



## Disability and nutrition programming: evidence and learning

Jenny Holden and Nick Corby

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**Query:** Please summarise the evidence on approaches to ensuring people with disabilities are reached through nutrition programming, focusing on children, adolescents, and women of reproductive age in low and middle-income countries – including both what has and hasn't worked, and lessons learned on factors that may act as barriers and enablers to success as well as any unintended consequences of these approaches.

**Enquirer:** Nadeem Hasan, Nutrition Advisor, Nutrition Policy Team, DFID

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### Definitions

**Disability:** DFID follows the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in promoting a **human rights approach** to disability. **Persons/people with disabilities** are: '*...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*' (Article 1, CRPD)

This concept of disability moves away from the traditional individual, medical-based perspective characterised by a focus on physical deficits (impairments), to one that encompasses the **attitudinal, environmental and institutional barriers** that limit or exclude people with impairments from participation.

**The term malnutrition** covers both undernutrition and overnutrition. **The term undernutrition** includes stunting (low height for age), wasting (low weight for height), underweight (low weight for age) and micronutrient deficiencies or insufficiencies (a lack of important vitamins and minerals). **The term overnutrition** includes overweight, obesity and diet-related noncommunicable diseases.

**Note:** The review focuses on links between undernutrition and disability, although it is important to note that overnutrition-associated conditions such as diabetes are also increasingly important causes of disability, notably in older age-groups. (Groce et al, 2014)

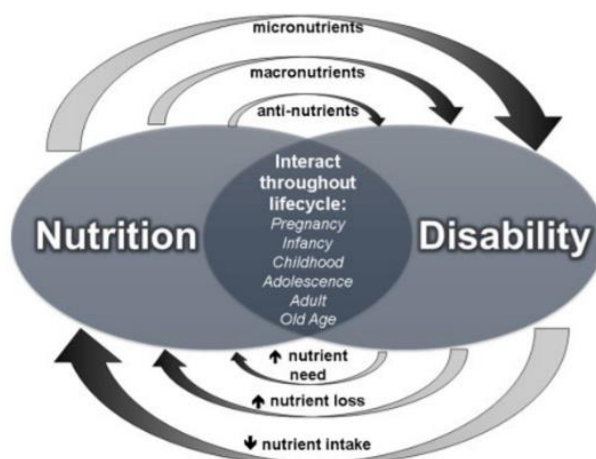
## 1. Overview

**Undernutrition and disability are inherently linked**, with the former both a cause and a consequence of the latter, and people with disabilities at increased risk of being malnourished (Kuper et al., 2014; Groce et al., 2013a:2013b). Both undernutrition and disability are also key human rights concerns with the Universal Declaration of Human Rights (Article 25) and its General Comments recognising the rights of people with disabilities to access adequate food; the right to health care, education and social participation documented in the 2006 UN Convention on the Rights of Persons with Disabilities; and the rights of all children, including children with disabilities to have adequate nutrition as stated in the Convention on the Rights of the Child (CRC). There is now increasing global interest in the causal links between undernutrition and disability, most commonly focusing on undernutrition as a cause of disability. However, despite these similarities and potential linkages, **the two are rarely linked in policy and programming**. (Groce et al, 2014; Groce et al, 2013; Hume-Nixon and Kuper, 2018)

**This document provides a rapid review of the evidence on approaches to ensuring people with disabilities are reached through nutrition programming**, focusing on children, adolescents, and women of reproductive age in low and middle-income countries (LMICs). The purpose of this review is to support DFID advisers and partners designing and implementing programmes with nutrition components to ensure they are more inclusive of people with disabilities. After outlining the methodology in Section 2, Section 3 includes an overview of available evidence on what works to ensure nutrition programming reaches people with disabilities, as well as an assessment of the strength of the evidence, and highlighting key research gaps. Section 4 provides a summary on factors affecting access for people with disabilities, and Section 5 concludes by drawing a series of considerations for policy and programming to ensure that people with disabilities are not left behind when it comes to government-led and development partner-led programmes to tackle malnutrition. Case studies of approaches are included in annex 1 to give further insights on promising practices and key learnings.

**Children, adolescents and women of childbearing age with disabilities have poorer overall nutritional status than their peers without disabilities** (Kuper et al., 2014; Groce et al., 2013a:2013b). Countries with high levels of malnutrition and nutrient deficiency often report higher rates of disability and developmental delays (WHO, 2012).

Groce et al (2014) present a **conceptual framework** (see diagram) for how nutrition and disability interact throughout the lifecycle. The framework highlights the two-way interactions where malnutrition can cause or contribute to a variety of different disabilities; and disabilities can cause or contribute to malnutrition. In particular, Groce et al (2013) categorise causal pathways between disability and undernutrition into three categories: 1) medical, 2) educational, and 3) attitudinal, cultural and social.



