

## Global Partnership on Children with Disabilities

Concept Note – 09 September, 2012

### Background

Children with disabilities (CWD)<sup>1</sup> are among the most stigmatized and excluded of children around the world; girls and adolescent girls with disabilities are among the most disadvantaged due to discrimination against their sex, disability and other factors, such as poverty and ethnicity. Children with disabilities are likely to have poorer health, less education, less economic opportunity, live in greater poverty and deal with more inequalities than their counterparts without disabilities.<sup>2</sup>

‘Disability’ is an evolving concept – it can be physical, mental, intellectual and/or sensory; some children are born disabled and others become disabled due to an accident, injury, malnourishment or disease. Disabilities can range from moderate to severe, some are permanent and others are temporary. Many are preventable and are linked directly to poverty (lack of health care and immunizations, poor nutrition, etc.)

It is estimated that over 1 billion people in the world today live with a disability, which includes about 80% living in developing countries and 20% of the world’s poorest and most disadvantaged people.<sup>3</sup> It is calculated that about 1 in every 10 children in the world copes with a disability and only 2-3% of disabled children in low income countries go to school.<sup>4</sup> In general, data on people with disabilities, particularly children with disabilities, are lacking or underestimated. This is due to factors such as stigma, isolation, families hiding disabled children and not being counted in census reports.

While significant progress has been made – e.g. over 100 countries have ratified the Convention on the Rights of Persons with Disabilities (CRPD), and actions by governments and the international development community to support children with disabilities appear to be increasing – the Forum on the Global Partnership on Children with Disabilities is a **Call to Action** to address the significant need for more effective coordination and cooperation to:

- a) systematically promote and achieve concrete, sustainable and equitable results on inclusive development that focuses on the rights of children with disabilities
- b) promote synergy in mainstreaming children with disabilities in advocacy, policy and programming
- c) avoid duplication of efforts.

This Concept Note was prepared to support establishing a platform upon which to advance discussions and actions to better shape the form and substance of a Global Partnership on CWD. It covers points of consensus; principles and approaches; areas of concern; general discussion points and opportunities; the mainstreaming of children with disabilities in specific programmatic areas and opportunities; and next steps.

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<sup>1</sup> CWD (children with disabilities) refers to all children and adolescents with disabilities 0-18 years old.

<sup>2</sup> CBM. CBM Position paper on the post-2015 MDGs global framework. 2012. [www.cbm.org](http://www.cbm.org)

<sup>3</sup> WHO/World Bank. 2011. World Report on Disability. Geneva. <http://www.who.int/disabilities/worldreport/2011/en/index.html> ; <http://youthink.worldbank.org/print/476>

<sup>4</sup> Ibid.

## 1. Points of Consensus to support a Global Partnership on Children with Disabilities<sup>5</sup>

A Global Partnership on CWD can:

- **bring together and facilitate an active network** of representatives from the UN, governments, NGOs, civil society, disability networks and organizations, donors, academic institutions, etc. working in areas of relevance to CWD and their families or other caregivers
- **be inclusive of all relevant stakeholders**, including children, adolescents, mothers, fathers, grandparents and other caregivers of children with disabilities
- **employ a human rights-based approach**, a gender equality approach, an equity focus, a life cycle perspective and principles of inclusive development
- **focus on mainstreaming CWD** in both the broader development agenda and disability-specific initiatives in stable and emergency situations
- **play a consultative and coordination role**, including providing a global platform for and with CWD and their families to have their voices heard, raise issues and challenges, bring forth new ideas and lessons learned, and build knowledge and awareness on equity for and inclusion of CWD
- **consolidate and use evidence to address legislative, policy and programming** issues and concerns within and beyond UNICEF and the UN system, including giving attention to integrating CWD in programme processes and systems related to situation analysis, programme strategy development & implementation, advocacy, communication, monitoring, evaluation, research, reporting and financing
- **support donor coordination** to promote and support CWD
- **involve governments and financial institutions as active partners** to ensure national commitment and sufficient resources are available for CWD, enabling good governance, participation, collaboration, coordination, strategic plans and actions, systematic data/information collection and analysis, and dissemination of lessons learned and successful practices/models
- **designate UNICEF, global advocate for children, to play a leading initial role** in bringing together and overseeing the Global Partnership on CWD.

