

Supporting Children with Feeding Difficulties and Disabilities in Nutrition Programs Tools for Action webinar

Webinar Transcript

Cat Kirk

Thanks very much Yaritza. I'm seeing some chat messages come in that the ASL interpretation is no longer showing up. Maybe you can help fix that as I have the pleasure to introduce Kellie Stewart who will be opening our webinar today. Kelly is the acting Deputy Director for the Office of Maternal and Child Health and Nutrition, and the Chief of the Nutrition and Environmental Health Division in the Bureau for Global Health at USAID. Welcome Kelly and over to you.

Kellie Stewart

Thank you very much Cat and it is truly my pleasure to open today's webinar on improving nutritional care for children with feeding difficulties and disabilities. And it's wonderful to see so many colleagues from around the world joining us for this really important webinar. I think as many of us know, 80% of the world's one billion persons with disabilities live in low- and middle-income countries. And nearly 240 million children worldwide live with the disability. The majority of whom have limited access to critical health and nutrition support and services.

Promoting the rights and inclusion of persons with disabilities, including children with disabilities, is a commitment made in numerous USAID policy documents that guide our work. For example, USAID is updating the Agency Disability Policy with consideration for disability inclusive nutrition services, and has held pre-draft consultations the disability community stakeholders to ensure that the voices of the disability community are leading those efforts to create an inclusive policy. In the USAID Bureau for Global Health, we are promoting inclusive early childhood development in line with the Global Child Thrive Act. And we do this in close partnership with our children and adversity team and with our mission colleagues. We're working together to identify where we can collaborate on integrated programming, for maximum impact, to promote nurturing care

including nutrition support for children with feeding disabilities. We know that how families support a child with loving care plan and stimulation is as important as feeding for improved childhood outcomes. Building on available evidence and global guidance for improving early childhood development we've supported missions to design inclusive programs to integrate caregiving practices with nutrition interventions. For example, nutrition programs in Cambodia, Rwanda and Mozambique work to promote the nurturing care that all children need for positive early childhood development outcomes. These programs include a component focusing on early identification of development delays and disability, so children and their families may receive the targeted support that they need. We have invested in global tools and resources to support this important integration such as the Responsive Care and Early Learning Addendum developed under USAID Advancing Nutrition, which also covers support for feeding difficulties and caregiver mental health and well-being. Which is also an incredibly important aspect of this work.

Now successfully piloted in three countries, this addendum can be integrated into the UNICEF Community Infant Child and Young Child Feeding Counseling Package, already used in at least 60 countries. I myself have seen firsthand the critical need for these resources. After the zika epidemic emerged in 2015, I was directly involved in the agency's response as the Zika Coordinator for Central America and the Dominican Republic. In this position, I had the invaluable opportunity to meet families from across a variety of communities that were caring for infants and small children - children living with zika related disabilities. Time and time again these families spoke of the feeding difficulties that their children faced. These families desperately needed support. Caring and motivated health workers staff worked hard to fill this need but often the resources and information were just severely lacking. Seeing these complications from having contracted the Zika virus and their affected babies underscored for me how critical community support can be to help promote nurturing care for all children. There is a great need for more inclusive health and nutrition services. Poor nutrition as a cause or a contributor to disease and disability are well documented in the scientific literature. But there are also disabilities that affect individuals' malnutrition. Nutrition and disability are intimately linked. Malnutrition can cause or contribute to a variety of different disabilities, and disabilities can cause or contribute to malnutrition.

Countries with high levels of malnutrition and nutrient deficiency also often report higher rates of disability and developmental delay. 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 and we really hope to be changing that now with this work that we're supporting today. To assist nutrition and disability program managers in designing and implementing effective nutrition programs, we have supported USAID Advancing Nutrition to create an Open Access Resource Bank with information and guidance for improving nutritional care for children with disabilities. You'll hear more details today. But the content covers identifying and managing feeding difficulties, identifying disabilities, supporting children with disabilities and their families, and promoting disability inclusion.

I want to thank the USAID Advancing Nutrition team and the members of the Technical Advisory Group who helped to inform this important work stream which will help to advance our agency's inclusive nutrition approaches. I also want to give a huge thanks to our speakers today for sharing their experiences and their work in the field. Thanks again to all participants for joining this launch of the Resource Bank. Back over to you Cat.

Cat Kirk

Thank you so much Kellie for those important remarks sharing the agency's commitment and the efforts to date to promote more inclusive nutrition services. I will now be introducing two members of the Technical Advisory Group of persons with lived experience who have helped to guide USAID Advancing Nutrition and all of the work that you will hear about today.

First, we will hear from Shona McDonald who is the Executive Director of ShonaquipSE in South Africa. And then we will hear from Christine Karungi who is the Executive Director of the Uganda National Association of Cerebral Palsy. Over to you Shona.

Shona McDonald

Hi, good afternoon, morning everybody. I really just want to open this meeting with my thoughts and memories of how nutrition has been such a significant driver in the care of my daughter. In 1992, my second child was born with severe birth injuries, with cerebral palsy. And the medical

advice was to put her in a home and have another child. As somebody who really was questioning everything that the doctors were telling me, I decided rather to go on a route of my own and try and prove that her life could be of value too. The first challenge that struck us within weeks of her being born was her inability to suck properly and breastfeed. Working through that took 20 hours a day and ended up with many tears and lots of blood. But once she started being able to breastfeed and we knew in what position to uphold her, we were able to succeed. Then we started moving on to solids. As many people will know in this meeting, the ability to swallow and breathe and coordinate that process for kids with severe CP is really difficult. But I was determined that she would enjoy food and enjoy being part of family meals in the same way that my other children were. This really led us on a journey from survival of the basic first year or two of breastfeeding to actually one of promoting quality of life around eating, drinking and managing the levels of nutrition. Absolutely, step one was to ensure that her posture and her positioning while eating and swallowing and feeding was 100 percent correct or she would end up aspirating. This brought me into a whole new field of designing posture support equipment that would enable children to be able not only to improve function of hands and mobility, but also of breathing and swallowing and coordinating those functions.

