



# Virtual Convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities: Day 1

## Webinar Transcript

### Lori Baxter

Difficulties and Children with Disabilities. I'm Lori Baxter, a consultant for USAID Advancing Nutrition. I will be your lead moderator for the next two days. Next slide. If you have any questions or issues during today's convening, please reach out to Ben Cox by sending a message to Tech Support Ben or Yaritza by sending a message to Tech Support Yaritza via the chat box, or you can email [info@advancingnutrition.org](mailto:info@advancingnutrition.org).

Before we begin today's sessions, I just want to mention that today's plenary sessions are being recorded and the recording and the materials will be shared on USAID's Advancing Nutrition website after the event and emailed to all registered participants. Now I will briefly review the Zoom environment. Next slide.

We aim for full and effective participation for all convening participants. Therefore, while presentations will be in English, we will also have American sign language or ASL interpretation, which is pinned to the main channel, and Spanish interpretation. If you are listening in English, please make sure to select English from the interpretation channels to hear comments and questions from colleagues when they are interpreted from Spanish to English. [Spanish language] Next slide, please.

We have enabled the Zoom closed captioning feature. To start viewing live subtitles on your screen during today's meeting simply click the closed caption icon and select show subtitle. These captions are available in English only, so please do not adjust the language settings. We kindly remind all speakers, moderators, and participants to speak slowly and clearly in order to maximize accuracy of interpretation and captioning to maximize everyone's full participation. Next slide.

If you are unable to hear, please make sure you've connected your audio by selecting the headphones icon at the bottom of your Zoom window. Or you can leave the meeting and join it again with the link or call in using the phone number you got in your invite. Please send a message to everyone to introduce yourself or to ask for troubles shooting support during today's convening. You are welcome to turn on your video when speaking, presenting, or engaging with other participants, but please remember to mute yourself and turn your video off when others are speaking or delivering presentations. Next slide.

We'll be using the Q&A for questions for speakers during various sessions. To access the Q&A box, click on the icon in your Zoom control bar labeled Q&A. To submit your question in a Q&A box, type your question in the space provided and press enter on your keyboard. Next slide.

We will be using the chat box for introduction, general reflections, or technical issues. To access the chat box, click on the icon in your Zoom control bar labeled Chat. To send a message in the chat box,

type your message in the space provided and press enter on your keyboard. Finally, two quick reminders for our speakers. First, Courtney will be advancing presentation slides, so if you have them just verbally indicate when it's time to move to the next slide. Second, in the interest of keeping to our agenda, I may provide you a verbal cue in case you exceed your allocated time. Next slide.

Please use your participant program that was emailed to you or available on the event webpage that Lauren has added to the chat box to 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 Katherine Guernsey, the Disability Rights Coordinator for USAID, followed by Grainne Moloney, a Senior Nutrition Advisor at UNICEF, who will get us started today. Over to you, Katherine.

## Katherine Guernsey

Thank you. USAID is pleased to support this important convening over the next two days. 80% of the world's more than 1 billion persons with disabilities live in low and middle-income countries, and they're estimated to be nearly 240 million children with disabilities worldwide. The majority of whom have limited access to critical health and nutrition support and services.

The evidence in early childhood is clear. Children with disabilities are more likely to experience feeding difficulties, be malnourished, and die due to underlying malnutrition. These inequities are driven not by any underlying medical condition, but due to societal discrimination and inaccessibility of essential services. Up to 80% of children with disabilities and up to 45% of children without disabilities experience feeding difficulties. Yet the role of feeding difficulties in young children's nutrition has not been given adequate attention.

Over the next two days, we look forward to learning from many of you on how we can come together to better support improved nutrition among children with feeding difficulties and children with disabilities, and chart forward a path where children, families receive the care and support they need so that children with disabilities are able to fully participate in society.

USAID has a longstanding commitment to the empowerment and inclusion of the 1 billion persons with disabilities around the world, approximately 16% of the world's population. The agency believes societies that are inclusive of their diverse populations are more likely to be democratic, participatory, and equitable. USAID works to transform lives, communities, and economies in a way that is inclusive of all members of society, including persons with disabilities.

USAID promotes the inclusion of persons with disabilities across all USAID-funded work and supports projects working to reduce barriers that limit the participation of persons with disabilities in their societies, communities, and families. Since 2005, USAID's Disability Program Fund has supported more than 150 programs and activities in over 65 countries working with various organizations and implementing partners. In many instances, these are civil society organizations run by and/or persons with disabilities.

USAID is updating the agency disability policy, including addressing the needs of persons with disabilities across the life course, and has held pre-draft consultations with disability community stakeholders to ensure that the voices of the disability community are leading efforts to create an inclusive policy. One sector that we can see needs more attention is around support for children with disabilities and their families. If countries are to achieve their development potential, persons with disabilities must be able to fully participate in, benefit from, and contribute meaningfully to their societies.

We recognize that the period of early childhood is not as well addressed in our work and that of our implementing partners as it should be. We know that identifying children as early as possible and connecting them with appropriate services and considering support needs for families is what is

necessary for the best outcomes for children and families. However, services often for sure, and ableism perpetuates broader stigma and discrimination.

USAID is proud to support this important convening that provides an opportunity for global stakeholders across different sectors to come together to learn from one another and find solutions to meet the needs of children with feeding difficulties, children with disabilities, and their families. We need to work together across sectors and areas of expertise to support all children and families. We need to ensure that we're including persons with disabilities and caregivers of children with disabilities in shaping this agenda. This convening aims to catalyze these conversations, and we're delighted to have UNICEF join USAID Advancing Nutrition in co-organizing this event. With that, I wish everyone a good and fruitful two days of thoughtful conversations and handed over to Grainne.

## Grainne Moloney

Thank you so much, Katherine, and good morning everybody. It's such a pleasure to be online with you all today for such an important convening. [clears throat] Excuse me. UNICEF is the world's leading children's rights agency, is committed to promoting the rights and well-being of all children, including those with disabilities around the world. We are committed to ensuring that all children can meet their potential for nutrition, growth, and development.

Unsurprisingly, and as we heard earlier from Katherine, there is a strong inter-relationship between nutrition and disability. Though disability is often absent from nutrition research and policy. Children with disabilities and feeding difficulties are three times more likely to be malnourished and twice as likely to die from malnutrition during childhood than children without disabilities. Compared to children without disabilities, children with disabilities are a third more likely to be stunted and 25% more likely to be wasted.

Now, these nutritional risks are likely due to a number of interrelated risk factors besides some of the physical challenges caused by disabilities. As we also heard earlier, disability may also increase the risk of poverty, lower wages, and increased cost of living with a disability, all of which increase the risk of food and nutrition insecurity, particularly of the poorest, most marginalized, women and children.

While we don't have fully global representative figures on the percentage of malnourished children with feeding difficulties, we are delighted to say that the latest flagship report of UNICEF, The State of the World's Children just released last week now includes a table that reports on the percentage of children with disabilities suffering from different malnutrition across the life cycle and does present some alarming figures.

For example, it was reported that in Nepal, 56% of underweight and 51% of stunting occurs in children between the ages of two and five years with a disability. Proper nutrition, safe feeding, and nurturing care during early childhood lay the foundation for lifelong health and well-being for all children, including children and young people with disabilities. Particularly for infants and young children, ensuring a successful start of breastfeeding is key towards safeguarding their nutrition, development, and well-being. Then starting at six months of age, ensuring that children have access to adequate complementary feeding, helps prevent all forms of malnutrition.

However, we know that children with feeding difficulties often have limited access to specialized feeding support, including feeding therapy, assistive technology, and nutrition counseling. This may be due to a lack of trained healthcare professionals, a limited availability of specialized equipment, and inadequate policies and funding for disability-inclusive services. Children with feeding difficulties may also face social exclusion and discrimination which can further limit their access to essential services and opportunities with proper growth and development.

At UNICEF, we are committed with all of you to ensure the children with disabilities have access to nutrition services that are inclusive and responsive to their specific needs. UNICEF's Nurturing Care Practice Guide provides practical approaches in health and nutrition services to strengthen caregivers' capacity, to provide nurturing care to children and young infant. Our new inclusive health practice guide provides practical guidance on how to integrate nutrition services across health system.

We are also committed to supporting the development and implementation of nutrition programs that are inclusive and accessible to children with disabilities, and feeding difficulties, working in partnership with government, civil society organization, and other stakeholders. What is key is we need more data. We need to know what is happening to our children and where they are.

We need to promote reflection and analysis of data on the nutritional stages of children with disabilities, to better understand the challenges that they face, and inform national effective policies and programs. We need to promote research and advocacy to improve the understanding of the links between disability and malnutrition and identify evidence-based interventions to give them the best chance and nutritional outcomes.

Finally, we need to raise awareness among the parents, caregivers, and communities about the importance of good nutrition for all the children, and promoting positive attitude towards inclusion and the rights of the children with disabilities. For that, UNICEF with partners is currently working on **[inaudible 00:14:13]** community, infant and young child feeding, counseling package to ensure that provisions for addressing feeding difficulties are incorporated and represented.

Well, we can't do this alone. Together with all of you, we need to prioritize actions, policies, and ensure resources to ensure that all children including those with feeding difficulties are identified and assessed very early on in life and provided the appropriate support and interventions to give them the best start in life to grow and thrive. UNICEF is delighted to be joining forces with USAID in organizing this important convening. Over the next two days, we will all hear inspiring stories of such efforts that need to be taken to scale. We wish you a wonderful and successful convening. Thank you very much.

## Lori Baxter

Thank you very much for those words, Katherine and Grainne. Now I will take us through an introduction and overview to the convening, so you know what's in store over the coming days. All of you have been specifically invited to join us here today. We wanted to bring together global stakeholders that can bridge this gap in improving nutrition among children with feeding difficulties and children with disabilities.

These are some of the objectives that we attend to accomplish over the next two days. Reviewing the gaps in policy programming and research, sharing and discussing approaches to identify support and track children with feeding difficulties. Identify key steps that stakeholders can take to address the gaps. Finally, to discuss priorities for future research and learning. Next slide, please.

The way that we will accomplish this is through two action-packed days. Today is day 1 of our convening, Wednesday, April 26th, and we're focused on scene setting. Soon we will move to the keynote presentation, setting the stage, followed by a plenary presentation, strengthening services for children with feeding difficulties and children with disabilities. We'll have a brief break followed by breakout sessions where we can dive deeper into some sub-thematic areas relating to identifying and supporting children with feeding difficulties and children with disabilities. Then we'll have a storytelling panel about nutrition and disability in action before we wrap up our day. Next slide.