**This review finds that whilst there is increasing evidence of the two-way links between disability and undernutrition in LMICs<sup>1</sup>, there is limited evidence to suggest that the nutritional needs of people with disabilities are recognised in policy and programming** (Jones et al, 2018; Groce et al, 2013). As Groce et al

<sup>1</sup> Including a recent systematic review which provides some evidence that undernutrition is associated with childhood disability in LMICs (Hume-Nixon and Kuper, 2018).

observed in their 2013 article in The Lancet ‘...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’ (p.180). This review has not found evidence to suggest that the policy and programming landscape has changed significantly since 2013, with limited programming guidance in this area.<sup>2</sup>

**The lack of relevant systematic reviews and comprehensive evidence reviews point to a scarcity of high-quality, rigorous research globally on policy and programming in this area.** Most disability-focused organisations don’t appear to be working on this issue, and there is limited evidence on what strategies have worked (or not) to increase access for people with disabilities within mainstream nutrition programming, due to a lack of visibility of disability within mainstream nutrition programming metrics and data.

**Overall, the evidence base on the impact of approaches to ensuring people with disabilities are reached through nutrition programming is limited, with most evidence regarding approaches targeting children with disabilities.** The most common types of approach appear to be advocating for the inclusion of children with disabilities in general nutrition programmes and providing nutrition education for families with children with disabilities. However, the evidence on the impact of these interventions is scarce, with this review identifying few robust evaluations in this area, and a lack of disability disaggregated data within nutrition sector programming.

**Particular gaps in the evidence and therefore priorities for future research include:** limited evidence of what works to improve the nutrition of adolescents and women of reproductive age with disabilities; a lack of evidence of programming in humanitarian settings; a lack of research on nutritional outcomes for people with different types of impairment; and a lack of disaggregated data.

**A summary of the key factors affecting access to nutrition programming** is provided in the table below (see Section 4 for further information and examples).

<b>Factors affecting access to nutrition programming for people with disabilities</b>			
<b>Individual</b>	<b>Environmental</b>	<b>Attitudinal</b>	<b>Institutional</b>
<p><b>Intersecting and compounding</b> forms of discrimination and disadvantage, with barriers differing depending on <b>type and severity of impairment</b>, and:</p> <p><b>Universal factors</b> (fixed aspects of one’s identity regardless of setting), including age, gender, disability and health status.</p> <p><b>Contextual factors</b> (more complex and changeable factors and those that vary</p>	<p><b>Physical barriers to access</b> at health and education services and facilities e.g. a lack of ramps, adjustable beds, wheelchairs and accessible sanitation facilities.</p> <p><b>Centralisation</b> of specialist health and nutrition centres and specialised staff in urban areas.</p> <p><b>Long and difficult journeys to clinics</b>, particularly in rural and remote areas.</p> <p><b>Accessibility of communications</b>, e.g.</p>	<p><b>Poor knowledge of parents and caregivers which may affect diet and feeding practices.</b></p> <p><b>Stigma, negative attitudes and discrimination</b> from health workers.</p> <p><b>Social and cultural attitudes</b> which devalue the lives of people with disabilities, leading to harmful and neglectful feeding and health seeking practices.</p>	<p><b>Lack of national guidelines and disability specific guidance</b> for nutrition programming.</p> <p><b>Lack of age-, gender- and impairment-disaggregated data</b> on access to nutrition programming.</p> <p><b>Lack of technical expertise</b> around nutrition programming from a disability perspective.</p> <p><b>Lack of training and awareness in early identification and intervention.</b></p>

<sup>2</sup> Notably, none of the DID consortium partners and broader disability specialist organisations contacted for this query provided information on nutrition-focused programming, although the Helpdesk team were unable to confirm whether this was because they do not work in this area, and Professor Nora Groce confirmed that there has been little work in this area in recent years.

<p>by setting), including language, caste, migration and refugee status, family status.</p> <p>Note: <b>Girls with disabilities</b> may more often be underweight than boys with disabilities due to culturally determined gender preferences.</p>	<p>difficulty understanding radio messages for people with hearing impairments, or TV not captioned or sign language for people with visual impairments.</p> <p>Lack of contextualised and standardised <b>screening tools</b> for disability</p>		<p><b>Suboptimal care and lack of follow up.</b></p>
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Given the multiple factors affecting access for people with disabilities, most studies highlight the **need for a multi-component approach** using a range of tailored strategies, with considerations for policy and programming highlighted in section 5 of this report.

## 2. Methodology

This rapid research query has been conducted as systematically as possible within 4.5 combined days of researcher and expert time. The methodology is described below.

