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** | 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.  
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. |
| **Español** | Haga clic en el icono de "interpretación" para escuchar la reunión en español. Para escuchar sólo en español, desactiva el audio original. |

![Zoom Language Interpretation Interface](image)
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
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
WELCOMING REMARKS

Katherine Guernsey
Grainne Moloney
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

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

Presenter bios and agenda available at: [https://sites.google.com/view/jsi-disability-convening-2023/](https://sites.google.com/view/jsi-disability-convening-2023/)
**Agenda Overview—Day 2, Thursday, April 27th**

Bringing Nutrition and Disability Together

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

Presenter bios and agenda available at: [https://sites.google.com/view/jsi-disability-convening-2023/](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

<table>
<thead>
<tr>
<th>Disability</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability Inclusion</td>
<td>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.</td>
</tr>
<tr>
<td>Stunting</td>
<td>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.</td>
</tr>
<tr>
<td>Wasting</td>
<td>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.</td>
</tr>
<tr>
<td>Undernutrition</td>
<td>A result of deficiencies in a person's intake, absorption of energy and/or nutrients, or illness, increasing risk of illness and death.</td>
</tr>
</tbody>
</table>

Sources & additional terminology available at: [https://www.advancingnutrition.org/resources/disability-resource-bank/terminology](https://www.advancingnutrition.org/resources/disability-resource-bank/terminology)
GUIDING FRAMEWORKS
Guiding Frameworks: 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

- Specialized services
- Additional contacts and benefits
- National policies, information and basic support

Intensity of Intervention

- Families of children with additional needs
- Families and children at risk
- All caregivers and children

Population Coverage

- Indicated support
- Targeted support
- Universal support

Relevance to the Convening

- Early intervention, rehabilitation, and other support and family services for children with disabilities
- Management of feeding difficulties through universal services, including malnutrition treatment
- Accessibility of universal services for all children and identification of children requiring targeted and/or indicated supports

Guiding Frameworks: Socio-Ecological Model

KEYNOTE ADDRESS

Vivian Fernández de Torrijos
KEYNOTE PRESENTATION

Hannah Kuper
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
What is childhood disability?
Medical Model
Social Model
WHO-Endorsed Model

Health Condition
(disorder or disease)

Body Functions & Structure

Activity

Participation

Environmental Factors

Personal Factors
WHO-Endorsed Model: Example

Visual representation:

- **Cataract**
  - **Vision**
  - Environmental Factors
    - Personal Factors
  - Walking
  - School
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

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

- Experience a range of health conditions:
  - Acute respiratory infection
  - Fever
  - Diarrhea

- Lower development index

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

- Underweight: 19, 28, 42
- Stunted: 30, 43, 53
- Wasted: 5, 7, 12
- Overweight: 3, 3, 2

- Children without functional difficulties
- Children with one or more functional difficulties
- Children with more than one functional difficulty

UNICEF report
Malnutrition

Specific conditions
Developmental delay

Childhood disability

Poverty
Feeding difficulties
Poor care
Exclusion
Frequent illness
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.”

Children with Disabilities Out of School

- Primary:
  - No disability
  - Any disability
  - Severe disability

- Lower secondary:
  - No disability
  - Any disability
  - Severe disability

- Upper secondary:
  - No disability
  - Any disability
  - Severe disability
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!
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
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)
Tools for Identifying Feeding Difficulties

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

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

| Governance | • NGOs and civil society organizations provide services instead of governments ("charity")
| | • Lack of inclusive policies and programs |
| Information systems | • Disability-disaggregated data not available in nutrition and health services |
| Financing | • Lack of funding for disability-specific programming |
| Service delivery | • 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 | • Assistive products to support feeding unavailable in the health system |
| Workforce | • 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

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

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

Additional features:

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

Can’t find what you’re looking for or see something that’s missing? Contact us at info@advancingnutrition.org
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

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
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

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Programme activities</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Main stream</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Include children with disabilities in all aspects of development</td>
<td></td>
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<td></td>
<td><strong>Equality</strong> of rights and opportunities for children with disabilities</td>
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<tr>
<td></td>
<td><strong>Disability Specific</strong></td>
<td></td>
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<td></td>
<td>Specific initiatives to identify and empower children with disability</td>
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</tbody>
</table>
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
Community based, family centered intervention for all children with developmental delay
Monitor and Support Child’s Development
Caregiver education, skill training and empowerment