## 2. Principles and approaches promoted and supported by the Global Partnership on CWD

- **human rights principles**, including non-discrimination, respect for dignity, autonomy, independence of the individual, gender equality and respect for difference and diversity
- **a human rights-based approach** informed by the Convention on the Rights of the Child (**CRC**), the Convention on the Rights of Persons with Disabilities (**CRPD**) and the Convention on the Elimination of all Forms of Discrimination against Women (**CEDAW**), which dovetail, reinforce, and elaborate each other, contributing towards the goals of equity, equality and inclusive development<sup>6</sup>
- **gender equality and respect for diversity approach**, including elimination of discriminatory attitudes, practices and behaviours, with a special focus on girls and women with disabilities

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<sup>5</sup> The points of consensus to support a Global Partnership on Children with Disabilities were arrived at through consultations with partners, including a core group of representatives from the International Disability Alliance, International Disability and Development Consortium, Global Partnership on Disability and Development, Inter-Agency Support Group on the CRPD, and governments.

<sup>6</sup> Lansdown, G. (2012) Using the human rights framework to promote the rights of children with disabilities: Working Paper An analysis of the synergies between CRC, CRPD and CEDAW, New York: UNICEF

- **Inclusive, participatory and equitable approaches** ensuring the full and effective participation of children with disabilities and their families and/or other caregivers at all levels of decision-making and programming – recognizing that children with disabilities have the same rights and needs as children without disabilities – and supporting local level empowerment and country ownership.
- **holistic, multi-disciplinary policy and programming approaches** that support, facilitate and sustain mainstreaming of children with disabilities.
- **accessibility and universal design of infrastructure and information approaches** to enable children with disabilities to fully access facilities, services, organizations, shelters, etc.
- **independent living approaches** that support children with disabilities to become self-sufficient as much as possible and participate in all aspects of life.

### **3. Major areas of concern to address through the Global Partnership on CWD**

A literature review on children with disabilities identified several key areas of concern that are in themselves representative of potential opportunities for the Global Partnership to address. They are as follows:

- The rights and needs of children and adolescents with disabilities are not sufficiently addressed in the Disability and Child Rights global to national movements and agendas, which, if they were, it would potentially strengthen the level of coordinated advocacy and action needed to raise the profile of this vulnerable group of children.
- There is much to do to ensure that children with disabilities are included *front and centre* in an *inclusive* post-2015 development agenda.
- There are persistent myths surrounding CWD, particularly in developing countries, perpetuating incorrect beliefs and perceptions about the abilities and potential of these children, which indicate insufficient attention being given to changing attitudes, practices and behaviours.
- CWD and their families are rarely given sufficient attention in existing and planned mainstream efforts aimed at all children, which would also require the integration of disability-specific efforts, as needed, to ensure CWD are provided the support and opportunities they need to reach their full potential.
- Coordination of and collaboration on mapping and supporting existing and planned legislation, policies, programmes and services that are inclusive of CWD is either missing or needs improvement.
- Policy and programming that takes into account the rights and needs of CWD *across the life cycle*, from infancy through childhood and adolescence to young adulthood is far from the norm, which requires the development of a comprehensive, systemic and coordinated approach.
- There is a paucity of consistent, credible, user-friendly evidence on CWD that is necessary to build on and inform current and future policy and practice.

### **4. General discussion points linked to concerns; opportunities for the Global Partnership on CWD**

- a. Integrate CWD rights and needs in Disability and Child Rights Movements**

**Discussion point:** Global and regional child-related programmes supported by UN agencies and/or NGOs rarely address the rights and needs of CWD. When and where they do, it is often through support of a discrete, country-level project that does not become linked to or integrated in ongoing programmes or systems. As a result, resources are not adequately allocated to CWD, and awareness of project successes do not reach the scale to capture attention and support from the Disability and Child Rights Movements.

