



mami
Global Network

Identifying and supporting infants under 6-months with feeding difficulties and **disabilities**: an overview of resources and evidence

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1. Introduction

The MAMI Global Network is comprised of practitioners working to improve care of small & nutritionally at-risk infants under six months and their mothers (MAMI) worldwide. Central to the MAMI approach is integrated continuity of care between existing systems and services across health (including maternal, neonatal and paediatric) and nutrition services. The [MAMI Care Pathway Package](#) is a resource that applies an integrated care pathway model to the context of at-risk mother-infant pairs. The MAMI Care Pathway supports infant and maternal nutrition, health and maternal mental health to reduce the risk of adverse outcomes among infants under six months of age (u6m).

Increasingly, attention and concern are being directed towards the needs and rights of infants and young children with disabilities. In the context of MAMI, there are increasing requests on “how” to manage infants with feeding difficulties or suspected/confirmed disability and concerns regarding the lack of attention to this age group and little evidence to guide care. Through the [MAMI Global Network](#), a MAMI Implementers’ Group meeting was held in October 2023 to exchange experiences in programming and share some of the tools and work ongoing. This led to this short compilation of key resources by ENN, focused on infants u6m and their mothers, to help consolidate existing guidance and research for mother-infant pairs.

This brief is divided into sections on **Practice, Policy Guidance, Evidence, and Ongoing Initiatives** related to disability. Practical resources related to u6m and their mothers are detailed below and have been extracted from the [Feeding and Disability Resource Bank](#) work by USAID Advancing Nutrition and UNICEF, through consulting with practitioners from the MAMI Global Network and/or who are working with disability, and content in the [MAMI Care Pathway Package](#) and [WHO guidance on wasting](#). It provides some key policies related to disability, a summary of relevant evidence around nutrition and disability, and details of ongoing or planned work that has been shared with the MAMI Global Network. We have not appraised or prioritised content and this is not an exhaustive review but a first step to help take this critical area forward in 2024.

What do we mean by disability? (in this brief)

Disability refers to a range of health conditions or impairments which, in interaction with various barriers, limit a person’s functioning and participation in society.¹ In infants, common health conditions that can lead to disabilities include cleft lip/palate, cerebral palsy, Down syndrome and a range of other conditions. Preterm infants born with low birth weight (or increasingly those with substance exposure^a) are at a higher risk of developmental disabilities, including cerebral palsy and retinopathy of prematurity. Many documents (see **Table 2**) describe the conditions in more detail. Nutrition and disability are highly inter-related. Malnutrition can lead to or worsen impairments, and children with disabilities are at higher risk of malnutrition due to existing health conditions and exclusion from basic nutrition services.^{2,3}

It can be difficult to identify disability in infants u6m; some infants may have feeding difficulties from early in life but a disability not identified until much later when developmental milestones are not met. We therefore consider and include ‘feeding difficulties’ within the scope of this brief, which may (or may not) be an early marker of a disability but irrespective of this, require quality care to support the growth and development of the infant irrespective of the underlying cause. This is also in line with the USAID/UNICEF Resource Bank. Feeding difficulties refers to a range of problems with eating or drinking that are not age-appropriate and is associated with medical, nutritional, feeding skills, and/or psychosocial challenges.⁴ Feeding difficulties in turn can increase risk of malnutrition and infections and the potential for a child to develop a disability or exacerbate an existing disability. Upwards of 25-45% of children without disabilities experience feeding difficulties⁵ and as much as 80-90% of children with disabilities.⁶

The burden and cost

Statistics on disability and inclusive nutrition programming is increasingly being collected across organisations and there is a real need for these infants and children to be recognised. Both [Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities](#)⁷ and [The Missing Billion](#) (www.themissingbillion.org) initiative highlight the scale of the problem of exclusion and the need for disability inclusive services. Furthermore, a recently released paper [Are children with disabilities more likely to be malnourished than children without disabilities? Evidence from the Multiple Indicator Cluster Surveys in 30 countries](#)⁸ clearly makes the case that children with disabilities are significantly more likely to experience all forms of malnutrition and the pressing need to focus on disability inclusion within nutrition programmes as part of the goal to end all forms of malnutrition.

