

Virtual Convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities

April 26, 2023 (Day One)



Please introduce yourself
in the chat box
(name, title, location)



Zoom Meeting Overview

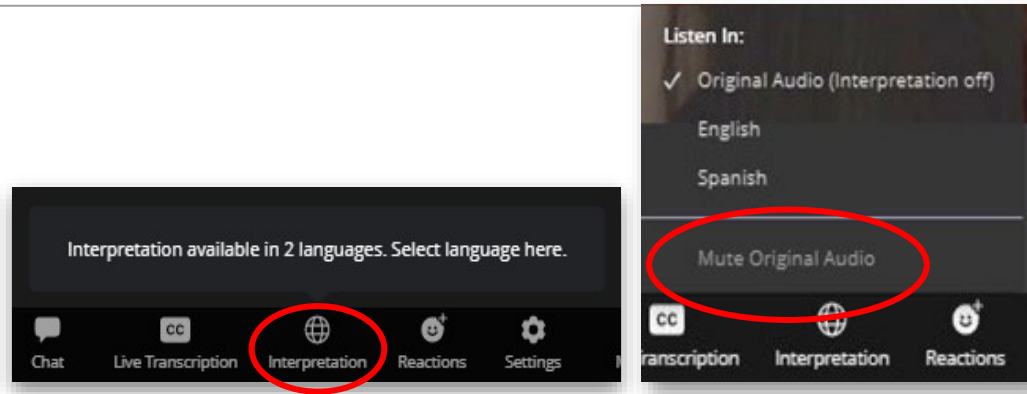
If you have any questions or issues during today's Convening, please reach out to either **Tech Support 1—Ben** or **Tech Support 2—Yaritza** in the chat box, or emailing info@advancingnutrition.org

Please note that plenary sessions during today's meeting are being recorded.

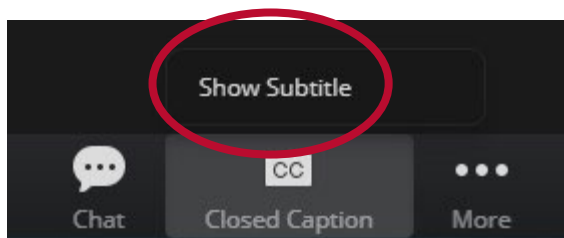
Recording and materials will be shared on USAID Advancing Nutrition's website after the event and emailed to all registered participants.

Accessibility—Zoom Language Interpretation

English	<p>Click the Interpretation icon to have the option to hear the meeting in Spanish. To hear the meeting only in Spanish, select Mute Original Audio.</p> <p>If you are listening in English, please make sure to select English from the interpretation channels to hear comments/questions from colleagues when they are interpreted from Spanish to English.</p>
Español	<p>Haga clic en el icono de "interpretación" para escuchar la reunión en español. Para escuchar sólo en español, desactiva el audio original.</p>

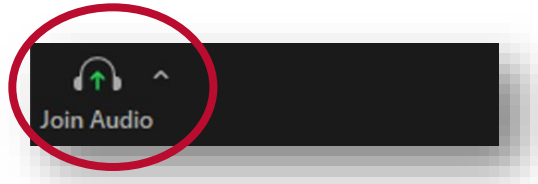


Accessibility—Zoom Meeting

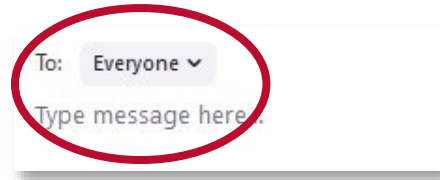


- We have enabled the Zoom closed captioning feature. To start viewing live subtitles on your screen during today's meeting click the **Closed Caption** icon and select **Show Subtitle**.
- Speak slowly and clearly to maximize accuracy of interpretation and closed captions

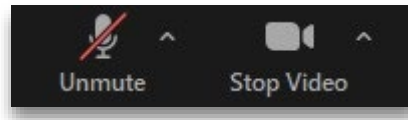
Housekeeping—Zoom Meeting



- If at any point you are unable to hear the speakers, check to make sure you've connected your audio by clicking on the headphones icon in your Zoom controls.



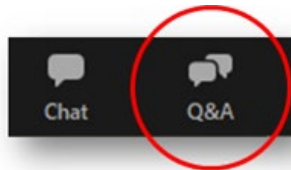
- Send a message to *Everyone* to introduce yourself to all the other participants, to send in your comments and questions, or ask for tech support.



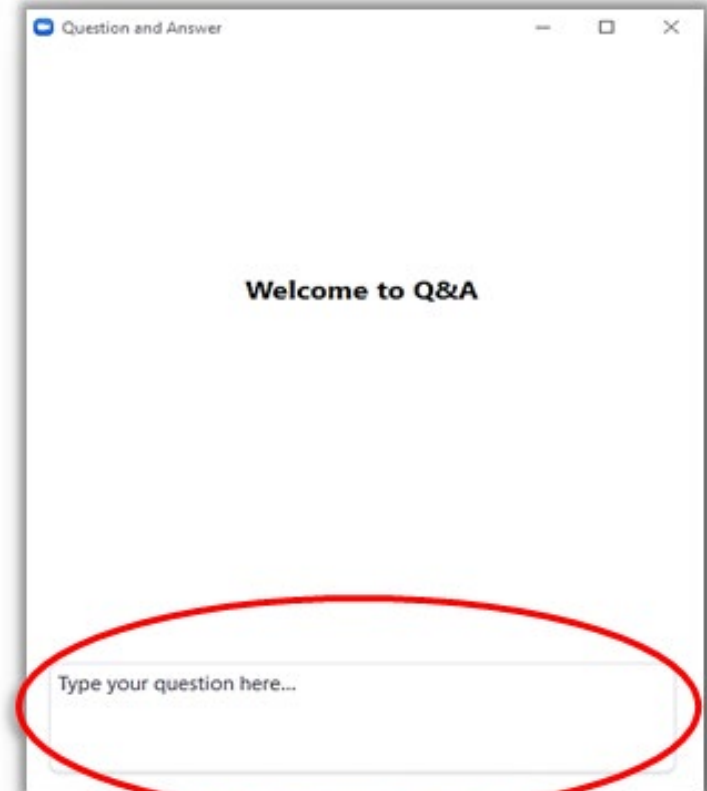
- You are welcome to turn on your video when speaking, presenting, or engaging with other participants, but please remember to mute yourself and turn your video off when others are speaking or delivering presentations.

Housekeeping—Q&A box

- We will be using the Q&A for questions for speakers during the various sessions
- To access the Q&A box, click on the icon in your Zoom control bar labeled **Q&A**

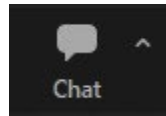


- To submit your question in the Q&A box, type your question in the space provided and press “Enter” on your keyboard

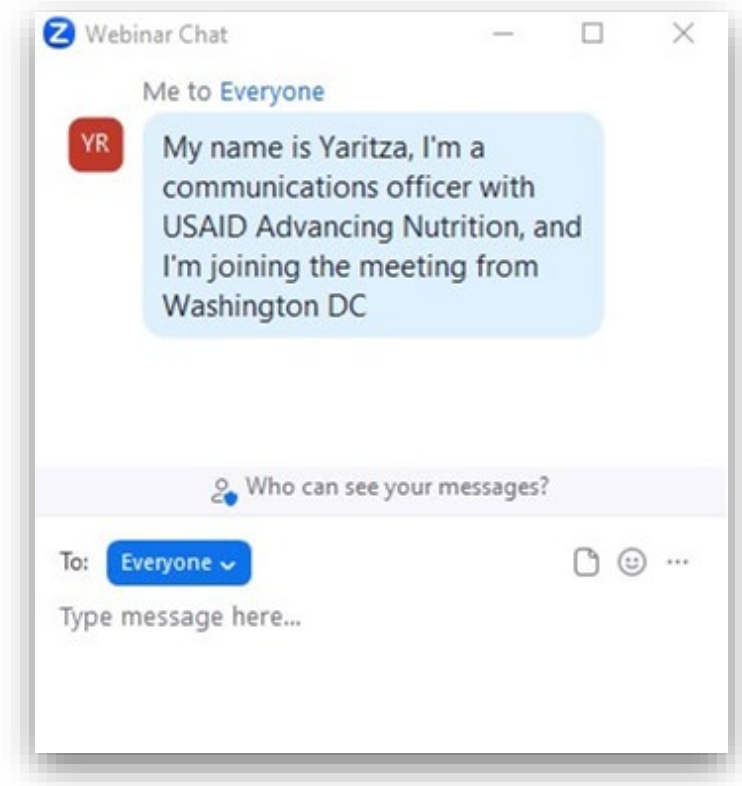


Housekeeping—Chat box

- We will be using chat box for introductions, general reflections, or technical issues
- To access the chat box, click on the icon in your Zoom control bar labeled **Chat**



- To send a message in the chat box, type your message in the space provided and press “Enter” on your keyboard





USAID
FROM THE AMERICAN PEOPLE



for every child

WELCOMING REMARKS

Katherine Guernsey
Grainne Moloney



USAID
FROM THE AMERICAN PEOPLE

unicef



| for every child

CONVENING INTRODUCTION & OVERVIEW

Lori Baxter

Convening Objectives

1. Review gaps in policy, programming and research related to sufficiently supporting children with feeding difficulties and disabilities and their families;
2. Share and discuss approaches to identify, support, and track children with feeding difficulties and disabilities in nutrition programs for young children;
3. Identify key steps stakeholders can take to address some of these gaps
4. Discuss priorities for future research and learning.

Agenda Overview—Day 1, Wednesday, April 26th

Scene Setting

Time EDT	Session Name
8:00–8:15 EDT	Formal Welcome
8:15–8:30 EDT	Convening Introduction and Overview
8:30–9:00 EDT	Keynote Presentation: Setting the Stage
9:00–9:30 EDT	Plenary Presentation: Strengthening Services for Children with Feeding Difficulties and Children with Disabilities
9:30–9:45 EDT	Break
9:45–10:25 EDT	Breakout Sessions: Identifying and Supporting Children with Feeding Difficulties and Disabilities
10:25–11:10 EDT	Storytelling Panel: Nutrition and Disability In Action
11:10–11:20 EDT	Day 1 Wrap-up

Presenter bios and agenda available at: <https://sites.google.com/view/jsi-disability-convening-2023/>

Agenda Overview—Day 2, Thursday, April 27th

Bringing Nutrition and Disability Together

Time	Session Name
8:00–8:15 EDT	Welcome and Day 2 Overview
8:15– 9:00 EDT	Panel Discussion: Evidence and Tracking
9:00–9:45 EDT	Breakout Sessions: Learnings and Next Steps
9:45–10:00 EDT	Break
10:00–10:45 EDT	Panel Discussion: Bridging the Gap and Breaking Down Silos
10:45–11:05 EDT	Next Steps
11:05–11:15 EDT	Closing

Presenter bios and agenda available at: <https://sites.google.com/view/jsi-disability-convening-2023/>

1. Which region are you associated with and/or joining from?

- Pacific (Oceania)
- Asia
- Africa
- Eastern Europe
- European Union
- Middle East
- North America
- Latin America and the Caribbean

2. How do you identify yourself?

- person with a disability
- person without a disability
- prefer not to disclose

3. How would you classify your professional focal area and expertise?

(please choose your primary area)

- Disability
- Nutrition
- Maternal and/or Child Health
- Early Childhood Development
- Other

Key Definitions

Disability	Persons with disabilities include those with 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.
Disability Inclusion	Disability inclusion is the process that ensures that all persons with disabilities enjoy their full and fundamental rights and freedoms to fully and effectively participate with and within their families, communities, and societies without barriers and on an equal basis as those without disabilities.
Stunting	Shorter than expected for a healthy child of the same age, because of long-term effects of inadequate diet, illness or both. Low height-for-age.
Wasting	Thinner than expected for a healthy child and at increased risk of death, often because of inadequate diet or illness. Low weight-for-height or low MUAC.
Undernutrition	A result of deficiencies in a person's intake, absorption of energy and/or nutrients, or illness, increasing risk of illness and death.