I think a few of the elements that has really influenced my input into this work with USAID over the last few months has been to ensure that assistive technology is highlighted. The need for appropriate posture management biomechanical alignment. And then most importantly how to use that equipment is prioritized. On another level though, we started noticing that our daughter's nutritional level was not equal to her peers. She was not flourishing and thriving the same way they were. And it was only after some time that we realized that the powders and smoke supplements that we were forced to give, her because she couldn't chew, didn't contain micronutrients and that set us on another path of looking at the actual content of the food the children are able to swallow and eat, and what is expected. Because many people will promote that they just eat as softer food as possible. But actually, that is not ideal in the long term.

So my journey continues, now that she's 40, with still looking at how do we ensure that her diet is as diverse as possible; how do we make sure we train people all around her not only her healthcare providers but her peers, her sisters, her family on how to feed her correctly without

her swallowing; and how do we ensure these cross-cutting policies between Health Care, Education, Social Services also accommodate elements that promote and support not only good nutrition but access to all the assistive technology and the services and training that parents and families need in order for them to really, not only be able to understand what's needed but to be able to action that information, so that families of children with disabilities in the future never need to experience their child as less valued like I did. Thank you very much.

Cat Kirk

Thank you so much Shona for sharing both your personal journey and the important systemic work that needs to happen to better support children like your own. Now over to you Christine.

Yeah, we can see you very well Christine.

Christine Karungi

Okay, good evening, everyone. My name is actually Christian. I'm living with Cerebral Palsy (CP) disability and I'm the Executive Director of Uganda National Association of Cerebral Palsy. I'm very happy to be part of this important webinar today. This is very important most especially in the lives of persons, mostly children living with multiple severe disabilities and their families. As a person who has grown up with cerebral palsy, I've really realized that it's not easy. Most especially, to take care of a child with cerebral palsy, families go through a lot where a family takes care of those children without any support. Yet in such a time the family, the caretaker, and even those children themselves they need support in different ways when we talk about nutrition. Children with disabilities, most especially those with multiple disabilities, face a number of barriers compared to their counterparts without disabilities.

When we talk about nutrition, it's one of the key things if we really are designing strategies that can support children with disabilities to reach their full potentials. This is because in nutrition, we are looking at a number of components like positioning, how to prepare the food, and also help support them to try to use their strengths. So, it's very important and indeed we really need to work to bring the family on board. If we are to achieve and to sustain such a program, families need to be brought on board. And also, we need to build and strengthen the community-based

support systems because at the end of it all these children grow and transit to another level, and they need to live within their families. So, how will that happen if the community where they are living there are no supporting systems for them to really feel at home or to live in that environment that is friendly and enabling. And this calls upon our State, the development partners, the implementers, and the organizations of persons with CP disabilities. It's very important that whenever we are implementing such strategies those people are brought-in to play a part. I really love this webinar because the whole program is focusing on the area that in most cases is being left behind. Whenever programs, strategies or plans are being involved, this unique area with very interesting and challenging components is always left out. See for example in times of crisis or disasters, when they are developing the mitigation plans ... our children are always left out. I'm not seeing any sustainable development in our States ...

Cat Kirk

Christine, it seems like we are having some trouble. Your video has frozen so maybe to conserve bandwidth you may want ... Yes, we're having trouble hearing you and seeing you well on the video so you may need to just disable or turn off your video to be able to hear you better.

Christine Karungi

I think it's that ...

Can you see me now?

Cat Kirk

Yes, we can hear you, Christine. The video is on.

Christine Karungi

So, do you think that I can repeat? Because I'm trying but I think my camera is not okay.

Cat Kirk

Yes, you can continue speaking.

Christine Karungi

Okay, I'll repeat again. I was saying that me as a person, Christine, I really love this webinar because it's focusing on the most vulnerable and marginalized category. In most cases, most development patterns and when our States are developing plans and programs, they tend to forget this unique category. Yet, they chase compounded variabilities compared to their counterparts without disabilities. And I went ahead by saying that bringing up a child with multiple disabilities, for example cerebral palsy, calls upon for a holistic approach. In that I mean that the family should be brought on board. We need to build and strengthen the community-based support systems if we have a sustainable program. Because without nutrition, children with severe disabilities cannot reach their potentials.

Therefore, we call upon all the development Partners to really support this kind of program because we all know that children transit to another stage. So, if we are really looking at an inclusive society, we need to support the children. If they are not supported at the early age, then chances are very few for them to improve at a later stage. So, I really emphasize that families should be brought on board when we are implementing these programs. And why we need the Community Support Systems in such a program, we are looking at the sustainability. But again, we are looking at building and also improving an enabling environment. Families need psychosocial support but even the children themselves. That type of intervention is very key for the development of children with disabilities. Thank you.

So, I really thank you for coming up with this program because I know it's going to help me and I also call upon other development partners to see that as they are adopting a number of programs on how to mitigate disasters, crisis, natural calamities, let them not forget this category because the number is very big. For example, cerebral palsy is one of the common childhood disabilities. Therefore, to improve their lives, we need the interventions to be done as soon as possible. Thank you so much.

Cat Kirk

Thank you so much Christine for sharing the importance of supporting families and working with communities. Organizations of persons with disabilities such as your own are such key advocates and partners for all of this work in any community. Now we will hear from two of my colleagues

at USAID Advancing Nutrition on the work that USAID Advancing Nutrition has been doing to improve nutritional care for children with feeding difficulties and disabilities. Alyssa Klein is a Technical Advisor and will be sharing the results of a scoping review on this topic. And then Malia Uyehara, our Project Officer, will be providing an introduction to the Feeding and Disability Resource Bank that Kellie mentioned in her opening. Over to you Alyssa.

