

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

April 27, 2023 (Day Two)



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



## Zoom Meeting Overview

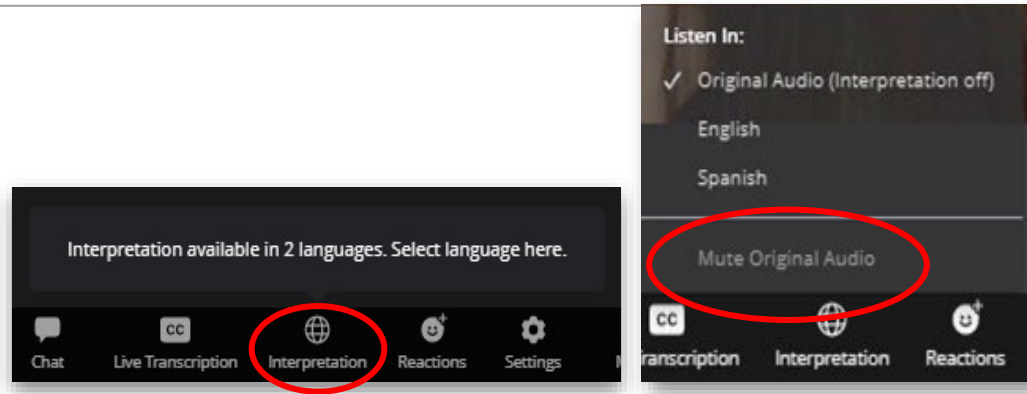
If you have any questions or issues during today's Convening, please reach out to either **Tech Support—Ben** or **Tech Support—Yaritza** in the chat box, or emailing [info@advancingnutrition.org](mailto:info@advancingnutrition.org)

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

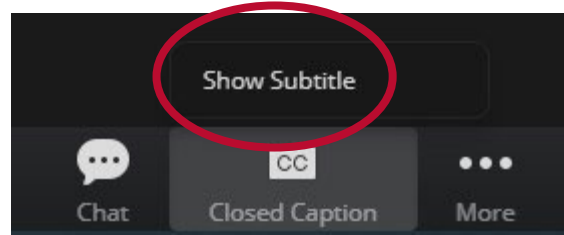
*Recording and materials will be shared on USAID Advancing Nutrition's website after the event*

# Accessibility—Zoom Language Interpretation

<b>English</b>	<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 <b>select English from the interpretation channels</b> to hear comments/questions from colleagues when they are interpreted from Spanish to English.</p>
<b>Español</b>	<p>Haga clic en el icono de "interpretación" para escuchar la reunión en español. Para escuchar sólo en español, desactiva el audio original.</p>

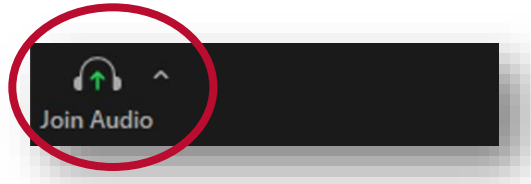


## Accessibility—Zoom Meeting

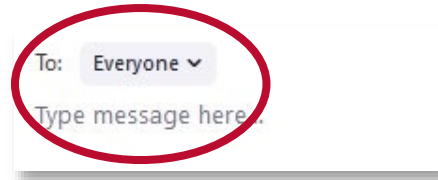


- We have enabled the Zoom closed captioning feature. To start viewing live subtitles on your screen during today's meeting click the **Closed Caption** icon and select **Show Subtitle**.
- Speak slowly and clearly to maximize accuracy of interpretation and closed captions

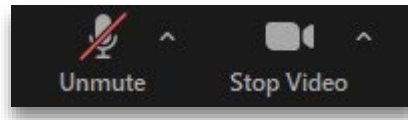
# Housekeeping—Zoom Meeting



- 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.



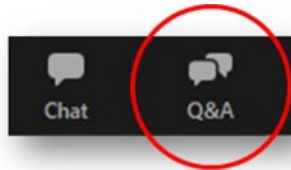
- Send a message to *Everyone* to introduce yourself to all the other participants, to send in your comments and questions, or ask for tech support.