**Opportunity for the Global Partnership on CWD:** *Coordinate/collaborate on advocacy for CWD at all levels along with more programming and resources for CWD to enhance awareness and contribute to making CWD a priority in the movements and agendas on Disability and Child Rights.*

#### **b. Supporting an inclusive post-2015 development agenda**

**Discussion point:** An inclusive post-2015 development agenda requires an overall vision of what is in the best interest of CWD – including goals, standards and guidance, which should be in relation to the goals, standards and guidance on optimal development for the rights of all children - and support from all partners for CWD.

**Opportunity for the Global Partnership on CWD:** *Coordinate advocacy and establish task forces in sectoral and cross-cutting areas to gain support for CWD in the post-2015 development agenda, including the specific inclusion of CWD in the various child rights goals, strategies and guidance.*

#### **c. Debunk (Bust!) persistent myths surrounding CWD**

**Discussion point:** The greatest barriers to inclusion of CWD relate to discrimination, prejudice and stigma, leading to their isolation in society and causing myths to persist about the causes of disability and limitations of CWD. Incorrect knowledge and negative attitudes, beliefs, practices and behaviours are difficult to dispel or change even among those working in international development, health and other domains.

**Opportunity for the Global Partnership on CWD:** *With a broad range of partners from the multiple sectors and cross-cutting areas, devise and lead a multi-level and integrated advocacy and communication for development (C4D) strategy promoting the rights of CWD aimed at behavioural and social change, leading to transformation in society with regard to debunking the discriminatory myths against CWD.*

#### **d. Integrate CWD in mainstream efforts with disability specific support**

**Discussion point:** CWD and their families need access to services and resources and specific support so that CWD can grow, develop and realize their full potential as they evolve during childhood and transition into adulthood – this includes access to good nutrition, quality health care, child-friendly / adolescent friendly education, basic sanitation, clean water, special medical and rehabilitative services, safe and supportive family, school and community environments, social protection and economic opportunities. However, many CWD and their families are overlooked when mainstream policies are formulated, programmes are designed and implemented, and research and M&E are conducted on the situation of children– in spite of the fact that the CRPD calls for the inclusion of CWD in development efforts and the CRC underscores inclusion of CWD.

**Opportunity for the Global Partnership on CWD:** *Using evidence and successful models of practice as well as identifying inappropriate practices and gaps to address, collaboratively advocate for, dialogue and share information on CWD to be integrated in mainstream policy and programming efforts with disability-specific interventions where needed.*

#### **e. Give particular attention to protective environments for/with CWD - family and community**

**Discussion Point:** Using a coordinated and collaborative approach at all policy and programming levels, support families with CWD in understanding their child's disability and being informed of family

and community-based services, networks and support systems to help protect their child and fulfill his/her potential. This may include, for example, social protection services, including income support (such as cash transfers) to provide families with CWD living in poverty the support they may need to keep their family together and gain access for their CWD to health care, education and other services. Furthermore, it can involve families and communities working together to develop the protective environments necessary to protect this particularly vulnerable group of children from child abuse, violence and exploitation.

**Opportunity for the Global Partnership on CWD:** *Using a coordinated and participatory process involving families and communities, develop a child protection/social protection system interlinked at all levels that develops and sustains protective environments, beginning with the family, which generally has the lion's share of responsibility for raising a child with a disability(s) even when inclusive policies and strategies are in place.*

#### **f. Map and improve coordination/collaboration at country level for CWD**

**Discussion point:** Lack of coordination and collaboration *for* and *with* children with disabilities and their families in policy-making, programmes, services and systems frequently results in significant gaps, missed opportunities, and ineffectiveness and inefficiencies that cumulatively neglect the rights and needs of CWD. An example of a key consequence relates to missed opportunities to effectively advocate for and inform families and their CWD about available services and opportunities.

