

# Improving Nutrition among Children with Feeding Difficulties and Disabilities: Call to Action for Policymakers

## INTRODUCTION

In the spring of 2021, USAID Advancing Nutrition conducted a scoping review of programs supporting nutritional care of children with feeding difficulties and disabilities.

**The review found insufficient policies, programs, and evidence to support children with feeding difficulties and disabilities, as well as their families.**

Feeding difficulties can negatively impact children's growth and development, quality of life for themselves and their families, and limit children's opportunities for social and familial connections during shared mealtimes. A disproportionate burden of these negative effects is experienced among children with disabilities and their families.

Policies across health, social welfare, agriculture, education, and other sectors **must promote disability inclusion and targeted approaches** to address nutrition among children with feeding difficulties and disabilities to—

- strengthen systems
- provide adequate support to children and families
- generate evidence on best practices.

## STATUS OF FEEDING DIFFICULTIES AND NUTRITION

The prevalence of feeding difficulties ranges from 25 to 45 percent in children without disabilities to 33 to 80 percent in children with disabilities,<sup>1</sup> yet the role of feeding difficulties in young children's nutrition is often overlooked. One in eight people worldwide—one billion people—are persons with disabilities.<sup>2</sup> Eighty percent live in low- and middle-income countries (LMICs), and nearly 100 million are children.<sup>3,4</sup>



There is growing risk of increasing malnutrition due to negative impacts of COVID-19, climate change, and political insecurity.<sup>5</sup> Malnutrition can cause disability in the short and long term, while disability can also lead to malnutrition.<sup>6</sup> Children with disabilities are more likely to be malnourished and to die from malnutrition.<sup>7</sup> Children with disabilities living in LMICs may be more at risk of malnutrition due to the failure of public health systems to provide nutritional support for children with feeding difficulties.<sup>8</sup> This speaks to a perpetual cycle of malnutrition, disability, and poverty, which have large societal and economic costs.



Source: Kuper and Heydt 2019

## KEY MESSAGES

- Failing to address feeding difficulties can negatively affect growth and development and contribute to high stress on families.
- A disproportionate burden of feeding difficulties and the associated consequences are experienced by children with disabilities and their families.
- Policies across sectors must promote disability inclusion and targeted approaches to address nutrition among children with feeding difficulties and disabilities in order to strengthen systems, provide adequate support to families, and generate evidence on best practices.

### TYPES OF FEEDING DIFFICULTIES

- Difficulty Coordinating Suck/Swallow
- Poor Attachment
- Poor Suction
- Dysphagia (difficulty swallowing)
- Oral-Motor Impairments
- Picky Eating
- Restricted Food Intake
- Sensory Processing
- Tongue Tie

### GLOBAL PREVALENCE OF FEEDING DIFFICULTIES

**25–45%** Children **without** disabilities

**33–80%** Children **with** disabilities







Lefton-Greif and Arvedson 2007

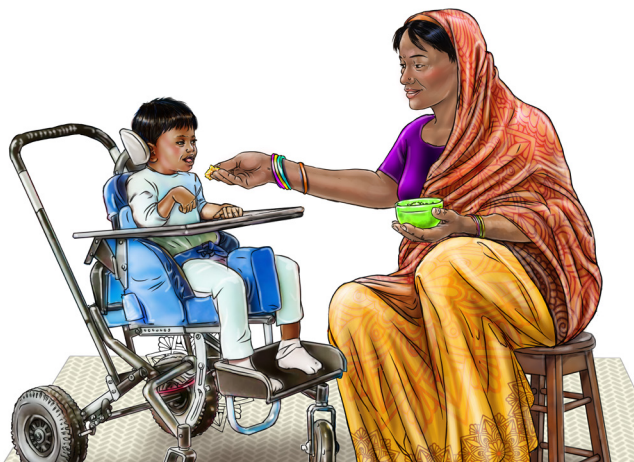
## APPROACH AND RESULTS OF THE SCOPING REVIEW

We reviewed peer-reviewed and gray literature and interviewed key informants. The review found gaps in services and systems to support children with feeding difficulties, whether or not they have a disability (table 1). While some resources and promising approaches exist, they are not standardized or universally used, staff are not trained to use them, and there is insufficient funding to implement them.

Challenges in identifying feeding difficulties and disabilities, a lack of understanding of the link between disabilities and feeding, and weak or nonexistent referral or specialized services put these children at risk of malnutrition. Additionally, families face challenges providing the care they need, including coping with high care demands, accessing support, obtaining appropriate foods, and managing stigma.