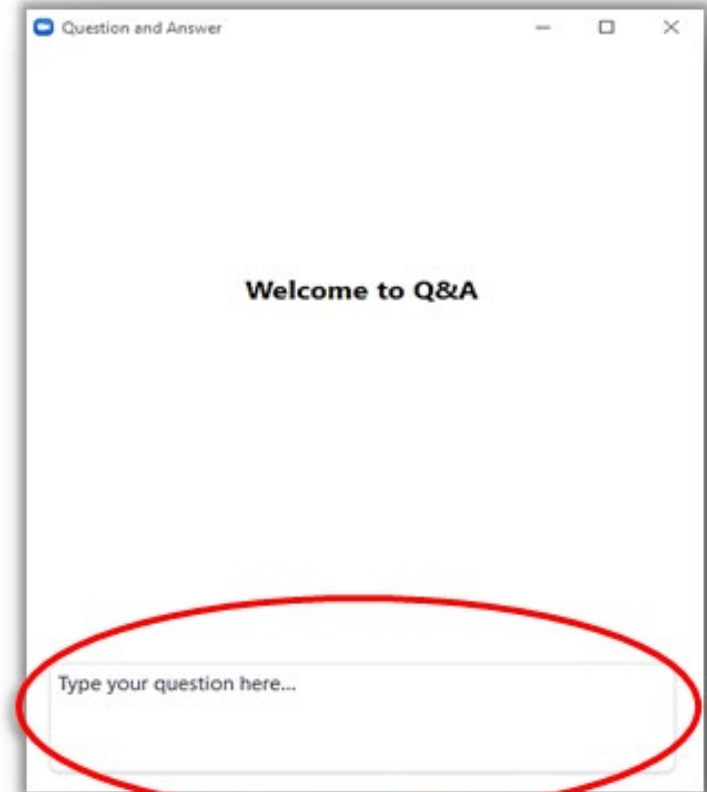
- You are welcome to turn on your video when speaking, presenting, or engaging with other participants, but please remember to mute yourself when others are speaking or delivering presentations.

## 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**

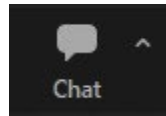


- To submit your question in the Q&A box, type your question in the space provided and press “Enter” on your keyboard

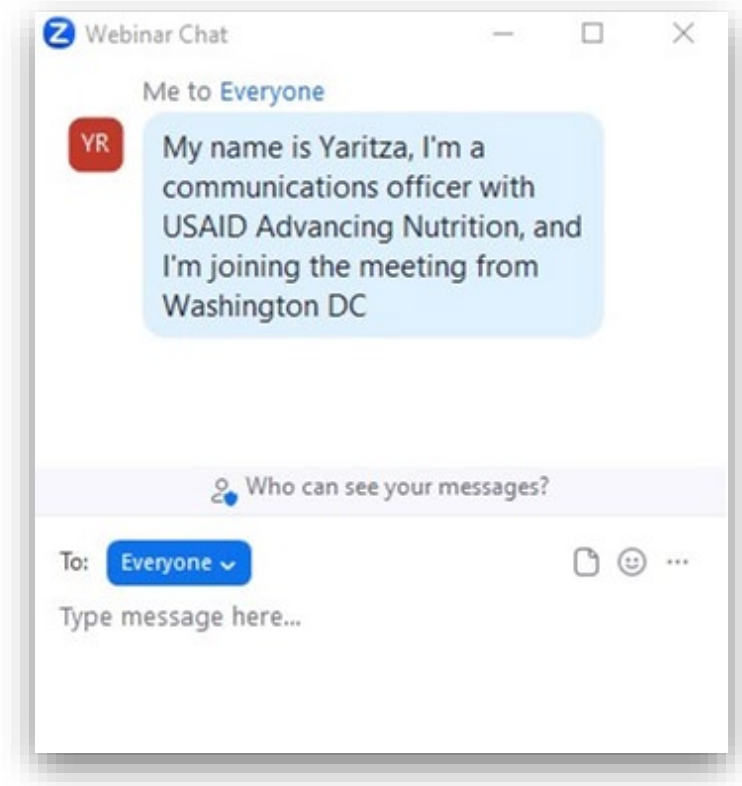


## Housekeeping—Chat Box

- 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



# Agenda Overview—Day 2, Thursday, April 27<sup>th</sup>

## 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/welcome>





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## WELCOMING REMARKS

Gopal Mitra  
Kellie Stewart



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## EVIDENCE AND TRACKING PANEL

Glenn I. David

Daniella Akellot

Kaloyan Kamenov

Moderator: Shona McDonald



# Personal Background & Relation to Disability Research

**Name:** Daniella Akellot

**Position:** Research Coordinator at CoRSU  
Rehabilitation Hospital

**CoRSU:** A specialized hospital for people with disabilities

**Invisible Disability:** Ehlers Danlos Syndrome (EDS)—Connective tissue disorder

**Signs/symptoms of EDS:**

- Abnormally flexible joints
- Dislocations/subluxations
- Elastic skin that easily bruises
- Chronic pain
- Chronic fatigue etc...



## Daniella's Recording

- Daniella USAID Panel Answer 1



- Daniella USAID Panel Answer 2






# Disability Research and Key Considerations

- Specify objectives of research
- Seek out disability research funding
- Be intentional & advocate
- Include Persons with Disabilities as researchers

**A Seat for Every Child: Creating Safe and Dignified Mealtimes**  
 Paula Rabaej MPH, Ph.D., OTR/L, Natalie Bruno, OTR/L, Marissa Smith, OTR/L  
 Kate Miller, MS, SLP-CCC, CLC and Daniela Akellot, MPH



**Purpose**

The aim of this pilot research study was to determine the feasibility, usability, and acceptability of a low-cost feeding chair for children with disabilities in low resourced settings.