Tomorrow is day 2, Thursday, April 27th. We'll be focused on bringing nutrition and disability together. We'll have a panel discussion on evidence and tracking. Breakout sessions where we discuss learnings

and next steps. Another panel discussion about bridging the gap and breaking down silos, followed by a reflection activity to really think about our next steps.

Next slide. Because we have brought together such a wide diversity of participation, we are going to have a brief poll just to see who we have in our room today, our virtual meeting room. Ben, can you please launch the poll? This first question says, which region are you associated with and/or joining from? You should see the question pop up on your screen. You can simply select the answer that pertains to you and click submit. We'll wait a moment for everyone to answer before I review the results together.

Okay, Ben, you can now close the poll. Let's see those results. Great. It should pop up on your screen that we can see we have about 36% of our participants joining from North America, we have about 33% from Africa, 19% from European Union, 7% from Latin America, and a few from Asia and other. Really great to have this diversity. Next slide, please, Ben.

Our next question, how do you identify yourself? Do you identify yourself as a person with a disability? Actually, it looks like we have the next question coming, so we'll do that one. Let's go forward one slide, Courtney. How would you classify your professional focal area and expertise? Is it disability, nutrition, maternal and/or child health or early childhood development, or other? We do ask you to select just one because we want to see what people's primary focus areas are. We realize many of you bridge across a few of these. Please select your answer and click submit. We'll wait a moment.

Okay, Ben, you can close the poll, and let's see the results. Great. Really nice to see this representation. We have about 33% of our participants today with their primary focal area as disability, about 35% with nutrition, 11% MCH, maternal and/or child health, and 10% ECD, early childhood development, and 11% other. Excellent. We're really happy to have this diversity.

Let's launch the final poll, Ben, if you still have it, and if you don't, that's fine. Great. Courtney, go back one slide, please. How do you identify yourself? Do you identify yourself as a person with a disability, a person without a disability, or prefer not to disclose? This is just so we can get a feel for who we have present and taking part in the convening today.

Okay, Ben, you can close that poll. All right, so as suspected, we do have the majority as persons without disability, 85%, but we're also very pleased to have persons with disability present and represented today with 14%. Just as a reminder, we equally value all voices in this virtual room. Thank you, Ben. You can close the poll.

Courtney will move forward two slides. Great. Now I'm going to walk us through just a little bit of some definitions that will help us to be on the same page. Realizing that we come from diverse background, it's important to have the same definition for disability. Persons with disabilities include those with long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. Disability inclusion is the process that ensures that all persons with disabilities enjoy their full and fundamental rights and freedoms to fully and effectively participate with and within their families, communities, and societies without barriers and on an equal basis as those without disabilities.

A few nutrition definitions that you will hear that might be helpful, especially for some of our disability colleagues. The first is stunting. That means shorter than expected for a healthy child of the same age, because of long-term effects of inadequate diets, illness, or both. Simply put, it's low height-for-age. Wasting is when a child is thinner than expected for a healthy child and at an increased risk of death often because of an adequate diet or illness. Simply put, it's low weight-for-height or low MUAC.

Lastly, the term is undernutrition, and that is a result of deficiencies in a person's intake, absorption of energy and/or nutrients, or illness, increasing risk of illness and death. We do recognize that overnutrition is another topic, but not one that we are planning to be covering in our discussions today.

Next slide, please. Now I'm going to walk us briefly through a few guiding frameworks. This is going to help us lay again that common foundation as we move forward today. Next slide, please, Courtney.

Here you can see the social model of disability. This says that persons with impairments are disabled by the barriers operating in society that exclude and discriminate against them. These social barriers may be environmental, attitudinal, or institutional labeled as organizational on this slide. You'll hear more about this model in a few minutes during the keynote presentation.

Next slide. The social model of disability and the previously introduced definition of disability make it clear that in order to improve the lives of persons with disabilities it is not sufficient to only give support to individuals with disabilities on the basis of their impairment, for example, by providing rehabilitation, education, or healthcare. It's equally essential to address the societal and environmental barriers which lead a person with an impairment to be excluded in society.

Briefly, in this image, you can see the synergy of the two tracks. On the left, we have track 1 which is empowerment, enabling and empowering persons with disabilities and their families to access disability-specific support services such as healthcare. In the context of the convening, this means that children with intellectual and developmental disabilities who are experiencing feeding difficulties can receive targeted support from trained staff such as therapists and dieticians when compared to the general population of children.

On the right, we have track 2, mainstreaming disability. This is working to identify and overcome the previously mentioned barriers in society that persons with disabilities face. In the context of the convening, this means that children with disabilities can access mainstream inclusive services on an equal basis as children without disabilities. The convening's going to highlight how programs and interventions require a combination of these two tracks in order to improve nutrition and hence, quality of life for children with disabilities. Next slide.

Briefly, I wanted to mention this model, which is the Universal Progressive Model. It is aligned with the twin-track approach and it comes from the Nurturing Care Framework. It aims to ensure that the needs of all children and families are met and that no child is left behind. This means that the level of support, and thus the intensity of services matched the needs of the child and their family.

The Universal Progressive Model includes the Foundation Universal Services and Support that every child and caregiver needs, and it works its way up to the highly specialized services that are indicated for children and caregivers with additional needs. Just to give a few examples relating to nutrition intervention. If we think about that bottom layer of Universal Support, that could include IYCS, Infant and Young Child Feeding Counseling. Or GMP, Growth Monitoring, and Promotion.

If we move up one level for Targeted Services, that could be additional supplementation for children with growth faltering or additional follow-up for a low birth weight infant. At the very top levels, Indicated Services could be early intervention, rehabilitation, or other services to address feeding difficulties among children with developmental disabilities who are at a really high risk for acute malnutrition, and consequently, for early life mortality. During the convening, we're also going to touch upon, how to have referral processes that enable children and their families to move between the various levels of intervention. Next slide, please.

Finally, the Socio-Ecological Model. This is another guiding framework that we'll be using throughout the convening. The figures shown here comes from the Nurturing Care Framework. It demonstrates the enabling environments of policies, services, communities, and families that are required to help children reach their full developmental potential. During the convening, we're going to discuss how interventions at these various levels can collaboratively influence the health and nutrition of young children. Next slide.

Next, we're moving into our keynote presentations. We first have a keynote address from Vivían Fernández de Torrijos. She is an independent expert for the Committee on the Rights of Persons with Disabilities. Over to you, Vivian.

[pause 00:27:04]

## Lori Baxter

You're on mute Vivian. We can see you, but you're muted.

## Vivían Fernández de Torrijos

Thank you. Are we on?

## Lori Baxter

You're great. Thank you.

## Vivían Fernández de Torrijos

Thank you so much. Thank you, USA. Thank you, UNICEF and all participants. As an independent expert for the committee on the right of persons with disabilities and the implementation of the convention by all state parties that ratified it. I have to set the stage of this forum stating, that the Convention on the Rights of Persons with Disabilities, CRPD is an international treaty that was adopted by the United Nations General Assembly in 2006. This treaty recognizes that persons with disabilities have the same rights and fundamental freedoms as persons without disabilities.

The objective of the CRPD is to promote, protect, and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities. Promote respect for their inherent dignity through the construction of inclusive policies in institutions, and the strengthening of civil society who works for and with persons with disabilities. Congratulations on this initiative and the objective of this forum, which is to promote and improve nutrition among children with disabilities.

Article 7 of the CRPD refers to children with disabilities and establishes that states must take measures to guarantee that all children with disabilities fully enjoy all human rights and fundamental freedoms on an equal basis with other children. This includes the right to an inclusive education. The right to family life. Access to health and rehabilitation services. The right to participate in cultural and sports life among others. States are encouraged to take measures to promote and protect their rights, including ensuring that children with disabilities have equal access to education and healthcare services. Providing support services such as rehabilitation and assistive devices, IT devices to enable children with disabilities to develop their full potentials. This includes nutrition and feeding. This includes a healthy life through nutrition.

On the other hand, article 25 of the CRPD refers to the right of persons with disabilities to enjoy the highest possible level of health without discrimination. Very important to underline without discrimination. This includes the quality of health services, nutrition, the right to health information, disability prevention and health promotion, and access to emergency healthcare.

The implementation of this article, the 25, is crucial to ensure that children with disabilities are not discriminated against in healthcare settings and that they have equal access to healthcare services,

including the nutrition information they need for their lives. This also includes access to preventative healthcare, diagnosis, treatment, nutrition, rehabilitation, and palliative care if needed.

Governments and healthcare providers have a responsibility to ensure that Article 25th of the CRPD is implemented in practice. This can be achieved through a range of measures, including training healthcare providers on how to accommodate the needs of a person with disability in developing accessible healthcare facility and ensuring that policies and practices are inclusive for all. It is very important to highlight that the CRPD, the convention not only recognizes the rights of persons with disabilities but also establishes the obligations of states to guarantee these rights. The CRPD is an important tool to promote equality and inclusion of persons with disabilities in society.

In summary, our convention is an important treaty that recognizes the rights of persons with disabilities and childrens with disabilities, and establishes the obligation of states to guarantee these rights. Articles 7 on children and 25 on health are particularly important to ensure that children with disabilities are persons with disabilities, in general, fully enjoy of their human rights and fundamental freedoms, including nutrition. I wish you all the best in this conference on nutrition. Hope it will be a successful platform for knowledge sharing and collaboration towards addressing malnutrition, and promoting healthy nutrition for children with disabilities. We can make a positive impact on the life of millions of people around the world. Best wishes.

## Lori Baxter

Thank you so much, Vivian. Just as a reminder, anyone who would like to read the full bios for any of our panelists, facilitators, or speakers, you can find them in the participant program which is on our webpage and has been emailed to you. The website is posted in the chat box. Now I will pass the microphone onto Hannah Kuper, co-director of the International Center for Evidence in Disability within the London School of Hygiene and Tropical Medicine for her 15-minute presentation. Over to you, Hannah.

## Hannah Kuper

Good morning. Good afternoon, everybody, and thank you so much for inviting me to give this talk. Next slide, please. Today I'm going to be setting the scene adding to what some of the other people have said already, talking about childhood disability, exclusion, and nutrition. As I've been introduced, I'm at the London School of Hygiene and Tropical Medicine, but I'm also one of the founders of the Missing Billion Initiative. Next slide, please.

