Children Living with Disabilities Are Absent From Severe Malnutrition Protocols: A Guideline Review

Magdalena Engl,[a*] Paul Binns,[b] Indi Trehan,[c] Natasha Lelijveld,[d] Chloe Angood,[d] Marie McGrath,[d] Nora Groce,[e] Marko Kerac [f, g]

[a] Faculty of Infectious and Tropical Diseases, London School of Hygiene & Tropical Medicine (LSHTM), London, UK

[b] Action Against Hunger, UK

[c] Departments of Pediatrics, Global Health, and Epidemiology, University of Washington, Seattle, USA

[d] Emergency Nutrition Network, Oxford, UK

[e] International Disability Research Centre, Department of Epidemiology and Health Care, University College London

[f] Department of Population Health, London School of Hygiene & Tropical Medicine, London, UK

[g] Centre for Maternal, Adolescent, Reproductive & Child Health (MARCH), London School of Hygiene & Tropical Medicine, London, UK.

*Corresponding author: Magdalena Engl, Keppel St, London WC1E 7HT. Email: Magdalena.Engl1@alumni.lshtm.ac.uk

ABSTRACT

Purpose Children living with disabilities (CLWD) are at high risk of malnutrition but have long been marginalised in malnutrition treatment programmes and research. The 2013 World Health Organization (WHO) guidelines for Severe Acute Malnutrition (SAM) mention disability but do not contain specific details for treatment or support. This study assesses inclusion of CLWD in national and international SAM guidelines.

Methods National and international SAM guidelines available in English, French, Spanish, or Portuguese were sourced online and via direct enquiries. Regional guidelines or protocols sub-specialising in a certain patient group (e.g. people living with HIV) were excluded. Eight scoping key informant interviews were conducted with experts involved in guideline development to help understand possible barriers to formalising malnutrition guidance for CLWD.

Results 71 malnutrition guidelines were reviewed (63 national, 8 international). National guidelines obtained covered the greater part of countries with a high burden of malnutrition. 85% of guidelines (60/71) mention disability, although mostly briefly. Only 4% (3/71) had a specific section for CLWD, while the remaining lacked guidance on consistently including CLWD in programmes or practice. Only one guideline mentioned strategies to include CLWD during a nutritional emergency. Most (99%,70/71) did not link to other disability-specific guidelines. Of the guidelines that included CLWD, most only discussed disability in general terms despite the fact that different interventions are often needed for children with different conditions. Interviews pointed towards barriers related to medical complexity, resource constraints, epidemiology (*e.g.*, unrecognised burden), lack of evidence, and difficulty of integration into existing guidelines.

Conclusion Children living with disability are not recognised in most SAM guidelines. Where they are, recommendations are very limited. Better evidence is urgently needed to identify and manage CLWD in malnutrition programmes. More inclusion in the 2022 update of the WHO malnutrition guidelines could support this vulnerable group.

Keywords: disability, malnutrition, malnutrition guidelines, undernutrition, severe acute malnutrition, children living with disabilities, wasting

INTRODUCTION

Globally, some 291 million children and adolescents live with a disability, as shown in a recent analysis of the Global Burden of Disease Study 2017 data.[1] It is also estimated that 47 million children aged under 5 years are suffering from wasting [2], and that a significant, but as yet unknown number of children living with disabilities (CLWD) are amongst these millions of children. Disability and malnutrition interact in many ways: feeding problems related to anatomic or motor impairments, nutrient malabsorption or social exclusion are some of the ways in which underlying disability can increase the risk of malnutrition.[3, 4] A 2014 paper explains the pathways neurodisabilites can both cause and be caused by malnutrition. While decreased food intake, increased nutrient losses or increased nutrient requirements increase the risk for malnutrition, macro - and micronutrient (*e.g.* iodine, iron, Vitamins A or B6) deficiencies can in turn lead to neurodisabilities. [5] A 2018 systematic review found the pooled odds ratio for undernutrition was three times higher for CLWD, compared to non-disabled children (double for stunting and wasting, respectively).[6] CLWD also have greater risk of adverse outcomes, including death, following treatment for severe acute malnutrition (SAM).[7]

There is an imperative through the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals [2, 8] for international actors to commit to greater inclusion of persons living with disabilities in health care and in related sectors such as humanitarian practice initiatives.[9-11] The 2013 update of the WHO SAM guidelines recognises disability as an underlying factor for malnutrition. However, disability is only briefly mentioned as a possible reason for referral for specialised care and there are no specific recommendations for this vulnerable patient group. The guideline does not include details on a proactive screeing for disability, any specific feeding, nutrition or medical treatment recommendations, counselling advice for caregivers, prevention strategies or references to disability-specific guidelines (see **table 4**). [12] The needs of children living with disabilities may differ from other children regarding more complex feeding problems, slower weight gain

despite the same treatment, and higher risk of not achieving nutritional recovery. Anthropometry can be more challenging: measuring weight-for-length may be difficult due to spastic contractures (and different target values may apply, *e.g.* in children with growth restrictions), and mid-upper arm circumference (MUAC) accuracy may be influenced by differences in muscle mass or body composition [13] changes.

