



Virtual Convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities: Key Takeaways and Resources

KEY TAKEAWAYS

Data

- 80% of the world's one billion persons with disabilities live in low- and middle-income countries (LMICs), and there are more than 240 million children with disabilities worldwide.
- Up to 80% of children with disabilities and 40% of children without disabilities experience feeding difficulties; this often lacks prioritization and attention.
- Children with disabilities are 3 times more likely to be underweight, 2 times more likely to be stunted, 2 times more likely to be wasted, and twice as likely to die during childhood from malnutrition.
- We cannot scale up if we do not collect data on this issue. Early-identification systems and screening services lack needed infrastructure.
- No country systematically collects disability data. Integrating questions to identify children with disabilities to better collect data is crucial. Routine administrative data is needed for nutrition interventions. Countries need to invest and prioritize.

Guiding Frameworks

- The Convention on the Rights of Persons with Disabilities (UNCRPD) is an international treaty adopted by the UN; Article 7 (children) and Article 25 (health) are particularly relevant to the Convening. The UNCRPD establishes the obligations of states to guarantee these rights.
- The social model of disability states that persons with impairments are “disabled” by the barriers operating in society that exclude and discriminate against them. These social barriers may be environmental, attitudinal, or institutional (or organizational).
- The twin track approach states that it is not sufficient to give support to individuals with disabilities on the basis of their impairment alone, for example, by providing rehabilitation, education, healthcare, etc.; it is equally essential to address the societal and environmental barriers that block a person with an impairment from being included in society.
- The universal progressive model from the Nurturing Care Framework aims to ensure that the needs of all children and families are met. This means that the level of support matches the needs of the child and their family. The universal progressive model includes the universal

services and support that every child and caregiver needs and works its way up to the highly specialized services that are indicated for children and caregivers with additional needs.

Challenges

- Services often fall short and ableism perpetuates stigma and discrimination.
 - Availability and access to services are limited; there is a lack of 1) social services and safety net programs, 2) rehabilitative services (which are often disconnected from the health system); 3) workforce to support these children (or there is limited funding to employ them in the public sector or in rural areas).
- If stigma is not addressed, no other services or interventions will help.
- Disability and poverty are very closely linked—childhood disability further exacerbates poverty, and vice versa.
- In humanitarian settings, one major challenge is data collection. It is difficult to understand the number of cases and how to reach them and what the barriers are. Are the barriers the kind of food we are giving, is it stigma? Can cash programs make this easier?
- Knowledge about assistive devices is fractured; we need to widely disseminate information so we invent but do not reinvent.
- There are limited professionals in LMICs with expertise related to feeding difficulties and disabilities.

Strategies, Approaches, and Solutions

- Principles for inclusive nutrition programs:
 - Adopt a twin track approach: inclusion in mainstream, reach with targeted programs.
 - Work in partnership with persons with disabilities (e.g., Organizations of Persons with Disabilities [OPDs]) to ensure the program is designed appropriately.
 - Mandate specific budget line items to promote disability inclusion and monitor indicators to ensure disability inclusion is happening.
 - Given the magnitude and severity of the issue, no one agency can improve the situation. Agencies, experts, and partners must work collaboratively to advance progress on this issue.
 - Prioritizing nutrition for this population requires pointing to the Sustainable Development Goals and making a strong moral argument that stakeholders cannot focus primarily on the numbers. This is a human rights issue.
- What are strategies that the government and partners can implement to improve inclusion?
 - Address the different levels of stigmas, train health workers about childhood disability and how to treat these children. Create community-level changes through mass-media programs. Empower parent/caregiver groups to fulfill the rights of their children.
- UNICEF is finalizing a toolkit for children with disabilities that face stigma and discrimination.
 - Task-shift to train existing professionals. Establish remote, mobile, and telemedicine programs. Increase support for having more of these professionals.
- Indicators

- Measure whether children with disabilities are coming to programs and compare this to the general population. Compare indicators and outputs by childhood disability.
- Example: UNICEF model of care
 - Screening and developmental monitoring of all children
 - Addressing stigma and discrimination, even in health service providers
 - This model describes a pathway to care for children with disabilities, starting from promoting universal screening in the early years, then promoting inclusion into mainstream early childhood development programs, building in care pathways so these children can receive further assessments and more targeted assistance.
- Example: [Ummeed Mealtimes Made Easy program](#) in India
- Be intentional and advocate to include persons with disabilities as both participants and researchers; encourage persons with disabilities to apply for grants and to conduct research.

