels, scarves, or boxes.
    - Let's brainstorm some ideas about ways to support more ideal positioning of key body parts.
- Ask participants to share their ideas about how they can support each of the key body parts:
        - Hips
        - Trunk
        - Shoulders
        - Head
        - Knees
        - Feet
- Record responses on a flipchart.
- Use the content provided below to supplement the discussion with additional strategies:

    Hips
    - To achieve stable hips, buttocks resting all the way back in the seat, and weight on both sides:
        - Use a seatbelt, scarf, or soft strap pulled down and back to secure low and across the hips. Make sure it is tight enough to support stable hips, but not too tight to cause discomfort. Avoid securing above the hips or around the child's stomach.
        - If the child is independently seated on the floor, but is sinking or sliding down too far, try putting a firm, folded towel or blanket under the child's buttocks.

    Trunk
    - To achieve symmetrical trunk, in the middle, in a straight line up from the hips:
        - Use small pillows or rolled towels placed along both sides of the trunk.
        - Some children have postural control that affects one side of the body more than the other. They may only need a rolled towel to provide support on one side of their body. Focus on getting the trunk in alignment, straight up from the hips.
        - Provide a table or tray and adjust the chair, table, or tray to allow the child to rest their arms and elbows on the surface.

    Shoulders
    - To achieve symmetrical and relaxed shoulders:
        - Provide a table or tray and adjusting the table, chair, or tray so that the child can rest their arms and elbows to help provide support.
        - When seated in a chair, lap, or on the floor, try bringing the child's arms forward to rest on their lap. This will bring the shoulders forward.

    Head

- To achieve an upright and neutral head and neck position:
  - Place shaped pillows or rolled towels along both sides of the head or a head rest.
  - While seated on a caregiver's lap, the caregiver can use the upper arm firmly against the back of the child's head (not the neck) for support.
  - If the caregiver is seated on the ground, have the caregiver try raising one knee and resting the upper arm on the knee while supporting the back of the child's head (not the neck).

Knees:

- To achieve knees bent comfortably over the edge of the chair or seat:
  - Add a cushion behind the child to bring them forward in the chair.

Feet

- To achieve feet flat on a surface while sitting in a chair:
  - Use a footrest, stool, or box if the child's feet cannot reach a flat surface.

- Conclude this section:
  - Check for questions and clarify understanding.
  - Distribute the handout on strategies for addressing positioning.

Activity 6.2.3 (30 minutes)
Food textures

Activity Summary	Key message(s)	Slides & Material(s)
Food texture experience activity	5	Slides 282-286 Food items: soft and mashable food (bananas or avocados), crunchy and dissolvable food (Marie biscuits, crackers) Flipchart, markers, utensils (spoons, forks), plates or bowls for food samples

Instructions

Note: The International Dysphagia Diet Standardisation Initiative (IDDSI) uses specific descriptions for the textures of foods and drinks and is working to make those descriptions consistent across the globe. Their descriptions are in line with WHO recommendations. While simplified terms have been used to refer to food textures throughout this training, the descriptions are in line with IDDSI specifications. Please note, there are a number of other specific levels of textures that are not covered within this lesson.

- Introduce this section by telling participants that now that we have discussed positioning, let's take a look at the other key strategy for safe and efficient feeding: food textures that match the child's feeding skills.
- Present information about food textures:
  - It is important to ensure that children are being provided with food textures that are appropriate for their age and abilities. The WHO recommends that the consistency of complementary foods "should change across the first year of life and should adapt to the child's requirements and abilities."
  - When food texture is too difficult, the child may gag or choke. It can make digestion more challenging, too. When children do not advance to more difficult textures at

the appropriate time, they may miss important developmental opportunities to learn independence and build feeding skills.
    - Understanding the difference between various textures of food will help you know how to support caregivers to prepare foods in the manner that is most appropriate for the child.
- Present a description of the food textures that will be used in this session:
    - **Puree:** This consistency of food is smooth, without any lumps. It usually is eaten with a spoon. A puree holds its shape on the spoon and falls off fairly easily if the spoon is tilted *(IDDSI-4: puree)*
    - **Mashed:** This consistency is soft and moist and tends to be thicker and more textured than puree. It might be lumpy or chunky. It may be scooped on a fork without liquid dripping or crumbs falling. *(IDDSI-5: minced and moist)*
    - **Soft and bite-sized:** This consistency of food is soft, tender, and moist, but without liquid dripping from the food. Foods that are soft and bite-sized should be tender enough that if you were to push down on a piece with a fork, the food would smash completely and not retain the original shape. *(IDDSI-6: Soft and bite sized)*
    - **Crunchy and dissolvable solid** (also called a meltable solid): foods that are firm or crispy, but that dissolve easily with munching or mashing or minimal chewing. *(IDDSI: Transitional foods)*
    - **Mixed textures:** are foods that contain more than one food texture. This includes foods such as soup with broth and pieces of meat or vegetables. This texture is the most difficult for children to learn to manage. *(IDDSI-7: regular)*

<u>Activity (20 minutes):</u>
- Introduce activity by telling participants that they are now going to practice preparing food in different food textures.
- Distribute each of the food items (soft, mashable food and crunchy dissolvable food), utensils and plates or bowls to all participants. *Note: The soft, mashable food will be used for puree, mashed, and soft & bite-sized textures. Participants will need to use a utensil to prepare their food in the appropriate texture.*
- Explain the activity:
    - You have two food items in front of you.
    - Your task will be to modify each food item in front of you so it matches each food texture. You will then sample each texture and consider the following questions:
        - What do you have to do with your mouth (jaw, lips, tongue) to easily eat this food texture?
        - What are examples of foods from your country that are already prepared or can easily be prepared in this texture?
    - As a group, we go through this activity step-by-step, one texture at a time, and discuss each food texture before moving to the next,
- Lead the large group through the activity in this order:
    - Soft & bite-sized
    - Mashed
    - Puree
    - Crunchy & dissolvable
- Use the content provided below to prompt each food texture and lead a discussion about each food texture:
    - *Soft & bite-sized*
        - Prepare your food item as a soft and bite-sized texture. This can easily be done by cutting soft foods (those that are soft when ripe or cooked to an appropriate texture) with a knife or the edge of a spoon or fork. The size of the pieces should be appropriate for the child's mouth.
        - Skills: The ability to bite off a piece of food is not necessary, but the ability to chew pieces so they are safe to swallow is required. The tongue moves

side to side to move food to gums or teeth to mash or chew, jaw moves up/down.
        - Examples: Diced soft fruits and vegetables (avocado, banana, cooked sweet potato), scrambled eggs, tender pieces of fish cooked soft enough.
    - *Mashed*
        - Prepare your food item as a mashed texture. This can be easily done by mashing a soft or tender food with a fork, spoon, or other utensil to a soft consistency with small lumps.
        - Skills: No biting is necessary and only minimal mashing is required. Lumps can be easily mashed with the tongue before swallowing. The ability to bite off a piece is not necessary. Tongue moves up/down to mash, forward and back to move the food to swallow.
        - Examples: oatmeal, porridge, or soft, not sticky, rice with a thick, smooth sauce to hold it together. Many other foods, though, can be modified to a mashed texture.
    - *Puree*
        - Prepare your food item as a pureed texture. This can easily be done with soft foods using a spoon, fork, or other utensil to mash it to a smooth consistency without lumps. A smooth puree can also be prepared using a high-speed blender, when available.
        - Skills: It does not require any chewing, usually eaten with a spoon. Tongue moves forward/back to move purees.
        - Examples: Yogurt, hummus, custard, blended soft or cooked fruits or vegetables
    - *Crunchy & dissolvable solid*
        - This food is already in the appropriate texture. Foods of this texture are generally prepared commercially and are often pre-packaged.
        - Skills: The ability to move the jaw up/down to mash or munch is necessary, but more advanced chewing skills are not necessary. Texture easily dissolves with addition of moisture from saliva or water. Because the texture dissolves easily, it can be a useful texture to safely help children learn the jaw and tongue movements for early chewing skills with less risk of gagging or choking. While foods in this texture can support skill development, they are not nutrient-dense and therefore, should not make up the bulk of a child's diet.
        - Examples: biscuits, crackers, rice rusks.

- Conclude this section:
    - As children grow, they develop skills to eat more advanced textures of food. Children eat safely when we match the texture of the food to the child's feeding skills and advance to include a variety of textures as the child learns.
    - By gradually increasing the texture of the food, a child can improve feeding skills safely and become a more competent feeder. This allows them to improve chewing skills as well as increase ability to tolerate the texture.
    - We can modify the texture of food very easily to match the texture to the skill of a child. As a child is able, we can change the texture to slowly offer opportunities to practice and develop more feeding skills.

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. Proper positioning provides a stable foundation for children to develop feeding skills, learn to eat and drink safely and efficiently, and become more independent during feeding.

2. The hips are the foundation of stability while seated, so it is important to begin there when observing and improving positioning for feeding.
3. While changing a child's position can improve their safety for feeding, making sudden changes to their typical position can also put some children at risk for more difficulties.
4. Work systematically to help children sit as upright as possible. While ideal positioning may not always be possible, small changes and using available objects for support can help the child feel more stable and safer during feeding.
5. We can modify food textures to match the feeding skills of a child. As a child is able, we can gradually change the texture to offer opportunities to practice and develop more feeding skills.

6.3 Building Skill for Positive and Safe Feeding

Time: 45 minutes

Preparation & materials required: Slide Deck, flipchart, markers, adaptive feeding tools cards, adaptive feeding tools handout.

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

- Describe four ways to support children to build skills for feeding.
- Discuss adaptive feeding tools and equipment and how they can be used to build skills and increase participation for feeding.

Key message(s) to take away for learners:

1. We can support a child to build skills for feeding by modeling skills, providing physical support, making modifications, and offering opportunities to practice at the appropriate level for the child.
2. Adaptive feeding tools, such as modified or adapted feeding utensils, are designed to help children with disabilities participate in feeding and, for many, may help facilitate learning to eat as independently as possible.

Activity 6.3.1 (20 minutes)
Strategies to build skills for feeding

Activity Summary	Key message(s)	Slides & Material(s)
Building skills brainstorm	1	Slides 287-291 Flipchart, markers

Instructions

- Introduce this section by telling participants that you will discuss some simple strategies to help caregivers support their child with a disability to build skills for feeding.
    - All children learn and develop new skills over time when
        - they are offered the opportunity to try tasks that are appropriate for their age and abilities,
        - provided with support to complete those tasks, and
        - given the chance to practice.

    - Some children with disabilities need more assistance and require more practice in order to build feeding skills. This sets them up for safer and more enjoyable mealtimes and more independence.
- Present information on strategies to build feeding skills:
    - *Physical support*
        - Physical support is when a caregiver directly assists a child to carry out a mealtime task. Physical support can and should be decreased as the child is able to complete more of the task on their own. With practice, children can become more independent.
        - This may include providing hand-over-hand support – when an adult places their hand directly over the child's hand to guide a task.
        - Some children may need less physical support to begin with, like when an adult holds the bowl while the child scoops or simply sits near the child ready to offer help when assistance is needed.
    - *Modelling skills*
        - Children learn a great deal by observing others. Mealtime is a great opportunity for caregivers to model feeding skills and other mealtime behaviors. When caregivers are engaged in mealtime with children, they can demonstrate skills, including how to try new foods, how to use utensils, and how to participate in other mealtime routines.
    - *Modifications*
        - Modify the environment by reducing distractions or changing how or where the child sits for mealtime.
        - Change the tools by adapting utensils to help children be more successful when they practice new skills.
        - Modify the food by selecting specific types of food or changing how we present the food.
    - *Opportunities to practice*
        - Offer opportunities to practice at the appropriate level for the child. Children learn and get better at new skills when they are provided with tasks that are appropriate for their age and development and are given the chance to practice them. Feeding occurs multiple times per day and can be used to provide opportunities to practice specific feeding skills. Practicing skills during play and outside of mealtime can also support building skills for feeding, too.

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

- Tell participant that we will now brainstorm some ideas on how to build skills in common feeding tasks.
- Divide participants into five groups.
- Assign each group a feeding task:
    - Self-feeding with a spoon
    - Drinking from a cup
    - Pouring liquids
    - Washing hands before or after a meal
    - Using a napkin or cloth to clean face or hands during a meal
- Ask each group to discuss examples of the ways they can help a child learn the skills for their assigned feeding task.
- After 5 minutes, bring groups back together to share their ideas. When appropriate, encourage groups to demonstrate how they might help.

- Conclude this section:
    - We can help a child build skill by providing physical support, modeling skills, making modifications, and offering opportunities to practice at the appropriate level for

the child. When children are given the opportunity to try new foods and textures, or to feed themselves, they experience less fear and stress. This helps them learn to enjoy eating and build important feeding skills.
  - Ask participants to reflect:
    - What cultural beliefs or practices around feeding and care might make it harder for children to build independence and feeding skills?
    - How do you expect these to be different, or not, for children with disabilities?
    - Can you share examples from your own experience or community? *(Prompts: ask about who feeds the child, how much mess is acceptable, or when a child should start feeding themselves).*

Activity 6.3.2 (25 minutes)
Adaptive feeding tools

Activity Summary	Key message(s)	Slides & Material(s)
Small group discussion Review activity	2	Slides 292-316 Mod 06_Activity Sheet_Adaptive Feeding Tools Cards (1 set) Mod 06_Handout_Adaptive Feeding Tools

Instructions

- Introduce this section:
- Present information about equipment and tools:
  - Some children may benefit from assistive technology (AT), such as adapted or modified feeding tools, that make it easier to participate in feeding or to build independence with feeding themselves.
  - Specialty feeding utensils or other feeding equipment are meant to help children with disabilities participate in feeding and many of them may help facilitate the child to eat as independently as possible, too.
- Ask: What specialty equipment, utensils, or tools have you seen or used with children with disabilities?
  - Some examples might include:
  - A curved fork or spoon
  - A utensil with a larger handle that is easy to hold
  - A strap to hold a utensil on the hand so it is not so easily dropped
  - A cup with a lid that helps prevent spilling
  - Pads or mats that prevent bowls or plates from sliding on the table or tray
  - A bowl with a curved edge to prevent food from falling out of the container or off the spoon while scooping

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

- Prior to training, prepare one set of adaptive feeding tools cards by cutting along the dotted lines.
- Divide participants into four groups.
- Distribute two adaptive feeding tools cards to each group.
- Explain the activity:
  - Review your assigned tools with your group, including the purpose of the tool.
  - Discuss with your group who the tool might be most useful for

    - After 5 minutes, each group will take turns presenting about their assigned tools and who the tool might be most useful for.
    - Use the images on the slide deck to show each tool as groups present about them. Use the Adaptive Feeding Tools handout to support the discussion about for whom the tool is most beneficial.
    - To conclude the activity, explain that specialized equipment can be difficult to find or too expensive in some places. If we look at these adaptive feeding tools, we may be able to come up with ideas for ways to adapt and change the tools we do have access to in order to meet the same needs.
    - Ask participants: Do you have any ideas for ways to change or adapt a readily available utensil or tool to make it easier for a child to participate in feeding?
- Distribute the Adaptive Feeding Tools handout to all participants.

<u>Activity (5 minutes):</u>

- Tell participants:
    - As we conclude this section, let's do an activity to help bring it all together.
- Explain the activity:
    - I will read a scenario of a health worker addressing a feeding difficulty for a child with disability. The scenario is broken into small parts. After each part, your task is to identify which strategies discussed today is being used.
- Display the first part of the scenario on the slide.
- Read it aloud and pause to let participants respond. Ask: "Which strategy is being used in this part of the scenario?"
- Then, advance the slide to reveal the correct answer.
- Repeat this process for each part of the scenario.
- You have the full scenario text, with key components underlined and corresponding strategies indicated between brackets for your reference during facilitation.
    - Sarah is a 3-year-old with cerebral palsy and has not yet learned to drink from a cup. On the few occasions when she has been given the opportunity to try, she tilted her head all the way back, spilling water everywhere and coughing as the water flooded her mouth. Her mother does not know how to help her and is nervous to try. *[no strategies to identify]*
    - During her last visit, the health worker offered to help mom work on cup drinking. The health worker began by getting a glass of water for herself, for Sarah, and for Sarah's mother so they could <u>all drink water together</u>. [*modelling*]
    - The health worker encouraged Sarah's mother to hold Sarah <u>supported on her lap, using one arm to support along Sarah's body</u> and the other to offer the cup for small sips of water. [*positioning*]
    - Sarah's mother <u>placed her daughter's hand on her own</u> as she held the cup and tilted it to pour water into Sarah's mouth very slowly. (*physical support*)
    - As the water filled her mouth, <u>Sarah began to grimace and lean away from her mother. Sarah's mother noticed the change</u> and asked the health worker what she should do. [*responsive feeding*]
    - Sarah's mother was given <u>a small cup, with one side cut out to make room for Sarah's nose during drinking</u>. The health worker coached Sarah's mom to place the rim of the cup on Sarah's bottom lip and bring the liquid to the edge of the cup for small, single sips, one at a time. [*adaptive feeding tools*]
    - Sarah took several small sips and her mother smiled at her warmly to encourage her. As they ended their session, the health worker asked the mother to <u>think about 1-2 times each day that she could do this again for just a few minutes with Sarah</u>. Sarah's mother knew just how to add it to their routine and was eager to see how Sarah's abilities might improve. [*opportunities to 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. We can support a child to build skills for feeding by modeling skills, providing physical support, making modifications, and offering opportunities to practice at the appropriate level for the child.
2. Adaptive feeding tools, such as modified or adapted feeding utensils, are designed to help children with disabilities participate in feeding and, for many, may help facilitate learning to eat as independently as possible.

MODULE 7

Practicing Disability-Inclusive Nutrition and Feeding Support

(Total time: 180 minutes)

7.1 Disability-Inclusive Nutrition and Feeding Scenarios

Time: 3 hours

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

Preparation and materials required for option 1: Contextualize scenarios A, B, C, and D.

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

- Apply disability-inclusive nutrition and feeding interventions and counseling for children and mothers with disabilities.

Key message(s) to take away for learners:

1. Conduct disability-inclusive nutrition and feeding assessment and counseling in a safe environment to identify areas of strengths and work through priority challenges to effectively support children and mothers with disabilities.

Activity 7.1
Disability-inclusive nutrition and feeding scenarios

Activity Summary	Key message(s)	Slides & Material(s)
Practical	1	Slides 317-321 Contextualized Scenarios A, B, C, and D – all relevant documents: Mod 07_Scenario A_Full Assessment Mod 07_Scenario B_Full Assessment Mod 07_Scenario C Mod 07_Scenario C_Weight-for-age growth chart Mod 07_Scenario D_Full Assessment

		IYCF Counselling Cards (generic or country-specific) Mod 07_Handout_ Feeding Difficulties Screening Checklist_BW (in black & white) Mod 07_ActivitySheet_ Disability-inclusive Nutrition & Feeding Scenarios Mod 07_ActivitySheet_ Disability-inclusive Nutrition & Feeding Scenarios_Answers

Instructions

Note: The IYCF Full Assessment Form used in this activity is designed for children aged 0–23 months and is included in Scenarios A, B, and D. Scenario C involves a child older than 23 months and therefore uses different documentation. If the training is taking place in a country that has a similar assessment form tailored for children aged 24–59 months, it may be incorporated into Scenario C.

Adapt case studies to reflect the local context. This may include changing the names of children and towns, modifying details to align with the realities of the country or community where the training is taking place, and incorporating references to local systems, services, and programs.

<u>Activity (60 minutes for group work + 120 minutes for role play & discussion):</u>

- Explain that we are going to use some scenarios to apply what we have learned in this training.
- Divide participants in to four groups and assign each group a Scenario from A, B, C, and D.
    - Scenario A: 4-month-old female; suspected disability; high tone
    - Scenario B: 14-month-old male; Down syndrome
    - Scenario C: 3-year-old male; cerebral palsy; contractures
    - Scenario D: 20-month-old female; feeding difficulties; mother who is blind or partially-sighted
- Handout all the relevant documents for each of the assigned scenarios, one 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 **IYCF Full Assessment Form**. Read each section carefully to learn about the child and the mother.
    - Discuss each section in the form with your group and note down any concerns you have that you may want to address during a counseling session. You will prioritize these concerns before counseling the mother.
    - Based on information from the assessment form, complete the **Feeding Difficulties Screening Checklist**. This will help you summarize feeding-related concerns.
    - Complete the **activity sheet**:
        - *What are the risk factors for the mother and child?* Based on all the information you have, list the factors that contribute to malnutrition and feeding difficulties for the child, including factors related to the mother and/or the child.

        - *Feeding Difficulties Screening Checklist*. Using the checklist, what is your assessment of the child's feeding status? What aspects of feeding indicate risk?
        - *Identify two priority issues*. At this point, you may have identified several concerns that you would like to address with the mother. However, asking a mother to make too many changes at once may be unreasonable, discouraging, or overwhelming. So, it is important to prioritize the issues you want to address and focus on small, manageable changes. That means determining the order in which issues are addressed. You may need to focus on only a few that are more important or urgent than others. Consider:
            - Does it affect the child's safety? Then it is a top priority.
            - What do you know about the mother you are counseling? Listen to her ideas and what she cares about.
            - Is it feasible? Are there major barriers to overcome or limited access to resources to consider?
            - How complex is it? Do you need to break it down into smaller, simpler steps?
        - *Counselling cards, strategies, and adaptations*. Decide which of the counselling topics, C-IYCF Counselling Cards (if applicable), nutrition and feeding strategies, or adaptations would be useful to provide support to this caregiver and child, according to the challenges identified.
        - *Any other support needed? (e.g., referrals)*. Determine if the mother and child would benefit from additional support or services.
    - Complete **Section 11 (COUNSELLING ACTIONS/DECIDE ON CARE PLAN)** of the IYCF Full Assessment Form.
    - Discuss with your group a plan for counselling the mother.
    - Prepare a short role play of the first counselling session, targeting the priority problem(s) and using the identified counselling card(s) (if applicable).
- Walk around the room and answer questions as needed.
- After 60 minutes, ask each group to present their scenario, describing briefly the case of the child-mother pair (e.g., child's age, sex, health condition, nutritional status, feeding status, etc.), and then role-play their Scenario – one person as the counsellor and one person as the mother/ caregiver.
- After each role-play, 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 counselling topics and information given to the caregiver?
- For each scenario, allow 15 minutes for presentation and role-play and another 15 minutes for reflections and discussion. Add you own reflections to the discussion and review topics and strategies if you think additional training is needed.

At the end of the activity

- 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.
- When closing the session, make sure that participants are confident in their ability to apply the nutrition and feeding interventions to children and mothers with disabilities. Consider arranging follow up one-to-one support with individuals who have concerns, or you feel

could potentially use some additional training or encouragement. On-the-job mentoring and regular supportive supervision are 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. Conduct disability-inclusive nutrition and feeding assessment and counseling in a safe environment to identify areas of strengths and work through priority challenges to effectively support children and mothers with disabilities.