Sources & additional terminology available at: <https://www.advancingnutrition.org/resources/disability-resource-bank/terminology>



USAID
FROM THE AMERICAN PEOPLE

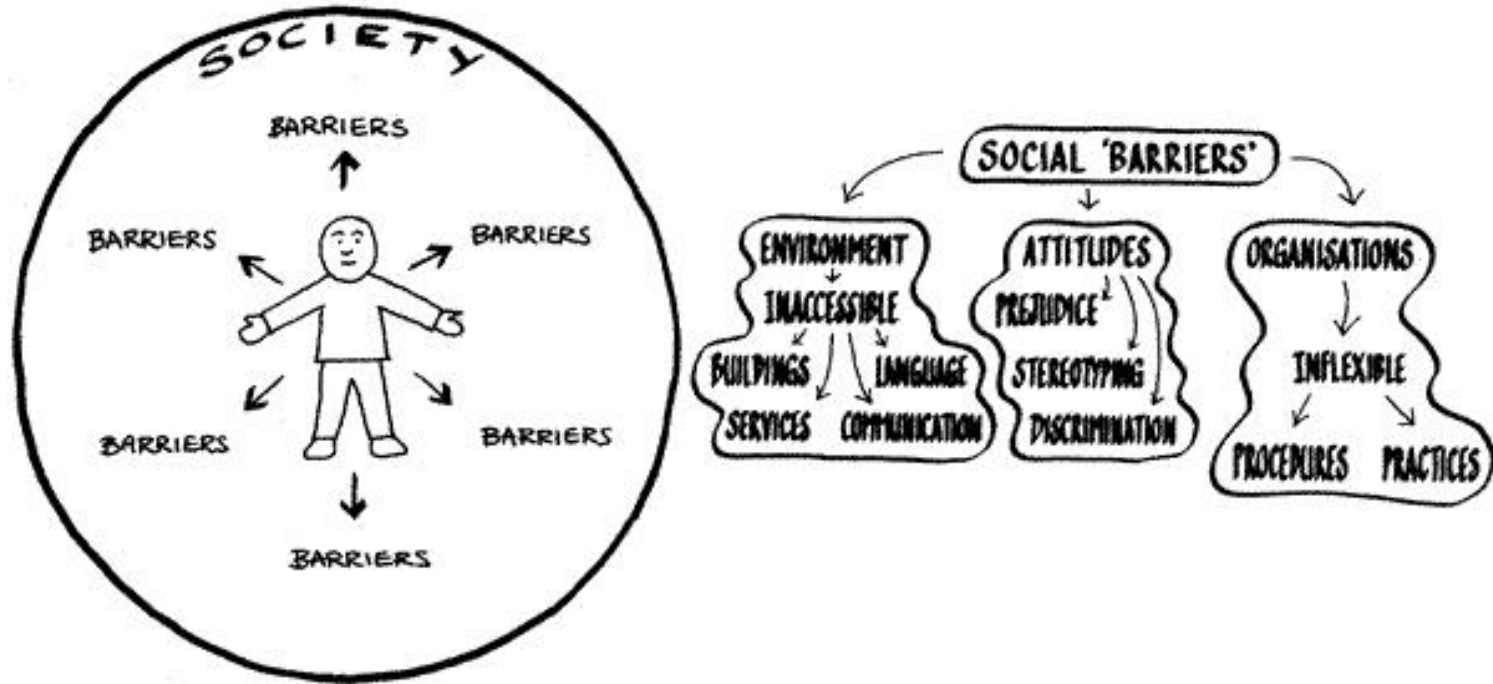


for every child

GUIDING FRAMEWORKS

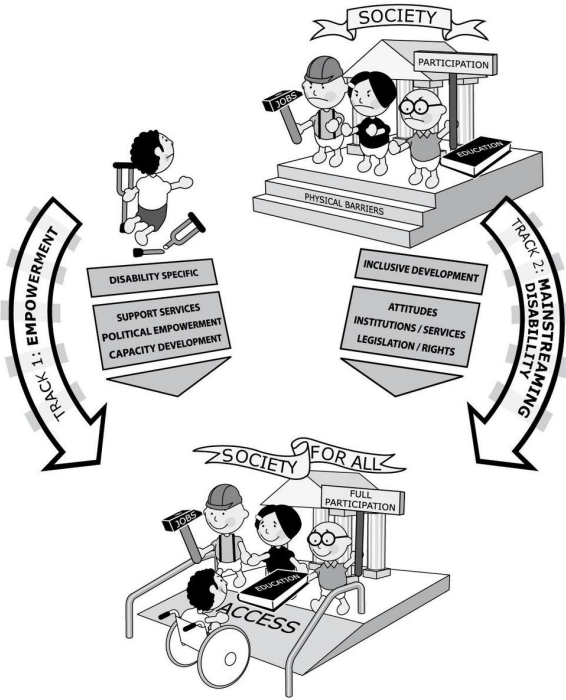
Guiding Frameworks: Social Model of Disability

THE SOCIAL MODEL OF DISABILITY



Guiding Frameworks: Twin Track Approach

TWIN TRACK APPROACH TO DISABILITY & DEVELOPMENT

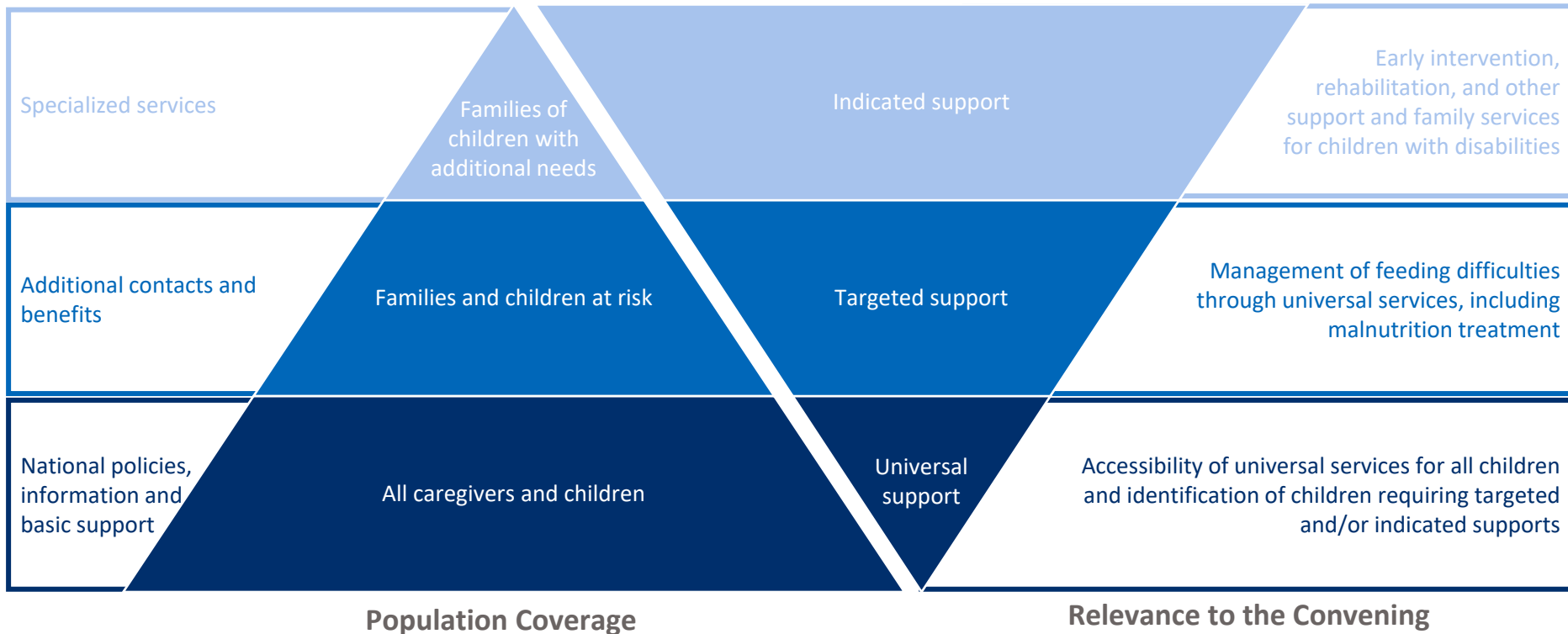


Source: CBM

Guiding Frameworks: Universal Progressive Model

Level of Support

Intensity of Intervention



Adapted from the Nurturing Care Framework (WHO, UNICEF, and the World Bank, 2018).

Guiding Frameworks: Socio-Ecological Model



Source: Nurturing Care Framework (WHO, UNICEF, and the World Bank, 2018).



USAID
FROM THE AMERICAN PEOPLE



| for every child

KEYNOTE ADDRESS

Vivían Fernández de Torrijos



USAID
FROM THE AMERICAN PEOPLE



| for every child

KEYNOTE PRESENTATION

Hannah Kuper



unicef | for every child

Setting the Scene: Childhood Disability, Exclusion, and Nutrition

Professor Hannah Kuper

London School of Hygiene & Tropical Medicine
Missing Billion Initiative



Outline

- Childhood disability
- Exclusions facing children with disabilities
- Childhood disability and nutrition



The Lancet

What is childhood disability?