**Opportunity for the Global Partnership on CWD:** *Using a coordinated and participatory process, promote and support the mapping of existing and planned legislation, policies, programmes and budgets as well as stakeholders and partnerships on addressing the rights and needs of CWD, and, in turn, use the results to pinpoint gaps and improve coordination and collaboration among partners for a more strategic, effective, efficient and holistic approach for and with CWD and their families.*

#### **g. Support CWD across the life cycle**

**Discussion point:** In many contexts, duplication of responsibilities in some areas and significant gaps in others have resulted in a tangle of disparate projects/programmes for CWD. Health services for CWD are often not connected to early child development efforts; education programmes including CWD are not usually linked to social protection programmes; and few government programmes or civil society efforts reach out to the disabled adolescent, especially the adolescent girl. Support of CWD across the life cycle - policies and programmes designed to follow the disabled child from birth (or point of initial impairment) to adulthood - means rethinking much of the current work on CWD and refocusing attention to the interrelated rights, participation and needs of the CWD over time, with the goal of ensuring CWD and their families are provided and engaged in shaping social, educational, protective and economic support and opportunities needed to enable CWD to fulfil their potential.

**Opportunity for the Global Partnership on CWD:** *Coordinate/collaborate on the development and implementation of programme strategies, using comparative advantage, to support a holistic life cycle approach to enable CWD to realize their full potential; identify gaps in situation analyses on CWD in each phase of child/adolescent growth & development; conduct participatory research, M&E to better understand barriers and obstacles, and find doable solutions to remove them; and facilitate communication and governance processes among stakeholders in support of CWD in each sector, across sectors and at different levels.*

#### **h. Build and maintain user-friendly evidence on children with disabilities, requiring close attention to systematic, disaggregated data collection & analysis on CWD**

**Discussion point:**

Accountability, monitoring, analysis and evaluation of services and other supports for CWD, and reporting mechanisms that do exist are frequently irregular and spotty. Research on CWD, especially research that extends beyond the medical and rehabilitation literatures, remains limited. While

significant gaps in knowledge exist for CWD in all countries, data and information on health, education, protection and the well-being of CWD living in low and middle-income countries are particularly limited. Coordinated and collaborative M&E systems and research on CWD can help to avoid duplication, improve efficiency and ensure wider dissemination and use.

***Opportunity for the Global Partnership on CWD: use a coordinated/collaborative approach to establish M&E and reporting systems on CWD that have clear accountabilities, and are rights-based, equity focused, disaggregated and systematic; establish baselines at all levels and within all relevant sectors and cross-cutting areas against which to track and report change in the situation of CWD, the effectiveness of policies and programmes for CWD, the level of resources and desired outcomes for CWD, etc. - which can be used to influence and improve policy and practice for CWD. When knowledge gaps on CWD are identified, coordinate and collaborate on research and its dissemination.***

## **5. Mainstreaming Children with Disabilities in Three Programmatic Areas – and potential opportunities for the Global Partnership on CWD to consider and discuss**

The Global Partnership on Children with Disabilities has and can cultivate a ‘multidisciplinary fluency’ required to promote and innovate to find sustainable development solutions to complex challenges, such as ensuring space for CWD and their families to have their voices heard across sectors and with multiple partners, and mainstreaming CWD in policies, programmes, services and systems that integrate disability support as needed.

The Global Partnership on Children with Disabilities will focus efforts on three programmatic areas in the coming year to test and assess its abilities to work together on integrating CWD in global thematic agendas. This does not bar partners’ efforts and partnering in other critical programmatic areas. The three areas are summarized as follows, along with some examples of potential opportunities to consider and discuss for coordination, collaboration and measurable actions.

### ***Disability and the Global Nutrition Agenda, including the Scaling Up Nutrition (SUN) Movement and the REACH Initiative***

Nutrition and disability are intimately related in terms of eliminating malnutrition and its consequences on children, and ensuring the health and well-being of children with disabilities. This is particularly critical given that over one billion people worldwide are undernourished, including an estimated 171 million children aged <5 years who are stunted due to being chronically malnourished<sup>7</sup> – leading to a number of preventable impairments. Maternal, infant and child nutritional deficiencies may relate to, for example, a range of intellectual, motor, neurological and hearing disabilities. The main causes of child under-nutrition are food insecurity, poor health and inappropriate care.