**Search strategy:** Studies were identified through a variety of search strategies; focusing on low and middle-income countries:

- **The review prioritised existing syntheses, evidence reviews, and systematic reviews** where possible in order to draw on the fullest range of evidence possible. However, only one systematic review on links between disability and undernutrition was available at the time of the review (Hume-Nixon and Kuper, 2018), with no such reviews available on the impact of policy and programming in this area.
- **The DFID Disability Inclusive Development Programme consortium partners<sup>3</sup> and relevant experts were contacted** for evidence recommendations (see page 17 for experts who responded).
- **Google and relevant electronic databases** (PubMed, Science Direct, and Google Scholar) for priority sources using a selection of key search terms<sup>4</sup> used in other systematic reviews to identify more recent materials. The review also considered programmes which may have useful lessons but were excluded from systematic reviews, due to less rigorous evaluation methodologies.
- **Review of key disability portals and resource centres**, including the Leonard Cheshire Disability and Inclusive Development Centre, Disability Data Portal, Source, International Centre for Evidence in Disability, the Impact Initiative, and Sightsavers Research Centre.
- **Disability-focused journals**, such as Disability & Society, and the Asia-Pacific Disability Rehabilitation Journal.

**Criteria for inclusion:** To be eligible for inclusion in this rapid review of the literature, studies had to fulfil the following criteria:

<sup>3</sup> The Disability Inclusion Helpdesk is funded under the DID programme. The DID consortium partners are ADD International, BBC Media Action, BRAC, Institute of Development Studies (IDS), International Disability Alliance (IDA), Humanity & Inclusion, Leonard Cheshire Disability, Light for the World, Sense, Sightsavers and Social Development Direct.

<sup>4</sup> Key search terms included: nutrition, under-nutrition, malnutrition, child feeding, food supplementation, stunting, wasting, AND disabled / disability / disabilities, impairment, deaf, blind, wheelchair AND children, adolescents, women, AND interventions, programmes, evaluations, reviews, research, study.

- **Focus:** Either targeted nutrition programming aimed at people with disabilities, or mainstream nutrition programming where outcomes for people with disabilities is tracked. This includes both government-led and development-partner led programmes. [*To note, this review included evidence on school-feeding programmes, which while DFID do not promote as a cost effective approach to improving nutritional outcomes, may have relevance to other types of programming, as well as offer insights for governments and other donors continuing to fund such initiatives to ensure they are more disability inclusive.*]
- **Exclusions:** The review excluded nutrition programmes that specifically address the nutritional needs of pregnant women or women of childbearing age for preventing disabling conditions of newborns and young children.
- **Time period:** 2008<sup>5</sup> – 2019.
- **Language:** English.
- **Publication status:** publicly available – in almost all cases published online.
- **Geographical focus:** LMICs.

### 3. Evidence base on approaches to reaching people with disabilities through nutrition programming

This section summarises the evidence base on approaches to reaching people with disabilities in nutrition programming, including children, adolescents with disabilities and women of child bearing age.

**Overall, the evidence base on the impact of approaches to ensuring people with disabilities are reached through nutrition programming is limited, with most evidence regarding approaches targeting children with disabilities.** A recent systematic review provides some evidence that undernutrition is associated with childhood disability in LMICs. (Hume-Nixon and Kuper, 2018) However, to date, there have been no systematic reviews or robust evidence syntheses of policy and programming in this area. The following provides a summary of the evidence on approaches to targeting people with disabilities (focusing on children, adolescents and women of childbearing age) in nutrition programming:

- **The evidence suggests a lack of both disability specific and disability inclusive nutrition programming in LMICs.** A 2013 mapping, undertaken by the Global Partnership for Children with Disabilities (GPCWD) Task Force on Nutrition, highlighted a scarcity of programmes that address the nutritional needs of children and youth with disabilities in LMICs (GPCWD, 2013). The mapping exercise (which included an online survey sent out widely to organisations working in nutrition), found just eight examples of programmes or programme components addressing the nutritional needs of children and young people with disabilities. Whilst it is beyond the scope of this query to undertake a comprehensive mapping, this review has not found evidence to suggest that the landscape has changed significantly since 2013.<sup>6</sup>
- **People with disabilities are largely invisible within mainstream nutrition programming data.** This makes it impossible to tell the extent to which such programming is reaching people with disabilities, and suggests significant knowledge gaps in terms of practical programming for disability inclusion.

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<sup>5</sup> Note: The Disability Inclusion Helpdesk reviews evidence from 2008 onwards as this is the year that the Convention on the Rights of Persons with Disabilities and its Optional Protocol came into force.

<sup>6</sup> Notably, none of the DID consortium partners and broader disability specialist organisations contacted for this query provided any information on nutrition focused programming in this area, and Nora Groce confirmed that there has been little work in this area in recent years.