BREAKOUT ROOM DISCUSSIONS

What are key challenges you have faced?

- People cannot use a lot of the resources in practice.
- A need for digital apps for capacity building was brought up in one group.
- There is a need to integrate feeding in disability services in all countries, and a need to integrate disability into nutrition and infant and young child feeding (IYCF) packages, which mostly leave out feeding difficulties and disability currently.
- The need to empower and support health workers to assess and refer children—they need training and resources.
- The need to train parents, specifically on feeding for acute malnutrition—otherwise inpatient treatment clinics see readmission of children with acute malnutrition with feeding difficulties who cannot be supported at home. Acute malnutrition protocols do not take into consideration feeding difficulties.
- There is also a need to shift curricula to improve how information is shared with parents and change the relationship between medical personnel and caregivers.
- Where food security is a challenge, feeding can be more difficult because access to food is limited—how to feed and what to feed.
- Stigma. Advocacy/actions to eliminate stigma are needed so that children are able to access and benefit from the resources available. There is a lack of comprehensive advocacy approaches.
- Lack of data on feeding difficulties makes it difficult to make recommendations for policy and investments; need strategies on using data.

What are key strategies you use in your work?

- Parent/caregiver support groups

- Outreach visits to support parents to identify feeding difficulties, including disability as vulnerability criteria to prioritize children
- Re-lactation strategies in emergencies and preparedness for emergencies
- A program in Zambia has worked with SPOON in health facilities to provide training and sensitization of staff about disability. Follow-up with parents has found that families with children with disabilities are now fast-tracked when they go to the facilities. This gives them more time to get home and care for their children who have disabilities. They also conduct cooking demonstrations that train parents on how to prepare food, modify textures, and use safe positioning.

What evidence do we still need to effectively support children with feeding difficulties and children with disabilities?

- Evidence on longer-term outcomes that decrease mortality
- What types of interventions will improve growth and nutritional status—hardest to achieve
- What do caregivers want? What do persons with disabilities themselves find useful?
- How to improve quality of life—hard to collect or measure how services do this
- Better data on how many children have disabilities and feeding difficulties
- More evidence on caregiver mental health and well-being
- More evidence on integration of fathers in caring for children with disabilities

What are priority actions that would have the most impact and greatest likelihood of success?

- Conduct a gap analysis and stakeholder mapping in countries.
- Strengthen services at all levels, including training health workers about the social model of disability, and build capacity for feeding techniques and support for caregivers and health workers.
- Focus on the community level and not just formalized services—community leaders, faith leaders, etc., who are critical to scale and sustainability.
- Standardize tools and resources—integrate feeding challenges and disability into nutrition packages and vice versa.
- Conduct screening in communities so children with disabilities don't fall through cracks.
- Invest in specialized services and in the capacity of local organizations of persons with disabilities (OPDs).
- Be considerate of how we define success in programs for young children so that we do not exclude children with disabilities whose progress might look different.
- Center the parent: all programs should empower parents to be advocates for what they need and how they need it. Service providers and funders must respect parent expertise.

How can we amplify good practices globally and build from successes?

- Involve all stakeholders at all levels from the start, including government.
- Share more on resources so that people can find what is there. Move away from ownership of data and collect it in a way that adds value to end users.
- Include the media in dissemination.
- Focus on empowering parents. Peer support groups are key to helping families; formalize them into legally recognized groups that can access resources.
- Include persons with disabilities in planning, development, and monitoring interventions.
- Leverage existing networks and forums and continue to reach out to people who joined this convening!

