



# Virtual Convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities: Day 2

## Webinar Transcript

### Lori Baxter

Okay. Welcome to the virtual convening on improving nutrition among children with feeding difficulties and children with disabilities. This is day two, Thursday, April 27th. Next slide. If you haven't already done so, please do introduce yourself in the chat box, your name, your location, your title, so we can see who is joining us today. I'm going to provide a quick Zoom meeting and overview before we jump into our first opening remarks.

If you have any questions that arise today, you can message tech support Ben or tech support Yaritza, who you can find in the participant list. If that's not working for you, you can also email [info@advancingnutrition.org](mailto:info@advancingnutrition.org). Please note that the plenary sessions today will be recorded and that all recordings and materials will be shared on USA at Advancing Nutrition's website after the event. Next slide. Just briefly, we want to encourage full and effective participation of all participants, so while our meeting will be in English today, we will have interpretation available in American Sign Language, as you can see spotlighted on your slide.

We will also have Spanish interpretation. If you want to listen to Spanish, you can click the interpretation icon to have the option to hear the meeting in Spanish. To hear the meeting only in Spanish, you need to select Mute Original Audio. If you're listening in English, make sure that it says English from the interpretation channels so that you can hear any Spanish comments that are spoken. [Spanish language]

### Lori Baxter

We also will have an enable Zoom close captioning feature. Enable to start viewing the live subtitles on your own screen. You can go to the Closed Caption icon and you can click Show Subtitle. It's only in English, so please don't change the settings, and we are just encouraging everyone to speak really slowly and clearly in order to maximize the accuracy of interpretation and closed captions. Next slide. We'll be using as well-- Just remember that if you're having any problems, you can go ahead and click the join audio. You can leave the meeting and come back, you can try to use your phone to call in as well.

We encourage you, as I mentioned earlier to write to everyone in the chat box, introduce yourself, say where you're joining from. Of course, when you're speaking, you can turn on your video, and when you're engaging with other participants, but otherwise, please mute yourself and keep your video turned off just to preserve bandwidth. Next slide. We're going to be using two main boxes to communicate today. One is the Q&A box, which you can find in the bottom of your screen, and this will be for

questions for speakers during the various sessions. You can see here you can find the icon that says Q&A.

You submit your question, you write it first and then you have to press enter. People can also respond, as well as our panelists can actually help to answer the question. Next slide. We'll also be using the chat box. Of course, that's more for introductions, general reflections, or technical issues. Most of you know how to access it, but you can see the chat box most likely on the right side of your screen, you write in the box, and then click submit. Next slide. Just briefly, our overview, we're going to jump into just a little bit more of a welcome, and then we will have our first two-panel discussion today.

It is our evidence and tracking panel to be followed by breakout sessions. Then we will have a break before we return for the second panel discussion, bridging the gap and breaking down silos. Then we will have an interactive next steps portion before moving on to our closing, so we do have an action-packed schedule. Just as a reminder for our panelists and speakers, we do ask you to stick to your allocated time. If you go over, we may need to verbally interrupt you just so that we can be conscious of our agenda.

Okay. As a reminder- next slide, please. As a reminder, please use your participant program that was emailed to you or available on the event webpage, and **[unintelligible 00:08:16]** is going to add that to the chat box. That's where you can find the full bios for our first two speakers, and all speakers, panelists, and facilitators that follow throughout the convening. I'm now very pleased to introduce Gopal Mitra, UNICEF's Global Lead on Disability and Development and Program Group. He will be followed by Kellie Stewart, Chief Nutrition and Environmental Health Division at USAID. Over to you, Gopal.

## Gopal Mitra

Thank you so, so much. It's really a pleasure to be joining the second day of the convening on nutrition of children with feeding difficulties and children with disabilities. Last night I was going through the notes from the first day and it was really heartwarming to see the momentum that was generated, the discussions. Ladies and gentlemen, the issue that we are discussing about nutrition or the lack of it of children with feeding difficulties and children with disabilities is huge. We have seen from the evidence that children with disabilities are 25% more likely to be stunted- 34% more likely to be stunted, and 24% more likely to be wasted.

It came out from yesterday's discussion that they're twice more likely to die out of malnutrition. There are 240,000,000 children with disabilities in this world, and the issue of feeding difficulty is not only restricted to children with disabilities, the universe is larger. We are talking about an issue of huge magnitude and with severe impact. I have been working in the field of disability inclusion for more than 20 years, and this is the first time that there is such a convening at a level brought by two leading players or actors in this area of nutrition, USAID and UNICEF. I'm thankful to our partner, USAID, and to each one of you for joining the convening.

What is clear is that we need decisive, urgent action, and action at scale. We have to raise this alarm, otherwise, we will not be able to draw attention. The urgency of the action and the alarm has to come out very clearly from this convening. Let me now focus on four points which are required to deliver at scale. Yesterday, we have heard great examples from Argentina, Zambia, India. Some of the solutions, if not all, are already there, right? What we need is commitment. What we need is not only commitment but commitment followed by investment.

We need to see more investment in this area, investment from donors, from national governments, from UN agencies like UNICEF, others, as well as investment time and energy from many other stakeholders, experts, the civil society organizations, organizations of persons with disabilities on this issue and so on. The second issue is capacity. If we deliver- we want to deliver at scale and what we

need to do to deliver at scale. We have to strengthen the capacity. It was clear from the discussions yesterday about the lack of capacity at different levels and knowledge, starting from national governments, decision makers to the frontline workers among donors, among UN agencies, and so on.

This capacity has to be built. The third is data. We cannot scale up if we don't have, if we don't monitor, if we don't collect data on this issue. We have seen yesterday's discussion how our early identification systems, our screening systems currently are not geared to capture data on nutrition of children with feeding difficulties and children with disabilities. They're pockets of good examples. As a system to scale up, we need to do it much more. The fourth point is adopting a cross-sectoral approach. I'm so happy to also see that in the next two sessions these will be discussed.

If nutrition, health education, ECD, early childhood development and education sectors and social protection do not come together, we will not be able to approach or address this issue at scale. I'm pleased to inform and update you that UNICEF, two months back in February, 2023, launched its first comprehensive disability inclusion policy and strategy. The policy and strategy lays in front of us a clear roadmap and framework to considerably accelerate and scale up disability inclusion. It has seven bold commitments. I was talking about the commitments, and then investment.

The first commitment is UNICEF has committed that it'll significantly enhance investment on children with disabilities with an aim to spend 10% of its budget to achieve disability inclusion by 2030. There are also specific commitments about building our capacity and generating data and evidence to inform our planning and investment. Not only that, through so many discussions on so many issues including the discussion yesterday, one of the major root causes is stigma and discrimination.

At UNICEF, we are currently finalizing a toolkit to address stigma and discrimination that children with disabilities experience, and across the organization there are examples of large-scale campaigns with follow-up studies that show that it's possible to address stigma prejudice and discrimination and raise awareness. Before I conclude, let me highlight one of the most important things. The centrality of engaging children, young people with disabilities, and organizations or persons with disabilities to address the issue of nutrition of children with feeding difficulties and children with disabilities.

Article four of the Convention on the Rights of Persons with Disabilities explicitly urges member states and all stakeholders to consult and meaningfully engage persons with disabilities to their representative organization, and this is non-negotiable. This is not only the right thing to do, it's the best thing to do. Organizations of persons with disabilities, and I'm so happy they're an integral part of this convening, have some of the knowledge, the advocacy power, the convening power in so many situations, and often the data.

This applies across development and humanitarian context and we cannot do more of it. Let me conclude with the fact that given the magnitude of the issue, the severity of its impact, no one stakeholder whether it's a donor or a government, or a UN agency, we cannot do it alone. We have to come together. Donors, UN agencies, national governments, civil organizations experts, and most importantly organizations of persons with disabilities.

This convening should be an important step to raising the alarm and the urgency to find pathways through which we can strengthen capacity, improve our data systems, strengthen our **[unintelligible 00:16:56]**, and also bring together the host of partners that are required to really advance the needle on this issue. Thank you, and it was a pleasure to join you at this convening. I now have the pleasure to hand over the floor to Kellie Stewart from USAID. Thank you.

**Lori Baxter**

Gopal, feel free to turn on your video because it was off, and that way everyone can see you as you are passing over the microphone. Over to you, Kellie.

## Kellie Stewart

Thank you—

## Gopal Mitra

Thank you, sorry for that.

## Kellie Stewart

No worries. Thank you so much, Gopal. Thank you for your passionate introduction and your call to action. You've said so many important things and I want to reiterate some of your points and expand on a few others before we get into day two. I really am so pleased and honored to open day two of this important convening, and also want to thank the organizers for making this expert exchange possible. The critical need for more inclusive health and nutrition services for children with disabilities is clear. Poor nutrition as a cause or a contributor to disease and disability are well documented in the scientific literature.

This knowledge drives much of our work in nutrition at USAID, but we need to bring an even greater focus to the link between disability and poor nutrition through various pathways, including feeding difficulties and stigma and discrimination, as Gopal mentioned. Yesterday, we heard powerful examples of approaches to improve nutritional care for children with feeding difficulties and children with disabilities. We will continue these discussions today to focus on how we can move this agenda forward, including the important need to ensure that we are building the evidence base of effective approaches, and also coordinating across sectors to provide high-quality, inclusive, and family-centered nutrition and support services for children with feeding difficulties and children with disabilities.

USAID is committed to promoting inclusive early childhood development in line with the Global Child Thrive Act. We're working to identify where we can collaborate on integrated programming for maximum impact to promote nurturing care, including nutrition support for children with feeding difficulties and children with disabilities. We know that how families support a child with love and care, play, and stimulation is as important as feeding for improved childhood outcomes. Building on available evidence and global guidance for improving ECD, we've supported USAID missions to design inclusive programs that integrate caregiving practices with nutrition interventions.

