ADVOCACY BRIEF

MAINSTREAMING DISABILITY IN NUTRITION PROGRAMS

BACKGROUND

Nutrition is fundamental for all children to grow, develop, and thrive.[i] Poor nutrition, especially in the first 1,000 days, can cause irreversible delays, and approximately 45% of all child deaths are related to undernutrition.[ii] Children with disabilities are at high risk of malnutrition. Early child development, including nutrition, supports long-term physical and cognitive development and can be particularly important for children with disabilities.[iii]

The Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child, as well as the Zambia Persons with Disability Act No. 6 of 2012, affirm the rights of children with disabilities to good health and health care. Including children with disabilities is also essential to unlock the benefits and return on investment of good nutrition on a national level. This brief explores the need and proposes solutions to mainstream disability into nutrition programs.

NUTRITION AND DISABILITY

Globally, more than 290 million children and adolescents have disabilities,[iv] and the Zambia National Disability Survey of 2015 estimated that 4.4% of children aged 2-17 in Zambia have a disability.[v] Disabilities in children can include physical, developmental, intellectual and other impairments. Social and environmental barriers often prevent children with disabilities from equal participation in their communities and society.[vi] Children with disabilities are three times as likely to be malnourished as other children, and twice as likely to die from malnutrition during childhood.[vii] Malnutrition can also lead to or worsen disabilities, while good nutrition can support children with disabilities to grow and thrive. Up to 85 percent of children with developmental disabilities experience feeding difficulties, such as difficulty chewing or swallowing.[viii] These difficulties, if not addressed, can lead to respiratory infections and undernutrition.

Children with disabilities are often excluded from public health programs, and typically have less access to nutrition and health services compared to children without disabilities.[ix] The National Disability Survey reported multiple gaps in accessing health and social services.[x] The Strategic Plan 2017-2021 for the Zambia Agency for Persons with Disabilities names limited health and social services, trained professionals, and equipment as key barriers to improving the health of people with disabilities in Zambia.[xi] Malnutrition and a lack of community-based services can also be driving factors for children with disabilities to be placed in institutional care, which has a known negative impact on children's growth and development.[xii]

Families of children with disabilities are also at risk of social isolation, economic burdens, and biases from healthcare or other service providers.[xiii] External stressors can increase these risks. For example, a rapid analysis of the impact of the COVID-19 pandemic on families of children with disabilities in Zambia found that 79% of families reported eating less or consuming food with lower nutritional value due to COVID-19, and 33% reported a loss of access to health services for their child.[xiv]

RATES OF MALNUTRITION AMONG CHILDREN WITH DISABILITIES

Data from the *Improving Nutrition and Safe Feeding Practices* project show high rates of malnutrition among children with disabilities in Zambia. An analysis of baseline data on 401 children with disabilities in communities revealed high rates of malnutrition. Children with disabilities showed high rates of underweight (63.9%), stunting (70%), wasting (27%), anemia (57%), and risk of feeding difficulty (66.3%).

A large proportion of children in residential care in Zambia are malnourished, with children with disabilities in residential care at especially high risk. Baseline data on 401 children in 22 residential care facilities in Lusaka, Southern, Central, and Copperbelt provinces showed high rates of underweight (22.4%), stunting (28%), wasting (7.1%), and anemia (58.3%) among all children, with children with disabilities and children under two years of age at increased risk. For example, 69.2% of children with cerebral palsy in residential care were underweight, and 71.4% were stunted. Risk for feeding difficulties was found in 41.4% of children with disabilities and 26.0% of children without disabilities.

The *Improving Nutrition and Safe Feeding Practices* project, led by Access to Health Zambia and SPOON, worked to improve nutrition and feeding practices for children with disabilities and those currently in, or leaving residential care. The project trained service providers at 13 facilities (residential care facilities, community-based rehabilitation centers, schools, a rural health clinic and one hospital) in growth, feeding, and anemia. Staff from ministries of Health and Community Development and Social Services were trained to support service providers to use *Count Me In*, a web application, to detect and respond to malnutrition and track children's growth over time. Preliminary data show improvements in anemia, wasting, and safe positioning during feeding for children with disabilities. This program now continues through Access to Health Zambia's Kusamala 3 initiative.

POLICY ENVIRONMENT

Currently, national policies provide limited guidance on disability inclusion in nutrition programs and services. Disability-inclusive nutrition has an important role to play to attain Zambia's policy objectives, including the goals of '*optimal health and nutrition for all*' as stated in the National Food and Nutrition Policy of 2006, the vision of '*Persons with disabilities enjoying equal opportunities that are fundamental for living and development by 2030*' as stated in the National Disability Policy, and the 8th National Development Plan objective of '*Socio-Economic Transformation for Improved Livelihoods*'.