PART I

DISABILITY-INCLUSIVE NUTRITION AND FEEDING FOR INFANTS AND CHILDREN

Facilitator Guide

Activity sheets, handouts, answer keys

SPOON

Save the Children

Save the Children

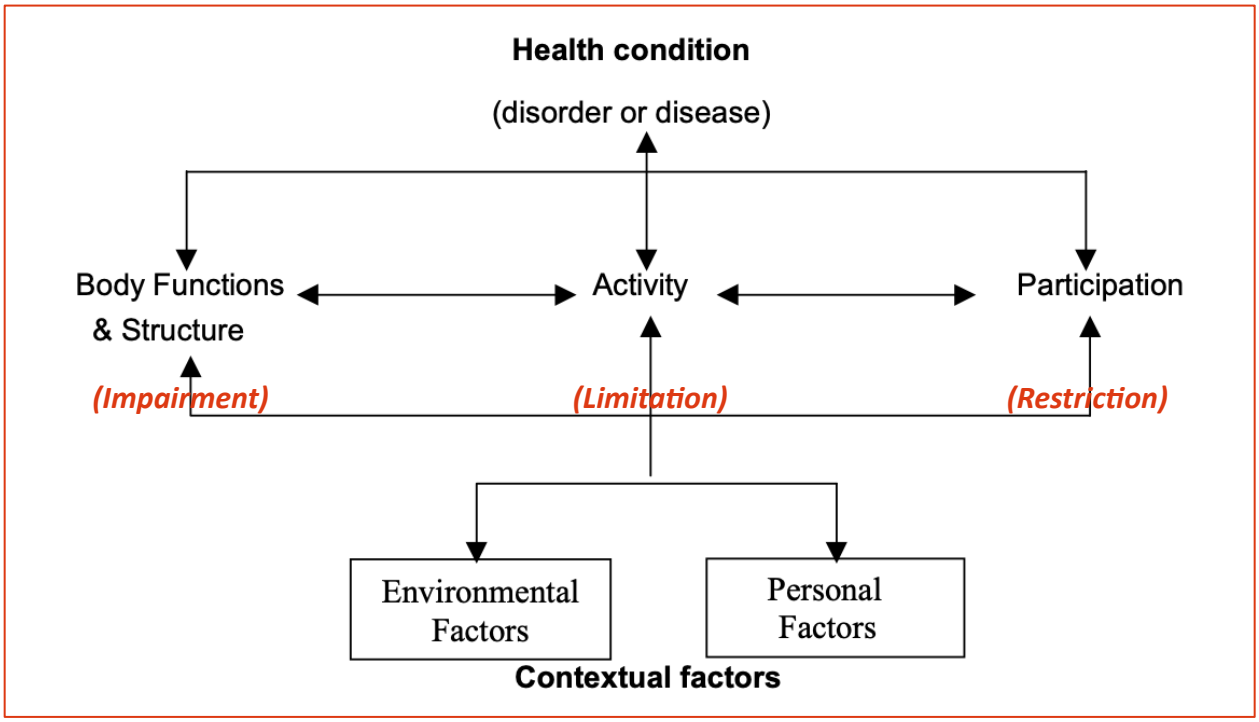
HANDOUT: UNDERSTANDING DISABILITY

[MODULE 1: Understanding Disability and Inclusion]

Persons with disabilities are "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**."

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), 2006

The International Classification of Functioning, Disability and Health (ICF)



World Health Organization (https://www.who.int/classifications/icf/en/)

Health conditions	Body functions & structures	Activity	Participation
Cerebral palsy, Down syndrome, autism, cleft lip/palate, spina bifida, intellectual disabilities, epilepsy, mobility or movement disorders, deaf or hard of hearing, blind or partially sighted	*Structures*: nose, mouth, brain, spinal cord, heart, nervous system, and limbs *Functions*: seeing, hearing, pain, sleep, attention, memory, language, digestion, muscle tone, mobility, immunity	Self-care, eating, drinking, reading, writing, speaking, walking, grasping or lifting objects, using transportation, playing a sport, socializing	Playing with friends, going to school, sharing meals with others, work and employment, accessing healthcare, community involvement
Contextual factors	*Environmental*: Stigma, discrimination, cultural beliefs, services, policies *Personal*: Gender, age, coping styles, education, finances, past experiences		

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ACTIVITY HANDOUT: CASE STUDIES – A

[MODULE 1: Understanding Disability and Inclusion]

As you read each case study:

- **Underline any contextual factors that could *negatively* impact the infant's life**
- **Circle any contextual factors that could *positively* impact the infant's life**

Then, discuss the following questions:

- **What is the context in which each infant lives?**
- **How might this context impact their experiences of disability and participation in everyday life, in a positive or negative way?**

Case Scenario 1

Maya is a 5-month-old infant with Down syndrome living in a rural village in northern Lebanon. Her father works as a farmer and her mother stays at home with her. Maya has low muscle tone, which makes breastfeeding difficult.

Maya's diagnosis of Down syndrome came as a shock to her parents, who had limited awareness of Down syndrome and were initially uncertain about how to care for her. Access to specialized services in their area is limited and traveling to the nearest specialist requires significant time and cost. A local primary healthcare center connected them with a community health worker who provided basic guidance on feeding and early stimulation.

Recently, Maya's mother joined a parent support group organized by a local NGO working with families of children with disabilities. Maya's grandmother, who lives nearby, is now actively involved in her care. She loves making Maya handmade toys.

While Maya does not have access to specialized services, her family is committed to making sure she has opportunities to progress in her development.

Case Scenario 2

Rami is a 5-month-old infant with Down syndrome living with his family in a densely-populated, low-income neighborhood on the outskirts of Beirut. His parents moved there with their two other young children in search of better opportunities but struggle to find stable jobs.

Rami has low muscle tone and has struggled with breastfeeding since birth. His father is often away from home for long hours looking for work, leaving Rami's mother without much support. She often places Rami in a playpen for long periods while attending to the needs of her two other young children.

His mother feels overwhelmed by his diagnosis and isolated saying that she often feels judged by her neighbors. Rami's parents are unsure of where to turn for help and rely on sporadic advice from overburdened community health workers who tell them that they have little experience working with infants with Down syndrome.

Despite these challenges, Rami's parents are trying to do their best for him. They are open to connecting with support networks if given the opportunity.

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ACTIVITY HANDOUT: CASE STUDIES – A (ANSWERS)

[MODULE 1: Understanding Disability and Inclusion]

As you read each case study:

- **Underline any contextual factors that could negatively impact the infant's life**
- **Circle any contextual factors that could positively impact the infant's life**

Then, discuss the following questions:

- **What is the context in which each infant lives?**
- **How might this context impact their experiences of disability and participation in everyday life, in a positive or negative way?**

The two case studies highlight the profound impact of environmental and personal factors on the experiences of two infants with Down syndrome. While Maya benefits from a supportive family and community and better access to resources, Rami faces significant barriers to his growth and development due to his family's socioeconomic challenges, stigma, and poor access to services and support. The contrast between Maya and Rami underscores how a person's impairment may be more disabling or less disabling depending on the context in which they live.

Case Scenario 1

Maya is a 5-month-old infant with Down syndrome living in a rural village in northern Lebanon. Her father works as a farmer and her mother stays at home with her. Maya has low muscle tone, which makes breastfeeding difficult.

Maya's diagnosis came as a shock to her parents, who had limited awareness of Down syndrome and were initially uncertain about how to care for. Access to specialized services in their area is limited and traveling to the nearest specialist requires significant time and cost. A local NGO working with families of children with disabilities connected them with a local community health worker who provided basic guidance on feeding and early stimulation.

Recently, Maya's mother joined a parent support group organized by the NGO. Maya's grandmother, who lives nearby, is now actively involved in her care. She loves making Maya handmade toys.

While Maya does not have access to specialized services, her family is committed to making sure she has opportunities to progress in her development.

Environmental factors:

- Limited access to specialized services in the rural village.
+ Presence of a local community health worker offering guidance and support.
+ Involvement in a parent support group, providing additional resources and information.
+ Availability of handmade toys made by Maya's grandmother that may support development.
+ Supportive family dynamics with active involvement from Maya's grandmother.

Personal factors:

- Limited knowledge about Down syndrome initially, leading to uncertainty and stress.
+ Maya's father's job as a farmer, providing financial stability to the family.
+ Maya's mother staying at home, enabling her to provide direct care to Maya.
+ Emotional support from Maya's grandmother, contributing to the family's resilience.
+ Commitment from Maya's family to ensure she receives opportunities for development despite limited access to specialized services.

Case Scenario 2

Rami is a 5-month-old infant with Down syndrome living with his family in a densely-populated, low-income neighborhood on the outskirts of Beirut. His parents moved there with their two other young children in search of better opportunities but struggle to find stable jobs.

Rami has low muscle tone and has struggled with breastfeeding since birth. His father is often away from home for long hours looking for work, leaving Rami's mother without much support. She often places Rami in a playpen for long periods while attending to the needs of her two other young children.

His mother feels overwhelmed by his diagnosis and isolated saying that she often feels judged by her neighbors. Rami's parents are unsure of where to turn for help and rely on sporadic advice from overburdened community health workers who tell them that they have little experience working with infants with Down syndrome.

Despite these challenges, Rami's parents are trying to do their best for him. They are open to connecting with support networks if given the opportunity.

Environmental factors:
- Limited access to resources and healthcare services.
- Absence of Rami's father for long hours reducing support for Rami's mother.
- Recent relocation, which could lead to lack of social support network in the community.
- Limited availability of experienced community health workers familiar with Down syndrome.
- Disability-related stigma from the community.

Personal factors:
- Struggle to find stable jobs, leading to financial instability and stress within the family.
- Overwhelmed mother with two other young children to care for, leading to limited time and attention for Rami's needs.
- Feelings of judgment from neighbors, contributing to the mother's stress and sense of isolation.
- Lack of knowledge about Down syndrome and uncertainty about where to seek appropriate support and resources.
- Past experiences with community health workers who were unable to help.
+ Family's commitment to do their best for Rami and openness to receiving support.

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HANDOUT: HEALTHCARE JOURNEY FLOWCHART

[MODULE 1: Understanding Disability and Inclusion]

The flowchart highlights the stages along the journey of a mother-child pair through health and nutrition services.

1 **Awareness of health and nutrition services**	2 → **Past experiences of health and nutrition services**	3 → **Leaving the house**
Is the mother aware of health and nutrition services? Is information about nutrition and feeding accessible and available in accessible formats?	Is the mother willing to access health and nutrition services based on prior experiences with these services and health workers?	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?
4 → **Finances**	5 → **Transport**	6 → **Entering the health clinic**
Can the mother afford healthcare and transport? Does she receive any financial support? Is she aware of existing social services?	Can the mother access and afford transport? How far is the clinic? Is public transport to the clinic available? Does the clinic offer transport services?	Does the clinic have ramps? Is clinic signage accessible? Is staff, including reception and security, welcoming and respectful?
7 → **Waiting for an appointment**	8 → **During the appointment**	9 → **After the appointment**
Is the waiting area accessible? Are toilets accessible? Do staff follow any discriminatory practices?	Is the health worker responsive to the mother's needs? Does the health worker provide reasonable accommodation? Is the communication method appropriate?	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?

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ACTIVITY HANDOUT: ATTITUDINAL BARRIERS

[MODULE 1: Understanding Disability and Inclusion]

Match each statement by a health worker from the left-hand column with the type of negative attitude from the right-hand column.

Health worker statements	Type of negative attitudes
1. We usually see the mothers with disability after we have seen all of the other mothers because if they miss out on an appointment it doesn't matter as much for them.	**A.** Stereotyping
2. When a mother who is deaf or hard of hearing comes to the clinic, I leave her to be seen by the other staff. I don't know sign language and I am worried I won't be able to communicate with her.	**B.** Pity
3. No need for a screening. Refer this mother with disability to specialized services because she most likely struggles with feeding her child.	**C.** Fear and avoidance
4. This mother says she has a disability but she looks the same as everyone else to me. Why should I spend longer counseling her?	**D.** Inferiority
5. When I see children with disabilities at the clinic, I feel sorry for their mothers. I talk to them about how hard it must be for them.	**E.** Denial

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ACTIVITY HANDOUT: ATTITUDINAL BARRIERS (ANSWERS)

[MODULE 1: Understanding Disability and Inclusion]

Match each statement by a health worker from the left-hand column with the type of negative attitude from the right-hand column.

Health worker statements	Type of negative attitudes	Notes
1. We usually see the mothers with disability after we have seen all of the other mothers because if they miss out on an appointment it doesn't matter as much for them.	**D.** Inferiority	The health worker has a belief that the needs of mothers with disabilities are inferior to mothers without disabilities and therefore, it is okay to give them lower priority.
2. When a mother who is deaf or hard of hearing comes to the clinic, I leave her to be seen by the other staff. I don't know sign language and I am worried I won't be able to communicate with her.	**C.** Fear and avoidance	The health worker is avoiding seeing a mother who is deaf or hard of hearing for fear of not knowing how to communicate with her. She is managing her own discomfort by avoiding the mother.
3. No need for a screening. Refer this mother with disability to specialized services because she probably struggles with feeding her child.	**A.** Stereotyping	The health worker is stereotyping the mother and making assumptions about her feeding and needs solely based on her disability.
4. This mother says she has a disability but she looks the same as everyone else to me. Why should I spend longer counseling her?	**E.** Denial	The health worker does not recognize that some disabilities are not visible. Based on that belief, she is denying the mother the extra time she needs to be effectively counseled.
5. When I see children with disabilities at the clinic, I feel sorry for their mothers. I talk to them about how hard it must be for them.	**B.** Pity	The health worker is pitying the mother for having a child with a disability.

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ACTIVITY HANDOUT: PROMOTING DISABILITY-INCLUSIVE ATTITUDES

[MODULE 1: Understanding Disability and Inclusion]

For each type of negative attitude, come up with a more disability-inclusive statement that a health worker can say instead.

Negative attitudes	Disability-inclusive attitudes
1. **Inferiority:** Believing persons with disability are inferior because of their impairment. *"We usually see the mothers with disability after we have seen all of the other patients because if they miss out on an appointment it doesn't matter as much for them."*	**Statement:**
2. **Fear and avoidance:** Avoiding a person with disability because of fear of saying or doing the "wrong" thing. *"When a mother who is deaf or hard of hearing comes to the clinic, I leave her to be seen by the other staff. I don't know sign language and I am worried I won't be able to communicate with her."*	**Statement:**
3. **Stereotyping:** Assuming what persons with disabilities need or do not need *"No need for a screening. Refer this mother with disability to specialized services because she most likely struggles with feeding her child."*	**Statement:**
4. **Denial:** Not believing a person with disability or recognizing the impact of the impairment, or denying reasonable accommodation where needed. *"This mother says she has a disability but she looks the same as everyone else to me. Why should I spend longer counseling her?"*	**Statement:**
5. **Pity:** Feeling sorry for a person with disability, leading to patronizing behavior *"When I see children with disabilities at the clinic, I feel sorry for their mothers. I talk to them about how hard it must be for them."*	**Statement:**

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ACTIVITY HANDOUT: PROMOTING DISABILITY-INCLUSIVE ATTITUDES (ANSWERS)

[MODULE 1: Understanding Disability and Inclusion]

For each type of negative attitude, come up with a more disability-inclusive statement that a health worker can say instead.

Negative attitudes	Disability-inclusive attitudes
1. **Inferiority:** Believing persons with disability are inferior because of their impairment. *"We usually see the mothers with disability after we have seen all of the other patients because if they miss out on an appointment it doesn't matter as much for them."*	**Approach:** Persons with disability have equal entitlement to health care as all other people under the UNCRPD. **Statement:** *"Mothers with disabilities are entitled to be seen at our clinic like all other mothers. We will make sure they get the health services they need."*
2. **Fear and avoidance:** Avoiding a person with disability because of fear of saying or doing the "wrong" thing. *"When a mother who is deaf or hard of hearing comes to the clinic, I leave her to be seen by the other staff. I don't know sign language and I am worried I won't be able to communicate with her."*	**Approach:** Try our best to communicate with all mothers and find alternative ways of communicating if required. Don't worry about saying the wrong thing – it is more important to try to communicate and find out what their needs are than to always "get it right". **Statement:** *"When a mother who is deaf or hard of hearing comes to the clinic, although I don't know sign language, I can still find a way to communicate with her."*
3. **Stereotyping:** Assuming what persons with disabilities need or do not need. *"No need for a screening. Refer this mother with disability to specialized services because she most likely struggles with feeding her child."*	**Approach:** Offer persons with disabilities the same access to health services as others. Make referrals based on actual needs or on what they request and do not make assumptions. **Statement:** *"I will offer this mother and her child the same access to screening and assessment just like all mothers and children. Just because the mother has a disability, it does not imply the child is nutritionally at risk."*
4. **Denial:** Not believing a person with disability or recognizing the impact of the impairment, or denying reasonable accommodation where needed.	**Approach:** Not all disabilities are visible. Listen to mothers when they communicate what their specific needs are and provide reasonable accommodation when required.

"This mother says she has a disability but she looks the same as everyone else to me. Why should I spend longer counseling her?"	**Statement:** *"It is important that I accommodate the needs of this mother. I will take the time to communicate with her in a way she understands, and I will make sure she has time to process information and ask any questions that she has."*
5. **Pity:** Feeling sorry for a person with disability, leading to patronizing behavior. *"When I see children with disabilities at the clinic, I feel sorry for their mothers. I talk to them about how hard it must be for them."*	**Approach:** Ask a mother if she need any specific assistance and provide it if requested, but do not insist on helping her or make her feel embarrassed. **Statement:** *"When I see mothers with children with disabilities at the clinic, I will ask them if they need any specific assistance but if they say no, I just see them for their screening the same as all the other children."*

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ACTIVITY HANDOUT: MOTHERS WITH DISABILITIES SCENARIO CARDS

[MODULE 1: Understanding Disability and Inclusion]

✂ -

SCENARIO CARD 1

The mother’s disability: **blind or partially sighted**

The mother’s child is sick and she feels anxious, tired, and stressed.

✂ -

SCENARIO CARD 2

The mother’s disability: **deaf or hard of hearing**

The mother needs to schedule a follow-up visit.

✂ -

SCENARIO CARD 3

The mother’s disability: **blind or partially sighted**

The mother needs instructions on textures of food she can give her 9-month-old.

✂ -

SCENARIO CARD 4

The mother’s disability: **intellectual (difficulty thinking)**

The mother is struggling to calm her child who is crying a lot and not sleeping.

✂ -

SCENARIO CARD 5

The mother’s disability: **deaf or hard of hearing**

The mother wants to know when and how to introduce solid foods to her infant.

✂ -

SCENARIO CARD 6

The mother’s disability: **intellectual (difficulty remembering)**

The mother needs advice on what to eat while breastfeeding.

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Bingo Card ID 01

Child Disability Bingo

Cleft lip/palate	Hydrocephalus	Autism
Down syndrome	Cerebral palsy	Meningitis
Spina bifida	Anemia	Wasting

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Bingo Card ID 02

Child Disability Bingo

Spina bifida	Autism	Meningitis
Hydrocephalus	Developmental disabilities	Stunting
Cerebral palsy	Cleft lip/palate	Down syndrome

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Bingo Card ID 03

Child Disability Bingo

Stunting	Wasting	Hydrocephalus
Cleft lip/palate	Meningitis	Cerebral palsy
Rickets	Anemia	Spina bifida

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Bingo Card ID 04

Child Disability Bingo

Down syndrome	Cerebral palsy	Meningitis
Developmental disabilities	Hydrocephalus	Spina bifida
Stunting	Autism	Cleft lip/palate

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Bingo Card ID 05

Child Disability Bingo

Down syndrome	Anemia	Meningitis
Spina bifida	Cerebral palsy	Cleft lip/palate
Autism	Wasting	Developmental disabilities

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Bingo Card ID 06

Infant Disability Bingo

Cleft lip/palate	Developmental disabilities	Hydrocephalus
Meningitis	Anemia	Wasting
Spina bifida	Down syndrome	Stunting

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Bingo Card ID 07

Infant Disability Bingo

Developmental disabilities	Rickets	Hydrocephalus
Wasting	Cerebral palsy	Meningitis
Autism	Stunting	Anemia

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Bingo Card ID 08

Infant Disability Bingo

Autism	Spina bifida	Anemia
Developmental disabilities	Cerebral palsy	Down syndrome
Cleft lip/palate	Hydrocephalus	Meningitis

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Bingo Card ID 09

Infant Disability Bingo

Spina bifida	Stunting	Cerebral palsy
Down syndrome	Hydrocephalus	Wasting
Meningitis	Rickets	Developmental disabilities

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Bingo Card ID 10

Infant Disability Bingo

Cleft lip/palate	Developmental disabilities	Rickets
Meningitis	Cerebral palsy	Anemia
Stunting	Wasting	Down syndrome

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Bingo Card ID 11

Infant Disability Bingo

Cleft lip/palate	Cerebral palsy	Hydrocephalus
Spina bifida	Rickets	Wasting
Developmental disabilities	Anemia	Down syndrome

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Bingo Card ID 12

Infant Disability Bingo

Rickets	Meningitis	Cleft lip/palate
Stunting	Autism	Hydrocephalus
Wasting	Cerebral palsy	Anemia

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Bingo Card ID 13

Infant Disability Bingo

Spina bifida	Down syndrome	Stunting
Developmental disabilities	Hydrocephalus	Meningitis
Rickets	Anemia	Cerebral palsy

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Bingo Card ID 14

Infant Disability Bingo

Rickets	Down syndrome	Wasting
Developmental disabilities	Autism	Meningitis
Anemia	Cerebral palsy	Hydrocephalus

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Bingo Card ID 15

Infant Disability Bingo

Rickets	Spina bifida	Cleft lip/palate
Cerebral palsy	Hydrocephalus	Down syndrome
Autism	Meningitis	Anemia

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Bingo Card ID 16

Infant Disability Bingo

Cerebral palsy	Wasting	Meningitis
Anemia	Stunting	Autism
Spina bifida	Down syndrome	Cleft lip/palate

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Bingo Card ID 17

Infant Disability Bingo

Down syndrome	Hydrocephalus	Cleft lip/palate
Rickets	Spina bifida	Stunting
Anemia	Autism	Wasting

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Bingo Card ID 18

Infant Disability Bingo

Cleft lip/palate	Wasting	Anemia
Down syndrome	Spina bifida	Stunting
Autism	Meningitis	Hydrocephalus

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Bingo Card ID 19

Infant Disability Bingo

Autism	Meningitis	Developmental disabilities
Stunting	Wasting	Spina bifida
Down syndrome	Hydrocephalus	Cerebral palsy

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Bingo Card ID 20

Infant Disability Bingo

Meningitis	Anemia	Rickets
Cleft lip/palate	Spina bifida	Autism
Wasting	Developmental disabilities	Cerebral palsy

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Bingo Card ID 21

Infant Disability Bingo

Rickets	Cerebral palsy	Down syndrome
Developmental disabilities	Hydrocephalus	Stunting
Anemia	Cleft lip/palate	Meningitis

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Bingo Card ID 22

Infant Disability Bingo

Wasting	Anemia	Down syndrome
Stunting	Cleft lip/palate	Cerebral palsy
Spina bifida	Autism	Developmental disabilities

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Bingo Card ID 23

Infant Disability Bingo

Autism	Stunting	Anemia
Developmental disabilities	Spina bifida	Wasting
Meningitis	Rickets	Down syndrome

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Bingo Card ID 24

Infant Disability Bingo

Meningitis	Cleft lip/palate	Autism
Down syndrome	Rickets	Spina bifida
Wasting	Anemia	Developmental disabilities

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Bingo Card ID 25

Infant Disability Bingo

Down syndrome	Developmental disabilities	Spina bifida
Wasting	Anemia	Stunting
Autism	Cleft lip/palate	Hydrocephalus

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Bingo Card ID 26

Infant Disability Bingo

Anemia	Rickets	Stunting
Meningitis	Cerebral palsy	Wasting
Autism	Down syndrome	Developmental disabilities

Save the Children

Bingo Card ID 27

Infant Disability Bingo

Rickets	Anemia	Cerebral palsy
Down syndrome	Wasting	Developmental disabilities
Spina bifida	Stunting	Autism

Save the Children

Bingo Card ID 28

Infant Disability Bingo

Autism	Meningitis	Anemia
Developmental disabilities	Cleft lip/palate	Down syndrome
Spina bifida	Stunting	Hydrocephalus

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Bingo Card ID 29

Infant Disability Bingo

Autism	Cleft lip/palate	Anemia
Down syndrome	Rickets	Cerebral palsy
Developmental disabilities	Wasting	Spina bifida

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Bingo Card ID 30

Infant Disability Bingo

Rickets	Cerebral palsy	Meningitis
Hydrocephalus	Autism	Down syndrome
Cleft lip/palate	Wasting	Developmental disabilities

ACTIVITY HANDOUT: STRESS CONNECTION SCENARIO CARDS

[MODULE 2: Disability, Feeding, and Nutrition in Children]

✂ -

SCENARIO CARD 1

Mother: The mother is experiencing severe postpartum depression and has difficulty bonding with her infant.