Guardian newspaper November 2008

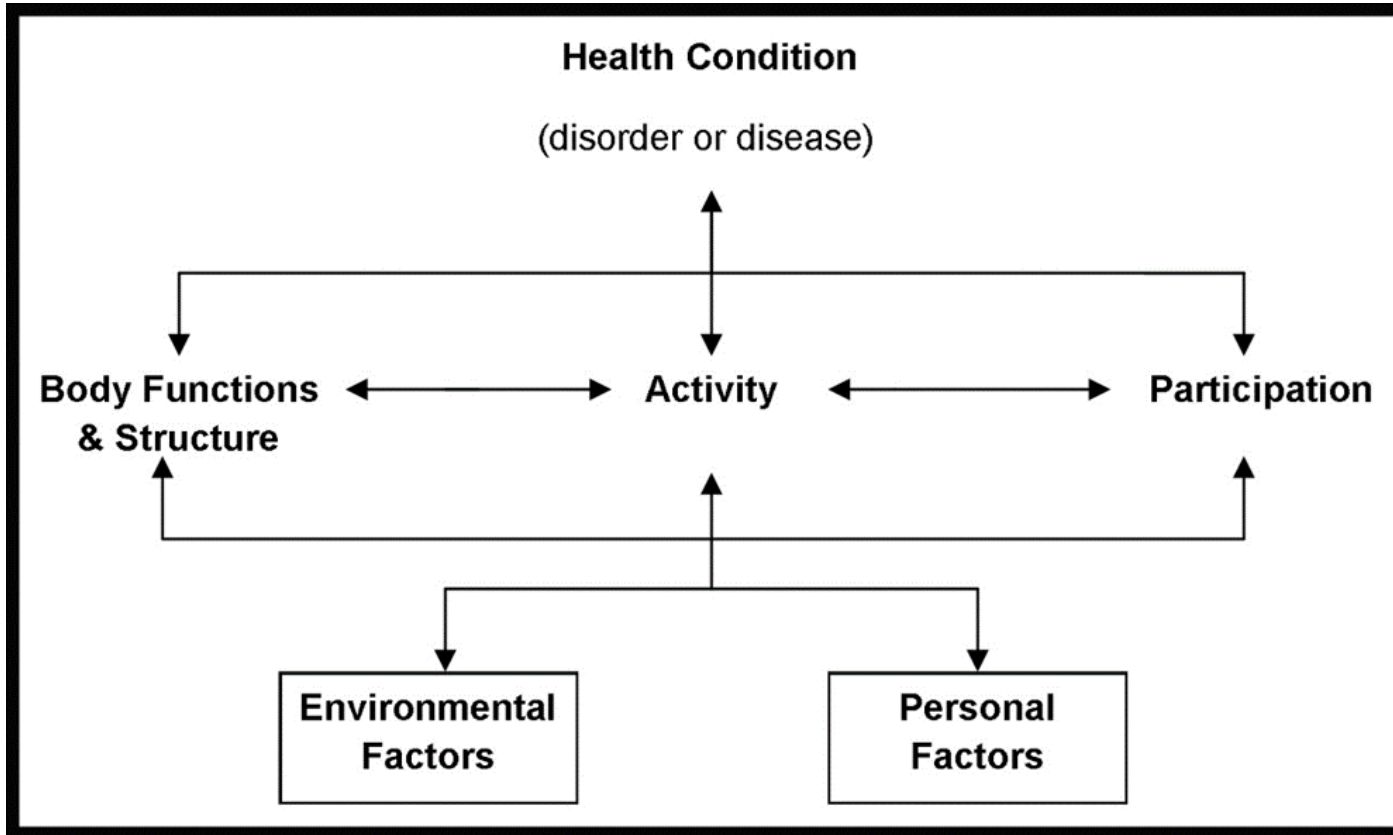
Medical Model



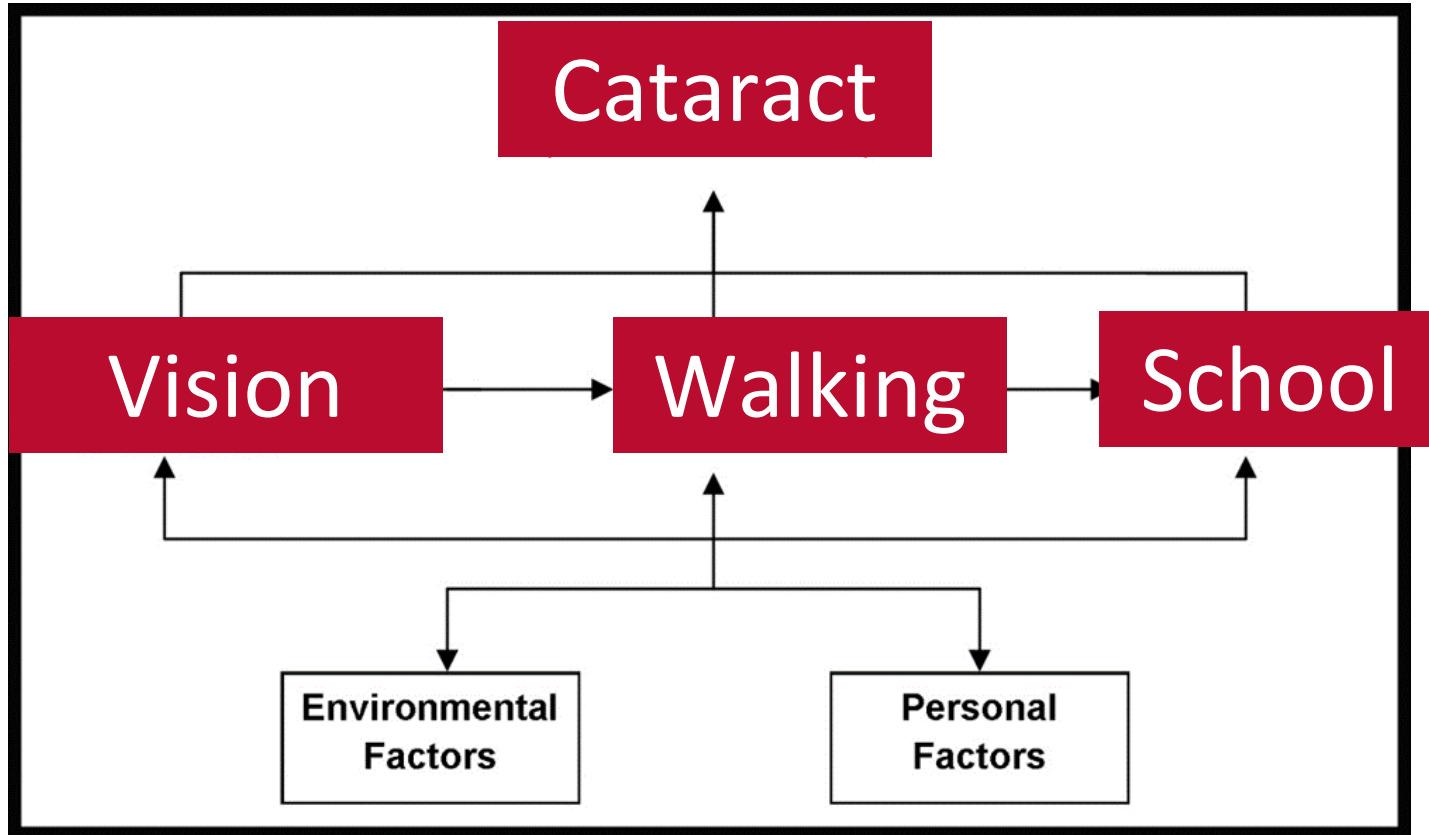
TMS website

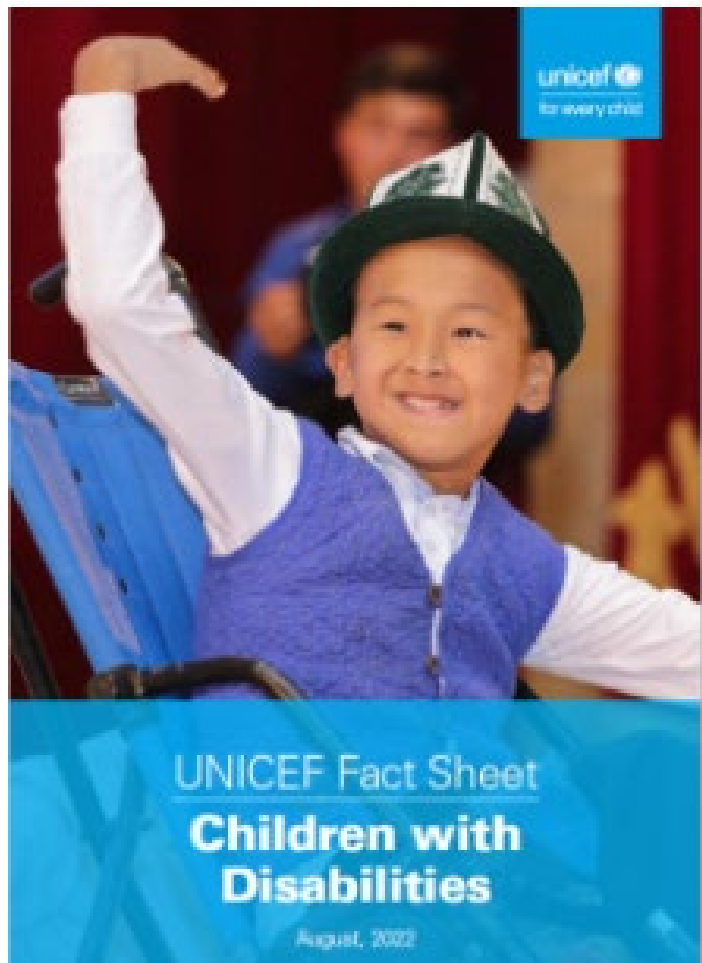
Social Model

WHO-Endorsed Model



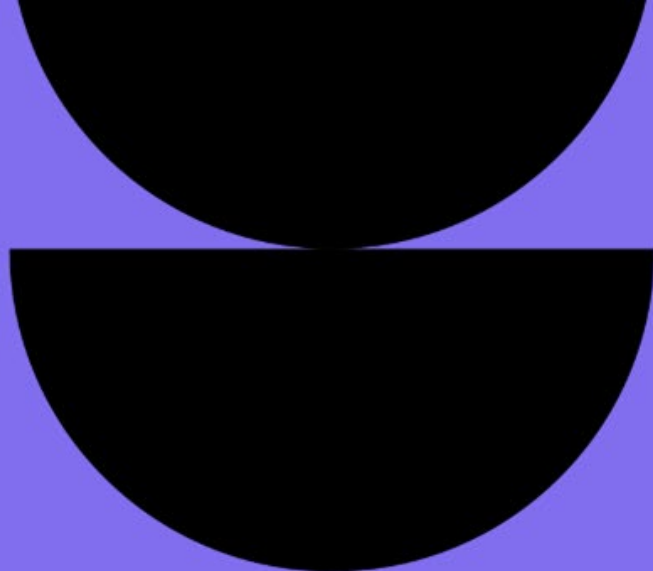
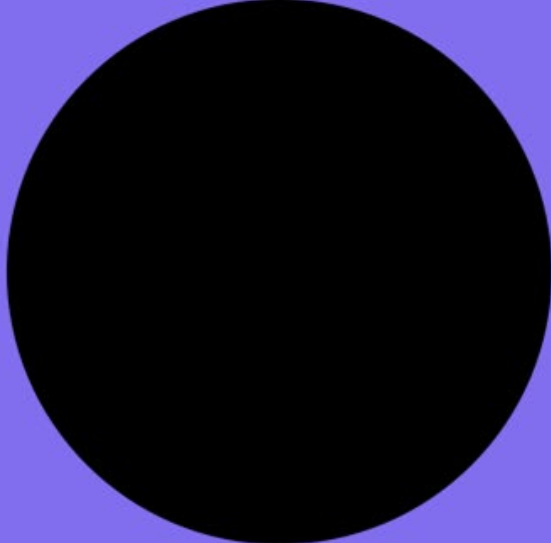
WHO-Endorsed Model: Example





Childhood Disability: The Facts

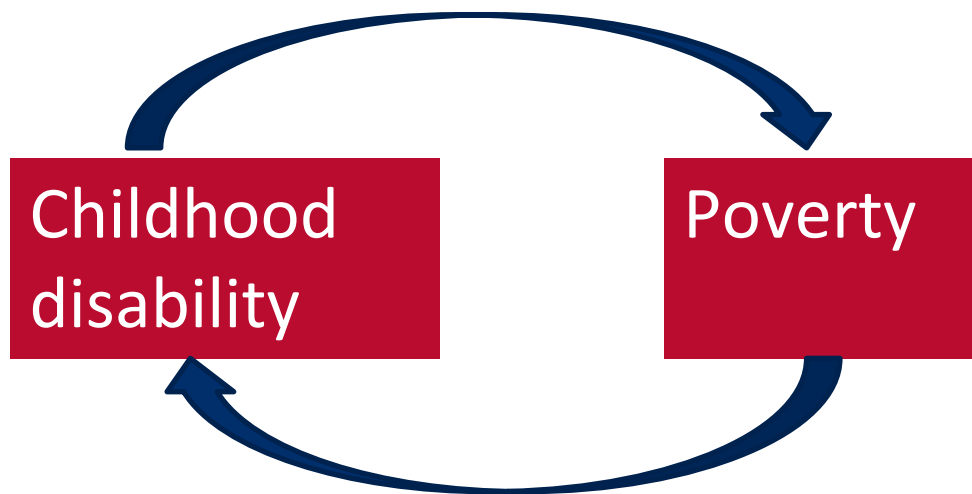
- 240 million children
- 10% of all children
- 80% live in low- and middle-income countries



**Disability
is extremely
diverse**



Poverty and Childhood Disability Closely Linked



“I am not able to make as many mats as other women make. I only make one mat every month while other women make even 5 mats. Sometimes I am not able to make any mats at all.”

“We are unable to save any money for the future because almost everything is spent on the treatment of our child....”

Talk point: Fighting the stigma of disability

Mosharraf Hossain has battled against prejudice in Bangladesh. Find out about him and other people living with disability across the globe

Interactive: Global development voices - living with disability



📷 People living with disability face daily challenges. Photograph: PhotoAlto/Michele Constantini/Getty Images/PhotoAlto

Children with Disabilities Face Widespread Negative Attitudes and Stigma

“Some say that it is God who is annoyed with them.”

Children with Disabilities Left Behind across SDGs



Children with Disabilities are More Likely....

Seriously ill as a child
10 x more likely

Experience early mortality
5 x higher mortality

Lower development index

Experience a range of health conditions:

- Acute respiratory infection
- Fever
- Diarrhea

Lower vaccination levels (some settings)

Systematic Review: Malnutrition and Childhood Disability in LMICs

17 studies

Children with disabilities:

3 x more likely to be underweight

2 x more likely to be stunted

2 x more likely to be wasted

Systematic Review

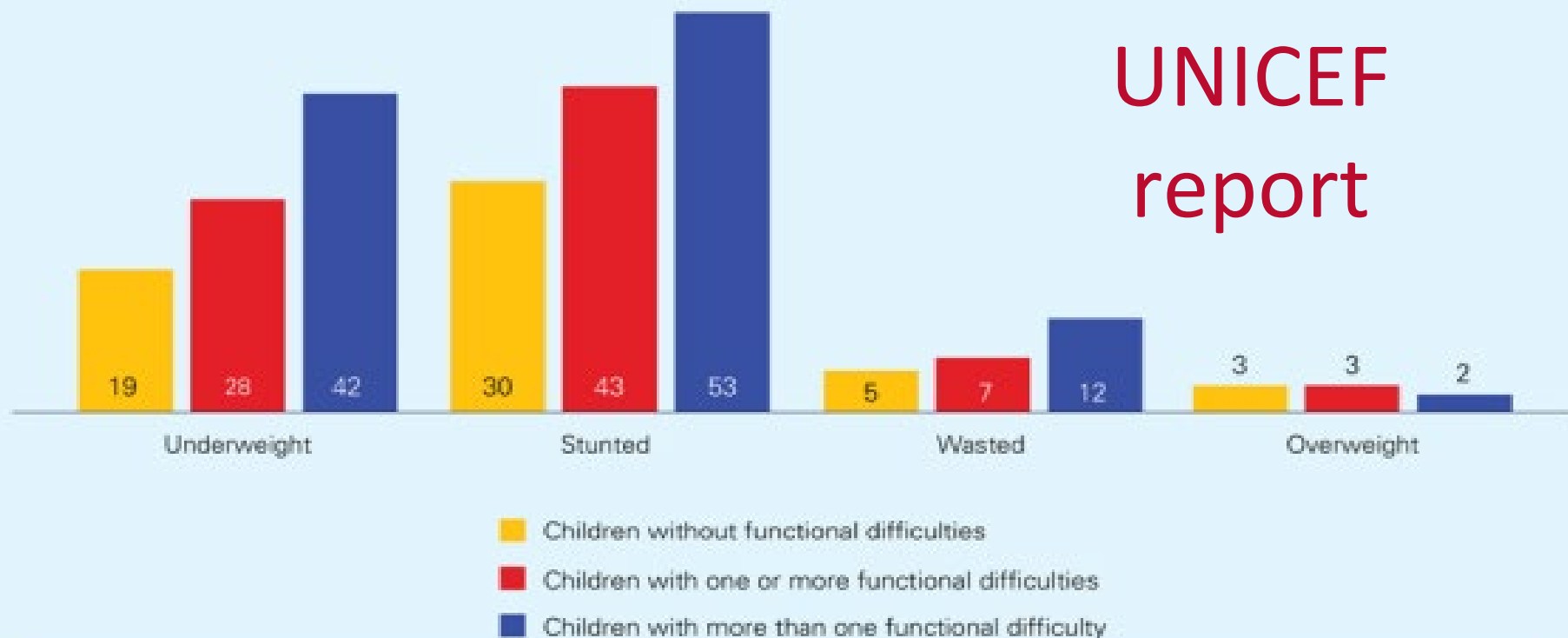
The association between malnutrition and childhood disability in low- and middle- income countries: systematic review and meta-analysis of observational studies