There is an evidence gap around the identification and management of malnutrition in CLWD [3, 4] and disability can be an exclusion criterion in some studies on malnutrition.[14] Greater inclusion of disability in nutrition research has been called for numerous times in the academic literature. [4, 5, 15] Still, there remain a number of "unexplored opportunities for collaboration" between malnutrition and disability programmes, a need for more political and resource commitment, and a need for malnutrition policies and guidelines to contain detailed guidance specific to CLWD leading to higher visibility of people living with disabilities in front-line practice.[15]

This study aims to provide an overview of the current status of recommendations for CLWD in national and international SAM guidelines, in light of the ongoing 2022 WHO malnutrition guideline update. These new guidelines will influence malnutrition care over the coming decade, and we hope this study will help highlight the need of more inclusivity.

METHODS

We aimed to identify the most current version of available national and international guidelines focusing on SAM in children aged 0-18 years. These were searched online using manual searching via common search engines, and using resource collections of national health ministries, malnutrition working groups, and international organisations. Contacts of the co-authors, UNICEF regional office teams, and respondents to a call posted on the Emergency Nutrition Network (ENN) global technical forum (https://en-net.org) helped identify additional guidelines. **Table 1** provides details on guideline search strategies and sourcing. The most current final or draft/interim version of national and international protocols were included.

Protocols in English, French, Spanish, or Portuguese were reviewed. Incomplete documents, regional guidelines, or protocols sub-specialising in a certain patient group (e.g. people living with HIV) were excluded. After a full-text review of each guideline, relevant content on disability-specific information, clinical recommendations, monitoring and evaluation indicators, malnutrition prevention strategies and links to other pertinent guidelines were extracted into an electronic database.

Scoping key informant interviews were conducted to understand perceived barriers to formalising guidance specific to malnourished CLWD. Based on previous work, we aimed for 10 participants to reach content saturation.[16]

Interview participants sought were experts on malnutrition involved in malnutrition guideline development in various roles (e.g. clinicians, academics, policy makers, independent consultants) and countries. They were contacted by purposive sampling via email using established professional networks, via an ENN forum call, and by snowball sampling.

Informants received an information sheet, signed a consent form, and were sent a previously piloted interview guide. They commented purely in a personal capacity, not representing any institutions or organisations.

Interviews were conducted by the lead author via an online video call and lasted approximately 45 minutes. The interview was recorded, transcribed and anonymised, and participants were offered the transcripts to verify accuracy. Thematic analyses of the transcripts were performed following the steps outlined by Richie and Spencer.[17]

RESULTS

71 malnutrition guidelines were identified, of which 89% (63/71) were national guidelines from 56 countries (see **table 2**). For seven countries, more than one guideline was included as separate protocols existed *e.g.* for inpatient/outpatient treatment. National guidelines were distributed across the following UNICEF-designated regions: 32% (20/63) from West and Central Africa, 29% (18/63) from Eastern and Southern Africa, 14% (9/63) from

South Asia, 14% (9/63) from East Asia and the Pacific, 6% (4/63) from the Middle East and North Africa, and 5% (3/63) from Latin America and the Caribbean. The final 11% (8/71) were international guidelines from one or more NGOs.[18-25] 75% (53/71) were published in 2013 and later.

While 85% of the guidelines (60/71) mention disability, most did so briefly. Only 4% (3/71) have a dedicated section on children living with disabilities. No international guideline is amongst these.

