Introduction

Malnutrition and disability are both major global health problems. There are an estimated one billion people worldwide living with a disability of whom some 93 million are children aged under 14 years. 1,2 Worldwide, almost one billion people are malnourished. 3 Malnutrition remains a major cause of child mortality, with the latest estimates suggesting that under-nutrition causes 3.1 million child deaths annually; 45% of all child deaths. 4 Over-nutrition is also a problem: overweight and obesity being key factors underlying the growing epidemic of non-communicable disease. 5

At present, although malnutrition 6 and disability are rarely linked in policy or programming, there is increasing awareness of the interrelationships between the two. 7 Malnutrition can lead to disability. Disability can also lead to malnutrition. This paper will focus mainly on under-nutrition causing disability and disability causing or contributing to under-nutrition – though it is important to also recognise that over-nutrition-associated chronic disease can also result in disabilities, through conditions such as stroke.

Both nutrition and disability matter for many reasons, not least because they are both key human rights issues. The right to food, an important determinant of nutritional status, is articulated in the Universal Declaration of Human Rights (Article 25) 8 and the General Comment on the Right to Food, which specifically mentions the rights of people with disabilities to have physical access to adequate food. 9 The right to healthcare, education and...

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5 Wagner KH, Brath H. A global view on the development of non communicable diseases. Preventive medicine 2012; 54 Suppl: S38-41
6 In this paper malnutrition is defined according to WFP as “a state in which the physical function of an individual is impaired to the point where he or she can no longer maintain natural bodily capacities”. Though often used to mean just under-nutrition, strictly speaking, it incorporates both under- and over-weight (http://www.wfp.org/hunger/glossary). Undernutrition is defined by UNICEF as “the outcome of insufficient food intake (hunger)”. Under-nutrition includes being underweight for one’s age, too short for one’s age (stunted), dangerously thin (wasted), and deficient in vitamins and minerals (micronutrient malnutrition)” http://www.unicef.org/progressthroughchildren/2006n4/index_undernutrition.html
8 UN (1948) Universal Declaration of Human Rights http://www.ohchr.org/EN/UDHR/Pages/Language.aspx?LangId=eng
social participation are articulated in the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD)\textsuperscript{10} now ratified by 134 countries.\textsuperscript{11}

There is increasing knowledge about optimal nutrition-related practices and implementation of often low cost interventions to tackle issues of malnutrition in children. It is essential that governments, international actors and service providers consider and include the needs of children with disabilities in these efforts to ensure that children with disabilities have equitable access to nutrition in order to allow them to grow and thrive.

**The relationship between disability and nutrition**

Malnutrition and disability are closely interrelated and have a number of points of convergence. Commonly this relationship is framed as a lack of appropriate nutrition in both pregnant and breastfeeding mothers and young children leading to impairment. Therefore most international efforts focus on improving maternal and child nutrition to prevent or mitigate disability.

However the relationship is more nuanced and can be considered as having two-way interactions. Figure 1 illustrates the inter-relationship between malnutrition and disability throughout the life-cycle, including pregnancy and childhood.\textsuperscript{12} The model highlights how on the one hand, many types of disability can be caused by malnutrition: through lack of micronutrients or macronutrients, or exposure to high concentrations of antinutrients (e.g. toxins in poorly processed cassava can lead to permanent neurological damage).\textsuperscript{13} Equally as significant it illustrates how having a disability can also lead to malnutrition, due to decreased nutrient intake, increased nutrient loss, and need for increased nutrients, which can put children at risk of further complications. Countries with high levels of malnutrition and nutrient deficiency often also report higher rates of disability and developmental delays.\textsuperscript{14}

\textsuperscript{11} 134 countries have ratified the convention, and 77 have ratified the optional protocol: \url{http://www.un.org/disabilities/} as of 17th September 2013
\textsuperscript{12} Kerac M et al (forthcoming) The interaction of malnutrition and neurological disability in Africa. *Seminars in Paediatric Neurology*
Malnutrition can cause disability:

Malnutrition in pregnant women, infants and children leading to developmental delays and physical, sensory and intellectual disabilities is well-documented in maternal and child health as well as disability-specific literature.