- **The most common types of approach appear to be advocating for the inclusion of children with disabilities in general nutrition programmes and providing nutrition education for families with children with disabilities.** However, there are few robust evaluations in this area, and a lack of disability disaggregated data within nutrition sector programming. (See annex 1 for example case studies with further details on the types of approaches).
- **In particular, there appears to be a lack of programming at the national and regional level.** The majority of the projects identified in the 2013 mapping were at the community-level, with a lack of programmes at the regional or national level. (GPCWD, 2013)
- **There is some small but significant evidence that caregiver training programmes can improve parental feeding practices for children with cerebral palsy.** A 2017 evaluation of a training programme for caregivers of children with cerebral palsy in Ghana (age 18 months to 12 years old), found that the 11 month intervention ‘getting to know cerebral palsy’ – which included monthly half-day sessions – led to self-reported improvements in mealtime experiences reported by caregivers, with some improved nutritional content, and improvements in the positioning of the child.<sup>7</sup> However, levels of malnutrition remained high at both baseline (63%) and endline (65%), reflecting persistent challenges including positioning of children with severe cerebral palsy, attitudes and behaviours amongst family members without primary responsibility for care, caregivers having sufficient time available for food preparation and feeding, significant variation in the quality of referrals for additional nutritional support, and poor accessibility of local health services overall. (Zuurmond et al, 2017)<sup>8</sup>. The International Centre for Evidence on Disability (ICED) has developed a similar health promotion training programme with caregivers of children with Congenital Zika Syndrome (a condition similar to cerebral palsy) in Brazil. Although not yet evaluated, the approach (consisting of 10-11 sessions delivered over 3 months), which has been piloted in 2018, is promising; in addition to covering essential care practices such as feeding and positioning, it aims to address disability rights and how parents can advocate for their child’s education, healthcare and receipt of disability benefits. (Kuper H et al, 2018)
- **There is some promising evidence on the impact of specialist feeding programmes within institutional settings.** The SPOON Foundation have developed tools and trainings to address and improve the nutritional and feeding needs of children with disability in institutional care facilities in low resource settings. The tools address many of the root causes of malnutrition, including feeding techniques, nutrition screening and optimising diet and supplementation. The approach has been applied through national partners in Cambodia, Vietnam, Russia, Zambia, Russia, Mauritius and Oregon, USA. According to the SPOON Foundation’s 2017 Annual report, the approach has proved effective with an evaluation in three countries finding the approach drastically reduced levels of stunting by 32%, wasting by 11% and anaemia by 28%.
- **There is limited evidence that mainstream school-feeding programmes<sup>9</sup> are reaching children with disabilities (PWD, 2015).** The nutritional needs of children with disabilities are rarely included in these programmes, and there is a lack of disaggregated data on their reach (Ibid, 2015). Specialist institutions and orphanages may be overlooked in food programmes (Groce et al, 2014), although a promising example from Laos is provided in annex 1. Evidence

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<sup>7</sup> The study included 75 caregivers and their children with cerebral palsy.

<sup>8</sup> The study was a pre-post mixed-methods design included 76 families and children at baseline, and 64 families were followed up after one year at endline.

<sup>9</sup> Note: DFID no longer support school-feeding programmes as a cost effective approach to improving nutritional outcomes.

suggests that targeted food aid for children with disabilities coupled with awareness raising at the community level may increase school attendance.<sup>10</sup>

- **Evidence suggests that the nutritional needs of people with disabilities in humanitarian settings are not being met.** A 2018 report by the Women's Refugee Commission including research in five humanitarian settings found that in nearly all field sites, refugees with disabilities did not receive additional or special food rations, nor were they prioritised in food distribution systems. The study identified accessibility issues with food distribution points and lengthy wait times presenting particular barriers (WRC, 2008). Similarly, a 2009 lobbying paper by the International Disability and Development Consortium highlights that people with disabilities are not taken into account in humanitarian settings, including through lack of special food rations despite specific nutritional needs; use of schemes such as food-for-work which (unintentionally) discriminate against those who are unable to work; and difficulties to carry home food rations (IDDC, 2009).
- **There is evidence to suggest that a number of organisations are starting to mainstream disability issues** within their broader maternal, new-born and child health and nutrition (MNCHN) programmes.<sup>11</sup> However, there is scarce evidence of the effectiveness of these approaches, with a lack of publicly available data on the numbers of people with disabilities being reached, or evaluations of these initiatives.