Regular integration of CLWD into the body of the guidelines was also rare. With few exceptions, the extent of referencing disability in guidelines is limited to side notes:

- 43/60 (72%) note disability as a possible indication for nasogastric tube feeding (e.g. cleft lip/palate)
- 39/60 (65%) acknowledge disability as a possible reason for treatment failure or non-response
- 18/60 (30%) suggest disability as a reason for inpatient treatment
- 6/60 (10%) recognize disability as a risk factor for malnutrition

Cerebral palsy and cleft lip/palate were commonly mentioned disabilities, while some refer broadly to “congenital abnormalities”. Almost no guidelines responded to specific needs of CLWD:

- 1/60 outlined specific breastfeeding advice for children with cleft lip/palate (Timor-Leste 2016[26])
- 1/60 specified a multidisciplinary approach for managing children with cerebral palsy and gave feeding counselling advice (Lebanon CMAM 2017[27])
- 18/60 (30%) recommend the “medical referral” of CLWD to a specialist

While 70% (42/60) of guidelines mention the need to identify disability in the physical assessment of a child, this primarily meant listing a box to check “disability yes/no” on a

physical assessment form. Only one guideline (Ethiopia CMAM 2019[28]) advises users to "proactively screen for disability". One other protocol (Timor-Leste 2016[26]) specifies to "also look for developmental delay".

One protocol (Lebanon 2017[27]) linked the use of their protocol to other disability-specific guidance available (a cerebral palsy feeding and nutrition review[29]). 6/60 protocols (10%) mentioned social or mental health support for CLWD and their families:

- 1/60 to establish a link with supporting families in nutritional emergency situations
- 1/60 to prioritise CLWD for psychosocial support
- 1/60 discussed informing caretakers on realistic outcome expectations (e.g. slower weight gain)
- 1/60 recommended home visits for CLWD
- 2/60 encouraged to provide counselling on the nutritional needs of CLWD
- 3/60 to "refer to appropriate support services" (no specifics)

Very few guidelines (3/60, 5%) include any Monitoring and Evaluation (M&E) indicators specific to disability.

There were four positive examples of more inclusive guidelines that are highlighted in **Table 3.** Three of these contain separate chapters on CLWD and the fourth mentions strategies to support CLWD in the context of a humanitarian emergency.

Perceived barriers to formalising recommendations

Eight malnutrition experts (three female, five male) were recruited for the scoping interviews (zero participation refusals). Participants worked as clinicians, academics, policy makers and/or independent consultants; all had been involved in the development of malnutrition guidelines. Regarding perceived barriers to including CLWD in malnutrition guidelines, five main themes emerged: *Medical expertise, Resources, Epidemiology,*

Evidence, and *Guideline Structure*. Within *medical expertise*, subthemes identified were *available diagnostics* and *staff knowledge.*

Regarding medical expertise, the perceived medical complexity, wide range of disabilities and difficulty in developing a guideline that fits all were brought up by several experts (5/8) as a key challenge. As one participant said, *"That's where the problem starts to get really complicated (…). Is it mental or is it physical? (…) what is it that's causing the disability? What are the functional outcomes (…)?"*.

Several informants (5/8) mentioned a weak evidence base for recommendations, including around the correct use of anthropometrics (*e.g.*, special growth charts for CLWD). One participant said, *"I have looked hard enough for it. But (…) I found very little…".* Another mentioned the difficulties of designing studies to include CLWD as the various disabilities make for a complex and heterogenous study population, with arising data difficult to interpret.

Three participants brought up possible resource constraints, one clinician pointing out that *"They have a much harder time recovering (…), so then they get treated again (…)And they're in the program for months (…) So, it become very expensive to the program (…)".*

Epidemiology was discussed by four informants, *e.g.* noting that CLWD may not be officially registered (and thus the prevalence remaining unrecognised).

Two participants commented on guideline structures, one saying that recommendations on CLWD may be hard to fit into a space-constrained document. Another discussed the benefits and drawbacks of the creation of many separate guidelines (*e.g.*, for malnutrition in people living with HIV, in the elderly, in CLWD,…).

DISCUSSION

This study shows that children living with disabilities are still largely invisible in most national and international malnutrition guidelines. Due to the wide range of disabilities, this can be a complex topic, as some children living with different types of disability need tailored approaches. An important concept within the move towards more inclusivity is the 'twin-track

approach', combining mainstreaming (addressing inequalities in all areas of programmes, ensuring equal access to basic needs and interventions) with targeted and individualized support of persons with disabilities. [30]