Today I'm going to talk a little bit more about childhood disability and the exclusions facing children with disabilities. Then I'm going to focus more specifically on childhood disability and nutrition. Next slide, please. First, we have to ask ourselves, what do we mean by childhood disability? There've been some models presented already, so forgive me that I will go through them again briefly. Next slide.

Traditionally people have been thinking about disability in a medical model. That means that you think a child is blind therefore the child is disabled. A child has a hearing loss therefore the child is disabled. Things aren't that simple. If you know that a child is blind that doesn't necessarily tell you the level of exclusion or discrimination that child faces. Maybe he or she can go to school because he's getting support or has assistive technologies, or maybe somebody with a milder impairment faces more exclusions because of stigma. There's been a move away from the medical model for that reason, but also because it puts the idea of disability very much on the person. The person is disabled because of something in his or her body. Next slide.

The swing back from that is the social model which is that society disables not so much the body. That is the reason why this child would not be able to go to this school in this picture perhaps not because he or she is a wheelchair user, but because the school is not accessible because there's stairs instead of



ramps. It really highlights the importance of society in disabling. Some feel that this is a swing back too far and that the body is still important, that if you're in pain all the time, you're in pain all the time, and that social modifications may not be able to change that. That within low-middle countries, in particular, there's still very large healthcare gaps.

Now I'll move on to briefly describe the WHO-endorsed model, which is what's used really to frame a lot of our thinking about disability. It takes into account both the body, so the medical model as well as the impact of society. What this model says is that a person with disability underlying has a health condition. It could be cataract, it could be Zika, it could be Down syndrome. Because of that health condition, they may experience abnormalities in body functions or structures. Impairments, visual impairment, hearing, cognitive, and so on.

That these impairments may limit activities like walking or seeing and therefore participation like going to school. That this flow from the health condition to lack of participation is not the same for all children or all people but will vary by environmental factors as such as inclusive policies, ramps, environments, as well as personal factors such as the level of social support the person has or their educational wealth. Next slide.

If I look at a specific example, when we're thinking about a child with disabilities, imagine that the underlying condition is a cataract and that affects the vision and therefore the ability to walk around independently, and it could affect the child's ability to go to school. On the other hand, if there's an inclusive school or the child has social support, it can enable school attendance. Why this model is important is it helps us to think more clearly about disability, not just about the kind of levers that we can shift in terms of providing medical care or treating impairments, but also how we can think about changing environments and changing personal factors to still support participation. Next slide, please.

With that kind of thinking in mind, what are the kinds of facts that we're talking about with childhood disability? UNICEF has just conducted a very large study and has produced a fact sheet and report, which I encourage you all to read. Basically what it says is that there are 240 million children with disabilities globally. That 10% of all children have some kinds of disabilities, and the 80% of those children live in low and middle-income countries. Disability in childhood is clearly a very important issue when we're thinking about provision of any kind of services for children because 10% of the clients will be people of children with disabilities. Next slide.

Disability is very diverse. It includes children from different parts of the world, different types of impairment, boys and girls, but there are a couple of commonalities and there are two in particular that I want to draw out. Next slide.

The first is that disability and poverty are very closely linked. People living in poverty are more likely to have children with disabilities and childhood disability can exacerbate poverty by different mechanisms as illustrated by these quotes. One mother says, "I'm not able to make as many mats as other women make. I only make one mat every month. While other women make even five mats." Sometimes they're not able to make any mats at all. This is a mother of a child with disabilities. Another mother says, "We are unable to save any money for the future because almost everything is spent on the treatment of our child." So it's to really highlight that childhood disability further exacerbates poverty, and there's a strong link.

The second commonality with disability often is in terms of negative attitudes. Next slide. On this slide, there's one of very many articles that I could show you in the news about fighting stigma of disability, but children with disabilities and their parents face-wise about negative attitudes and stigma says one mother of a child with disability say, "Some that say that it is God who is annoyed with them."

Because of these negative attitudes and because of poverty, it drives a lot of exclusion in discrimination that children with disabilities face. Next slide, please. Because of this, children with disabilities are being left behind across the SDGs. I'm going to focus on the top ones. There's clear evidence that children

with disabilities are more likely to live in poverty and experience hunger, that they on average have worse health. There's widespread exclusion from education that girls with disabilities may be particularly marginalized and that children and adults with disabilities experience widespread difficulties having access to WASH.

I'm going to drill down a little bit first on SDG 3. The evidence that children with disabilities are left behind. Next slide. Our analysis showed that children with disabilities have about five times higher mortality rate as children without disabilities, they're 10 times more likely to be seriously ill as a child. The UNICEF data shows that on average they have a lower development index. They experience a range of health conditions including acute respiratory infection, fever, and diarrhea. Some of the UNICEF data shows that children with disabilities have lower vaccination levels.

Now drilling down even more and looking at malnutrition. Next slide. We undertook a systematic review of malnutrition and childhood disability in low-middle-income countries. Across 17 studies, we found that children with disabilities were three times more likely to be underweight, two times more likely to be stunted, and two times more likely to be wasted. This in many settings, was areas where there was already widespread malnutrition. Even against that background, children with disabilities had the worst outcomes. Next slide.

These findings have also been confirmed in the recent UNICEF report. This slide shows the yellow bar which is children without disabilities, red bar children with one or more functional difficulties, and blue bar children with more than one functional difficulties. You see for underweight, stunted, and wasted, that the greater experience and depth of functional difficulties, the higher the prevalence of malnutrition. Next slide.

This association between childhood disability and malnutrition occurs for a number of reasons and it goes in both directions. On the one hand, children who are malnourished are more likely to become disabled because certain kinds of deficiencies may lead to specific condition. For instance, rickets may lead to physical impairments, and Vitamin A deficiency to vision impairment.

Additionally, children with disabilities are more likely to become malnourished. One of the ways was through poverty, which I've already explained. Children with physical impairments may experience feeding difficulties because of stigma, then maybe poor care and exclusion. People with children with disabilities because of frequent illnesses may therefore be even more vulnerable to malnutrition. Next slide.

This issue really matters. By this issue, I mean, the 240 million children with disabilities globally are more likely to experience malnutrition. It matters because of the achievement of sustainable development goals and other goals because we need to respect the human rights of children with disabilities and work to maximize the quality of life and human capital. I noticed in the chart that somebody talked also about obesity and this is a factor in high-income countries while in low-middle-income countries we haven't seen much evidence that children with disabilities are more vulnerable to obesity. Although, of course, they are in high-income countries which is rightly pointed out to be an important point.

What does this all mean? What does this mean for the next two days of your discussions of the programs? Next slide, please. What are the implications of the link of childhood disability and malnutrition? Well, I'm going to give a little bit of food for thought. Next slide. The first thing I'll say is that the kinds of barriers or difficulties that cause malnutrition among children with disabilities will also make it more difficult for them to access feeding programs.

Here are a couple of examples from quotes from parents with children of disabilities. One says, "I have not received any help so far. We're still waiting for aid. My sister's children however receive maize and beans in school." The children with disabilities who are not attending school are therefore being excluded from these programs. "There's a food-for-work program within the area but I'm not a

beneficiary. There's no way I can leave the child and go to work." The kinds of difficulties and poverty that created malnutrition in that child makes it also difficult for the parent to go and access the services.

"I used to carry my child across the lake, where distribution of food used to take place. I would pay for a bicycle to transport the food to the lake shore, then put it on a boat and crossover. It's much easier for parents without children with special needs." The parents of children with disabilities will face additional barriers in accessing those services. I'm going to drill down a little bit about education. Next slide, please.

The latest UNICEF data shows that children with disabilities are much less likely to go to school. The blue bar is children with no disabilities, red bar were children with any disabilities, and gray is children with severe disabilities. You can see that by upper secondary, the majority of children with severe disabilities are not at school. Next slide. However, many feeding programs focus on school. I've just picked the World Food Program, but I could have picked others, where they very proudly present-- 418 million children are receiving school meals globally, but what about the children who are not at school? What is happening to these children?

When we've done work in Kenya, for instance, we found that lack of school attendance was a very important reason why children with disabilities were malnourished, because they're excluded from these school meal programs, and therefore, missing the opportunity for one meal of the day. Next slide.

Here are some principles that I've thought through for inclusive nutrition programs based on these findings. The one, and it was already introduced earlier, is to adopt a twin-track approach. That means that programs need to think about how to include children with disabilities in mainstream programming, so making sure that they are accessible, that the information is given in the right way, and that the program managers accept and have positive attitudes towards children with disabilities. Also, consider how to reach children with disabilities and targeted programs. For instance, the school feeding program should be inclusive, but may also need to have add-on components to be able to reach the children with disabilities not in school.

The second is that the programs need to work in partnerships with people with disabilities or parents of children with disabilities, to ensure that the program is designed appropriately to be inclusive and to reach the children. What we have found is that those are good starts. It's a good idea to advocate and raise awareness about inclusion, but it's not enough without this third step, which is that there should be mandating of a specific budget line to promote disability inclusion and monitoring to ensure that children with disabilities are being included. Without step three, which is the carrot-and-stick to ensure that children with disabilities are included. Raising awareness through the first and designing appropriately is unlikely to be sufficient.

With that, I'm going to close there some times for Q&A. I wish you the very best of luck with the next few days and with this very important meeting. It is great start that such serious consideration is given to the inclusion of children with disabilities in nutrition programming.

## Lori Baxter

Thank you so much, Hannah, for that very clear address. We do indeed have a few questions. They have already shown up in the Q&A box, and if you have not written your question there yet, please feel free to open the Q&A box which you see in the bottom of your screen and you can add your question there. The first question that I would like to ask you is relating to your slide about school nutrition. What are the main causes of school dropout for children with disabilities? Over to you, Hannah.

## Hannah Kuper

That is a very complicated question. There's the side from the school side and then there's the side from the child side. If we think about the drivers from the child side, the child may have difficulties accessing, there may be transport barriers. So we hear about children with disabilities being carried to school. There may be cost implications that the family may not be able to afford schooling or may not want to invest in the child with disabilities. On the other hand, the school itself may not be accessible, so the teachers may not have the resources or training to be able to include the child with disabilities, or the school or its toileting facilities may not be inclusive.

I think it can operate on both sides. The ways around it is to ensure that schools built are accessible, that teachers know how to teach children with disabilities and know that they must teach children with disabilities, and that parents are supported to send their children to the school and see the advantage of investing in that child.