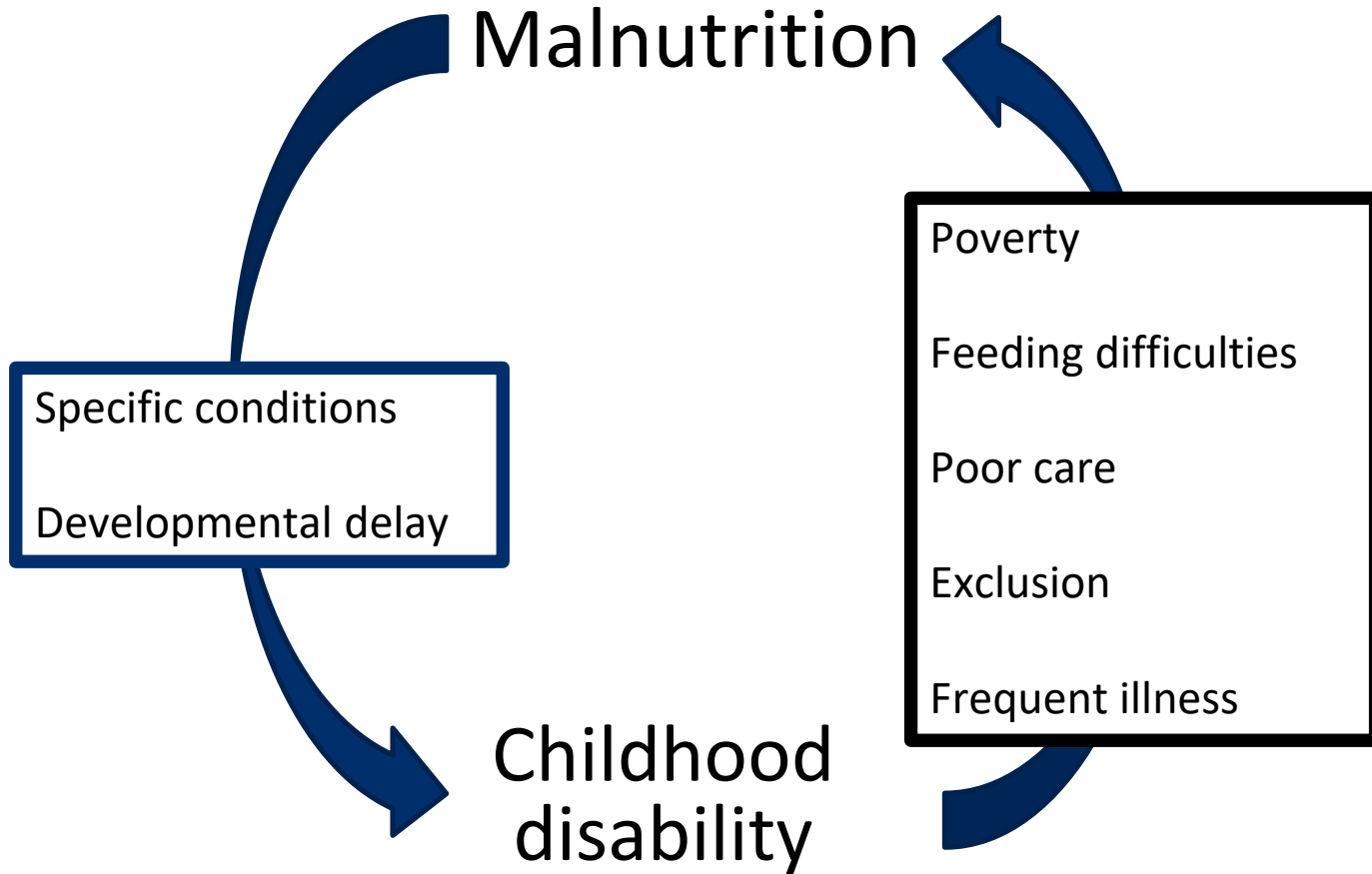
Maeve Hume-Nixon¹ and Hannah Kuper²

1 Hutt Hospital, Lower Hutt, New Zealand

2 International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, London, UK

FIGURE 3 Percentage of children aged 24 to 59 months who are underweight, stunted, wasted or overweight





This Issue Matters

- Achievement of Sustainable Development Goals and other goals
- Respecting human rights
- Maximising quality of life
- Maximising human capital

What are the implications of the link of childhood disability and malnutrition?

The Barriers that Caused Malnutrition Will Make Accessing Programs Difficult

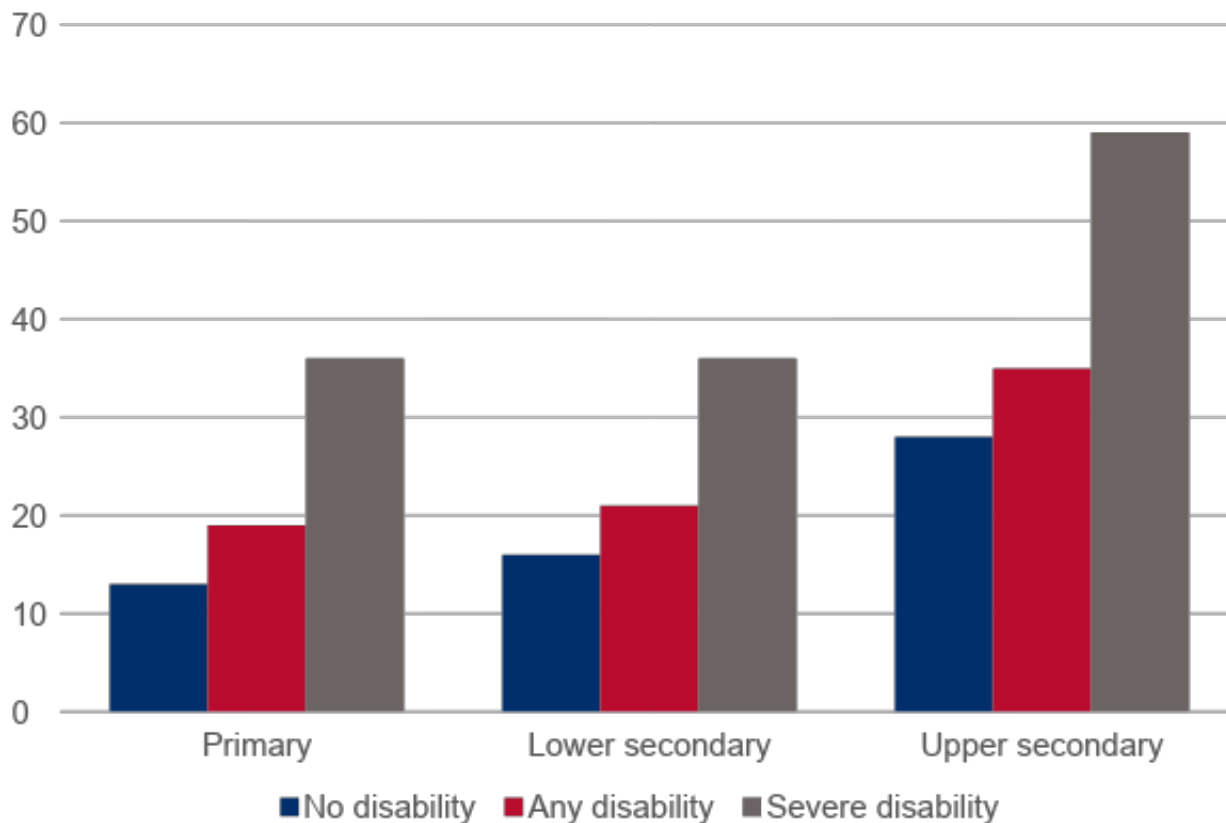
“I have not received any help so far. We are still waiting for aid. My sister’s children however ... [receive] maize and beans in school.”

“There is a food-for-work programme within the area, but I’m not a beneficiary. There is no way I can leave the child and go to work.”

“I used to carry my child across the lake ... where distribution of food used to take place. I would pay for a bicycle to transport the food to the lake shore, then put it on a boat and cross over. It is much easier for parents without children with special needs.”

Zuurmond et al., *African Journal of Disability*, 2016.

Children with Disabilities Out of School



School meals

418 MILLION

children are receiving school meals globally

US\$1 INVESTED

in school meals has a US\$9 return on investment

73 MILLION

vulnerable children are still in need of school meals



Principles for Inclusive Nutrition Programmes

1. Adopt a twin track approach
 - Inclusion in mainstream
 - Reach with targeted programmes
1. Work in partnership with people with disabilities
2. Mandate specification of budget line and monitoring indicators to promote disability inclusion

Thank you for your time and attention.

Question and Answers

Please put any questions in the Q&A Box!





USAID
FROM THE AMERICAN PEOPLE



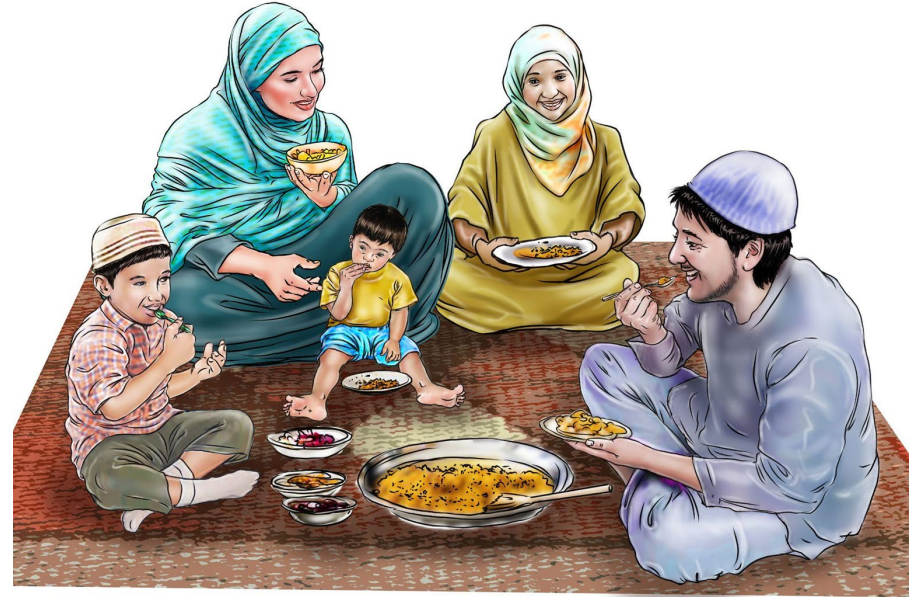
for every child

STRENGTHENING SERVICES FOR CHILDREN WITH FEEDING DIFFICULTIES AND CHILDREN WITH DISABILITIES

Alyssa Klein and Malia Uyehara
Raoul Bermejo

Improving Nutritional Care for Children with Feeding Difficulties and Disabilities

Alyssa Klein and Malia Uyehara, USAID Advancing Nutrition



Mixed Methods Scoping Review

- Objective: Understand the needs of children with feeding difficulties and children with disabilities

— Inclusion criteria:

- Age range: 0–5 years
- Feeding practices: breastfeeding and complementary feeding
- Settings: low- and middle-income countries

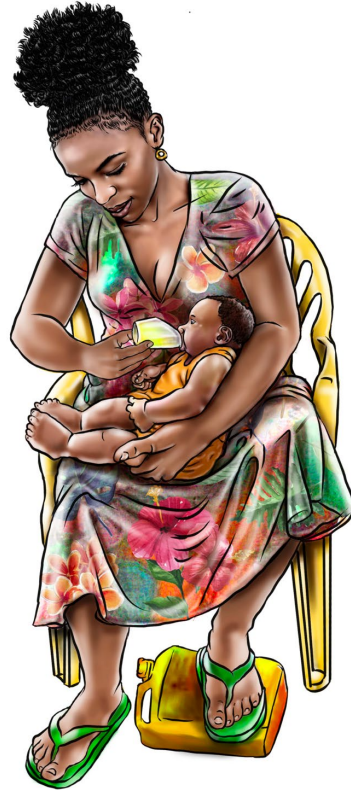


Topics

- Feeding difficulties (74)
- Disability (56)
- Complementary feeding (34)
- Screening and assessment of feeding difficulties (33)
- Breastfeeding (28)
- Routine services (24)
- Caregiver experiences (24)
- Small and sick newborns (17)
- Child development (16)
- Malnutrition treatment (10)

Klein, Alyssa, Malia Uyehara, Andrew Cunningham, Madina Olomi, Kristen Cashin, and Catherine M. Kirk. 2023. “Nutrition Care for Children with Feeding Difficulties and Disabilities: A Scoping Review.” *PLOS Global Health*. <https://doi.org/10.1371/journal.pgph.0001130>.

Identifying Feeding Difficulties



Children with disabilities may miss routine care for acute issues, because it gets 'hidden' or attributed to a disability.

(Health and Rehabilitation Workers)

It is a self-fulfilling prophecy: health workers don't treat the child with a disability (for malnutrition) because they say child is just going to die. And of course they die, because their malnutrition went unaddressed.