Maternal nutrition:

Maternal malnutrition can affect the development of the foetus, cause intrauterine growth delays and increase the risk of the infant developing impairments. For example, low maternal folate levels are associated with increased risk of the child being born with a neural tube defect. Folic acid supplementation of the mother enabling adequate folate levels at conception can not only improve the mother’s health and nutrition levels, but also prevent up to 70% of neural tube defects in the unborn child. Vitamin D deficiency in pregnant women can result in inadequate calcium supply to the foetus for bone development, potentially leaving the child prone to rickets or with sub-standard bone mineralisation.

Mothers who are malnourished are more likely to give birth to low birth weight babies, a risk factor for mild intellectual disability. Iodine deficiency during pregnancy has been reported to increase incidence of poor foetal growth and low birth weight babies. Anaemia – a deficiency of iron – prevalent in 42% of pregnant women in low- and middle-income

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15 Blencowe H, Cousens S, Modell B, Lawn J. Folic acid to reduce neonatal mortality from neural tube disorders. *Int J Epidemiol* 2010; 39 Suppl 1: i110-21
countries and half of children in pre-school is considered one of the leading causes of disability worldwide as well as increasing the risk of maternal mortality.\textsuperscript{2,4,18} Anaemia in the mother is associated with low birth weight and traumatic delivery and can affect a child’s cognitive development.\textsuperscript{4,19}

Suboptimal pelvic growth in girls, which itself can be caused by malnutrition, can also lead to inter-generational problems when they reach child-bearing age. A small pelvis is more likely to result in cephalo-pelvic disproportion, a cause of obstructed labour, which in turn is a cause of foetal injury and birth asphyxia. This is a particular problem in resource poor or developing countries where as well as higher rates of under-nutrition, there are also poor obstetric and neonatal services and hence greater likelihood of any difficulty around birth resulting in more permanent problems such as cerebral palsy.\textsuperscript{20}

Infants whose mothers were severely malnourished when they were in-utero (such as in the ‘Dutch famine’ during World War II – a highly studied group from whom many key lessons were learnt) are reported to have a higher incidence of mental illness and can be up to twice as likely to develop schizophrenia in later life. This may be due in part to slow neurodevelopment and altered brain shape and size of the foetus in utero.\textsuperscript{21}

Maternal obesity can also lead to adverse birth complications such as increased risk of infection and trauma during delivery which may increase the likelihood of the infant developing a disability. Maternal overweight at conception can also lead to the child being overweight and developing chronic diseases in later life.\textsuperscript{4}

Finally the importance of the mother’s nutrition does not end with birth. Low B12 in breast milk can lead to developmental delay and neurocognitive impairment.\textsuperscript{16} Children who are not breast fed during infancy are more likely to have positive findings when screened for disability at age 2-4.\textsuperscript{22}

**Child nutrition:**

Infants and young children who are underweight and stunted as a result of malnutrition are also more likely to screen positive for disability.\textsuperscript{22}

Specific micronutrient deficiencies, including lack of iodine, iron and vitamin A, and malnutrition related to lack of protein and energy, are considered risk factors for physical, sensory and cognitive impairment.\textsuperscript{4,23} For example, each year between 250,000 – 500,000 children become blind as a result of Vitamin A deficiency despite the existence of an inexpensive supplement to reduce its occurrence.\textsuperscript{24} There is also evidence to suggest that iodine deficiency may affect the motor development of young children under age four, and


less consistently their cognitive development, with effects on very young children being irreparable.\textsuperscript{4}

Post-natally, a child lacking in macro-nutrients or with sub-optimal nutrition will be more susceptible to infections – such as cerebral malaria, or meningitis – both of which have high risk of leaving the affected child with permanent neurological damage and disability.\textsuperscript{25}

Malnutrition can also cause structural damage to the brain and affect motor and exploratory skills as well as future cognitive development and schooling.\textsuperscript{21} For example, stunting is defined as height for age lower than 2 standard deviations below the median. It is caused in very early childhood by a range of determinants related to nutrition, lack of essential minerals or vitamins, and diarrhoea and can lead to cognitive delays which later affects educational performance. Stunting can continue to negatively impact upon the growth, development and survival of children and adults throughout their lives increasing a child’s susceptibility to infectious disease and future adult risk of chronic diseases such as diabetes or heart disease, all high risk factors for developing a disability.\textsuperscript{2,26}