## **Lori Baxter**

Thanks, Hannah. Also, I wanted to highlight that in our chat box, we have a colleague from Cambodia who has also written some of the reasons why they are seeing the school dropout in children with disabilities in Cambodia. Thank you for sharing that, Channy, and thank you, Hannah, for your answer.

## **Hannah Kuper**

Just to add, we see it more in certain groups of children with intellectual disabilities, for instance, are most likely to drop out. That implies that it's many school-side barriers as well are important.

## **Lori Baxter**

Excellent, thank you. There's a question that came through with our registration, so we gave people the opportunity to ask a question at that point. One question specifically relates to some of your conversations. You have explained how malnutrition can reinforce other childhood vulnerabilities and vice versa. Can you provide maybe a couple of examples of how sectors can collaborate to maximize the impact for child well-being.

## **Hannah Kuper**

You've asked me about why children with disabilities aren't going to school. Well, it might not just be about the school, it may be about the transport that the school may be accessible, but the transport system is not. I'll give you another example where we've worked with mothers of children with cerebral palsy to train them about nutrition specifically, and they've then become empowered, and they've gone to the health sector, to the nutrition programs who've said, "No, this child is not eligible here." A lot of these things are not so bucket by bucket. We can focus on the education bucket, or we can focus on the health bucket, but a lot of the issues are intersectoral, so that we have to focus on transport, as well as health and education. As I've already said, education links to health.

It is really important that inclusion is thought about across those different sectors to try and maximize the child's well-being. I think some of the most positive programs that are being scaled up at the moment have been about social protection and child social protection, just as an example. For instance, we are working at the moment in Lawas, looking at a UNICEF-supportive program of a cash transport program. They work particularly well where they're intersectoral. For instance, where it is not just that a family gets cash, but they also may get health insurance and transport benefits, and maybe education

allowances. These intersectoral approaches are going to be the most important for addressing well-being.

I think cutting across it, as I said right at the beginning, two very important cross-cutting issues are poverty and negative attitudes. Those are both things which will need an intersectoral response.

## Lori Baxter

Thank you, Hannah. I thought it was particularly interesting how you were mentioning the importance of the social protection mechanisms, and what benefit those can have on children and their families. Thank you for highlighting that.

Another question which you have seen some of the conversation in the chat, but specifically there's a question relating to obesity. Have you found issues around obesity in your work on childhood disability?

## Hannah Kuper

We have not in our work in low-middle-income countries, and that's both true for adults and for children. There's clearly a link with malnutrition, but not in obesity. All the evidence from high-income countries suggests that the levels of obesity are much higher among children with disabilities than children without. It's something that varies a little bit setting by setting.

## Lori Baxter

Thank you, Hannah. We have one more question. That was, again, a prepared question that came with the registrations. You mentioned stigma as being a barrier that can keep families from accessing care. What are a few strategies-- Sorry, my question just moved away. What are a few strategies that governments and their development partners can implement to ensure that children with disabilities are included in nutrition programs?

## Hannah Kuper

I think stigma's very multi-layered. There can be self-stigma, where people may feel that they do not deserve something, or stigma from the family towards the child with a disability, or stigma from the program provider, or stigma from the community. Those different aspects would need to be addressed. I'd say very important things is training of healthcare workers or program implementers about charter disability that they understand not only that it is common, but also that they cannot exclude children on the basis of their disability. I think healthcare worker or program training is very important.

I think community-level changes can come quite well through mass media programs. We've seen that a lot in the UK, and it's also happening in different countries where introducing disabled characters or disabled storylines, for instance, and soap operas, can really, if it's done in the right way, can really raise awareness and start trying to tackle different kinds of issues. I think what we found works quite well for children with disabilities is parent groups, that parents working together can be empowered to start demanding the fulfillment of the rights of their child.

## Lori Baxter

Excellent, and your response makes me think of the new Sesame Street character as well, who is a girl with a disability.

## Hannah Kuper

Exactly.

## Lori Baxter

One question just came through the chat box. I think we have time for one, maybe two more. How would we factor in the human resources, considering nutritionists or speech and language therapists or pathologists, especially in low-income countries where these types of professionals are scarce?

## Hannah Kuper

Well, I suppose they're all the kinds of different approaches that you can take. There can be task shifting. What can you train existing staff to be able to do, and maybe they can do some things like identify children with disabilities with nutritional programs, or do some simple feeding techniques. Then there's also can be remote, so telemedicine or mobile apps or smartphone-based programs. I'm working with somebody in India, for instance, who's developing mobile based speech and language diagnostics.

Then, obviously, also there needs to be increased support for having more of these professionals. It might be a multi-layered approach, and also thinking about what works in different settings.

I also see somebody's just asked about the indicators, and I'm just going to jump in on that because this is something that I'm really interested in, and I think it is really important. I think the one is you can measure whether children with disabilities are coming to your program, and then will probably be estimates within the general population so that you can see whether at least the same proportion of children with disabilities in the general population are coming to your program, or if you seem to be excluding children with disabilities. Then you can also compare indicators, outputs or outcomes by childhood disability. I think those kinds of indicators can be quite helpful.

## Lori Baxter

Thank you so much, Hannah. We are at time for this portion of our keynote address. There's maybe one unanswered question, and so I'll make sure to tag you in the chat box in case you haven't seen it.

All right, thank you so much both to Vivian and to Hannah for your wonderful keynote addresses. We're going to move on to our plenary presentation, *Strengthening Services for Children With Feeding Difficulties and Children With Disabilities*.

First I will hand the microphone over to my colleagues from USAID Advancing Nutrition Project. They'll be sharing the USAID advancing nutrition scoping review findings, and that will be from Alyssa Klein, technical advisor, and Malia Uyehara, project officer. Immediately following will be Raoul Bermejo, a health specialist from the health program team at UNICEF's headquarters, who will be describing UNICEF's early intervention approach.

First over to you, Alyssa.

## Alyssa Klein

Great, thank you so much. Wonderful.

Welcome and thank you, everybody, for joining us. As Lori just said, I am presenting an overview of the scoping review that the USAID Advancing Nutrition Project conducted, looking at nutritional care for children with feeding difficulties and children with disabilities. Malia and I are representing our much larger team today.

Next slide, please.

First of all, thank you to Hannah and all of our opening speakers for such thorough presentations, which is going to allow me to skip over all of the background and focus on our findings and recommendations.

Briefly, we focused on the zero to five-year age range. We looked at breastfeeding and complimentary feeding. Conditions that we focused on included feeding difficulties, nutrition among children with disabilities, high risk infants and young children with feeding difficulties, and malnutrition treatment among this population.

We primarily focused on low and middle-income country contexts, although we did include examples of services from high-income settings if they could be adapted for low and middle-income countries. In addition to reviewing 166 documents, we conducted 42 interviews with experts from all over the world. For more details on our methodology, please take a look at the published report, which is going to be put into the chat box.

Next slide, please.

Identifying a feeding difficulty is the first step in providing adequate care. Our review found many challenges to identifying feeding difficulties. We found limited skills among primary health workers, and limited time for health workers, who often only have a few minutes to assess a situation. We found that there are often weak or nonexistent referral pathways for specialized or specialized services, especially outside of major urban areas. Respondents pointed to a limited understanding of the link between disabilities and feeding, saying that health workers often accept malnutrition as normal for children with disabilities. One researcher said it is a self-fulfilling prophecy. Health workers don't treat the malnourished child with a disability because they say that child is just going to die, and, of course, they die because their malnutrition went unaddressed.

Next slide, please.

The review did find a number of tools for identifying feeding difficulties in children zero to five years, either aimed at health workers or at caregivers. I'm not going to go into them here because they are available in our resource bank, which Malia is going to discuss next. Even with the existence of these resources, they are not standardized or universally used, and health workers often lack training to identify feeding difficulties in all children. Many tools are not designed to identify disability or provide linked support for families. One review found variations in how tools are adapted and validated, and highlighted a real need for valid tools to identify at-risk children in low and middle-income countries.

Next slide, please.

After feeding difficulties are identified, caregivers need targeted services to manage them, which requires a well-trained and well-resourced workforce. We found tools for how to manage feeding difficulties also exist, though, again, they aren't standardized or universally used, and health workers are not usually trained to use them. Some of these tools have been evaluated and have shown positive results associated with their use, though often only in small-scale observational studies. For example, studies have shown a decrease in feeding difficulties, decreased anemia and wasting, improved breastfeeding practices in neonatal care units, and improvements in mealtime cooperation and caregiver stress.

While these are positive outcomes, a number of these evaluations did not find improvements in child growth. Additionally, not all tools have been evaluated, and additional evaluations would provide useful information about how to adapt, scale, and use these and other tools in various contexts, especially in low and middle-income countries.

Next slide, please.

Our review found that children with disabilities may not be included in routine nutrition services. This is true even in countries with large nutrition and early childhood development programs. One review that looked at 100 clinical trials of early childhood development interventions found that 50% of those trials excluded children with disabilities. Even if a food security and nutrition program does not explicitly exclude these children, programs are often not designed in accessible ways, and might not reach them because of cultural stigma or physical barriers.

Our review found challenges related to knowledge, attitudes, and practices of health workers towards children with disabilities, in general, and to addressing feeding difficulties more specifically. Health workers are expected to provide counseling to correct breastfeeding and complimentary feeding difficulties, but they're not trained to identify when these children or their caregivers need additional support. They often don't have the time or resources to provide any kind of counseling that allows for trial and error of different interventions.

Next slide, please.

Availability and access to services related to feeding difficulties and disabilities are limited. Respondents mentioned a lack of social services or safety net programs to support families. They said that rehabilitation services are either not available or are of poor quality, and are often disconnected from the health system. There is not enough of a specialized workforce to support these children, such as speech and language pathologists experienced in feeding difficulties or other therapists as well.

Where there is a workforce, they often work in the private sector because there's limited or no funding to employ them in the public sector. Or they may work in major urban areas but not reach districts or communities farther away. Travel costs often make these services prohibitive, and referral systems are weak. Respondents emphasize the need for governments to provide scale-up and sustain services, which are instead often provided by civil society or by donor organizations.

We did see some promising practices for strengthening government systems. In Ghana, they're building a pipeline of speech and language therapists through a university training program, and they're working with the government to overcome barriers to integrating this workforce into routine services. In Rwanda, we saw that they're working to integrate follow-up care for small and sick newborns, which includes specialized feeding and developmental support.