(Disability Researcher)

Images accessed from the USAID Advancing Nutrition-UNICEF IYCF Image Bank

Tools for Identifying Feeding Difficulties

- Tools and resources do exist!
- Not standardized or universally used
- Need for training
- Limited funding
- Testing and validation varies

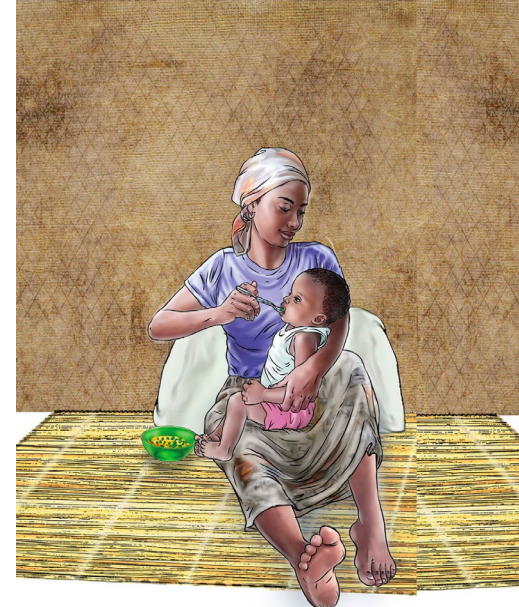


Image accessed from the USAID Advancing Nutrition-UNICEF IYCF Image Bank

Targeted Services for Managing Feeding Difficulties



The nutrition sector needs to provide program staff with better guidance and training on how to manage children with neurodisabilities. Further research is needed to understand the needs of nutrition sector staff and develop appropriate training.
(Donkor et al 2018)



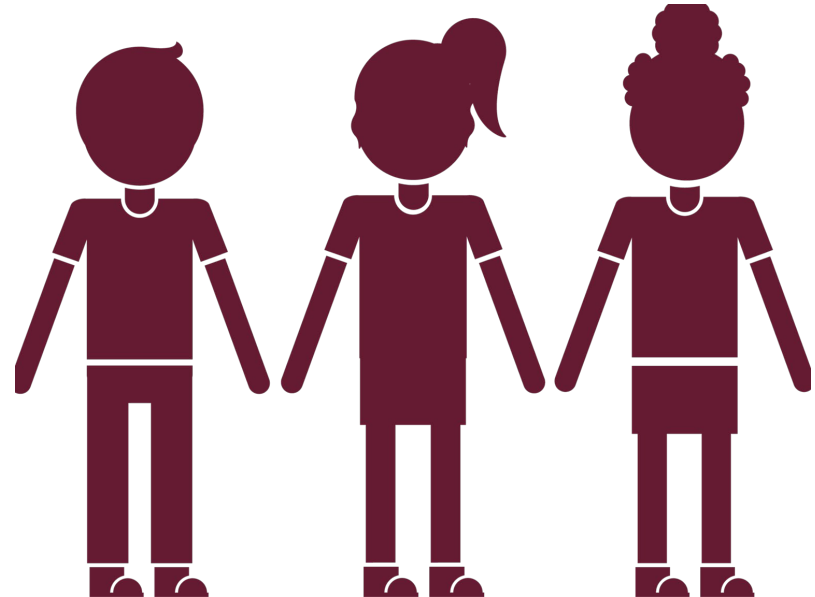
Images accessed from the USAID Advancing Nutrition-UNICEF IYCF Image Bank

Inclusion in Universal Services

- Exclusion and lack of access
- Data not disaggregated
- Knowledge, attitudes, and practices of health workers
- Provider time for counseling or support
- Lack of knowledge about feeding small and sick newborns
- Healthcare systems overstretched and underfunded for all children

You'll be lucky to get quality care for an acute health problem. If you're lucky you get one counseling session. But these contacts are insufficient.

(Health worker)



Indicated Services for Nutritional Care of Children with Disabilities



Image accessed from the USAID Advancing Nutrition-UNICEF IYCF Image Bank

Challenges

- Limited availability of and access to services
- Disconnected services and health systems
- Insufficient specialist workforce
- Services provided by civil society or donors

Promising examples

- Ghana university training program
- Rwanda early intervention
- Caregiver support groups

Enabling Environment in Communities and Families

Challenges

- Limited social support for caregivers
- Stress, stigma and exclusion
- Limited access to services
- Assistive technology not available

Promising Practices

- Day care centers
- Caregiver support groups
- Assistive products using locally-available materials



Photo Credit: Partners In Health/Inshuti Mu Buzima

Recommendation: Build the Evidence Base

- Conduct formative research with caregivers of children with disabilities.
- Intentionally include and track children with feeding difficulties and disabilities in implementation research on nutrition programs.









Working with children with complex needs and disabilities is seen as a ‘niche’ area and it doesn’t get the funding it needs. Have to find ways to get creative with funding to direct to the needs of these children.

(Rehabilitation Worker)

There is so much we still don’t know about supporting nutrition among children with disabilities because even countries that have massive general nutrition programs leave these children out.

(Disability Researcher)

Recommendation: Strengthen Health Systems

 Government	<ul style="list-style-type: none">● NGOs and civil society organizations provide services instead of governments (“charity”)● Lack of inclusive policies and programs
 Information systems	<ul style="list-style-type: none">● Disability-disaggregated data not available in nutrition and health services
 Financing	<ul style="list-style-type: none">● Lack of funding for disability-specific programming
 Service delivery	<ul style="list-style-type: none">● Lack of inclusion in routine nutrition services● Missed opportunities for early identification and intervention● Poor quality of rehabilitation services (where they exist)● Lack of guidelines and tools to address feeding difficulties and malnutrition
 Medicines and technology	<ul style="list-style-type: none">● Assistive products to support feeding unavailable in the health system
 Workforce	<ul style="list-style-type: none">● Limited skills and in-service training opportunities among primary health care workers● Lack of specialized workforce and job pipelines for rehabilitation trainees● Stigma and attitudinal barriers among health providers

Recommendation: Provide Direct Support to Families

- Foster family peer-to-peer support groups
- Include in nutrition and ECD services
- Provide access to assistive products
- Create guidance on inclusion in food distribution programs
- Prioritize in social protection and food supplementation programs



Photo Credit: Karen Martin/Ubuntu Hub

We need to have services at the community level, which is easier for families to access. The hospital should not be the only place these kids can go for support.

(Health worker)

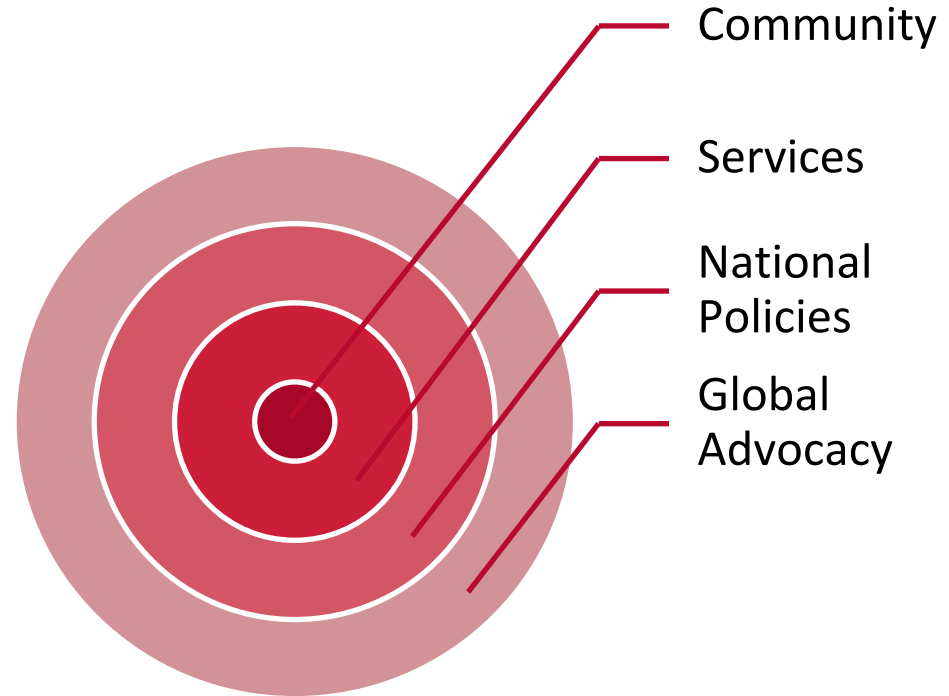
Recommendation: Conduct Advocacy

Policy-level

- Inclusion during donor and global forums
- Stakeholder workshops on needs, opportunities, and existing resources

Community-level

- Community-based inclusive development approaches



Feeding and Disability Resource Bank

- Web-based, open-access repository of resources to address feeding difficulties and disability inclusion in nutrition programs
- What is included:
 - manuals
 - job aids
 - training curricula
 - guidance documents
 - tools

Feeding and Disability Resource Bank

A collection of resources to address feeding difficulties and disability inclusion in nutrition programs

[SEARCH THIS RESOURCE BANK](#)

The Feeding and Disability Resource Bank is a repository of materials that help nutrition and disability program managers, government leaders, and donor agency staff design and implement effective nutrition programs for children with disabilities. According to the [United Nations Convention on the Rights of Persons with Disabilities](#) (CRPD), children with disabilities include those with, "long-term physical, mental, intellectual, or sensory impairments, and who may experience barriers that may hinder their full and effective participation in society on an equal basis with others."

[What Is in the Resource Bank?](#)



[Why Focus on Children with Feeding Difficulties and Disabilities?](#)



[Who Should Use the Resource Bank?](#)



<https://www.advancingnutrition.org/resources/disability-resource-bank>

Feeding and Disability Resource Bank Features

Resources are grouped into five sections:

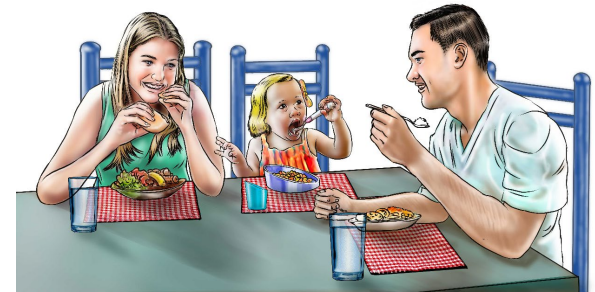
- Identifying Feeding Difficulties
- Managing Feeding Difficulties
- Identifying Disabilities
- Supporting Children with Disabilities and Their Families
- Promoting Disability Inclusion

Can't find what you're looking for or see something that's missing?

Contact us at info@advancingnutrition.org

Additional features:

- Search by technical area, population, program area, age group, and geography
- Terminology page
- Find original images: [IYCF Image Bank](#)



What's Inside?

- 83 resources, and counting
- 10+ languages
- Pertains to multiple audiences and topics

Published by: Multi-Agency International Training Support (MAITS)

Publication Date: 2018

Training Material

Low-Resource Setting

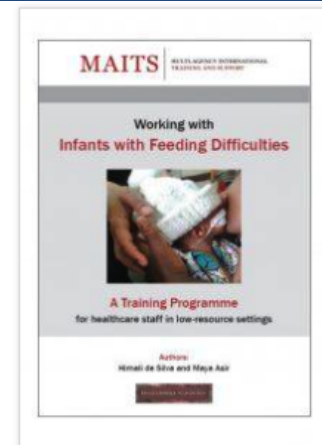
English

Experts working for MAITS have developed this 2-day training program to improve the knowledge and skills of neonatal healthcare professionals to support breastfeeding and nutrition in infants struggling to feed due to prematurity, low birthweight, or underlying disability in low- and middle-income countries. It can be taught as a stand-alone or as a supplement to regular breastfeeding training programs. This training program is intended to be delivered by a skilled trainer

[MAITS Working with Infants with Feeding Difficulties Training Package](#)



Resource Bank Section(s): [Identifying Feeding Difficulties](#), [Managing Feeding Difficulties](#)



<https://www.advancingnutrition.org/resources/disability-resource-bank>



UNICEF Early Intervention Program

Care and Development for Young Children with Developmental Delays and Disabilities

A Service Delivery Model for Early Identification and Early Interventions for Children with Developmental Delays and Disabilities

Global Challenges for Children with Developmental Delay and Disability



Stigma, neglect, discrimination leads to exclusion

- Social and behavioural change
- Inclusion and participation

Lack of services meeting their specific needs

- Services providing support, intervention & education

Poor quality, outdated methods

- Evidence based methods

Early childhood is a window of opportunity

- Neuroscience
- Emerging evidence on benefit of early intervention

Governing principles



- The rights of children with disabilities
 - UNCRC; UNCRPD
- ICF – model
 - Participation/Inclusion/Visibility
 - Family centred & community based
 - Multi-professional; inter-sectorial
- Evidence based
- New science
 - Early childhood a window of opportunity

Objective



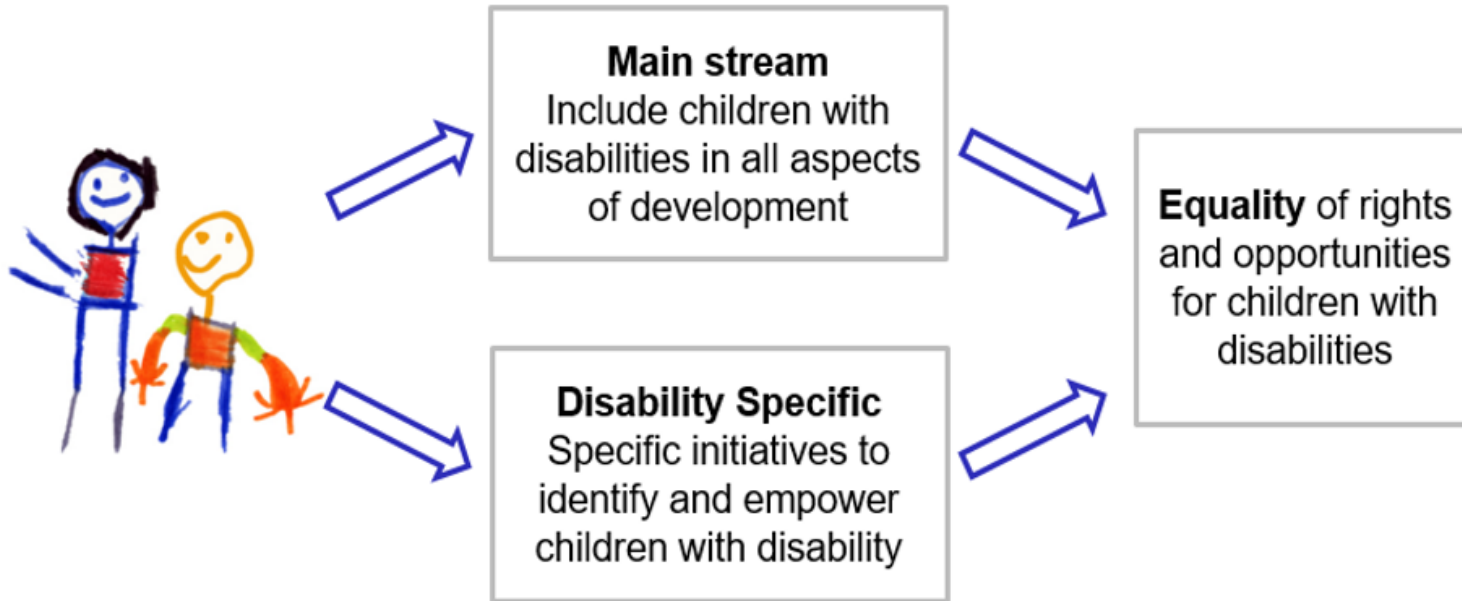
Develop a model program for early identification and intervention of children with developmental delay and disability

