



# GLOBAL PARTNERSHIP ON CHILDREN WITH DISABILITIES

**A Survey Report on Nutrition Programme Initiatives for  
Children with Disabilities in Low- and Middle-Resourced Countries:  
A Task Force on Nutrition and Children with Disabilities Project  
of the Global Partnership on Children with Disabilities (GPCWD; 2012-13)**



Photo © Johanna de Tessières / Handicap International

## **I. Background**

There are numerous links and points of convergence between nutrition and disability. First, under-nutrition in children can lead to lifelong impairments that are otherwise preventable. Children who are otherwise typically-abled may become disabled by specific micronutrient deficiencies if their critical nutrition needs are not met. Conversely, the increase of non-communicable diseases globally suggests that over-nutrition is an increasing challenge relating to health and wellbeing, potentially leading to childhood disabilities. Finally, pre-existing disabilities put children at increased risk for under-nutrition that may result in poorer health outcomes and acquisition of preventable secondary disabling conditions. Feeding and swallowing problems related to neuromuscular conditions, for example, can lead to poorer

nutritional intake, of particular concern for those children who often have greater nutritional requirements than their non-disabled peers. Nutrition programs that are exclusively school-based may not capture children with disabilities as school inclusion and mean years of education rates are significantly lower for these children (WHO & World Bank, 2011<sup>1</sup>). Moreover, general food security campaigns, including those that address nutrition and hunger, often are not designed in accessible ways and reportedly do not reach children with disabilities due to cultural stigma and devaluation of the lives of these children (Groce et al., 2013<sup>2</sup>; WHO, 2013<sup>3</sup>; UNICEF, 2013a<sup>4</sup>; UNICEF, 2013b<sup>5</sup>; Groce, N., Deluca, M., & Cole, E., 2012, in press<sup>6</sup>).

The Global Partnership for Children with Disabilities (GPCWD) Task Force on Nutrition (TF) was established at the inaugural GPCWD Forum in September 2012 with the following aims to influence the global development agenda: 1) raising awareness of the important link between nutrition and disabilities, 2) increasing access for children and mothers with disabilities to nutrition services, and 3) promoting the need for a twin-track approach that includes both disability mainstreaming and special services when needed to reach children with disabilities and their families/caregivers in routine and emergency contexts.

## **II. Task Force on Children with Disabilities and Nutrition: Survey Process**

A core team of Antony Duttine of Handicap International and Evelyn Cherow of GlobalPartnersUnited serving as co-chairs, and Amy Farkas of UNICEF—with input from mapping, disability and nutrition subject experts—developed a survey under the umbrella of the GPCWD Task Force on Nutrition.<sup>7</sup> The idea to map nutrition initiatives addressing children and youth with disabilities emanated from the Task Force members' discussion at the 2012 GPCWD Forum that included 57 experts and advocates from UN agencies, INGOs, and Disabled People's Organizations (DPOs) from around the world. At that time, the group prioritized the need to document nutrition program development and implementation targeting children with disabilities in low- and middle-resourced countries (LMIC). The survey objectives were to glean child nutrition/disability-focused program profiles and indicators extant or planned for implementation, disseminate results widely, possibly map the programmes, and strategize the Task Force's future action planning based on results. The

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<sup>1</sup> World Health Organization & World Bank. (2011). World Report on Disability. WHO: Geneva.

<sup>2</sup> Groce, N., Kerac, M., Farkas, A., Schultink, W., & Berman Bieler, R. Inclusive nutrition for children and adults with disabilities. *The Lancet Global Health*, Early online publication; 19 August, 2013. doi:10.1016/S2214-109X(13)70056-1. <http://www.thelancet.com/journals/langlo/article/PIIS2214-109X%2813%2970056-1/fulltext>

<sup>3</sup> WHO Draft Action Plan 2014-2021: Better health for persons with disabilities; July 31, 2013. [http://www.who.int/disabilities/policies/actionplan/disability\\_action\\_plan\\_en.pdf](http://www.who.int/disabilities/policies/actionplan/disability_action_plan_en.pdf)

<sup>4</sup> UNICEF. (May, 2013). The state of the world's children 2013: Children with disabilities. [http://www.unicef.org/sowc2013/files/SWCR2013\\_ENG\\_Lo\\_res\\_24\\_Apr\\_2013.pdf](http://www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf)

<sup>5</sup> UNICEF. (May, 2013). Children and young people with disabilities: Fact Sheet.

<sup>6</sup> Groce, N., Deluca, M., Cole, E. (2012, in press). Fact sheet on children with disabilities. New York: UNICEF.