Support groups for caregivers of children with disabilities are another resource that we saw providing integrated services. For example, Ubuntu Hub House has three caregiver support group packages. These packages have been adapted for use in a number of countries, and evaluations have found numerous benefits for both caregivers and children who use these groups, but, again, they did not see improved growth.

Next slide, please.

We looked at challenges that caregivers face also, and we found that, broadly, there is limited social support for caregivers, that families face eye stress and significant stigma, and that there's not enough access to appropriate inclusive and quality services. Community programs and schools often do not include children with disabilities. Overwhelmingly, families caring for children with disabilities said that there's a lot of stigma and often blame, leading to shame, sometimes even hiding these children or intentionally not feeding them. The stress of feeding children with feeding difficulties was found to lead



to less responsive and even abusive feeding practices. Multiple respondents stated that if stigma is not addressed, no other services or interventions will adequately support children with disabilities.

A shortage also exists in the availability of safe and affordable foods and tools needed to support feeding and nutrition of these children. Assistive products to support feeding are often not available, and certainly not at scale or tailored to specific needs. These can be things like adaptive seating to position children in a way that makes eating and drinking safer and easier, lenders to modify food textures, or adaptive feeding utensils to help children feed themselves, or consume food or drinks from utensils safely.

One type of support mentioned in an interview was daycare rehabilitation centers that are run by caregivers of children with disabilities. The centers provided a safe place for children with disabilities to receive care while caregivers were at work [sound cut] to test solutions, followed by scale-up.

Next slide, please.

I want to talk now about our recommendations. There's limited research on children with feeding difficulties, and even more limited research on children with disabilities. Much of the existing research has small sample sizes, research questions that do not include nutritional status, or short study durations. Interventions that do include feeding often struggle to improve growth and nutritional status even when they're successful in other measures.

Therefore, our first recommendation is to build the evidence base on interventions for identifying and supporting children with feeding difficulties, and their families. This should include formative research with caregivers to prioritize approaches that directly respond to their needs. It should include conducting implementation research, ideally leveraging existing tools as a starting point, and it should include intentionally including and tracking children with feeding difficulties and disabilities in research and in monitoring. Research exploring which interventions impact growth and nutritional status for children with disabilities is necessary, as those outcomes have been the hardest to achieve.

Next slide, please.

The next recommendation is to strengthen systems to improve identification, early intervention, and inclusion of children with complex needs in primary health care services, as well as expanding the availability of specialized services for children with indicated needs and their families. Our scoping review revealed gaps across all six of the WHO Health System's building blocks for children with feeding difficulties and disabilities. Closing these gaps will require system strengthening and quality improvement at all levels of service, identifying children who need support, providing the support, and more holistically, including and supporting children with disabilities in nutrition services, programs, and policies to help them thrive.

Interventions should include capacity strengthening and addressing misperceptions and biases among health workers, and revising guidelines and care protocols related to nutrition and health to include appropriate guidance and support for these children. The second missing billion report which was recently published says that Health systems need to expect, accept, and connect children with disabilities to nutrition and other programs which aligns with this recommendation.

Next slide, please.

Next, families need direct support. Formative research and collaboration with families can identify ways to strengthen social support for families, and increase their access to services. Opportunities include establishing peer-to-peer support groups, providing access to assistive products developed by trained personnel, and providing standardized guidance on caring for children with disabilities and feeding difficulties in food distribution and nutrition programs. Policymakers could ensure that these children and their families are priority groups in social protection schemes and in food supplementation programs.

Next slide, please.

Finally, advocacy is needed to raise awareness on the needs and opportunities to support these children and families. This includes addressing high levels of stigma at the community level, advocating for inclusive and sufficient services at the health system's level, advocating for national-level policies, and inclusive global agendas and strategies. Without advocacy, system strengthening and direct support to families will be insufficient to address feeding difficulties.

This is particularly relevant for children with disabilities who face the most stigma and inclusion. At the policy level, we must ensure disability-inclusive nutrition programs are included in government and donor-funded guidance documents, program descriptions, or other nutrition-related resources. At the community level, we should promote uptake of community-based inclusive development approaches that provide information on the causes, needs, and care of children with disabilities.

For more details on the scoping review, please take a look at the full published paper. We also have a policymaker call to action brief with specific actions that policymakers can take available on our website in English, French, and Spanish, and I think it's going to be placed in the chat box. Malia is now going to briefly share the resource bank that USAID Advancing Nutrition developed after we completed the scoping review. Thank you.

## Malia Uyehara

Thanks, Alyssa. Hi, everyone. As Alyssa mentioned, once we conducted our scoping review, we decided to build an online open-access repository of resources that address feeding difficulties and disability inclusion and nutrition programs. This bank is targeted at Nutrition and Disability Program managers, government leaders, and donor agency staff to help them design and implement effective nutrition programs for children with disabilities. Our hope for this bank is that it will increase access to these resources.

In terms of what's inside, we have a large variety of resources. If you access the bank, what you'll find is manuals, job aids, training curricula, guidance documents, tools, online materials, videos, and more. We've included the link down at the bottom of the screen here, and we'll also place it in the chat in case you would like to visit it, and we encourage you to.

Next slide, please.

When you access the resource bank, you will notice that there are five main sections that it is divided into. All of our resources fall into one or more of those sections. You can access the sections to read more about their importance and to see the resources that fall under that section, or you can also see what section they're under when you click on a resource as well.

We did want to highlight that we have original illustrations depicting children with feeding difficulties and disabilities, enjoying meals with their family. We created a set of six illustrations. Those are featured on the resource bank, and they're also available for download and use through the USAID **[inaudible 01:14:57]** infant and young child feeding image bank. We'll provide the link to that image as well.

Next slide, please.

Currently, the resource bank houses 83 resources, and we are updating it on a regular basis. We're very happy to include more resources, particularly if there are any that you all find are missing from the bank or as they're released and developed, please feel free to send them our way. We will get them uploaded on a regular basis. Again, we have 83 plus or over 80 resources now, and then they cover over 10 languages as well. Hopefully there is something for everyone through the bank. They cover multiple audiences and topics, including types of feeding difficulty or disability.

On the right hand side here, you can see an example of what a resource on the bank looks like. We have some background information on it, for example, publication date, who it was published by, what kind of material it is, and the geography that it targets, and then a brief description. Then we also provide a link to the resource as well.

Again, we'll put those relevant links in the chat, and we hope that you all will take a look at the bank, and we hope that it will be of use to you. Again, please feel free to send us any resources that you think should be available through it.

Next, I will pass it over to Raoul Bermejo from UNICEF to walk us through their early intervention program. Over you, Raoul.

**[pause 01:16:42]**

## **Malia Uyehara**

Oh. Looks like you're muted, Raoul.

## **Lori Baxter**

I hear you. We see you, Raoul, but we cannot hear you. Can you check your microphone, please?

## **Raoul Bermejo**

Can you hear me now?

## **Lori Baxter**

Great. You can continue. Thanks, Raoul.

## **Raoul Bermejo**

Thank you. Thank you, everybody, and thank you for the invitation as introduced. I'm Raoul Bermejo. I'm a health specialist at UNICEF, New York headquarters in the health team, and have been for a number of years now working with a number of partners in a number of countries on putting together a service delivery model for early identification, and early interventions for children with developmental delays and disabilities.

Right at the start, let me say that what I will describe this service delivery model is not specific to children with feeding difficulties, but rather a broad early identification and early interventions model, but that it can provide opportunities to also identify and address feeding difficulties, and facilitate linkages to nutrition program and other social support programs for children with developmental delays and disabilities. With that caveat, let me then continue.

Next slide, please.

Previous speakers have pointed out some of the key challenges for children with developmental delays and disabilities globally. Stigma and discrimination being really a very key component and challenge of the lived experience of many families with children with disabilities and children with disabilities themselves. A lot of people have also pointed out the lack of access to services, meeting their general, but also their

specific disability needs. While there are new evidence-based methods that are just coming to fore, there's lack of adaptation and broad use of many of them. Although we know now that the early childhood really provides for us an important window of opportunity to provide support and care, and provide early interventions, very much in line with the evidence emerging from neuroscience, but also practice.

Next slide, please.

Just some of the governing principles that we have been using in building up this model very much aligned to what many of the previous speakers have also mentioned, that this is really about promoting rights of children with disabilities, and that is all about the outcome we want to see is not only in health, but really being able to participate in society that's underpinned in the CRC and the CRPD.

Hannah described also the WHOICF model earlier that provides a framework to understand how impairments and body functions and activities, what children are able to do and their participation, all provides a framework how we can understand that, but therefore also help us design intervention programs accordingly.

Next slide, please.

Our objective was really to develop a model program for early identification and early interventions for children with developmental delays and disabilities. We are trying this out in a few sites in Uganda, Bulgaria, and Peru.

Next slide.

It also adopts a twin-track approach, that many speakers have also pointed out, that on the one hand, we want to make sure that children with disabilities are able to access mainstream ECD programs and other social support services, but that on the other hand, on the second track, that we also are able to develop disability specific interventions and support programs based on being able to identify the child early, and then provide that early interventions, and that we see these two streams together really promoting equality and equity, and for these children to be able to participate in society.

Next slide.

I will focus a little bit more on the disability specific track. Our work is focusing on the early years with promoting screening, and monitoring of development in all children between zero to three, and promoting family-based community centered early intervention services, building the capacity of frontline providers to be able to provide those, and then describe pathways of care for children that need more support. In that universal progressive framework, that was also part of the introduction, having a peered approach for some children that require further help can get an assessment of what further needs they have, and early intervention programs to be then designed for those specific needs.

Then underlying all this effort is really addressing stigma and discrimination, self-stigma within the families, but also within communities, and even frontline providers who have been known to also exhibit stigma and discrimination against children with disabilities in their families.

Next slide. Next slide, please.

This might be difficult to read for some of you, but I will describe it in details.

This is the model that we are working with in the three countries. It describes a pathway of care for children with different kinds of delays and disabilities. It's a peered approach, really starting from promoting on the first year universal screening for various impairments, but also developmental monitoring and screening in the early years. Then promoting inclusion into mainstream ECD programs, in particular for children with delays or challenges, so that they're also included in those ECD programs. Then the upper part, tier three and tier two, are really describing pathways of care for, on the one hand,

community-based, family-centered early interventions delivered close to the family, but at the same time, for those children that require further help so that they can get further assessments based on the kinds of difficulties and impairments that they have. Then have more specific early interventions for those specific conditions and problems.