There remain considerable **gaps in the evidence base** on inclusive approaches to nutrition programming, reflecting limited policy and programming in this area to date. In particular,

- **Scarce evidence on nutrition outcomes for adolescent girls and women of childbearing age with disabilities or what works to reach these groups with nutritional programming.** (Jones et al, 2018) In particular, there appears to be a lack of both disability specific and disability inclusive programmes addressing the nutritional needs of these two groups.
- **A lack of disaggregated data and disability focused metrics within mainstream disability programmes,** which effectively renders people with disabilities as invisible.
- **A lack of research on how different types of impairments impact on different nutritional outcomes,** in particular intellectual and psychosocial impairments.
- **Lack of evidence on how nutrition programming can be used as an entry point for detection and referrals for impairments.**
- **A lack of evidence on what works to reach people with disabilities with nutrition programming in humanitarian settings.**

#### 4. Factors affecting access to nutrition programming

Given the paucity of evidence on what works to ensure people with disabilities are reached through nutrition programming, the following section summarises the evidence on factors affecting access to nutrition programming, based on a framework used by the Disability Inclusion Helpdesk that combines a recognition of **individual factors** that can marginalise people with disabilities (e.g. multiple intersecting factors such as age, gender, impairments) and the **environmental, attitudinal and institutional barriers** that limit or exclude people with impairments.<sup>12</sup>

##### 4.1 Individual factors

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<sup>10</sup> The CounterPart Food Aid for Disabled Children project (2011-2013) found a 20% increase in school attendance. See case study in annex 1 for further details.

<sup>11</sup> In particular a number of UNICEF country offices, see annex 1 for further details.

<sup>12</sup> Disability Inclusion Helpdesk training by Lorraine Wapling (December 2018)

**DFID's Strategy for Disability Inclusive Development 2018-23 recognises that people with disabilities face intersecting and compounding forms of discrimination.** Disability intersects with other sources of discrimination or social disadvantage which might limit access to health and nutrition programming such as age, gender, sexuality, ethnicity, impairment type, or economic poverty (Wapling, 2018; DFID, 2018).

In this paper, we use a **marginalisation framework**<sup>13</sup> to distinguish between individual factors affecting access to nutrition programming. This framework highlights intersections between disability, and other aspects of an individual's identity (such as age and gender), and contextual factors (such as refugee status, geography and economic situation).

**Evidence suggests that these multiple factors intersect and create a nuanced picture,** depending on context, with for example people with disabilities in rural, humanitarian and conflict-affected settings much more likely to be excluded from health services and support (Jones et al, 2018). Girls with disabilities may more often be underweight than boys with disabilities (Tüzün et al, 2013). In disadvantaged communities experiencing limited resources and food shortages, families following culturally determined gender preferences may choose to prioritise the nutritional needs of a boys with disabilities over girls with disabilities (Groce et al, 2013b).

**Barriers can differ depending on the types and severity of impairment and can require different solutions to access nutrition programming.** People with some types of physical or intellectual disabilities may have difficulty feeding themselves – e.g. conditions such as cleft palate or cerebral palsy. Further, some people with disabilities may need special diets or increased calorie intake to maintain a healthy weight (Groce et al, 2013b; UNICEF, 2013). Services and information will therefore need to be tailored, and there is no one-size-fits-all approach to ensuring nutrition programmes are accessible to children, adolescents and women with disabilities. For example, the Partnership for Child Development (PCD) recommend a range of specific measures depending on the type of impairment and degree of functional limitations, which need to be taken into account to ensure outreach, accessibility and inclusion of children with disabilities in school health and nutrition programmes. (PCD, 2015)

#### 4.2 Environmental factors

Mainstream approaches to improve nutrition may be **less accessible** to people with disabilities, particularly those living in poverty or remote locations. Examples of environmental barriers cited in the literature include:

- **Physical inaccessibility:** including of health and education facilities (where nutrition programming is often based) e.g. a lack of ramps, adjustable beds, wheelchairs and accessible sanitation facilities. (Groce et al, 2014; PCD, 2015)
- **Centralisation of specialist services:** A concentration of specialist health and nutrition centres and staff in urban areas. (Abou Samra et al, 2018)
- **Accessibility of communications:** in particular food security campaigns on nutrition and hunger not being designed in an accessible way e.g. difficulty understanding radio messages for people with hearing impairments, or TV not captioned or sign language for people with visual impairments. (PCD, 2015)
- **Lack of accessible transportation:** Long distances and lack of accessible transportation/high transportation costs.
- **Lack of contextualised and standardised screening for disability:** For example, one of the most common challenges identified by organisations consulted during a 2013 mapping of nutrition and disability programming, was difficulty identifying children and youth with disabilities

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<sup>13</sup> As used by DFID's Girls' Education Challenge (GEC) programme to understand who is marginalised based on their universal and contextual characteristics (Wapling, 2018).



in this age range among their project population. (GPCWD, 2013) Early identification of disabilities and developmental delays within health services may vary significantly, with a lack of contextualised and standardised screening tools cited as a challenge in Lebanon. (Abou Samra et al, 2018)

- **Children with disabilities are often excluded from mainstream education services** (UNESCO, 2008:2010), meaning that for example school feeding programmes are unlikely to reach children with disabilities not in school. (Groce et al, 2014; PCD, 2015; Kuper et al, 2015) Kuper et al's (2015) study on malnutrition and disability in Turkana, Kenya (an area prone to famine) found that the World Food Programme had established a school-based feeding programme, which often was the main meal of the day for children in the area. However, many children with disabilities were not at school and so were excluded from the programme.