<sup>7</sup> The TF on Nutrition core team offers gratitude for contributions of Alana Officer and Chapal Khasnabis (WHO/DAR), David L. Clark (UNICEF Nutrition Specialist), Nora Groce and Marco Kerac (Leonard Cheshire Disability and Inclusive Development Centre/University College London), Seth Packrone (UNICEF Intern), Danielle Heiberg, Yesenia Garcia, and Jennifer Rigg (InterAction 1,000 Days Map and NGO Aid Map projects), Andrew Schroeder (Disaster Relief International and The Fistula Foundation's Fistula Map project), Dave Johnson (Development Seed), and Valery Gilbos (Handicap International).

survey design deliberately did not attempt to capture the already well-documented nutrition programs that specifically address the nutritional needs of pregnant women or women of childbearing age for preventing disabling conditions of newborns and young children. Our aim herein was to investigate and document unexplored approaches to implementing and advocating for nutrition program and policy for children with disabilities.

The core team drafted the survey questions and requested select representatives of non-governmental organizations (NGOs) and UNICEF nutrition and disability experts to review the draft questions and provide input. Once finalized, the survey questions were uploaded to the *Survey Monkey*<sup>TM</sup> platform and disseminated on May 16, 2013 to all GPCWD TF organizations as well as to numerous disability and global nutrition networks' members requesting a reply by June 21, 2013. UNICEF disability staff project coordinator, Amy Farkas, received 54 survey responses from 45 distinct organizations.

Of the respondents, 26 indicated that their organization currently conducts or plans to conduct a programme that addresses the nutritional needs of children and youth with disabilities either as a primary or secondary programme focus. However, only eight organizations responded to a follow-up request for concrete details describing either their programme's components or a plan for a programme that addresses the nutritional needs of children and youth with disabilities. To gain clearer understanding about the scope of these programmes for survey analysis, five respondents participated in phone interviews and elaborated with details about their programmes.

The *Snapshots* in Part IV below were developed based on this process.

### **III. Discussion Points**

While the survey is not a comprehensive overview of global child nutrition and disability programme initiatives, the findings yielded several discussion points of note:

- Despite disseminating the survey widely, only 45 distinct organizations responded. Of these 45, only ten reported programmes that were addressing the nutritional needs of children and youth with disabilities in some manner.

Though the core team considers the survey to be a nascent effort to profile current target nutrition program activity for children with disabilities, it was widely disseminated among agencies and organizations that have familiarity with and/or are involved with nutrition initiatives in LMICs. UNICEF staff followed up by interviewing agency representatives leading to identification of ten programmes (in progress or planned) that address the nutritional needs of children with disabilities. The low prevalence of programmes reported represents several possible scenarios: 1) the survey design or overall query process was inadequately framed or disseminated to capture the desired scope of information about the current or planned nutrition programmes, 2) there is a true scarcity of nutrition programming addressing the nutritional needs of children with disabilities, and/or 3) the metrics are lacking in nutrition programme design for determining which of the children receiving nutrition services have disabilities. Perhaps any or all of these analyses are valid; further

investigations could address these factors and others that may be postulated once the findings are disseminated.

Furthermore, most responses received came from international or national non-governmental organizations implementing programmes at the community level vs. nationally or regionally. An interpretation of this latter finding is that the types of organisations creating community level initiatives are those that had access to and/or information about the GPCWD TF survey.

- The survey input failed to yield clear descriptive data for those organizations indicating current or planned child-focused, disability-related nutrition projects/programmes; i.e., even when organizations specified that they had such nutrition programs in development or in progress, they omitted answers to survey questions that asked respondents to choose general or specific descriptors of the types of programs, geographic region specificity, and targeted populations' profiles.
- Of those positively responding organizations, an overwhelming majority of the projects were nutrition-focused projects that also included as a goal targeting children and youth with disabilities. Only one of the ten programmes profiled below in *Section IV, Snapshots*—that conducted by the National Union of Disabled Persons of Uganda—was a disability-specific project that included a focus on the nutritional needs of children with disabilities.
- With regard to the types of implemented activities reported, the most common included *advocating for the inclusion of children with disabilities in general nutrition programmes* and *providing nutrition education for families with children with disabilities*.
- The most common challenges that the respondents report facing in implementing their projects are 1) lack of trained professionals, 2) lack of funding, 3) cultural and social norms, and 4) difficulty identifying children and youth with disabilities in this age range among their project population.
- Several respondents mentioned that while their organization did not plan at programme inception to specifically address the nutritional needs of children with disabilities, the interrelationship between nutrition and disability soon became apparent and children with disabilities' nutrition needs impossible to ignore. This finding suggests that raising awareness among nutrition-focused organizations could be an important and effective avenue for positive change as originally postulated by TF members and co-chairs.