**Background**

- Assistive technology is an important tool to support children with disabilities to maintain proper positioning during mealtimes, but only 5-15% of people with disabilities in low-income countries have access to the assistive devices they need (Sacco, 2018)
- 85% of children with disabilities have a persistent feeding problem that interferes with safe eating (Skusey, 2017) and puts them at increased risk for poor health, development, and early childhood mortality.
- Proper positioning is necessary for safe feeding, eating, and swallowing (Hwang et al., 2017; Bennett & Bennett, 2018)
  - Improves functioning of multiple body systems
  - Decreases risk for aspiration
  - Improves responsive feeding practices
- Difficulty during mealtimes can lead to social and health consequences, including caregiver stress and burnout (Bernal, 2017; Sieder et al., 2011)

**Design and Methods**

20 caregiver/child pairs with cerebral palsy EDAC score of 3, 4, or 5


**Quantitative data:**

- Parent subsection of the Feeding Impact Scale
- Chair observation form
- Pre/post scores of:
  - Non-communicating Children's Pain Checklist
  - Assessment of Feeding Position (Rabaej, 2020)

**Qualitative data:**

- Focus groups with caregivers
- Photos
- Videos coded for responsive feeding

**Analysis**



**Figure 1: Feet/OM in Chair: Standard Position**

Position	Yes	No
Back Height	18	2
Seat Depth	10	10
Seat Height	2	18

**Figure 2: Feet/OM in Chair: Tilt Position**

Position	Yes	No
Back Height	18	2
Seat Depth	10	10
Seat Height	2	18

**Results**

55-70% increase in correct hip, head, and trunk positions when the children were seated in the feeding chair  
 70% of children utilized tilt for best feeding position  
 65% increase in responsive feeding practices in caregiver/child dyads

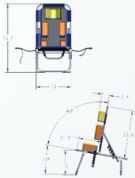
Common themes of focus group:

- Both child and caregiver were more comfortable during feeding than before
- Child participants were calmer and more relaxed
- Child participants were able to see caregiver faces

*"My child can go to a party and not be left behind or lying in a corner"*  
*"It's faster in that chair to feed than on the floor, it's upright, calm...everything is much better...less crying and shaking"*  
*"Previously feeding the baby was passive, like it was forceful feeding because of how they hold her or their posture. But now when she's seated comfortable in the chair, I feel like it can even make me want to feed"*

**Conclusions**

- SPoon chair has feasibility and acceptability to improve mealtime experiences for CWD in LMIC
- Chair prototype modifications with engineer
- Phase 2 longer term usability study with refined design
- Modifications: wider, hip and trunk pads, revised head rest, longer seat belt, additional Velcro

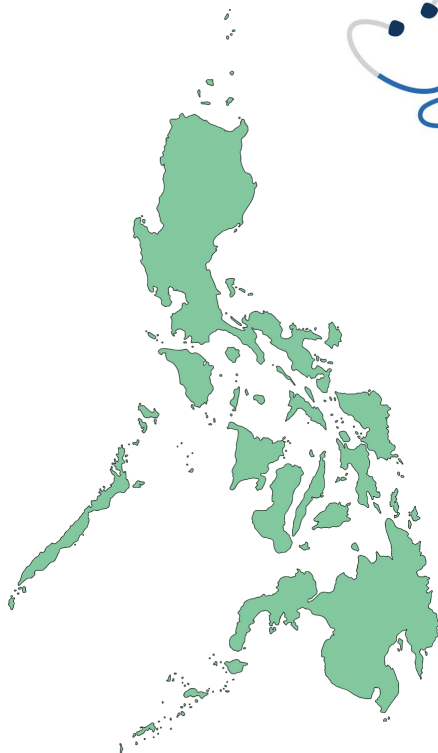


**References**

References available upon request.

Additional research team members: David Kiborge, OT, Rhona Anstey, OT, Maria Ndabwanga.  
 Acknowledgments to SPoon Foundation and CoRSU Rehabilitation Hospital.  
 Photos provided with permission.

# Philippines



Population<sup>1</sup> **113M**

Gross Domestic Product (GDP)<sup>1</sup> **5.7%**

Total Health Expenditure<sup>2</sup> **6.0%**

Out of pocket (OOP) spending<sup>2</sup> **41.5%**

Outpatient Benefits

Inpatient Benefits



Benefits

Catastrophic Benefits



Maternity Benefits



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Sources:

<sup>1</sup>World Bank Data

<sup>2</sup>Philippine National Health Accounts (2021)



# PhilHealth Benefits for Persons with Disabilities

## Benefits

### Mobility, Orthosis, Rehabilitation, Prosthesis Help (ZMORPH)

- Upper and lower limb prosthesis
- Lower limb orthoses
- Spinal orthosis
- Rehabilitation sessions