Infant: The infant is colicky and cries for long periods each night.

Healthcare Provider: The healthcare provider is feeling overwhelmed with a high caseload and lacks adequate support.

✂ -

SCENARIO CARD 2

Mother: The mother has a physical disability that makes it challenging to perform daily childcare tasks.

Infant: The infant has a congenital heart defect that requires regular medical visits.

Healthcare Provider: The healthcare provider did not get the pay increase she was expecting since taking on new responsibilities.

✂ -

SCENARIO CARD 3

Mother: The mother is a single parent and is struggling with financial instability.

Infant: The child has been diagnosed with cerebral palsy and has difficulty feeding himself.

Healthcare Provider: The healthcare provider feels guilty for spending little time with her young children because of her long working hours.

✂ -

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SCENARIO CARD 4

Mother: The mother is feeling depressed after a traumatic birth experience and her infant's condition.

Infant: The infant has a cleft lip and milk often gets into his nose. He is not gaining weight as expected.

Healthcare Provider: The healthcare provider is under pressure from her supervisor to reduce consultation times, leading to rushed appointments.

✂ -

SCENARIO CARD 5

Mother: The mother has a chronic illness that limits her energy and ability to care for her child.

Infant: The child has cerebral palsy and is experiencing frequent respiratory infections.

Healthcare Provider: The healthcare provider is coping with grief after the recent loss of a close family member.

✂ -

SCENARIO CARD 6

Mother: The mother is deaf or hard of hearing, making communication and receiving support challenging.

Infant: The child is showing signs of developmental delay and has poor appetite.

Healthcare Provider: The healthcare provider is coping with grief after a recent miscarriage.

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SCENARIO CARD 7

Mother: The mother is facing stigma within her community due to her child's disability.

Infant: The child has Down syndrome. He has intellectual delays and is often constipated.

Healthcare Provider: The healthcare provider is working in an emergency context with limited resources, making it difficult to provide adequate care.

✂ -

SCENARIO CARD 8

Mother: The mother is dealing with anxiety and is constantly worried about her child's weight.

Infant: The child has autism and refuses to eat most foods.

Healthcare Provider: The healthcare provider is frustrated by a recent interaction she had with an uncooperative mother.

✂ -

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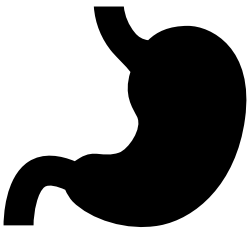
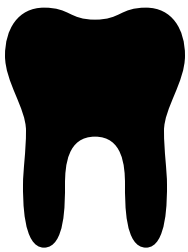
ACTIVITY HANDOUT: NUTRITIONAL CONCERNS MATCHING CARDS

[MODULE 3: Nutrition Considerations for Children with Disabilities]

"Concerns" Card Set (7 cards)

Constipation	Celiac Disease
Gastroesophageal Reflux Disease (GERD) 	Poor Oral Health 

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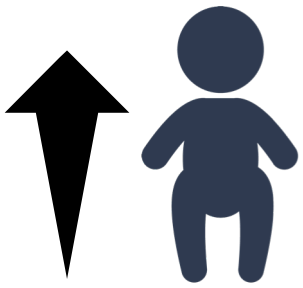
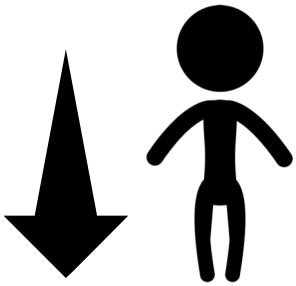
Micronutrient Deficiencies	**Unintended Weight Gain** 
Poor Weight Gain 	

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"Symptoms" Card Set (7 cards)

Symptom: Infrequent, hard, or difficult-to-pass bowel movements	**Symptom:** Pain or heartburn after eating
Symptom: Abdominal pain, diarrhea, or constipation after eating gluten	**Symptom:** Tooth pain, gum discomfort, or plaque buildup

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Symptom: Frequent infections or poor immunity, fatigue, or pale skin	**Symptom:** Falling below expected growth patterns
Symptom: Overweight or obesity	

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"Risk Factors" Card Set (26 cards)

Risk factor: Limited mobility	**Risk factor:** Low muscle tone
Risk factor: Low fiber intake	**Risk factor:** Difficulty drinking fluids

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Risk factor: Delayed gastric emptying (slow digestion)	**Risk factor:** Long periods of lying flat
Risk factor: Constipation	**Risk factor:** Low or high muscle tone

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Risk factor: Has Down syndrome	**Risk factor:** Eats wheat, rye, or barley
Risk factor: Dry mouth	**Risk factor:** Keeps food in mouth

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Risk factor: Sensory sensitivities affecting tooth brushing	**Risk factor:** Reflux causing dental erosion
Risk factor: Diet low in nutrient-dense foods	**Risk factor:** Restricted diets due to food allergies

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Risk factor: GI conditions that lower nutrient absorption	**Risk factor:** Diet low in energy/protein
Risk factor: High muscle tone increasing energy needs	**Risk factor:** Recent surgery

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Risk Factor: Chronic stress/neglect	**Risk Factor:** Difficulty signaling when hungry
Risk Factor: Difficulty signaling when full	**Risk Factor:** Takes medication that increases appetite

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Risk Factor: **Low physical activity or mobility, reducing energy expenditure**	**Risk Factor:** **Overfeeding**

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ACTIVITY HANDOUT: NUTRITIONAL CONCERNS MATCHING (ANSWERS)

[MODULE 3: Nutrition Considerations for Children with Disabilities]

NUTRITIONAL CONCERN	SYMPTOM	RISK FACTORS
Constipation	Infrequent, hard, or difficult-to-pass bowel movements	• Limited mobility • Low muscle tone • Low fiber intake • Difficulty drinking fluids
Gastroesophageal Reflux Disease (GERD)	Pain or heartburn after eating	• Delayed gastric emptying • Low or high muscle tone • Long periods of lying flat • Constipation
Celiac Disease	Abdominal pain, diarrhea, or constipation after eating gluten	• Has Down syndrome • Eats wheat, rye, or barley
Poor Oral Health	Tooth pain, gum discomfort, or plaque buildup	• Sensory sensitivities affecting tooth brushing • Reflux causing dental erosion • Keeps food in mouth • Dry mouth
Micronutrient Deficiencies	Frequent infections or poor immunity, fatigue, or pale skin	• Diet low in nutrient-dense foods • Restricted diets due to food allergies • GI conditions that lower nutrient absorption
Poor Weight Gain	Falling below expected growth patterns	• Diet low in energy/protein • High muscle tone increasing energy needs • Recent surgery • Chronic stress/neglect • Difficulty signaling when hungry
Unintended Weight Gain	Overweight or obesity	• Difficulty signaling when full • Takes medication that increases appetite • Low physical activity or mobility, reducing energy expenditure • Overfeeding

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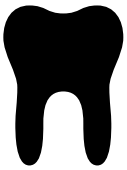
HANDOUT: COMMON NUTRITIONAL CONCERNS IN CHILDREN WITH DISABILITIES QUICK GUIDE

[MODULE 3: Nutrition Considerations for Children with Disabilities]

NUTRITIONAL CONCERN	DESCRIPTION / SYMPTOMS	COMMON RISK FACTORS
Constipation	Infrequent, hard, or painful bowel movements; bloating; poor appetite	• Low or high muscle tone • Limited physical activity • Low fiber intake • Difficulty drinking fluids • Chronic stress
Gastroesophageal Reflux Disease (GERD)	Reflux of stomach acid; heartburn; pain; food refusal; vomiting; dental erosion	• Delayed gastric emptying • Low or high muscle tone • Long periods of lying flat • Difficulty swallowing • Constipation • Skeletal abnormalities • Medication side effects
Celiac Disease	Autoimmune reaction to gluten; excessive gas; abdominal pain; diarrhea; constipation; weight loss; anemia	• Down syndrome • Other genetic disorders
Poor Oral Health 	Tooth decay; gum inflammation; plaque buildup; toothaches; reduced intake; difficulty feeding; aspiration risk	• Sensory difficulties • Motor difficulties • Communication difficulties • Behavioral difficulties • Food retained in the mouth • Dry mouth • Chronic reflux

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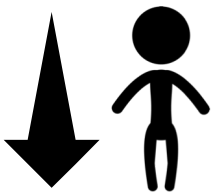
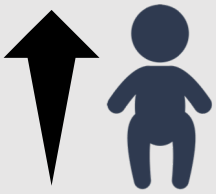
NUTRITIONAL CONCERN	DESCRIPTION	COMMON RISK FACTORS
Micronutrient Deficiencies	Lack of essential vitamins/minerals; anemia; weak immunity; infections	• Feeding difficulties • Diet low in nutrients • Restricted diets • GI conditions • Medication side effects • Tube feeding
Poor Weight Gain 	Below expected growth due to poor intake, nutrient losses, poor absorption, or an underlying condition	• Feeding difficulties • Diet low in energy/protein • Low or high muscle tone • Difficulty signaling hunger • High energy needs • GI conditions/GERD • Genetic conditions • Medication side effects • Recent surgery • Chronic stress/neglect
Unintended Weight Gain 	Caloric intake exceeds energy needs; overweight; obesity	• Limited mobility/activity • Low muscle tone • Short stature • Hypothyroidism • Altered body composition • Difficulty signaling fullness • Overfeeding • High fat/sugar intake • Medication side effects

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ACTIVITY HANDOUT: CAUSES OF MALNUTRITON CASE STUDIES

[MODULE 3: Nutrition Considerations for Children with Disabilities]

Why are these children at risk for malnutrition? Identify potential causes within the following categories: *what* the child eats, *how much* they eat, or how their body *uses* nutrients.

Case Scenario 1: Musa – 18-month-old boy with cerebral palsy

Musa has significant motor impairments and his muscles are always tense. He cannot sit or feed himself on his own. His mother finds it difficult to feed him and reports that it can take over an hour. Musa is fed mashed foods and drinks thin liquids from a spoon. During meals, he often coughs or gags, which makes feeding stressful for him and his mother.

Case Scenario 2: Miriam – 4-year-old girl with autism

Miriam has become extremely selective about food over the past six months. She will only eat five specific foods: white bread, plain rice, chicken nuggets, apples, and plain yogurt. Her father is concerned she refuses fruits and vegetables. Her growth is currently normal, but she is often constipated.

Case Scenario 3: Joseph – 7-month-old boy with Down syndrome

Joseph was born with a heart defect, which was repaired one month ago. He is recovering well but still tires easily. He recently started complementary feeding and currently drinks expressed breast milk from a bottle, along with small amounts of pureed cereal and fruit. His mother reports that he often falls asleep during feeding. He is not yet sitting up independently.

Case Scenario 4: Amina – 3-year-old girl with developmental delays

Amina lives with her grandmother and three young brothers. The family has limited income and often struggles to afford enough food. Amina is small for her age and has had frequent colds this past year. Her grandmother says Amina eats less than her brothers and tends to spit out food or refuse to eat unless she's given biscuits, juice, or cereal with a lot of sugar.

Case Scenario 5: Omar – 5-year-old boy with spina bifida

Omar uses a wheelchair to move around but spends most of his time lying down. His mother says that he struggles with constipation and often goes several days without a bowel movement. His constipation got worse after he started iron supplements for his anemia. His mother says he has a good appetite but only for high-fat, high-sugar snacks.

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ACTIVITY HANDOUT: CAUSES OF MALNUTRITON CASE STUDIES (ANSWERS)

[MODULE 3: Nutrition Considerations for Children with Disabilities]

Why are these children at risk for malnutrition? Identify potential causes within the following categories: *what* the child eats, *how much* they eat, or how their body *uses* nutrients.

Case Scenario 1: Musa – 18-month-old boy with cerebral palsy

Musa has significant motor impairments and his muscles are always tense. He cannot sit or feed himself on his own. His mother finds it difficult to feed him and reports that it can take over an hour. Musa is fed mashed foods and drinks thin liquids from a spoon. During meals, he often coughs or gags, which makes feeding stressful for him and his mother.

WHAT: Feeding difficulties may limit food variety; limited textures; relies on caregiver for food offered

HOW MUCH: Long feeding times suggests fatigue and low intake; tense muscles increase his energy needs; coughing/gagging may reduce appetite; relies on caregiver for feeding, which could result in underfeeding

USE: Tense muscles use up a lot of energy; stressful mealtime interferes with digestion and nutrient absorption; frequent coughing could suggest risk of respiratory illness, which increases nutrient needs

Case Scenario 2: Miriam – 4-year-old girl with autism

Miriam has become extremely selective about food over the past six months. She will only eat five specific foods: white bread, plain rice, chicken nuggets, apples, and plain yogurt. Her father is concerned she refuses most fruits and all vegetables. Her growth is currently normal, but she is often constipated.

WHAT: Very limited food variety; diet lacks nutrient-rich foods; preference for plain, low-fiber foods contributes to constipation; sensory sensitivities associated with autism

HOW MUCH: Selective eating limits sufficient intake of key nutrients; constipation may lead to poor appetite

USE: Constipation; possible stress related to mealtime interferes with digestion and nutrient absorption

Case Scenario 3: Joseph – 7-month-old boy with Down syndrome

Joseph was born with a heart defect, which was repaired one month ago. He is recovering well but still tires easily. He recently started complementary feeding and currently drinks formula milk from a bottle, along with small amounts of pureed cereal and fruit. His

mother reports that he often falls asleep during feeding. He is not yet sitting up independently.

WHAT: Limited variety in complementary foods; not yet receiving iron-rich foods (common concern at this age); receives formula milk but no information on its composition

HOW MUCH: Fatigue and falling asleep during feeding which means he likely is not meeting post-surgery energy and nutrient needs

USE: Low muscle tone associated with Down syndrome may cause constipation; post-surgery recovery increases energy and nutrient needs

Case Scenario 4: Amina – 3-year-old girl with developmental delays

Amina lives with her grandmother and three young brothers. The family has limited income and often struggles to afford enough food. Amina is small for her age and has had frequent diarrhea this past year. Her grandmother says Amina eats less than her brothers and tends to spit out food or refuse to eat unless she's given biscuits, juice, or cereal with a lot of sugar.

WHAT: Food insecurity may result in poor food diversity and low intake of nutrient-dense foods; picky eating, possibly due to sensory sensitivities; frequent intake of high-sugar foods

HOW MUCH: Eats less than others in the household; food insecurity may result in inconsistent access to enough food; diarrhea can often cause poor appetite; consumption of juice may displace nutrient-dense foods

USE: Frequent diarrhea may reduce nutrient absorption and increase nutrient loss; chronic stress related to food insecurity, living conditions, and mealtime challenges may affect nutrient absorption

Case Scenario 5: Omar – 5-year-old boy with spina bifida

Omar uses a wheelchair to move around but spends most of his time lying down. His mother says that he struggles with constipation and often goes several days without a bowel movement. His constipation got worse after he started iron supplements for his anemia. His mother says he has a good appetite but only for high-fat, high-sugar snacks.

WHAT: Low fiber intake, which may cause constipation; iron supplements, which worsens constipation; frequent consumption of high-fat, high-sugar snacks may displace nutrient-dense foods, worsen constipation, and put him at risk for unintended weight gain; low intake of iron-rich foods and vitamin C-rich foods worsens anemia

HOW MUCH: Consuming more calories than needed for his activity level; low intake of vitamin C-rich foods causes lower absorption of iron from food and supplements

USE: Limited mobility increased risk of constipation; spends long periods lying down, which may affect digestion and increase risk for reflux; GI conditions associated with spina bifida may affect nutrient absorption

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ACTIVITY HANDOUT: GROWTH ASESSMENT FLASHCARDS

[MODULE 3: Nutrition Considerations for Children with Disabilities]

True or False. If a child is unable to straighten his legs, I can still measure length. I just need to do it carefully.	**True or False.** The median growth line, or green line, is followed by the majority of children who are well nourished.
True or False. Positive z-score lines always indicate healthy growth.	**True or False.** Negative z-score lines always indicate poor growth.
True or False. Boys and girls have the same growth charts because they grow the same way.	**True or False.** Growth rate depends on the child's age.
True or False. In general, growth points between the +2 and -2 z-score lines are considered to be in the normal range.	**True or False.** WHO growth charts should only be used for children who are breastfed.
What are two measurements you can use to find out if the child has **wasting or acute malnutrition**?	Which growth chart do you use to find out if the child is **underweight**?

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If a 3-year-old child is **unable to stand**, how can you measure their weight?	At what ages do you measure **length vs. height**?
You want to measure **MUAC** but the child is unable to straighten their elbow. What do you do?	Which growth chart do you use to find out if the child is **stunted**?
What z-score value do you use to determine if the child has **stunting, wasting, or underweight**?	Describe two **growth patterns** that generally indicate a concern and require further attention.
Can **wasting** be reversed?	Can **stunting** be reversed?
There are several steps involved in growth assessment. **Place them in the correct order.** A) Design a care plan B) Counsel caregiver C) Plot measurements D) Weigh and measure E) Follow up F) Determine risk	When reviewing a one-year-old girl's weight-for-length growth chart, you notice that she's been growing consistently at an expected rate for her age. However, her growth line is below the -2 z-score line. **Are you concerned and why?**

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ACTIVITY HANDOUT: GROWTH ASESSMENT FLASHCARDS (ANSWERS)

[MODULE 3: Nutrition Considerations for Children with Disabilities]

True or False.

If a child is unable to straighten his legs, I can still measure length. I just need to do it carefully.

False. The child's ability to fully straighten legs is essential to get an accurate length measurement. Some children may have contractures and are unable to straighten their legs. Forcing the legs straight can cause pain and harm to the child. Taking accurate measurements can be difficult for children with certain impairments. For those children, it is important to select the measurements that can be done safely and accurately.

True or False.

The median growth line, or green line, is followed by the majority of children who are well nourished.

True. The median or green line illustrates how most children would grow if they are well-nourished and cared for. It is equal to a z-score of 0.

True or False.

Positive z-score lines always indicate healthy growth.

False. A positive z-score indicates the growth point is above average. It may indicate a concern; the further away from the median, the more serious the concern.

True or False.

Negative z-score lines always indicate poor growth.

False. A negative z-score indicates the growth point is below average. It may indicate a concern; the further away from the median, the more serious the concern.

True or False.

Boys and girls have the same growth charts because they grow the same way.

False. Boys and girls grow differently. That is why growth charts are sex-specific.

True or False.

Growth rate depends on the child's age.

True. Age is an important component of many growth charts. How rapidly children grow depends on their age.

True or False.

In general, growth points between the +2 and -2 z-score lines are considered to be in the normal range.

True. But, one growth point is not enough to determine if a child is growing well. A series of

True or False.

WHO growth charts should only be used for children who are breastfed.

False. WHO growth charts can be used regardless of the method of feeding. While the WHO growth charts illustrate how healthy children grow under ideal conditions including

plotted points is needed to establish a trend or pattern.	breastfeeding, good feeding practices, adequate nutrition, and proper care, they can be used for children who are not breastfed.
What are two measurements you can use to find out if the child has **wasting or acute malnutrition**? MUAC, or weight and length/height. Then, MUAC cut-off points or the weight-for-length/height growth chart are used to determine if the child has wasting.	Which growth chart do you use to find out if the child is **underweight**? The weight-for-age growth chart.
If a 3-year-old child is **unable to stand**, how can you measure their weight? Weigh the child with the help of the mother. Ask the mother (or an assistant) to stand on the scale, zero the scale (tare function), then place the child in the mother's arms.	At what ages do you measure **length vs. height**? Length for ages < 24 months and height for ages ≥ 24 months.
You want to measure **MUAC** but the child is unable to straighten their elbow. What do you do? Inspect the other arm. If the child is also unable to straighten the other arm, do not measure MUAC. Do not force the arm straight as it may cause pain and harm to the child. Some children with disabilities may not be able to straighten their elbow due to contractures or deformities.	Which growth chart do you use to find out if a child is **stunted**? The length/height-for-age growth chart.
What z-score value do you use to determine if the child has **stunting, wasting, or underweight**? A z-score < -2 on the appropriate growth chart is used to indicate stunting (length/height-for-age), wasting (weight-for-length/height), or underweight (weight-for-age). A z-score < -3 indicates severe malnutrition.	Describe two **growth patterns** that generally indicate a concern and require further attention. The following growth patterns generally indicate a concern and require further attention: • A growth line showing a sharp incline • A growth line showing a sharp decline • A flat growth line

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Can **wasting** be reversed? Explain your answer.