#### 4.3 Attitudinal factors

Attitudinal and social barriers may discourage inclusion in particular:

- **Poor knowledge of parents and caregivers:** Parents, carers and service-providers may lack knowledge of how to feed children with disabilities effectively. *'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.'* (Groce et al, 2014, p.311) Family members may treat children with disabilities as infants, continuing to give a liquid-only diet, believing that the child will not be able to take solid foods, leading to severe malnutrition and even death. (Groce et al, 2014)
- **Social and cultural attitudes which devalue the lives of people with disabilities,** may lead to harmful and neglectful practices regarding feeding and health seeking practices. For example, children with disabilities may be fed less, denied food or provided with less nutritious food than siblings without disabilities. In some cultures, mothers may be discouraged from breastfeeding new-borns with disabilities, due to incorrect beliefs that children with disabilities may die anyway or not be able to lead a productive life. (Groce et al, 2014; PCD, 2015; Kuper et al, 2015)

#### 4.4 Institutional factors

Institutional factors include:

- **A need for clear national guidelines and guidance for inclusive nutritional programming.** The 2013 updates to the WHO guidelines on the management of severe acute malnutrition (SAM) recognise a strong link between disability and SAM which needs to be considered and addressed. *'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)'* (Groce et al, 2014, p.313).
- **A lack of disaggregated programme data** prevents practitioners and academics from understanding if and to what extent people with disabilities are accessing programming. (Jones et al, 2018; Groce et al, 2013b).
- **A lack of technical expertise at the delivery level** - including limited training and awareness of staff in early identification and intervention, and how to communicate with people with different types of impairments. *'..disability is often seen as a specialist subject and therefore not mainstreamed into education for practitioners in nutrition, health and child development'* (Groce et al, 2014, p.312).
- **Suboptimal care:** A 2014 study in Malawi followed children treated for severe malnutrition and found that having an underlying disability was second only to HIV as a risk factor for mortality, which could be due to sub-optimal care (i.e. not focused on specific needs of disabled children),

more severe malnutrition on admission, and lack of follow-up after discharge from the nutritional treatment facility. (Kerac et al, 2014)

## 5. Considerations for policy and programming

Special attention is needed to ensure the full inclusion of people with disabilities in the design, implementation, monitoring and evaluation of nutrition programming, by ensuring that these programmes target and effectively reach people with disabilities, services are tailored to their special needs, and mechanisms exist to include them in complementary development interventions, which also impact on nutritional status (i.e. WASH, social protection). This section provides a series of considerations to inform DFID's programming in this area.

Given the multiple factors affecting access (individual, attitudinal, environmental and institutional), most studies and agencies underscore the importance of a **twin-track approach to nutrition programming** in order to meet the needs of people with disabilities which includes both disability mainstreaming and setting up special services, where needed, to reach children with disabilities and their families or caretakers.

**Specific lessons emerging** from the literature include:

- **Improve monitoring and data systems to track access and outcomes** disaggregating data at a minimum by age, gender and disability using the Washington Group Short Set of Questions where possible and appropriate according to the context. Disability disaggregated data will increase the likelihood that programmes are targeting the areas of greatest need. Better data on disability and nutrition is crucial to better understand the specific nutritional needs of people with different types of impairments and take them into account in the planning and implementation of programmes.
- **Ensure political and resource commitments to tackling nutrition and disability as related issues.** In their seminal briefing note on nutrition-disability links and synergies, Groce et al (2014) assert it is imperative that future nutrition policy and programming: recognises and plans for the malnutrition and disability link, and more importantly ensures resources are made available and action is taken to address these issues.
- **Collaboration between the health and disability agendas** including strategic communications which are accessible, do not further stigmatise, and reach the target audience. In particular, there is a need for better linkages with disability-focused policy and programming – with disability programmes offering great potential to serve as an entry point for nutrition services. (Groce et al, 2013b)
- **Inclusion of people disabilities in the development of nutrition policies and programmes,** in line with the principle of 'nothing about us, without us'. Programmes should actively partner with DPOs to ensure that strategies are flexible and responsive to the context-specific needs of people with disabilities.
- **Ensure international and national nutritional plans and policies are explicit about disability-related links and interactions, and provide disability-specific guidance. (Groce et al, 2014)** This includes the need for clear guidance on specific nutritional needs by impairment type.
- **Efforts need to be made to include children with disabilities within food supplementation programmes,** and school-based programmes alone may be inadequate to meet this need. Specific measures recommended include reaching out to parents and DPOs to engage them

and promote school-feeding through their institutions and networks, and ensuring nutrition information and education materials are accessible to the different types of disabilities. (PCD, 2015)