The **cost of not including disability** has been highlighted by agencies including UNICEF,⁹ and the nutrition-disability inter-relationship and **conceptual framework** linking the relationship of nutrition to disability with a call to action/policy is clearly illustrated in this key paper: [Malnutrition and disability: unexplored opportunities for collaboration](#).¹⁰

^a And increasingly those with substance (alcohol and drug) exposure (personal communication)

A recent [scoping review for children with feeding difficulties and disabilities](#)¹¹ also stresses the need to bring attention to nutritional aspects and feeding difficulties to the disability sector, including four areas or recommendations: (1) *Strengthen systems to improve identification and service provision*; (2) *Provide direct support to families to address determinants that affect nutrition outcomes*; (3) *Conduct advocacy to raise awareness of the needs and opportunities*; and (4) *Build the evidence base on effective interventions to identify and support these children and their families.*"

2. Practice

Assessment

Early detection of feeding difficulties or disability in infants can be overlooked as they start breastfeeding and before they start eating semi-solids/solid foods when it is easier to pick up issues. Stigma around disability can also limit or delay assessment efforts. Feeding difficulties could indicate a possible disability or developmental delay and can lead to poor growth and development of infants. Providing practical support to caregivers to ensure infants are safely and enjoyably breastfeeding and consuming adequate calories could reduce the risk of malnutrition among vulnerable infants and early detection is critical.¹² Developmental screening tools do not diagnose disability, but can be used to assess a child's overall development, and indicate when more support or further assessment is needed.

Often assessment tools are more adapted for the older child and there is a need use tools more appropriately in developing contexts,¹³ some existing tools can be found in **Table 1**.

Table 1: Examples of assessment tools

Document	Description
Early detection tools for children with developmental delays and disabilities UNICEF Middle East and North Africa	Technical brief developed to support specialists in countries of the Middle East and North Africa (MENA) region to select which early detection tools best fit their needs and context by comparing various tools and lessons learned in using and adapting those tools to local contexts. (2022) <i>(English, French, Arabic, Farsi)</i> . Includes: <ul style="list-style-type: none"> • Ages and Stages Questionnaire (ASQ) • Bayley Scales of Infant and Toddler Development (BSID) • Denver Development Screening Test (DDST) • Malawi Developmental Assessment Tool (MDAT)
Cambodia Developmental Milestone Assessment Tool (CDMAT)	Community-based version (CB-DMAT) https://cdmat.org/ Culturally-sensitive and environmentally appropriate tool that assesses the milestones of Cambodian children and to promote early detection of developmental delays.
Global Scales for Early Development (GSED)	WHO tool for obtaining information on child development, as opposed to disability, for children below 36 months.
ICFQ© 6-question screener	Quick 6-question screening tool that identifies and differentiates between children who are struggling with feeding and can be used by healthcare workers.
Malawi Development Assessment Tool (IDEC)	Shortened form of the MDAT used in Uganda for village health workers; piloted with UNICEF.

[Note: the **Washington Group on disability statistics** have produced various assessment tools, including *Child Functioning Modules for 2-4 years: Assessment. Above 2 years.* (washingtongroup-disability.com). They have not developed a version of the *Child Functioning Module* for use with children under 2 years of age given the unique challenges related to creating a tool that can be used in surveys for this age group. Additionally, UNICEF developed an *Early Childhood Development instrument* but for children aged 2 to 4 years (<https://data.unicef.org/resources/early-childhood-development-index-2030-ecdi2030/>)

Challenges include: often detection of a disability is made once the infant is starting complementary feeding (from 6 months) and not before; disability or identification of developmental delays are not always included in routine or humanitarian screening tools; routine services for acute malnutrition/wasting rely on anthropometry (mid-upper arm circumference (MUAC), head circumference, weight and height) and cut offs which are not appropriate to all types of disability. Other standards, including SPHERE, mention use of “visual assessment, skinfold measures, length or arm span, demi-span or lower leg length” as other methods but these are not systematically found in routine practice and would require additional training and tools.

Practical resources to support care

*The **Feeding and Disability Resource Bank**^b was presented at the [Virtual Convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities](#), conducted in April 2023 by USAID Advancing Nutrition and UNICEF, followed by [key takeaways](#). It has brought together many tools for different disabilities and age groups in one place. **Table 2** below summarises practical resources that support the feeding of infants u6m with disabilities and their mothers, extracted from the Resource Bank and/or resources shared by members of the MAMI Global Network and/or disability networks.

Table 2: Practical resources to support the feeding of infants u6m with disabilities and their mothers