Children with anaemia before age 2 may suffer irreversible delays even if iron is repleted at a later age. Malnourished children, such as those with anaemia or rickets, often score lower on language, personal, motor and social development scores compared to expected scores in children of the same age who are not malnourished, in part because the child lacks the ability to engage his parents and caregivers and to interact with the surrounding environment.\textsuperscript{4,14}

Evidence from high income countries, and increasingly also from low- and middle-income countries suggests that malnutrition in infancy and childhood also has adult sequelae, such as high blood pressure and metabolic disease. These are key risk factors for disabling conditions such as diabetes, heart disease and stroke.\textsuperscript{22}

**Disability leading to malnutrition in children**

While the majority of nutrition programme strategies related to malnutrition focus on how to prevent disability, it is equally important to note that children who are born with or who acquire a disability, such as children with craniofacial anomalies (cleft lip and/or palate), certain genetic syndromes, cerebral palsy, or more subtle oral-motor feeding and swallowing problems, also face significant issues related to malnutrition.

Children with disabilities who do not receive enough food or enough nutritious food are susceptible to acquiring secondary conditions (such as stunting or wasting) as a result of micronutrient deficiencies, or in extreme cases may die as a result of severe acute malnutrition.

Children with disability are consistently reported to have high incidence of malnutrition, stunting, and wasting.\textsuperscript{27} For example, children with cerebral palsy can be up to three times more likely to be underweight compared to non-disabled children.\textsuperscript{28} Factors contributing to


\textsuperscript{26} UNICEF (2009) Tracking progress on child and maternal nutrition: a survival and development priority  


this include difficulties associated with chewing or swallowing food, and feeding difficulties, increasing with the severity of the disability. This may result in poorer health and development outcomes, leading to a perpetuating cycle of suboptimal nutrition, disability and worsening health status.29

Girls with disabilities may present more often as underweight compared to boys with disability.28 In disadvantaged communities experiencing limited resources and food shortages, families following culturally determined gender preferences may choose to prioritise the nutritional needs of a disabled boy child over that of a disabled girl child. Furthermore, as noted above, poor nutrition leading to stunting and malnutrition also can cause suboptimal pelvic growth in girls – this includes girls with disabilities, the majority of whom will have children of their own.

Recent studies have found that children with disabilities admitted and treated for malnutrition are more than two times more likely to die than non-disabled children. Possible reasons for this increased mortality include delayed presentation at the health or nutrition facility; suboptimal care (i.e. not focused on specific needs of disabled children); more severe malnutrition at admission; and lack of follow-up post-discharge from the nutritional treatment facility.30 Underlying factors such as infections or neglected health care needs of a child with a disability, in particular those with severe impairments, may exacerbate issues related to malnutrition and therefore also play a role in leading to higher risk of death.14

Compounding this, the systems that exist to improve the nutrition of children, including health, nutrition and early development interventions are often less accessible to meet those most in need, such as children with disabilities, particularly those living in poverty or in remote locations.31 Community-based health or nutrition services may be frequented less by children with disabilities due to difficulties bringing these children to the centres (inaccessible or cost prohibitive transportation and inaccessibility of buildings) or lack of understanding by nutritionists and service providers in these programmes about how to support and treat children with disabilities and raise awareness among families and caregivers about appropriate interventions. In addition, many child nutrition campaigns are run through schools, and children with disabilities are less likely to attend school at all ages, compared to non-disabled children.2 This results not only in children with disabilities lagging behind their peers in educational attainment, but also in not benefiting from school-based nutrition initiatives. In extreme cases some families or communities may place a lower status on a disabled child and prioritise nutrition and health services for their non-disabled siblings. Finally, children with disabilities are disproportionately represented in many institutions and orphanages, and these facilities are often also overlooked in food programmes. An additional concern in institutions is the often poor quality of the food that is provided. While of concern to all institutionalised children, children with disabilities may be at increased risk.