That is the model that we are trying to pilot in a number of countries. At the core of it, is this idea of really promoting universal developmental screening and monitoring, but also early universal vision screening, and early universal hearing screening. Then channeling them to pathways of care that is anchored on community-based family-centered approaches at the community close to where families are.

Next slide.

This is just describing further what the tier two intervention package looks like. All children that have screened positive of any of the screening or monitoring tools, we are including them in community-based family-centric interventions that include close monitoring of the child's development, but also then providing support to the child in particular through the family, through care, caregiver education and skills training, and empowerment of the family and the child. Then also having social behavioral change communication strategies to address stigma and discrimination.

Next slide.

Just to have a quick look of how this model is being adapted and implemented in Uganda, they are still continuing to build the system, so what they have in place is tier one and tier two.

Please, next slide.

They are promoting early vision screening for all children. They're doing this at six weeks during the first dose of DPT for those children to undergo vision screening. For those children that pass the vision screening, they continue with all the other mainstream ECD services that they need to receive, also including nutrition and feeding advises. For example, [inaudible 01:27:40] to then have a further vision assessment at the district or the regional hospital. Then for those who pass, to then promote their continuous access of mainstream ECD services. Then for those who fail their vision assessment, to then be able to be referred to get care for those issues.

Next slide, please. Next slide. Sorry, here.

A similar pathway for hearing.

Next slide.

Then we are promoting developmental screening in Uganda. They're doing it at 9 months and at 18 months using a short form of the Malawi Developmental Assessment Form. This is then the pathway of care that they follow based on the assessment through the MDAF.

Next slide.

Yes. I think that's the last slide. Again, that describes very general early identification and early interventions model that then provides pathways for children to access further care and support. We see this as an opportunity to also identify their feeding difficulties. Many people, previous speakers have already said that children with disabilities are at higher risk, of course, for not only feeding problems, but also having broader nutritional issues. The model provides opportunities to also address nutrition related issues.

Thank you.

## Lori Baxter

Thank you so much, Raoul. Thank you to Alyssa and Malia as well. We have not had too many questions come through. We're actually at time for this plenary session. What I did notice was one of our registration questions was about how early screening for disability can be incorporated at scale within health systems

I think, Raoul, you gave some really nice examples of ways to really practically integrate screening into health systems. Thank you for answering that question without even knowing that it was a question.

What I'm going to propose right now is that if there are more questions or reflections relating to the content that's been covered so far, please write the questions in the Q&A box. Any reflections or communication can go in the chat box. I'm going to have everyone break for 10 minutes. There'll be some music playing, and there'll be a little timer showing so that you know when you should come back. In the meantime, our panelists will answer some questions written via the chat box.

I also wanted to mention that when we return, we're going to move into our breakout sessions. That will be first introduced by my colleague, Cat Kirk. That's what we'll be coming back to. Please, if you're able, you can stand up, move around, grab a drink of water or some coffee, and then come back in 10 minutes. We'll see you soon.

[music]

## Cat Kirk

When you registered for the event, we asked you to select themes that were of interest to you. We have grouped our participants into seven breakout groups based on these themes. There are two groups for one of the themes. You'll be assigned based on the preferences you put in your initial registration, and you will be part of this thematic group, both today and tomorrow. We do want to note that we've assigned Spanish and ASL interpretation to specific groups. If you requested Spanish interpretation, you will be in the Managing and Supporting Feeding Difficulties group that stays in this main room. Our ASL interpreters will be joining the Promoting Disability Inclusion group as well.

I'll talk through in a moment about how to get into the groups, and what we'll do in the groups, but I do just want to flag if you, for any reason, do not have the right accessibility supports that you need once you get assigned, you can put into chat for tech support to help you. You should be able to also choose your group if you need to. Just a reminder, so Spanish will be staying in the main room, and ASL will be in this Promoting Disability Inclusion small group.

If you go to the next slide, in our breakout groups, we're going to be using a tool called Jamboard, and don't worry, you don't have to know how to use it. You'll have a facilitator to help you. It basically functions like a virtual whiteboard where we can put up sticky notes of ideas. In your groups, you'll have a technical facilitator and a second facilitator who will help with the Jamboard.

We do really encourage you to come off mute and use this time to talk with one another, and really share your experiences and your expertise.

We won't do formal introductions in the small groups, just for the sake of time, we only have about 30 minutes. Please do introduce yourself in the chat box, and please do introduce yourself when you come off to speak and share your ideas.

When you get into the Jamboard, you'd be able to add your own little sticky notes using a panel on the left side. There's a small box as shown on the screen here with a little sticky note. When you click on it, you can type what you'd like to say, click save, and it will add your ideas to the board. Also, if you have any issues with it, please feel free to just speak.

All right, next slide I think is going to show us a little bit about how to find the breakout rooms. You should have been pre-assigned. We've done our best for technology, and we're hoping for the best here since this is our first breakout group. You should automatically be sent to the breakout rooms. If you have any issues, certainly message tech support in the chat box. In the bottom of your screen, you should also see a little icon that has these four squares that says breakout rooms. You may not see it yet until I open the rooms, but in just a moment, hopefully, it will be there. If you find that you're in the wrong room or need to move, you should be able to use that to navigate, again, with Spanish translation in the main room, and ASL interpretation in the disability inclusion room.

Now for the moment of truth, I am going to attempt to open all the breakout rooms, and we'll probably need a moment to do any final shuffling around. We'll have 30 minutes of newsrooms, and there won't be a report back today from the breakout groups, but tomorrow, we'll be doing a full report back from all of the small group discussions.

All right, here we go.

[silence]

Great, thanks, everyone. Sorry, bouncing around from small group to the next session, but really, really excited about our next session today, and our final plenary group session before we close for day one. This session, we're joined by three wonderful organizations who will be sharing their experience about work that they have been doing in various settings to better address nutritional needs among children with feeding difficulties and children with disabilities. I just want to double check. I hope everyone's on the line after we've come back from our breakout rooms. Looks like they are.

We'll hear from four different speakers today. Our first speaker will be sharing his work, is, well, Juan Cobenas. He is a fellow with the International Disability Alliance, and focuses efforts on how to better support children and individuals with disabilities in humanitarian settings.

Juan, the floor is yours.

## Juan Cobeñas

Yes. Thank you very much. I am Juan Cobenas from Argentina. I thank you for having me today. I am fellow of the International Disability Alliance for the Disability Reference Group to include persons with disabilities in humanitarian action.

Following, please. Next, please.

My assistant will read about IDA.

## Assistant

The International Disability Alliance motto is advancing the rights of persons with disabilities. IDA is a network of eight global organizations of persons with different disabilities and six regional networks. It brings together more than 1,000 organizations. IDA advocates in the United Nations for a more inclusive world for everyone. IDA advocates for the implementation of the convention of the Rights of Persons with Disabilities and the achievements of the SDGs. IDA is strongly promoting the right of underrepresented groups of persons with disabilities, among whom are children with feeding difficulties.

Back to Juan.

## Juan Cobeñas

I will not use more slides. These are all the slides, please. I personally am involved in raising awareness of feeling difficulties in humanitarian action. IDA promotes the YESK inter-agency guidelines for the inclusion of persons with disabilities in humanitarian action, which dedicates a chapter to this issue to nutrition and feeding.

The link to the guidelines will be in the chat box.

Now, I will tell you the story of a child. He was 14 and weighted 9 kilos when he died of tuberculosis in a province far away from the capital of my country, Argentina. He belonged to an ethnic minority, the **[unintelligible 01:39:44]** Qom indigenous peoples. It is a very sad story because the governor of the province and the health authorities said that the family did receive food supplies from the government, that the child was malnourished because of TB, and basically because he had neurological problems.

I feel this child very deep in my heart, because I was malnourished, weak, and I may have felt the same he felt at some point of my life. This is the extreme powerlessness, the feeling of being too weak to be seated, the terror when they put food in my mouth, but I lived near the best pediatric hospital in Latin America, and my family had the appropriate support to learn what to do. I have a gastrostomy, and I feed through a tube with a formula that my social security covers provides. The main difference is that I arrived at a good health center where they did not discriminate me, and where they could teach my parents and provide them with the correct support.

I think it is clear from these stories what we need to do. Advocacy needs to be directed to destroy the believe that this disability makes a person less valuable. We, OPDs, advocate for the right of every child with disability to have the access to support, to feel well and be active, to have energy to live. On the other hand, parents need support to understand what happens and to learn practices that are complicated in order to make feeding a safe process.

Our best recommendations for professionals are what you have already said, teach parents how to feed, discuss with them the practices because sometimes parents do not completely understand what happens, and it goes in directions that are completely against what they know so far. Help them to understand what is happening to their child and how to overcome the difficulties.

Use peer support among parents, but always be sure to transmit in every word and every attitude that their child is of great value as every other child in the community. Thank you very much.

## Cat Kirk

Thank you so much, Juan, and thank you for sharing your personal experience and your advocacy around these issues. I think you highlighted so many important points, particularly when it comes to children on the very big importance of supporting families, but also making sure that the services around those families are there and able to support, and that we always focus on centering the value of every child no matter what different circumstances they may be experiencing.

Thank you for that. We'll have some question and answer for all of our panelists after they all have a chance to go. It is my pleasure now to introduce our next speakers who come from the Ummeed Child Development center in Mumbai, India. We are joined today by Vrushali Kulkarni, she is the lead occupational therapist, and Payal Shah, a pediatric occupational therapist, both at Ummeed. Over to you, Vrushali.

## Vrushali Kulkarni

Thank you, Catherine. I'm presenting Mealtimes Made Easy. Next slide, please. I'll briefly talk about Ummeed Child Development Center, which is a not for profit organization based in Mumbai, India. It



works towards supporting all children to reach their maximum potential so that they do what they want to do in the larger society. Towards this, the activities that we meet could be divided under clinic training, research, and advocacy verticals. Next slide, please.

Ummeed's work with mealtimes and nutritional difficulties could be divided across individualized interventions conducted by speech therapists and mental health workers, and group-based interventions where developmental pediatricians conduct a training for caregivers to talk about nutritional aspects and how to make it accessible for children with disabilities, and occupational therapy and physiotherapy team conduct Mealtimes Made Easy program, which I'm going to be referring to as MME in further presentation. Next slide, please.