#### **IV. Snapshots of Nutrition Programmes for Children with Disabilities**

Based on the low numbers of nutrition programmes for children with disabilities reported, fulfilling our mapping goal at this time was infeasible. However, the valuable follow up interviews staff conducted with agencies indicate some programmes in development or underway, and yielded examples of current practices for review and sharing. These are assembled below for knowledge sharing and to stimulate discussion among GPCWD partners and other development actors to enhance practices in the critical areas of nutrition access and food security domains. Sample programme descriptions also address advocacy for nutrition as well as the unique needs of children with specific feeding and swallowing disabilities.



Photo Courtesy of Spoon Foundation

### 1) ***SPOON Foundation***

Two adoptive mothers of children who were malnourished while receiving institutional care started the SPOON Foundation to address the nutritional needs of children living in institutions and foster care systems.<sup>8</sup> SPOON is based in the United States, but the agency works in countries around the world to improve the nutritional outcomes for children living in institutions and the foster care system. While SPOON does not focus specifically on children and youth with disabilities, considering that a large part of the population entering and exiting institutional care is composed of children with disabilities, all of SPOON's programmes are inclusive of children with disabilities. SPOON reported on three of its programmes that address the nutritional needs of children and youth with disabilities.

#### ***a) Project Title: Adoption Nutrition (Multinational)***

Through the *Adoption Nutrition* programme, SPOON Foundation focuses on providing feeding and nutrition resources to adoptive and foster families, including a website, webinars, and a Nutrition Starter Guide. Given the high percentage of adopted and foster children with disabilities, SPOON dedicates a section of its website specifically to the unique feeding and nutritional needs of children with disabilities. In addition to its "Ask the Expert" section, that allows parents and caregivers to consult with SPOON-affiliated health professionals, the website features disability-specific webinars, such as "Feeding and Nutrition for Children with Special Needs." While the Adoption Nutrition programme is exclusively educational, SPOON encourages parents and caretakers to seek support from health care professionals.

#### ***b) Project Title: Nutrition Screening System (Haiti and India)***

In Haiti and India, SPOON Foundation operates the *Nutrition Screening System* to identify children living in institutions or the foster care system who are malnourished to secure on site care. The programme is specifically tailored to the growth, nutrition and feeding problems common among children with disabilities. The screening system includes several levels of programming: a nutrition screening form and electronic database, treatment and referral protocols, and an instruction manual. The treatment and

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<sup>8</sup> <http://spoonfoundation.org/>

referral protocols address a wide range of nutrition and feeding considerations for common disabilities reported in India and Haiti. The instruction manual is written for in-country staff and includes chapters on specific disabilities.

Upon the launch of the programme, in-country staff participated in a one-week intensive training with SPOON's nutrition scientist focused on applying the techniques to children and youth with disabilities, including training on growth measurement for children with disabilities. Following the launch, SPOON has continued to review the database of feeding and nutrition management and appointed an on-site monitor at each pilot programme to ensure the implementation of the techniques from the training. In addition to soliciting ongoing feedback for programme modifications from clinical staff, six- and twelve-month comprehensive programme evaluations will be conducted and progress measured against numerous nutrition-related indicators. Indicators include improvement in feeding, increased percentage of children receiving proper iron-fortified cereal at four-to-six months, and decreased percentage of children receiving cow/buffalo milk at less than twelve months of age. The success of the programme is evident from its planned expansions: the Government of India has expressed interest in scaling up the programme to more institutions and foster care programmes, and SPOON plans to expand the programmes to China and Vietnam in 2014, and Ethiopia and Uganda in 2015.

This programme will be followed by a pilot in India in 2014 of a comprehensive nutrition and feeding curriculum, including different feeding techniques and positioning to improve swallowing and optimize food intake. This training curriculum and model will be adapted and scaled to the above-mentioned countries in the next two-to-four years.

***c) Project Title: Kazakhstan Infant Nutrition and Feeding, Nurturing Together***

SPOON Foundation started the *Infant Nutrition and Feeding, Nurturing Together* programme in January, 2013 with training for the chief physicians and directors of 21 baby houses in Kazakhstan. The training included a range of nutrition-related topics for children and youth with disabilities, including raising awareness of complications associated with feeding children with disabilities, strategies for feeding children with cerebral palsy, and identifying needs for specialized feeding equipment (chairs, spoons, cups, and bottles). Following the training, monitors observed feeding practices in the baby houses for the next five months, interviewed baby house staff, and identified equipment needs for children with disabilities.