Description of resource and relevance to u6m/mothers	
Resource hubs	
Feeding and Disability Resource Bank (USAID and UNICEF April 2023)	Practical compilation of tools for feeding difficulties and disabilities in one place. Use the search tool to identify resources for infants u6m.
YCF Image Bank (USAID, in transition to UNICEF)	Includes images of infants and children with disability, including breastfeeding, from various geographic regions, that can be used in counselling materials.
Ubuntu-hub (LSHTM 2021) (Available in English and Kinyarwanda)	Programme developed to support families of very young children (0 to 2 years) with an evolving developmental disability (e.g. following birth asphyxia). Includes a facilitator manual along with images and display materials. Each module has some information relevant to infants u6m.
Guidance and Toolkits	
Disability-Inclusive Humanitarian Action Toolkit (UNICEF)	Operational guidance on including children with disabilities in humanitarian response.
Guidance: Including Children with Disabilities in Humanitarian Action (UNICEF)	Guidance consisting of six booklets (General, Education, Health and HIV/AIDS, Nutrition, Protection and WASH). The nutrition guidance includes the need to overcome stigma when feeding an infant with a disability (<i>page 13</i>); using baby-friendly spaces and mother and infant groups to support mothers with disabilities and caregivers of infants (<i>page 57</i>); breastfeeding positioning and feeding tips related to specific disabilities, including cleft lip/palate and infants affected by Zika Syndrome (<i>pages 58- 60; Section 7.4.p-y</i>).

^b Note the resource bank is in the process of being handed to UNICEF for management. Other resources included for 6-59 months and related to complementary feeding, [helping children who are blind](#) (page 74) etc are in the Resource Bank but not included here as for the older child.

<p><u>Essential Actions on Disability-Inclusive Humanitarian Action Checklist: Nutrition</u> (UNICEF)</p> <p><u>Inclusion of Children and Young People with Disabilities in Routine General Health Care: Practice Guide</u> (UNICEF 2022)</p>	<p>Package of essential actions required to ensure disability-inclusive nutrition humanitarian action is in line with emergency guidance. It is a companion to UNICEF’s Guidance on including children with disabilities in humanitarian action: nutrition. Information on breastfeeding infants with disabilities (page 4). <i>[also covers older infants with difficulties swallowing, chewing, or eating independently.]</i></p> <p>Focuses on systems-wide and service-specific (e.g. newborn care, immunisation and HIV/AIDS) measures for ensuring disability inclusion, and provides illustrative entry points for programmes (including mothers with disabilities) and stresses the need of assessment and early diagnosis.</p>
<p><u>Disability-Inclusive IYCF Package Entry Points & Tools</u> (Save the Children 2023)</p>	<p>Package of practical tools intended for health and nutrition frontline workers, technical officers, programme managers, specialists, academics and any other professionals who are implementing Infant and Young Child Feeding (IYCF) programming, in development or emergency/humanitarian settings. It presents global resources that support the inclusion of mothers, infants, and young children with disabilities in nutrition programming.</p>
<p><u>Disabled Village Children. A guide for community health workers, rehabilitation workers, and families</u> (Hesperian Health Guides 2022)</p>	<p>Includes description of key disabilities, assessment, feeding management and stimulation. Includes sections on mainstreaming into growth monitoring, and chapter 36 on feeding and nutrition.</p> <p><i>[See other guides for Pregnant or lactating women with disabilities; Caregivers with disabilities and Infants and young children with disabilities]</i></p>
<p><u>Family Care for Children with Disabilities: Practical Guidance for Frontline Workers in Low- and Middle-Income Countries</u> (USAID, World Learning, and Partnerships for Every Child 2018)</p>	<p>Basic case management approaches should be the same for all children, but there are additional and specific issues for children with disabilities. Includes breastfeeding information.</p>

<p><u>Feeding and Positioning Manual: Guidelines for Working with Babies and Children</u> (Holt International 2019)</p> <p><u>Child Nutrition Program Flipbook</u> (https://www.holtinternational.org/research/)</p> <p><u>The Child Nutrition Program Community Resource Manual</u></p> <p><u>Feeding and Training Curriculum</u> (Holt International 2022)</p> <p>(multiple languages; useful for audiences with varying literacy levels)</p>	<p>Manual: Part 3, Chapters 6, 7.</p> <p>Training slides: Slides corresponding to Chapter 7 (Common Feeding Challenges and Solutions, from slide 80).</p> <p>Chapter 16 Disabilities and Medical Needs (see page 162 for feeding considerations for infants under 1 year). <i>(Note: includes section on specialist formula and bottle feeding.)</i></p> <p>Nutrition screening decision trees for various disabilities (see page 175).</p> <p>Key Handouts</p> <p>9:9a Feeding Skills Timeline: Eating and Drinking from Birth to 36 Months Old</p> <p>9:9b Typical Child Motor Development Milestones and Red Flags</p> <p>9:9g Common Items to Support Feeding</p> <p>9:9k Strategies for Calming and Waking Babies</p> <p>9:9L 1 Breastfeeding Tips</p> <p>9:9L 2 Feeding and Interaction Cues</p> <p>9:9n How Much Should Babies Eat</p> <p>Community manual provides key information to communities on various nutritional and health considerations and needs of children. It includes a chapter on “<i>Special Health Care Needs</i>” for children with disabilities, which covers the definitions, causes, signs, causes, feeding considerations, and treatment of several disabilities.</p>
<p><u>International Classification of Functioning, Disability and Health</u> (ICF)</p>	<p>Known more commonly as ICF, this is the WHO framework for measuring health and disability at both individual and population levels. ICF was officially endorsed by all 191 WHO Member States as the international standard to describe and measure health and disability.</p>
<p><u>MAMI Care Pathway V3</u> (ENN and LSHTM 2021)</p>	<p>For u6m-mother pairs. Inclusion of disability can be found within the MAMI Assessment Form as per Integrated Management of Childhood Illness (IMCI) questions to assess if an infant has a congenital condition or disability; is listed within the associated MAMI Assessment Guide, including notes as to whether a hospital referral is required and in the MAMI Care Pathway health worker support materials user booklet. Refer to Annex 1 for more detail.</p>