- Yes! Wasting can be reversed if conditions improve. Interventions should include:
  - treating infections and illnesses
  - improving food access and quality
  - improving child care practices
- Compared to height, weight responds faster to interventions. Generally, children gain weight first before they catch up in length or height.

Can **stunting** be reversed? Explain your answer.

- Yes and no! Generally, stunted children under the age of two years may regain some lost height potential when placed in environments where they are well-fed and cared for. This is called catch-up growth.
- After children reach two years of age, it becomes more difficult, but not impossible, to reverse stunting that has occurred earlier.
- While these children may remain shorter than what is expected for their age, they can continue to grow closer to their potential with proper nutrition and care.

There are several steps involved in growth assessment. **Place them in the correct order.**

A) Design a care plan
B) Counsel caregiver
C) Plot measurements
D) Weigh and measure
E) Follow up
F) Determine risk

Step 1: D) Weigh and measure
Step 2: C) Plot measurements
Step 3: F) Determine risk
Step 4: A) Design a care plan
Step 5: B) Counsel caregiver
Step 6: E) Follow up

When reviewing a one-year-old girl's weight-for-length growth chart, you notice that she's been growing consistently at an expected rate for her age. However, her growth line is below the -2 z-score line. **Are you concerned and why?**

I'm somewhat concerned and should gather more information. Even though the growth line tracks below the -2 z-score line, the child is growing consistently at an expected rate for age and sex. However, given the child's age, we want to evaluate her situation further and determine if other risk factors are present. It would be helpful to learn more about the child's nutrition, illnesses or medical conditions, feeding history, and care practices. It's also important to review her length-for-age growth chart to determine if she's also growing consistently in length.

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ACTIVITY HANDOUT: GROWTH EXPECTATIONS FOR CHIDLREN WITH DISABILITIES

[MODULE 3: Nutrition Considerations for Children with Disabilities]

Discuss the following questions:

1. **Do you expect this child to grow differently as part of their condition?**
2. **Are you concerned about the child's growth? Why or why not?**
3. **What information should you consider when interpreting this child's growth?**

Case Scenario 1: Low weight but steady growth

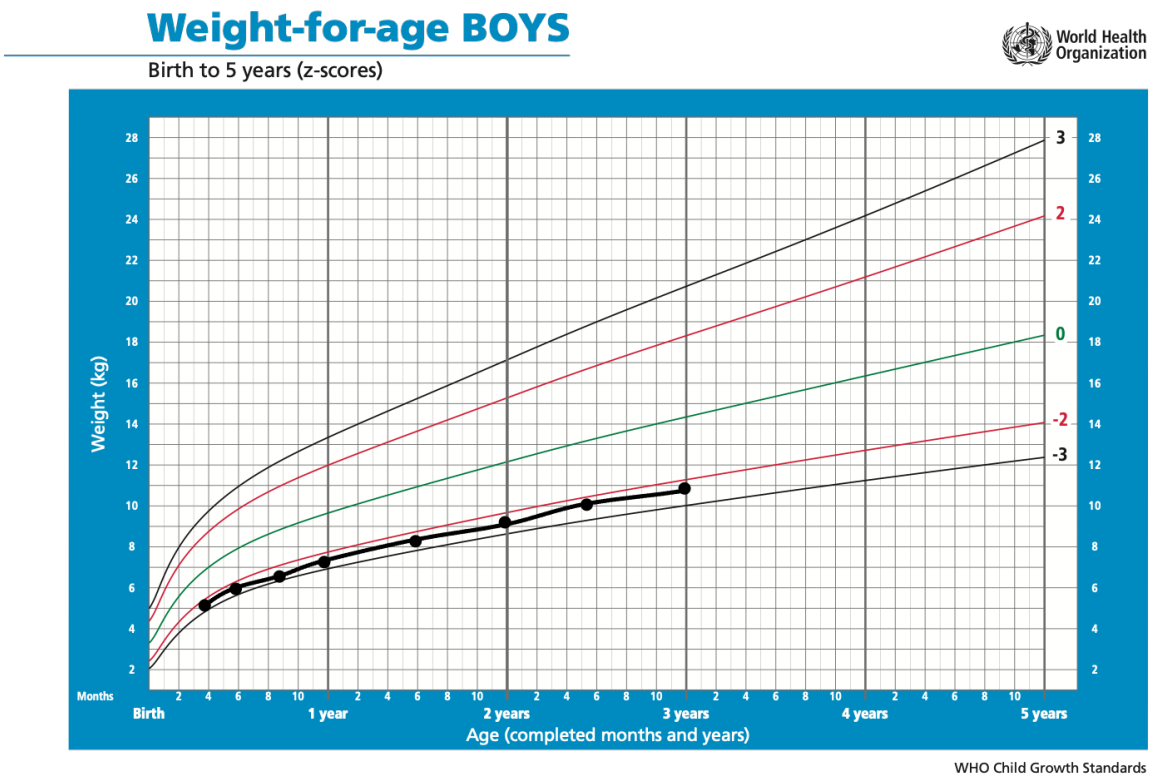
Name: Daniel

Sex: Boy

Age: 3 years

Disability: Cerebral palsy

Daniel has feeding difficulties and primarily eats puréed and mashed foods. He takes nearly an hour to finish each meal. His weight is below the -2 z-score, but it has consistently tracked along that same curve over the past year. He has good energy levels and seems to be doing well overall.



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Discuss the following questions:

1. **Do you expect this child to grow differently as part of their condition?**
2. **Are you concerned about the child's growth? Why or why not?**
3. **What information should you consider when interpreting this child's growth?**

Case Scenario 2: Slow length gain

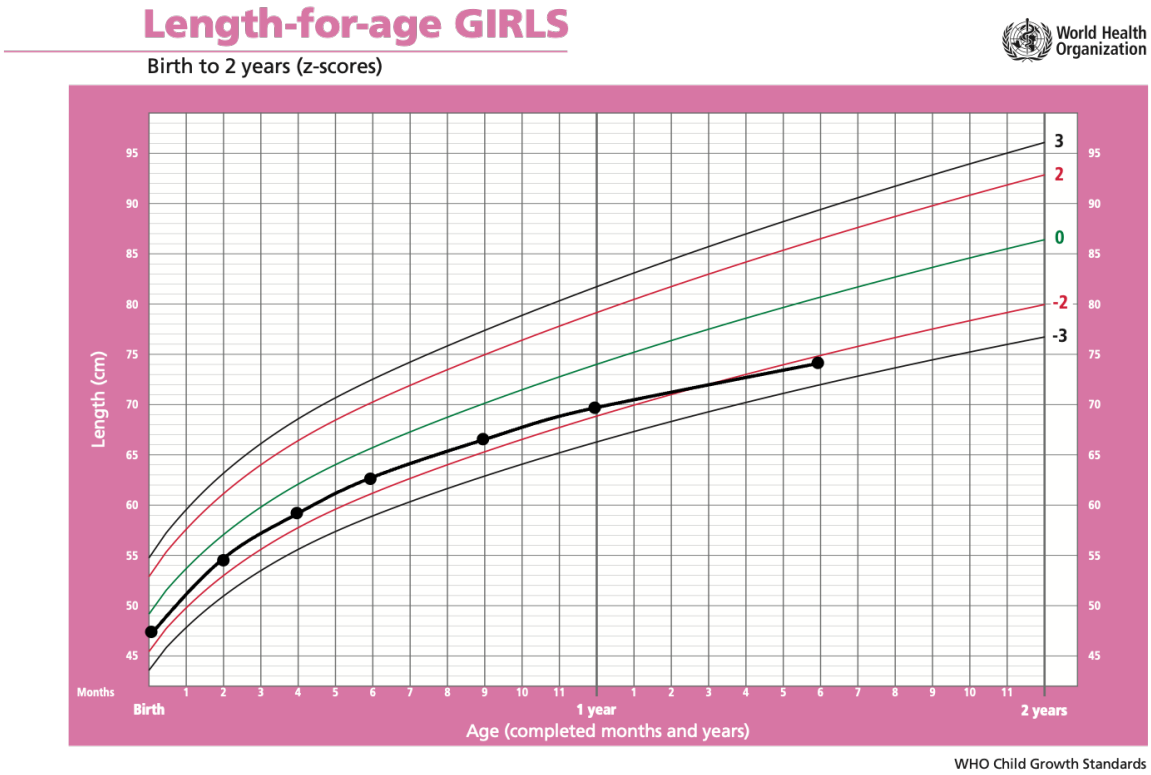
Name: Aisha

Sex: Girl

Age: 18 months

Disability: Down syndrome

Aisha's weight and length were within average ranges for the first year of life. Over the past 6 months, her length has dropped from the -1 z-score line to slightly below the -2 z-score line. She experiences some constipation. She's otherwise healthy, with good appetite and energy.



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Discuss the following questions:

1. **Do you expect this child to grow differently as part of their condition?**
2. **Are you concerned about the child's growth? Why or why not?**
3. **What information should you consider when interpreting this child's growth?**

Case Scenario 3: Sudden weight loss

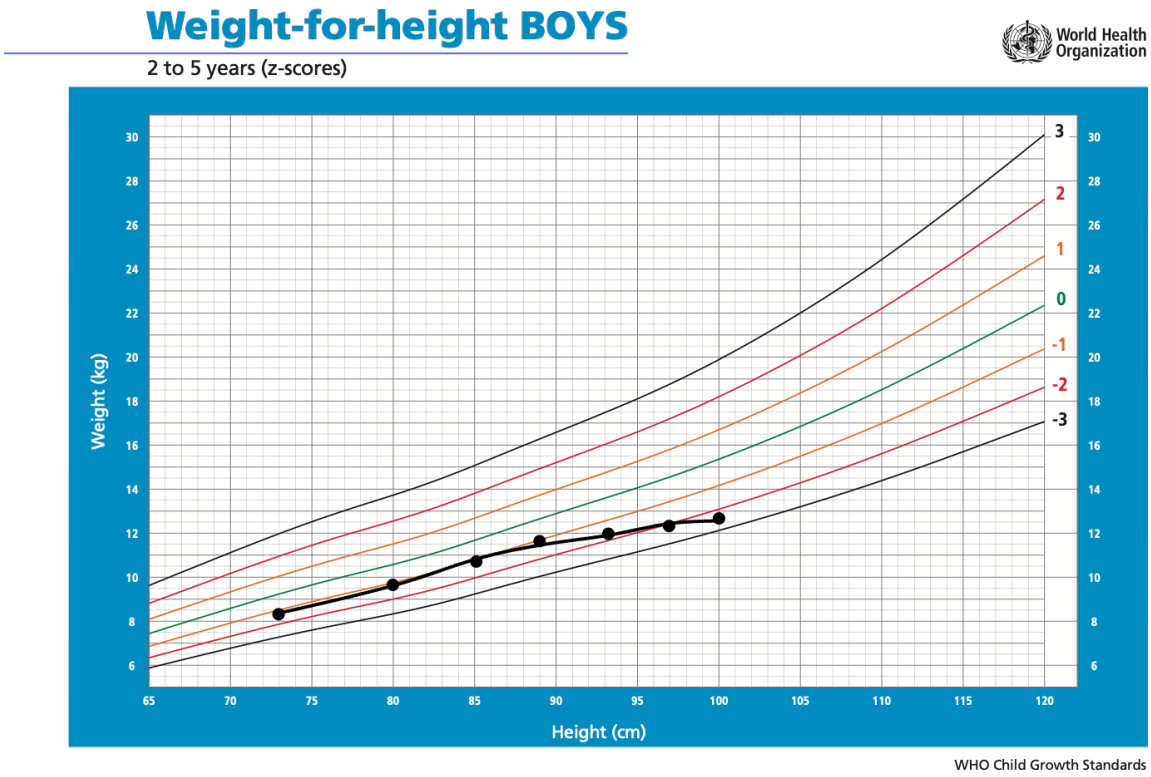
Name: Ziad

Sex: Boy

Age: 4 years

Disability: Autism

Ziad has become extremely selective about food over the past year, eating mostly dry, crunchy foods. He refuses fruits and vegetables and often skips meals altogether. His mother reports that he has lost noticeable weight, and his weight for height has dropped from the -1 z-score line to below the -2 z-score line.



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Discuss the following questions:

1. **Do you expect this child to grow differently as part of their condition?**
2. **Are you concerned about the child's growth? Why or why not?**
3. **What information should you consider when interpreting this child's growth?**

Case Scenario 4: Rapid weight gain

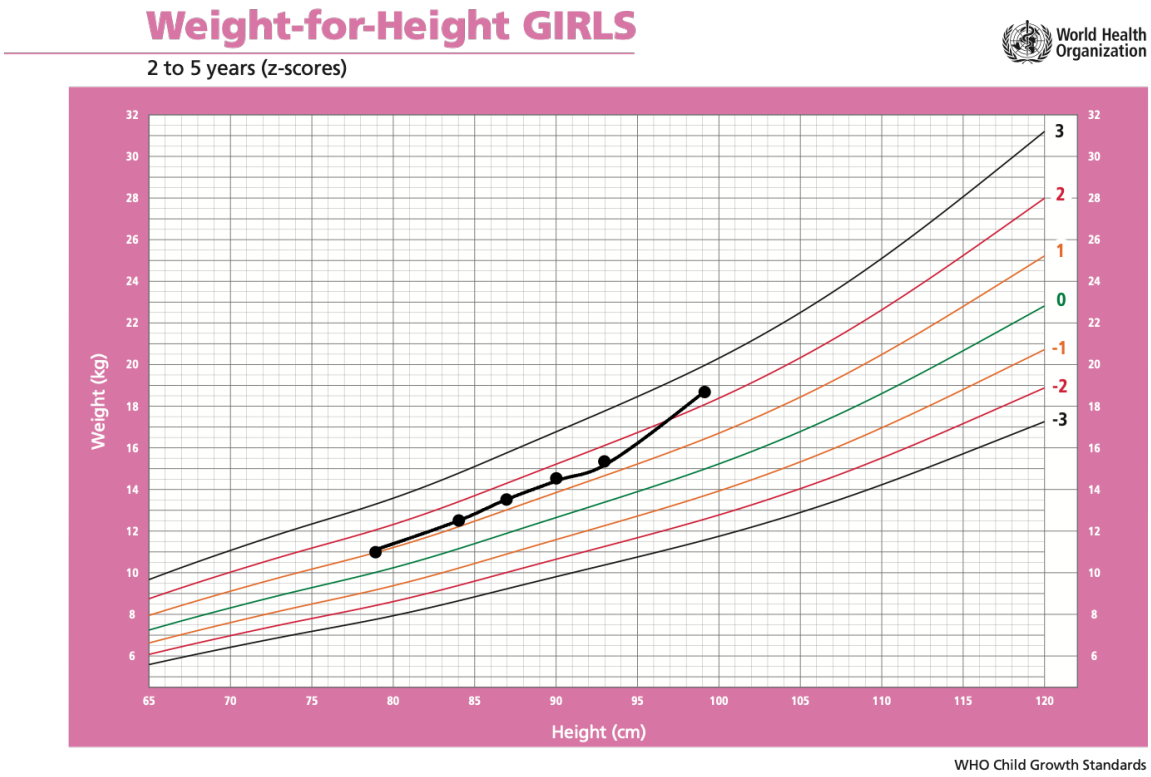
Name: Aya

Sex: Girl

Age: 5 years

Disability: Spina bifida

Aya's weight has jumped from the +1 to the +2 z-score over the past year, though her height has remained around the -2 z-score line. She has limited physical activity and prefers high-calorie, high-sugar foods. Her caregiver says she snacks often and is rarely hungry for lunch and dinner.



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ACTIVITY HANDOUT: GROWTH EXPECTATIONS FOR CHIDLREN WITH DISABILITIES (ANSWERS)

[MODULE 3: Nutrition Considerations for Children with Disabilities]

Discuss the following questions:

1. **Do you expect this child to grow differently as part of their condition?**
2. **Are you concerned about the child's growth? Why or why not?**
3. **What information should you consider when interpreting this child's growth?**

Case Scenario 1: Low weight but steady growth

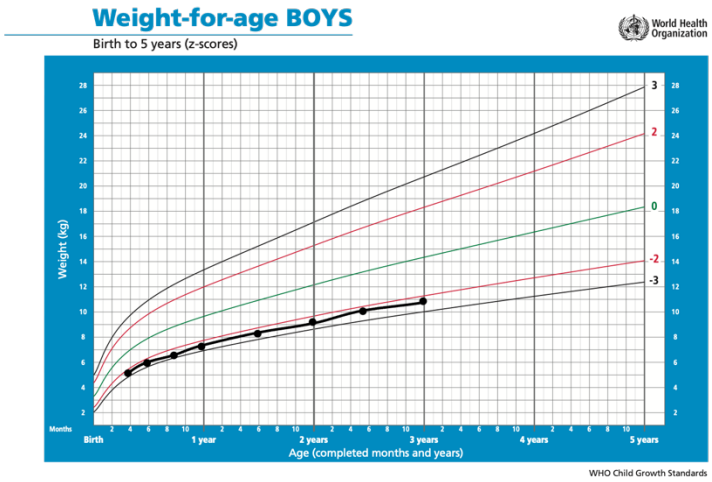
Name: Daniel

Sex: Boy

Age: 3 years

Disability: Cerebral palsy

Daniel has feeding difficulties and primarily eats puréed and mashed foods. He takes nearly an hour to finish each meal. His weight is below the -2 z-score, but it has consistently tracked along that same curve over the past year. He has good energy levels and seems to be doing well overall.



Answers

Do you expect this child to grow differently as part of their condition?

Yes, cerebral palsy can influence both height and body composition. Children with cerebral palsy often have higher body fat and lower lean body mass (muscles, organs, and bones). Because of this, they may be shorter and weigh less. In this case, it is possible that the disability itself (nonmodifiable) and other factors (modifiable) are contributing to the child's weight being below -2 z-score.

Are you concerned about the child's growth? Why or why not?

While the child's weight gain has been consistent over the past year and he is doing well overall – both important considerations, I would still be concerned about his growth due to his feeding difficulties, which means he is still at risk for faltering growth.

What other information should you consider when interpreting this child's growth?

Quality of his diet – does it have enough calories and protein to support his growth?

His energy needs – does he have high muscle tone that increases his needs?

Feeding difficulties – he takes a long time to finish a meal. Has he experienced coughing during feeding or any respiratory illnesses?

Height-for-age and weight-for-height growth charts (if height can be measured accurately) – while he may be low on these growth chart, has he grown consistently in height over the years? How does his weight look relative to his height?

Case Scenario 2: Slow length gain

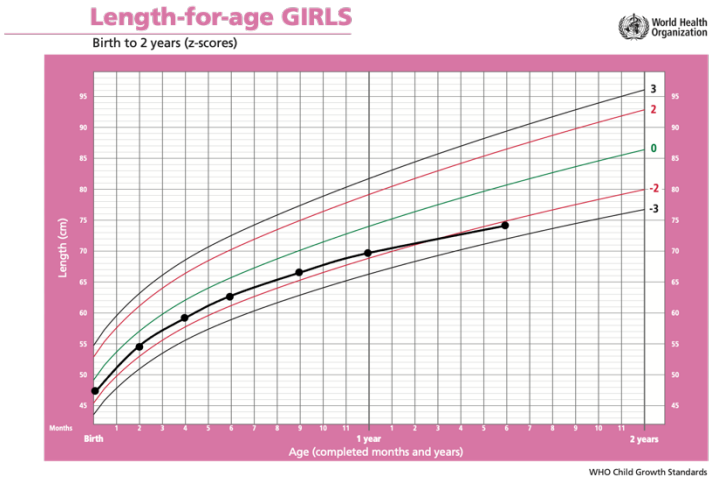
Name: Aisha

Sex: Girl

Age: 18 months

Disability: Down syndrome

Aisha's weight and length were within average ranges for the first year of life. Over the past 6 months, her length has dropped from the -1 z-score line to slightly below the -2 z-score line. She experiences some constipation. She's otherwise healthy, with good appetite and energy.



Answers

Do you expect this child to grow differently as part of their condition?

Yes, Down syndrome is a genetic condition that directly affects stature. As a result, children with Down syndrome are typically shorter than other children of the same age. In this case, the child's condition, which is not something we can modify, most likely plays the biggest role in her linear growth.

Are you concerned about the child's growth? Why or why not?

Given that short stature is a natural part of Down syndrome and that she is overall healthy with good energy, I'm not as concerned about her growth pattern. I would still want to monitor her growth closely and ensure that her weight gain remains consistent over time.

What other information should you consider when interpreting this child's growth?

Weight-for-length growth chart – does her weight gain stay consistent over the years?

Quality of her diet – does it have enough calories and protein to support her growth?

Fiber and fluid intake – is her diet rich in fiber and does she drink enough fluids? While this may not help me interpret her growth, it can inform dietary recommendations to manage constipation before it becomes severe and lead to poor appetite.

Case Scenario 3: Sudden weight loss

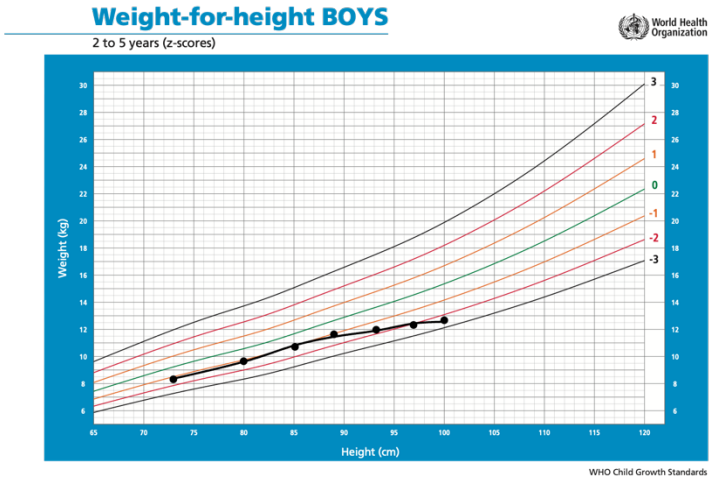
Name: Ziad

Sex: Boy

Age: 4 years

Disability: Autism

Ziad has become extremely selective about food over the past year, eating mostly dry, crunchy foods. He refuses fruits and vegetables and often skips meals altogether. His mother reports that he has lost noticeable weight, and his weight for height has dropped from the -1 z-score line to below the -2 z-score line.



Answers

Do you expect this child to grow differently as part of their condition?

No, while children with autism can have nutrition and feeding concerns that place them at an increased risk for faltering growth, the disability itself does not necessarily alter growth patterns. Therefore, poor growth in this case is something that can be addressed and managed.

Are you concerned about the child's growth? Why or why not?

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Yes, his growth pattern shows a sharp decline, which is concerning. According to his most recent growth weight-for-height point (below the -2 z-score line), he has wasting. If his selective eating is not addressed effectively, his growth may continue to falter.