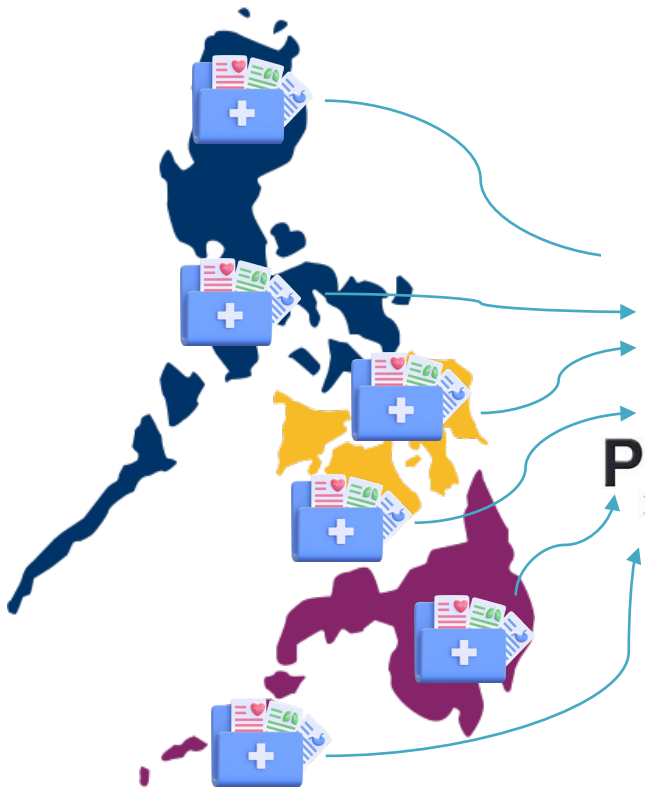
### Benefit Packages for Children with Disabilities (Assistive technologies and rehabilitation)

- Developmental disability
- Mobility impairment
- Visual disability
- Hearing impairment

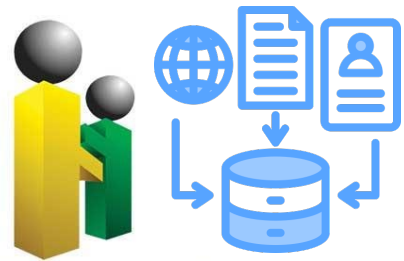
### Other Benefits Packages

- Z Benefits for Premature or Small Newborns
- Newborn Screening
- Inpatient Benefits for Malnutrition



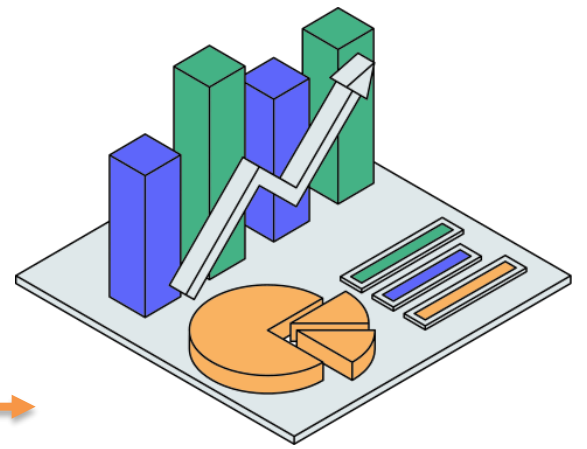


Claims submission



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PhilHealth Database



Quality of Care	Experience of Care – Patient Satisfaction
Financial Risk Protection	Detection of Adverse Practices

Monitoring Frameworks

# A Seat for Every Child: Creating Safe and Dignified Mealtimes

**A Seat for Every Child: Creating Safe and Dignified Mealtimes**  
 Paula Rabaey MPH, Ph.D., OTR/L, Natalie Bruno, OTR/L, Marissa Smith, OTR/L  
 Kate Mihl, MS, SLP/CCC, CLC and Daniela Alvariz, MPH

**Purpose**  
 The aim of this pilot research study was to determine the feasibility, usability, and acceptability of a novel feeding chair for children with disabilities in low resource settings.

**Background**

- Assistive technology is an important tool to support children with disabilities to maximize proper positioning during mealtimes, but only 6-15% of people with disabilities in low resource countries have access to the assistive devices they need (2021)
- Many children with disabilities have a persistent feeding problem that interferes with safe eating (2004, 2017) and puts their increased risk for poor health, development, and early childhood mortality.
- Proper positioning is necessary for safe feeding, eating, and swallowing (2004, 2017) to ensure access to the digestive tract and to support body systems.
- Difficulties with positioning increase the risk for aspiration, improve responsive feeding practices.
- Difficulties during mealtimes can lead to social and health consequences, including caregiver stress and burnout (2004, 2017) (2017).