<p><u>Multi-agent International Training Support (MAITS) resources</u> (info@maits.org.uk)</p>	<p>Training packages on feeding difficulties in children with developmental disabilities designed to improve knowledge and skills of health care professionals. Includes information on supporting breastfeeding and nutrition in infants struggling to feed due to prematurity, low birthweight, or underlying disability.</p> <ul style="list-style-type: none"> • Working with infants with feeding difficulties • Caring for Children with Developmental Disabilities: A guide for Parents • Working with Children with developmental Disabilities and their Caregivers <p><i>[Note also for older children e.g. Working with children with eating & drinking difficulties]</i></p>
<p><u>Nutrition Integration for the Children with Special Needs: A Facilitator’s Guide for Food Security, Nutrition, Livelihoods and Disability Inclusion Project Staffs</u> (LEARN Project 2020)</p>	<p>Module supports integration of disability inclusion into nutrition programming by providing information on nutritional concerns of children with disabilities. It covers topics such as relationship between nutrition and disability and how to breastfeed babies with disabilities.</p> <p>Access: visit LEARN Library, select “1. Facilitator’s Manual” and click on “6. Nutrition in Disability.</p> <p>Chapter 5 (see page 119 for information on breastfeeding infants with disabilities).</p>
<p>More specific to certain disabilities (shared by network members)</p>	
<p><u>Cleft Lip & Palate Association</u></p> <p><u>Palate Examination: Identification of Cleft Palate in the Newborn – Best Practice Guide</u> (RCPCH 2015)</p> <p><u>Feeding & Nutrition: Resources for Families</u> (cleft palate) and <u>Counselling and Support</u> (Smile Train 2021)</p> <p><u>Cleft Lip and Palate</u> (NHS UK)</p> <p><u>Breastfeeding Babies with Cleft Lip/Palate</u> (Australian Breastfeeding Association)</p>	<p>Provides information and images of cleft palate for identification. Visual inspection as part of a routine baby check can help identify cleft palate (less obvious than cleft lip) by a trained health worker checking inside the mouth. <i>[Note: if a cleft in hard palate alone occurs it can be missed unless actively looked for/ practitioners/carers know what they’re looking for.]</i></p> <p>Resources include a video and handouts to inform families on feeding children with cleft lips and/or palates to keep them healthy and strong. Includes tips and information on both breastfeeding (and complementary feeding). Scroll down the linked webpage to locate videos and handouts that relate to breastfeeding infants with cleft palate.</p> <p>Country examples of resources available.</p>
<p><u>Down Syndrome International</u></p> <p><u>Inclusion International</u></p> <p><u>Down Syndrome Resources</u> (Australian Breastfeeding Association)</p>	<p>Recently published Listen Include Respect, guidelines on including people with intellectual disabilities. https://www.listenincluderespect.com/consultations</p> <p>Country example of resources available.</p>
<p><u>Ubuntu</u> (previously <u>Getting to Know Cerebral Palsy</u>) (LSHTM, CBM)</p>	<p>Under the Ubuntu hub and on CBM site, Module 6 is on feeding. Resources and videos available at https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability/resources</p>

