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Inclusive nutrition for children and adults with disabilities



The Global Burden of Disease Study¹ notes a substantial decrease in long-established global health threats such as communicable diseases and malnutrition, while underscoring the rise in non-communicable diseases and years lived with potentially disabling illnesses and injuries. One important but largely overlooked specialty where these two trends intersect is that of nutrition and disability. Roughly 1 billion people are undernourished² and about 1 billion have a disability.³ Both problems can severely limit life opportunities; both are global development priorities; and sustainable progress for both is dependent on governments and international organisations addressing underlying poverty, equity, and human-rights issues.

The right to food—an important determinant of nutritional status—is recognised in the Universal Declaration of Human Rights (Article 25)⁴ and its General Comment on the right to food, which specifically mentions the rights of people with disabilities to physical access to adequate food.⁵ The right to health care, education, and social participation are documented in the 2006 UN Convention on the Rights of Persons with Disabilities,⁶ which is now ratified by 133 countries. However, nutrition and disability are rarely linked. Whereas improved nutrition to prevent prenatal disability or disability in childhood receives attention, the nutritional needs of children and adults with disabilities are scarcely addressed.³ Reasons for this unequal attention include the fact that children and adults with disabilities scarcely have the same level of access to health and social services; health and development professionals are often unaware of, do not plan for, and are unable to communicate effectively with people with disabilities;⁴⁻⁸ and general health campaigns (eg, for HIV/AIDS and malaria) often fail to consider the special needs of people with disabilities.⁸ Deliberate omission is likewise an issue; for example, exclusion of children and adults with disabilities from nutritional outreach efforts on the basis of the incorrect belief that preserving of the life of a child or adult with a disability is of lower priority than preserving of the life of someone who is not disabled.⁷ In fact, people with disabilities are equally entitled to all resources needed to preserve health and life.⁶

Maternal undernutrition can lead to child impairments—eg, infants whose mothers are deficient

in folic acid might have neural tube disorders;¹⁰ maternal iodine deficiency can result in intellectual, motor, and hearing problems in infants;¹¹⁻¹⁵ and undernutrition, which causes poor or distorted pelvic growth, is associated with increased risk of obstructed labour, a substantial cause of perinatal injury and subsequent disability.¹⁴ Undernutrition in children can also cause lifelong impairments: vitamin A deficiency can cause blindness,¹⁶ and reduced resistance to infection secondary to macronutrient and micronutrient deficiencies can increase the risks of disorders such as malaria and meningitis, complications of which are leading causes of neurodisability worldwide.¹⁵ Access to nutritious food for pregnant women with disabilities is consistently overlooked in both the nutrition and disability sectors, placing these women and their children at increased risk.

Although issues of undernutrition are often framed in terms of disability prevention, good nutrition is also vital to those who already live with a disability. Infants and children with disabilities suffer the same ill-effects of undernutrition as those without: poorer health outcomes; missing or delayed developmental milestones; avoidable secondary impairments; and, in extreme circumstances, premature death. In some cases, undernutrition is a direct consequence of specific physical anomalies or medical problems (eg, infants with a cleft palate might not be able to breastfeed effectively; children with cystic fibrosis cannot effectively absorb or use the nutrients they do get). In Bulgaria, the London-based non-governmental organisation Lumos reported substantial malnutrition in 250 institutionalised children with disabilities. The issue was not a shortage of food, but a shortage of time—insufficient staffing and competing priorities meant that caretakers were unable to devote more than 2 min per meal per child to help feed children with disabilities with eating and drinking difficulties.¹⁷

Poor knowledge among caretakers of how to work with disability-related disorders could also be an issue. For example, poor knowledge of how to correctly position a child with severe cerebral palsy could lead to inadequate feeding; at worst, these efforts can cause aspiration and even death. Social and cultural beliefs and practices can lead to or exacerbate an already

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fragile nutritional state. For example, the choice not to breastfeed neonates with visible disabilities is a form of traditional infanticide practised in some communities.¹⁸ In other communities, stigma and discrimination mean that a child or adult with a disability is denied food or offered less food than other household members.¹⁸ Some disabilities might increase nutritional needs (eg, nutritional supplementation is associated with reduced pressure sores after stroke).¹⁹

Little research has been done of the effects of poor nutrition on children with pre-existing disabilities in the context of poverty and malnutrition; individuals often assume that these children do not grow and thrive because of their disability. However, in some cases, what is assumed to be disability-associated ill-health and wasting might in fact be connected with feeding problems or the withholding of adequate nutrition, particularly in households and alternative care settings with scarce resources when it is believed a child with a disability will not live to adulthood.

In view of the strong links between nutrition, disability, poverty and human rights, awareness of and stronger links between nutrition and disability issues is urgently needed at all levels. A so-called twin track approach is needed whereby nutrition services include (mainstream) disability and also provide disability-specific services, while disability programmes ensure that specific nutrition-focused support is provided when needed.²⁰ Finally, more and better data are needed. The forthcoming International Classification of Diseases 11th revision is a unique and timely opportunity to address present gaps. Stronger evidence and understanding of the interactions and associations between nutrition and disability is key to unlock future policymaking and funding in this too often neglected intersection of crucial global health concerns.

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