RESOURCES SHARED

Day 1

- [The State of the World's Children 2023- UNICEF](#)
- [Inclusion of Children and Young People with Disabilities in Routine General Health Care: Practice guide- UNICEF](#)
- [Is stress a disability?](#)
- [Is Job-Related Stress Covered by the ADA?](#)
- [Nutritional care for children with feeding difficulties and disabilities: A scoping review](#)
- [Improving Nutrition among Children with Feeding Difficulties and Disabilities: Call to Action for Policymakers](#), USAID Advancing Nutrition (available English, French and Spanish)
- [Feeding and Disability Resource Bank](#), USAID Advancing Nutrition
- [The association between malnutrition and childhood disability in low- and middle- income countries: systematic review and meta-analysis of observational studies](#)
- [IYCF Image bank](#), USAID Advancing Nutrition and UNICEF
- [IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action](#)
- [Additional information about the International Disability Alliance](#)
- [Individuals using the Internet \(% of population\) - Low & middle income](#)
- [Update on the WFP disability inclusion road map \(2020–2021\)](#)
- [SPOON resources and training package](#)
- [Smile Train Feeding and nutrition resources for cleft palate](#)
- [Responsive Care and Early Learning Resources](#), USAID Advancing Nutrition

- [Shonaquip caregiver resources](#)
- [Guidelines on maternal, infant, young child and infant \(MIYCAN\) Nutrition](#), Uganda MOH
- [PATH newborn nutrition resources](#) (PATH is also currently developing a specialized lactation-support training curriculum)
- [Nifty Cup](#) - tool for feeding
- [Ubuntu Hub resources](#)
- [Getting to know cerebral palsy](#), LSHTM
- [MAMI Care pathway MAMI Care Pathway Package, Version 3](#), ENN (for infants under 6 months)
- [Washington Group/UNICEF Child Functioning Module \(CFM\)](#) (ages 2-4 and ages 5-17)
- [IYCF Image Bank](#) Disability Search, USAID Advancing Nutrition website
- Interdisciplinary Lactation Care, Second Edition
- [Holt International's Feeding and Positioning Manual](#) - for all children (with and without disabilities)

Day 2

- [Baby Friendly hospital initiative for small/sick newborns](#)
- [Infant feeding guidance in areas of Zika transmission](#)
- [WFP Guidance Inclusive Nutrition Programming for Persons with Disabilities](#)
- [Watch ATscale short film](#)
- [Watch ATscale explainer animation](#)
- [Learning Brief: Kenya County Disability Networks & Care Reform](#)
- [Inclusion of Children and Young People with Disabilities in Routine General Health Care: Practice guide](#), UNICEF
- [Advancing Protection and Care for Children in Adversity Resource Landing page](#), USAID

MENTI POLL RESPONSES:

- I. **What is one thing that you can commit to do this month to improve nutrition among children with feeding difficulties and children with disabilities?**
 - Advocate for integrating feeding difficulties and children with disabilities within nutrition and IYCF tools and guidance.
 - Conduct disability-inclusive research.
 - Use data to advocate for changes in policy and funding practices.

- Advocate for inclusion in data collection efforts.
- Learn more about which assistive devices are most useful in enabling feeding.
- Strengthen capacity to support and manage feeding difficulties.
- Send follow-up information and resources from this convening to participants and more broadly.
- Share resources.
- Raise awareness.
- Connect parents caring for infants with similar disabilities to allow them to share successful strategies.
- Advocate for investment in supporting persons with disabilities.
- Widely share the resource bank (Compartir lo máximo posible el banco de recursos).
- Share learnings from this meeting with our network.
- Advocate with partner organizations about the need to focus on feeding issues for children with disabilities as an essential piece of their mission.
- Incorporate inclusive practices in a proposal I'm working on.
- Share the outcomes of this meeting with colleagues within my agency to kickstart sensitization efforts.
- Advocate for more funding.
- Better understand existing resources on identifying and/or supporting feeding difficulties.
- Share with my department the discussions of this virtual meeting. I think it will have an impact on those working in complementary feeding and wasting at WHO.
- Share new developments with the ministry of health.
- Teach all healthcare staff and share this convening with staff.
- Share the learnings from the webinar with the larger health and nutrition team and the disability committee at World Vision to see how we could share our experiences and learnings with external partners.
- Strengthen my network with the summary of this meeting.
- I will be following up with my colleagues to share the takeaways from this event so we can take action.
- Explore the resource bank to know what exists.
- Connect with as many convening participants as possible and explore collaborations.
- Discuss and raise the issues at the disability network meeting with colleagues from regions.
- Sharing the learning.
- Utilize outcomes of this meeting to inform program design/implementation.