What other information should you consider when interpreting this child's growth?

Height-for-age growth chart – has he grown consistently in height over the years?

Food intake – what does he typically eat? How much? Does his diet contain energy-dense and nutrient-dense foods to support growth?

Illnesses – has he experienced any recent illnesses that are contributing to his poor growth?

Nutritional supplements - is he receiving any supplements (protein/energy, vitamins or minerals)

Medications – is he on any medications that affect nutrient absorption?

Feeding practices – how is his mother addressing his feeding difficulties? What are mealtimes like?

Case Scenario 4: Rapid weight gain

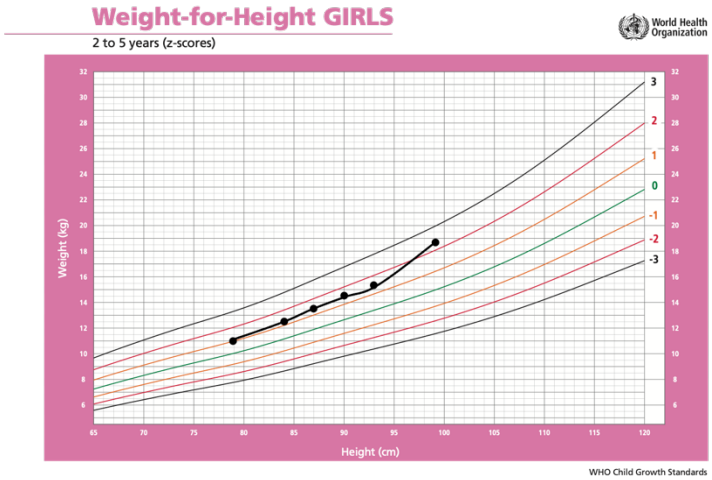
Name: Aya

Sex: Girl

Age: 5 years

Disability: Spina bifida

Aya's weight has jumped from the +1 to the +2 z-score over the past year, though her height has remained around the -2 z-score line. She has limited physical activity and prefers high-calorie, high-sugar foods. Her caregiver says she snacks often and is rarely hungry for lunch and dinner.



Answers

Do you expect this child to grow differently as part of their condition?

Yes, spina bifida may cause disproportionate growth of the lower body resulting in short stature. It's also often associated with a growth hormone deficiency, which slows metabolism, increasing

the risk of unintended weight gain. In this case, the child also has limited physical activity, which can contribute to unintended weight gain. Also, because of the short stature, we expected to see a growth point that is high on the chart when plotting weight relative to height. In this case, growth is altered in part by the disability itself but there also factors that we may be able to manage – a growth hormone deficiency can be managed medically and the disability – associated limited mobility could be addressed with physical therapy.

Are you concerned about the child's growth? Why or why not?

Yes, her growth pattern shows a sharp incline. If her weight does not stabilize, this can be concerning. Her limited physical activity combined with her preference for high-calorie- and high-sugar foods put her at a high risk for unintended weight gain and potentially overweight/obesity.

What other information should you consider when interpreting this child's growth?

Height-for-age growth chart (if height can be measured accurately), has she grown consistently in height over the years?

Food intake – what does she typically eat? How much? Does her diet contain energy-dense and nutrient-dense foods to support growth?

Growth hormone therapy – is she receiving growth hormone therapy?

Physical therapy - is she receiving physical therapy to help increase her mobility and access to physical activities she enjoys?

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ACTIVITY HANDOUT: DEVELOPMENTAL MILESTONE SORTING ACTIVITY

[MODULE 4: Feeding Difficulties in Infants and Children with Disabilities]

Makes sounds and noises Language/Communication	Copies sounds Language/Communication	Says single words Language/Communication
Speaks in short phrases Language/Communication	Asks simple questions Language/Communication	Tracks objects with eyes Cognitive

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Reaches for toys with one hand Cognitive	Looks for objects that you hide Cognitive	Pretends during play such as feeding a doll Cognitive
Sorts shapes and colors Cognitive	Recognizes parents Social/Emotional	Smiles Social/Emotional
Copies actions Social/Emotional	Plays near others Social/Emotional	Participates in group activities Social/Emotional

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[Demonstration set (1 copy)]

Rolls Physical/Movement	Sits Physical/Movement	Crawls Physical/Movement
Walks Physical/Movement	Runs Physical/Movement	

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ACTIVITY HANDOUT: DEVELOPMENTAL MILESTONE SORTING (ANSWERS)

[MODULE 4: Feeding Difficulties in Infants and Children with Disabilities]

Physical/Movement:

1. Rolls
2. Sits
3. Crawls
4. Walks
5. Runs

Cognitive:

1. Tracks objects with eyes
2. Reaches for toys with one hand
3. Looks for objects that you hide
4. Pretends during play such as feeding a doll
5. Sorts shapes and colors

Social/Emotional:

1. Recognizes parents
2. Smiles
3. Copies actions
4. Plays near others
5. Participates in group activities

Language/Communication:

1. Makes sounds and noises
2. Copies sounds
3. Says single words
4. Speaks in short phrases
5. Asks simple questions

HANDOUT: DEVELOPMENTAL MILESTONES UP TO 2 YEARS

[MODULE 4: Feeding Difficulties in Infants with Disabilities]

	2 months	4 months	6 months	9 months	12 months	18 months	2 years
Social & Emotional	• Starts to smile • Attempts to look at parents	• Smiles spontaneously • Tries copying movements and facial expressions	• Is often happy • Starts to differentiate familiar faces and strangers • Enjoys playing	• Has fear of strangers • Reaches for favorite toys	• Cries when parents leave • Is shy around strangers • Helps with dressing	• Shows affection to familiar people • Points to show interest • Has some tantrums	• Copies adults and other children • Is more independent
Language	• Alerts and turns to sounds • Makes cooing noises	• Cries different for hunger, pain, or tired • Babbles and copies sounds	• Responds to name • Makes sounds to show emotions	• Points with fingers • Understands "no" • Copies movements and sounds	• Says basic words like “mama” • Babbling sounds like speech • Responds to simple requests • Tries to repeat words	• Shakes head “no” • Says several single words • Points to what he wants	• Says short sentences • Knows some body parts • Recognizes familiar people • Follows simple instructions

Brain Development	• Starts to track with eyes • Gets fussy if bored • Pays attention to faces	• Is responsive to affection • Tracks moving objects • Reaches for toys with one hand	• Is curious, looks at and tries to grab objects • Passes objects from one hand to the other • Brings hands to mouth	• Looks for things you hide • Tracks objects as they fall • Puts objects in mouth • Picks up small objects with thumb and index finger	• Copies movements • Uses objects correctly • Follows simple directions • Puts objects in/out of containers	• Recognizes everyday objects • Pretends to feed favorite toys • Points to body parts • Follows one-step commands	• Sorts shapes and colors • Completes sentences in familiar stories • Follows two-step instructions
Movement & Physical	• Has smoother arm and leg movements • Pushes up while on belly and holds head up	• Brings hands to mouth • Holds head up without support • Rolls onto back • Pushes down on legs when feet on firm surface • Shakes a toy	• Sits with minimal support • Rolls in both directions • Pushes down on legs when feet on firm surface	• Gets into sitting • Sits without support • Pulls up to stand • Starts to crawl	• Takes few steps without support • Pulls up to stand • Walks while holding onto furniture	• Can walk alone • Can help undress • May start walking up stairs • Pulls toys while walking	• Can run, kick a ball and throw a ball over head • Climbs up and down without help
Feeding & Nutrition	• All nutrition needs met by breastmilk. • Easily sucks and swallows to feed. • Tongue moves back and forward	• Begins to signal hunger by putting hands near mouth	• Shows interest in food • Opens mouth when fed • Moves food from front to back of mouth • Easily eats smooth pureed foods	• Easily eats thicker, mashed foods • Stays full for longer periods • Reacts strongly to new smells and tastes	• Eats a variety of foods • Easily eats soft & bite-size textures • Learns to eat on own • Chews food • Learns to use an open cup	• Eats regular foods, except very difficult to chew foods • Can hold and drink from a cup	• Chews with full jaw movements • Eats regular foods and mixed textures • Uses utensils with some spills

Child Development Milestone chart compiled and adapted based on UNICEF's Developmental Milestone resources:
Child development. UNICEF Parenting. (n.d.). Retrieved December 1, 2022, from: https://www.unicef.org/parenting/child-development
Images accessed from Save the Children's CHW MAMI Screening Tool and the USAID Advancing Nutrition-UNICEF IYCF Digital Image Bank: iycf.advancingnutrition.org

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ACTIVITY HANDOUT: FEEDING SCREENING SCENARIOS

[MODULE 4: Feeding Difficulties in Infants and Children with Disabilities]

For each scenario, consider: Is it appropriate for the child's age? Is it appropriate for the child's stage of development? Does it affect the child's safety?

Feeding Scenario	Is this appropriate for the child? Explain
1. A two-year-old child eats independently with some help from a caregiver.	
2. A three-month-old infant is being fed food from a spoon.	
3. A three-year-old child has not yet been offered liquids from a cup.	
4. A four-year-old child with cerebral palsy eats only puree and mashed food textures. The child has motor delays and cannot yet walk.	
5. A six-year-old child with Down syndrome takes more than 45 minutes to finish a meal.	

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ACTIVITY HANDOUT: FEEDING SCREENING SCENARIOS (ANSWERS)

[MODULE 4: Feeding Difficulties in Infants and Children with Disabilities]

For each scenario, consider: Is it appropriate for the child's age? Is it appropriate for the child's stage of development? Does it affect the child's safety?

Feeding Scenario	Is this appropriate for the child? Explain
1. A two-year-old child eats independently with some help from a caregiver.	*Answer:* Yes. *Notes:* A child this age should eat independently, or with some help. They will benefit from opportunities to practice self-feeding to continue developing independence Why might a 2-year-old not yet be independent? • The child may not yet have the skills to eat more independently. • If the child has never been given the opportunity, skills may be delayed. • If the child has other conditions that have interrupted typical development, skills may be delayed. • The child may have deficits due to a condition that affects body structures or limits body function.
2. A three-month-old infant is being fed food from a spoon.	*Answer:* No. *Notes:* A child this age should be exclusively breastfed until 6 months of age. Infants who are unable to breastfeed may be fed breastmilk using an alternative method, like cup, spoon, or, if proper sanitation is possible, infant bottles. Complementary foods should not be introduced until 6 months of age and when the child can sit with minimal or no support. Spoon feeding foods at this age may suggest difficulty with breastfeeding. This would be a good opportunity to counsel the child's mother on breastfeeding and responsive feeding that supports optimal growth and nutrition.
3. A three-year-old child has not yet been offered liquids from a cup.	*Answer:* No.

	Notes: A child this age should be able to drink liquids from a cup. You can offer support to caregivers to introduce cup drinking and practice skills, but more in-depth assessment or observation may be required to help you understand why the child has not yet transitioned to cup drinking. This could be due to limited opportunities, delayed introduction, delayed feeding skills, or other difficulties.
4. A four-year-old child with cerebral palsy eats only puree and mashed food textures. The child has motor delays and cannot yet walk.	*Answer:* No. And yes. *Notes:* A child this age should typically be able to eat all food textures. However, we know that this child likely has motor delays. This can affect his ability to move the key parts of his mouth in order to be able to chew foods. In that case, the textures may actually be appropriate for the child's development. That is, the texture matches his feeding skills. More in-depth assessment will be necessary to provide important information about his feeding difficulties and to identify strategies to support safety, efficiency, and build skills for effective and safe eating.
5. A six-year-old child with Down syndrome takes more than 45 minutes to finish a meal.	*Answer*: No. *Notes:* Mealtime for all children, regardless of age or stage of development, should last about 20-30 minutes. Anything longer than that would be considered a prolonged mealtime. Prolonged mealtimes reduce efficiency and the child may not be able to meet their nutritional needs. More in-depth assessment and observation will be required to help you understand the reason for prolonged meals. It may indicate that the child does not yet have the skills to eat the food offered. Perhaps the mealtime is prolonged because the child requires more help than is being offered.

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HANDOUT: FEEDING DIFFICULTIES SCREENING CHECKLIST

[MODULE 4: Feeding Difficulties in Infants and Children with Disabilities]

Instructions: For children 0 to 5 years of age, ask each question to the primary caregiver who most often feeds the child. Concerns identified in **two or more** areas suggest increased risk for feeding difficulties.

Screening Checklist			
Question	**Yes**	**No**	**Comments:**
Hunger and Fullness Cues **Does the child let you know when they are hungry or full?**			
Enough Food **When there is enough food available, do you think the child eats enough?**			
Duration **Does the child usually take about the same amount of time to feed as other children the same age?**			
Respiratory Problems **Are there frequent signs of airway or respiratory problems?**			
Effort **Do you often need to put in extra effort to get the child to eat?**			
Growth **Over the past month, do you think the child has lost weight or did not gain enough weight?**			
Mealtime Stress **Are mealtimes stressful for you and/or the child?**			
Caregiver Concerns **Do you have concerns about the child's feeding?**			

Notes or observations:

Color Key:

This aspect of feeding is going well	Possible area of concern or sign of difficulty	Red flag, consider referral for further medical evaluation

References:
Arvedson, J. (2017, October 27). Evaluation Feeding and Swallowing Disorders in Infants and Children. Lecture.
Silverman et al (2020). (Silverman AH, Kristoffer BS, Linn C, et al. Psychometric Properties of the Infant and Child Feeding Questionnaire. Journal of Pediatrics. 2020 August; 223:81-86.e2. DOI: 10.1016/j.jpeds.2020.04.040.)

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HANDOUT: FEEDING DIFFICULTIES SCREENING CHECKLIST

[MODULE 4: Feeding Difficulties in Infants and Children with Disabilities]

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Screening Checklist			
Question	**Yes**	**No**	**Comments:**
Hunger and Fullness Cues **Does the child let you know when they are hungry or full?**			
Enough Food **When there is enough food available, do you think the child eats enough?**			
Duration **Does the child usually take about the same amount of time to feed as other children the same age?**			
Respiratory Problems **Are there frequent signs of airway or respiratory problems?**			
Effort **Do you often need to put in extra effort to get the child to eat?**			
Growth **Over the past month, do you think the child has lost weight or did not gain enough weight?**			
Mealtime Stress **Are mealtimes stressful for you and/or the child?**			
Caregiver Concerns **Do you have concerns about the child's feeding?**			

Notes or observations:

Color Key:

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HANDOUT: BREASTFEEDING POSITIONS

[MODULE 5: Strategies to Address Feeding Difficulties for Infants with Disabilities]

Position	Best for
Cradle 	• Full-term or larger infants • Infants with breastfeeding already established • Mothers and infants who are comfortable in this position
Underarm 	• Infants with low tone • Infants with tight or small jaw • Feeding twins • A good view of the infant's latch • Mothers and infants who are comfortable in this position
Cross cradle 	• Small infants or newborns • Infants in need of positioning support • Infants with weak suck • Mothers and infants who are comfortable in this position

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Reclined 	• Supporting a deep latch • Skin to skin and closeness to help calm an infant • Mothers and infants who are comfortable in this position
Side lying 	• Larger infants • Tired mothers • Mothers and infants who are comfortable in this position
Upright 	• Older infants • Infants with difficulty coordinating suck-swallow-breathe • Infants with frequent reflux • Infants with tongue tie • Infants with low tone • Infants with cleft lip • Mothers and infants who are comfortable in this position

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ACTIVITY HANDOUT: APPLYING STRATEGIES DURING FEEDING

[MODULE 5: Strategies to Address Feeding Difficulties for Infants with Disabilities]

Condition	Anticipated challenges during feeding	Recommended position or strategy	Reason for recommendation
Down syndrome	Low muscle tone May tire quickly A weak seal and uncoordinated sucking May need support for positioning. Reduced sensation 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.		
Cleft lip	If associated with a syndrome, there could be further complications. 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. May lose milk from the mouth frequently due to the opening.		

Cerebral palsy	Likely to have issues with muscle tone. For high muscle tone, the stiffness may impact how the infant moves their tongue, jaw, and lips Infant may need support to achieve a stable and safe position. Difficulty opening the mouth wide enough or opening it too wide, making it difficult to achieve and maintain a good latch. May be at high risk for aspiration.		
Spina bifida/ hydrocephalus	The impact of spina bifida and/or hydrocephalus can vary widely. Infant's movement skills may be impacted, which could mean the infant requires support for body positioning. Infant may have difficulty achieving and maintaining good attachment and to suck effectively. Frequent vomiting or reflux possible.		

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ACTIVITY HANDOUT: APPLYING STRATEGIES DURING FEEDING (ANSWERS)

[MODULE 5: Strategies to Address Feeding Difficulties for Infants with Disabilities]

Condition	Anticipated challenges during feeding	Recommended position or strategy	Reason for recommendation
Down syndrome	Low muscle tone May tire quickly A weak seal and uncoordinated sucking May need support for positioning. Reduced sensation 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.	Cross cradle position Underarm position Dancer hold Breast compressions	A **cross cradle position** could provide good support for positioning. An **underarm position** may give mother a good view of the infant's attachment and provide good support for positioning. The **dancer hold** supports the jaw and cheeks and helps maintain a lip seal around the breast **Breast compressions** may encourage continued sucking if the infant's suck is weak or fatigues quickly.
Cleft lip	If associated with a syndrome, there could be further complications. 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. May lose milk from the mouth frequently due to the opening.	Dancer hold Upright position Breast compressions	The **dancer hold** supports the jaw and cheeks and helps maintain a lip seal around the breast The **upright position** may help direct the flow of the milk and reduce the amount of milk the infant loses out of the mouth or nose **Breast compressions** may encourage continued sucking if the infant's suck is inefficient and fatigues quickly.

Cerebral palsy	Likely to have issues with muscle tone. For high muscle tone, the stiffness may impact how the infant moves their tongue, jaw, and lips Infant may need support to achieve a stable and safe position. Difficulty opening the mouth wide enough or opening it too wide, making it difficult to achieve and maintain a good latch. May be at high risk for aspiration.	Cross cradle position Underarm position Dancer hold	A **cross cradle position** could provide good support for positioning for an infant with high tone that makes it difficult to maintain body position. **Underarm position** may improve jaw opening for a jaw that is tight due to high tone. For excessive jaw opening, use the **dancer hold** to support the jaw and cheeks and help maintain a lip seal around the breast.
Spina bifida/ hydrocephalus	The impact of spina bifida and/or hydrocephalus can vary widely. Infant's movement skills may be impacted, which could mean the infant requires support for body positioning. Infant may have difficulty achieving and maintaining good attachment and to suck effectively. Frequent vomiting or reflux possible.	Cross cradle position Upright position Side-lying position	A **cross cradle position** could provide good support for positioning the infant's body. An **upright position** could be helpful for an infant with frequent vomiting or reflux. A **side-lying position** may be helpful for an infant with hydrocephalus because it provides support to an infant's head.

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ACTIVITY HANDOUT: COMMUNICATION FOR FEEDING SORTING CARDS

[MODULE 6: Strategies to Address Feeding Difficulties for Children with Disabilities]

Mouth open	Looking at feeder
Mouth empty	Awake and alert

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Bringing hands to mouth	Leaning forward
Falling asleep	Crying

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Turning or leaning away	Spitting out or pushing food away
Mouth full of food	Mouth closed

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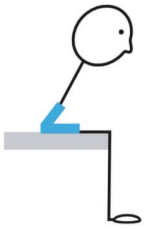
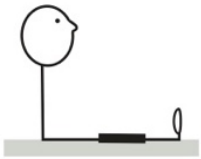
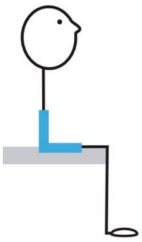
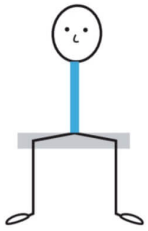
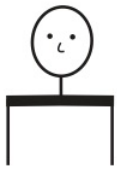
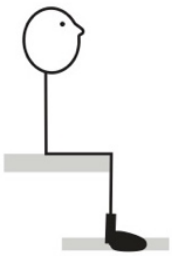
ACTIVITY HANDOUT: OBSERVING POSITIONING CARDS

[MODULE 6: Strategies to Address Feeding Difficulties for Children with Disabilities]

Position 1: Child seated on the floor leaning forward		
Hips	**Trunk**	**Shoulders**
		
Head	**Knees**	
		

Position 2: Child seated in a chair		
Hips	Trunk	Shoulders
		
Head	Knees	Feet
		

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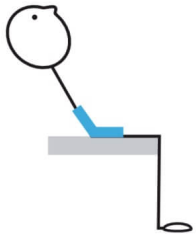
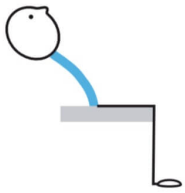
Position 3: Child seated in reclined position with chin up and shoulders raised		
Hips	**Trunk**	**Shoulders**
		
Head	**Knees**	

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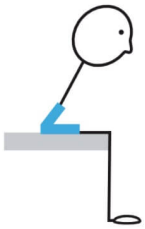
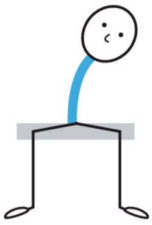
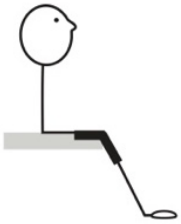
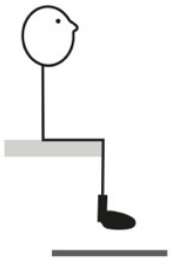
Position 4: child seated leaning to one side		
Hips	**Trunk**	**Shoulders**
		
Head	**Knees**	**Feet**
		

Position 5: child lying flat on the ground

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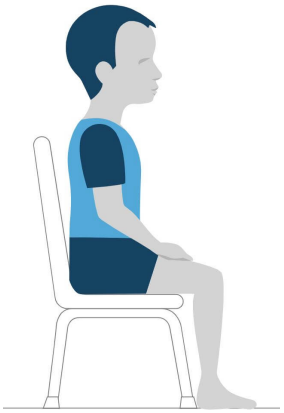
HANDOUT: STRATEGIES TO ADDRESS POSITIONING

[MODULE 6: Strategies to Address Feeding Difficulties for Children with Disabilities]

POSITION THE CHILD AS UPRIGHT AS POSSIBLE



- **Hips** all the way back in the seat, at about a 90-degree angle, with weight evenly on both sides of buttocks
- **Trunk** in a straight line up from hips
- **Shoulders** relaxed and the same on both sides
- **Head** upright and neutral position
- **Knees** bent comfortably over edge of chair with thighs supported
- **Feet** rest flat on a firm surface

MAINTAIN THE IMPROVED POSITIONING

Some children are not able to maintain proper positioning on their own. Children with disabilities that affect their body movement or posture may need support in different positions to make feeding safer.