**Design and Methods**

- 20 caregivers (100 child pairs) with cerebral palsy (GMFCS level of 3, 4, or 5)
- Parental submission of the Feeding Impact Scale
- Chair observation form
- The basic version of the Child's Area Checklist - Assessment of Feeding Position (Rabaey, 2023)
- Observation data
- Focus groups with caregivers
- Video coded for responsive feeding

**Analysis**

Figure 1  
 Feeding Chair Observation

Figure 2  
 Child's Area Checklist - 70 Feeding

Figure 3  
 Child's Area Checklist - 100 Feeding

**Results**

55-70% increase in correct hip, head, and trunk positions when the children were seated in the feeding chair  
 70% of children utilized tilt for least feeding position  
 65% increase in responsive feeding practices in caregivers/OTRD dyads

Common themes of focus group:

- Both child and caregiver were more comfortable during feeding time before
- Child participants were calmer and more relaxed
- Child participants were able to use caregiver breast

"My child can go to a party and not be left behind or being in a corner"  
 "It's easier on their chair to feed than on the floor, it's upright, calm... everything is much better... less crying and chewing"  
 "Previously feeding me better was stressful, like it was stressful feeding because of how they hold her or their posture. But now when she's seated comfortably in the chair, it's that she'd it can even make me want to feed"

**Conclusions**

- SPOON chair has feasibility and acceptability to improve inclusive mealtimes for CWD in LMIC
- Chair prototype modifications with engineer
- Phase 2 larger scale usability study with refined design
- Modifications: wider, hip and trunk pads, revised head rest, larger seat belt, additional velcro

**References**

Rabaey, 2023 available upon request  
 International Council on Disabilities, World Health Organization, UNICEF, World Bank, UN Women, UNFPA  
 International Day of the Girl Child  
 International Day of the Girl Child  
 International Day of the Girl Child



Scientific poster accessible:  
<https://www.spoonfoundation.org/wp-content/uploads/2023/04/SPOON-Chair-Poster-Rabaey.pdf>

# Question and Answers

Please put any questions in the Q&A box





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## BREAKOUT SESSION INTRODUCTION

Malia Uyehara

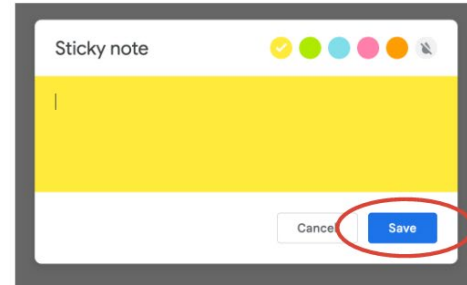
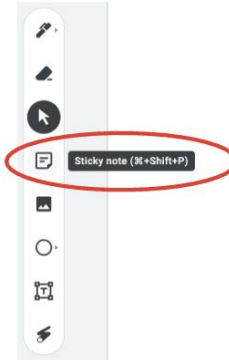
## Breakout Room Themes

- 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.**





Break: 15 minutes



- We encourage you to take a break to move around, as able
- You may also want to use this time to review the agenda & speaker bios



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## BRIDGING THE GAP AND BREAKING DOWN SILOS PANEL

David Mwesigye

Barbara Goedde

Juan Pablo Peña-Rosas

Filippo Dibari

Moderator: Linda Shaker Berbari

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

**Dr Juan Pablo Peña-Rosas**

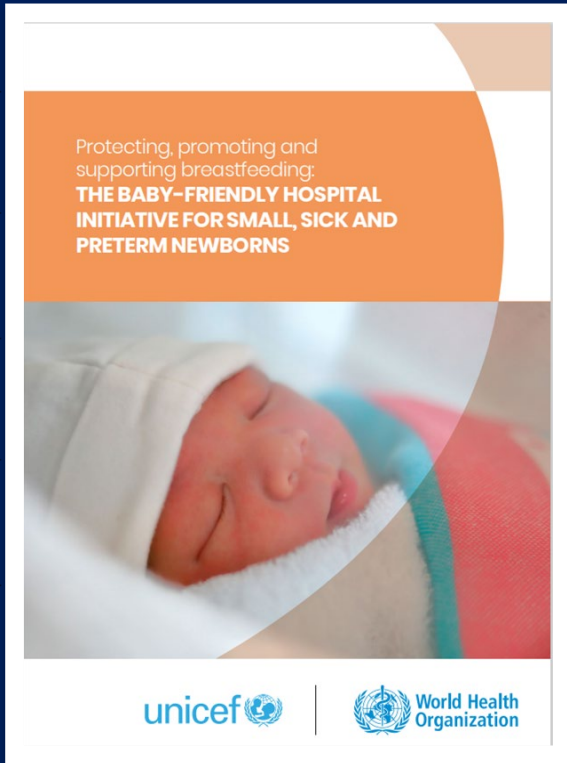
**Department of Nutrition and Food Safety**