Key resources for mothers/caregivers ^c	
<p>A Health Handbook for Women with Disabilities (Hesperian Foundation 2007)</p>	Includes: Chapter 3: Mental Health; Chapter 9: Pregnancy Chapter 10: Labor and Birth; Chapter 12: Caring for your baby.
<p>Inclusion of Children and Young People with Disabilities in Routine General Health Care: Practice guide (UNICEF 2022)</p>	<p>Section 6 relates to service-specific measures to ensure inclusion of people with disabilities in health services:</p> <p>6.1. Antenatal care for women with disabilities</p> <p>6.2 Intrapartum and postpartum care for young women with disabilities</p> <p>6.3 Newborn care for young women with disabilities</p>
<p>Communicating Effectively with Caregivers of Children with Disabilities (disability-inclusive counselling)</p> <p>Caregiver Psychosocial Support Session Guide: Helping Young Children with Disabilities Meet their Potential (MCSP 2019)</p>	<p>See "Supporting children with disabilities and their families" section of the feeding & disability resource bank.</p> <p>Session guide to facilitate caregiver psychological support sessions.</p>
General	
<p>Growth Charts for Children with Special Health Care Needs (Center for Disease Control 2014)</p>	Module describes some effects that special health care needs can have on growth of children and illustrates how CDC Growth Charts can be used to assess. Includes a section that discusses weighing of preterm and low birth weight infants.
<p>Learn First Aid for a Baby Who is Choking (British Red Cross 2020)</p>	Relevant to infants with swallowing difficulties and at risk of aspiration.
<p>Videos of Care of Small Babies (Global Media Health 2017)</p>	Series of videos on care for small babies (not disability specific), including feeding issues.
Practical links	
<p>Assistive Products and Inclusive Supplies (UNICEF)</p> <p>Global Report on Assistive Technology (WHO, UNICEF)</p>	<p>Minimal mention of feeding/nutrition but provide an excellent baseline for many aspects of assistive technology, including for young children.</p> <p><i>[Note: not specific to under 6 months but also Assistive Technology (AT) ATScale (short films: Link and Link)</i></p>
<p>Better Care Network</p>	Resources for children with disabilities.
<p>International Disability Alliance</p>	Advancing the rights of individuals with disabilities.
<p>Spoon Foundation</p>	Resource library includes briefing documents relevant to infant feeding. (Note: SPOON chair exists but for older children; poster).

^c There is a need to consider both mothers/givers with disabilities, and sufficient care and support for mother/caregivers and families with an infant who has a disability

3. Policy Guidance

Inclusion of infants and children with disabilities is increasingly present in organisational policies and guidance. As progress is made towards realizing the rights of every child to a full and health development, there are resources to support policy and advocacy efforts for disability inclusive services and mainstreaming support through nutrition and health services, such as those in Table 3. (Note: This document is not intended as a desk review of all relevant policy guidance related to infants and their mothers but to be an overview of some relevant resources.)

Table 3: Examples of policy guidance

Document
Disability Inclusion in Nutrition Programming (Global Nutrition Cluster Technical Alliance 2023)
Minimum Standards and Guidelines on Age and Disability in Emergencies (ACAPS 2015)
Operational guidance for infant feeding in emergencies (OG-IFE) (IFE Core Group 2017) Includes disability and feeding considerations in emergencies and update OG-IFE-Update Disability.pptx (live.com) (slides 18-23)
Policy brief: Improving Nutrition Among Children with Feeding Difficulties and Disabilities: Call to Action for Policymakers (USAID Advancing Nutrition 2022; English, Spanish and French)
UNICEF Disability Policy and Strategy (DIPAS) 2022-2030 (UNICEF 2023)
WFP Disability Inclusion Roadmap (2020-2021) (WFP 2020)
WHO policy on disability (May 2021), factsheet Global report on health equity for persons with disabilities (WHO 2022)
Examples of specific guidelines with reference to disability in u6m
Guideline: Counselling of Women to Improve Breastfeeding Practices (WHO 2018) Common challenges and contexts are outlined in the recommendations section and include “ <i>the specific needs of mothers...with mental health difficulties; mothers of infants with special needs, e.g. low birth weight or disability:...</i> ” [pages 12, 44] Anticipatory breastfeeding counselling that address specific challenges that include those mothers with infants with special needs e.g. low birth weight or disabilities ^d [pages 15, 45; key question 6 page 62] and the need for “ <i>more specialist capacity to counsel mothers with heightened needs, such as stressed or traumatized mothers, malnourished infants and mothers, low-birth-weight infants, and infants with disability and feeding difficulties, may be needed.</i> ”
Guidance for prevention and management of wasting and nutritional oedema (WHO 2023) Includes various references to assessment, referral, continuity of care for infants at risk of poor growth and development: see section below for more information (see comments below this table)

^d Note: not mentioned in guidance but anticipatory breastfeeding counselling could also be relevant for mothers living with a disability

<p>Statistics</p> <p>Global Report on Children with Developmental Disabilities (WHO 2023)</p> <p>Global Report on Health Equity for Persons with Disabilities (WHO 2022)</p> <p>Seen, Counted, Included: Using Data to Shed Light on the Well-being of Children with Disabilities (UNICEF 2021)</p> <p>The State of the World's Children 2013. Children with Disabilities (UNICEF 2013)</p>
<p>Other general resources related to disability in emergencies</p> <p>Disabilities Among Refugees and Conflict Affected Populations: Resource Kit for Field Workers (WRC 2008)</p> <p>Disability and Emergency Risk Management for Health. Guidance Note (UNICEF, WHO, UNISDR, CBM, ICRC, IOM 2013)</p> <p>2023 Global Survey Report on Persons with Disabilities and Disasters (UN Office for Disaster Risk Reduction 2023)</p> <p>Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action (IASC 2019)</p>