Try using objects that are easy to find to provide additional support. This includes scarves, towels, pillows, boxes, stools, and even your own body.

NOTE: Make changes with care and observe child for signs of distress. Changing position too quickly can be harmful.

Hips

Use a seatbelt (scarf, towel, or strap) positioned down and back and secured low, across the hips.

Trunk

Use small pillows or rolled towels along both sides of the trunk.

Shoulders

Adjust the chair, table, or tray to allow the child to rest their arms and elbows.

Head

Use shaped pillows or rolled towels placed along both sides of the head or a head rest.

Knees

If the seat is too deep, add a cushion behind the child to bring them forward in the seat.

Feet

Use a footrest, stool, or box if the child's feet cannot rest flat on the floor.

All illustrations from SPOON

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ACTIVITY HANDOUT: ADAPTIVE FEEDING TOOLS CARDS

[MODULE 6: Strategies to Address Feeding Difficulties for Children with Disabilities]

Purpose: prevents food from falling out of container or off spoon while scooping

Purpose: easier to hold

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Purpose: prevents spilling

Purpose: Easier to deliver food to mouth without spilling

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Purpose: Easier to tilt cup to sip; encourages neutral head position for drinking

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Purpose: prevents dish from sliding during self-feeing

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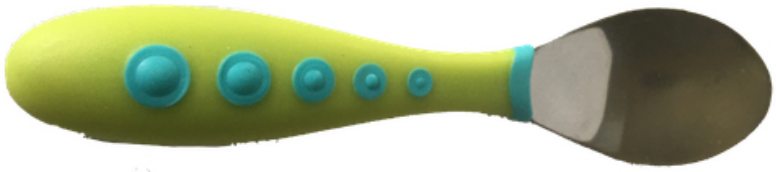

Purpose: easier to hold

Purpose: attaches utensil to the hand so it is not easily dropped

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HANDOUT: ADAPTIVE FEEDING TOOLS

[MODULE 6: Strategies to Address Feeding Difficulties for Children with Disabilities]

When a child has feeding difficulties or delayed feeding skills, there are many ways to make mealtimes safe and efficient and to help the child build skills.

Specialty equipment or tools can be a valuable way to provide additional support to a child with feeding difficulties so they can participate in mealtime or build independence with feeding themselves. Adaptive feeding tools should facilitate eating as independently as possible.

Adaptive technology refers to special versions of already existing technology or tools that allow one to perform tasks with greater ease or independence. Adaptive feeding tools are one type of assistive technology.

Adaptive Tool	Purpose	For Whom
Curved spoon		
	Easier to deliver food to the mouth without spilling	For a child who has some, but limited, ability to move the arm to bring food toward the mouth
Utensil with large handle		
	Easier to hold	For a child who does not have a strong enough grip to hold a typical utensil
Utensil holder or strap		
	Attaches utensil to the hand so it is not easily dropped	For a child with limited or no strength to hold a utensil
Cup with lid		
	Prevents spilling	For a child who spills while lifting the cup to the mouth or who overfills the mouth

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Cut-out cup

	Easier to tilt cup for a sip and encourages neutral head position for drinking	For a child who frequently tilts the head back to drink or with limited ability to raise arms to lift cup

Cup with handle(s)

	Easier to hold	For a child who does not have a strong grip to hold a cup

Non-slip pad or mat

	Prevent dish from sliding during self-feeding	For a child who has difficulty using both hands, one to hold the dish and the other to scoop the food

Adaptive bowls or plates

	Prevent food from falling out of container or off spoon while scooping	For a child with difficulty scooping food onto utensils

Creative solutions: In some places specialty tools and equipment can be difficult to find or too expensive. Understanding the purpose of the adaptive tools may help you come up with creative ways to modify the tools you do have. For example:

- Build up the handle of a spoon using foam tubing, strips of fabric, tape, or other materials.
- Create a cut-out cup by cutting a disposable cup with scissors.
- Use a rubber band or hair tie as a strap to attach a utensil to a child's hand. Make sure the band is not too small so that it fits comfortably on the child's hand.

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ACTIVITY HANDOUT: DISABILITY-INCLUSIVE NUTRITION AND FEEDING SCENARIOS

[MODULE 7: Practicing Disability-Inclusive Nutrition and Feeding Support]

Scenario Letter	What are the risk factors for the mother and child?	Feeding Difficulties Screening Checklist	Identify TWO priority issues	Strategies, adaptations, and counselling cards (if applicable)	Any other support needed? (e.g., referrals)

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ACTIVITY HANDOUT: DISABILITY-INCLUSIVE NUTRITION AND FEEDING SCENARIOS (ANSWERS)

[MODULE 7: Practicing Disability-Inclusive Nutrition and Feeding Support]

Scenario Letter	What are the risk factors for the mother and child?	Feeding Difficulties Screening Checklist?	Identify TWO priority issues	Strategies, adaptations, and counselling cards (if applicable)	Any other support needed? (e.g., referrals)
A	• 4-month-old girl with suspected disability • High muscle tone • Feeding difficulties • Poor growth – child has severe malnutrition according to WAZ and MUAC. Causes likely include low intake due to feeding difficulties, increased energy demand due to high muscle tone, and possibly poor nutrient absorption due to stress.	Long feeding duration Mealtime stress Mother concerned about feeding	1. Address feeding difficulties 2. Address poor growth	Use strategies to manage tone. **Swaddling** may be a good strategy to suggest to the mother to help support stable positioning for breastfeeding. Work with mother to identify positioning that is supportive for an infant with high tone and helpful to improve the infant's latch. The **cross-cradle** position may provide good support to the baby and the **underarm** position will give the mother a good view of her latch, good support for positioning, and may improve jaw opening if the infant's jaw is tight due to high tone. Counsel mother to learn and **follow the infant's cues** to begin breastfeeding at the earliest hunger signs. And to end feeds when the infant is becoming fatigued. May consider shorter,	Enrol for counselling. Referrals needed: • Pediatric assessment of failure to thrive and to assess the need for supplemental feeding. • Mental Health & Psychosocial Support (MHPSS) assessment for the mother. • Health & ECD services to address mother's concerns about the child's growth and development.

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				more frequent feeds if needed. C-IYCF Counselling Cards for Breastfeeding Positions (Card 6) and Good Attachment (Card 7) Infant is severely malnourished based on WAZ and MUAC: →Assess ability to measure length safely and accurately because of stiffness. If possible, measure length and review length-for-age growth chart to assess linear growth and weight-for-length to evaluate wasting using with second indicator (in addition to MUAC).	A follow-up should be scheduled in 2 weeks.
B	• 14-month-old boy • Congenital condition: Down syndrome • Signs of aspiration • Moderate malnutrition/at risk for poor growth based on MUAC. Causes may be linked to feeding difficulties – coughing/choking is associated respiratory illness, which increases energy/nutrient needs. Meal frequency meets the	Frequent coughing during feeding Mealtime stress Concerns for feeding	1. Address safety to reduce or eliminate signs of aspiration 2. Address feeding difficulties	Make sure the child is as upright as possible for feeding. Counsel mother on **proper positioning** for feeding Make sure mother provides **food textures** that **match the child's feeding skills**. Counsel mother on how to modify nutrient-dense foods to the appropriate texture to match child's skills. Counsel mother on strategies to	Enrol in counselling. Referrals needed: • Pediatric assessment of frequent signs of aspiration may. • Due to the high rate of heart issues for children with Down syndrome,

	minimum but may need to be higher if the child has increased needs. *Note: Children with Down syndrome are typically short for their age because of the disability itself. This could explain why WFL Z-score is ≥ -2 while MUAC indicates risk. When length is low, a weight for length growth point may appear in the normal range on a growth chart. Growth needs to be interpreted carefully given that the disability alters growth patterns.*			help the child build skills for feeding including providing **physical support** to participate in feeding activities and **opportunities to practice** at the appropriate level for the child. While MUAC indicates moderate/at risk for malnutrition, addressing the safety concerns is a priority and may resolve issues around malnutrition. Counselling should include 1) information on **energy-dense foods that are also high in nutrients** (eggs, peanuts, meat, avocado) prepared in the appropriate textures; and 2) **increasing meal frequency** from 3 to 5 by including two nutrient-dense snacks. C-IYCF Counselling Cards for Complementary Feeding from 12 up to 24 Months (Card 15) and Food Variety (Card 16).	referral for further assessment may be necessary if the child has not yet been assessed. Rehabilitation services to determine if child would benefit from physical or occupational therapy services, if possible. • Health & ECD services to address mother's concerns about the child's growth and development. A follow-up should be scheduled in 2 weeks.

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C	• 3-year-old boy • Condition: cerebral palsy • Contractures, child cannot straighten legs • Severe malnutrition based on WFA Z-score and MUAC. Causes include poor dietary intake, increased energy/nutrient needs due to high tone, and poor absorption due to stress *Note: height or length were not measured due to the child's inability to straighten legs.*	Child does not eat enough Mother puts in extra effort to get child to eat Feeding takes a very long time	1. Address feeding difficulties 2. Address poor growth.	Make sure the child is as upright as possible for feeding. Counsel mother on **proper positioning**. Given the child's contractures, make sure the mother understands the principles of **do no harm** as she adjusts the child's positioning or teaches others to do so. Work with mother to **problem solve positioning** and use objects she has readily available to help the child achieve and maintain positioning that is as upright as possible for feeding. Encourage mother to 1) boost the nutritional value of the child's meals without increasing the volume by much. This means selecting energy-dense foods that are also high in nutrients (eggs, peanuts, avocado, meat); and 2) give small, frequent meals. Foods should be prepared in a **texture that matches the child's skills**.	Enrol in counselling. Address mother's beliefs around poor growth being a part of the disability. Referrals needed: • Physical or occupational therapy, if possible. • Pediatric assessment of severe malnutrition. • Social protection services/cash transfers to address food insecurity. A follow-up should be scheduled in 2 weeks.

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D	• 20-month-old girl with suspected feeding difficulties • Mother who is blind or partially sighted • Child's growth is okay based on MUAC and WFL Z-score	Feeding takes a long time Feeding is stressful for child and mother More effort is required to get child to eat compared to children the same age; child is easily distracted	1. Address feeding difficulties 2. Address mother's mental health and support needs	Counsel mother on strategies to support the child to build skills for feeding. **Skill building strategies** may need to be adapted to rely more on tactile, audio, or other non-visual support. Engage mother in identifying strategies or ideas to offer **opportunities to practice** and **model** skills. Counsel mother on **responsive feeding** strategies. The mother may need additional support or problem-solving to implement strategies that rely on tactile, audio and other non-visual cues. Counsel mother on strategies to **modify the environment** and reduce distractions during feeding. Counsel mother to provide support and reassurance. Mother expressed a number of worries about feeding and shared about her isolation within her community. Praise mother on the child's diverse diet.	Enrol for counselling. Refer mother for MHPSS assessment. A follow-up should be scheduled in 1 month.

IYCF FULL ASSESSMENT FORM: 0-23 MONTHS

SCENARIO A

1. COLLECT BASIC INFORMATION

Counsellor's ID	*111*	Location		Date of assessment	*05/06/25*
Caregiver's name	*Abeer*	Relationship to child	Mother/Father/Grandmother/Sibling/Other: _____		
Child's name	*Lama*	Sex	Male/Female	Child's ID No.	*101*
Child's D.O.B.	*01/02/25*	Child's age	*4* months	Caregiver's age	*25* years
				Is caregiver an adolescent?	❑ Yes ❑ No
Caregiver's name		Relationship to child			
Facility ID	*12*	Facility name		District	*Akkar*
Source of referral	❑ Self-referral ❑ SRA – from_____ service ❑ No SRA – direct from_____ service				
Is the child living with disability that impacts feeding or access to care?	If yes, please describe: *Suspected disability, tight muscles. Stiff a lot of the time. Feeding has been a struggle.*	Is the mother or primary caregiver living with disability that impacts feeding or access to care?	If yes, please describe: *No*		
No. of previous children:	*0*	No. of previous breastfed children:	*0*		
MUAC *(if measured)*	*109.1 mm*	WFA/WFL Z-score	*WFA<-3 Z-score*		

Anthropometric Assessment Table for Infants Aged 6 Weeks to 5 completed months and 6 months to 23 completed months

MUAC 6 weeks to 5 completed months			
Indicator	Severe	Moderate / At Risk	Normal
Mid-Upper Arm Circumference (MUAC)	< 110 mm	Not well defined*	≥ 110 mm (not at risk)**
MUAC 6 to 59 months			
Mid-Upper Arm Circumference (MUAC)	<115mm	≥ 115 to >125	≥ 125
All children birth to 59 months			
Weight-for-Length Z-score (WLZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Weight-for-Age Z-score (WAZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Bilateral pitting oedema	Present (regardless of other indicators)	—	Absent

** MUAC thresholds for moderate risk in 0–6 months are not standardized globally; use MUAC <110 mm as an indicator of severe risk only per 2023 WHO guideline.*
*** MUAC alone should not be used for monitoring or discharge in infants <6 months. Combine with clinical signs, weight gain, and feeding assessment*

2. CHECK FOR DANGER SIGNS[2]

Lethargic/unconscious?	❑ Yes	❑ No
Vomits everything?	❑ Yes	❑ No
Unable to drink/breastfeed?	❑ Yes	❑ No
Difficulty breathing? (respiration rate, chest indrawing)	❑ Yes	❑ No
Low or high temperature? (< 35.5 or ≥ 38°C)	❑ Yes	❑ No
Bilateral pitting oedemata? (+/++/+++)	❑ Yes	❑ No
Caregiver appears out of touch with reality or infant appears to be at risk from caregiver's behaviour?	❑ Yes	❑ No

ACTION: IF ANY MARKED AS YES → URGENT REFERRAL TO HEALTH SERVICES BEFORE CONTINUING IYCF ASSESSMENT

3. ASK ABOUT FEEDING PRACTICES

Please tell me about your experiences of feeding your baby. What concerns or questions would you like to discuss today?	*Stiff a lot of the time. Feeding has been a bit of a struggle for mother. Trouble breastfeeding, hard to get her to take in enough. Mother worried about her weight gain and is experiencing a lot of stress.*

What and how is the baby fed? *(Select all that apply)*	❑ Breastfeeding – at mother's breast ❑ Expressed breastmilk – mother's own ❑ Expressed breastmilk – informally shared ❑ Donor human milk ❑ Breastfed by a woman who is not the child's mother ❑ Some artificial feeding (BMS) ❑ Fully artificially fed (BMS) ❑ Fully artificially fed (BMS)
	❑ Bottle ❑ Spoon ❑ Cup

Does the baby eat or drink anything other than breastmilk?[3]	❑ **Yes**	❑ **No**
(If yes) What else do you give the baby?	❑ Infant formula ❑ Other milks ❑ Water ❑ Tea/coffee ❑ Sugary drinks/soda ❑ Juice: _____ ml/cups Medicine ❑ Food ❑ Other[4]: ____	

ACTION: IF NON-BREASTFED OR PARTLY BREASTFED → COMPLETE FULL ASSESSMENT – NON-BREASTFED CHILD CARE PLAN

Do you use a pacifier for the baby?	❑ **Yes**	❑ **No**
Is the baby currently sick?	❑ **Yes**	❑ **No**

***(If sick)* Since your baby has been sick, have there been any changes in the way you have been feeding?**

Breastfeeding	❑ More/no change	❑ Less often	❑ Stopped
***(If 6-23 months)* Complementary feeding**	❑ More/no change	❑ Less often	❑ Stopped
Extras	❑ Extra nutritious food	❑ Infant formula	

4. CHECK DIAPER OUTPUT

How many wet diapers does baby have in 24 hours?	*5* _____ times		
Does the baby's urine have a strong smell or colour?	❑ **Yes**	❑ **No**	
How many soiled diapers does baby have in 24 hours?	*2* _____ times[5]		
Have there been any recent changes from usual?	❑ Less frequent stooling	❑ Diarrhoea	❑ No changes

ACTION: IF DIAPER OUTPUT IS LOW/CONCERNING → EXPLORE POSSIBLE LOW MILK SUPPLY
ACTION: IF CHILD HAS DIARRHOEA → REFER TO HEALTH SERVICES

5. ASK ABOUT BREASTFEEDING/BREASTMILK FEEDING

How often do you breastfeed/feed your baby breastmilk?	*5* _____ times total	*1* _____ times in the night
How do you decide when to feed your baby?	❑ Responsive	❑ Scheduled
***(If breastfeeding)* Do you experience any pain or discomfort while breastfeeding?**	❑ **Yes** ❑ Extreme ❑ Moderate ❑ Mild	❑ **No**

6. REQUEST PERMISSION TO OBSERVE THE MOTHER BREASTFEEDING (IF APPLICABLE)

Assess breast health: *Did not assess*	***Colour:*** ❑ Normal ❑ Redness ***Condition:*** ❑ Normal ❑ Shiny ❑ Hard ❑ Warm ❑ Engorged ❑ Damaged nipple ❑ Suspected blocked duct ❑ Suspected mastitis ❑ Suspected thrush ❑ Suspected breast abscess

ACTION: IF THRUSH, BREAST ABSCESS OR MASTITIS → REFER TO HEALTH SERVICES FOR TREATMENT

Signs breastfeeding is going well	Signs of possible difficulty
BODY POSITION ❑ Mother relaxed and comfortable ❑ Mother's back and arms are well supported ❑ Baby's body close, facing breast ❑ Starts feed with baby's nose opposite nipple ❑ Baby's head free ❑ Baby's head and body straight (in line) ❑ Baby's chin touching breast	**BODY POSITION** ❑ Shoulders tense/leaning over baby ❑ Baby's body far away from mother's body ❑ Starts feed with baby's mouth opposite nipple ❑ Baby's head cannot move back freely ❑ Baby's neck twisted/not in line with shoulder and hip ❑ Baby's chin not touching breast
Signs breastfeeding is going well	**Signs of possible difficulty**
RESPONSES ❑ Baby reaches for breast if hungry ❑ [Baby roots for breast] ❑ Baby explores breast with tongue ❑ Baby calm and alert ❑ Baby stays attached to breast ❑ [Signs of milk ejection] – leaking, afterpains	**RESPONSES** ❑ No response to breast ❑ [No rooting observed] ❑ Baby not interested in breast ❑ Baby restless or crying ❑ Baby slips off breast ❑ [No signs of milk ejection] ❑ Mother shows signs of pain/discomfort ❑ Baby coughs/gags/chokes
EMOTIONAL STATE AND BONDING ❑ Secure, confident hold ❑ Eye contact ❑ Mirroring of facial expressions between parent and child ❑ Much touching by mother ❑ Responsive to baby's needs	**EMOTIONAL STATE AND BONDING** ❑ Nervous/limp hold ❑ No eye contact ❑ Shaking or poking baby/breast ❑ Little touching ❑ Struggles to soothe baby when crying
SUCKLING/ATTACHMENT ❑ Mouth wide open ❑ Lower lip turned outwards ❑ Tongue cupped around breast ❑ Cheeks round ❑ More areola above baby's mouth ❑ Slow deep sucks, bursts with pauses ❑ Can see or hear swallowing	**SUCKLING/ATTACHMENT** ❑ Mouth not wide open/points forward ❑ Lower lip turned in ❑ Baby's tongue not seen ❑ Cheeks tense or pulled in ❑ More areola below baby's mouth ❑ Rapid sucks only ❑ Can hear smacking or clicking
END OF FEED ❑ Baby releases breast ❑ Nipple looks normal/round/erect ❑ Baby suckled for 5+ minutes ❑ Mother keeps breast available/offers other breast ❑ Baby's hands are relaxed/open ❑ Baby looks relaxed/satisfied/sleepy ❑ Breasts feel softer	**END OF FEED** ❑ Mother takes baby off breast ❑ Nipple looks creased/squashed/flattened ❑ Baby suckled for <5 minutes ❑ Mother does not keep breast available offer other ❑ Baby's hands are clenched/near face ❑ Baby fusses/cries/appears unsatisfied

Time spent breastfeeding 15 minutes

7. ASSESS MATERNAL/CAREGIVER WELLBEING[6]

Over the last two weeks, have you experienced any of the following feelings?			*(If yes)* Frequency in the last 2 weeks?		
Feeling anxious or worrying uncontrollably	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day
Difficulties coping with daily chores	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day
Little interest or pleasure in doing things that you used to enjoy	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day
Feeling down, depressed or hopeless	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day

On a scale of 1 (very unsupported) to 5 (very supported), how supported to you feel by family and friends in caring for your baby?	1	2	3	4	5

Who do you mostly rely on for support, if anyone?	*Mother*
How does your family feel about you breastfeeding?	*Family thinks breastfeeding is not working, telling mom to start complementary feeding.*

ACTION: IF ANSWERED YES – OFTEN / ALMOST EVERYDAY OR SCORE 1 – 3 ➔ COMPLETE FULL ASSESSMENT **AND REFER FOR MHPSS ASSESSMENT**

Do you have any concerns about the baby's growth and development or level of alertness, compared to other babies of a similar age?	❑ Yes	❑ No

ACTION: IF ANSWERED YES ➔ CONTINUE WITH FULL ASSESSMENT **AND REFER TO HEALTH AND ECD SERVICES**

How is your current health?	*Tired but okay.*

8. ASSESS COMPLEMENTARY FEEDING PRACTICES (6-23 MONTHS. IF UNDER 6 MONTHS, SKIP)

Who helps/assists the child with eating?	
How many times did (name) eat solid, semi-solid or soft foods yesterday during the day or at night? ***Times*_____**	

To meet minimum meal frequency: ***Breastfed children:*** *should receive complementary foods at least twice a day between 6-8 months and at least three times a day between 9-23 months* ***Non-breastfed children****: should receive solid, semi-solid, or soft foods (including milk feeds) at least four times a day.*	Is the child meeting the Minimum Meal Frequency?	❑ Yes	❑ No

Yesterday, during the day and night what did you give your child to eat? *(minimum diet diversity)*	WHAT?	HOW MUCH? (cups/handfuls)	TEXTURE? (thick/thin/ chopped/whole)
Breast milk			
Grains, roots, tubers, and plantains			
Pulses, beans, legumes, lentils, and nuts			
Dairy products (e.g., milk, infant formula, yoghurt, cheese)			
Flesh foods (e.g.; meat, fish, poultry, liver/organ meats)			
Eggs			
Vitamin A rich fruits and vegetables (e.g., spinach, carrots, sweet potatoes, mangoes)			
Other fruits and vegetables			
Check: ≥ 5 food groups?		❑ Yes	❑ No
Did you give your child micronutrient powder (MNP)?		❑ Yes	❑ No
What do you use to feed your child liquids?	❑ Open cup ❑ Cup with spout ❑ Bottle		

At what important times in the day do you wash your hands with water and soap?	❑ Before preparing food ❑ Before eating ❑ Before feeding child ❑ NONE *(if none, understand why and counsel on hand washing)*