A first step in making CLWD visible in guidelines and front-line practice is recommending active screening for disability during case finding and admission to malnutrition treatment programmes, be that inpatient or community-based. Recent work suggests that formal screening tools may help with this: many types of disabilities, especially those that are less severe or less obvious are missed via routine clinical examination alone.[7] Some disabilities can be challenging to diagnose clinically, and malnutrition treatment failure, relapse cases or malnutrition in older children should prompt investigations towards disability. Technical difficulties in measuring the height or length of children with postural impairments (*e.g.*, muscle contractures in cerebral palsy) also need to be addressed, for example via alternative indicators.[31] Not including specific indicators for CLWD during M&E processes perpetuates their invisibility, increasing the likelihood that the scale of the problem will remain difficult to recognise. A first step here could simply mean including an indicator in tally sheets of malnutrition programmes to record all children admitted with any disability (ensuring no double-counting in the process), and to record their types of discharges (*e.g.* cured, default, non-response, transfer, referral, death) to shed light on the scale of patient load and outcomes. In a future step, differentiations between types of disabilities could be made, to allow more tailored support of prevalent disabilities.

Reiterating the human rights imperative of providing every child with the chance to survive and thrive, there are a variety of opportunities for increasing the chances of CLWD to receive optimal care, ranging from awareness of risk and the early identification of CLWD to appropriate treatment, more intensive follow-up, and linking with social, economic and mental health support for the child and family. A small but increasing number of resources exist to support feeding and nutrition in children with disabilities, ranging from models for social

support to more clinical guidance or to specific feeding support, *e.g.* for children with cerebral palsy. [32-40]

The evidence base relating to malnutrition in CLWD is sparse and needs to be strengthened by acknowledging this as a research priority. Whilst it is good that the 2013 WHO SAM guideline update mentions disability, details in the guideines are very limited and so it is arguably unsurprising that eight years on, there is a continuing lack of tailored recommendations in the protocols reviewed in this study. Many national and international malnutrition guidelines are modelled on the WHO guidelines, and several are based on template guidelines. In the case of the protocols reviewed here, several were derived from the 2011 IMAM Generic Protocol developed by Golden and Grellety.[41] Changes in these widely used templates towards more inclusion of CLWD, or the creation of new guides to mainstream disability into all aspects of CMAM guidelines could have a significant impact on protocols globally. The upcoming 2022 update of the WHO wastingguidelines is a good opportunity to create more inclusive guidelines. It offers the opportunity to include disability in the search strategy of the systematic reviews commissioned for evidence collection. Guidelines may consider a distinct section for the treatment of SAM in CLWD to highlight their vulnerability and respond to their needs. Another option may be the integration of CLWD all throughout updated guidelines, as this may still further their inclusion if viewed as an integral part of all treatment programmes rather than a separated patient group. However, the evidence base for such guidance remains sparse.

Recommendations need to go beyond mentioning disability as a side note. There is a need to be specific and detailed to allow health workers without extensive experience in disability to provide optimal care. Stating ‘provide feeding as adequate for the respective condition’ is insufficient without specifying what this would mean for children with different types of disability; there needs to be more detailed ‘how-to’, step-by-step guidance. In order to create this kind of guidance, disability needs to be included in the systematic evidence

gathering for malnutrition guideline development and should be highlighted as a research priority.

Integrating disability into M&E and nutrition and coverage surveys is another vital step to ensure the actual caseload of CLWD more visible. National guidelines would benefit from including country-specific information on available support services for CLWD, calling upon the expertise of both national and international advocates and experts. If the scope of the guidelines does not allow for this level of detail, a link to other guidance should be established. The option of entirely separate country-specific protocol documents for malnutrition in CLWD (similar to existing stand-alone guidelines for malnutrition in people living with HIV), a related template guideline, and/or a guide to mainstream disability into national CMAM protocols could be discussed, and may be appropriate for some countries although the merits and drawbacks of these approaches must be considered on a country-by-country basis.

Table 4 shows initial suggestions of areas of inclusion for more inclusive guidance on managing malnutrition in CLWD, to be further developed and built upon.

This study has several limitations. First, even if a guideline contains specific recommendations for CLWD, this does not necessarily translate into practical, effective implementation, which is likely to vary in different settings. Second, not all existing national and international guidelines could be identified for inclusion in this study. Nevertheless, the 63 national guidelines included cover the greater part of countries with a high burden of malnutrition, thus, we believe, valid conclusions can still be reached. Finally, interviews were scoping interviews to help with initial undertstanding of the issues. Future work would include a wider range of key informants, *e.g.* government officials involved in guideline development and front line staff working in implementation and management of malnourished CLWD.

In conclusion, children living with disabilities are still largely marginalised in malnutrition guidelines intended for all children. Though recognition is an important first step, much work needs to be done to expand guidance on the specifics of identification and management of

CLWD. We hope our findings can help raise awareness of the need for a commitment towards greater visibility and inclusion of malnourished children living with disabilities.