The [WHO guidance for prevention and management of wasting and nutritional oedema](#) (2023) includes a section on Infants at Risk of Poor Growth and Development. This “living guideline” contains various references to disability/ disabilities, with those relevant to u6m and their mothers outlined below:

- The need for **in-depth assessment** to consider if inpatient admission or outpatient admission is needed for an infant with a disability, this includes cerebral palsy or other physical disabilities [page 12]
- **Comprehensive assessments of the mother/caregiver-infant pair** and following best practices for the management of breastfeeding/lactation challenges and underlying factors contributing to these challenges [pages 56, 59] and ensuring consideration of any “maternal-related or social issue needing more detailed assessment or support (e.g. disability, depression of the caregiver...)” [pages 13-14, 49]
- **Feeding assessments** should include “the following domains: infant and mother/caregiver health status (including assessing for disabilities)...” [remarks page 50]
- **Linkage to related services:** “consider how best to link with related services (e.g. Integrated Management of Newborn and Childhood Illness; immunizations; growth monitoring; mental health; disability treatment services)
- **Safe and effective follow up, including need for longer term follow up, referral, transfer to services after inpatient care and emphasis on continuity of care** [pages 54, 57, 72 B3, 75 B4]: “medical problems needing mid or long-term follow-up care and with a significant association with nutritional status could include congenital heart disease, HIV, tuberculosis, cerebral palsy or other physical disabilities” and more specifically “physiotherapy/speech and language therapy for feeding difficulties associated with cerebral palsy or other disabilities, psychological support groups for children and their caregivers, etc.”
- **Research needs** [pages 53, 56, 60]: “Future studies should include infants with disabilities” and “consider how best to link with related services (e.g...disability treatment services)”^e

^e And inclusion into country level healthcare systems.

4. Evidence

Disability Evidence Portal (DEP)

In Africa, the **Disability Evidence Portal (DEP)** (disabilityevidence.org) has been established as “a knowledge exchange platform that seeks to enable and empower decision makers with evidence-based knowledge to make decisions on how best to improve access, health, education, livelihood and social outcomes for people with disabilities worldwide.....through acting as a repository of solutions, evidence and tools for strengthening decision-making within Disability-Inclusive Development.” DEP aims to do this through the following steps:

- Identifying questions that highlight gaps in knowledge around disability-inclusive development
- Informing disability-inclusive policy- and decision-making through high-quality evidence synthesis (“briefs”)
- Address the evidence-to-action gap using innovation digital knowledge management solutions.

DEP is implemented through the [Institute for Life Course Health Research](#) at Stellenbosch University in South Africa and was founded by the [International Centre for Evidence on Disability](#) (ICED) at the London School of Hygiene and Tropical Medicine. The inaugural conference on “Disability, Inclusion, and Health in Africa and beyond” will be followed by a series of webinars outlining country experiences.

Research gaps

There is a critical need for **relevant practical research** for disability-inclusion. Infants with disability are often excluded from health and nutrition research trials, which contribute to a huge gap in evidenced guidelines that comprises care. They are also often excluded from being counted in census data and other data collection tools that help us understand how big the issue is. Several studies highlight critical consequences and important considerations for researchers, practitioners and policy-makers, some of which are listed below.

- **Long term nutritional consequences of disability**,¹⁴ found for those with disabilities and those who are malnourished having increased risk of developing disabilities or exacerbating existing disabilities and the urgent need for nutrition and **disability** programmes to work more inclusively.^{15,2}
- Infants and children with disabilities are **more likely to be malnourished**,^{3,8,9,16,17} with the risk of specific disabilities such as **cerebral palsy**^{18,19} and **cleft palate**^{20,21,22} well documented.
- There is **exclusion of children with disabilities in malnutrition protocols and guidelines**.²³ “Only 4% of guidelines reviewed had a specific section for children living with disabilities, while the remaining lacked guidance on consistently including them in programmes or practice. Only one guideline mentioned strategies to include children living with disabilities during a nutritional emergency.”
- **Vulnerable sub-populations include infants residing in institutions**^{24,25,26} should not be forgotten. (The second study showed that in institutions 22.7% of young infants and children had disabilities, 55.9% were low birth weight; 39.7% premature and 11.3% had feeding difficulties.)
- Available **training programmes**^{27,28,29} for caregivers and health workers of infants with disabilities exist but require assessment on their feasibility, outcomes and scalability.
- Which **anthropometric measures** may be appropriate for certain disabilities for both assessment and monitoring of nutritional status, including **mid-upper arm circumference**,³⁰ **assessment of neurodisability and malnutrition**³¹ and which growth references/standards are appropriate (as infants with disabilities may follow other growth trends) are important aspects to consider for correct interpretation and management.
- Need to consider the needs of **mothers/caregivers with disabilities**³² to better support them as they care for their infants. Addressing caregiver needs can improve child outcomes, strengthen families and reduce risk of family separation.
- **Exclusion of children with disabilities in research**, the need for more data,³³ especially for prevalence in infants u6m, and the need to involve participation of individuals with disabilities or caregivers in research.³⁴