**Division of Universal Health Coverage and Healthier Populations**

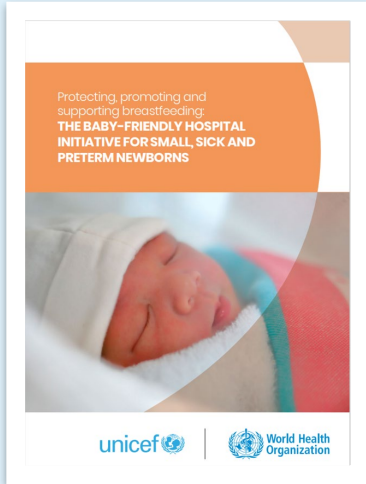
**26<sup>th</sup> – 27<sup>th</sup> Apr-2023**



**World Health  
Organization**



World Health Organization & United Nations Children's Fund (UNICEF). (2020). Protecting, promoting and supporting breastfeeding: the baby-friendly hospital initiative for small, sick and preterm newborns. World Health Organization. <https://apps.who.int/iris/handle/10665/333686>. License: CC BY-NC-SA 3.0 IGO




## 2. The role of facilities in providing neonatal services to small, sick and/or premature newborns

The WHO Framework on integrated people-centred health services (750) states that all people should have equal access to quality health services that respect individual needs. For breastfeeding to succeed in neonatal wards the staff should focus on the individual mother and her situation, and the facility should provide overall family-centred care within a supportive environment.

### 2.1. Critical management procedures and support

#### Step 1: Facility Policies

##### Step 1a: Compliance with the Code

*Step 1a: Comply fully with the International Code of Marketing of Breast-milk Substitutes and relevant World Health Assembly resolutions.*

**Rationale:**

Families are most vulnerable to the marketing of breast-milk substitutes during the prenatal, perinatal and postnatal period when they are making decisions about infant feeding (1). Hospital staff may unintentionally undermine breastfeeding by providing formula companies access to patients via commercial literature and formula marketing strategies, such as baby clubs, gift bags, and no cost formula (751-753). Food for facility staff, patient education materials with commercial logos, and other gifts are attractive and perceived as no cost, but formula prices include the costs of those materials. Medical staff wearing lanyards and badge holders, or using pens, pads, and coffee mugs with formula company logos, even when unintended, implies endorsement. By providing low cost or no cost supplies to hospitals, companies expect their products will be introduced to patients and families, who may then be influenced to continue to purchase that brand after discharge. Due to increased needs for specialised supplies and equipment, neonatal wards caring for small, sick and/or preterm infants may be under significant pressure to accept no cost items from commercial interests that conflict with breastfeeding.

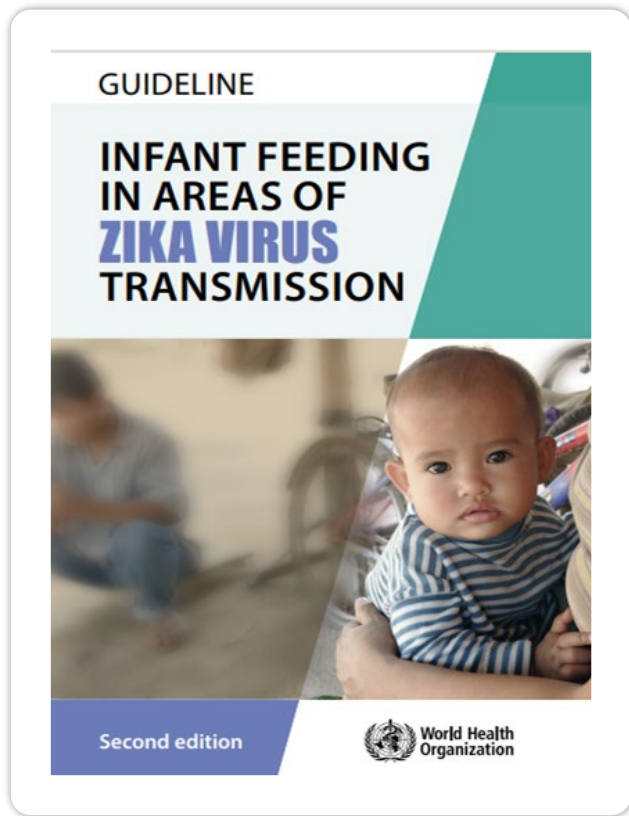
**Clinical guidance:**

**Purchase of supplies**

- Neonatal wards and their related areas use many specialized supplies in addition to formula, feeding bottles and teats. These include fortifiers (concentrated nutrients), breast milk collection kits and bottles, IV tubing, needles, sterile dressings, blankets, measuring tapes, scales, etc. To avoid any conflict of interest, all supplies in the neonatal ward should be purchased through normal procurement channels.

7

Some extremely preterm infants may not be able to suckle effectively immediately after birth, even with very small volumes of colostrum. In infants not stable enough for immediate breastfeeding, immediate hand expression of maternal colostrum and application to the infant's oral mucosa with a 1mL syringe or cotton swab is well tolerated and can serve as immunomodulatory therapy (214, 215).