A Twin Track Approach

Challenge

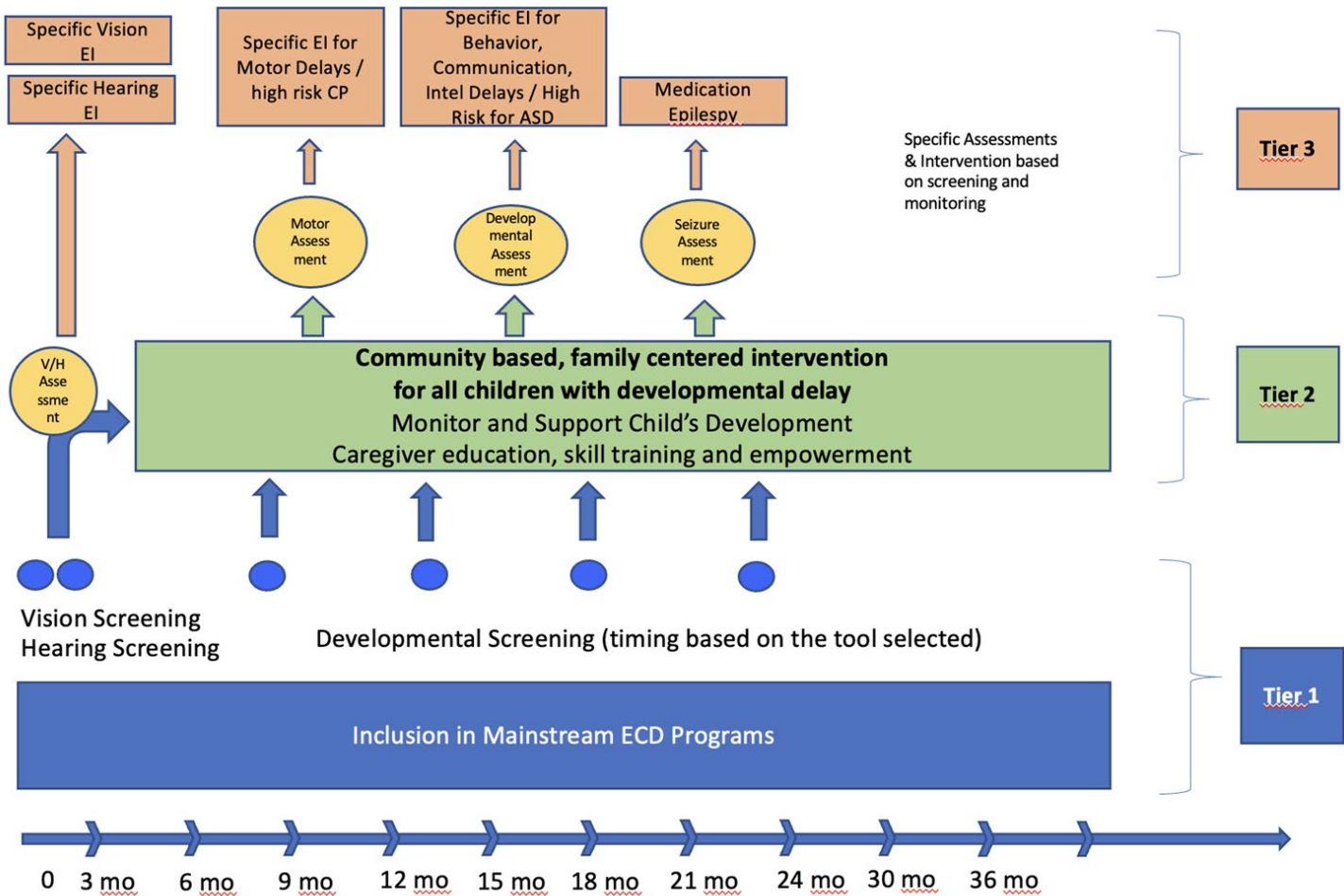
Programme activities

Goal



Disability specific track

- Early identification (< 3 years)
 - Screening/Developmental monitoring of all children
- Family-based Community-centred early intervention services
- Further Assessment
- Specific Early Interventions for those children needing more support
- Addressing Stigma and Discrimination





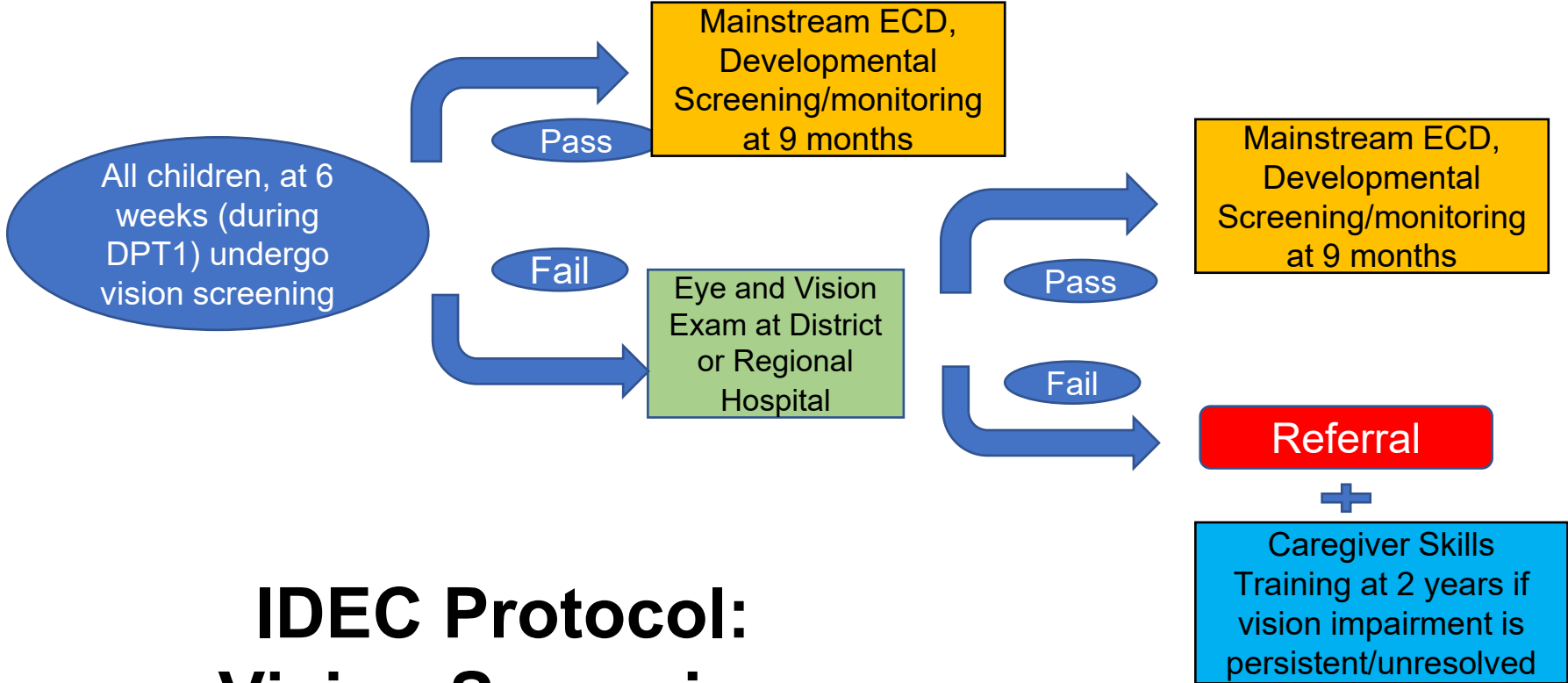
Early intervention (Tier 2)

All children that have screened positive on any of the screening tools shall be included in a community- based, family-centered intervention program including:

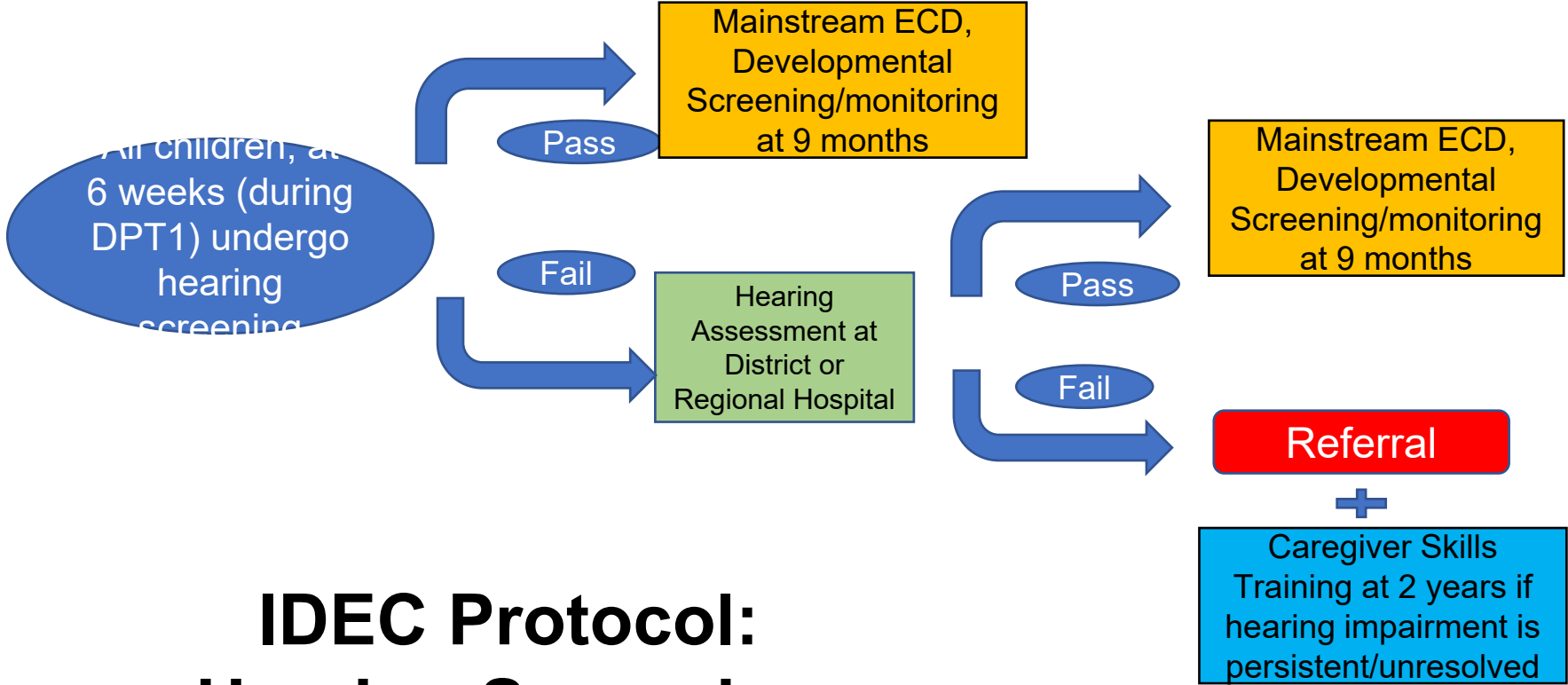
- Monitoring child's development
- Supporting child's development
 - Caregiver education and skill training
 - Empowerment of the family and the child
- Addressing Stigma and Discrimination

Example how the model is adapted in Uganda

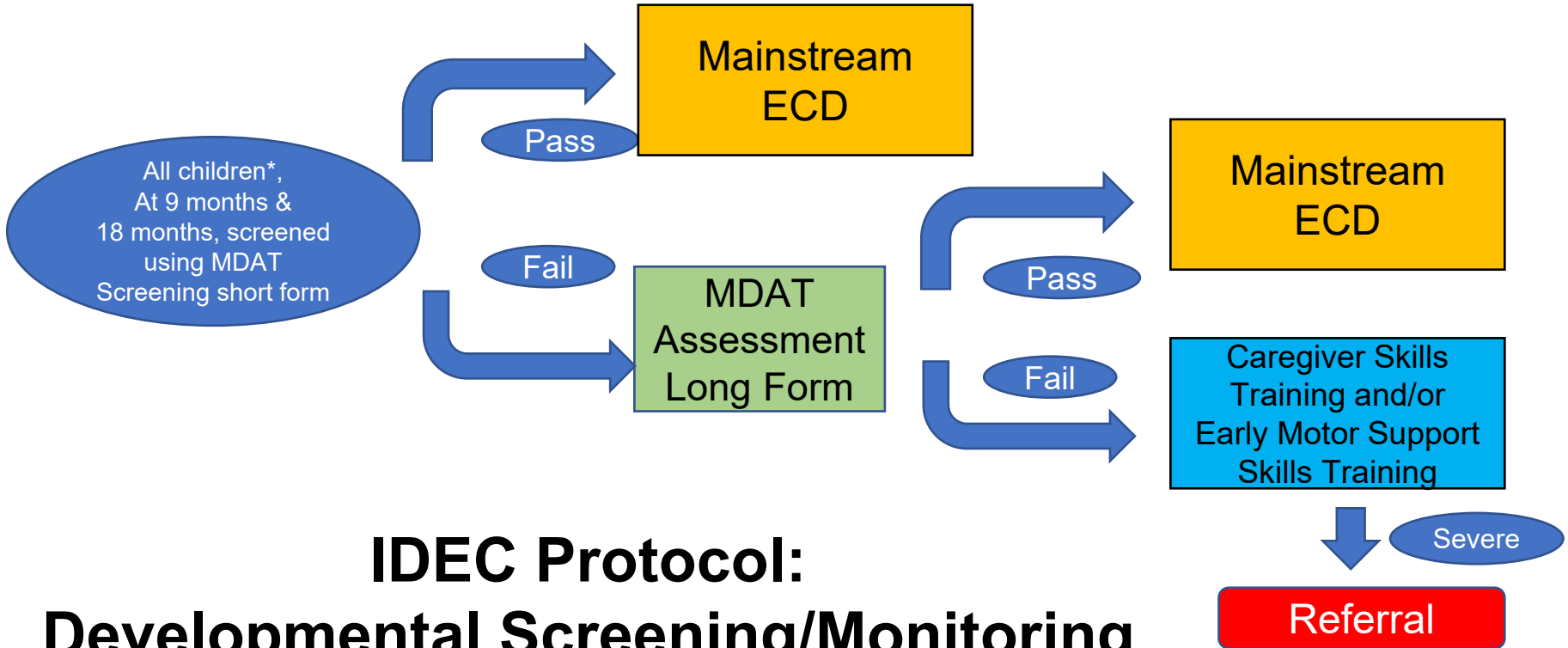
Interventions for Disabilities in Early Childhood (IDEC)



IDEC Protocol: Vision Screening



IDEC Protocol: Hearing Screening



IDEC Protocol: Developmental Screening/Monitoring

* Sick children consulting at the HC/OPD should not undergo developmental screening/monitoring

Question and Answers

Please put any questions in the Q&A box!