This is our MME team, which involves occupational therapists and physiotherapists who have conceptualized and delivered this program. Next slide, please. I talk about, why MME? To talk about statistics, 70% of children with cerebral palsy in India have mealtimes related difficulties, and this globally, it goes up to 33% to 80% of prevalence for children across all developmental disabilities. Apart from statistics, food has immense socio-cultural value in India, like in probably many other countries where it is a central theme to any significant social event or community gathering. When a group of caregivers are together, there is so much sharing of nutritional recommendations, recipe ideas, successes, and challenges in implementing some of these ideas with their children.

That sharing itself is a rich learning. So grouping all caregivers together was one of the key ideas of-- one of the key focuses of MME. Along with that, caregivers, be it for a child, with or without disabilities are important stakeholders. MME recognizes that and holds onto this idea and empowers caregivers to support their children during mealtimes. Next slide, please.

On this next slide, I'll be talking about key idea of MME which talks about three main factors. First one, next, is the child where we talk about preferences, abilities, and the neurological difficulties impacting mealtimes for this particular child. Next, please. Next factor is the activity of eating and drinking itself, where we talk about texture, variety, consistency, food amount, duration, frequency of meals, and all of that. Next, please. The third factor is environment where we talk about is the child sitting comfortable enough to be able to have fun during mealtimes. What about the people involved? Are they warm welcoming for the child to have fun and ease during mealtime?

MME helps caregivers build strategies across all these three factors, next, but more interestingly, what MME also does is helps caregivers connect these three factors, bring alignment between these three factors so that the mealtimes are fun. Next slide. Like I said, the objective of MME is to make the activity of mealtime fun and easy for caregivers and children with motor delays in the home context.

Caregivers expressing concerns like difficulty chewing, prolonged mealtime, stressful act of feeding, undergo a screening using the tool ability for basic feeding and swallowing scale for children where any child with oral hypersensitivity issue is excluded out of the group. Other than that, for me, motor delays are included in the group. Assessments are viewed based using a self-made questionnaire where the three factors that I mentioned on the previous slide are assessed in detail and also video analysis done during mealtime.

Next, please. Ummeed is committed to run two online groups, where each online group has a package of 10 sessions, starting off with pre-assessment, and then four weeks of intervention. It begins with sharing a didactic teaching video of a pre-recorded session where the concepts, the key ideas are talked about. Using these key ideas into one hour long sessions twice a week. There is brainstorming, problem solving with a group of caregivers to talk about what strategies are applicable in their context.

Then the caregivers practice these strategies with their children and share these videos on a WhatsApp group where the feedback is gained by other caregivers as well as the facilitators of this group. After the intervention is over, there is post-assessment using the same measures that I talked about earlier, followed by a group feedback session using semi-structured interview done by a therapist who was not

part of MME in that round. This interview is elicited to understand the impact of MME on the child caregiver and mealtimes overall.

I'll hand it over to Payal from here to talk about Aza's story.

## Payal Shah

Hi. Let us listen to Aza's story. Next slide. Aza is a four-year-old child. He loves to play with his sister and his mother. He used to take online sessions with us and in one of the online sessions the mother shared that mealtimes are becoming very stressful for her and that's why he was screened for the Mealtime Made Easy group. Based on the screening he was taken for Mealtime Made Easy group. We did an assessment where we came to know that Aza is fed semi-solid food. Most of the time, he has difficulty in eating solid foods and his position has changed almost 90% of the time during the whole process of feeding and even his mother's position has changed.

She has to change her position while making him eat. He also has neck-causing extension. His head, trunk, and pelvis are not aligned by the process of mealtime and he-- while drinking water there is lot of spillage while drinking water. This all leads to lot of reflux and coughing almost 75% of time taking mealtime to almost an hour. His mother is the only person who is responsible for his mealtime, there is no help, and his family feels that he should eat solids, and it's very important for him. She also exhibited responsiveness around 10% of time where she mentioned that she doesn't wait for the clues from him and she keeps on putting food in his mouth while making him eat.

Next slide. In the Mealtime Made Easy, we focused on these three factors. We formulated strategies that tackle these three factors and the interaction. Then we thought of strategies for his partial alignment and jaw control. Thinking of adaptive devices that could get some alignment into his posture. Also, we brainstorm on the consistency of food. The, let's think for the smaller meals, thought of more frequent meals, and also using a flat spoon and a cutout glass. We discuss, how can we apply Observe-Wait-Listen technique, that's the responsive feeding. His mother mentioned that now she waits for him till he clues and asks for the next morsel.

We explored opportunities where mealtime can be fun mealtime with the family. It can be fun family time also. Next slide. During the post-assessment, there were changes seen at multiple places. The frequency of the change of position that was happening was decreased by 25% and even his mother's position, but she used to keep on changing the position decreased. His posture was aligned using the adaptive devices and this all led to reduce in coughing, reduce in reflux to 25%. Also when food was placed on the side of his mouth, he could chew solids 25% of time and a spillage of water using a cut-out glass was also decreased.

A whole thing led to the meal time decrease to 10 to 15 minutes only. Also the responsiveness then was seen like her mother now waits for his clues that he will sign and for him to tell, and mealtime has become a ritual for his family. Now all the now time are fun mealtime for him.

Next slide, please. Some of the aha moments, you have to click three times. The most outstanding aha moments was that now-- previously, they never used to take Aza to any family restaurants or family gatherings or restaurants, because the mealtimes were very difficult. Now they take him to restaurants, to weddings, since the mealtimes have become very easy.

Next. One more click. **[unintelligible 01:55:46]** brings me to the summary. The next slide, that these are the three factors that are very important while considering mealtime. That brings me to the two strategies, that the three factors and the alignment of these three factors are very important when we are thinking of mealtime. Also supporting the caregiver to identify some opportunities where practicing

mealtime is easy, and also fun. It's like a fun time with their child. These are the acknowledgments references, and the acknowledgment. Thank you.

## Cat Kirk

Thank you so much Vrushali and Payal for sharing the work at Ummeed. I particularly like how you highlighted the role of the program to try and really be able to make that mealtime fun and social event that it is for many, many children but often cannot be for children who have feeding difficulties that are not adequately supported. Thank you so much for sharing that. Our last panelist before we go into our question and answers is Elizabeth Mubukwanu. She'll be sharing the work of Access to Health Zambia's Kusamala Program which she manages. Over to you, Elizabeth.

## Elizabeth Mubukwanu

Good afternoon, everyone. Thank you so much for this opportunity to be part of this convening. I will share our experience or our story as Access to Health Zambia's Kusamala Program. Next slide, please. Access to Health Zambia is formally Catholic Medical Mission Board Zambia. We are a faith-based organization that provides long-term and community-based medical support to communities affected by poverty. We've been operating in Zambia since 1965, but we recently changed to Access to Health Zambia as part of the localization just a month ago in March. We do work with the government of the Republic of Zambia at a local level, that's at the community level.

The government ministries we work with include Health, Community Development and Social Services, General Education. We also work with the local municipalities. We work with the police victim support unit. We work with the Churches Association of Zambia and also we work with a traditional leadership. Next slide, please. Our main areas of focus include child protection, which also includes the support for children with disabilities, orphans, and other vulnerable children. We also have the SGBV prevention. We also have HIV prevention.

We have livelihoods, water and sanitation and hygiene, nutrition, health system strengthening, and maternal newborn and child health. Next slide, please. The Kusamala project is a child protection project that implements programs within specific communities, three communities in Lusaka, which is the main capital of Zambia. Then we mainly focus on children that are at risk of separation, children that have been separated from their families, children with disabilities, and children with feeding difficulties.

We implement our programs and activities within Lusaka, the three communities I just mentioned.

For the feeding and disability programming, we extend to other communities within Lusaka, which is Mtendere, Ng'ombe, and Matero. Sometimes depending on the activity we are conducting, for example, if we are reunifying a child from a childcare facility and that child has a disability, we do go to other communities and provide services there. We also have interventions in another town which is in the central part of Zambia in Kabwe. We have a programming in Makululu, which is one of the biggest low income communities in Southern Africa.

Then we also have programming in Kafue and in Mambwe districts. Basically, the way we implement our program and our activities is through case management. We have community volunteers that work with us. Our entry point in the community is the health facility, which is within the community. We use the community volunteers to identify children that are vulnerable in the community. We implement the clinic-to-community, community-to-clinic, a type of approach where at the clinic level, the health personnel can identify children with disabilities or those that need support in the communities. These are referred to our community caregivers.

Also, we do have our community volunteers that also have community outreach programs in churches and also they do door-to-door activities, and they identify children with disabilities. Sometimes the identification is also done through other stakeholders within the communities like the police. We also have the local authorities and also just from probably community dialogues.

Of course, the workforce, we have the community caregivers that we work with. These are volunteers and these are being supervised by health personnel that are at clinic level. The services they provide include home visits, church sensitization, and basic physiotherapy. Then we have another cadre of volunteers who we call Men Taking Action so that these are men that sensitize other men on the importance of caring for their families and also being involved in the care for children at the household level.

Next slide, please. Our main activities in line with children with disabilities and those with feeding difficulties, I think goes back to 2017 when we initially started working with St. Catherine's University, who are currently providing technical support around disability. When they came on board, they initially came on board as our funder for the disability component and provided funding for us to be able to identify children with disabilities in the communities. Also, to implement interventions that would prevent stigma within the communities.

The common practice in most of these communities was that most children living with disabilities were locked up in their homes. St. Cate's came in and they provided the funding. We brought on board community volunteers and supervisors from the clinics who included physiotherapists, and mother and child health nurses, and other health personnels like doctors that were interested in being part of the programming.

We identified these children, sensitize communities, we had play therapy sessions, we had registration of these children with the Zambia Association for Persons with Disabilities so that they could have disability cards to be able to access other services. Then we had our church sensitization. Being a faith-based organization, we utilize all the churches within the communities to sensitize on the importance of including children with disabilities in all the activities that happen within the communities. Then in 2019, we were privileged to have SPOON Foundation. Mainly they supported us with trainings.

First of all, we had a training for master trainers in their patented Count Me In app which is a very useful app that provides feeding for children with disabilities. It provides recommendations for children with disabilities, and also helps monitor and improve their growth, motor skills, and nutritional status. From the time we started working with them, we've worked with quite a number of partners, but at the moment we have 10 active partners and the partnership is actually growing.

We also have the play therapy which I just mentioned, and we do conduct play therapy within the community where we have parents of children with disabilities coming with the children with disabilities. We try as much as possible to have children without disabilities coming into play with the children with disabilities.