For example, nutrition programs in Cambodia, Rwanda, and Mozambique work to promote the nurturing care that all children need for positive early childhood development outcomes. These programs include a component focusing on early identification of developmental delays and disability, so children and their families may receive the targeted support they need. We have invested in global tools and resources to support this important integration, such as the Responsive Care and Early Learning Addendum, developed under USAID Advancing Nutrition, which also promotes the social model of disability and cover support for feeding difficulties in caregiver, mental health and well-being.

The Responsive Care and Early Learning Addendum has been successfully piloted in three countries, and the learnings have helped to inform an update to the UNICEF Community, Infant and Young Child Feeding Counseling package already used in at least 60 countries. In Kyrgyz Republic, the government has recently approved the Responsive Care and Early Learning Addendum to be part of their official professional development training packages for health workers. This means health workers across the

country will gain skills to better counsel caregivers of young children about early childhood development, and importantly ensure counseling is responsive to the needs of children with disabilities.

I personally have seen the needs of this work firsthand when the Zika epidemic emerged in 2015. I worked as USAID Zika coordinator in Central America and Dominican Republic. Through this position I had the invaluable opportunity to meet families across variety of communities that were caring for infants and small children living with Zika-related disabilities. Time and time again, families spoke of the feeding difficulties that their children faced. These families desperately needed support. Caring and motivated health worker staff worked hard to fill this need but often resources information were severely lacking.

Seeing these families managing complications from Zika underscored for me how critical community support can be to help promote nurturing care for all children, and the critical need for greater resources. To address this gap, we supported USAID Advancing Nutrition to create the open access feeding and disability resource bank with tools and guidance to assist nutrition and disability program managers in designing and implementing effective and inclusive programs that improve nutritional care.

Since its launch in late 2022, people from 100 different countries have accessed this resource. This convening is another crucial step in USAID's efforts to bring attention to these issues so that we can support better prepared health systems and nutrition services to respond to the needs of all children and their families. Thank you so much for taking time to participate in this critical convening, and I wish everyone a wonderful day full of fruitful discussions. Back to you, Lori.

## **Lori Baxter**

Thanks so much Kellie, and thank you Gopal as well. I'm really happy to introduce our next panel. It's going to be moderated by Shona McDonald, founder of Shonaquip SE and member of the technical advisory group for feeding difficulties and disabilities for USAID Advancing Nutrition. Over to you Shona, to introduce our panel and our panelists.

## **Shona McDonald**

Hi. Good morning, everybody. Thanks. I just start by introducing myself. I'm Shona, and I'm firstly a mom of three girls. One of my daughters was injured at birth over 40 years ago and has severe cerebral palsy. Feeding her and helping her swallow safely and communicate her needs has been really challenging, and set me on a journey to advocate for early intervention and support for children with disabilities living in more under-resourced regions in Africa.

I spent the last 35 years working to ensure that through appropriate assistive devices knowledge to make informed choices and actually the agency to action that information, a family of a child with a disability never needs to experience their child as less valued. I started obviously to build the resources behind this, and we run Shonaquip as a hybrid social enterprise with ISO-certified products. We use a really ecosystemic approach, which talks to what Gopal was mentioning, this ecosystem of support around the family and the child. We work with stigma, advocacy, strengthening referral pathways, providing assistive technology and outreach clinical services.

Together, we bring this together with a network for parents using WhatsApp technology to upskill them and empower them and collect data so that they can inform the policies that need to drive the way forward for them and their families. The only way to change this fractured system, and again, Gopal mentioned it, is to provide support and primary parents and primary care support providers with clear access, uninterrupted access to information that delivers on the policies that have been put in place to predict their child's rights.

It, therefore, gives me great pleasure to introduce to you our first panelist, Kaloyan, a technical officer in disability at the World Health Organization, where he's been responsible for coordinating the development of the WHO global report on health equity. Kaloyan, we understand that you contributed to this World Health global report on equity for persons with disabilities. Can you tell us a bit more about how data contributed to that report? Can you briefly summarize key recommendations within the report related to the evidence and tracking, particularly related to children with disabilities?

## Kaloyan Kamenov

Thank you very much and good morning, good afternoon to everyone. Thank you for inviting me to be part of this panel. Indeed, our team published in December last year, the global report on health equity for persons with disabilities. The report documents evidence on health inequities for persons with disabilities, and also the factors that contribute to these inequities. We also make evidence-based recommendations to stimulate country action. For the report we used on the one hand, the available evidence coming from research to understand better the inequities and the contributing factors.

On the other hand, we also looked at available data, both population-based data and also facility-based data. While population-based data can be identified in many countries, either through census or national service that integrate a set of questions on disability, the data coming from facilities is practically missing. In fact, across all levels of healthcare, it is evident that disability has been largely underprioritizing national health information systems. To our knowledge, no country systematically collects information across health information systems. When not integrated into the systems, of course, disability becomes invisible and underprioritized.

In terms of recommendations, in the report we have recommended actions around data and research. In terms of data, we recommend two types of actions. One is more general integration of indicators to track disability inclusion in countries' health systems. This means that, for example, if a country decides to make their public health campaigns accessible, say to improve nutritional status of children and they take the necessary actions to integrate disability considerations on this campaign, it is important to monitor and evaluate how this campaign reaches children with disabilities, whether information is accessible, et cetera.

The second type of actions target specifically health information systems and this aggregation of data by disability. This can happen through integrating questions in routine, their collection in facilities to identify persons with disabilities. Ideally, this can happen through collecting data on functioning. For example, WHO introduced the supplementary section for functioning assessment in the new revision of the ICD, the International Classification of Diseases. The section of functioning incorporates WHODAS, it's a disability tool that WHO has developed.

This is the major step forward I think in collecting data on disability within the health information systems because most countries already use ITB, and now they also have an opportunity to use and collect functioning information. Another good example is the first-ever global DHIS, the District Health Information System Standard Nutrition Module that UNICEF, with support from WHO, launched in 2021 because it provides countries with already standardized data package to strengthen using collection of data on nutrition monitoring efforts, using routine administrative data for interventions like vitamin A supplementation or infant and young child feeding or wasting.

Possibilities exist, however countries need to invest and prioritize data collection in this respect. I'll finish also by saying that in the report, we also have a recommended countries to develop a national health systems and policy research agenda because this agenda will really seek to produce evidence to determine how to organize the health systems to ensure health equity for persons with disabilities. I'll stop here. Thank you.

## Shona McDonald

Thanks, Kaloyan. We'll get to more questions on that later. Now I'd like to welcome Daniella Akellot, a public health expert and research scientist and author of various and very interesting publications and books. Daniella's got bandwidth problems today, so we'll be listening to a pre-recording, answering the question on can you provide some examples of how to intentionally design studies that are inclusive of persons with disabilities, including children?

[pause 00:30:23]

## Daniella Akellot

Hello, everyone. My name is Daniella Akellot, I'm from Uganda. I am a research coordinator at CoRSU Rehabilitation Hospital. This is a specialized hospital for people with disabilities. I have an invisible disability called Ehlers-Danlos Syndrome or EDS in short. Well, EDS is a connective tissue disorder which affects my skin, my joints, and my blood vessels. Some of the symptoms of EDS include abnormally flexible joints, dislocations or subluxations, elastic skin that easily bruises, chronic pain, chronic fatigue, to mention but a few. In this picture, I share a photograph taken of me when I was six months pregnant while I was at work. You can see here that I'm wearing knee braces to support my knees, and compression socks to support my swollen legs. Because of my pregnancy and because of having EDS, my knees became unstable.

This is because the weight of my unborn child pressing on my hip joints and my knee joints and my ankle joints. This affected the way I moved and worked every day. Thankfully, CoRSU **[unintelligible 00:34:07]**, a rehabilitation hospital, are able to access these assistive devices that helped me work all throughout my pregnancy. You can also see an exercise ball at the back of the room. I had to replace my chair for an exercise ball because I had intense hip and back pain due to the pressure that my unborn child's weight was pressing. CoRSU, The Physical Therapy Department, was able to lend me this exercise ball for a duration to help alleviate the pain I felt while I was sitting.

To answer the question of how to intentionally design studies that are inclusive of persons with disabilities, including children, I find it helpful to first of all specify the objectives of research to include children with disabilities or persons with disabilities. This we can do in our project title, in our research question, in our objectives, in our aims, as well as the methodology where we specify the population of the study. This will help clarify the need to include children and persons with disabilities in research. Secondly, we need to seek out disability research funding.

We find that this type of funding is limited and highly competitive. I've had proposals that have sat on my shelf because every time I apply for general funding, I get rejections. This has hindered research in certain areas, and if there was more available and accessible with disability site funding, these studies would've taken place. I advocate for more disability research funding to be available. Thirdly is to be intentional and advocate for people with disabilities to be included in research as both participants and researchers. I've been working with a disability research group in one of the institutions in Uganda, which is working with the university in the UK to encourage more people with disabilities to participate in research.

Last year there was a PhD fellowship advertised from this institution, encouraging people with disabilities to apply. Well, I was among the three who were shortlisted. Unfortunately, I came in second place. If we had more opportunities for people with disabilities to conduct research in this area, I think this would be a way to generate more research in this field, and get more papers published in this area. Thank you.

## Shona McDonald

Thank you, Daniella. Sorry for the disruptions in your recording coming through clearly. Let me invite Glenn David, a senior social insurance specialist working in the development of special benefits in the research department at the Philippine Health Insurance Corporation. Glenn, with your really different lens on this, can you share an overview of the benefit packages for children with disabilities that you've developed in the Philippines?