Alyssa Klein

Thanks Cat, good morning and afternoon and evening everyone depending on where you're located. First of all, I just wanted to reiterate thank you to Shona and Christine. I also have a daughter with cerebral palsy who was born prematurely and feeding her has been a journey. I very much appreciate how vulnerable it can feel sharing your own personal experiences, so I really appreciate it. I will be presenting a brief overview of the scoping review that the USAID Advancing Nutrition leadership program conducted. We were looking at nutritional care for children with feeding difficulties and disabilities. As Cat shared, Malia and I are representing our larger team today.

As Kellie already told us, when we're talking about people with disabilities we're not talking about a small number of people. 15% of the world's population or approximately 1 billion people are disabled. Nearly 53 million children under five who live in low- and middle-income countries are disabled. Some common disabilities include things like epilepsy, ADHD, intellectual disability, hearing or vision loss, autism spectrum disorder and neuromuscular disorders such as cerebral palsy. So, our scoping review focused on the top half of the sphere which is how having a disability can increase your risks of malnutrition.

Disabled people often have decreased nutrient intake or increased nutrient loss. Additionally, some conditions like cystic fibrosis or cerebral palsy actually require additional nutrients due to how the condition affects the body. For example, if you have cerebral palsy, your muscles are always working and burning more calories. So, our scoping review included a document review of 166 documents as well as 42 key informant interviews with people with diverse backgrounds and experiences. We focused on the 0 – 5 year age range although we did include documents and spoke with people that focus on a wider age range, so long as 0 – 5 years was included within

that. Secondly, we looked at both breastfeeding and complementary feeding. We also listed on this Slide the topics that we focused on. Some of which included feeding difficulties, nutrition among children with disabilities, small and sick newborns, and malnutrition treatment. We primarily focused on low- and middle-income country contexts although we did include examples of services from high income countries since they could be adapted for low- and middle-income countries. Lastly, we also included caregiver perspectives and experiences. We also conducted 42 key informant interviews. We tried to identify key informants from diverse regions and you can see on this map the geographic distribution of our respondents. In terms of background and experience, 35 of our respondents were female which is about 86 percent and around half worked for an NGO. We also interviewed seven respondents who worked for a government, three who worked for UN agencies, and nine who worked in Academia primarily as researchers. 19% of our respondents had a background in nutrition, 38% in health and 43% in disability. More specifically, 13 of our respondents had experience as either a doctor or a nurse, though some were working in other capacities when we interviewed them. 13 respondents were licensed to either physical therapists, occupational therapists, or speech and language therapists, although not all had active caseloads when we interviewed them. And six of our respondents highlighted that they were registered dietitians, nutritionists, or breastfeeding consultants.

So, disabled people are up to three times more likely to be malnourished than non-disabled people, and they're twice as likely as non-disabled people to die from malnutrition. Additionally, many studies have found significantly higher rates of stunting, wasting, underweight and anemia, in children with disabilities. Studies have also found that 33 to 80 percent of children with disabilities have a feeding difficulty, but feeding difficulties can impact any child. 25 to 45 percent of typically developing children have a feeding difficulty at some time in their lives. Feeding difficulties can include challenges related to breastfeeding like poor suck and swallow, poor attachment or tongue tie. They can also be things like sensory issues around food, restricted food intake, or even severely picky eating. Those are all common types of feeding difficulties that we see in young kids.

So, I would like to start talking about our findings by beginning with sort of the end in mind. Our review ended up coming up with four broad recommendations. These include:

- strengthening systems, especially Health Systems
- providing direct support to families
- conducting and supporting advocacy and that's at all levels, and
- building the evidence base on effective interventions for identifying and supporting these children and their families.

I'm going to briefly go through how we got to each of these recommendations over the next few minutes and then I'll share them again at the end.

Our scoping review found gaps throughout the health system that need to be addressed. This table lists gaps for all of the health system's building blocks but I'm just going to touch on a few of them today. When we look at service delivery, you find that children with disabilities may not be included in routine nutrition services and often they're explicitly excluded. This is true even in countries that have large nutrition and early childhood development programs. In fact, one review that looked at 100 clinical trials of early childhood development interventions found that 50 of those trials excluded children with disabilities. Additionally, even if a food security and nutrition program does not explicitly exclude these children, the programs are often not designed in accessible ways and might not reach these children anyways because of things like cultural stigma, physical barriers or devaluation of their lives. When we looked at medicines and technology, we found that assistive devices to support feeding are often not available in health systems, and certainly not at scale or tailored to specific needs. These can be things like adaptive seating, to position children in a way to make eating and drinking safer and easier, things like blenders to modify food textures, adaptive feeding utensils to help children feed themselves or to consume food and drinks safely from utensils. When we looked at workforce, we found limited skills among primary health workers when it comes to identifying feeding difficulties, and limited skills to provide support to caregivers of children with disabilities or to caregivers of small and sick newborns who are also at higher risk. We did find that some tools and resources for health workers exist but we also found that they're not standardized or universally used, and health workers are not usually trained on how to use them. Health workers also have limited time to provide any kind of counseling, that allows for trial and error, of different interventions. They're

often overstretched and underfunded which affects the quality of support services for all children. So based on the health systems' gaps, we identified some activities that would start to address these challenges. A few examples to highlight are adapting and testing tools on how to identify feeding difficulties, training health workers on disabilities to promote inclusion and to reduce stigma, and building health worker competencies to support caregivers.

In addition to Health Systems challenges, we looked at challenges that caregivers face in caring for children with feeding difficulties and disabilities. We found that, broadly, there is limited social support for caregivers; that families face high stress and significant stigma; and that there's not enough access to appropriate inclusive or quality services. Community programs and schools often do not include children with disabilities. Overwhelmingly, families caring for children with disabilities said that there is a lot of stigma and often blame which leads 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. We also found that a severe shortage exists in the availability of safe and affordable foods and tools needed to support feeding and nutrition of these children.