Inclusion in Mainstream ECD Programs

Vision Screening
Hearing Screening

Developmental Screening (timing based on the tool selected)

Specific Assessments & Intervention based on screening and monitoring

Tier 3

Tier 2

Tier 1

0 3 mo 6 mo 9 mo 12 mo 15 mo 18 mo 21 mo 24 mo 30 mo 36 mo
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)
All children, at 6 weeks (during DPT1) undergo vision screening

- **Pass**: Mainstream ECD, Developmental Screening/monitoring at 9 months
- **Fail**: Eye and Vision Exam at District or Regional Hospital

- **Pass**: Referral
- **Fail**: Caregiver Skills Training at 2 years if vision impairment is persistent/unresolved

**I'DEC Protocol: Vision Screening**
All children, at 6 weeks (during DPT1) undergo hearing screening.

**Pass**

**Fail**

- Hearing Assessment at District or Regional Hospital

**Mainstream ECD, Developmental Screening/monitoring at 9 months**

**Pass**

**Fail**

- Referral

**Mainstream ECD, Developmental Screening/monitoring at 9 months**

**Caregiver Skills Training at 2 years if hearing impairment is persistent/unresolved**

**IDECA Protocol: Hearing Screening**
All children*, At 9 months & 18 months, screened using MDAT Screening short form

MDAT Assessment Long Form

Mainstream ECD

Pass

Fail

Mainstream ECD

Pass

Fail

Caregiver Skills Training and/or Early Motor Support Skills Training

Severe

Referral

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!
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
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.
• 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
CLINIC

CLINIC TRAINING

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

Child
- e.g., preferences, abilities, and neurological assessment in context of mealtime

Activity of eating and drinking
- e.g., texture, consistency, amount and Variety

Environment
- e.g., people, adaptive equipment, attitudes of people involved in the activity
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 Prerecorded 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

<table>
<thead>
<tr>
<th>Child</th>
<th>Activity</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aza’s mother kept on changing his position during the process of eating 90% of times</td>
<td>He ate semisolid food 100% of times, had no solids</td>
<td>90% of time Aza's mother kept changing her posture and used chair and pillow to support Aza.</td>
</tr>
<tr>
<td>He exhibited neck extension, and his head, trunk, and pelvis were not aligned in a line</td>
<td>10% time only he could drink water comfortably with spillage</td>
<td>Only mother was involved during mealtimes</td>
</tr>
<tr>
<td>Reflux, coughing was 75%.</td>
<td>Mealtime would take around an hour</td>
<td>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”</td>
</tr>
</tbody>
</table>
Intervention through MME

**Child**
Strategies for postural alignment and jaw control technique

**Activity of eating and drinking**
Modifying the consistency and amount of meal intake

**Environment**
Adaptive seating, flat spoon, cut out glass, Practcing Observe-Wait-Listen with mother, encouraging and supporting involvement of extended family
**Post assessment**

<table>
<thead>
<tr>
<th>Child</th>
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<tbody>
<tr>
<td>The frequency of his mother changing his position during the eating</td>
<td>He began to eat 25 % solids</td>
<td>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.</td>
</tr>
<tr>
<td>process decreased to 25 % indicating ability to decide and achieve</td>
<td></td>
<td></td>
</tr>
<tr>
<td>maintenance of appropriate posture.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reflux and coughing reduced to 25%.</td>
<td>50% time he could drink water comfortably</td>
<td>Increased responsiveness during mealtimes by 50%, mealtime with family as a ritual started</td>
</tr>
<tr>
<td></td>
<td>with spillage</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mealtime duration reduced to 10 – 15</td>
<td></td>
</tr>
<tr>
<td></td>
<td>minutes</td>
<td></td>
</tr>
</tbody>
</table>
Aha moments!

From the feedback session

“Mealtime is no more a task for me.”

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

“Now planning to go out to restaurants or weddings have become easy.”

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

Child

Activity of feeding & drinking

Environment
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


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

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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
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
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.
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.
Question and Answers

Please put any questions in the Q&A box!
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?
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.