While there is a high priority placed on equity and reaching vulnerable groups, no policy provides a strong mandate to prioritize the needs of children with disabilities or provides sufficient practical guidance to ensure nutrition services are available and appropriate for children with disabilities and their families. The lack of specific rationale and recommendations make it difficult to advance inclusive practices at the scale that will be needed to meet these goals. For example, policies that do mention disability often do not provide a definition or a clear link to Zambia's national nutrition goals, and there is no clear measurement or accountability framework for disability inclusion in child nutrition services. Policies reviewed for this brief were: the National Food and Nutrition Policy 2006, National Health Policy 2012, National School Health and Nutrition Policy 2006, National Policy on Disability 2012, 8th National Development Plan 2022-2026, and the Food and Nutrition Act no. 3 of 2020.

RECOMMENDATIONS TO IMPROVE FEEDING AND NUTRITION FOR CHILDREN WITH DISABILITIES

Promote safe feeding and nutrition practices for children with disabilities: Simple techniques such as good positioning, feeding children appropriate food textures to match their skill levels can allow families, caregivers, and service providers to ensure that children are positioned to eat safely and fed appropriate food in a nurturing environment. In addition, children with disabilities may be helped to develop independent feeding skills over time.

Like all children, children with disabilities need a diverse, nutrient-dense diet to develop and thrive. Children with disabilities and children with special health care needs often have different or increased dietary needs.[xv] Healthy diets do not necessarily require new or expensive foods. It is important that families are encouraged to incorporate nutritious foods that may be available in their communities but not typically eaten by the family or served to children. This can be done by, for example, health workers.

Support health workers to provide disability-inclusive nutrition services: Children with disabilities have the same right to health as all children, including access to mainstream services provided to all children, as well as any targeted services they may need. Health workers may need to adapt their approach to provide nutrition services that meet the needs of children with disabilities. For example, children who are unable to stand independently require consistent growth monitoring as all children do, but may need adapted measurement techniques.[xvi] Children's needs may vary greatly based on multiple individual factors, and adaptations should be based on a thorough assessment.

Including nutrition and feeding for children with disabilities in curricula for nutritionists, physiotherapists, and other related professionals will prepare the workforce to mainstream disability into existing services. Digital technologies have the potential to support this type of training,[xvii] particularly when disability is integrated into existing tools, such as growth charts and counseling aids. Health workers should have pre- or in-service training in disability-inclusive nutrition practices, including basic skills and knowledge to support families, deliver basic services such as growth monitoring and nutrition counseling, and refer when needed. This should link to clear referral pathways and access to indicated support when needed.

Build inclusive nutrition programs: Many of the nutritional issues facing vulnerable children have existing solutions that are simply not reaching them. Currently, existing nutrition projects and services are often inaccessible to children with disabilities, or are not prepared to meet their needs. Including children with disabilities in nutrition programs must include policy guidance, training, and program integration to respond to children's needs.

Nutrition program leaders must take deliberate steps to ensure that programs are not only accessible to children with disabilities, but also provide appropriate services. This will involve dedicated outreach to children with disabilities and their families, steps to remove barriers to participation, and efforts to ensure providers have the training and tools they need to serve children with disabilities in an effective

and dignified way. Programs serving children with disabilities, such as early identification and intervention, rehabilitation, and social protection, can help to meet this need by also incorporating key nutrition messages and activities in outreach and training efforts.

Prioritize disability inclusion in policies, guidance, and budgets: Nutrition policies should lay out a clear vision for disability-inclusive nutrition. Policy makers should ensure that relevant policies, strategies, and legal frameworks specifically name children with disabilities as a priority group; include specific steps, targets and accountability measures to ensure their needs are met; and are reflected in relevant budgets. These should be supported with additional guidelines where needed, for example by amending infant and child nutrition guidelines to include guidance related to the care of children with disabilities. These changes should be developed in partnership with persons with disabilities, organizations of persons with disabilities, disability rights groups, and relevant government agencies.

Improve data and accountability: There are significant gaps in research and data on nutrition issues for children with disabilities, as well as best practices to optimize their nutrition.[vi] This area should be prioritized for future research to guide decision-making. Research and data collection activities should seek to understand: 1) the nutrition-related priorities and needs of children with disabilities, including those outside family care; 2) the extent to which existing nutrition programs are reaching children with disabilities; and 3) effective practices to rapidly scale up disability-inclusive nutrition practices.

The nutrition sector must set specific targets for disability inclusion. Monitoring and accountability structures should also include disability- disaggregated data. Population-level surveys can fill this gap by collecting information about disabilities in children and disaggregating data by disability status. Digital tools can improve accuracy and availability of data, often allowing decision makers to access data in real time.

Key Actions

- Support families and caregivers to implement safe, responsive nutrition and feeding practices
- Provide training, resources, and referral pathways for health workers to deliver inclusive services
- Raise awareness among stakeholders on the need for improved nutrition for children with disabilities
- Expand nutrition programs to deliberately include children with disabilities and provide appropriate care
- Update policies, guidelines, and budgets to prioritize children with disabilities
- Incorporate disability into nutrition and feeding data collection and use

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