- **There is a need for improved access to nutrition services for pregnant and breastfeeding mothers with disabilities** (Groce et al, 2013b)
- **Mainstream disability in all early-intervention nutrition, health and development efforts;** for example, early screening for malnutrition should be adapted to ensure that it is more accessible to children with disability and their families. (Groce et al, 2013)
- **Community-based interventions provide useful entry points to strengthen and support families to meet children's special needs for care.** Early screening and diagnosis must be linked to the provision of timely and appropriate nutrition support and advice.<sup>14</sup>
- **Tackle supply-side barriers and improve delivery** – through training and awareness raising of health workers on links between disability and nutrition including specific nutrition requirements of people with particular impairments would help to expand inclusive programmes and practice. (Groce et al, 2014)
- **Support disability-specific services which target and address needs of people with disabilities and their caregivers.**

The following text box provides a series of principles for inclusive school health and nutrition programming, with relevance to broader nutrition programmes.

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<sup>14</sup> [https://www.unicef.org/disabilities/index\\_65943.html](https://www.unicef.org/disabilities/index_65943.html)

### Three principles for inclusive school health and nutrition programming

PCD (2015) outline three principles that need to be addressed and carefully monitored when implementing inclusive school health and nutrition programming:

**PRINCIPLE 1: Make children and adolescents with disabilities visible.** Improved health, education and disability data will increase the likelihood that programmes are targeting the areas of greatest need. It is crucial to combat the invisibility of children and adolescents with disabilities, beginning with the collection of basic information and statistics in order to better understand their needs and take them into account in the planning and implementation of programmes.

**PRINCIPLE 2: Ensure access to the programmes.** Ensuring access to health and nutrition programmes for children with disabilities implies addressing issues of physical access as well as the delivery of services and information in a way that is adapted to their needs and functional styles:

- **The accessibility of the physical environment:** meaning access to the school premises and to health and nutrition services and spaces where activities take place, including health care centres and community centres where prevention or education programmes are offered.
- **The accessibility of information,** which means ensuring that all information, education and communication materials and campaigns are designed in such a way as to effectively reach children with different types of disability, taking into account the diversity of their functional characteristics.
- **The accessibility of communication,** which entails training for health and nutrition staff to ensure that they can communicate effectively with children and adolescents with disabilities, so as to provide them with the best possible treatment and care.

**PRINCIPLE 3: Promote family awareness and community-based responses.** It is very important to liaise with families and with community organisations that work with children with disabilities – such as DPOs, churches, special education centres and rehabilitation programmes – to promote their involvement in activities. Engaging these organisations and families in the dissemination of health and nutrition information and raising awareness of risks are critical for sustained inclusive programming.

Be aware that many of the available resources to include children with disabilities in health and education activities are outside the formal sector. Building bridges with informal institutions and empowering children and adolescents with disabilities also responds to a historical premise of the movement of people with disabilities: “Nothing about us without us.”

*Source:* PCD (2015) Inclusive School Health and Nutrition Programmes

## Annex 1: Case studies

This section provides a selection of case studies from nutrition interventions for people with disabilities with a brief description, summary of any outcomes, and lessons learned.

### SPOON Foundation Child Feeding Training

**Description:** The SPOON Foundation provides training and tools on how to feed children safely (including children with disabilities) in low resource settings. The approach includes a package of assessment and intervention tools that address what and how children are fed, incorporating the crucial nutrition and feeding needs of children impacted by disability and/or institutional care. The approach has been applied in multiple countries including Cambodia, Vietnam, Zambia, Russia, Mauritius and Oregon, USA.

**Outcomes:** According to the SPOON Foundation's 2017 Annual Report, the approach has proved effective with an evaluation of their approach in three countries over two years finding it drastically reducing levels of stunting by 32%, wasting by 11% and Anaemia by 28%.

**Lessons learned:** SPOON spreads its expertise and tools through international and local partners who are already established on the ground, leveraging their regional knowledge, relationships and staff presence to expand quickly and effectively. This strategy, ensures solutions that are locally contextualised, locally owned, and sustained over the long-term.