We also have the Photo Voice project, which we usually have annually, with support from St. Catherine's University. Basically, this is an intervention where we have the parents with children with disabilities. We give them an opportunity to take pictures of the child with a disability for a period of time, let's say 10 days. Then we do have an exhibition within the community where any community member can come through to look at the pictures and share their experiences.

What we found is that this Photo Voice project has actually reduced the stigma within the communities because the community members are able to identify who that child is and they have a little bit of a story to talk about or they'll say, "Oh, I know this child, this is so and so. Oh, how nice. Oh, so this child is able to do this and that." It's a very good experience.

We do also have cooking demonstrations that we incorporated. Initially would have them at the play therapies, but then now we are having them in units. They're 15 parents with children with disabilities that come together every fortnight and others monthly to learn on how to prepare food in terms of nutritional balance, texture. They are also taught on sitting positions and other things that are related to the nutrition for children with disabilities.

We are privileged to have the Safe FEED, which is a functional eating education guide that we're supported with by SPOON Foundation. This is a guide to safe and satisfying meal time for family caregivers or children with feeding challenges. We have a flip book which the caregiver uses to check on what needs to be done for them to have a satisfying meal time. Next slide, please.

That's basically the activities that we do. We do have quite a number of them. They are all interrelated. What I would want to recommend is that, through our programming we've actually learned that it's very important for communities to be part of a project design to actually be part of the programming as you start the project because there's an acceptance and parenting children with disabilities should suggest the best ways in which to support the children with disabilities. Taking note that each child is singular and unique.

I think this is very important because the programming then will not be a one shoe fits for all. We actually have within our programming what we call a household approach, where we tailor the support that we give to each child according to the needs of that child at the household level.

Then another recommendation would be to include economic strengthening. For example, you can have referrals for social cash transfer, and then you can provide startup capital and entrepreneurship training to the parents for children with disabilities. They can be trained on how they can engage in entrepreneurial activities without really leaving the child or they can do it from home or where it's most comfortable for them and the child. Then also they can also be part of savings groups.

We have most recently introduced parents with children's disabilities in what we call the village savings and lending associations, and it has worked well. Actually, we do have an example of a parent who we linked to social cash transfer and we provided a startup capital. They were trained in entrepreneurship and they're part of a village savings and lendings group. This village lending group was actually started by the parent with a child with disability, so that was a really plus for us. They've incorporated other parents with children without disabilities so that inclusiveness at the committee level.

Then also another recommendation is that where possible, respite care for parents with children with disabilities is needed. I know in most of our programming, I think there's a challenge in funding, but then even ECD could be a possible respite care where the parent with the child with a disability can take the child to school, and then they have that relief. Basically, those are the key recommendations that would provide. Thank you so much.

## Cat Kirk

Thank you so much, Elizabeth. I'm going to now ask that all our panelists turn on their video again, and if we can close the slides and see everyone. There's a few questions that have come through in the chat box and we have some questions that were actually shared in advance of our session that I think are really, really relevant to this. The first question was for you, Juan, around the services that you shared that you and your family were able to access. The question was, are those services available to all citizens within Argentina or are there restrictions to access?

## Juan Cobeñas

Yes, in Argentina, every person that arrives to the hospital gets the services. The problem is when the local health providers don't think that the child applies for the services. The family I mentioned received attention and food, but the doctors and nurses never thought that this child deserved to go to Buenos Aires, to the capital, or to any other center that had more complex attention. The problem was the perception of what the child deserved. Yes.

## Cat Kirk

Thanks so much, Juan, for sharing. I think that's so, so important to recognize. While services can be available, there's a number of other things we need to think about to make sure that they're accessible to children and families in many different ways. I'd like to address another question that's come up to you, Payal, and Vrushali. You shared a really nice example of the Ummeed model and you used a virtual component to be able to reach families. What do you think it would take to scale up a program like this to reach more children?

## Vrushali Kulkarni

Payal, should I go first? Okay. Also, Catherine, thank you for this question. This is something that even we are considering given the difficulties and the demand around it. One of the things that we had done earlier was to have Mealtimes Made Easy training program where we catered to caregivers, primarily, and where we talked about some of these factors and strategies around that as a way to help them with the mealtimes.

What happened is why we also added the component of working with children is because we realized that there is so much more than just talking about these strategies, but to also handhold caregivers and children together to figure out what works for them and to give feedback and to discuss some of these things which is why the MME developed from there. To answer your question very, very quickly, online trainings is something that could be used to scale up some of these things where caregiver empowerment could be possible.

However, MME I think by itself can hold onto six to eight people in one group and maybe conducting and delivering some of these models. Ummeed is also involved in training other organizations to be able to implement some of these models in their organizations. That is also one of the ways that we are hoping to create more masters, trainers, so to say, so that this could be transferred to other places. Payal, if you want to add something.

## Payal Shah

I think you've added the two.

## Cat Kirk

Thanks so much. I welcome Elizabeth, or Juan, if there's anything that you'd like to share about what you think it takes to scale programs to support children with feeding difficulties and children with disabilities.

## Elizabeth Mubukwanu

I think what it takes is, of course, you need the funding. Funding is a limitation. Also, I think in case of Zambia, we also need to have a research to get an idea where these children living with disabilities and also those with feeding difficulties. Like I mentioned earlier, for us to be able to know where these children were, we had to look for them in the communities where we were implementing. Research around the number of children with disabilities and where they are is very important. The funding for research and also funding for programming is usually a limit.

In Zambia, if you look at the Count Me In app, I think there's quite a number of organizations that are interested. Then to reach out to those organizations in terms of supervision would need resources. Funding, I think, is major and also research. Thank you.

## Cat Kirk

Thanks so much. We have maybe a minute for one more question, which I'd like to first direct to you, Juan, if you could respond about, what are some practical ways thinking about that socio-ecological model that we can support the needs of caregivers who are supporting their young children with feeding difficulties, or disabilities?

## Juan Cobeñas

Thank you. I think that the professionals should give parents long time, or enough time to get familiar with the new strategies. It's really difficult for parents to accept that their child has to use these strategies that are difficult to apply many times. The perception of parents is that accepting this, their child is losing a lot of his or her accepting. For example, my gastrostomy was very difficult for my parents. They thought it was the end of some kind of life that was better for me. When I got my nutrients and got weight, they were happy and surprised, but you need time to understand and accept. Thank you.

## Cat Kirk

Thanks so much, Juan, I think you're right. Parents need that extra support beyond just the time to support the child but this time to help talk through the parents' own needs and what the experience is like for them and their own wellbeing. Anyone else want to comment just before we'll have to unfortunately close up the panel? All right, well, with that, I just want to thank all four of our panelists for sharing your work and your stories.

I can see in the chat box lots and lots of positive feedback and gratitude for sharing these experiences. We can learn from all these different models and approaches to think about how we can better support children moving forward. I will hand it over to my colleague Natalia to wrap us up for day one.

## Natalia Mufel

The most important today but a little bit running out of time but I too want to highlight that you please add to the chat box some answers to three main questions. The main question is what are your key takeaways and what you did learn today that you would have will apply to your work? Another question is what you want to learn during the second day because we're approaching second day and based on what you feedback, it will be provided now, we can a little bit adjust.

Then it's also very important question to let us know if everything goes appropriate in terms of accessibility or you need something else that we can include. I would like first to highlight very strongly that you have notes for the day and we want very important planning. There is huge amount of people with the disabilities worldwide. Recent report highlighted that 230 million children with disabilities are living in the world.

34% of them most likely are stunted, 25% most likely are wasted. Then there are a lot of connections between disability and poverty that were highlighted today. Can you please start to answer the questions because we are really running out of time. I wanted really to highlight this point first.

## Cat Kirk

Natalia, I can support you by reading a few of the comments that are coming through so far. For question number one, we're seeing people are really interested in learning about the scoping review, hearing some of the resources and statistics, a lot of the practical examples. We have colleagues sharing about-- they're interested in learning the battles in early detection in Cambodia and Lesotho. Those are some that we are seeing come through so far.

## Natalia Mufel

Thank you, colleagues. I really want to highlight that you will continue answering to the questions because it's really essential and we can improve tomorrow our work and we can ensure that we are providing the most information that we can and you are looking for. Today, we also were looking through multiple very important issues related what is highlighted in CFPD, what is really twin track approach, because still not everybody understands fully what is twin track approach and how these premium and supplementary programs can be implemented.

Then we were sharing a lot of experience from countries and you can learn from these countries what can be done and how it can be done. Another important issue that we were highlighting is different models of disability. It was presented. Social model, it was presented. Medical model, and double issue approach, that was presented. Please, colleagues, can you help me whether we are getting some questions and answers. A little bit.

## Cat Kirk

Yes, we are seeing it says great to hear about the different networks that exist in the training. There's still some interest in having something to be learned. Maybe tomorrow would be video tools or available trainings. Maybe if some of our colleagues that are still on the line have links to some of those, that's something you can bring to the sessions tomorrow and share in the chat box or you could paste them now.

We're seeing a mix of people answering question number one and question number two. Maybe it looks like something that is needed would be measurement and documentation for different types of disabilities and implementation research in order to scale up services. That is relating to some of the evidence and tracking panel that we'll discuss tomorrow. I think that will be quite interesting for you, Jennifer. Yes, that's kind of what I'm seeing in the chat.

One thing I haven't seen come up in the chat yet is if there's any sort of ways that we as a team can approve to provide more accessibility for these events. If there's anything that didn't quite work well today, you can send an email as listed here and we'll drop that email in the chat box so that it's easier



for you as well. Or you can write it in the chat because we do want to make sure that everyone can have as full and effective participation as possible.

## Natalia Mufel

Thank you. What also I want to highlight that there were today oppose some solutions that we can attest related to figuring difficulties and children with disabilities and [unintelligible 02:27:37] for them and demand them. Of course, it's about addressing stigma and discrimination and community level changes should be happening at mass media. Then of course, human resources should be much more developed and supported in terms of training curriculum for applied [unintelligible 02:27:57]. The most important is that there are still issues on collecting of data and specific issue related to budget to ensure that disability inclusion is promoted and willing to cater for disability inclusion.

I think I am ready to close really on time because I do believe that due to time differences, people are in different time zones and some of them are already late. I'm really grateful for all of you to come to this important discussion. I'm looking forward that you will join tomorrow. We'll start tomorrow at 8:00 AM. We'll start on time. Thank you.

## Speaker 1

Thank you.

## Cat Kirk

Thank you, everyone. See you tomorrow.

## Juan Cobeñas

Thank you.

[02:29:02] [END OF AUDIO]



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