Here too we came up with activities that could be supported to address the gaps in support for families. One solution that came up in key informant interviews was daycare rehabilitation centers run by caregivers of children with disabilities. These centers provided a safe place for children with disabilities to receive care and supportive services while caregivers worked. They also provided an alternative to institutionalization. Another resource that was tested and has been tested in various countries are support groups for caregivers of children with disabilities. These have been shown to have social benefits and caregivers who've participated have mentioned positive changes related to positioning of their children, better feeding practices, and better communication with their children. Although I should note that they have not been shown to improve child growth.

Another recommendation that came out of our review was to create and provide access to assistive tools and devices using local resources. First, with small pilot programs to test solutions followed by a scale up. We also found a need to strengthen advocacy at all levels. And when I say all levels, I mean from addressing support and stigma within communities, to advocating for

inclusive and sufficient services within systems, to National level policies, and even inclusion in global agendas and strategies. Advocacy is a necessary component alongside strengthening systems and providing direct support to families and individuals. You need advocacy to create and implement the policies, and you need community level advocacy to reach families with support and to decrease stigma. This is something that came up over and over again in almost every interview. Respondents kept reiterating that without the advocacy piece, you will not be able to achieve your best results in other areas.

So, we broke down the illustrative activities related to advocacy into policy level and community level. At the policy level, activities like conducting webinars or presentations during existing donor or Global forums about including these children and their families in global nutrition work, or delivering workshops on the needs, opportunities and existing resources. At the community level, advocacy activities could include promoting uptake of community-based approaches that provide information on the needs of children with disabilities to reduce stigma, or things like putting together information and resources about programs that support these children and their families. The community level advocacy recommendations are not as directly tied to nutrition as the rest of the ones in our presentation. But because stigma and general exclusion of disabled children came out so strongly in our readings and in our interviews, we felt that it was important to include it here. Even if the advocacy here is broader than the others.

Another key finding from our research was that interventions for disabled children, that include feeding, still struggle to see improved growth and nutritional status. And that's even when they're successful in other measures like decreasing stress for caregivers, making meal times more enjoyable for everybody, or more tangible things like providing postural support to children to help them with chewing and swallowing. There were a number of reasons that came out in our interviews and readings for why this might be the case. This included problems with research methodology, small study samples, research questions that don't look specifically at nutritional status, exclusion of disabled children from studies or programs, studies that were too short in duration, and other reasons as well.

Ultimately, there were recommendations across the board that more and better research is needed. So, the illustrative activities in this category are all about doing more research and doing

better more inclusive research. We recommend conducting formative research with caregivers of disabled children to better understand their priorities around feeding and nutrition, we also recommend implementation research in programs that support feeding and nutrition. Additionally, we recommend being intentional about including and tracking the outcomes for these children and implementation research. Finally, larger scale and longer-term research is going to be key to learn what works and what does not work to improve nutrition outcomes for this population.

To finish my time today, I just want to reiterate that our scoping review came out with four broad recommendations. These are to strengthen systems, to provide direct support to families, to conduct and support advocacy at all levels, and to build the evidence base on effective interventions for identifying and supporting these children and their families.

We're going to share in the chat box a policy brief that we've just published with a call to action for policy makers. Additionally, the scoping review findings have been submitted as a manuscript for peer review. So hopefully it'll be published in the coming months. I'm going to hand it over to Malia who's now going to share something about the Feeding and Disability Resource Bank that the USAID Advancing Nutrition project created as a follow-up to this scoping review. Thank you very much.

Malia Uyehara

Thank you so much Alyssa. As Alyssa mentioned, at the end of our scoping review, we had put forth a set of four recommendations to improve and monitor nutritional care for children with feeding difficulties and disabilities within existing health and nutrition services. When we were developing our follow-on work to the scoping review, we wanted to be sure that we were addressing at least one of these recommendations in the work that we were doing. So, as a result and response to recommendations 1 and 2 that Alyssa just went over, which were to strengthen systems and to provide direct support to families, we decided to develop an online repository of resources that address feeding difficulties and disability inclusion in nutrition programs. We've titled this repository the Feeding and Disability Resource Bank. Which is one of the reasons that we've brought you all here today. The bank is officially live on our website and ready for use.

In just a few minutes, we'll have a brief demonstration on how to navigate and use the Resource Bank but I wanted to start with some background information on its development. To start with, we've kept the types of resources that are available on the bank quite broad, as long as they fit the aim of the bank. So, you can find manuals, job aids, training curricula, tools and more all through the bank. Secondly, our primary audience of the Resource Bank is nutrition and disability program leaders from implementing partners and local Civil Society organizations. We've chosen them as our primary audience because of the direct contact and impact that they have on children with feeding difficulties and disabilities and their families. In addition, USAID missions, UN and donor agency staff who influence the design of these programs and policies may also find the bank to be of use to them. We also wanted to highlight the highly collaborative process that we went through to develop the Resource Bank. We briefly introduced this group at the beginning of the webinar and, so far, you've heard from two of them. But to recap, before embarking on the Journey of developing this Resource Bank, we wanted to ensure that we were hearing the voices of the end user in order to be sure that we were creating a useful, accessible, and appropriate repository. So, we assembled a group of five members with lived experience with disability to advise us on each component of the bank, and stage of the development process. And by lived experience we mean that either they themselves had a disability or that they were the parent or caregiver to a child with one.