USAID
FROM THE AMERICAN PEOPLE

unicef  | for every child

BREAKOUT SESSION INTRODUCTION

Cat Kirk

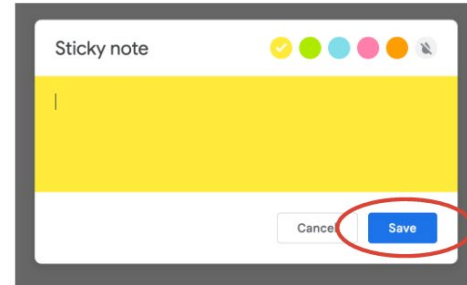
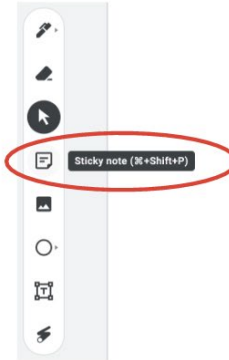
Breakout Room Themes

- Early detection
- Early identification
- Identifying feeding difficulties
- Managing and supporting feeding difficulties (two rooms)
- Addressing and treating malnutrition
- Promoting disability inclusion



Breakout Room Housekeeping

- Introduce yourself in the chat box, and before you speak if you come off mute!
- Jamboard is a virtual flip chart with sticky notes.
- We encourage you to **come off mute and share your feedback** and your Jamboard facilitator will help record ideas from the group in the Jamboard.
- You can also add your own sticky notes with ideas:
 - Click on the “Sticky Note” Icon on the left side of the screen.
 - Type your idea and click “Save”



Zoom Meeting Breakout Rooms

- You should be automatically assigned to your breakout room theme. If you have any issues joining the breakout room, you can click on the **Breakout Rooms** icon in your Zoom controls. **If you have any issues, put a message in chat for Tech Support (Ben Cox, Yaritza Rodriguez).**
- If you're in the wrong breakout room, click on the Leave Room button in the bottom right corner of your Zoom Window. You can use this feature if you would like to remain in the group with **Spanish translation in the Main Zoom Room** or **ASL interpretation in the Disability Inclusion Room.**





STORYTELLING PANEL

Elizabeth Mubukwanu

Juan Cobeñas

Vrushali Kulkarni and Payal Shah

Moderator: Cat Kirk

Virtual Convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities



Juan Cobeñas

IDA DRG Fellow

Argentina



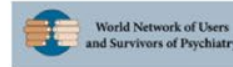
IDA

International
Disability Alliance

Advancing the rights
of persons with disabilities



Inclusion
international



INTERNATIONAL DISABILITY ALLIANCE

We are an Alliance of 14 global and regional organisations of persons with disabilities. We advocate at the United Nations for a more inclusive global environment for everyone.

Mostrar e

- We are an alliance of networks.
- IDA brings together over 1,100 organisations of persons with disabilities and their families
- Across eight global and six regional networks.

IDA Members

- [African Disability Forum](#)
- [Arab Organization of Persons with Disabilities](#)
- [ASEAN Disability Forum](#)
- [Down Syndrome International](#)
- [European Disability Forum](#)
- [Inclusion International](#)
- [International Federation of Hard of Hearing People](#)
- [International Federation for Spina Bifida and Hydrocephalus](#)
- [Pacific Disability Forum](#)
- [RIADIS](#)
- [World Blind Union](#)
- [World Federation of the Deaf](#)
- [World Federation of Deafblind](#)
- [World Network of Users and Survivors of Psychiatry](#)

What We Do

- Advocacy for the Convention on the Rights of Persons with Disabilities
- Advocacy for Sustainable Development
- Advocacy at the Human Rights Council

At the United Nations

Capacity Building: BRIDGE CRPD-SDG Training

Empowering organisations of persons with disabilities

Global Action on Disability (GLAD) Network

Inclusive Humanitarian Action and Disaster Risk Reduction

Intersectionalities

Webinars about the UN system & processes

Global Disability Summit



MEALTIMES MADE EASY (MME)

Ummeed Child Development Center
26th April 2023



CLINIC

UMMEED child development center



CREATING A MORE INCLUSIVE WORLD
so that ALL CHILDREN
CAN REACH THEIR MAXIMUM POTENTIAL



RESEARCH

TRAINING



ADVOCACY





Ummeed's work with mealtime and nutritional difficulties

Individualized intervention

- Speech therapy
- Mental Health

Group based intervention

- Developmental Pediatrician
- Occupational Therapy and Physiotherapy

Our MME team



Priyanka
Khuje



Roohina
Shaikh



Snehal
Talvelkar



Payal Shah



Priti Inje



Vrushali
Kulkarni

Why MME?



**70% OF CHILDREN WITH CEREBRAL PALSY
HAVE DIFFICULTIES WITH MEALTIMES IN
INDIA**

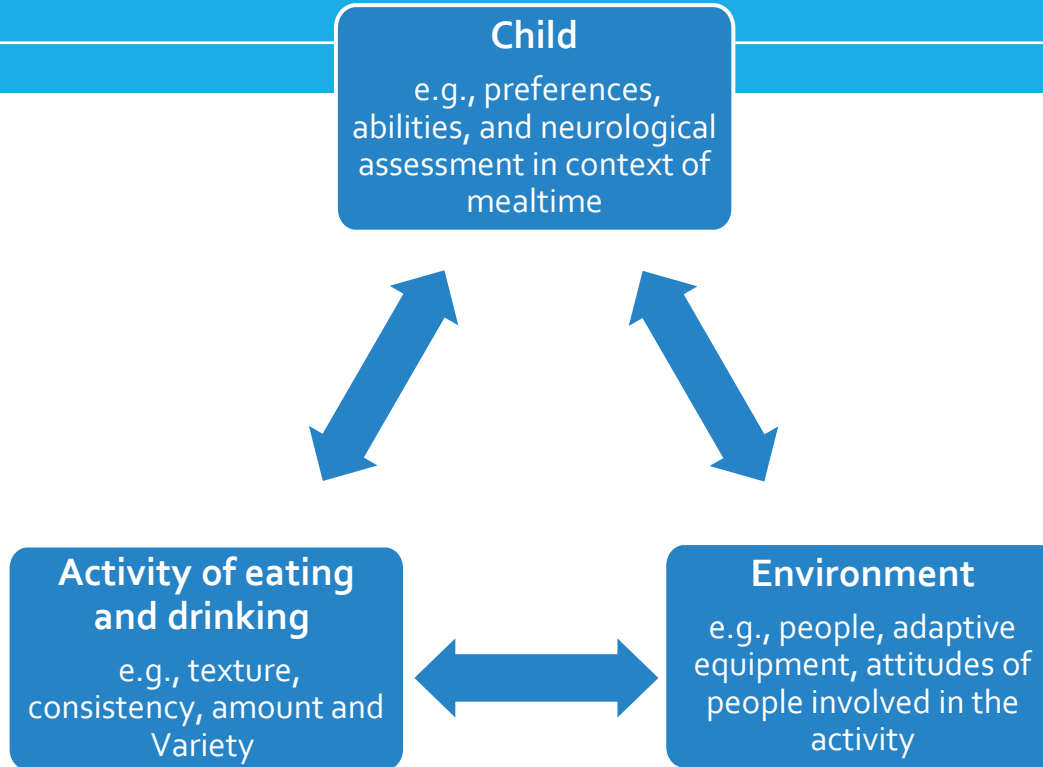
**33–80% OF CHILDREN WITH DISABILITIES
HAVE DIFFICULTIES WITH MEALTIMES
GLOBALLY**

SOCIO-CULTURAL VALUE OF MEALTIME

LEARNING THROUGH SHARING

**CAREGIVERS AS IMPORTANT
INFLUENCERS**

The key idea of MME





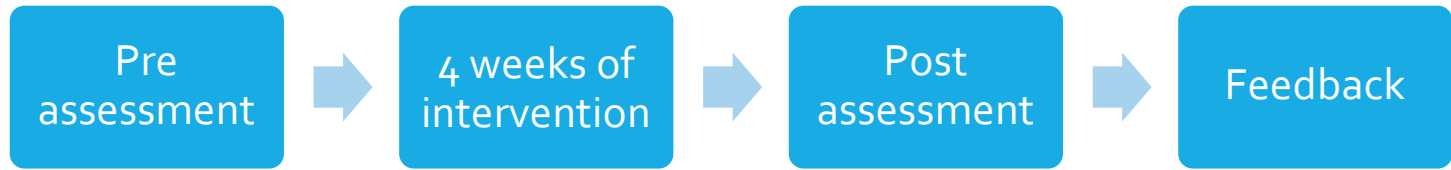
MME Program Details

- **Objective:** To make the activity of mealtime and eating easy for the caregiver of children with motor difficulties in the home context
- **Inclusion criteria:**
 - Children with motor delays impacting mealtimes with varied diagnosis of cerebral palsy, Down's syndrome, etc.
 - Age range: 2 to 8 years
 - Caregiver expressed concerns around mealtime like difficulty in chewing, prolonged mealtime, lack of variety of food being eaten, mealtime perceived as a task, and stressful
- **Screening tool:** (ABFS-C scale – Ability for Basic Feeding and Swallowing Scale for children): Minimum score of 0 or 1 score in 2 items from 3 (head control, saliva control, and oral motor items); Hypersensitivity score to be 3; wakefulness to be 2 or 3.
- **Assessment tools:** Self-made questionnaire (Likert scale measuring child, activity, and environmental factors) and video analysis of mealtime.



MME Program Details

Frequency: Two online groups per year with 6 to 8 children and their caregivers.



1. Didactic teaching of concepts through Pre-recorded videos
2. Twice a week sessions, one hour long for practicing and problem solving
3. Videos shared by the caregivers during the week on WhatsApp group

Let us listen to Aza'a Story!!!