World Health Organization. (2021). Guideline: infant feeding in areas of Zika virus transmission, 2nd ed. World Health Organization. <https://apps.who.int/iris/handle/10665/341810>. License: CC BY-NC-SA 3.0 IGO

GUIDELINE

**INFANT FEEDING  
IN AREAS OF  
ZIKA VIRUS  
TRANSMISSION**



Second edition



- **Infant feeding among infants affected by complications associated with Zika virus**
- Among infants (0–12 months) affected by complications associated with Zika virus infection, infant feeding practices should be modified (such as adjusting the environment, postural correction or thickening feeds) to achieve and maintain optimal possible infant growth and development (*strong recommendation, very-low certainty of evidence*).
- **Support for primary caregivers of infants (0–12 months old) affected by complications associated with Zika virus**
- Mothers and caregivers of infants affected by complications associated with Zika virus (such as feeding difficulties) should receive skilled support from health-care workers to initiate and sustain optimal infant feeding practices (*strong recommendation, very-low certainty of evidence*)

# Virtual Convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities Bridging the Gap and Breaking Down Silos Panel

27 April 2023



**ATscale**

GLOBAL PARTNERSHIP FOR  
ASSISTIVE TECHNOLOGY

Hosted by

 **UNOPS**



# How is Assistive Technology important for feeding?

In a best case scenario, an additional assistive device is not necessary because universal design principles have been adhered to: The design and composition of an environment is such that it can be accessed, understood, and used to the greatest extent possible by all people regardless of their age, size, ability or disability.

Example: a cup with two handles might be useful for many



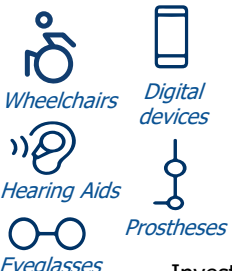
Assistive devices do not have to be complex: a standard disposable straw can be considered assistive drinking device.

Example on this slide:  
Straps that are made of soft, flexible food-grade silicone which allow for non-slip grip on objects of different sizes (cutlery, drinking cups etc.)  
[EazyHold]

Other example: wheelchairs with posture support that allow for positioning for feeding;




# Together, the ATscale partnership transforms and empowers people's lives through Assistive Technology (AT)



AT can **enable people** to live healthier, more productive, more independent, and more dignified lives, and to participate in education, the labour market and their communities.


More than **2.5 billion people in need** of one of more assistive products...  
But **less than 10% access** for those in need in low-income countries



A fast-growing global problem, with number of people in need is likely to rise above **3.5 billion by 2050**

**ATscale Goal:**  
Ensure that **500 million more people** globally are reached with life-changing AT by 2030

Investing in AT is not just the RIGHT thing to do, it is the SMART thing to do: **9:1 ROI**



**A cross-sector partnership**

- ✓ **Catalyst** for change
- ✓ **Amplify** existing work
- ✓ **Coordinate** and **mobilise** global stakeholders
- ✓ **Spearhead a unified strategy** to increase availability of and access to affordable and appropriate AT