I've included a list here of the main role that they played in developing the bank. But to summarize, they provided input into the resources, the design and layout, which included accessibility and the dissemination plan. We really want to emphasize that we truly could not have developed the bank without their guidance and input, nor should we have, and it was with their help that we were able to more than double the amount of resources that we collected. And they also fed into all of the text that you see on the bank to make sure that we were correctly and respectfully describing this work and its importance. And they've also been great links to help us grow our networks with like-minded Advocates helping us to bridge the gap between nutrition and disability and to ensure that this Resource Bank finds its way into the hands of its intended user. Next, I want to explain a bit about the layout and features that you'll see on the resource bank before we pull it up. First the Resource Bank is divided into five sections, the five of which are

listed here, and each section has its own landing page on the bank. So, each resource on the bank falls within one or more of these landing pages, and they can be accessed through them. We also have a terminology page that provides an overview of relevant terms like disability and inclusion, as well as relevant international standards. Additionally, if you visit the Bank, you'll see a set of six images in the sidebar that depict children with feeding difficulties and disabilities being fed or otherwise enjoying a meal with their families. I've included a few here on this slide. These are all original images that we created in collaboration with our tag and an illustrator Victor Nolasco, and they will all be made available for download and use through the IYCF or infant and Young Child Feeding Image Bank on the USAID Advancing Nutrition website.

Lastly, if there's a resource that you have in mind that you believe should be on the bank and it isn't yet there, please feel free to send it to us at info@advancingnutrition.org so that we can add it. Now let's head over to the Resource Bank so that you can see these features in action.

Demonstration of the Resource Bank

Here's the home page of the Feeding and Disability Resource Bank. You'll see we've included some information here about the bank which includes dropdowns on what is available in the Resource Bank, why it's important to focus on children with feeding difficulties and disabilities, and who the intended user is. On the right-hand side here and on every page of the Resource Bank, one of the six images that we developed will appear here. If you scroll down further, you'll see those five sections that I mentioned before. You can click on them to read a bit more about the section and what resources they house or you can also click on 'read more' to access the landing page for that section. On the landing page, you'll find a more in-depth description of the section and the importance of its resources along with a list of the resources that fall under that section.

If a resource falls under two or more sections, they've been made available through each of the relevant landing pages. As I mentioned, this is one way in which you can identify resources to suit your needs. You can click on any of these resources to be taken to their Resource page. Now let's explore the second way to find resources on the bank.

If we go back to the home page and scroll down to the bottom, you'll find our search function. You can type in a keyword or you can select a technical area or population from the dropdowns. If you'd like more options or to narrow your search further, click on 'advanced search' to search by program area, age group, or Geographic Focus. For example, if I were looking for a resource that touches on breastfeeding, I could select breastfeeding under the technical area and, I could even specify ages 0 to 6 months. When I press 'apply', I see that there are three resources that fit my search criteria. I can then look at the resource type, the author, and the publication year and read this brief description to find out which resource I would like to access. Clicking on 'view resource' then brings me to the resource page where I'm given additional information on the resource, like Geographic Focus or context, and the language that the document is in. This is where you'll also find the link to the resource. And I can click on this link here to be taken to the Mates website to access it. From here, I could access other Resource Bank sections, conduct another search or, go back to the home page.

Lastly, as I mentioned we do have a feeding and disability terminology page which you can access by clicking on this button on the home page. Here you can reference an overview of relevant terminology including feeding, disability, and disability inclusion, and relevant international standards including the World Declaration on Nutrition, the United Nations Convention on the Rights of Persons with Disabilities, and the United Nations Convention on the Rights of the Child. Those are all the main features and pages of the Resource Bank that we wanted to highlight but, we encourage you all to explore the Bank yourselves to access its more than 80 resources.

Malia Uyehara

Thanks, everyone. So, I'll conclude by just mentioning again that if there are any materials that you feel are missing from the Resource Bank, please feel free to send them to info@advancingnutrition.org so that we can add them to the site. We do hope to make this a robust and useful resource for programmers globally, and apologies for the bandwidth issues with the video just now, but we have put the link to the website in the chat box. So please, feel free to put it up on your computer and take a look. Next up, we'd like to provide a deeper dive into some of the resources that are available on the bank. So, with that, I'd like to hand it over to

Rachel Lassman from Baby Ubuntu and Lauren Hughley from SPOON who will walk us through their experiences implementing two of the resources that are available on the bank. Rachel over to you.

Rachel Lassman

Thank you very much and thank you for this opportunity to present today. It's very humbling, coming after all that amazing information and so much echoes what has already been said. My name is Rachel Lassman. I'm the global program coordinator for Baby Ubuntu which is an early care and support program for young children with developmental disabilities. So, our vision is inclusive families and communities, supporting young children with developmental disabilities to thrive. And, over the past seven years we've reached 785 families across East Africa with the support of our implementation Partners in Uganda, Rwanda. As Christine mentioned in her speech, our program rests on the importance of identifying children early, and providing appropriate support at an early age. The program sits within the Ubuntu Hub within the London School of Hygiene and Tropical Medicine. Ubuntu means "Humanity towards others" or "I am because you are" and the aim of the Hub is to improve the lives of children with developmental disabilities and their families. The Hub contains three programs: Ubuntu for children two to eleven years old, Baby Ubuntu that I work with for the younger age group; zero to three, and Juntos which is specifically for children with congenital zika syndrome. And we have a community of practice accessible on the website as are all the programs to download for free from the Ubuntu Hub website.

So, our program, the Baby Ubuntu program includes eleven modules, and it's a participatory group peer support program. It's facilitated by a healthcare worker and an expert parent; a parent of a child with a developmental disability and we use the participatory approach in all of our sessions to engage the caregivers and the children in fun practical learning in every session. So, themes of the program include: promoting participation and inclusion, maximizing child development potential and quality of life, empowering caregivers through information sharing and peer support, and using that peer support to address issues such as stigma, which I think was really important in the scoping review around having a holistic program that supports families

sort of across the board. So, the topics that we cover include understanding disability and development, positioning, beading, play, communication, everyday activities, and stigma. As you can see by the images, as I said the groups are participatory, so when we're learning about feeding, we are all participating in feeding and the caregivers are feeding the children in the group. We learn about positioning when we're actively doing positioning like this lovely little girl sat here practicing her sitting in the Basin and when we're learning about play, we're role modeling and we're demonstrating, and we're all playing together.