Currently, the programme is procuring and delivering specialized feeding equipment for children with disabilities and training staff members of the baby houses on the proper use of the equipment. In its partnership with the Kazakhstan Academy of Nutrition and the Ministry of Health, SPOON has been able to influence both national policy to improve food menus in baby homes and practical improvements in feeding practices for children with disabilities. SPOON is also working to build a grassroots movement in the community to demand individualized nutritional services in institutions in recognition of the unique nutritional needs of every child.

**2) UNICEF Bangladesh – Project Title: Supplementation Programme**

UNICEF has worked in Bangladesh for 60 years in a range of areas from providing relief to children after disasters to water and education programmes.<sup>9</sup> Currently, UNICEF Bangladesh is expanding its focus to include the nutritional needs of children with disabilities with its *Supplementation Programme*. To accomplish the programme’s two main objectives—inclusion of children with disabilities in national supplementation campaigns and prevention of iodine deficiency disorders—the country office is seeking to increase the knowledge about and sensitivity towards children with disabilities in nutrition screenings. By training government healthcare workers from a perspective that is sensitive to the needs of children and youth with disabilities, UNICEF Bangladesh strives to increase the visibility of children with disabilities within these screenings. UNICEF Bangladesh is working towards the long-term goals of shaping national healthcare training policies and mainstreaming nutrition issues relating to children with disabilities across sectors.

**3) UNICEF Bosnia and Herzegovina**

While UNICEF’s work in Bosnia and Herzegovina dates back to 1948, the focus of UNICEF’s programming has changed over time. After shifting from reconstruction to development, UNICEF is now working with Bosnia and Herzegovina to build a robust social protection system for children.<sup>10</sup> The country office’s current work around the nutritional needs of children with disabilities provides a strong example of how issues affecting children with disabilities should be mainstreamed across other sectors. As part of the country office’s *Early Detection and Intervention Services* for children with disabilities, the office 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. As the services are administered in the home, parents are fully involved and engaged. The country office is seeking to scale up the mainstreamed model of Early Detection and Intervention services in its support of a pilot programme in one canton and further support is provided to the Ministry of Health to reach more homes and more children with disabilities.

**4) UNICEF Viet Nam: Child Survival and Development Programme**

In 1975, UNICEF began its work in Viet Nam, which has since transitioned from emergency response and reconstruction, to health and education, and to the country office’s current focus on improving social services.<sup>11</sup> Linked with a sub-project in the Child Protection Section, *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 strives to identify and serve

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<sup>9</sup> [http://www.unicef.org/bangladesh/overview\\_363.htm](http://www.unicef.org/bangladesh/overview_363.htm).

<sup>10</sup> [http://www.unicef.org/bih/overview\\_16393.html](http://www.unicef.org/bih/overview_16393.html).

<sup>11</sup> [http://www.unicef.org/vietnam/overview\\_6909.html](http://www.unicef.org/vietnam/overview_6909.html)

children and youth with disabilities. The country office does not limit its work to the community level, however, as it 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.

**5) *World Vision Bangladesh: Integrated Health, Nutrition, and WASH Project in Partnership with UNICEF***

World Vision is a Christian humanitarian relief organization working in over 100 countries around the world with a focus on children. World Vision started its work in Bangladesh in 1970 in numerous areas, including education, health and nutrition, food security, WATSAN, disaster preparedness and child rights.<sup>12</sup> 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. Community volunteers conduct monthly home visits of all the children and youth with disabilities in the project coverage area to ensure full participation. During these 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.

**6) *National Union of Disabled Persons of Uganda – Project Title: Cerebral Palsy Project***

The National Union of Disabled Persons of Uganda (NUDIPU), an indigenous umbrella NGO composed of persons with disabilities, was established in 1987 to serve as a unified voice for persons with disabilities. As part of the *Cerebral Palsy Project*, NUDIPU addresses the nutritional needs of children with cerebral palsy through outreach visits and nutritional workshops. NUDIPU does not stop at the individual level, as it seeks to expand its impact on the nutritional needs of children with cerebral palsy by utilizing the media to educate the public about nutritional needs, the concept of cerebral palsy, and advocacy and lobbying efforts at both the government and NGO level. NUDIPU remains aware of the challenges facing families with children with cerebral palsy in Uganda, as one of its goals is to support low-income parents and caretakers on meeting the nutritional needs of children with cerebral palsy. Furthermore, NUDIPU through its cerebral palsy project, conducts trainings in care, treatment and social support with an emphasis on good

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<sup>12</sup> <http://bangladesh.wvasiapacific.org/about-us-mainmenu-84>



nutrition and physiotherapy of their family members with CP in the city of Kampala, surrounding districts, and villages across Uganda in accessible spaces.