**ATscale initial commitments...**

**75% at country level\*...**

- Towards AT national plans across 6 countries
- Roll-out ATKits in Ukraine

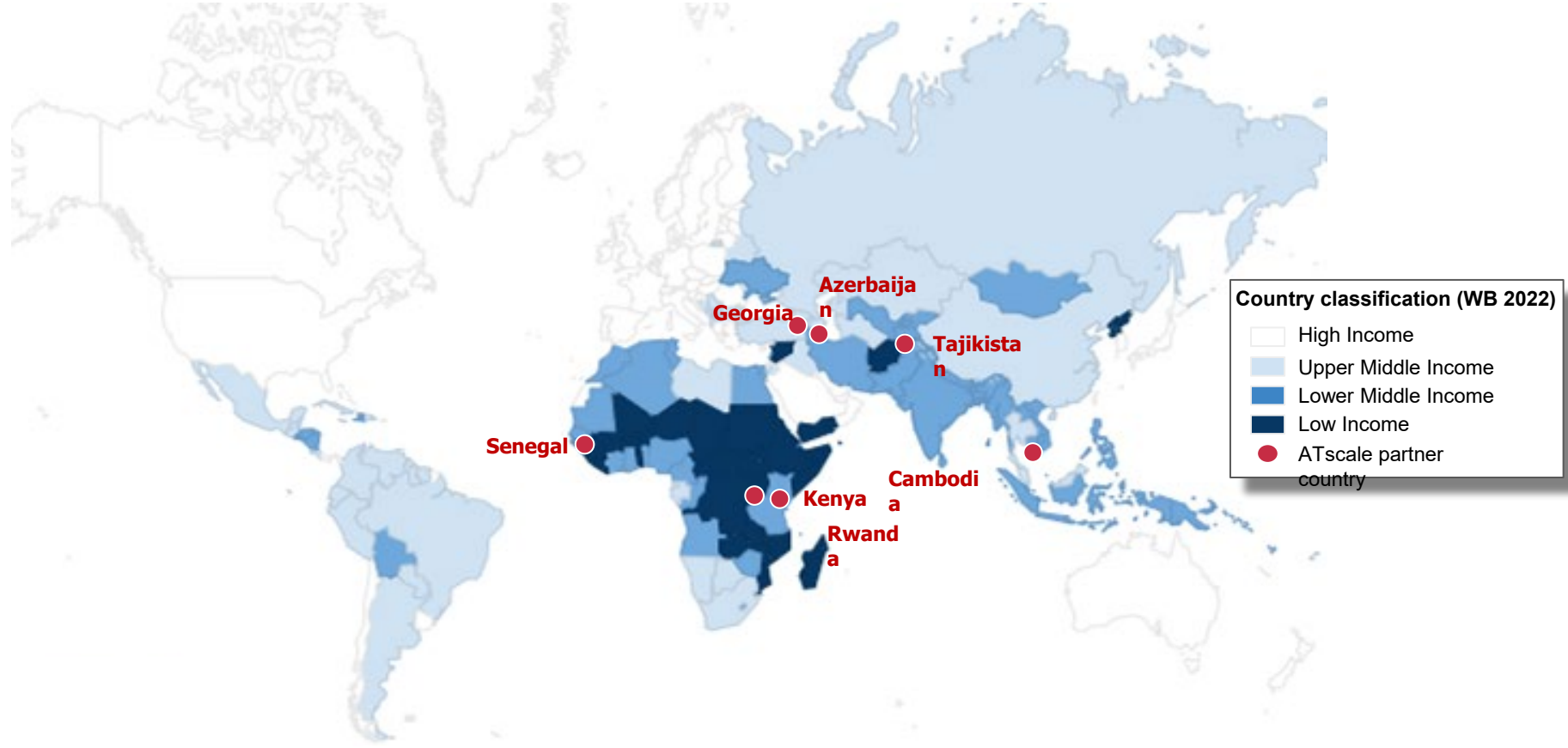
**25% towards global public goods...**

- Increasing market visibility
- Augmenting text-to-speech language availability
- Guidance on vision screening and eyeglass provision
- Pursuing market access deals for prosthetics in LMICs
- Etc.

1. Develop **enabling ecosystem** for increased access to AT in LMICs

2. Build and **shape markets** for priority products and their related services

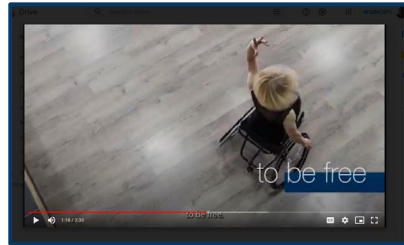
ATscale can work with all low- and middle-income countries, and is already directly active in 7 countries



Learn more  
about who  
we are and  
what we do !



*ATscale  
Secretariat  
Team*



*Watch ATscale short  
film:*

<https://youtu.be/G8ELHz35uos>

**Pascal Bijleveld**

CEO

[pbijleveld@atscalepartnership.org](mailto:pbijleveld@atscalepartnership.org)



*Watch ATscale explainer  
animation:*

<https://youtu.be/XkTmZW6O9Co>

**Barbara Goedde**

Strategy and Coordination Advisor

[bgoedde@atscalepartnership.org](mailto:bgoedde@atscalepartnership.org)

<https://atscalepartnership.org/>

# Question and Answers

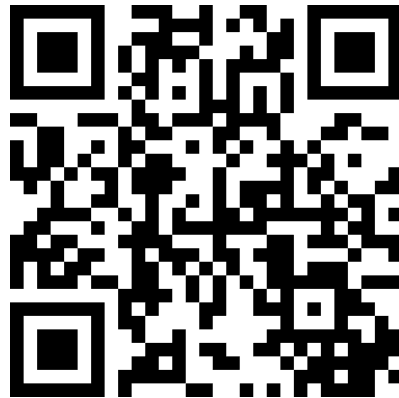
Please put any questions in the Q&A box!





## NEXT STEPS

Please go to Menti: <https://www.menti.com/al7j3aem8d24>





# Thank you!

- **Funding:** USAID Children in Adversity
- **Steering Committee:** Alyssa Klein, Cat Kirk, Linda Shaker Berbari, Lori Baxter, Malia Uyehara, Natalia Mufel, and Rosie Eldridge
- **Technical Advisory Group:** Christine Kirungi, Daniela Briñón, Mishelle Rudzinski, Shona McDonald, Tafadzwa Maseva
- **Tech Support Team:** Ben Cox, Yaritza Rodriguez, Lauren Wheeler, Courtney Meyer, Kossana Young, Annie Mullin



## USAID ADVANCING NUTRITION

IMPLEMENTED BY:

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Email: [info@advancingnutrition.org](mailto:info@advancingnutrition.org)

Internet: [advancingnutrition.org](http://advancingnutrition.org)

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