## Glenn David

Hi, Shona. Good day to everyone. First and foremost, I am Glenn David from the Philippines, and let me just provide a quick overview of our country and what is **[unintelligible 00:38:51]** all about. Then later on I will going to provide the general overview or background on what are the benefit packages for children with disabilities. Our country, the Philippines, is an archipelagic country, which is located in Southeast Asia and where consists of around 7,641 islands, and this is a home of around 113 million Filipinos. In 2021, our gross domestic product, or GDP is around 5.7%.

Based on the Philippine National Health accounts, we have a total health expenditure of about 6%, and add out a package spending of 41.5%. PhilHealth, or the Philippine Health Insurance Corporation is the National health insurance in the Philippines. We are mandated to provide health development or financial risk protections to all Filipinos, and giving a priority to underprivileged, the sick, elderly, persons with disability, women and children. Right now we have various benefits packages. We have an outpatient benefits, which provides a benefits packages for screening, consultation, basic diagnostic and laboratory services, including medicines.

We have also inpatient benefits for those medical and surgical procedures. We have also catastrophic benefits, which we call the Z Benefits, and we have also other benefits as the sustainable development goals covering for maternity package, newborn screening, including the outpatient HIV benefits packages. With regard to the children with disabilities, we started developing a benefits package for persons with disabilities in 2013, as we cover for adult. These are for ages 18 years old and above, and we call this as the ZMORPH or the Z Benefits for Mobility, Orthosis, Rehabilitation, Prosthesis Help.

This covers an upper and lower limb prosthesis, lower limb orthosis, spinal orthosis, and a rehabilitation session. Then later on through the technical assistance of the UNICEF or UNICEF Philippines, we were able to develop a benefits packages for children, so these are for age 0 to less than 18 years of age. We have four benefits packages for children, which cover the four most common types of disabilities among them. This includes developmental disability, mobility impairment, visual disability, and hearing impairment.

Now, the benefits packages for developmental visibility covers the provision of initial and discharge assessment by a medical specialist including allied health specialist and rehabilitation services, which will be provided by an occupational therapy and a physical therapy. For mobility impairment. we cover the provision of seating devices, prosthesis, orthosis, spinal stenosis, spinal bracing, including rehabilitation services. With regard to the hearing impairment, we include in our benefits packages an audiologic assessment. We have also assisted devices such as the hearing aid devices covering for the hearing aid fitting, the hearing aid devices itself, the batteries including the hearing molds through the fitting in, including the speech therapy session, if needed by these children.

With the children with visual disability benefits packages, we include an assessment assistive devices, which include the optical aid and electronic devices, and ocular prosthesis if needed. These benefits packages can be available to a contracted health facility that we engage in PhilHealth, who are assessed to provide a complete and quality services for patients who needed these benefits packages. Thank you very much.



## Shona McDonald

Thank you, Glenn. Could you maybe go on to really give us an insight in what have you learned from your experience to date, as you began to build the capacity in the health information system, and to disaggregate by disability, for example, to check children accessing services through this package, this PhilHealth package.

## Glenn David

All right, so thank you very much for that question. First and foremost, we need to include these children with disabilities in our system. We need to register them under the National Health Insurance Program so that we may know how many of these children are needing the benefits packages. How can we [unintelligible 00:44:07] to build our data for these children with disability? First and foremost, we build our database through the claim submission of the health facilities that we engage to provide these services. As they submitted their claims, we were able to reimburse the services that they provided to those eligible patients for the benefits packages that they have billed.

Then, once the data has been submitted to PhilHealth, the claims will be processed for reimbursement based on our set rules and the data are stored in our data warehouse. Now, the claims data includes the demographic of the patients. What are the- say services that was provided by these contracted facilities, including the professional fees of the doctors? The health information systems from PhilHealth will be used to determine the following domains based on our monitoring framework, which include the quality of care.

We also want to determine the experience of care or the patient satisfaction, financial risk protection, if this patient- how much of them spend for health services or do they have no co-payment and finally, to detect any adverse practices. Overall, in the future, PhilHealth aims to have an efficient and an effective health information system that we can track all the patients that reimburse to PhilHealth, to ensure that all the services provided by our engaged health facilities are of quality and par to standards. Thank you.

## Shona McDonald

Thanks so much, Glenn. Thanks. Fascinating. So good to see. From our experience in so many places we've worked and work, there's historically no access to data, and yet data's the only way to change these fractured systems and support parents and primary care providers to understand their reality. Kaloyan, can I ask you, what are some of the key considerations, including the benefits as well as the challenges or risks for tracking young children with health conditions that contribute to their disabilities?

## Kaloyan Kamenov

Thank you for this question, Shona. The report that I mentioned before that we published last year recommends the inclusion of early identification management, rehabilitation for conditions for children, and in a very smoother way to what the colleague from the Philippines said and indeed, when such- to include these interventions in the country's packages of care. Indeed, when such interventions are integrated in the packages of care, there need to be a corresponding data collection as part of the national health information systems to track progress in children.

Disaggregating data by disability across the different levels will help us track both the inequities that children might experience, and also the factors for these inequities. Meaning that we'll be able to see, for

example, health outcomes for children like if their functioning has improved, or what are the levels of mortality compared to children without disabilities. Also, understand some key factors associated with these health outcomes, like the coverage of any availability of services or the accessibility of services and infrastructure, or for example, whether assistive technology and equipment are available.

However, there are of course several challenges and risks that need to be taken into account when we speak about data collection in children. Some of them are ethical considerations which relate to things like safeguarding, inclusivity, and engagement. For example, we know that processes of information giving or consent and different methodologies for data collection are often insufficiently adapted to be entirely disability inclusive. There are also often negative assumptions about the capacity of children with disabilities to participate in generating data, or children and young people with disabilities that are frequently perceived as needing special protection, therefore excluded from evidence-generation activities about their own specific situation.

Of course, this is tricky because at the same time researchers or people who collect the data need to consider the importance of protecting children in data gathering, so there has to be a middle ground to have a solution. Another issue that relates to inclusivity and engagement is that very rarely someone actually asks children with disabilities, and their representative organizations on what they need or how they can be asked, and this is crucial. We have to be careful how we collect the data, but data certainly needs to be collected on everyone in one way or another.

When not integrated into the health information system, disability becomes, as I mentioned, for invisible and underprioritizing the health sector, and in this case information about children with disabilities. Just to mention that now after the report was published, WHO is now in a process of development of a strategic planning tool called Guide for Action on Disability, which we'll lay out the step-by-step guidance for governments to implement the recommendations of the global report.

We are starting now working with six countries that are interested in piloting the two, and of course a focus of each two and in the work with countries will be both data and the models of care specifically for children, as this is extremely important to advance health equity for children with disabilities in countries.

## **Shona McDonald**

Thanks, Kaloyan. The importance of accessing real-time data to inform more effective process has never been more important. Daniella, I'm really interested also with the work you're doing, that accessing data to inform product design, and capacity building, and actually practice. Can you please share about your research specifically relating to the feeding of children with disabilities, and how do you anticipate that this feeding chair that you've developed and the research can be translated into action? Again we are listening to a recording from Daniella to that question.

## **Daniella Akellot**

Hello, once again, thank you sure enough for those questions. To answer the question relating to the research that I've done, specifically on feeding children with disabilities, I'd like to share a study that we conducted at CoRSU in collaboration with SPOON Foundation and St. Catherine University. The title of this project was A Seat for Every Child: Creating Safe and Dignified Mealtimes.

For more information, please see the poster that I've shared. The aim of this pilot research was to determine the feasibility, usability, and acceptability of a low-cost feeding chair designed by SPOON for children with disabilities in low-resource settings, as you can see a picture of this chair and a child with cerebral palsy sitting in this chair in the slide that I shared. Well, just to give a brief background. We

found that 89% of children with disabilities have persistent problems interfering with safe eating and feeding.

This caused an increased risk in poor health and child mortality. We also found that this difficulty during mealtime led to social and health consequences including caregiver stress and burnout. What did we do? We collected data from 20 caregiver and child pairs of cerebral palsy. We used the index scores to identify and select participants for this study. We collected both quantitative and qualitative data. Quantitatively, we use the parents upsetting the feeding impact skill chair observation form, and pre and post-scores of then communicating children's prints, checklists and assessment of reading position to collect data.

Qualitatively, we organized two focus groups with caregivers to find out the experience while using the chair. We took photos and videos of children while they were feeding. You can see some of the pictures in the poster as well as the slides. Our findings were that 55% and 70% increments was observed in correct hip, head, and truck positions when the children were seated in the feeding chair.

Secondly, there were 70% of these children who utilized the tilt for breastfeeding position. Lastly, there is 65% increment in responsive feeding practices with caregiver and child diets. The common themes that we received from the focus groups was that both child and caregivers were more comfortable during feeding than before. Child participants were calm and more relaxed, as well as the child participants were able to see the caregivers' faces.

We concluded that this chair was both feasible and acceptable to improve mealtimes for children with disabilities in low and middle-income countries. To answer the second question, of how we anticipate this feeding chair to be translated into action. First of all, we have developed a final feeding prototype basing on the recommendations made by the caregivers in the pallet studies. Secondly, we plan to apply for the USAID grant to find further research on usability of this feeding chair in a home environment for children with disabilities. Thirdly, we plan to develop a business plan to scale up production of the feeding chair. Lastly, we hope to identify a local manufacturer in Uganda. Thank you.

## **Shona McDonald**

Thanks, Daniella. I see there are a number of questions coming in. Shall we go ahead Lori and address some of the questions?

## **Lori Baxter**

Yes, let's do that first question that is listed in your document for Glenn.

## **Shona McDonald**

Yes. Zena asks or says, "Glenn, impressive to hear about the benefit packages offered to children with disabilities. How are you integrating management to feeding difficulties and tracking of data related to nutrition and feeding as part of the feed healthcare packages and what gaps need, if any, do you see?"