7) ***CHEER UP CBO (Kenya) –***

***Project Title: Nutrition Support for Those Living with a Disability***

**CHEER UP CBO** is a faith-based organization that works at the community level in the Central Province of Kenya and emphasizes the inclusion of persons with disabilities in the design phase of their programs. In public meetings, medical outreach programmes, churches, and schools around Kenya, CHEER UP community health workers trained by the government and other partners and staff members campaign about the need to enroll children with disabilities in nutrition programs. CHEER UP staff members conduct one-on-one nutrition education for children with disabilities during home visits by engaging with the caregivers, teachers of children with disability and medical personnel, hosting seminars and trainings on the nutritional needs of children with disabilities, and distributing pamphlets on nutrition education. CHEER UP's programs do not only provide education and training about the nutritional needs of children with disabilities, but also hands-on experience at its "demonstration farm" where caregivers of children and youth with disabilities are trained about how to maintain kitchen gardens and poultry.

8) ***ChildFund International (Timor Leste) –***

***Project Title: Improving Outcomes for Children in Cova Lima***

ChildFund International, a non-governmental emergency relief organization started in 1938 to help displaced children in China, now works in thirty-one countries supporting the healthy development of children from birth to young adulthood.<sup>[1]</sup> In Timor Leste, ChildFund International is discovering the ways in which disability intersects with their work to improve nutritional outcomes for all children. From 2013-14, the national office plans to promote awareness on the prevention of physical disabilities at the community level by training its field staff and volunteers to better identify disability and understand its links with malnutrition. ChildFund hopes to accomplish the same goals with government health workers to have a broader impact on the nutritional needs of children and youth with disabilities.

## **V. Conclusions and Recommendations**

The Task Force on Nutrition survey has provided a concrete first step in a historically under-investigated area within both the disability and nutrition sectors. The results of the GPCWD TF survey demonstrate that much remains to be done in the field of nutrition for children with disabilities. While the survey provided a number of snapshots of promising programs addressing the nutritional needs of children with disabilities in mainstreamed programs, the dearth of programs is startling based on the responses to this widely disseminated survey. However, considering that seven out of the eight agency respondents were nutrition-oriented programs that addressed children with disabilities, the data suggest that these organizations are starting to mainstream disability issues within their broader nutrition and maternal and newborn child health (MNCH) programs. Still, more advocacy, action and research are needed to support needed nutrition inclusion and equity in this area.

## VI. Potential Next Steps

This GPCWD Task Force on Nutrition survey report holds promise for stimulating global programme and policy development to meet the nutritional needs of children and youth with disabilities. Clearly, very few organisations or policy bodies are focusing on this issue, making the work to date of the Task Force relatively groundbreaking. The September 24, 2013 GPCWD forum agenda will address next steps in the context of TF scope, objectives and potential further use, refinement, and application of the survey and its findings.

Depending on levels of GPCWD members' interests, priorities, governance decisions, and funding availability, a range of next targeted actions with strategic planning could take place. These actions include, but are not limited to:

- Develop a plan for deploying and disseminating findings of the survey described in this report to a wide audience within the disability, MNCH, and nutrition sectors.
- Development of a more rigorous and scientifically-derived data collection methodology with academic institutions and/or research agencies in order to ensure appropriate sampling and a comprehensive valid and reliable survey on factors affecting child disability and nutrition outcomes.
- Consider reopening the survey for a longer time period with periodic reminders to collect a larger number of respondents. Undertake periodic (annual) analysis of the results.
- Develop a more in-depth analysis of the successes, constraints and findings from existing projects reported in the survey to generate a practical guidance on establishing nutrition 'preferred practices' activities for the growth and development of children with disabilities in typical and emergency contexts.
- Adoption and development of a Nutrition and Children with Disabilities Programme map to plot the geographic locations of projects onto a map similar to other effective development mapping projects; e.g., Thousand Days Nutrition Mapping project<sup>13</sup>, the joint Direct Relief International and The Fistula Foundation's global fistula mapping project<sup>14</sup>, NGO Aid map<sup>15</sup>, etc. Some investigation into the feasibility of launching, staffing and funding a map project has already taken place by the TF co-chairs in preparation of this survey that may inform such an initiative.

## Acknowledgements

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<sup>13</sup> <http://www.thousanddays.org/resources/nutrition-map>

<sup>14</sup> <http://www.globalfistulamap.org/>

<sup>15</sup> <http://ngoaidmap.org/>