The Global Partnership on Children with Disabilities can link to the Global Nutrition Agenda through different partners, such as those who come together in the *Scaling Up Nutrition (SUN) movement* and the *Renewed Efforts Against Child Hunger (REACH) joint UN/Government initiative*. SUN aims at involving all countries with populations experiencing under-nutrition and its relevant stakeholders to work together to fight hunger and under-nutrition.<sup>8</sup> REACH, linked to SUN, facilitates multi-sectoral coordination and capacity development mechanisms (e.g. joint UN/Government programming) that bring together different agencies and ministries in the most heavily burdened countries to prevent and address child under-nutrition and work towards achieving the Millennium Development Goal #10/Target 3 – ‘to halve the proportion of underweight children under 5 years old by 2015’.<sup>9</sup>

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<sup>7</sup> Scaling Up Nutrition. (cited:Available from: <http://www.scalingupnutrition.org/> )

<sup>8</sup> <http://www.scalingupnutrition.org/>

<sup>9</sup> <http://www.ncbi.nlm.nih.gov/pubmed/21916120> ;

<http://www.unmultimedia.org/radio/english/2012/06/reach-initiative-tackles-child-under-nutrition/>

<http://www.wfp.org/news/news-release/wfp-unicef-who-and-fao-hail-reach-initiative-child-undernutrition-foundation-susta>

**Some potential opportunities** for the Global Partnership on CWD to consider and discuss include:

- Link with the SUN movement and support children and women with disabilities through REACH and other similar efforts at global to local levels (e.g. UNICEF/WHO 7-Point Plan for Diarrhoea Control that has clear links to nutrition and disability).
- Increase awareness of the link between nutrition and disabilities among the nutrition and disability communities and governments at all levels.
- Increase and facilitate access for children and women with disabilities to nutrition services.
- Develop knowledge and increase understanding about the nutritional situation of children and women with disabilities and their families through monitoring, evaluation and reporting mechanisms framed by the principles and guided by the approaches aforementioned.
- Support nutrition campaigns and communication initiatives that are disability-friendly.
- Increase awareness of mainstreaming disability in nutrition policy and programmes, coupled with integration of special services needed to reach CWD and their families or caregivers.

### ***Disability and the Global Partnership on Education (GPE)***

Children with disabilities are entitled to a full and equal education.<sup>10</sup> Discriminatory attitudes toward CWD, as well as a lack of resources, awareness and commitment to accommodate these children with specific services as needed, compound the challenges CWD face in accessing education<sup>11</sup> and getting a quality education. UNESCO underscores the severity of the situation with data, estimating 98% of children with disabilities in developing countries do not attend school and 99% of girls with disabilities are illiterate.<sup>12</sup>

The Global Partnership on Children with Disabilities can link with and work together with partners involved in the Global Partnership on Education (GPE) to address the various challenges facing children with disabilities in education. The GPE, established in 2002 and comprised of 50 developing countries and more than 25 global public and private sector partners, including civil society, has a vision to ensure a quality education for all children, especially those living in poverty and who are most vulnerable. The GPE's multiple objectives focus on providing: access for all, learning for all, reaching every child, and building for the future. The GPE especially supports countries in the development of education sector plans and education partner coordination from country to regional to global levels.