DATA AVAILABILITY STATEMENT:

Data are stored in the LSHTM Data Compass repository and are available upon reasonable request.

ETHICS STATEMENT:

This study was approved by the London School of Tropical Medicine (LSHTM) ethics committee (Reference Number 21844).

ACKNOWLEDGEMENTS: We sincerely thank everyone helping to source the guidelines, and all the interviewees for taking time to share their insights with us.

COMPETING INTERESTS: IT acts as an Associate Editor at the Archives of Disease in Childhood, but was not involved in the peer review of this publication.

FUNDING: ME (part-funded), CA, NL and MM were funded by Irish Aid and the Eleanor Crook Foundation. MK also acknowledges the Eleanor Crook Foundation for funding support.

CONTRIBUTORS: MK and ME had the initial idea for this paper. Other authors contributed to a different earlier version of the guideline review project. MK led the design process. ME did the literature and guideline review. Interviews were conducted, transcribed and analysed by ME. The first draft of the paper was written by ME, which was reviewed and revised by all coauthors.

What is already known on this topic

There is a strong association between disability and malnutrition, but children living with disabilities are often marginalised in malnutrition research and treatment programmes.

The 2013 WHO guideline update for severe acute malnutrition mentions disability but does not contain specific details on managing malnutrition in this vulnerable patient group.

National and international malnutrition protocols are often based on WHO guidelines, and thus likely reflect this lack of disability specific recommendations within the WHO guidelines.

What this study adds

Many currently available national and international guidelines for severe acute malnutrition mention children living with disabilities, but few contain any specific management details.

Scoping key informant interviews identified key challenges to providing recommendations for malnourished children living with disabilities, related to medical expertise, resources, epidemiology, evidence, and guideline structure.

The identified lack of specific guidance for this vulnerable group should prompt future guideline developers to aim for more inclusive protocols.

REFERENCES

1. Olusanya BO, Wright SM, Nair MKC, et al. Global Burden of Childhood Epilepsy, Intellectual Disability, and Sensory Impairments. *Pediatrics*. 2020;146(1).
2. United Nations. The Sustainable Development Goals Report 2020 2020 [Available from: https://unstats.un.org/sdgs/report/2020/.
3. Kuper H, Nyapera V, Evans J, et al. Malnutrition and childhood disability in Turkana, Kenya: Results from a case-control study. *PloS one*. 2015;10(12):e0144926.
4. Groce NE, Kerac M, Farkas A, et al. Inclusive nutrition for children and adults with disabilities. *The Lancet Global Health*. 2013;1(4):e180-e1.
5. Kerac M, Postels DG, Mallewa M, et al. The interaction of malnutrition and neurologic disability in Africa. *Seminars in pediatric neurology*. 2014;21(1):42-9.
6. Hume-Nixon M, Kuper H. The association between malnutrition and childhood disability in low-and middle-income countries: systematic review and meta-analysis of observational studies. *Tropical Medicine & International Health*. 2018;23(11):1158-75.
7. Lelijveld N, Groce N, Patel S, et al. Long-term outcomes for children with disability and severe acute malnutrition in Malawi. *BMJ global health*. 2020;5(10):e002613.
8. The United Nations. Convention on the Rights of Persons with Disabilities. 2006.
9. Akerkar S, Bhardwaj R. Good practice guide: embedding inclusion of older people and people with disabilities in humanitarian policy and practice. *Age and Disability Consortium (ADCAP)*. 2018:1-160.
10. UNICEF. Core Committments for Children in Humanitarian Action 2020 [Available from: https://www.unicef.org/emergencies/core-commitments-children.
11. Stough LM, Kang D. The Sendai framework for disaster risk reduction and persons with disabilities. *International Journal of Disaster Risk Science*. 2015;6(2):140-9.
12. World Health Organization. Updates on the management of severe acute malnutrition in infants and children. *Geneva: World Health Organization*. 2013.
13. McDonald CM, Abresch-Meyer AL, Nelson MD, et al. Body mass index and body composition measures by dual x-ray absorptiometry in patients aged 10 to 21 years with spinal cord injury. *J Spinal Cord Med*. 2007;30 Suppl 1(Suppl 1):S97-S104.
14. Lelijveld N, Kerac M. A holistic approach to malnutrition follow-up care. *Journal of Public Health and Emergency*. 2017;1(4).
15. Groce N, Challenger E, Berman-Bieler R, et al. Malnutrition and disability: unexplored opportunities for collaboration. *Paediatrics and international child health*. 2014;34(4):308-14.
16. Read S, McGrath M. Community management of uncomplicated malnourished infants under six months old: barriers to national policy change. *Field Exchange 57*. 2018:27.
17. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. *The qualitative researcher's companion*. 2002;573(2002):305-29.
18. Médecins sans Frontières. Clinical Guidelines 2020 [Available from: medicalguidelines.msf.org.
19. Médecins sans Frontières. Nutrition guidelines 2014 [Available from: https://bibop.ocg.msf.org/docs/16/L016NUTM01E-P_Nutrition-2014.pdf.
20. Médecins sans Frontières OCG & OCBA. Protocols for Management of Nutritional Support in Children with Severe Acute Malnutrition. Internal Guideline - Pilot Version 2015 [Available from: https://bibop.ocg.msf.org/docs/16/L016NUTM19E-E_PEDNUT-Nut-EN_2015.pdf.
21. Médecins sans Frontières OCB Niger. Protocole Nutritionnel - Médical Nouveau-nés et nourrissons 2008 [Available from: No URL available (internal document).
22. Médecins sans Frontières OCBA. Therapeutic feeding programme - nutritional and medical protocol. All age groups. 2014 - revised 2015 [Available from: No URL available (internal document).