## **Glenn David**

All right. Thank you very much for that question. First and foremost, the C benefits packages for children with disabilities, specifically use the disease-based criteria. We used our criteria based on the type of disability or domains and this can be included in any of those four packages. As these children

enroll in the benefits packages, we aim that they improve their quality of life, which includes their activity of daily living and also their nutrition as well. Of course, we have some challenges, especially on the supply side because we all know that assistive devices are quite expensive.

Also, we have limited number of specialists such occupational therapies and those physical therapies that are working here in our country. Field Health is also developing an outpatient therapeutic care benefit packages for [unintelligible 00:58:12] which also complement for the children with disability benefits packages. As we treat the disability of these children, we also aim to treat the malnutrition of these children once the benefit packages for malnutrition has been implemented. Thank you very much.

## Shona McDonald

Thanks, Glenn. Daniella, you raised an incredibly important point on the need to do better to include persons with disabilities as both researchers and research participants. What advice can you give to other researchers who'd like to strengthen these types of partnerships to conduct better or actually more inclusive research?

## Daniella Akellot

Thank you. Hello once again, apologies for the connectivity issues. To answer the question, I would advise everyone to network with those who have already done successful research. At CoRSU, most of the research we do is in collaboration with other scientists from different parts of the world. We are working with University of California, San Francisco. We had a project with the London School of Hygiene & Tropical Medicine in the UK. We did a project also with Ghent University in Belgium.

I really encourage collaborations and the fact is that doing research in Uganda is expensive. Approvals alone, you can ask my colleagues who are here with me. Just getting ethical approval is about \$400, and that is regardless of whether you are a Ugandan investigator or an international investigator. After that, you have to get a research permit which is another \$300.

Responded for this study is that they first of all gave us \$1,000 to process the approvals, and once that was done, then we were able to move to the next phase. Also, there are delays in getting approvals. It's really important to be persistent. I've had researchers almost give up on the process, but I keep encouraging them. There's a study that took us two years to get approval. In Uganda, it is a challenge but persistence works and at the end of the day will succeed. I hope I've answered the question. Thank you.

## Shona McDonald

There's a fine balance between research and demands of ethics approval and getting products into production that are useful for the end users as fast as possible. I think we're all torn in many directions through that process. Kaloyan, you spoke about DHS and other household surveys and the opportunity to include provisions related to disabilities. We know that these surveys are often difficult to implement and a lot of capacity building occurs to ensure data is really robust. How do you recommend that this inclusion and disability, particularly linked to feeding difficulties, can be elevated and advocated for, and what are the really practical steps that should be taken?

## Kaloyan Kamenov

Thank you, Shona. It's a really good question and I would say that there are two elements that we need to consider here. First is the technical element of integrating the right questions that will collect the information that will really provide a good and comprehensive picture of the situation of persons with disabilities in the country or in the region. Particularly, if the research is interested in children with feeding difficulties.

Normally, we have two types of service. One is a disability-specific service. For example, the WHO Model Disability Survey. It's a household survey specifically designed to collect information not just on persons with disabilities, but also on the environmental factors and barriers, and facilitators. Integration, for example, of specific questions to understand more children with feeding difficulties can be one way to do that. The other option is to integrate a set of questions in general service like the DHS and here we have to really think because it is very costly to integrate questions.

There is a lot of resources and also sometimes training to interviewers to really know how to ask the questions. Because there is a lot behind, we have to make sure that the right set of questions are integrated. Now, based on our experience for example, with the Model Disability Survey, countries really have to have a commitment in order to do such a survey because it's costly, because it involves a lot of resources. I think the role of civil society and particularly organizations of persons with disabilities to really advocate to governments on the need to implement such survey and really as a first step to understand the situation of persons with disabilities is extremely important.

For example, I mentioned this guide for action that we are developing. There will be different phases for governments to follow but the first phase is really situation analysis and assessment to understand better what's happening in the country. Very often countries may decide to integrate questions on disability in their routine surveys and really based on that then to decide what type of actions need to be taken. Just to conclude the advocacy coming from civil society is extremely important for governments to really take action.

## **Shona McDonald**

Thank you so much. A 100%. I think we go back to go Paul's point and certainly our passion which is the really strong need for cross-sectoral approach in the sector that touches on nutrition, health, education, early intervention, inclusion, and social protection, all running concurrently. We've run out of time and I'd just like to thank Glenn, Kaloyan and Daniella so much for their input please continue to put your questions in the box and the panelists will answer them directly. Thank you so much.

## **Lori Baxter**

Over to you, Malia.

## **Malia Uyehara**

Thank you, Lori, and thank you Shona and all of our panelists. That was fantastic. Hi everyone. Hopefully, you recognize me from yesterday. My name is Malia. I will be walking us through today some information on our next session, which will be a bit more interactive. We'll be heading into our breakout rooms in just a minute. Next slide, please, Lauren. If you were on the call yesterday, this will look pretty familiar to you, so I'll just run through it, pretty quickly.

As I mentioned, our next session will be breakout rooms. We have, six breakout room themes listed up here. If you registered for the event, you selected your theme. You have been preassigned to your rooms. If you were here yesterday, you will be moved into the same room that you were in yesterday.

For those who maybe weren't able to register or weren't here yesterday, you still have been preassigned, so you don't need to worry about choosing a room. You will automatically be sent to one.

Next slide, please. Just a few housekeeping items before we begin or before we open the rooms. Once you are in your breakout rooms, please feel free to introduce yourself in the chat box. Our time is a little bit limited today, so we won't be doing a formal round of introductions or anything. The chat box feature will still be available, so please feel free to type in your name, your role, and where you're joining us from. Or if you come off mute to answer a question during the discussion portion, you can also feel free to introduce yourself before providing your response as well. It's highly encouraged. We will be using the same interactive format as yesterday with the jam board if you'll recall.

That's our virtual flip chart or whiteboard. We'll be utilizing the sticky notes feature. Each breakout room, once again will have a jam board facilitator. That person will be responsible for sharing their screen with the jam board and for recording the conversation. They will use the sticky notes to record anything, that is said during the discussion that is not already on the board. As such, we encourage everyone to come off mute and share your thoughts and your feedback verbally, and then your jam board facilitator will record those ideas. If, for example, you're having technical issues or you're not able to come off mute, you can also feel free to put in your own sticky notes.

We've included some instructions here for doing so, and I believe your jam board facilitators will go over those instructions briefly with you as well, but to keep it short, you can click on the sticky note feature or icon on the left-hand side of the screen, and a box will pop up for you to type in your sticky note and then if you press save, it will save your sticky note on the jam board. Next slide, please. As I mentioned, everyone has been preassigned to their breakout rooms, so in just a minute I will open the breakout rooms and it should automatically send you to your room.

Hopefully, you won't need to click anything, but if you have any issues, you can click on the breakout room box at the bottom to choose which room you would like to be sent to, and if you have any issues getting to your room, you can send a message in the chat box to our text support, so either Ben or Yaritza and they will help you get to the appropriate room. If you get to your room and find that you're in the wrong one, you can click the leave room button and it will send you back to this main room here.

This main room that we're in right now, will have the Spanish translation, so if you need the Spanish translation, please stay in this room, and if by any chance you need ASL interpretation, you can go to the promoting disability inclusion room and we'll have the ASL interpreters there. All right, I think that covers all of our instructions. I will go ahead and open the rooms right now. I'm wishing you all a fruitful discussion, and again, if you have any issues, please send a message in the chat box to our tech support. We'll see you all back here in a little bit.

**[pause 01:10:53]**

## **Alyssa Klein**

Excellent breakout sessions. Yesterday, I was not able to jump between them, but today I did. You may have seen me coming in and out and that was fantastic. Really interesting to see the exchanges, the intimate conversations, the exchange of resources, really great. We hope that you enjoyed those as well and we will be compiling and sharing everything that was shared in all of the breakout groups with the whole group because I know you may have been interested in multiple themes.

With that, I just wanted to give a very brief teaser to let you know we are about to break, but please do come back after a break because you have a very interesting panel that will be awaiting you. You can find the bios in your participant program and you won't want to miss it. Stand up if able, move around, grab a drink of water, enjoy the music, and we'll see you back here in 10 minutes.

## Linda Shaker Berbari

Welcome back, everyone. I hope you had an enriching discussion during the breakout sessions. This is definitely a platform to share experiences and learnings contributing to hopefully successful outcome of this convening. Before we move into our next panel, I just wanted to highlight that there are a few questions and answers from our previous panelists that have been added to the Q&A box. You can find the written responses under both the open and answered tabs.

Please feel free to check those. Great. We come now to our second part of the day, this is day two. We are going to be discussing how do we actually work together. How do we bridge gaps and break silos? We saw during the first day that us as participants, constitute professionals from both the disability and nutrition disciplines. This is definitely a really valuable opportunity for us to come together. We learned earlier about the importance of having close collaboration, a multidisciplinary approach, including joint visions and plans and platforms and frameworks.

I personally, coming from the nutrition field, have found the discussion, really eye-opening, and I'm excited for the opportunity to make a contribution. I really hope that you're all also excited for that. For that and without further ado, we are going to be speaking with four esteemed panelists who will share their experiences from their own organizations. I would like to first introduce David Mwesigye, he is a nutrition specialist in the Rwanda Ministry of Health, and his main role is to coordinate the efforts to fight all forms of malnutrition, with more emphasis in reduction of under-five child stunting.

Our second panelist is Barbara Goedde, and she's a strategy and coordination advisor at ATscale, the global partnership for assistive technology. ATscale is a cross-sector partnership with a mission to transform people's lives through assistive technology. Next is Juan Pablo. He serves as Head of Global Health Initiatives in the Office of the Director of the Department of Nutrition and Food Safety at the World Health Organization in Geneva, where he works on practice and science-informed global guidelines and supports their implementation.