Do you wash the child's hands with clean water and soap before they eat?	❑ Yes	❑ No
Have you noticed the child experiencing any difficulties when eating? *(If yes, please check below)*	❑ Yes	❑ No

❑ Coughing/choking ❑ "Wet"/"gurgly" voice breathing ❑ Discomfort ❑ Watery eyes ❑ Changes in colour/breathing

ACTION: IF SIGNS OF POSSIBLE ASPIRATION ARE PRESENT → CONTINUE FULL ASSESSMENT AND REFER FOR PAEDIATRIC ASSESSMENT

9. NOTE DOWN ANY KNOWN RISK FACTORS (e.g., noted when referred)

Child	❑ Premature ❑ Low birth weight ❑ Under 6m with growth failure ❑ Sick ❑ Multiple ❑ Malnourished ❑ Disability impacting feeding ❑ Signs of extreme distress ❑ Maternal orphan ❑ Separated/unaccompanied
Mother/caregiver	❑ Malnourished ❑ Severely ill ❑ Recovering from Caesarean birth/difficult birth ❑ Disability impacting feeding Voluntary disclosure only: ❑ MHPSS difficulties ❑ SGBV survivor ❑ HIV positive ❑ First time mother ❑ Adolescent mother

ACTION: IF RISK FACTOR(S) ARE PRESENT → ENROL FOR COUNSELLING + REFER TO REQUIRED SERVICES

10. NOTE DOWN ANY OBSERVATIONS MADE DURING THE ASSESSMENT

Quality of mother's/caregiver's-child interaction (holding, touching, visual contact, verbal exchange, mirroring, playing)	❑ Poor	❑ Moderate	❑ Good
Child's reaction to the mother's/caregiver's stimulation	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's reaction to the child's calls for attention and need for comfort	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's awareness of child's movements	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's response to child needing correction	❑ Poor	❑ Moderate	❑ Good
Child moves both arms and legs equally		❑ Yes	❑ No
Normal tone and posture		❑ Yes	❑ No
Mother/caregiver requested infant formula		❑ Yes	❑ No

11. COUNSELLING ACTIONS/DECIDE ON CARE PLAN

Possible problems:	
Counselling actions taken:	❑ Positioning and attachment: _____ ❑ Stress management: _____ ❑ Information given on: _____ ❑ Supplies provided: _____ ❑ Referrals made: health/nutrition/MHPSS/ECD/FSL/WASH/other: _____ _____ ❑ Other: _____

Further counselling needed?	❑ Yes	❑ No
ACTION: IF NO → REFER FOR OTHER IYCF SERVICES	❑ Education ❑ Peer group support ❑ Other _____	
Reason for further counselling *(refer to triage tool)*		

Support to be provided

BASIC SUPPORT AND COUNSELLING	ADVANCED SUPPORT AND COUNSELLING
❑ Positioning and attachment ❑ Maternal confidence ❑ Milk expression ❑ Cup/spoon feeding ❑ Flat or inverted nipples ❑ Sore or damaged nipples ❑ Engorgement ❑ Increase/decrease milk production ❑ Restorative care/emotional support ❑ Wet nursing ❑ Breastfeeding in public/crowded spaces ❑ Breastfeeding at night ❑ Infection Prevention Control ❑ Rejecting donations of BMS/feeding bottles/teats ❑ Preparing for crisis/evacuation ❑ Encourage age-appropriate feeding ❑ Complementary feeding ❑ Maternal diet ❑ Other: _____	❑ Manage mastitis/thrush ❑ Manage tongue tie ❑ Breastfeed LBW or preterm infant/KMC ❑ Breastfeeding during maternal/child severe illness ❑ Feeding with a disability impacting feeding ❑ Feeding while experiencing mental health difficulties ❑ Relactation ❑ Suppress lactation (stillbirth/infant loss) ❑ Maintaining lactation during separation ❑ Breast refusal ❑ Other: _____

Follow up date:	
Time spent today:	

IYCF FULL ASSESSMENT FORM: 0-23 MONTHS

SCENARIO B

1. COLLECT BASIC INFORMATION

Counsellor's ID	*112*	Location		Date of assessment	*05/06/25*
Caregiver's name	*Nada*	Relationship to child	Mother/Father/Grandmother/Sibling/Other: _____		
Child's name	*Kareem*	Sex	Male/Female	Child's ID No.	*221*
Child's D.O.B.	*03/04/24*	Child's age	*14* months	Caregiver's age	*35* years
				Is caregiver an adolescent?	❑ Yes ❑ No
Caregiver's name		Relationship to child			
Facility ID	*11*	Facility name		District	*Beirut*
Source of referral	❑ Self-referral ❑ SRA – from_____ service ❑ No SRA – direct from_____ service				
Is the child living with disability that impacts feeding or access to care?	If yes, please describe: *Yes, Down syndrome*	Is the mother or primary caregiver living with disability that impacts feeding or access to care?	If yes, please describe: *No*		
No. of previous children:	*3*	No. of previous breastfed children:	*3*		
MUAC *(if measured)*	*119.5 mm*	WFA/WFL Z-score	*WFL ≥ -2 Z-score*		

Anthropometric Assessment Table for Infants Aged 6 Weeks to 5 completed months and 6 months to 23 completed months

MUAC 6 weeks to 5 completed months			
Indicator	Severe	Moderate / At Risk	Normal
Mid-Upper Arm Circumference (MUAC)	< 110 mm	Not well defined*	≥ 110 mm (not at risk)**
MUAC 6 to 59 months			
Mid-Upper Arm Circumference (MUAC)	<115mm	≥ 115 to >125	≥ 125
All children birth to 59 months			
Weight-for-Length Z-score (WLZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Weight-for-Age Z-score (WAZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Bilateral pitting oedema	Present (regardless of other indicators)	—	Absent

** MUAC thresholds for moderate risk in 0–6 months are not standardized globally; use MUAC <110 mm as an indicator of severe risk only per 2023 WHO guideline.*
*** MUAC alone should not be used for monitoring or discharge in infants <6 months. Combine with clinical signs, weight gain, and feeding assessment*

2. CHECK FOR DANGER SIGNS[2]

Lethargic/unconscious?	❑ Yes	❑ No
Vomits everything?	❑ Yes	❑ No
Unable to drink/breastfeed?	❑ Yes	❑ No
Difficulty breathing? (respiration rate, chest indrawing)	❑ Yes	❑ No
Low or high temperature? (< 35.5 or ≥ 38°C)	❑ Yes	❑ No
Bilateral pitting oedemata? (+/++/+++)	❑ Yes	❑ No
Caregiver appears out of touch with reality or infant appears to be at risk from caregiver's behaviour?	❑ Yes	❑ No

ACTION: IF ANY MARKED AS YES → URGENT REFERRAL TO HEALTH SERVICES BEFORE CONTINUING IYCF ASSESSMENT

3. ASK ABOUT FEEDING PRACTICES

Please tell me about your experiences of feeding your baby. What concerns or questions would you like to discuss today?	*Frequent coughing & choking every time he eats. It took a while for breastfeeding to get started as an infant, but figured it out with some help and then did quite well. He still breastfeeds some. Complementary feeding started okay but having difficulty for the past 5-6 months. Feeding has been messy and stressful and mother is worried about the coughing.*

What and how is the baby fed? *(Select all that apply)*	❑ Breastfeeding – at mother's breast ❑ Expressed breastmilk – mother's own ❑ Expressed breastmilk – informally shared ❑ Donor human milk ❑ Breastfed by a woman who is not the child's mother ❑ Some artificial feeding (BMS) ❑ Fully artificially fed (BMS) ❑ Fully artificially fed (BMS)
	❑ Bottle ❑ Spoon ❑ Cup

Does the baby eat or drink anything other than breastmilk?[3]	❑ **Yes**	❑ **No**
(If yes) What else do you give the baby?	❑ Infant formula ❑ Other milks ❑ Water ❑ Tea/coffee ❑ Sugary drinks/soda ❑ Juice: _____ ml/cups ❑ Medicine ❑ Food ❑ Other[4]: _____	

ACTION: IF NON-BREASTFED OR PARTLY BREASTFED → COMPLETE FULL ASSESSMENT – NON-BREASTFED CHILD CARE PLAN

Do you use a pacifier for the baby?	❑ **Yes**	❑ **No**
Is the baby currently sick?	❑ **Yes**	❑ **No**

***(If sick)* Since your baby has been sick, have there been any changes in the way you have been feeding?**

Breastfeeding	❑ More/no change	❑ Less often	❑ Stopped
***(If 6-23 months)* Complementary feeding**	❑ More/no change	❑ Less often	❑ Stopped
Extras	❑ Extra nutritious food	❑ Infant formula	

4. CHECK DIAPER OUTPUT

How many wet diapers does baby have in 24 hours?	*6* _____ times		
Does the baby's urine have a strong smell or colour?	❑ **Yes**	❑ **No**	
How many soiled diapers does baby have in 24 hours?	*1* _____ times[5]		
Have there been any recent changes from usual?	❑ Less frequent stooling	❑ Diarrhoea	❑ No changes

ACTION: IF DIAPER OUTPUT IS LOW/CONCERNING → EXPLORE POSSIBLE LOW MILK SUPPLY
ACTION: IF CHILD HAS DIARRHOEA → REFER TO HEALTH SERVICES

5. ASK ABOUT BREASTFEEDING/BREASTMILK FEEDING

How often do you breastfeed/feed your baby breastmilk?	*4* _____ times total	*0* _____ times in the night
How do you decide when to feed your baby?	❑ Responsive	❑ Scheduled
***(If breastfeeding)* Do you experience any pain or discomfort while breastfeeding?**	❑ **Yes** ❑ Extreme ❑ Moderate ❑ Mild	❑ **No**

6. REQUEST PERMISSION TO OBSERVE THE MOTHER BREASTFEEDING (IF APPLICABLE)

Assess breast health:

Did not observe breastfeeding

Colour: ❑ Normal ❑ Redness ***Condition:*** ❑ Normal ❑ Shiny ❑ Hard ❑ Warm

❑ Engorged ❑ Damaged nipple ❑ Suspected blocked duct

❑ Suspected mastitis ❑ Suspected thrush ❑ Suspected breast abscess

ACTION: IF THRUSH, BREAST ABSCESS OR MASTITIS → REFER TO HEALTH SERVICES FOR TREATMENT

Signs breastfeeding is going well	Signs of possible difficulty
BODY POSITION	**BODY POSITION**
❑ Mother relaxed and comfortable	❑ Shoulders tense/leaning over baby
❑ Mother's back and arms are well supported	❑ Baby's body far away from mother's body
❑ Baby's body close, facing breast	❑ Starts feed with baby's mouth opposite nipple
❑ Starts feed with baby's nose opposite nipple	❑ Baby's head cannot move back freely
❑ Baby's head free	❑ Baby's neck twisted/not in line with shoulder and hip
❑ Baby's head and body straight (in line)	❑ Baby's chin not touching breast
❑ Baby's chin touching breast	

Signs breastfeeding is going well	Signs of possible difficulty
RESPONSES	**RESPONSES**
❑ Baby reaches for breast if hungry	❑ No response to breast
❑ [Baby roots for breast]	❑ [No rooting observed]
❑ Baby explores breast with tongue	❑ Baby not interested in breast
❑ Baby calm and alert	❑ Baby restless or crying
❑ Baby stays attached to breast	❑ Baby slips off breast
❑ [Signs of milk ejection] – leaking, afterpains	❑ [No signs of milk ejection]
	❑ Mother shows signs of pain/discomfort
	❑ Baby coughs/gags/chokes
EMOTIONAL STATE AND BONDING	**EMOTIONAL STATE AND BONDING**
❑ Secure, confident hold	❑ Nervous/limp hold
❑ Eye contact	❑ No eye contact
❑ Mirroring of facial expressions between parent and child	❑ Shaking or poking baby/breast
❑ Much touching by mother	❑ Little touching
❑ Responsive to baby's needs	❑ Struggles to soothe baby when crying
SUCKLING/ATTACHMENT	**SUCKLING/ATTACHMENT**
❑ Mouth wide open	❑ Mouth not wide open/points forward
❑ Lower lip turned outwards	❑ Lower lip turned in
❑ Tongue cupped around breast	❑ Baby's tongue not seen
❑ Cheeks round	❑ Cheeks tense or pulled in
❑ More areola above baby's mouth	❑ More areola below baby's mouth
❑ Slow deep sucks, bursts with pauses	❑ Rapid sucks only
❑ Can see or hear swallowing	❑ Can hear smacking or clicking
END OF FEED	**END OF FEED**
❑ Baby releases breast	❑ Mother takes baby off breast
❑ Nipple looks normal/round/erect	❑ Nipple looks creased/squashed/flattened
❑ Baby suckled for 5+ minutes	❑ Baby suckled for <5 minutes
❑ Mother keeps breast available/offers other breast	❑ Mother does not keep breast available offer other
❑ Baby's hands are relaxed/open	❑ Baby's hands are clenched/near face
❑ Baby looks relaxed/satisfied/sleepy	❑ Baby fusses/cries/appears unsatisfied
❑ Breasts feel softer	

Time spent breastfeeding 10 minutes

7. ASSESS MATERNAL/CAREGIVER WELLBEING[6]

Over the last two weeks, have you experienced any of the following feelings?			*(If yes)* Frequency in the last 2 weeks?		
Feeling anxious or worrying uncontrollably	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day
Difficulties coping with daily chores	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day
Little interest or pleasure in doing things that you used to enjoy	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day
Feeling down, depressed or hopeless	❑ Yes	❑ No	❑ Sometimes	❑ Often	❑ Almost every day

On a scale of 1 (very unsupported) to 5 (very supported), how supported to you feel by family and friends in caring for your baby?	1	2	3	4	5

Who do you mostly rely on for support, if anyone?	*Mother and sister*
How does your family feel about you breastfeeding?	*Family didn't think breastfeeding would work because of his diagnosis; glad to see it has gone well for more than a year.*

ACTION: IF ANSWERED YES – OFTEN / ALMOST EVERYDAY OR SCORE 1 – 3 ➔ COMPLETE FULL ASSESSMENT **AND REFER FOR MHPSS ASSESSMENT**

Do you have any concerns about the baby's growth and development or level of alertness, compared to other babies of a similar age?	❑ Yes	❑ No

ACTION: IF ANSWERED YES ➔ CONTINUE WITH FULL ASSESSMENT **AND REFER TO HEALTH AND ECD SERVICES**

How is your current health?	*Mother doing well but stressed about feeding.*

8. ASSESS COMPLEMENTARY FEEDING PRACTICES (6-23 MONTHS. IF UNDER 6 MONTHS, SKIP)

Who helps/assists the child with eating?	*Mother feeds the child.*

How many times did (name) eat solid, semi-solid or soft foods yesterday during the day or at night? ***Times*****_____*3*____**

To meet minimum meal frequency: ***Breastfed children:*** *should receive complementary foods at least twice a day between 6-8 months and at least three times a day between 9-23 months* ***Non-breastfed children****: should receive solid, semi-solid, or soft foods (including milk feeds) at least four times a day.*	Is the child meeting the Minimum Meal Frequency?	❑ Yes	❑ No

Yesterday, during the day and night what did you give your child to eat? *(minimum diet diversity)*	WHAT?	HOW MUCH? (cups/handfuls)	TEXTURE? (thick/thin/ chopped/whole)
Breast milk	*Breastfeeding*	*10 min per feed*	
Grains, roots, tubers, and plantains	*Rice* *Bread*	*½ cup* *1 piece*	*Whole*
Pulses, beans, legumes, lentils, and nuts	*Lentils*	*¼ cup*	*Whole*
Dairy products (e.g., milk, infant formula, yoghurt, cheese)	*Yogurt*	*¼ cup*	*Thick*
Flesh foods (e.g.; meat, fish, poultry, liver/organ meats)	*Chicken*	*¼ cup*	*Chopped*
Eggs			
Vitamin A rich fruits and vegetables (e.g., spinach, carrots, sweet potatoes, mangoes)	*Carrots*	*1*	*Soft and bite-size*
Other fruits and vegetables	*Squash*	*1*	*Soft and bite-size*
Check: ≥ 5 food groups?		❑ Yes	❑ No
Did you give your child micronutrient powder (MNP)?		❑ Yes	❑ No
What do you use to feed your child liquids?	❑ Open cup	❑ Cup with spout	❑ Bottle

At what important times in the day do you wash your hands with water and soap?	❑ Before preparing food ❑ Before eating ❑ Before feeding child ❑ NONE *(if none, understand why and counsel on hand washing)*

Do you wash the child's hands with clean water and soap before they eat?	❑ Yes	❑ No
Have you noticed the child experiencing any difficulties when eating? *(If yes, please check below)*	❑ Yes	❑ No

❑ Coughing/choking ❑ "Wet"/"gurgly" voice breathing ❑ Discomfort ❑ Watery eyes ❑ Changes in colour/breathing

ACTION: IF SIGNS OF POSSIBLE ASPIRATION ARE PRESENT → CONTINUE FULL ASSESSMENT AND REFER FOR PAEDIATRIC ASSESSMENT

9. NOTE DOWN ANY KNOWN RISK FACTORS (e.g., noted when referred)

Child	❑ Premature ❑ Low birth weight ❑ Under 6m with growth failure ❑ Sick ❑ Multiple ❑ Malnourished ❑ Disability impacting feeding ❑ Signs of extreme distress ❑ Maternal orphan ❑ Separated/unaccompanied
Mother/caregiver	❑ Malnourished ❑ Severely ill ❑ Recovering from Caesarean birth/difficult birth ❑ Disability impacting feeding Voluntary disclosure only: ❑ MHPSS difficulties ❑ SGBV survivor ❑ HIV positive ❑ First time mother ❑ Adolescent mother

ACTION: IF RISK FACTOR(S) ARE PRESENT → ENROL FOR COUNSELLING + REFER TO REQUIRED SERVICES

10. NOTE DOWN ANY OBSERVATIONS MADE DURING THE ASSESSMENT

Quality of mother's/caregiver's-child interaction (holding, touching, visual contact, verbal exchange, mirroring, playing)	❑ Poor	❑ Moderate	❑ Good
Child's reaction to the mother's/caregiver's stimulation	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's reaction to the child's calls for attention and need for comfort	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's awareness of child's movements	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's response to child needing correction	❑ Poor	❑ Moderate	❑ Good
Child moves both arms and legs equally		❑ Yes	❑ No
Normal tone and posture		❑ Yes	❑ No
Mother/caregiver requested infant formula		❑ Yes	❑ No

11. COUNSELLING ACTIONS/DECIDE ON CARE PLAN

Possible problems:	
Counselling actions taken:	❑ Positioning and attachment: _____ ❑ Stress management: _____ ❑ Information given on: _____ ❑ Supplies provided: _____ ❑ Referrals made: health/nutrition/MHPSS/ECD/FSL/WASH/other: _____ _____ ❑ Other: _____

Further counselling needed?	❑ Yes	❑ No
ACTION: IF NO → REFER FOR OTHER IYCF SERVICES	❑ Education ❑ Peer group support ❑ Other _____	

Reason for further counselling *(refer to triage tool)*	

Support to be provided	
BASIC SUPPORT AND COUNSELLING ❑ Positioning and attachment ❑ Maternal confidence ❑ Milk expression ❑ Cup/spoon feeding ❑ Flat or inverted nipples ❑ Sore or damaged nipples ❑ Engorgement ❑ Increase/decrease milk production ❑ Restorative care/emotional support ❑ Wet nursing ❑ Breastfeeding in public/crowded spaces ❑ Breastfeeding at night ❑ Infection Prevention Control ❑ Rejecting donations of BMS/feeding bottles/teats ❑ Preparing for crisis/evacuation ❑ Encourage age appropriate feeding ❑ Complementary feeding ❑ Maternal diet ❑ Other: _____	**ADVANCED SUPPORT AND COUNSELLING** ❑ Manage mastitis/thrush ❑ Manage tongue tie ❑ Breastfeed LBW or preterm infant/KMC ❑ Breastfeeding during maternal/child severe illness ❑ Feeding with a disability impacting feeding ❑ Feeding while experiencing mental health difficulties ❑ Relactation ❑ Suppress lactation (stillbirth/infant loss) ❑ Maintaining lactation during separation ❑ Breast refusal ❑ Other: _____
Follow up date:	
Time spent today:	

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HANDOUT: SCENARIO C

[MODULE 7: Practicing Disability-Inclusive Nutrition and Feeding Support]

Ibrahim is a 3-year-old boy with cerebral palsy and a history of poor growth. He has high tone and contractures in both legs, which makes it difficult to fully straighten his legs. He is the youngest of six children and lives with his family in a village. Access to food is not always consistent for the family. But even when food is available, his mother says that he eats very little. Feeding him takes a long time and a lot of effort, and mealtimes can be stressful for her. Although she feels tired after feeding him, she is not too worried about his growth or development. She believes his small size and feeding difficulties are just part of his condition.

During the visit, you weighed Ibrahim, asked the mother about his dietary intake, and observed his mother feeding him liquid from a cup. **Plot his weight on a growth chart and complete sections C and D.**

A. BASIC INFORMATION					
Counsellor's ID	*113*	Location		Date of assessment	*05/06/25*
Caregiver's name	*Roula*	Relationship to child	Mother/Father/Grandmother/Sibling/Other: _____		
Child's name	*Ibrahim*	Sex	Male/Female	Child's ID No.	*333*
Child's D.O.B.	*15/05/22*	Child's age	*3* years	Caregiver's age	*37* years
				Is caregiver an adolescent?	❑ Yes ❑ No
Facility ID	*13*	Facility name		District	*Akaar*
Is the child living with disability that impacts feeding or access to care?	If yes, please describe: *Yes, cerebral palsy*		Is the mother or primary caregiver living with disability that impacts feeding or access to care?	If yes, please describe: *No*	
No. of previous children:	*5*				
MUAC *(if measured)*	*112.5 mm*	Weight (kg)	*9.2*	Length/height (cm)	*Not measured*

Anthropometric Assessment Reference Table

Indicator	Severe	Moderate / At Risk	Normal
MUAC 6 to 59 months			
Mid-Upper Arm Circumference (MUAC)	<115mm	≥ 115 to >125	≥ 125
All children birth to 59 months			
Weight-for-Length Z-score (WLZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Weight-for-Age Z-score (WAZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Bilateral pitting oedema	Present (regardless of other indicators)	—	Absent

B. FEEDING PRACTICES	
Who helps/assists the child with eating?	*Mother feeds the child.*
How many times did (name) eat solid, semi-solid or soft foods yesterday during the day or at night? Times____*3*___	

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Yesterday, during the day and night what did you give your child to eat?	WHAT?	HOW MUCH? (cups/handfuls)	TEXTURE? (thick/thin/ chopped/whole)
Grains, roots, tubers, and plantains	*Rice* *Potato*	*½ cup* *1 small*	*Whole* *Chopped*
Pulses, beans, legumes, lentils, and nuts	*Beans*	*¼ cup*	
Dairy products (e.g., milk, infant formula, yoghurt, cheese)			
Flesh foods (e.g.; meat, fish, poultry, liver/organ meats)			
Eggs			
Vitamin A rich fruits and vegetables (e.g., spinach, carrots, sweet potatoes, mangoes)	*Carrots*	*1*	*Chopped*
Other fruits and vegetables	*Squash* *Banana*	*1* *½*	*Chopped* *Whole*
Check: ≥ 5 food groups?		❑ Yes	❑ No
What do you use to feed your child liquids?	❑ Open cup ❑ Cup with spout ❑ Bottle		

C. POSITIONING FOR FEEDING	Is position as upright as possible for safe feeding?		❑ Yes	❑ No
This was Ibrahim's position when drinking from a cup.	**Hips**	❑ Ideal ❑ Needs improvement	Notes:	
	Trunk	❑ Ideal ❑ Needs improvement	Notes:	
	Shoulders	❑ Ideal ❑ Needs improvement	Notes:	
	Head	❑ Ideal ❑ Needs improvement	Notes:	
	Knees	❑ Ideal ❑ Needs improvement	Notes:	
	Feet	❑ Ideal ❑ Needs improvement	Notes:	

Image by Werner, David (1987), Disabled Village Children [book].