5. Ongoing Initiatives

There are many ongoing initiatives around disability. The following highlights some work in this area that could be relevant to MAMI Global Network members.

- **DEP research focus (disability in Africa) and webinar series** (disabilityevidence.org)
- **Feeding Difficulties and Disability resource bank:** transition to and management by UNICEF (www.advancingnutrition.org)
- **IYCF Image bank:** transition to UNICEF and inclusion of disability in the UNICEF IYCF counselling cards
- **Disability webinar** (IFE-Core Group, MAMI Global Network, Global Nutrition Cluster Technical Alliance (*planned early 2024*) (<https://www.nutritioncluster.net/events>)
- **Strengthening disability inclusive nutrition in humanitarian contexts** (GNC/Alliance): consultancy to develop an interactive tool for frontliners in identifying and managing feeding difficulties and addressing the nutritional needs of young children (and potentially caregivers) with disabilities. (*Terms of reference to be shared*)
- **Field Exchange articles featuring practical examples of managing disabilities** (fex@enonline.net)
- **Forthcoming Lancet series on disability and nutrition** (2024)

The MAMI Global Network will continue to share existing resources and research in its monthly newsletter, at its various group meetings and via its network. We invite all to contribute new resources or examples of ongoing research or practical work to add to this brief.

Please share with mami@enonline.net

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Annex 1 Inclusion of disability in the MAMI Care Pathway V3 (2021)

The MAMI Care Pathway approach applies an integrated care pathway model to the context of at-risk mother-infant pairs. The associated Package provides practitioners with a resource to screen, assess, and manage small and nutritionally at-risk infants under six months and their mothers. Disability is found in the following sections of the MAMI Care Pathway package:

- Found within the **MAMI Assessment Form** as per Integrated Management of Childhood Illness (IMCI) questions to assess if an infant has a congenital condition or disability:

STEP 2 ASSESS CLINICAL SIGNS AND SYMPTOMS (infant)

CLINICAL SIGNS & SYMPTOMS	Classify according to IMCI	Green	Yellow	Pink
	Diarrhoea	none	mild/moderate	severe
Fever	none	mild/moderate	severe	
Cough	none	mild/moderate	severe	
Severe pallor (anaemia)	none	–	severe	

CLINICAL SIGNS & SYMPTOMS	Classify according to IMCI	Green	Yellow	Pink
	Any other illness (refer to IMCI)	none	mild/moderate	severe
Specify other illness:				
Congenital condition/disability causing feeding difficulty (e.g. cleft lip, tongue tie)	none	yes:		

- Listed within the associated **MAMI Assessment Guide** including notes as to whether a hospital referral is required. *Note:* this is further described in recent WHO guidance (see 3.1) for prevention and management of acute malnutrition/wasting which recommends referring infants with disability for “in-depth assessment” to determine inpatient or outpatient care.



MAMI Assessment Guide

Management of small & nutritionally at-risk infants under six months & their mothers

Notes
 1. Refer to MAMI Counselling Cards and Support Actions Booklet.
 2. Cleft lip/palate and tongue tie may not require hospital referral depending on severity, age of infant, and service availability. Referral to community-based specialist may be sufficient.
 3. If a child has a congenital condition/disability but normal anthropometry, then non-urgent hospital referral is appropriate.
 4. Failure to gain adequate weight is defined as weight gain less than 5g/kg/day or failure to gain weight as reported by the mother.
 5. The decision to enrol infants from multiple births or from adolescent mothers or mothers with MUAC less than 230mm based on these criteria alone will depend on case load and context.
 6. The MAMI Maternal Mental Health Screening uses the Patient Health Questionnaire-2 (PHQ-2) which screens for depression. Information on calculating the score is provided in the MAMI Maternal Mental Health Summary

ASSESS

CHECK FOR:

1. DANGER SIGNS

GENERAL DANGER SIGNS:

- Unable to breastfeed / drink
- Vomits everything

Refer to IMCI for details on danger signs

MAMI-SPECIFIC DANGER SIGNS:

- Bilateral pitting oedema (+, ++, +++)
- Mother appears out of touch with reality or at risk of harming herself or infant; visible physical neglect (mother or infant)

2. CLINICAL SIGNS AND SYMPTOMS

IMCI MAIN SYMPTOMS:

ASK:

- Diarrhoea?
- Fever?
- Cough?
- Any other problem?