Last but not least, Filippo Dibari, and he's the regional senior nutrition advisor at the World Food Program of the UN Regional Bureau for Asia and Pacific. He's based in Bangkok. I'm really excited to be part of this panel and to facilitate this really valuable discussion. Therefore, if I may start by asking a first question to our colleague, Juan Pablo, related really to your organization, Juan Pablo and WHO. If it's possible to share with us some examples of existing norms and standards that integrate provisions for particularly feeding difficulties and explain a little bit how these support coordination, including, we always talk about monitoring and so including coordinated monitoring. Juan Pablo, the floor is yours.

## Juan Pablo Peña-Rosas

My camera is blocked, but I wanted to comment on the example. I have two examples that I wanted to share with the group, and it refers to the importance of-- when we talk about the normative work, or WHO, we have to think about sometimes is a guideline that goes into a higher level of decision making politicians that need to include good provisions. For example, including children with feeding difficulties or children with disabilities as part of the program.

That means probably additional resources, human resources, specialists, and sometimes the addition of some particularly assistive technologies. Sometimes we work at that level, which is mainly at the policymakers' levels so that they can have the consideration of the recommendations to include persons with disability in the school programs or in the interventions for feeding, promoting breastfeeding, or in the plans for sick care that I was mentioning in the small group.

This first example is an example of how-to. I spoke with my colleague Larry, who leads the unit of implementation of nutrition actions in health systems. He's leading the work on wasting, along with UNICEF and they're working also on complementary feeding. I think it is important that they're going to go into how the specific activities have to be done. This is an example I put the reference for you. I was not involved in this one, but this is the one that he gave me as an example of how you're going to do a specific activity with a child with efficiency. In the next slide, there is an example of-- I'm sorry, I had cataract surgery, so my vision is not very good.

## Linda Shaker Berbari

No worries at all.

## Juan Pablo Peña-Rosas

If you please excuse me. This is an example of the type of recommendations that are very much aimed at those who are implementing the program. The workers of the program are in the baby friend, in this case, baby-friendly hospital initiative. How are they going to be helping mothers to promote breastfeeding and avoid the interference of the formula feeding, formula companies, and proper marketing of breastfeeding in such a case?

This is one level of normative work that we do usually with implementers like UNICEF or other NGOs that are in the field, and capture the knowledge and the experience that they have and the expertise that they have in dealing with these patients and basically be civilized in concrete recommendation that can be then disseminated worldwide.

The other example that I coordinated, the next slide is Zika.

Zika, I think it was the year 2016 started as you know as an epidemic in Latin America, Brazil, with this condition, the Zika virus. At the beginning, the first question that arise was on whether we should continue recommending breastfeeding for women who were infected with the Zika virus, or they get the Zika virus.

Zika virus is transmitted through a mosquito, so some of the interim guidelines that we had to put on in emergency was based on what we knew from experts in the field, and they were facing and understanding the cycle of the transmission, and the recommendation was because they were in the same environment, breastfeeding the mother. You don't know if at the end, the transmission goes through the breast milk, through this blood, or through the saliva.

Some of the things that are related to breastfeeding itself or is through the breast milk, and we had an intervention. That interim guideline became then a rapid advice guidelines because the interim guidelines of those are made in emergencies, and they have a validity of only three to six months. We converted it now with the use of evidence, and a guideline development group into rapid advice guidelines, so that was the first edition of the infant feeding in areas of Zika virus transmission.

We had to make it a standard guideline, the epidemic had already passed, and they were doing all kinds of preventive measurements, but there was a lot of learning, and they wanted to make it a standard guideline so that in the future if there is another epidemic they know what to do. This is where new questions arised to us related to infant feeding of children who had sequelae from the Zika virus.

The question was no longer on the transmissibility of breastfeeding, but rather on how to deal with children who have congenital Zika syndrome, or other type of difficulties related to Zika, and also what were the consideration related to the caretakers or the caregivers so that they would be considered in the programs that were related to the management of Zika. At the time, this was an important



consideration because we needed to visualize, and make visible that this was something that required additional resources, additional professionals to be giving support, dealing with the stress and anxiety of parents, and also incorporating a wider set of stakeholders in the guidelines.

I think that one other question was whether there should be different modifications in the feeding programs in children with Zika. We didn't find studies done on this. We use indirect evidence. Some of the direct evidence identified dysphagia, motor development delays. In some cases, the detection of the Zika syndrome became like one year when they were growing and the head was not growing, is when they started to notice that development was a congenital Zika syndrome.

Then also the support that the primary caretakers needed so that they would be put in the programs of Zika where they were funding for. I think that this is an example of the two types of normal and normative standards and normative selling products that WHO produces. One is at the policy level and the other is at the implementer of the intervention. I think it was a great experience that I wanted to share with you. Thank you.

## Linda Shaker Berbari

Absolutely. Thank you so much, Juan Pablo. This is really useful. I know during the breakout rooms, there was a lot of discussion around the role of health professionals, and specifically, lactation professionals, and the opportunity to integrate into existing resources as an important action. Thank you so much for giving us these valuable examples. I will now turn to you, Barbara, and ask you about ATscale's role in coordination with development partners to ensure appropriate assistive technology that they're available through the public health system or even other avenues, as this is an important prerequisite, of course, in terms of supporting children with feeding difficulties and disabilities. Over to you, Barbara.

## Barbara Goedde

Sure. Thank you. Thanks for inviting me. It's been really interesting listening in as much as I could. I couldn't listen the whole time. If you could move to the next slide, please? Before answering the question, I just wanted to maybe refer back because there have been questions about that also during the discussions yesterday and today about how is assistive technology important for feeding.

There I just wanted to raise two or refer to two basic things. One is that if we adhere to what's called universal design principles, which means that a product can be used by all people, regardless of their age, size, ability, or disability, then in many cases, hopefully, we wouldn't need a specific assistive device. An example would be a cup with two handles, which actually might be useful for many, not only for people with disabilities or some kind of difficulty in grabbing.

The others, I just wanted to also recall that an assistive device does not have to be complex, so, in the end, if you think about it, a disposable straw could be considered an assistive drinking device. Also, in that context, it has been mentioned before that, hopefully, assistive devices can be produced with local materials, so really simple solutions can often work. Just one example that I wanted to point out, which I learned about recently in a UNICEF webinar, which is straps made of silicone, which allow to be slipped onto objects, and then really enable a non-slip grip on those different objects.

I've put a few photos here to show the examples. They can be put onto cutlery that is otherwise difficult to grab, they can be put onto drinking cups, et cetera. Just to say, just because it's called an assistive device, it doesn't have to be difficult or complex. Next slide, please. Now to ATscales role in coordination. As Linda has already said, we are the global partnership for assistive technology.

We are a cross-sectoral partnership, so that means already that we bring together multilateral organizations such as WHO and UNICEF. We bring together donors active in the field. For example, USAID, and also from the United Kingdom FCDO. We bring together program countries, organizations of disabled persons, very importantly, and nongovernmental organizations at a global level. It was already mentioned several times that also in the underlying report for this consultation, that there is a lack of assistive technology to support feeding in most situations, and, unfortunately, that is not something that is surprising because access to assistive technology is very low overall.

On the right-hand, upper side of the slide, I've put here a graph that shows that the access to assistive technology can vary between only as low as 2% in some low-income countries, but can be as high as 84% in some high-income countries, but overall, it is estimated that globally 2.5 billion people need at least one type of assistive technology.

At ATscale, we work with all stakeholders to increase awareness and political will and to support innovation and investment in assistive technology markets, systems, and services. Just to kind of think about how that can look at a country level. We provide governments and relevant stakeholders with support to co-create integrated national assistive technology strategies and plans. Then we provide catalytic investment to implement the plan over three years initially, and we invite other partners to collaborate.

If we could have the next slide, please? I just wanted to show where we are in effect working. We are a young partnership, so, unfortunately, we're not working in that many countries yet, but we have started more comprehensive national investments in Kenya, in Cambodia, and in Senegal. Then we're just starting a program in Rwanda, which, however, is only focused on hearing. Then in three countries in Georgia, Tajikistan and Azerbaijan, we support a regional program that works on the integration of primary healthcare. That's where we work at the global level, but also at the national level.

## **Linda Shaker Berbari**

Fantastic. Thank you so much, Barbara, this is really impressive. As you said, it's simple tools that make a huge difference and it's really about making these accessible and available particularly in public health systems. Thank you so much for that. I'm going to now move to you, Filippo, to talk a little bit about the World Food Program. We know that as an organization you have a large role in food assistance and nutrition, and so I wanted to ask about that, about WFP's role in providing food assistance to those who need it most, including persons with disabilities and children with unique feeding needs. Over to you, Filippo.

## **Filippo Dibari**

Thank you so much. Well, first of all, thank you for the opportunity to learn a lot from so many other colleagues. The World Food Program does not work specifically with children or mothers, but it works actually with the entire population. We serve on daily basis more than 80 million people globally and mostly in emergency settings. That's really where we have the largest footprint.

Therefore, we face severe limitations when in this kind of settings. Just to give an example, a pictorial example. Try to imagine the long queues of refugees waiting for the food ration and the type of assistance that we can tailor for specific groups, it's really a challenge.

That said, we definitely have since 2021/2022 guidelines to work in nutrition and disabilities, and the guidelines that I'm going to be sharing later, or with the web link in the chat box are strongly encouraged to be taken up by our partners who we implement through in our programs across the world. The guidelines are needed to look at the type of programs that we are working.

We're working with not only food security programs where we provide food rations, so we reach really the most vulnerable ones, but also school feeding, social protection, climate, and resilience programs. There is a large variety of possibilities that we can tap into. The main challenges that we face are definitely the data collection, given the type of work that we do, understanding the numbers that's an exercise that we have just set up in our region, for example.

Trying to understand what is the number of cases and how to reach them and what are the type of barriers, for example. Are the barriers only related to the type of food that we are giving, or is this also related to stigma when they come out to reach out for the services? Could our cash base transfer programs be helpful to reduce the access barriers in terms of transport or other types of barriers?