23. ACF International. Guidelines for the integrated management of severe acute malnutrition: in- and out-patient treatment 2011 [Available from: https://www.actionagainsthunger.org/publication/guildines-integrated-management-severe-acute-malnutrition-and-out-patient-treatment.
24. FANTA III UNICEF Concern et al. Training Guide for Community-Based Management of Acute Malnutrition (CMAM) 2018 [Available from: https://www.fantaproject.org/focus-areas/nutrition-emergencies-mam/cmam-training.
25. World Vision. Community-Based Management of Acute Malnutrition (CMAM) - Project Model 2017 [Available from: https://www.wvi.org/nutrition/project-models/cmam.
26. Ministry of Health Timor-Leste. Specific Nutrition Intervention Package (SNIP) Guidelines 2016 [Available from: No URL available, obtained through contacts.
27. Republic of Lebanon Ministry of Public Health. Management of Acute Malnutrition - National Guidelines 2017 [Available from: No URL available, obtained through contacts.
28. Government of Ethiopia Federal Ministry of Health. National Guideline for the Management of Acute Malnutrition in Ethiopia 2019 [Available from: No URL available, obtained through contacts.
29. Ferluga ED, Archer KR, Sathe NA, et al. Interventions for feeding and nutrition in cerebral palsy. *Comparative Effectiveness Reviews*. 2013;94.
30. DFID. Disability, poverty and development 2000 [Available from: https://hpod.law.harvard.edu/pdf/Disability-poverty-and-development.pdf.
31. Yousafzai AK, Filteau SM, Wirz SL, et al. Comparison of armspan, arm length and tibia length as predictors of actual height of disabled and nondisabled children in Dharavi, Mumbai, India. *European Journal of Clinical Nutrition*. 2003;57(10):1230-4.
32. Zuurmond M, O'Banion D, Gladstone M, et al. Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PloS one*. 2018;13(9):e0202096.
33. Holt International. Holt International's Feeding and Positioning Manual: Guidelines for Working with Babies and Children 2019 [Available from: https://www.holtinternational.org/about/child-nutrition/feeding-and-positioning-manual/.
34. MCAI (Maternal & Childhealth Advocacy International). International Maternal & Child Health Care: A practical manual for hospitals worldwide: Radcliffe Publishing Ltd. ; 2014.
35. SPOON. Count Me In http://www.spoonfoundation.org/what-we-do/our-approach/count-me-in/; 2019.
36. Werner D. Disabled Village Children: The Hesperian Foundation; 1987 [Available from: https://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00201.html#index.
37. LSHTM, ICED, CBM, et al. Getting to know cerebral palsy (module 0) 2013 [Available from: https://www.lshtm.ac.uk/media/24276.
38. LSHTM, ICED, CBM, et al. Getting to know cerebral palsy - module 6 (feeding your child) 2013 [Available from: https://www.lshtm.ac.uk/media/24306.
39. Banerjee R, Kundu M, Arundhuti B. Feeding for the child with cerebral palsy Indian Institute of Cerebral Palsy: Indian Institute of Cerebral Palsy; 1995 [Available from: https://asksource.info/pdf/A933_feedingthechild_1995.pdf.
40. CBM. Humanitarian Hands-On Tool (HHOT) [Available from: https://hhot.cbm.org/en/.
41. Golden M, Grellety Y. Golden MH Grellety Y, Integrated Management of Acute Malnutrition (IMAM) Generic Protocol ENGLISH version 6.6.2 2011 [Available from: https://www.researchgate.net/publication/292131715_Golden_MH_Grellety_Y_Integrated_Management_of_Acute_Malnutrition_IMAM_Generic_Protocol_ENGLISH_version_662.
42. Government of Malawi Ministry of Health. Guidelines for community-based management of acute malnutrition 2016 [Available from: https://www.fantaproject.org/sites/default/files/resources/Malawi-CMAM-Guidelines-Dec2016.pdf.