Impairments can lead to malnutrition

For some newborns and children with disability, their existing impairment can be a direct cause of malnutrition. Children may have difficulty taking solid foods, or have poor oral motor skills. For example, a cleft palate condition can affect sucking, chewing and feeding.

Up to an estimated 90% of children with cerebral palsy have difficulty feeding, that can result in malnutrition, lower health status and in many cases early death.\textsuperscript{24,32}

Nutrient malabsorption is common for children with certain conditions, including cystic fibrosis, rendering the child unable to absorb and use the nutrients their body requires to develop and thrive. Reduced nutrition associated with the primary impairment or condition may lead to increased muscle wasting and loss of function, due to insufficient intake of energy and nutrients. This in turn increases risk of further debilitating and recurring infections.\textsuperscript{33} Children with such conditions, therefore require high calorific or special diets in order to maintain strength and health.

Similarly, children with disabilities may need additional nutrients to cope with the health problems associated with their disability. For example a child with a physical disability may be prone to pressure sores due to immobility that can become seriously infected. He or she needs a high quality diet for prompt healing and to control infections. Poor families may struggle to meet these increased nutritional needs or lack ready access to these necessary dietary supplements.

Parents, carers and service providers may also lack knowledge about how to feed their child effectively or how to teach their child to feed themselves. This is especially important for children with conditions such as cerebral palsy who may need special seating or positioning to control muscle spasms or for children with Down’s syndrome who are at increased risk of choking and developing pneumonia. Difficult meal times can lead to increased stress levels for both the caregiver and child, which can result in insufficient food intake.\textsuperscript{29,32} Another concern related to improper feeding is the heightened risk of aspiration, which often leads to pneumonia and ultimately can be life threatening, particularly for children with compromised immune systems.

Although the focus of concern for children with disability is generally around malnutrition and under-nutrition, becoming overweight is also a concern for some children with a disability. For example, children with certain physical disabilities are less mobile and therefore at risk of becoming overweight.\textsuperscript{34} Children with certain types of genetic impairments (e.g. Sotos syndrome) or intellectual or mental health disabilities may have eating disorders that place them at higher risk of becoming overweight. Overweight children can also have micronutritional deficiencies that go unnoticed by parents and health care workers with serious long-term consequences for that child’s health and development.

**Social and Cultural Barriers:**

There is a common assumption that children with disabilities do not grow and thrive as a result of their impairment. Whilst that is sometimes true, it is also important to note that there may be other factors which partly or even sometimes completely explain a failure to thrive. These include physical, attitudinal and socio-economic barriers.

For example, in some cultures, mothers of newborns with a disability may be discouraged from breastfeeding, assured by family and midwives that their child will die anyway or would not lead a productive life. This becomes a self-fulfilling prophecy as these newborns will

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quickly starve. Stigma surrounding disability may result in children with disabilities being given less nutritious or smaller quantities of food, or intentionally not fed at all, with families rationalising that limited resources should be devoted to children who have a greater chance of surviving and contributing to the household. This reasoning is not only incorrect but denies these children the right to grow and thrive.

Feeding practices are also of concern. Family members may treat a child with disability as an infant, continuing to give a liquid only diet, believing that the child will not be able to take solid foods. This can lead to severe malnutrition and in extreme cases, death.

Parents and carers may also assume that a child with a disability cannot learn and develop in the same way as other children, and therefore these children may not be encouraged to feed themselves. Children with disabilities may therefore be more reliant on family members for food, placing severe time constraints and economic burdens on the caregivers, and in households. The burden of feeding children with disabilities is also a gender issue as the responsibility of feeding such children falls most heavily on female members of the household. These women must balance the needs of the child with a disability with all the other chores they have to perform. The result is that the child may get less food because it is time consuming to feed a child with low tone and spasticity and no one in the household has the time or energy to provide such feeding. Nor is this an issue only in households. The UK based international NGO Lumos recently reported that caretakers of children with disabilities in Bulgarian institutions were unable to devote more than two minutes of their time to each child during meal times due to time and work constraints, despite the fact that these children needed additional support with feeding and drinking.