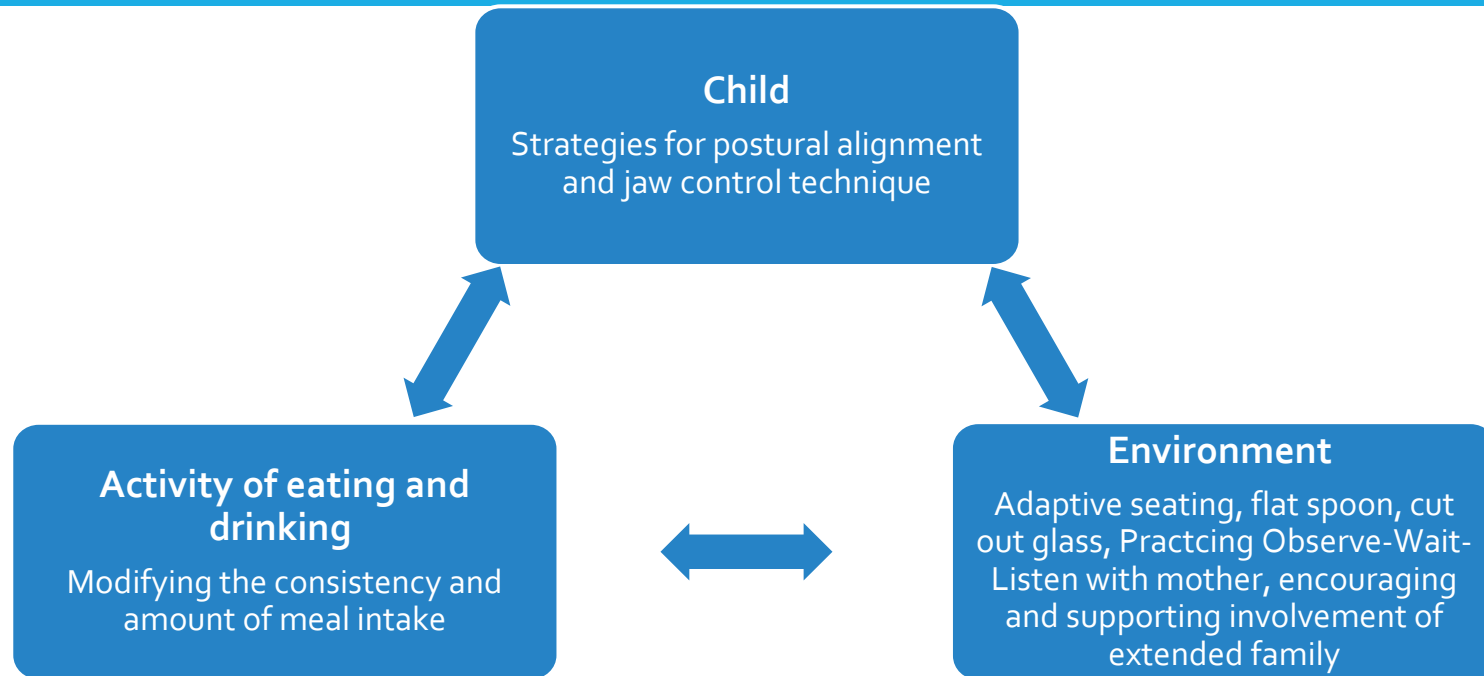


Pre assessment



Child	Activity	Environment
Aza's mother kept on changing his position during the process of eating 90% of times	He ate semisolid food 100 % of times, had no solids	90% of time Aza's mother kept changing her posture and used chair and pillow to support Aza.
He exhibited neck extension, and his head, trunk, and pelvis were not aligned in a line	10% time only he could drink water comfortably with spillage	Only mother was involved during mealtimes
Reflux, coughing was 75%.	Mealtime would take around an hour	His mother exhibited responsiveness 10% of times during mealtimes. His mother used to put food in his mouth and not wait for any clues or gestures from him. Attitudes of family members like "should eat solids"

Intervention through MME



Post assessment



Child	Activity	Environment
The frequency of his mother changing his position during the eating process decreased to 25 % indicating ability to decide and achieve maintenance of appropriate posture.	He began to eat 25 % solids	His posture was aligned, and neck was maintained in neutral with help of adaptive seating. Change of position by caregiver reduced to less than 10% Flat spoon and cutout glass helped.
Reflux and coughing reduced to 25%.	50% time he could drink water comfortably with spillage	Increased responsiveness during mealtimes by 50%, mealtime with family as a ritual started
	Mealtime duration reduced to 10 – 15 minutes	

Aha moments!

From the feedback session

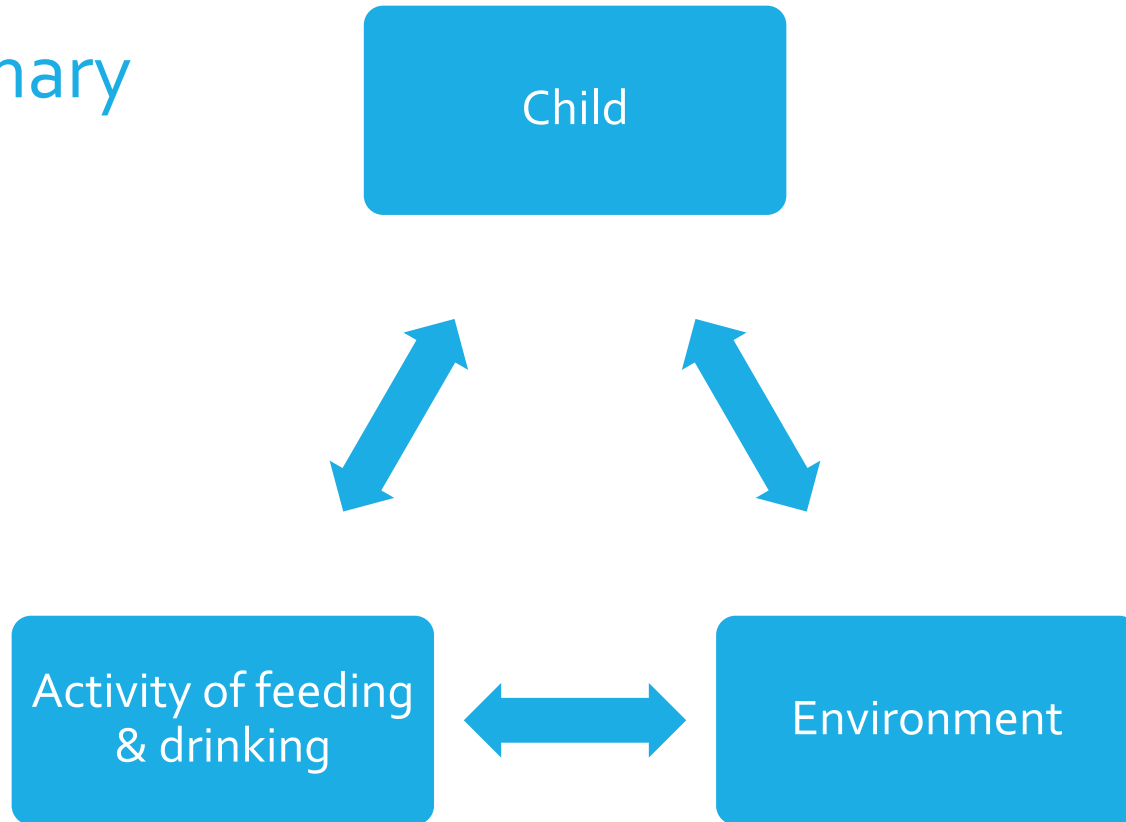
"Mealtime is no more a task for me"

"Now planning to go out to restaurants or weddings have become easy"

"This was the first time I thought about myself and my posture and this made me feel good"

By giving him time to respond, I came to know that my child can make choices and express them through gestures

Summary





Strategies

- Bring all the **three factors** of child, activity and the environment **in alignment** with each other during mealtime.
- **Support** the **caregivers** to **identify opportunities** where they can practice mealtimes easily and have fun with their child.



References

- Kamide, A., Hashimoto, K., Miyamura, K., & Honda, M. (2015). Assessment of feeding and swallowing in children: Validity and reliability of the ability for basic feeding and swallowing scale for children (ABFS-C). *Brain and Development*, 37(5), 508–514.
<https://doi.org/10.1016/j.braindev.2014.08.005>
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9–23.
<https://doi.org/10.1177/000841749606300103>
- Luttter, C., Mir, R., Pachon, H., Cheung, E., Sullivan, K., Creed-Kanashiro, H., Panjwani, A., Escobar, J., & Alam, K. (2013). Propan 2.0 (process for the promotion of child feeding): A tool for infant and Young Child Feeding Programming. *The FASEB Journal*, 27(S1).
https://doi.org/10.1096/fasebj.27.1_supplement.620.1
- Ramsay, M., Martel, C., Porporino, M., & Zygmuntowicz, C. (2011). The Montreal Children's Hospital Feeding Scale: A brief bilingual screening tool for identifying feeding problems. *Paediatrics & Child Health*, 16(3). <https://doi.org/10.1093/pch/16.3.147>
- Aggarwal S, Chadha R, Pathak R. Feeding difficulties among children with cerebral palsy: a review. *Int J Health Sci Res.* 2015; 5(3):297-308
- *Improving nutrition among children with feeding difficulties and disabilities: Call to action for policymakers.* Improving Nutrition among Children with Feeding Difficulties and Disabilities: Call to Action for Policymakers | USAID Advancing Nutrition. (2022, November 1). Retrieved April 25, 2023, from <https://www.advancingnutrition.org/resources/disability-advocacy-brief>



Acknowledgements

- Children and their caregivers for participating in the MME and helping us learn!
- Ummeed OTPT team members and entire staff for supporting the program!



THANK YOU!

To know more about Ummeed, please visit www.ummeed.org

Contact us:

payal.shah@ummeed.org

vrushali.kulkarni@ummeed.org



USAID
FROM THE AMERICAN PEOPLE



| for every child

Access to Health Zambia's Kusamala Program

Elizabeth Mubukwanu

About Access to Health Zambia

- Formerly called Catholic Medical Mission Board Zambia (CMMB-Z) is a faith-based local nongovernmental organization providing long-term, community-based medical and development aid to communities affected by poverty and unequal access to healthcare.
- Operating in Zambia since 1965 and changed its name to Access Health Zambia in March 2023
- Access Health Zambia partners at the local level with—
 - Ministry of Health
 - Ministry of Community of Development and Social Services
 - Ministry of General Education
 - Local authorities
 - Victim support of the Zambia police
 - Churches Health Association of Zambia
 - Traditional leadership



Source: CMMB-Z

About Access to Health Zambia

Our key areas of work include—

- Child Protection, including support for children with disabilities, orphans, and other vulnerable children
- Gender-based violence prevention
- HIV/AIDS prevention, care, and treatment, including prevention of mother-to-child transmission.
- Livelihoods (Economic Empowerment)
- Water, sanitation, and hygiene
- Nutrition
- Health System Strengthening
- Maternal newborn and child health



Source: CMMB-Z

Kusamala Program

- Child protection project including sustainable integration of activities at the community level for—
 - children at risk of separation
 - children that have been separated from their families
 - children with disabilities
 - children with feeding difficulties.
- Areas of Implementation: Lusaka (Kanyama, Chawama, Misisi, Mtendere, Ng'ombe, Matero) Kabwe (Makululu), Kafue and Mambwe districts.
- Implementation Approach
 - Technical support from St. Catherine University and SPOON
 - Use strategies to provide a continuum of care between the community and health facility.
 - Case management to support the service provision for children with disabilities paying attention to additional support they may need to be cared for at home
- Workforce
 - Community Caregivers (CCGs who are volunteers) supervised by health personnel - Home visits, church sensitization, basic physiotherapy
 - Men Taking Action (MTA) volunteers

Other Access to Health Zambia Activities

- SPOON's patented Count Me In (CMI) app which provides feeding CWD recommendations that help to monitor and improve their growth, motor skills, and nutritional status.
 - Working with 10 partners
- Play therapy and Zambia Association for Persons with Disabilities (ZAPD) registration
- Photo Voice
- Cooking demonstrations
- Safe FEED: Functional Eating Education
 - A guide to safe and satisfying mealtimes for family caregivers of children with feeding challenges.

COUNT ME IN
COUNT ME IN IS SPOON'S HEALTH APP TO PROMOTE NUTRITION AND SAFE FEEDING FOR VULNERABLE CHILDREN

THE NEED
Children with disabilities and children living in institutions often go without the regular monitoring needed to ensure they are growing and thriving. Basic signs of malnutrition can go unnoticed and untreated. Poor growth and delayed or absent or impaired developmental stages lead to feeding complications, improper feeding practices, especially for children with disabilities, not only contribute to malnutrition, but place children at risk for poor health, poor quality of life, and premature death.

HOW IT WORKS
Count Me In enables caregivers to screen for and track nutrition and feeding problems. It generates a customized care plan for each child and site. Real reports to assist with decision-making and critical care interventions are broken into three categories:

BUILT FOR SCALE
3 LANGUAGES
4 COUNTRIES
125 TRAINED USERS
...AND COUNTING

FEEDING
Caregivers assess children for feeding difficulties. If detected, the app takes them through feeding observations, assessing body positioning as well as aspects of feeding related to safety, self-feeding, and social development. Observations result in recommendations with educational content, linking caregivers through specialized techniques for feeding children with disabilities. Count Me In also ensures caregivers see best practices when feeding children, such as holding infants during feeding, using child-sized spoons, and interacting with children during meals.

GROWTH
Caregivers are prompted to measure children's growth based on a standard set child feeding schedule. Count Me In tracks weight, length/height, head circumference, and mid-upper arm circumference, an appropriate for each child. The app plots the results on the World Health Organization's growth charts and uses sophisticated logic to interpret the results. Organizational growth charts are flagged and an automated follow-up evaluation of the child is scheduled.

ANEMIA
Iron-deficiency anemia, one of the most common forms of malnutrition, is simple to detect and treat. Count Me In provides instructions for measuring hemoglobin, it interprets test results, and if the child is anemic, recommends supplementation and schedules the next follow-up screening.

SOLUTIONS 2019 SPRING 2019

SPOON | 101 SE Main Street, Portland, Oregon 97214 | 503.684.2024 | www.spoonfoundation.org

Aspiration

1. Good Posture
2. Safe Food and Drink
3. Small Bites

Actionable Recommendations

- **Local partnership**
 - Communities should participate in project design.
 - Parents with children with disabilities should suggest the best way in which to support CWD (taking note that each child is singular and unique).
- **Include economic strengthening**
 - For example, social cash transfer, start-up capital, entrepreneurship training, and village savings and lending associations (VSLAs) are key.
 - Where possible, provide respite care for parents and /or ECD services with children with disabilities.



Photo Credit: CMMB-Z

Question and Answers

Please put any questions in the Q&A box!





USAID
FROM THE AMERICAN PEOPLE



| for every child

DAY 1: CLOSING

Natalia Mufel

Interactive Question

(please answer in the chat box)

1. What is one thing you learned today that applies to your work?

Key Takeaways: Day 1

- Setting the Stage
- Evidence Gap
- Identifying and Supporting Children with Feeding Difficulties and Children with Disabilities
- Storytelling Panel: Nutrition and Disability in Action

Interactive Question

(please answer in the chat box)

1. What is one thing you hope to learn about or discuss tomorrow during Day 2?

Accessibility Check-In



Is there is anything that we can do to improve accessibility? Please send an email to rosie_eldridge@jsi.com or write it in the chat.