Table 1. Search terms, contacts and online resources used

Online search terms used (and respective translations to French, Spanish and Portuguese)	Combinations of “Guideline(s)”, “Malnutrition”, “IMAM”, “CMAM”, “SAM”, “Integrated Management of Acute Malnutrition”, “Community (based) Management of Acute Malnutrition”, “Severe Acute Malnutrition”, “Acute”, “Wasting”, “Unternutrition”, “Nutrition”, “National”, “International”
UNICEF regional/country offices contacted	UNICEF India, UNICEF East Africa, UNICEF West Africa, UNICEF South Asia, UNICEF Burundi, UNICEF New York
Accessed online databases and document libraries	Document libraries of National Health ministry homepages of countries listed in **table 2**, Paho.org, who.int, espen.org, unhcr.org, unicef.org, nutritioncluster.net, validinternational.org, en-net.org, nowastedlives.org, acutemalnutrition.org, fantaproject,org, reliefweb.org, imtf.org, www.ennonline.net

Table 2. Guidelines included in this review

UNICEF region	Country or organisation	Year	Draft (interim) or final	Malnutrition guideline type
East Asia and the Pacific	Cambodia (1)	2017	Final	Outpatient (to be used in conjunction with community + inpatient handbook)
	Cambodia (2)	2017	Draft	inpatient (to be used in conjunction with community + outpatient handbook)
	Indonesia	2019	Final	IMAM
	Lao PDR	2018	Final	IMAM
	Myanmar	2017	Final	IMAM
	Timor-Leste	2016	Final	IMAM + IYCF + other nutrition interventions combined
	Philippines (1)	2015	Final	IMAM (in conjunction with MAM guideline)
	Philippines (2)	2016	Final	IMAM (in conjunction with SAM guidelines)
	Vietnam	2016	Final	CMAM
South Asia	Afghanistan	2018	Final	IMAM
	Bangladesh (1)	2017	Final	CMAM
	Bangladesh (2)	2017	Final	inpatient
	India (1)	2011	Final	Inpatient
	India (2)	2019	Draft	CMAM with inpatient focus
	India (3)	2020	Draft	CMAM
	Nepal	2017	Final	IMAM
	Pakistan	2009	Final	CMAM
	Sri Lanka	2007	Final	SAM
Middle East and North Africa	Lebanon	2017	Final	CMAM
	Sudan	2009	Interim	CMAM
	Yemen	2013	Interim	CMAM
Eastern and Southern Africa	Angola	2019	Final	IMAM
	Botswana	2019	Final	IMAM
	Burundi	2018	Draft	IMAM
	Comoros	2013	Final	IMAM
	Eritrea	2010	Final	IMAM
	Ethiopia	2019	Final	CMAM
	Eswatini	2010	Final	IMAM
	Kenya	2020	Final	IMAM
	Madagascar	2018	Final	IMAM
	Malawi	2016	Final	CMAM
	Mozambique	2018	Final	CMAM
	Rwanda	2018	Final	CMAM
	Somalia	2019	Final	IMAM
	South Africa	2015	Final	IMAM
	South Sudan (1)	2017	Final	CMAM