Definitely, a lot of work that we needed to do in research and development for products as well with our colleagues from supply chain. Let alone all the work that we are doing with the community-based management of acute malnutrition, that's another potential entry point for us, and basically, please have a look at the guidelines that we have produced and help us to implement them. Thank you.

## Linda Shaker Berbari

Perfect. Thank you so much, Filippo. A lot to really build on and take this as an opportunity. I'm also, again, thinking about the conversations during the breakout rooms and the recommendations around what actions need to be made and the importance of having those guidance, the tools on the how-to. Thank you for that. Lastly, for this round of questions. I'd like to hear from you David and your experience amidst what colleagues have just shared.

I specifically wanted to ask you within Rwanda, what type of coordination mechanisms are in place to facilitate this collaboration across nutrition and disability? We've first heard about guidance and norms and documents that can help us with this coordination. We'd like really to hear from you about practically what are some of the mechanisms at the country level that you've been engaged in? Over to you, David.

## David Mwisige

Thank you, Linda. Before going to that, I want to share with you that Rwanda is trying hard to eliminate the issue of child stunting. As you have seen our colleagues have shown that child disability and feeding disability is a significant cause of child stunting. As you understand, child stunting or child malnutrition is a complex issue that needs collaboration between different partners.

In Rwanda, actually, everyone who touches the lives of people like different ministries and agencies where we work together to identify issues, to identify the progress, to identify where do we need to really focus our resources. On our part as ministry of health, we provide creative interventions especially on children with disabilities. If it's a disability that can't be cured, at least, we provide rehabilitation services and we have health professionals that have that capacity.

The issue starts when they get to their homes in the village. How do mothers continue following up? Do they have skills? Do they have tools like my colleagues have said? Do they know how to care or provide special care to children with feeding disabilities or child with disabilities in general? We work with different organizations, stakeholders, non-governmental organizations to implement very different innovative approaches to improve inclusiveness of children with disabilities. For example, recently, in 2020, we started implementing a USAID project. We name it in Nyarwanda as [foreign language] to mean including every child, either you are disabled or you are a normal child, but make sure that every child benefits from all health structural and nutrition services or other nurturing services that children deserve. The best part is these services or these hubs are located at village level to allow or to

accommodate children from closer to their homes. We also do follow up to make sure that these facilities or these hubs are accessible by every child.

This project is being implemented by a pool of partners and NECD, which is the agents that promote nutrition, child protection, and better development of child development. With complexity of these issues, there is a need to work together with different partners than we used to. We just can't work it alone. However, with different approaches and **[unintelligible 01:40:38]**, there are some issues and challenges as my colleagues have said. Currently, we have data management information system at the central level where health centers or hospitals provide their data about how many children with disability or people with disability that have been reached with health care services.

However, there's segregation, knowing that this child is under five and has disability, has been screened. It's quite a bit challenging. That's something that we want to work with RBC, Rwanda Biomedical Center, which is our implementing agents, to establish a monitoring system so that we get the necessary information for us to be able to follow up and provide necessary action and work responses. The other is, again, the guidelines that we have, they include necessary guidance on how to feed children, do they provide what food do children need, special food. As we have seen, the guidelines are not inclusive as we want it to be. The last one is currently we have a National Council of Persons with Disabilities or NCDP. They work with NUDOR or Union of Disability Organization in Rwanda. This is an umbrella of more than 13 organizations that have disability component or works with people with disability. They work together to advance advocacy and they raise issues is our policies, our strategies. They're inclusive. From there we get what we need to do or the gap we need to solve. Thank you.

## Linda Shaker Berbari

Thanks so much, David, for sharing this experience, which is not only related to coordination platform, but bringing everyone together and also making sure that the necessary tools are in place, but of course, the challenge of maintaining that and supporting that. Thank you so much for that. Actually, my next question, I think you've answered part of it about the existing coordination efforts. I will ask that question to Filippo in terms of what are some of the fora that we have, or even that we need, for ongoing coordination to improve the nutritional care for children with feeding difficulties and children with disabilities. I'll actually ask this question to all four of you. If so, please feel free to compliment each other as we move forward. Thank you.

## Filippo Dibari

If I understood correctly, the question what are the fora where that kind of topic, definitely in the setting of emergency response. Definitely, one of the fora to target would be the food cluster and the nutrition cluster. That's without any doubt. More in the development settings, that would be the usual plethora of platforms and entry points, but in emergency, yes, definitely these are the two clusters, I would say. That's in a nutshell.

## Linda Shaker Berbari

Thank you. Maybe I can ask Barbara as well the same question, please.

## Barbara Goedde

Yes. I think given that I don't come from the nutrition side, I would like to put it a bit differently and say what would the fora have to do? I think what is transferable is that we see that it's really important to get everyone who is concerned around the table because assistive technology like this topic is something that very often falls between different responsibilities. If a Ministry of Social Affairs, for example, is seen as in charge, then a Ministry of Health might not be active at all in the area. To get everyone who is concerned and to make them aware that they are concerned. Then a second point would be that the two-track approach that has been mentioned since yesterday is very important here as well.

That on the one hand we probably need dedicated coordination, but we shouldn't only focus on dedicated coordination on this topic because we need to raise the awareness of the topic in other coordination fora that are not primarily engaged in this to ensure that there is a wider reach. Maybe a last very specific task for coordination fora in this area would be just to say that knowledge is very fractured, I think on assistive devices that are useful here. It's a bit of a niche issue, as I already said in one of the breakout groups.

There's little knowledge of what exists. I've had that same experience. I've had difficulty with breastfeeding and only a very experienced midwife pointed out something that was very simple, that worked for us. This knowledge isn't there. Sometimes there is a feeling that not only is something not available in terms of affordability, but it doesn't even exist. Very often things exist but are not very well known. I would encourage that forum to also be sharing knowledge about that, so that we invent, but we do not reinvent.

## Linda Shaker Berbari

Thank you so much, Barbara. This is really important, as you flag that not only to have a coordination platform but as you say, I don't know if I can use that word, infiltrate other platforms to raise the profile and advocate for the needs of children with feeding difficulties. Juan Pablo, the same question for you. What fora do we have or do we need for this coordination?

## Juan Pablo Peña-Rosas

I think this is the type of fora where you have people from different parts of the world. I saw the distribution of participants yesterday and it was very impressive that you really having a global reach. I wanted to also take the opportunity to call for-- I know that in USAID there are different areas. We have worked with HIV Department. Now, this is the first time that I am working with disability.

We are working with the Department of Disability here with **[unintelligible 01:48:12]** and we are incorporating disability perspective in the guidelines for integrated management of children with obesity and children within our organization using the primary health care approach. These guidelines are aimed to improve health functioning and obesity. This is the title of the guideline; Obesity-Associated Disabilities.

One of the things that we have done apparently for the preparatory work is assess whether disability has been considered in any of the existing guidelines for treatment of obesity in children with obesity and children with **[unintelligible 01:48:53]**. What we have found is that they have not been included, so many of the recommendations really need to have an assistive device and additional considerations.

To be able to adapt that you need to make it, again, visible and to make it aware that some conditions, genetic conditions come with disabilities and are children that live with obesity. When you do recommendations of physical activity or different types of training when you have different drugs or pharmacological interventions or dietary intervention, you have to mention it and you have to make it a

point so that those policymakers that are going to be adapting and adapting those guidelines to the national implementation guide level may think about it. Because otherwise there are so many areas that you don't think about.

Digital intervention is another important intervention that we are going to be recommending and it has to be adapted to children living with disabilities also because otherwise, it's not going to be the same. I think that having this type of fora I continued disseminating people, using all of our networks and cross-fertilization of the issues, and getting outside of our comfort zone and our microclimate of experts in a particular area, I think generates more richness in the discussions and I think this is what we're doing in WHO now with the inclusion and the mandatory part of the guidance review committee.

We have to make inclusion of disability consideration. Beyond disability consideration, we are including the recommendation for children with obesity and disabilities at the same time. Also, with considerations of gender equity and human rights. You make it a requirement so that people have to think about it, have to put it there, and then the policymakers need to think about it and then make it a part of the policy and allocate funding resources for them.

## **Linda Shaker Berbari**

Absolutely. Thank you so much. I just wanted to confirm before we move to the Q&A whether, David, you have any additional contributions in terms of the existing platforms or foras, other than what you have mentioned.

## **David Mwisige**

Thank you, Linda. Actually, it was a point I missed. Thank you for reverting back to that. With NCPWD, the National Council for People with Disability, they work with NUDOR, that umbrella that has organizations that works with people with disability certain members. They have a forum that is connected on a quarterly basis, where different ministries and organizations and partners convene, and they discuss on issues that they have on progress and inclusiveness. This forum we have a representative from various other ministries out there, representatives.

I think that's where the issue of our guidelines being not inclusive that were raised in that forum, so it's an important forum. I'm not sure if every organization or every partner that works on disability is in that organization or attends that forum because they have a component of disability that is not so strong, which I devised that they all have that inclusiveness as well. The last point before I finish is, we may provide inclusiveness in our policies and the guidelines, but the engagement of parents, give us-- it needs to be increased, it needs to be reinforced for them to understand that a child with feeding disabilities needs extra special care and they need to expose them. Because most of the mothers or caregivers as well, they do not expose them. Those children are at risk of missing out other essential services they deserve. Thank you.

## **Linda Shaker Berbari**

Thank you so much. Absolutely. First of all, thank you so much for answering those panel questions. We do have a question in the Q&A, one which I relate a lot to, from Caroline asking, in situations when we're advocating for disability inclusion in nutrition programs, we do often hear that programs are focused on reaching the highest possible number of children, and therefore targeting specific groups is difficult and asking whether our panelists have any advice on how we've been able to prioritize inclusion in that context. I leave it up to you to volunteer to answer. Barbara, is that you?