So, the feeding module as Shona and Christine spoke about feeding, we know that children with disabilities are more likely to have malnutrition and to experience feeding difficulties. So, this module, this session sets out to understand the difficulties that children may have with eating and drinking and support parents in learning ways to feed their child safely. We touch on what a healthy nutritious diet is, and how to prevent malnutrition and we also look at supporting parents to introduce solid foods at the right time because often, children with developmental disabilities are not weaned at the correct time. Okay so, in terms of difficulties that children with developmental disabilities, may have with feeding, they may have trouble controlling their body and their head movements, and controlling their mouth and their lips, and their tongue movements; leading to difficulties with swallowing and chewing. They might have difficulty closing their mouth, meaning that food and drink will spill out, and they may cough or choke and aspirate while eating. They may have other problems relating to reflux and constipation, and as Shona and Christine and the scoping review talked about, it's incredibly frustrating when you're unable to feed your child in the way that you want to. Our first job as mothers is to feed our children and when we can't do that, it is incredibly stressful for us as parents.

So, I want to show you some of the very simple accessible things that are included in Baby Ubuntu in the feeding module. As Shona said, positioning is essential for safe feeding. So, if I were to ask you very quickly to look at picture number 4 that I've highlighted, which picture A or B shows the better feeding position? The quickest person can pop it into the chat if they want to. So, in terms of correct position, it's really important. Yeah B, it's really important that the child is upright, that their head and neck are supported well so that the food can go down the right way.

So, we teach how to do that with our caregiver sitting on chairs, sitting on the floor, and also exploring postural support seating as well.

Okay so, a safe spoon-feeding technique is also one of the things we focus on because even if you're addressing malnutrition through the correct supplements, if the feeding technique is poor and unsafe, the impact of that nutritional support won't be felt. And as it's been mentioned, getting the correct feeding utensils can be difficult. Even things as simple as a small soft plastic spoon which is the ideal for feeding an under three-year-old with a developmental disability. So, we teach in the sessions how to feed with the spoon safely because, a lot of our parents will be using large spoons or their hands and putting quite a large amount of food into their child's mouth, and the mother is often in charge of the process of feeding. If we change that dynamic, if we put the child in charge so that you bring the spoon straight, rest it on the child's top lip so the child can feel it and they are then able to take the food using either sucking, as they would as a reflex from breastfeeding or with their top lip, remove the food from the spoon. They are then in charge and they are then developing their own feeding skills which makes feeding a lot safer in the long term.

Food textures are also really important, particularly in this young age group. So, liquids often move very quickly and are hard to control which can lead to coughing, choking, and aspiration. So, we can make simple adaptations. The difference between water or milk versus yogurt or mango juice is in terms of the thickness and the ability of a child to control the swallow. And then when we come to weaning onto solid foods, chewing and swallowing harder or lumpy foods can be difficult for children with disabilities. So, the first foods that we need to feed children need to be soft smooth purees. And then we can work up to foods that are thicker as soon as a child is able to feed safely.

So, I just wanted to share some of our parents' voices. "My child doesn't look the way he looked before. He has improved in his health. He was so small and I didn't know how to feed him, but ever since I was taught, I practiced and now my child is healthy".

"I had given up work because no one could accept to stay with my child but because I learned to feed him and how to make him calm, I've been able to return to work and leave him with one of my family members."

Cat Kirk

Rachel sorry to interrupt quickly, but our Spanish interpreters are on the incorrect channel. Please if you're a Spanish interpreter, please move into the correct Spanish Channel. Thank you. Please go ahead, Rachel. Sorry for the interruption.

Rachel Lassman

I have a small case study here from our work in Rwanda of this young boy who was presented to the group with severe malnutrition and severe acute malnutrition. During the feeding module, his mum was trained on correct positioning and correct feeding techniques. Within the space of three months, he was stronger. He had better head control. He was still malnourished but he gained a kilo in a month which is more than he'd gained in a considerable amount of time, and he was able to take a bigger variety of foods. So, the Baby Ubuntu program is supported by a portfolio of evidence including implementation, economic and impact evaluations, and mixed method reviews of the program in Uganda and Rwanda. Our hope is, over the next 18 months, to start impact evaluation at a scale of the impact of the program. So, our research is still ongoing. In conclusion, I'd like to echo what has already been said; that malnutrition and feeding difficulties are common in children with developmental disabilities. And the treatment of malnutrition must be coupled with good positioning and safe feeding techniques, and to be impactful. I'd also like to echo the results from the scoping review that feeding is a really important component of the Baby Ubuntu program. But alone, it's not enough, and that what Baby Ubuntu offers is a holistic program that provides a safe and supportive environment for caregivers and their children to learn together, and improves caregiver skills and knowledge around disability, and challenge stigma.

We heard very strongly about the impact of the stress and the burden of caring for a child with a disability and the need for peer support as well as knowledge and skills. So, that is something that Baby Ubuntu has at heart; share the process of peer support and knowledge sharing. So, I would like to say thank you for the opportunity to present and pass it on to our next presenter. Thank you very much.

Lauren Hughey

Thank you, Rachel. Good morning and good afternoon to everyone. My name is Lauren Hughey. I'm a program officer with SPOON which is a U.S based organization, focused on improving nutrition and feeding for our children with disabilities and children outside of permanent family care. We work with caregivers, healthcare providers, and governments around the globe by providing training and tools, and by supporting data generation and advocacy efforts. We focus on the nutrition and feeding needs of children with disabilities and children outside of permanent family care because they are highly vulnerable to malnutrition and poor health outcomes as a consequence of the many barriers they face. Today, I wanted to share about SPOON's nutrition feeding resources and how they've been put into practice in our work in Zambia. SPOON has four resources within the Resource Bank that we want to highlight today.