	South Sudan (2)	2018	Final	Inpatient
	Tanzania	2018	Final	IMAM
	Uganda	2020	Draft	IMAM
	Zimbabwe	2020	Draft	IMAM
West and Central Africa	Benin	2011	Final	CMAM
	Burkina Faso	2014	Final	IMAM
	Cameroon	2013	Final	IMAM
	Central African Republic	2014	Final	IMAM
	Chad	2014	Final	IMAM
	Congo	2015	Final	IMAM
	Democratic Republic Congo	2016	Final	IMAM
	Gambia	2013	Final	IMAM
	Ghana	2010	Interim	CMAM
	Guinea	2012	Final	IMAM
	Guinea-Bissau	2013	Final	IMAM
	Liberia	2012	Final	IMAM
	Mali	2011	Final	IMAM
	Mauritania	2011	Final	IMAM
	Niger	2016	Final	IMAM
	Nigeria (1)	2011	Final	CMAM
	Nigeria (2)	2016	Final	Inpatient
	Senegal	2013	Final	CMAM
	Sierra Leone	2014	Final	IMAM
	Togo	2013	Final	IMAM
Latin America and Caribbean	Haiti	2010	Final	CMAM
	Honduras	2004	Final	Inpatient
	Guatemala	2009	Final	inpatient (in Centro de Recuperación Nutricional =CRN, not a hospital)
International Guidelines	FANTA, ACF, WV, Valid, Concern, UNICEF, FHI360, ALIMA, ENN, IRC, IMC, Save the Children	2018	Final	CMAM Training Guide
	ACF International	2011	Final	IMAM
	World Vision	2017	Final	CMAM Project Model
	MSF - Intersectional	2019	Final	SAM (book chapter)
	MSF OCG & OCBA	2015	Draft	SAM
	MSF - OCBA	2014	Final	Therapeutic Feeding Programme
	MSF-B Niger	2008	Final	SAM
	MSF	2014	Final	Overall nutrition guidelines (SAM, MAM, Nutrition Assessments and more)

Table 3. Positive examples of guidelines with recommendations for children living with disabilities

Ethiopia 2019 CMAM[28]	○ Specific chapter ("Vulnerable groups") ○ Recognises link between disability and malnutrition ○ Proactively screens for disability ○ "Offer disability-specific feeding advice" (but does not specify) ○ Counselling on realistic outcome expectations ○ Regular home visits ○ Referral to support services
Lebanon 2017 CMAM[27]	○ Specific chapter on CLWD ○ Extensive information on cerebral palsy: team treatment approaches (including gastroenterologists, speech therapists, dieticians, nurses, psychologists), feeding advice, providing daily micronutrient supplements ○ Link with support structures ○ Refers to guidance document on cerebral palsy
Malawi 2016 CMAM[42]	○ Specific sub-heading (SAM in CLWD) ○ Recognises link between disability and malnutrition ○ Proactively look for CLWD ○ Proposes substituting RUTF with F100 (e.g. if cleft palate, cerebral palsy) ○ Counsel and advise parents about disability ○ "Offer disability-specific feeding and treatment" ○ "Provide realistic outcome expectations" ○ Refer to appropriate services
Timor-Leste 2016 Specific Nutrition Intervention Package Guidelines[26]	○ Lists CLWD as vulnerable group in emergencies (but notes that prevalence of malnutrition in this group is unknown) ○ In emergencies: give general ration, organize food distribution adapted to their needs, link disabled people with supporting families for joint preparation of meals, health/nutrition/hygiene education, gives feeding advice for children with oral malformations

Note: CMAM = Community-based management of acute malnutrition RUTF = Ready to use therapeutic food

Table 4. Including children living with disabilities for future severe malnutrition guidelines: suggested areas for inclusion

Suggested areas for inclusion	Included in 2013 WHO SAM guideline update	Included in x number of guidelines analysed for this study
Link of disability with malnutrition	briefly	6/60 (10%) - briefly
Proactive screening for disability and developmental delay	No	Proactively screen: 2/60 (3%) Disability yes/no on physical assessment form: 42/60 (70%)
Multi-disciplinary team management (as available): speech and language therapy, dieticians, physiotherapists, occupational therapy, psychologists, nurses, medical team (including neurology, gastroenterology), social services	No	1/60 (1,5%)
Disability-specific feeding advice, medical advice (as context-appropriate, possibly including advanced feeding techniques, e.g. percutaneous gastrostomy)	No	2/60 (3%)
Continued support within the home (e.g. home visits, home adaptations)	No	1/60 (1,5%)
Referral mechanisms	No	18/30 (30%) – mosly unspecific (“referral to specialists”)
Counselling and advice for caregivers (including management of expectations)	No	4/60 (7%)
Monitoring and evaluation	No	3/60 (5%)
Consideration of children living with disabilities in nutrition emergencies, malnutrition prevention strategies	No	1/60 (1,5%)
Linking to local and context-specific organisations / groups providing additional support	No	3/60 (5%): “refer to appropriate support services” (few specifics)
Linking to other relevant guidance	No	1/60 (1,5%)