## **Barbara Goedde**

Yes, if that's okay. I can give a try. Just to say, not necessarily a direct answer, but just one about being transferrable. Again, what we often say is that in that case, you need to make a strong advocacy argument for the SDGs and leaving no one behind and making a moral argument that you can't just be focused on the numbers. Then, however, in our case, we did also try and build an investment case, which we managed to do. We came up with a number that for every dollar invested, you get \$9 in return. If there were that evidence, also use that about the long-term outcomes. Otherwise, I think, in this case, a moral argument has to be made.

## **Linda Shaker Berbari**

Thank you. Sorry David, did you want to make a contribution?

## **David Mwisige**

Yes, I wanted to make a contribution.

## **Linda Shaker Berbari**

Very briefly.

## **David Mwisige**

Yes. The issue, as my colleagues have said, is about identification. When you identify these children, it becomes easy for you to target them and provide the social services that they need. We have social workers and village leaders that provide information and they do provide reports about which children need these specific interventions, which children need to be transferred at health centers or health facilities. Recently we've been targeting provisions based on social categories. That has changed. We are moving on to registries. This registry will help in identify all children result taking into account the awareness categories in order for the benefits which are-- well, that's a change.

## **Linda Shaker Berbari**

Absolutely. Thank you. I think we are on time in terms of this panel discussion unless any of our panelists want to make any additional contributions. Yes, Filippo, please go ahead.

## **Filippo Dibari**

No, just to be a little bit provocative, I think it would be also a role for donors to be sensitized, and probably also incentivize them to take an earmark percentage of funding dedicated to this topic. Whenever there is funding provided for food assistance or nutrition programming, there should be a certain percentage earmarked for nutrition disability. It would be concrete. Maybe I'm shooting in my own feet, but very important.

## Linda Shaker Berbari

No, very important indeed. If you're asked to include it, you would include it. That's the simplest motivation. Thank you so much. This has been a fascinating discussion, really inspirational. Thank you so much for your contributions and really fruitful discussion. I think that I will now thank you again, and hand over to my colleague, Alyssa. Thank you.

## Alyssa Klein

Thank you. Thank you all so much, this has been such a rich discussion. The panel was great, the breakouts are great. I now have the challenging task of taking a very few minutes to summarize everything that was discussed in the breakouts for both days in about five minutes. Thank you to all the **[unintelligible 01:59:12]** board facilitators for sharing some key takeaways. This obviously is just a very small snippet. We'll share more afterwards as follow-up materials as well. On day one yesterday, the breakout groups discussed resources that people use in their work, as well as resources that they wish were more inclusive of either nutrition or disability.

We're going to put together a list of all the resources that were mentioned. Like I said, we'll share them as a follow-up. Groups spoke about a wide variety of resources from global resources like UNICEF packages, spoon trainings, other USAID defunded packages, but also there were a number of examples of country where program-specific packages, for example, Safe Haven Cambodia developed a training package to fill a gap. Many of the tools and resources that were mentioned are already on the USAID Advancing Nutrition Resource Bank, but we can look into adding others that were shared as well.

Groups yesterday also discussed challenges that they face in their work. One that came up in a number of groups was that people cannot use a lot of the resources in practice, and a need for digital apps for capacity building was brought up in one group. A number of groups said that there's a need to integrate feeding in disability services in all countries, and a need to integrate disability into nutrition and IYCF packages, which mostly leave out feeding difficulties and disability currently.

Another challenge that a number of groups mentioned was the need to empower and support health workers to assess and refer children. They need training and resources was stated. Also, the need to train parents was brought up in at least two groups. They specifically talked about supporting parents related to acute malnutrition, saying that otherwise, inpatient treatment clinics see readmission of children with acute malnutrition, with feeding difficulties, who cannot be supported at home, and that acute malnutrition protocols do not take into consideration feeding difficulties.

There was also a comment in one group that there's a need to shift curricula to improve how information is shared with parents and change the relationship between medical personnel and caregivers. A number of groups talked about stigma. One said that advocacy and actions to eliminate stigma are needed so that children are able to access and benefit from the resources that are available and that there's a lack of comprehensive advocacy approaches. There was also discussion about lack of data which makes it difficult to make recommendations for policies and for investments, as well as there's a need for strategies to actually use data that does exist.

The groups also talked about strategies that have been seen to work. They mentioned things like parent support groups, outreach visits to support parents to identify feeding difficulties, re-lactation strategies, and emergencies. One group also specifically spoke about programming in Zambia. In Zambia, they've worked with health facilities to provide training and sensitize staff, and found in follow-up with parents that the families that use those health clinics are now fast-tracked when they go to those facilities, which gives them more time to get home and care for their children who have disabilities.



In Zambia, they also have cooking demonstrations that train parents on how to prepare food, modify textures and use safe positioning during mealtimes and that is also working with the health personnel from the facilities. Today in group two, all of the groups talked about evidence that is still needed. A lot came out of those panels or of those Jamboards. We need evidence on longer-term outcomes that decrease mortality. We need to know what types of interventions will improve growth and nutritional status because those are the hardest to achieve. We also need evidence on what caregivers want and what people with disabilities themselves find useful.

A few groups also mentioned looking at quality of life. It's a hard-to-collect measure and we also want to know how receiving services improves quality of life. Also, a need for better data on how many children have disabilities and feeding difficulties, more evidence on caregiver mental health, and wellbeing. More data on integration of fathers in caring for children with disabilities. Today we also spoke about what are some of the priority actions and how to amplify good practices globally and build on them. There were a lot of really interesting suggestions. One was the need for a gap analysis in countries and doing stakeholder mapping with all stakeholders.

Another was a priority need to strengthen services at all levels, training health workers about social models of disability, building capacity for feeding techniques, and supporting caregivers and health workers. A number of the groups today talked about the need to focus on the community level and not just on formalized services and facilities, but instead including community leaders, faith leaders, and that this would be critical to scale and sustainability. Another one that was brought up in a number of groups was standardizing tools and resources and integrating feeding challenges and disability into nutrition packages and vice versa.

Another one was the need to invest in specialized services like therapists and then as well to invest in capacity of local OPDs or Organizations of Persons with Disability. One that I really liked was to be considerate of how we define success in programs for young children, to not exclude children with disabilities whose progress might look different, and also to center the parent that all programs should empower parents to be the advocates for what they need. I'm guessing, Lori, you're flagging me to wrap up.

I'll just quickly say, in the how to amplify good practices, there was a number about sharing resources, involving stakeholders, empowering parents, and finally to leverage existing networks and forums and to continue to reach out to the people who joined this convening to build relationships. I will wrap up there.

## Lori Baxter

Thanks, Alyssa. Indeed, you did have a very challenging task of wrapping up almost two hours of breakout sessions in five minutes. Well done. Now we are doing the interactive portion to close us out before we move to our closing remarks, I ask that everyone either grab your phone and scan the QR code that you can see on your screen, or you can use the web address, which I will now drop into the chat box and click on that web address and bend it as well.

You can click on either of those links, they're the same. That will take you to menti.com. That's something that we're going to use in order to tabulate and share in real-time some of our reflections and our plans for next steps. Please stick with us. Just click on that link, go over to Menti and now we are going to see the Menti screen show up in just a quick moment on a shared screen, and we have a couple of questions that we, together, we have about 58 of us still online, we're going to together answer them, and see the responses. Again, if you haven't followed so far, you're going to Menti either with your phone by scanning to get the QR code or by clicking on the link in the chat box and answer this one question.

Great, lots of people are already there. What is one thing that you can commit to do this month to improve nutrition among children with feeding difficulties and children with disabilities? You can answer the question and then make sure you press submit and that way we can see these answers in real-time. I'm going to make them appear bigger on my screen so I can read some as they scroll through. Disability-inclusive research use data to advocate for changes in policy and funding, advocacy for investment in supporting persons with disability. Advocate with partner organizations for the need to focus on feeding issues for children with disabilities.

Advocate for more funding. Understanding better-existing resources on identifying and/or supporting feeding difficulties. Sharing the learnings from the webinar with the larger health nutrition team. Great. That's someone from World Vision sharing that. Nice to hear you. Explore the resource bank, the Feeding and Disability Resource Bank, which was shared earlier. Share the new developments with the Ministry of Health. Strengthen my network. Great. I do encourage you. You can look through that participant program that we shared and if you see some colleagues that you've interacted with, feel free to send LinkedIn invitations or get connected with them because that is part of what we had this event for, is to stimulate that kind of ongoing conversation.

If for any reason you're having trouble submitting your answer in Menti, you can also share it in the chat box and I'll read it out from there. Teach all healthcare staff and share this convening with other staff. I see something about wasting. Ben, is there a way to scroll back up so we can see maybe some of those first responses that we missed? Okay, that's all right. I couldn't quite read them fast enough. There we go. Thank you, Ben. Great, and I see that we have a response shared in Spanish. Compartir lo maximo posible el banco de recursos. To sharing as much as possible, the resource bank, you can scroll back up toward the very top, I think those are the ones that I missed.

Excellent. Advocate for inclusion in data collection efforts. Learn more about which assistive devices are most useful in enabling feeding and supporting feeding, integrating feeding difficulties and children with disabilities within nutrition, and IYCF tools and guidance. Great. Awareness raising lots of people commenting about sharing resources. Very nice. I'll let you do one slow scroll down, Ben, so people can read in their own time. Go ahead, you can keep scrolling.

[silence]

Good, someone's working on a proposal, they're going to incorporate inclusive practices.

[silence]

Excellent, really neat to hear all of the things that you plan to commit to do this month. Great work. Let's do the next question. Now we're going to zoom back and think a little bit about bigger picture. What is one thing that you can commit to do in the next six months to one year to improve nutrition? You're going to answer the same way. If you didn't manage to get connected with Menti, don't worry, you can just still add your reflection in the chatbox. When I see those responses coming, I will start to read them.