LOOK:

- Severe pallor (anaemia)
- Any other illness (refer to IMCI)

CHECK for congenital condition/disability causing feeding difficulty:

- Breathlessness or excessive sweating when feeding
- Coughing and eye tearing while feeding (signs of unsafe swallowing)
- Abnormal tone or posture
- Cleft lip or palate
- Tongue tie
- Other

MEASURE:

SIGNS	CLASSIFY	ACT
<p>ANY ONE OR MORE OF THE FOLLOWING SIGNS:</p> <ul style="list-style-type: none"> • Not able to feed at all or • Convulsions or • Severe chest indrawing or • Fast breathing or • High or low body temperature or • Movement only when stimulated or no movement at all or • Bilateral oedema (+, ++, or +++) 	VERY SEVERE DISEASE (INFANT)	<p>Provide pre-referral treatment according to IMCI</p> <p>Refer URGENTLY to hospital (treatment of acute problem(s) plus MAMI-specific support)¹</p> <p>OR</p> <p>If referral is REFUSED or NOT FEASIBLE, treat at nearest health facility until referral is feasible</p>
<ul style="list-style-type: none"> • Mother appears out of touch with reality or at risk of harming herself or infant; visible physical neglect (mother or infant) 		SEVERE MENTAL HEALTH CONCERN (MOTHER)
<p>IMCI MAIN SYMPTOM(S) REQUIRING HOSPITAL REFERRAL OR</p> <p>ANY CONGENITAL CONDITION/DISABILITY CAUSING FEEDING DIFFICULTY²</p>	HIGH RISK (INFANT)	<p>IMCI MAIN SYMPTOM(S) → Hospital referral</p> <p>Congenital condition/disability → Hospital referral³</p>
<p>ANY ONE OR MORE OF THE FOLLOWING SIGNS:</p> <ul style="list-style-type: none"> • Infants under 6 weeks: MUAC less than 110 mm • Infants 6 weeks to less than 6 months: MUAC less than 115 mm or • WAZ less than -2 or • WLZ less than -2 or • Recent weight loss or failure to gain weight⁴ or • Neonate has not regained birthweight by two weeks of age <p>AND CLINICALLY STABLE, ACTIVE & ALERT</p>	MODERATE RISK (INFANT)	<p>Manage any minor illness according to IMCI</p> <p>Enrol in MAMI Outpatient Care</p>

• **MAMI Care Pathway health worker support materials user booklet:**

STEP 2: ASSESS CLINICAL SIGNS AND SYMPTOMS (infant)										
CLINICAL SIGNS & SYMPTOMS	Classify according to IMCI	Green	Yellow	Pink	CLINICAL SIGNS & SYMPTOMS	Classify according to IMCI	Green	Yellow	Pink	Infants should be assessed and classified for clinical signs and symptoms according to IMCI protocols with appropriate actions (e.g. those with mild/moderate illness go to outpatient care, severe illness to inpatient care).
	Diarrhoea	none	mild/moderate	severe		Any other illness (refer to IMCI)	none	mild/moderate	severe	
	Fever	none	mild/moderate	severe		Specify other illness:				
	Cough	none	mild/moderate	severe		Congenital condition/ disability causing feeding difficulty (e.g. cleft lip, tongue tie)	none	yes:		
	Severe pallor (anaemia)	none	–	severe						
	Specify other illness:									Any congenital condition/ disability causing feeding difficulty should be noted and referred to hospital or specialised services for treatment. If a child has a congenital condition/ disability but normal anthropometry, then non-urgent hospital referral is appropriate.
	Congenital condition/ disability causing feeding difficulty (e.g. cleft lip, tongue tie)	none	yes:							

[Note: disability is further described in recent WHO guidance (see policy section) for prevention and management of wasting which recommends referring infants with disability for “in-depth assessment” to determine inpatient or outpatient care rather than always direct admission to inpatient care.]

Tongue or lip tie can contribute to feeding difficulties. See:

Messner AH, Walsh J, Richard M, Rosenfeld RM et al. Clinical consensus statement: ankyloglossia in children. Otolaryngology–Head and Neck Surgery 2020, Vol 162(5) 597–611. <https://doi.org/10.1177/0194599820915457>



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