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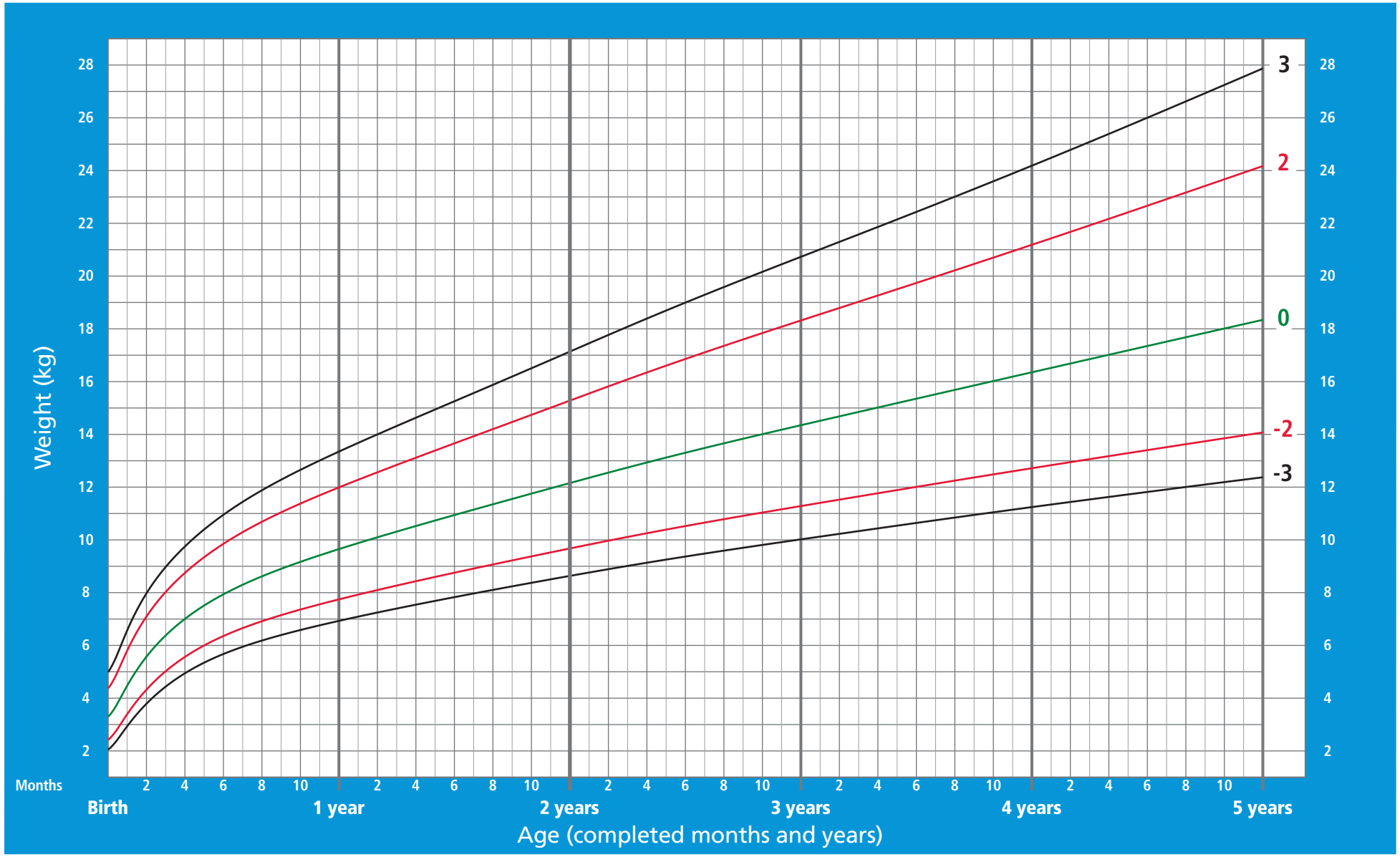
D. COUNSELLING ACTIONS/DECIDE ON CARE PLAN		
Possible problems:		
Counselling actions taken:	❑ Positioning: _____ ❑ Stress management: _____ ❑ Information given on: _____ ❑ Supplies provided: _____ ❑ Referrals made: health/nutrition/MHPSS/other: _____ _____ ❑ Other: _____	
Further counselling needed?	❑ Yes	❑ No
ACTION: IF NO → REFER FOR OTHER SERVICES		❑ Education ❑ Peer group support ❑ Other _____
Reason for further counselling		
Support to be provided		
BASIC SUPPORT AND COUNSELLING		ADVANCED SUPPORT AND COUNSELLING
Follow up date:		

Weight-for-age BOYS

Birth to 5 years (z-scores)

World Health Organization



WHO Child Growth Standards

IYCF FULL ASSESSMENT FORM: 0-23 MONTHS

SCENARIO D

1. COLLECT BASIC INFORMATION

Counsellor's ID	*114*	Location		Date of assessment	*05/06/25*
Caregiver's name	*Maya*	Relationship to child	Mother/Father/Grandmother/Sibling/Other: _____		
Child's name	*Joelle*	Sex	Male/Female	Child's ID No.	*234*
Child's D.O.B.	*04/10/23*	Child's age	*20* months	Caregiver's age	*20* years
				Is caregiver an adolescent?	❑ Yes ❑ No
Caregiver's name		Relationship to child			
Facility ID	*14*	Facility name		District	*Beirut*
Source of referral	❑ Self-referral ❑ SRA – from_____ service ❑ No SRA – direct from_____ service				
Is the child living with disability that impacts feeding or access to care?	If yes, please describe: *No known disability; concerns for feeding difficulties*	Is the mother or primary caregiver living with disability that impacts feeding or access to care?	If yes, please describe: *Yes, blind or partially sighted*		
No. of previous children:	*0*	No. of previous breastfed children:	*0*		
MUAC *(if measured)*	*125.5 mm*	WFA/WFL Z-score	*WFL ≥ -2 Z-score*		

Anthropometric Assessment Table for Infants Aged 6 Weeks to 5 completed months and 6 months to 23 completed months

MUAC 6 weeks to 5 completed months			
Indicator	Severe	Moderate / At Risk	Normal
Mid-Upper Arm Circumference (MUAC)	< 110 mm	Not well defined*	≥ 110 mm (not at risk)**
MUAC 6 to 59 months			
Mid-Upper Arm Circumference (MUAC)	<115mm	≥ 115 to >125	≥ 125
All children birth to 59 months			
Weight-for-Length Z-score (WLZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Weight-for-Age Z-score (WAZ)	< -3 Z-score	≥ -3 to < -2 Z-score	≥ -2 Z-score
Bilateral pitting oedema	Present (regardless of other indicators)	—	Absent

** MUAC thresholds for moderate risk in 0–6 months are not standardized globally; use MUAC <110 mm as an indicator of severe risk only per 2023 WHO guideline.*
*** MUAC alone should not be used for monitoring or discharge in infants <6 months. Combine with clinical signs, weight gain, and feeding assessment*

2. CHECK FOR DANGER SIGNS[2]

Lethargic/unconscious?	❑ Yes	❑ No
Vomits everything?	❑ Yes	❑ No
Unable to drink/breastfeed?	❑ Yes	❑ No
Difficulty breathing? (respiration rate, chest indrawing)	❑ Yes	❑ No
Low or high temperature? (< 35.5 or ≥ 38°C)	❑ Yes	❑ No
Bilateral pitting oedemata? (+/++/+++)	❑ Yes	❑ No
Caregiver appears out of touch with reality or infant appears to be at risk from caregiver's behaviour?	❑ Yes	❑ No

ACTION: IF ANY MARKED AS YES → URGENT REFERRAL TO HEALTH SERVICES BEFORE CONTINUING IYCF ASSESSMENT

3. ASK ABOUT FEEDING PRACTICES

Please tell me about your experiences of feeding your baby. What concerns or questions would you like to discuss today?	*Feeding has been difficult for mother. It takes a long time to finish meals; the child is often crying or very distracted. Mother can tell child wants to feed self, but unsure how to help her. Both mother and child are often stressed during feeding. Mother is worried that feeding takes so much longer than for other children that are the same age in her family.*

What and how is the baby fed? *(Select all that apply)*	❑ Breastfeeding – at mother's breast ❑ Expressed breastmilk – mother's own ❑ Expressed breastmilk – informally shared ❑ Donor human milk ❑ Breastfed by a woman who is not the child's mother ❑ Some artificial feeding (BMS) ❑ Fully artificially fed (BMS) ❑ Fully artificially fed (BMS)
	❑ Bottle ❑ Spoon ❑ Cup

Does the baby eat or drink anything other than breastmilk?[3]	❑ **Yes**	❑ **No**
(If yes) What else do you give the baby?	❑ Infant formula ❑ Other milks ❑ Water ❑ Tea/coffee ❑ Sugary drinks/soda ❑ Juice: *150*_____ml/cups ❑ Medicine ❑ Food ❑ Other[4]: _____	

ACTION: IF NON-BREASTFED OR PARTLY BREASTFED → COMPLETE FULL ASSESSMENT – NON-BREASTFED CHILD CARE PLAN

Do you use a pacifier for the baby?	❑ **Yes**	❑ **No**
Is the baby currently sick?	❑ **Yes**	❑ **No**

***(If sick)* Since your baby has been sick, have there been any changes in the way you have been feeding?**

Breastfeeding	❑ More/no change	❑ Less often	❑ Stopped
***(If 6-23 months)* Complementary feeding**	❑ More/no change	❑ Less often	❑ Stopped
Extras	❑ Extra nutritious food	❑ Infant formula	

4. CHECK DIAPER OUTPUT

How many wet diapers does baby have in 24 hours?	*5*_____ times		
Does the baby's urine have a strong smell or colour?	❑ **Yes**	❑ **No**	
How many soiled diapers does baby have in 24 hours?	*2*_____ times[5]		
Have there been any recent changes from usual?	❑ Less frequent stooling	❑ Diarrhoea	❑ No changes

ACTION: IF DIAPER OUTPUT IS LOW/CONCERNING → EXPLORE POSSIBLE LOW MILK SUPPLY

ACTION: IF CHILD HAS DIARRHOEA → REFER TO HEALTH SERVICES

5. ASK ABOUT BREASTFEEDING/BREASTMILK FEEDING

How often do you breastfeed/feed your baby breastmilk?	_____ times total	_____ times in the night
How do you decide when to feed your baby?	❑ Responsive	❑ Scheduled
***(If breastfeeding)* Do you experience any pain or discomfort while breastfeeding?**	❑ **Yes** ❑ Extreme ❑ Moderate ❑ Mild	❑ **No**

6. REQUEST PERMISSION TO OBSERVE THE MOTHER BREASTFEEDING (IF APPLICABLE)

Assess breast health:	***Colour:*** ❑ Normal ❑ Redness ***Condition:*** ❑ Normal ❑ Shiny ❑ Hard ❑ Warm ❑ Engorged ❑ Damaged nipple ❑ Suspected blocked duct ❑ Suspected mastitis ❑ Suspected thrush ❑ Suspected breast abscess

ACTION: IF THRUSH, BREAST ABSCESS OR MASTITIS → REFER TO HEALTH SERVICES FOR TREATMENT

Signs breastfeeding is going well	Signs of possible difficulty
BODY POSITION ❑ Mother relaxed and comfortable ❑ Mother's back and arms are well supported ❑ Baby's body close, facing breast ❑ Starts feed with baby's nose opposite nipple ❑ Baby's head free ❑ Baby's head and body straight (in line) ❑ Baby's chin touching breast	**BODY POSITION** ❑ Shoulders tense/leaning over baby ❑ Baby's body far away from mother's body ❑ Starts feed with baby's mouth opposite nipple ❑ Baby's head cannot move back freely ❑ Baby's neck twisted/not in line with shoulder and hip ❑ Baby's chin not touching breast
Signs breastfeeding is going well	**Signs of possible difficulty**
RESPONSES ❑ Baby reaches for breast if hungry ❑ [Baby roots for breast] ❑ Baby explores breast with tongue ❑ Baby calm and alert ❑ Baby stays attached to breast ❑ [Signs of milk ejection] – leaking, afterpains	**RESPONSES** ❑ No response to breast ❑ [No rooting observed] ❑ Baby not interested in breast ❑ Baby restless or crying ❑ Baby slips off breast ❑ [No signs of milk ejection] ❑ Mother shows signs of pain/discomfort ❑ Baby coughs/gags/chokes
EMOTIONAL STATE AND BONDING ❑ Secure, confident hold ❑ Eye contact ❑ Mirroring of facial expressions between parent and child ❑ Much touching by mother ❑ Responsive to baby's needs	**EMOTIONAL STATE AND BONDING** ❑ Nervous/limp hold ❑ No eye contact ❑ Shaking or poking baby/breast ❑ Little touching ❑ Struggles to soothe baby when crying
SUCKLING/ATTACHMENT ❑ Mouth wide open ❑ Lower lip turned outwards ❑ Tongue cupped around breast ❑ Cheeks round ❑ More areola above baby's mouth ❑ Slow deep sucks, bursts with pauses ❑ Can see or hear swallowing	**SUCKLING/ATTACHMENT** ❑ Mouth not wide open/points forward ❑ Lower lip turned in ❑ Baby's tongue not seen ❑ Cheeks tense or pulled in ❑ More areola below baby's mouth ❑ Rapid sucks only ❑ Can hear smacking or clicking
END OF FEED ❑ Baby releases breast ❑ Nipple looks normal/round/erect ❑ Baby suckled for 5+ minutes ❑ Mother keeps breast available/offers other breast ❑ Baby's hands are relaxed/open ❑ Baby looks relaxed/satisfied/sleepy ❑ Breasts feel softer	**END OF FEED** ❑ Mother takes baby off breast ❑ Nipple looks creased/squashed/flattened ❑ Baby suckled for <5 minutes ❑ Mother does not keep breast available offer other ❑ Baby's hands are clenched/near face ❑ Baby fusses/cries/appears unsatisfied

Time spent breastfeeding ____ minutes

7. ASSESS MATERNAL/CAREGIVER WELLBEING[6]

Over the last two weeks, have you experienced any of the following feelings?			*(If yes)* Frequency in the last 2 weeks?		
Feeling anxious or worrying uncontrollably	☐ Yes	☐ No	☐ Sometimes	☐ Often	☐ Almost every day
Difficulties coping with daily chores	☐ Yes	☐ No	☐ Sometimes	☐ Often	☐ Almost every day
Little interest or pleasure in doing things that you used to enjoy	☐ Yes	☐ No	☐ Sometimes	☐ Often	☐ Almost every day
Feeling down, depressed or hopeless	☐ Yes	☐ No	☐ Sometimes	☐ Often	☐ Almost every day

On a scale of 1 (very unsupported) to 5 (very supported), how supported to you feel by family and friends in caring for your baby?	1	2	3	4	5

Who do you mostly rely on for support, if anyone?	*Sister but mother feels isolated and not supported in her community*
How does your family feel about you breastfeeding?	

ACTION: IF ANSWERED YES – OFTEN / ALMOST EVERYDAY OR SCORE 1 – 3 ➔ COMPLETE FULL ASSESSMENT **AND REFER FOR MHPSS ASSESSMENT**

Do you have any concerns about the baby's growth and development or level of alertness, compared to other babies of a similar age?	☐ Yes	☐ No

ACTION: IF ANSWERED YES ➔ CONTINUE WITH FULL ASSESSMENT **AND REFER TO HEALTH AND ECD SERVICES**

How is your current health?	*Tired, but currently stable.*

8. ASSESS COMPLEMENTARY FEEDING PRACTICES (6-23 MONTHS. IF UNDER 6 MONTHS, SKIP)

Who helps/assists the child with eating?	*Mother feeds the child, child starting to try to feed self.*

How many times did (name) eat solid, semi-solid or soft foods yesterday during the day or at night? ***Times*** *4*

To meet minimum meal frequency: ***Breastfed children:*** *should receive complementary foods at least twice a day between 6-8 months and at least three times a day between 9-23 months* ***Non-breastfed children****: should receive solid, semi-solid, or soft foods (including milk feeds) at least four times a day.*	Is the child meeting the Minimum Meal Frequency?	☐ Yes	☐ No

Yesterday, during the day and night what did you give your child to eat? *(minimum diet diversity)*	WHAT?	HOW MUCH? (cups/handfuls)	TEXTURE? (thick/thin/ chopped/whole)
Breast milk			
Grains, roots, tubers, and plantains	*Rice* *Bread*	*½ cup* *1 piece*	*Whole*
Pulses, beans, legumes, lentils, and nuts	*Peas*	*¼ cup*	*Whole*
Dairy products (e.g., milk, infant formula, yoghurt, cheese)	*Cow's milk* *Yogurt*	*1 cup* *½ cup*	*Thin* *Thick*
Flesh foods (e.g.; meat, fish, poultry, liver/organ meats)	*Ground beef*	*¼ cup*	*Chopped*
Eggs	*Egg*	*1*	*Soft and bite-size*
Vitamin A rich fruits and vegetables (e.g., spinach, carrots, sweet potatoes, mangoes)	*Carrots*	*1*	*Soft and bite-size*
Other fruits and vegetables	*Orange juice* *Cabbage*	*1 cup* *½ cup*	*Soft and bite-size*
Check: ≥ 5 food groups?		☐ Yes	☐ No
Did you give your child micronutrient powder (MNP)?		☐ Yes	☐ No
What do you use to feed your child liquids?	☐ Open cup	☐ Cup with spout	☐ Bottle

At what important times in the day do you wash your hands with water and soap?	❑ Before preparing food ❑ Before eating ❑ Before feeding child ❑ NONE *(if none, understand why and counsel on hand washing)*	
Do you wash the child's hands with clean water and soap before they eat?	❑ Yes	❑ No
Have you noticed the child experiencing any difficulties when eating? *(If yes, please check below)*	❑ Yes	❑ No
❑ Coughing/choking ❑ "Wet"/"gurgly" voice breathing ❑ Discomfort ❑ Watery eyes ❑ Changes in colour/breathing		
ACTION: IF SIGNS OF POSSIBLE ASPIRATION ARE PRESENT → CONTINUE FULL ASSESSMENT AND REFER FOR PAEDIATRIC ASSESSMENT		

9. NOTE DOWN ANY KNOWN RISK FACTORS (e.g., noted when referred)

Child	❑ Premature ❑ Low birth weight ❑ Under 6m with growth failure ❑ Sick ❑ Multiple ❑ Malnourished ❑ Disability impacting feeding ❑ Signs of extreme distress ❑ Maternal orphan ❑ Separated/unaccompanied
Mother/caregiver	❑ Malnourished ❑ Severely ill ❑ Recovering from Caesarean birth/difficult birth ❑ Disability impacting feeding Voluntary disclosure only: ❑ MHPSS difficulties ❑ SGBV survivor ❑ HIV positive ❑ First time mother ❑ Adolescent mother
ACTION: IF RISK FACTOR(S) ARE PRESENT → ENROL FOR COUNSELLING + REFER TO REQUIRED SERVICES	

10. NOTE DOWN ANY OBSERVATIONS MADE DURING THE ASSESSMENT

Quality of mother's/caregiver's-child interaction (holding, touching, visual contact, verbal exchange, mirroring, playing)	❑ Poor	❑ Moderate	❑ Good
Child's reaction to the mother's/caregiver's stimulation	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's reaction to the child's calls for attention and need for comfort	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's awareness of child's movements	❑ Poor	❑ Moderate	❑ Good
Mother's/caregiver's response to child needing correction	❑ Poor	❑ Moderate	❑ Good
Child moves both arms and legs equally		❑ Yes	❑ No
Normal tone and posture		❑ Yes	❑ No
Mother/caregiver requested infant formula		❑ Yes	❑ No

11. COUNSELLING ACTIONS/DECIDE ON CARE PLAN

Possible problems:		
Counselling actions taken:	❑ Positioning and attachment: _____ ❑ Stress management: _____ ❑ Information given on: _____ ❑ Supplies provided: _____ ❑ Referrals made: health/nutrition/MHPSS/ECD/FSL/WASH/other: _____ _____ ❑ Other: _____	
Further counselling needed?	❑ Yes	❑ No
ACTION: IF NO → REFER FOR OTHER IYCF SERVICES	❑ Education ❑ Peer group support ❑ Other _____	

Reason for further counselling *(refer to triage tool)*	

Support to be provided

BASIC SUPPORT AND COUNSELLING	**ADVANCED SUPPORT AND COUNSELLING**
❑ Positioning and attachment ❑ Maternal confidence ❑ Milk expression ❑ Cup/spoon feeding ❑ Flat or inverted nipples ❑ Sore or damaged nipples ❑ Engorgement ❑ Increase/decrease milk production ❑ Restorative care/emotional support ❑ Wet nursing ❑ Breastfeeding in public/crowded spaces ❑ Breastfeeding at night ❑ Infection Prevention Control ❑ Rejecting donations of BMS/feeding bottles/teats ❑ Preparing for crisis/evacuation ❑ Encourage age appropriate feeding ❑ Complementary feeding ❑ Maternal diet ❑ Other: _____	❑ Manage mastitis/thrush ❑ Manage tongue tie ❑ Breastfeed LBW or preterm infant/KMC ❑ Breastfeeding during maternal/child severe illness ❑ Feeding with a disability impacting feeding ❑ Feeding while experiencing mental health difficulties ❑ Relactation ❑ Suppress lactation (stillbirth/infant loss) ❑ Maintaining lactation during separation ❑ Breast refusal ❑ Other: _____

Follow up date:	
Time spent today:	