[silence]

First, we were thinking about something very immediate, and now we're thinking about something much more big-picture and long-term. Do more research. Have discussions in global platforms on how to integrate feeding difficulties with existing guidance and tools. Publish data on nutrition and feeding status of children with disabilities and feeding difficulties. Disability inclusive indicators and results frameworks. Great, we're seeing a lot about evidence and tracking. Reflect on how feeding fits within our approach, so looking internally within your own organization. Help my organization's nutrition advisors put some of these tips into our upcoming internal nutrition guidance revision. Great.

Host a webinar on feeding difficulties and disabilities. Wonderful. Let's keep the information sharing going. Ensure a better multi-sectorial coordination and early identification and nutrition programming,

policy and advocacy. Share learning from our pilot projects where children with disabilities were included with external partners. Really nice, highlighting those best practices. Organize a meeting with our member organizations to share experiences.

One thing I haven't seen written yet that I do think is a good reminder is just the importance and the value of partnering with organizations of persons with disabilities. We've been fortunate to have a few represented today and they can be really ideal partners in this area of work. Train primary healthcare workers, parents in feeding techniques and early identification and intervention, especially for children with severe disabilities. Support the development of SharePoint for staff that includes important resources. Really nice. Actually, I know myself personally, I now love to share that feeding and disability resource bank because it's so much more efficient than me going and finding the files that I would usually just put as attachments when colleagues ask for resources.

Incorporate disability into nutrition learning agendas in new projects. Remind and work with health workers to prioritize disability and feeding difficulties during IYCF counseling. Really great, and we do have a lot of existing resources that can help with that, including the RCEL addendum cards, which are intended to accompany IYCF and include a card on feeding difficulties. Highlight importance of feeding difficulties, identification and intervention. I'm going to read one from the chat while, Ben, you can scroll up and slowly scroll back down in case anyone missed any. Juan Pablo shares in the chat, I raised the issue of the campaign walk the talk where some colleagues living with disabilities are incorporated.

Good, talking about the use of language and how we can use language appropriately, appropriate terminology. Thank you, Juan Pablo, for sharing that example from your own experience. Read *Feed the Baby* an Inclusive Guide to Nursing Bottle Feeding and everything in between. Wow. Interesting.

[silence]

Thanks, Ben. Oh good, and something about linking stakeholders to develop a basic red flag sign for community health workers to identify children and then link to service providers. Excellent. Now if we can all deliver on these intended commitments, then we will definitely make a lot of progress in this area. Thank you so much for participating in the Menti poll.

I know we asked you to do that extra step, but we really appreciate your thoughts and your reflections. I'm going to introduce our speakers who are going to help close us out.

We are going to hear from two speakers Rory Nefdt, Senior Advisor of Health at UNICEF and the lead of the Child Community Health and non-communicable disease and injuries unit at UNICEF. And then Rebecca Levy, a US government Special Adviser on children in adversity, and director of the Inclusive Development hub within USAID's Bureau for Development, Democracy, and Innovation. Before handing over the microphone to Rory, I just want to thank everyone for coming and, again, remind everyone that we will be sharing the materials soon via email, including the recordings and the slide decks, as well as some other fun materials that we will be putting together. Over to you Rory.

## **Rory Nefdt**

Thank you so much. Can you hear me?

## **Lori Baxter**

Yes, perfect.

## Rory Nefdt

Okay, brilliant. I'm very impressed with that Menti. Wow, there seems to be a lot of excitement and a lot of ideas around. [chuckles] It's great. I wish I could have been joining you throughout the meetings for the two days but I'm lucky to have Natalia and Raoul who updated me. I'm just going to give some remarks. I would like really to start by really congratulating the organizers of USAID and UNICEF on this two-day global convening to engage the stakeholders in advancing nutritional care for children with feeding difficulties and children with disabilities.

We've had a number of discussions and recommendations for strengthening systems, provide direct support to families, conduct advocacy, and build an evidence base to better address feeding difficulties in small children with disabilities and their family. That's really, I think, great strides forward that will come out of this. Disability inclusion is not a new priority for UNICEF, and it has now become more institutionalized in **[unintelligible 02:17:13]**, that's the good news because it is included in the 2022 to '25 strategic plan and has been a growing area of work for us for a decade.

It was highlighted in the meeting that UNICEF launched the UNICEF disability inclusion policy and strategy, DIPAS, guided by the National Convention on the Rights of Persons with Disabilities, NCRPD, and the Convention on Rights of the Child, CRC, and United Nations Disability Inclusion Strategy. Each somatic sector at UNICEF is already making progress towards its own commitments on disability and inclusion. What is new though is that DIPAS provides a roadmap for cross-sectoral coordination and shows us how we can strengthen service delivery in communities by working together strategically and across sectors.

As I UNICEF, we will drive more efficient and effective outcomes for children with disabilities. The DIPAS lays the foundations for building truly inclusive communities. I've been asked to illustrate this cross-sectoral work. I would really like to give you one example on the practice guide Inclusion of children, young people with disabilities in routine general care healthcare that was finalized recently. This is the inclusion of children and young people with disabilities in routine general healthcare. It was done through an intensive process and reviewed by core people and has a specific chapter in nutrition of children with disabilities.

Moreover, the nurturing care framework that was presented during the discussions yesterday, is finalizing the thematic brief for children with developmental delays and developmental disabilities through series of intensive discussions reviewed by external reference group, which includes participants from this convening. It's a multi-partner product and it'll be available soon. There's a need to promote further the collection analysis of data on children with feeding difficulties and children with disabilities to have the evidence base for development of national policies and programs.

We started the discussions on the link between disability and nutrition, but we need more knowledge and analysis to understand the best interventions and innovations. For this Twin Track Approach is important to develop the most suitable programs towards disability inclusion. Finally, the main message that I have here is together with my colleagues who have been working in a more detailed way on all this, is to identify and assess the children with feeding difficulties and disabilities in early life, and provide them with resources needed to give them a good start to life through cross-sectoral family-centered intervention. Thank you to everyone for all this work, and all the best. Over to you.

## Lori Baxter

Thanks, Rory. Over to you, Rebecca.

## Rebecca Levy

Thank you so much and thank you to everyone for joining us these last two days. I also wasn't able to join for the whole time, but so appreciate the information and participation for the sessions I was able to join. I especially want to thank the steering committee from USAID advancing nutrition, from UNICEF, and my colleagues at USAID, especially Kat Kirk, who worked to organize this event, as well as everyone here for spending time with us these past two days and for learning about how we can and how we must work together across sectors to ensure that all children receive the appropriate support they need.

When it comes to nutrition, the discussions helped highlight a number of important actions that are needed to ensure children with feeding difficulties and children with disabilities have access to high-quality and inclusive services. I loved the Mentimeter activity, so I know all of you are thinking very directly about what that means for you and how you can support that, which is just so wonderful. We know that feeding and food are an important cultural and social time of connection and community and families. We've heard at this convening that that important social time can be interrupted tremendously when children have feeding difficulties.

Meal times can become a source of great stress and frustration for families, and that can contribute to children who have feeding difficulties, ending up with malnutrition and cycling in and out of services that have not been designed to be able to appropriately identify and support them. The challenges are really great, but we also heard today, especially about how much work we have to do to build the evidence base on effective approaches. This includes ensuring that we are closely monitoring inclusion of persons with disabilities through health information systems.

The Philippines shared a really nice example of both their robust packages of services for children with disabilities and their plans for monitoring. Lots for us to learn from. There's also a need, we heard, to improve how we conduct and fund research, including more funding for disability research, including persons with disabilities as researchers, and very importantly, ensuring persons with disabilities are ethically able to participate in research. In addition, as this event comes to a close, there was a rich discussion about how we can come together more across sectors for a more unified response to support children with feeding difficulties.

We heard about the specific challenges of doing this in humanitarian settings and how coordination of our responses can only be done well with good data and ensuring our guidelines are inclusive of children with feeding difficulties and children with disabilities. These discussions and everything that we've been covering in terms of how to support children who are marginalized and their families are core to the work of the US Government under our advancing protection and care for children in adversity Strategy, which outlines the US Government commitment to build strong beginnings in the early years to ensure all children grow up in loving family-based care and to protect children from all forms of violent neglect, exploitation, and abuse.

As we close today, I just want to reaffirm USAID's commitment to the empowerment and inclusion of 1 billion persons with disabilities around the world, and particularly from the Children and Adversity team, the 240,000,000 children with disabilities. There are millions more children who will benefit from improved health and nutrition services that are able to appropriately monitor children's development to identify feeding issues and to provide necessary services and support to families. We recognize that these conversations are just an initial step and what needs to happen next are a lot of concrete actions to move this forward. Again, I just thank everybody so much for brainstorming with us and thinking about what your role in that concrete action can be.

It was just a really inspiring and really informative two days and we look forward to continuing on this journey together with you and to continuing to partner with you to advance this agenda and ensure we

are fully addressing the needs of children with feeding difficulties and children with disabilities. I'll close there, but just thank you again so much for joining and back over to you.

**Lori:** Thank you so much to Rory and Rebecca for your closing remarks. I wanted to highlight that in the chat box. We have pasted the link to a Google form. This includes a post-event survey. We asked if you can kindly just open it. It is very short. I believe it's two or three questions. Hope you can just answer those briefly and that would really help us to improve our events.

I also wanted to thank you once again to our convening funder, to the steering committee, the technical advisory groups, as well as the technical support group, and of course, a very special thank you to our panelists and our facilitators. Thank you for joining and we now are going to close the convening. Thank you, everyone. Take care and enjoy the rest of your day, afternoon, or evening wherever in the world you are joining us from. Bye.

[END OF AUDIO]



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