First, there is a brief that describes SPOON's training package entitled: "SPOON's feeding and nutrition package for vulnerable children." The next is a link to SPOON's resource library that provides downloadable resources on nutrition, feeding best practices, and advocacy. Examples of downloadable resources include Identifying Feeding Difficulties in Infants and Petitioning for Meal Time. The third resource is a link to a free online introductory course that provides the learner with the foundation of knowledge on nutrition, feeding and healthy growth, and their intersection with disability. It also introduces you to SPOON's digital health app called Count Me In. This course includes five self-paced modules on these topics and may take you about one hour to complete. The last resource I wanted to highlight is a brief that describes SPOON's app Count Me In, which is a web-based digital app that I will go into more detail about later on in the presentation.

To address the gaps and needs of children's disabilities that have been highlighted in this webinar, SPOON designed an intervention model that utilizes the resources within the Feeding and Disability Resource Bank. SPOON combines training in adaptive nutrition care with a digital health tool which is called Count Me In, which then informs national and international advocacy with the goal of creating disability-inclusive health systems. In the next few slides, I'll provide a bit more detail about how our tools fit in with this intervention model. The foundation of our model

is training frontline professionals such as nutritionists, physiotherapists, and nurses. We work with our in-country partners to develop training plans which may include in-person classroom training, as well as distance learning that includes online training modules such as the introductory course linked within the Feeding and Disability Resource Bank. The training can be modified to be appropriate for program staff training trainers, and frontline professionals.

The pieces of training are facilitated by SPOON's technical experts to ensure fidelity to our intervention model, ensure the do-no-harm principles are adhered to, and tools and techniques are being used accurately. This training equips our partners and frontline professionals to integrate our app, Count Me In, into their system of care. Count Me In is a web-based digital health app that supports these frontline professionals to monitor children's growth, anemia, and developmental feeding skills, and then recommends individualized interventions when problems within these domains are identified. And by providing real-time data and reporting, Count Me In offers insight to frontline professionals, program managers, and key decision-makers.

We and our partners use the data generated from Count Me In to advocate for inclusive policies, investments, and actions that improve nutrition and feeding for children. Through our advocacy, we aim for policies to clearly reflect that children with disabilities are a priority group and that investments and changes are needed but also there's accountability for the resources to be spent in a way that advances inclusion, rather than it being seen as an extra. We also advocate for support for the health workforce so that they have the skills, training, and resources they need to offer appropriate, accessible, inclusive services to children's disabilities and their families.

Lastly, we aim to provide data and advocate for an increase in data so that it is available to be used to guide decisions. An example of how a program can work to strengthen systems at multiple levels is the Kusamala+ program in Zambia. Kusamala+ is implemented by the Catholic Medical Mission board Zambia in partnership with SPOON as well as Saint Catherine's University, JHR Foundation, CSO Sun, and our technical Advisory Group. The project aims to meet the needs of children's disabilities by creating a Continuum of Care between the community and the Clinic. This integrated programming is currently implemented in two hospitals and one clinic in the capital Lusaka. SPOON's nutrition feeding interventions are integrated within the larger Kusamala+ programming which addresses other domains of nurturing care. We have integrated

nutrition and feeding interventions into Kusamala+ by training frontline professionals which include physiotherapists and nutritionists at the local clinics in nutrition, feeding best practices, and also equipping community health workers with the knowledge and tools to reinforce those nutrition-feeding best practices within the family-based setting. The trained frontline professionals within the nutrition and physiotherapy clinics use Count Me In for assessments and follow-up of children and they also use it as a decision support tool to help them coach families and caregivers on how to manage feeding difficulties. The Count Me In data generated through program activities informs our advocacy work. Our aim is for disability-inclusive nutrition to be reflected in the National nutrition system through policies, programs, and budgets and for children to have access to mainstream and targeted support they need. These components contribute to the continual care between the community, clinic and policy levels.

When a child with a disability receives care and services from one of the partnered Health Facilities, they are enrolled into the Kusamala+ program. Trained frontline professionals within the nutrition and physiotherapy departments then use Count Me In to assess the children's nutrition feeding needs and follow child-specific care plans based on their identified needs. The child is then assigned a Community Health worker called a community caregiver who then supports the family to utilize best care practices and integrate Count Me In's recommendations. The Count Me In data generated through program activity then informs our national advocacy work.

And I know we are tight for time but as an example, I wanted to highlight the needs that Count Me In has identified through our work within Kusamala+. Data from the Kusamala+ program shows that 90 percent of children assessed by Count Me In have one more indicator of malnutrition within the three clinics we work within, and additionally, Count Me In's reporting functions also allow us to track feeding indicators. The preliminary findings indicate that almost 31 percent of these children are coughing or choking during meal times, 5.5 percent are exposed to prolonged use of infant bottles and almost a little over 56 percent are safely positioned during Meal Time. Count Me In has the capability of reporting longitudinal data and trends over time which allows SPOON, our partners, and local stakeholders to learn about the prevalence and change over time and then make informed programmatic decisions. SPOON and our partners

also use this data and program examples to fuel our advocacy work which includes a Technical Advisory Group, policy resources such as briefs, media outreach, and direct outreach to decision-makers.

Through these actions SPOON and our partners advocate for inclusive policies, investments, and actions that improve nutrition feeding for children with disabilities. And, if you'd like to learn more about these components of the intervention model, please visit USAID's Feeding and Disability Resource Bank or reach out to me directly. Thank you.