**Source:** [www.spoonfoundation.org](http://www.spoonfoundation.org)

### UNICEF Home Visitation Programme, Bosnia and Herzegovina

**Description:** Home-visiting programmes – an approach that spans child protection, health and nutrition and early childhood development – gives families support and connects them to specialised services. UNICEF Bosnia and Herzegovina – through its Early Detection and Intervention Services for children with disabilities - is supporting health services during home visits to provide nutrition services for children from birth to age three years who exhibit feeding difficulties and for parents with additional training and counselling relating to their children's nutritional needs. The country office is seeking to scale up the mainstreamed model of Early Detection and Intervention services and further support is provided to the Ministry of Health to reach more homes and more children with disabilities.

**Outcomes:** No data publicly available on reach and outcomes.

**Lessons learned:** As the services are administered in the home, parents are fully involved and engaged.

**Source:** GPCWD (2013)

### UNICEF Child Survival and Development Programme, Vietnam

**Description:** The Child Survival and Development Programme is using an integrated work plan for Health, WASH, and Nutrition to address the nutritional needs of children and youth with disabilities. Through community-based health and nutrition services and community screenings, the country office seeks to identify and serve children and youth with disabilities.

**Outcomes:** No data publicly available on reach and outcomes.

**Lessons learned:** In addition to work at the community level, UNICEF has supported the Ministry of Health to develop and approve national guidelines on early identification and interventions for children with disabilities. These include guidance on how to address swallowing and feeding difficulties facing children with specific nutrition related disabilities.

**Source:** GPCWD (2013)

## World Vision Bangladesh: Integrated Health, Nutrition, and WASH Project in Partnership with UNICEF

**Description:** As part of an effort to raise awareness that children with disabilities face an increased risk of being malnourished, World Vision Bangladesh is mainstreaming the nutritional needs of children with disabilities as part of an integrated Health, Nutrition, and WASH project in partnership with UNICEF that targets young children, adolescent girls, and pregnant and lactating women. By strengthening the capacity of government health workers and increasing community demand for nutritional services for its targeted populations in Bhaluka and Khulna districts, World Vision harnesses the existing nutrition activities of the government health services to mainstream the nutritional needs of children with disabilities.

During home visits, community volunteers collect data on different nutrition indicators, including breastfeeding, complementary feeding, and hygiene practices. World Vision staff and volunteers ensure that children with disabilities receive access to nutrition programs by conducting education/awareness sessions with caregivers of children with disabilities and influential persons of the community, and encouraging these caregivers to take their children to nutrition facilities.

**Outcomes:** No data publicly available on reach and outcomes.

**Lessons learned:** Community volunteers conduct monthly home visits of all the children and youth with disabilities in the project coverage area to ensure full participation.

**Source:** GPCWD (2013)

## Counterpart International's Food Aid for Disabled Children Project 2011-2013

**Description:** The project provided two meals a day to impoverished children with disabilities in the capital of Niger. The project reached approximately 1,600 people with disabilities (mostly blind people) and engaged community leaders, parents of children with disabilities and community members through awareness raising activities.

**Outcomes:** Results reported on the website include an increase in school attendance by 20%.

**Source:** <https://www.counterpart.org/projects/food-aid-for-disabled-children-project/>

## World Food Programme, School-Meals Programme, Laos

**Description:** The World Food Programme (WFP) has extended its school meals programme to specialist institutions for children with disabilities in Luang Prabang and Vientiane. Students with disabilities receive daily school meals, and non-food items to establish vegetable gardens.

**Outcomes:** No data publicly available on reach and outcomes.

**Lessons learned:** WFP recently signed a partnership agreement with the Laos Disabled People's Association (LDPA), a civil-society organisation advocating for the rights of people with disabilities. Together with LDPA, WFP is building staff capacity and learning how to best support, promote and strengthen the empowerment of people with disabilities in its programmes.

**Source:** <https://www.wfp.org/news/news-release/wfp-supports-people-disabilities-through-school-meals-lao-pdr>

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## Expert contributors

Professor Nora Groce, Director of the Disability Research Centre at University College London.

Professor Hannah Kuper, Director of the International Centre for Evidence in Disability, LSHTM

**About Helpdesk reports:** The Disability Inclusion Helpdesk is funded by the UK Department for International Development, contracted through the Disability Inclusion Team (DIT) under the Disability Inclusive Development Programme. Helpdesk reports are based on between 3 and 4.5 days of desk-based research per query and are designed to provide a brief overview of the key issues and expert thinking on issues around disability inclusion. Where referring to documented evidence, Helpdesk teams will seek to understand the methodologies used to generate evidence and will summarise this in Helpdesk outputs, noting any concerns with the robustness of the evidence being presented. For some Helpdesk services, in particular the practical know-how queries, the emphasis will be focused far less on academic validity of evidence and more on the validity of first-hand experience among disabled people and practitioners delivering and monitoring programmes on the ground. All sources will be clearly referenced.

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