- Advocate with partner organizations/health workers to pay more attention to children with feeding difficulties.
- Organize a meeting to discuss this issue with our member organizations.
- Advocate to make feeding difficulties/disabilities higher profile, including in any organizational briefs.
- Collaborate with and support more capacity building, advocacy, and transfer of skills and data.
- Think of creating a basic tool for community to be used for identifying children with feeding difficulties.
- Assist other organizations in other countries to assemble and design more locally appropriate seating and positioning solutions that facilitate better feeding and swallowing practice.
- Expand the parent champion network into more surrounding countries and expand the ability to understand and measure need.

2. What is one thing that you can commit to doing in the next 6 months–1 year?

- Do more research.
- Use disability-inclusive indicators and results frameworks.
- Research effectiveness of specific interventions we use.
- Have discussions on global platforms on how to integrate feeding difficulties within existing guidance and tools.
- Reflect on how feeding fits within our approach.
- Host a webinar on feeding difficulties and disabilities.
- Publish data on nutrition and feeding status of children with disabilities and feeding difficulties.
- Help my organization’s nutrition advisors put some of these tips into our upcoming internal nutrition guidance revisions.
- Share learnings from our pilot projects where children with disabilities were included with external partners.
- Engage in policy advocacy.
- Advocate for assistive technology use for nutrition.
- Read “Feed the Baby: An Inclusive Guide to Nursing, Bottle-Feeding, and Everything In Between,” an upcoming book by International Board Certified Lactation Consultant (IBCLC) Victoria Facelli.
- Organize a meeting with our member organizations to share experiences.
- Support the development of a SharePoint file for staff that includes important resources.
- Incorporate disability into nutrition learning agendas in new projects.
- Ensure better multi-sectoral coordination in early identification and nutrition programming.

- Remind and work with health workers to prioritize disability and feeding difficulties during IYCF.
- Highlight importance of feeding difficulties identification and intervention.
- Link stakeholders to develop the basic red flag sign for community health workers to identify children then link to service providers.
- Create conducive environment for feeding children with feeding difficulty and children with disability.

VIRTUAL CONVENING ON IMPROVING NUTRITION

Among CHILDREN with feeding difficulties

and CHILDREN with disabilities

LEARNINGS and NEXT STEPS

Improve **DATA** and evidence on successful interventions for scale up



DISPEL STIGMA FIRST

Foster cross-sectoral **COLLABORATION**

MAP key stakeholders and prompt them to make relevant **COMMITMENTS**

Invest in **ASSISTIVE TECHNOLOGY**

INTEGRATE feeding into disability resources and integrate disability into nutrition packages

TRACK the inclusion of children with disabilities and children with feeding difficulties in nutrition programming



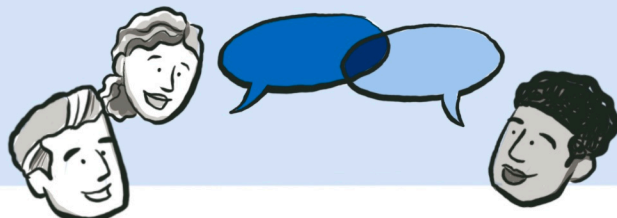
EMPHASIZE caregiver health and well-being

INCLUDE persons with disabilities at all stages of programming

Develop **STANDARDIZED** referral pathways for a clear continuum of care

EMPOWER caregivers to fulfill the rights of their children, including when, where, and how to seek support

Prioritize **FAMILY-CENTERED CARE** that values caregivers perspective and expertise



INVEST in the capacity of Organizations of Persons with Disabilities (OPDs)

TRAIN health workers, including rehabilitation providers, to identify and support children with feeding difficulties and disabilities

Ensure these children are included in mainstream services **AND** able to access specialized services

MAINSTREAM TARGETING





USAID ADVANCING NUTRITION

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May 2023

USAID Advancing Nutrition is the Agency's flagship multi-sectoral nutrition project, addressing the root causes of malnutrition to save lives and enhance long-term health and development.

This document is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of JSI Research & Training Institute, Inc. (JSI) and do not necessarily reflect the views of USAID or the U.S. Government.