Cat Kirk

Wonderful, thank you Lauren and Rachel for highlighting two of the great resources that you can find within the Resource Bank. I know we are running a little bit behind on time and there's been a tremendous number of great questions coming up in the Q & A box that we've been trying to answer as we go. What I'd like to do is pull out just a few that we can discuss live and ask all of our panelists to go ahead and turn on their videos. I have a few questions I will field to the group and I welcome everyone to respond. One question that I think is relevant for all of our panelists is that, following the scoping review, Alyssa you mentioned that one of the recommendations is to strengthen systems and one of our attendees asked if they could share more specific examples of areas that need to be strengthened and how? So, I might ask Alyssa if you want to go ahead and start on that but I welcome others to chime in because all of the students work in Ubuntu, and Shona and others talked about this as well. So first over to you Alyssa.

Alyssa Klein

Thanks, Cat. Yeah, I mean that's a very broad question. I feel like we probably could have spent the entire hour just talking about that you know. I think when we say systems it's also pretty general. The presentation today focused a lot on health systems and I think you know we talked a little bit about how to strengthen health worker competencies. Also, we didn't even get into it today but strengthening pre-service training and support and better integrating feeding difficulties and disability into everything from pre-service to in-service, training for health workers, strengthening community health workers' knowledge and skills as well around identification and

support. Once children are identified, you know, we also just found a great need in many countries within health systems for more specialized services. A lot of countries didn't have sufficient speech and language pathologists, physical therapists, occupational therapists; even in large cities let alone in rural areas where people might be living and struggling to access any services at all. It's like so broad but we also looked a little bit at food systems. There was a lack of appropriate or modifiable food in a lot of markets in a lot of countries. Again, it's the same challenge even within cities. There are often not the right kinds of foods year-round; you know even when you look at things like RUTF for refeeding often those are not a consistency that children with feeding difficulties can even consume. So, the only solution ends up being when your child becomes malnourished enough is inpatient care with tubes, and then when children are sent home, families are just saying; we can't, we don't have the right foods, the right blenders, the right seating. I mean, it gets so broad you know. We looked at education systems. Often, these kids are not in school at all and if they are in school, they're not being fed during the school day which we know for all kids that is a problem. If you're not eating during the day, you're not going to be learning appropriately; but it's really challenging for schools to be able to support these children. So, anyway I'll stop there because I feel like we could go system by system and it's just such a challenge that we found broadly throughout. So, I'll see if anybody else has anything to add.

Shona McDonald

Yeah, I suppose I could add to some of that. It's really important that parents are the knowledge holders of their child's nutrition. I think having to be dependent on health systems or social service systems really disempowers the family to take control and make decisions themselves. And we found through our work in Shonaquip that empowering parents with the skills themselves and upskilling them not just in the importance of the positioning, but actually the content of the food and how to physically engage and feed, and how to include the child in the family meal so that the child is ultimately part of that feeding circle. That is so important in social development.

I want to highlight here how we as a family have really been affected by the fact that socially, it isn't considered acceptable to feed a child with a feeding problem in public. And many times, we

were asked to leave restaurants because other people were finding it uncomfortable. I think if we look at nutrition and feeding and inclusion as a whole around society and welcoming diversity in our communities, feeding has to become an acceptable thing in the community. It cannot be a separate activity that happens in private in a back room. And, in doing that it totally disenfranchises a child from the community in which they have to flourish. So, through our work in Shonaquip with the Parent Champion Trust, there's a big focus on ensuring that policies and systems develop across all elements and are not just housed within health as a therapeutic intervention. But yes, therapeutic interventions inform better practice and better skills for parents.

Cat Kirk

Thank you so much Shona and Alyssa for those comments. I think we certainly could continue to talk about this but with about six minutes remaining I want to shift over to our closing remarks. Please feel free to continue entering questions in the Q & A. We'll stay on a couple of minutes and try and respond to those, but I will hand it over now first to Fazwa Maseva who is the executive director or deputy director of the disability HIV and AIDS Trust in Zimbabwe and one of our technical Advisory Group members.

Fazwa Maseva

Good day colleagues, good day everyone around the world. My name is Fazwa Maseva. I'm from Disability Champions Trust in Zimbabwe. I am one of the TAG members which is the Technical Advisory Group on the Advancing Nutrition project which is a USAID project. I am honored to have this opportunity to work with the rest of the team on this one-of-a-kind project. Firstly, I would like to say in terms of policy formulation and also in terms of the formulation of strategic documents, this is a wonderful experience for the government and also for advocates and activists to actually use this Resource Bank which is very much inclusive to formulate policies and also, on the implementation of our policies. It's a great resource in terms of formulation of National Strategic Documents that relate to nutrition and also being inclusive of children with feeding difficulties.

Secondly, I would like to say in terms of the engagement of CSOs which are Civil Society Organizations and also government departments, it's also a good tool to reflect on as it possesses a lot of great initiatives and great ideas. As we look back on the Resource Bank, they are the Ubuntu approach, the sports approach. Those approaches are great to reflect on as we go forward. Lastly, I would like to say in terms of parents and also caregivers of children with disabilities, it is also a great tool to reflect and get ideas to use a Resource Bank in terms of addressing the needs of children with feeding difficulties. Now it's left for us as advocates, as governments, and as nations to use these platforms. However, the job still lies in terms of disseminating the Resource Bank from the highest platforms to the lowest platforms; the grassroots. I repeat, this Resource Bank is one of its kind and has to be disseminated around the world. Thank you.

Cat Kirk

Thank you! And finally, over to Daniela Brignon who is the founder and Executive Director of Zona de Santidos and Zona de Comunidad.

Daniela Brignon

Speaks spanish

Cat Kirk

Thank you so much Daniela and thank you all for joining us today to discuss this important topic on how we can better support optimal nutrition for children with feeding difficulties and disabilities. I especially want to thank all of our presenters who share the latest evidence, practical tools, as well as personal journeys that can help us all strive for better and more inclusive services. Please do visit USAID's Advancing Nutrition Resource to access the recording from today, but all of the resources and more that were described in this webinar. Thank you again and we wish you all a great rest of your day.



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