**Some potential opportunities** for the Global Partnership on CWD to consider and discuss with regard to promoting and supporting disability-inclusive education and influencing the GPE's latest Strategic Plan, currently in the process of finalization, include:

- Link with the GPE to promote and support disability-inclusive education.
- Advocate for the use of existing funding and adaptation of new or existing plans and strategies to build accessibility and inclusion in education, including universal design of infrastructure that promotes accessible and inclusive learning spaces for children with disabilities.
- Invest in teacher training and child-friendly / child-centred pedagogy that are supportive of disability-inclusive education, which would require all director and teacher training to include a module(s) and related materials, accompaniment and assessment on inclusive education for

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<sup>10</sup> UNESCO. Education for All. <http://www.unesco.org/new/index.php?id=18646&L=0>

<sup>11</sup> Epstein, A (2010) Making the Case for an Equity Focus in Education, New York: UNICEF

<sup>12</sup> United Nations (2007) From Exclusion to Equality: Realizing the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol, United Nations, Geneva [www.un.org/disabilities/documents/toolaction/ipuhb.pdf](http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf)

children with disabilities – this would address negative attitudes, practices and behaviours, and develop capacity on the provision of special support for CWD and their families to help CWD realize their full potential.

- Collect and analyse school data & information and conduct research that is inclusive of CWD, starting with a baseline for monitoring and assessing mainstreaming of disability in the education system.

### ***Inclusive Emergencies and Humanitarian Actions for Children with Disabilities***

Children with disabilities are among the most invisible and routinely excluded in emergency responses.<sup>13</sup> Negative attitudes against CWD tend to escalate<sup>14</sup> and barriers faced by CWD and their families are seldom acknowledged or included in assessing the impact of emergencies on populations (WRD 2011: 36-37). Some CWD are dealing with a new disability acquired as a result of injuries caused by an emergency situation. Food, shelter, health care, education and psychosocial and other support services may be lacking or not inclusive of CWD. These children may not be able to access early warning systems or escape during a crisis. They may lose their assistive devices or become separated from family or other caregivers, making them extremely vulnerable to physical violence and sexual, emotional and verbal abuse. They may be hidden due to social stigma causing them not be registered or accounted for in data collection and assessments. They may be excluded from participating in child-friendly spaces and youth empowerment activities due to physical or attitudinal barriers, and experience environmental barriers, such as collapsed buildings/ramps, inaccessible camp infrastructure and / or unavailable services and community support systems. In the aftermath of emergencies, there is, however, the chance to “build back better”<sup>15</sup> for and with children with disabilities.

**Some potential opportunities** for the Global Partnership on CWD to consider and discuss include:

- Coordinate advocacy for a General Assembly resolution on inclusive humanitarian response, which would meaningfully include and engage children and persons with disabilities in emergency situations.
- Conduct disaggregated evidence-based research on CWD in emergency situations to support the development of more inclusive humanitarian policies and programmes.
- Establish monitoring and assessment mechanisms to identify and engage children and women with disabilities in informing and shaping inclusive humanitarian responses.
- Advocate for and support inclusive emergency infrastructure, reconstruction and rebuilding.

## **6. Next Steps for the advancement of the Global Partnership on CWD**

Following is a sampling of next steps that will be determined in a consultative process supported during the Forum on the Global Partnership on CWD:

- Identify and support a strategic number of countries to start the mapping process and increase partnerships on children with disabilities to enhance coordination and cooperation.
- Develop a one-year plan of action with indicators and M&E and reporting components to produce and share evidence on tracking the success of the Global Partnership on CWD from country to global levels.
- Explore the mechanisms for the Global Partnership on Children with Disabilities, including establishing Task Forces and accountabilities for the coming year:

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<sup>13</sup> [http://www.cbm.org/article/downloads/71140/Fact\\_sheet\\_Disability\\_in\\_Conflict\\_and\\_Emergencies.pdf](http://www.cbm.org/article/downloads/71140/Fact_sheet_Disability_in_Conflict_and_Emergencies.pdf)

<sup>14</sup> Ibid.

<sup>15</sup> See for example: [http://www.unicef.org/spanish/emerg/disasterinasia/files/TSUNAMI\\_E\\_BOOK\\_spreads.pdf](http://www.unicef.org/spanish/emerg/disasterinasia/files/TSUNAMI_E_BOOK_spreads.pdf)



- Advocacy and support of programmatic strategies
- Research and knowledge management
- Coordination / collaboration on ensuring an inclusive post-2015 development agenda, with and for children with disabilities, their families and / or caregivers, and representative organizations.