Finally, disability is often seen as a specialist subject and therefore not mainstreamed in to education for practitioners in nutrition, health, and development. Pre- and in-service training of health care, nutrition and development professionals on the links between disability and nutrition would help providers gain more awareness of the specific nutrition requirements of children with disabilities in expanding more inclusive programme and practice. As nutrition efforts are scaled up, the needs of children with disabilities must be integrated to ensure that they are reached with the same life-saving interventions as all other children.

Conclusion

Nutrition and disability are intimately linked: malnutrition can directly cause or contribute to disability and disability to malnutrition. This has intergenerational and life-course implications: poor maternal nutrition can lead to permanent childhood impairments; early life malnutrition can affect health and disability in later life. But disability itself can also lead to subsequent malnutrition. Though infants and children are especially vulnerable, older children and adults are also at risk, not least because early life malnutrition has long term effects. A malnourished child (whether disabled or not) is at increased risk of developing further debilitating disease, delayed development, and disability or compounded by further disability. Risk factors leading to malnutrition and disability are multi-faceted and encompass biological, physical, environmental, and social factors.

It is imperative that future nutrition policy and programming, maternal and child health and disability policy recognises and plans for the malnutrition and disability link. It is even more

important that resources are made available and action is taken to address these issues. Such action would also have important positive benefits: disability programmes have great potential to serve as an entry point to nutrition services; similarly, nutrition programmes to act as entry points to disability services. Nutrition interventions which benefit all children will also benefit children with disabilities. In order to ensure effective and inclusive nutrition, special attention should be paid by nutritionists, health care and community service providers to bring children with a high risk of becoming malnourished - such as those with existing disability or chronic disease - into existing nutrition programmes, as well as adapting or expanding community based models of care and reaching out to institutions where some children with disabilities live.

Finally children with disabilities must also be included in general nutrition prevention, food security and treatment interventions, to ensure they are afforded the best access to nutrition as a matter of equity and basic human rights. As children with disability frequently may also require additional nutrition interventions specific to their impairment, issues of disability should be fully integrated into nutrition programmes, policies and services so that malnutrition and disability can be addressed jointly in typical daily living or food security emergency crisis contexts.

Steps forward and Recommendations

The UN Convention on the Rights of the Child\textsuperscript{37} and the United Nations Convention on the Rights of Persons with Disability\textsuperscript{10} call for children with disability to have the same right to food and nutrition as all other children.

While there is evidence that international organisations, policy makers, and other members of the international community are beginning to recognize the complex relationship between nutrition and disability, there is still much to be done. Based on the evidence, as key steps forward, we suggest the following:

- The international community: governments, policy makers, multi- and bi-lateral donors and practitioners must ensure political and resource commitment to tackling nutrition and disability as related issues.

- To understand the links between nutrition and disability, better data is needed - including disaggregated data that will allow comparison of those with disabilities compared to their non-disabled peers.

- International and national nutritional plans and policies must be explicit about disability related links and interactions. One key opportunity to do this is during rollout of forthcoming new WHO guidelines on the management of Severe Acute Malnutrition (SAM). This clearly - albeit briefly – recognises disability as an underlying cause of SAM which needs to be considered and where relevant addressed as part of the overall treatment package. As this international-level guidance is translated and adapted for national use, it is vital that these key messages on disability are not lost but remain strongly made. Ideally, national SAM guidelines should not only mention disability but offer detailed disability-specific guidance (e.g. screen and intervene appropriately for children with disabilities resulting in feeding and swallowing impairments). An example is training community-based health and rehabilitation workers on how to manage children

http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx
cerebral palsy – a common disability and common cause of swallowing difficulties needing different management to other SAM children).

- There is a need for improved access to nutrition services for pregnant and breastfeeding mothers including those pregnant and breastfeeding mothers who are disabled.

- Disability should be mainstreamed in all early intervention nutrition, health and development efforts: for example early screening efforts for malnutrition need to adapt to ensure they are more accessible for children with disability and their families.

- For some children with disabilities, there is also a need for disability-specific services which target and address the needs of children with disabilities and their families or caretakers, including professional specialty and Community-Based Rehabilitation (CBR) services where these are available.

- Development professionals as well as those training in health care and nutrition should be trained to be aware of and knowledgeable about how to include children with disabilities.

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