**Table 1. Gaps in Services and Systems to Support Children with Feeding Difficulties**

SECTOR	GAP
 <b>Governance</b>	<ul style="list-style-type: none"> <li>• Lack of inclusive policies and programs</li> <li>• Nonprofit organizations (NGOs)/civil society organizations fund and provide disability services instead of governments</li> </ul>
 <b>Information systems</b>	<ul style="list-style-type: none"> <li>• Disability-disaggregated data not available in nutrition and health services</li> </ul>
 <b>Financing</b>	<ul style="list-style-type: none"> <li>• Inadequate funding for disability-specific programming</li> </ul>
 <b>Service delivery</b>	<ul style="list-style-type: none"> <li>• Children with disabilities, many of whom have feeding difficulties, may not be included in routine nutrition services</li> <li>• Missed opportunities for early identification and intervention for feeding and nutrition and lack of follow-up structures</li> <li>• Where they exist, rehabilitation services are often of poor quality and do not address feeding challenges</li> <li>• Lack of guidelines and tools to address feeding difficulties and malnutrition among children with disabilities</li> </ul>
 <b>Medicines and technology</b>	<ul style="list-style-type: none"> <li>• Limited availability of assistive products to support feeding in the health system as they are not prioritized by governments or locally produced</li> </ul>
 <b>Workforce</b>	<ul style="list-style-type: none"> <li>• Limited skills and in-service training opportunities related to feeding difficulties or supporting children with disabilities among primary health care workers</li> <li>• Lack of specialized workforce and job pipelines for rehabilitation trainees</li> <li>• Stigma and attitudinal barriers among service providers</li> </ul>



### WHO ARE CHILDREN WITH DISABILITIES?

According to the UN **Convention on the Rights of Persons with Disabilities** (CRPD), children with disabilities include those with long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers (such as negative attitudes, inaccessible transportation and infrastructure, limited social support, poor health systems, lack of access to assistive technology, inaccessible information and communications, discriminatory legislation and policies, etc.), may hinder their full and effective participation in society on an equal basis with others.

### SOCIETAL COST OF INACTION



Estimates suggest that excluding persons with disabilities costs countries between 3 and 7 percent of their Gross Domestic Product (GDP), meaning that they are not maximizing their citizens' potential.<sup>9</sup> This reduces innovation and entrepreneurship, as well as civic engagement. Social costs of exclusion include stigma and discrimination, dependency on others, increased pressure on caregivers and public systems, and residual health impacts that are associated with higher levels of poverty.<sup>10</sup>

Policymakers play a key role in supporting children with feeding difficulties and disabilities and their families. The CRPD reminds states to “take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.”<sup>11</sup> Like all children, children with feeding difficulties and disabilities need adequate nutrition, good health, responsive care, opportunities for early learning, and safety and security to enjoy their fundamental human rights and reach their potential.

### RECOMMENDATIONS

Policymakers from health, social welfare, agriculture, education, and other sectors are well placed to support children with feeding difficulties and their families. They can take a variety of actions, including but not limited to the following:

- **Require health professional education institutions to include competencies to identify and support children with feeding difficulties and disabilities**, and their families, in their curricula and in-service training opportunities.
- **Revise guidelines and care protocols** related to nutrition and health so that they include appropriate guidance to identify and support children with feeding difficulties and disabilities.
- **Leverage organizations of persons with disabilities and civil society** to establish peer-to-peer support groups for families with children with feeding difficulties and disabilities.
- **Allocate budget for the provision of assistive products** (such as supportive seating, adaptive feeding utensils, blenders, etc), including opportunities for local manufacturing through public-private partnerships.
- **Provide standardized guidance** on caring for children with feeding difficulties and disabilities in services for young children and their families, such as food distribution or early childhood development programs.
- **Ensure inclusion in eligibility criteria for social protection schemes and food supplementation programs** for children with feeding difficulties and disabilities.
- **Ensure that disability-inclusive nutrition programs are included in government- and donor-funded guidance documents**, program descriptions, or other nutrition-related resources.
- **Include functioning assessments of children in national surveys and disaggregate data** by disability in routine information systems for health, nutrition, social protection, and other sectors.
- **Governments should establish and strengthen community-based disability inclusion systems.**
- **Include monitoring of children's development in health services to support early intervention** for children with feeding difficulties and disabilities.

## CONCLUSION

Policymakers can strengthen systems to improve identification of and service provision for children with feeding difficulties and disabilities, as well as their families. This could include creating well-funded policies and programs to identify children who require support; providing support to manage feeding difficulties; and including and supporting children with disabilities in nutrition services, programs, and

policies to help them thrive. Policymakers can also help to improve the direct support that families receive to address determinants that affect nutrition outcomes. This would include scaling up the limited support that caregivers currently receive. Additionally, policymakers can ensure that services are available, accessible, appropriate, affordable, high-quality, and inclusive for all children who need them.

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## NOTES

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|----------------------------------|----------------------------------|------------------------|
| 1 Lefton-Greif and Arvedson 2007 | 5 FAO, UNICEF, WFP, and WHO 2022 | 9 Kanady, Shane. n.d.  |
| 2 WHO and World Bank 2011        | 6 Hume-Nixon and Kuper 2018      | 10 Kanady, Shane. n.d. |
| 3 WHO and World Bank 2011        | 7 Kuper and Heydt 2019           | 11 UNGA 2007           |
| 4 Kuper and Heydt 2019           | 8 Hume-Nixon and Kuper 2018      |                        |



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