

## **Cerebral Palsy Africa (CPA): Strategic Plan 2021-2022**

*CPA's end-goal is to improve the QUALITY OF LIFE of children with neurodevelopmental disability (NDD) and their parents through better interventions and services provided by well-equipped staff working in CBR-programs.*

### **WHY**

A large number of children with neurodevelopment disability (NDD) born in Low-and Middle-Income Countries (LMICs), and their parents/caregivers, are struggling to come to terms with the challenges of managing life (often from birth to adulthood).

While the needs of children with NDD and their parents are enormous and well documented, the tragedy is that LMICs resources (human- and material) for appropriate services/interventions to these children and their parents are scarce. In practice it means that there is a serious shortage of:

- competent rehabilitation professionals and field workers
- appropriate assistive technology

### **HOW**

CPA's purpose is a) to develop expertise and evidence of best practices on rehabilitation for children with NDD in LMICs and b) to provide training programs for fieldworkers to improve skills on identification and functional rehabilitation, including appropriate assistive devices, for children with NDD and their families. Training is always connected with concrete and practical implementation in the field, with the focus on participation of the child with NDD in family life and community. Monitoring evidence is part of the planning process.

### **WHAT**

- a) Facilitate local and/or regional African NDD-expert networks, operating in line with the Community Based Rehabilitation/ Community Based Inclusive Development (CBR/ CBID) strategy; support initiatives to promote parent associations; support initiatives to make appropriate assistive devices.
- b) Capacitate Master-Trainers to implement acquired expertise and become practical ToT's and coaches on functional rehabilitation for parents/caregivers, focusing on Quality of Life and coping, both for caregivers and for their child living with NDD.
- c) Evaluate and research:
  - 1) the effectiveness of functional training of children with NDD;
  - 2) the efficacy of low-cost assistive devices.

- 3) the results of coaching parents to cope with life in supporting their child;
- 4) Disseminate findings on concrete and practical evidence on the website, newsletters and publications in scientific journals.
- 5) Contribute to raise awareness on the position of children with NDD among stakeholders and policy makers, in order to reduce stigma attached to (having) children with NDD.

### **WHY in a wider context**

In 2006, the United Nations has stated the *Convention on the Rights of Persons with Disabilities* (CRPD), which aims to “*promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity*”. It reflects the major shift in global understanding and change attitudes and approaches to persons with disabilities as persons with rights and control of their own life.

The World Health Organization’s (WHO) first world Report on Disability (2) estimates that 95 million children worldwide have a disability, with 13 million children having a severe disability and experience significant difficulties in daily functioning. Country specific studies and statistics show that the prevalence of childhood disability and child mortality is higher in low-and middle-income countries (LMICs) than in high-income countries. In children with a disability, CP and neurological impairment have been identified as being one of the most common types of childhood disability worldwide, with 1.5 to 4 children per 1000 births (Division of Birth Defects and Developmental Disabilities 2017; Donald et al., 2014; Gladstone, 2010).

While CPA initially emerged out of a need for more attention and expertise on Cerebral Palsy (CP) in African countries, the reality is that CP and other neurodevelopmental-related disabilities are often misdiagnosed. As such, we broaden our scope to include children with a variety of NDDs.

For example, a study in Uganda (Kakooza-Mwesige et al., 2017) shows a prevalence of 2.9 per 1,000 children out of a sample of 31,756 children between the age of two and 17 years versus roughly 2.0 – 2.5 per 1,000 children in high income countries. The prevalence numbers in Uganda did not include the children with cerebral palsy who have passed away. Anecdotal information gives reason to believe the percentage of children with cerebral palsy who die under the age of 2 years is high and in part can be caused by complications such as malnutrition, but infanticide may continue to play a role in many societies. Disability among babies and young children is often viewed as a curse, or as a consequence of something the parents – especially the mother – did or did not do, which can result in attributions of blame and abandonment (Disability Report Uganda, 2020)

## HOW in practice

The *CPA-approach* is primarily focusing on improving Quality of Life for children with NDD, through information, skills and building capacity for caregivers on how to cope with NDD in daily life: *If parents do better, the child will do better.*

### 1) **CAPACITY BUILDING OF FIELDWORKERS** (focusing on activities and participation)

In low and middle-income countries, a major concern is the strategy to deliver effective interventions, appliances and services for children with *moderate and severe neurological disorders (NDDs)*. Frontline field workers often have limited training on NDD, both in terms of time and in terms of scope and quality of training. According to World Health Organization 5-15% of people with disabilities are able to access assistive devices. Most workshop are orthopedic workshops, producing standard orthopedic devices which are not tailor made or adjusted for children with NDD.

Training is focusing on functional activities such as sitting, standing, walking, all activities of daily life. Functional training has proven to be most effective, compared to routine interventions focusing on body functions and structures such as passive stretching, which is often without any functional goal, not to mention how unnecessary stressful and painful it can be for child and parent.

Within the training programs, the International Classification of Functioning, Disability and Health (ICF) is used. ICF is the WHO framework for measuring health and disability at both individual and population levels. The ICF the most-frequent used international classification of health and health-related domains. As the functioning and disability of an individual occurs in a context, ICF also includes a list of environmental factors. CPA will use the children and youth-version of ICF (ICF-CY).

An intervention package has been developed, using this ICF-CY classification and including training materials based on the London School of Tropical Medicine and Hygiene (LSTMH's) '*Getting to Know Cerebral Palsy*' manual. CPA adopts the train the trainer principle (ToT's): experts train local trainers who in turn train fieldworkers.

### 2) **SUPPORT OF PARENTS** (focusing on environmental factor)

Children with CP or with another neurological disorder are some of the most marginalized in their communities, often thought to be uneducable, with little understanding of how rehabilitation can dramatically improve their lives. These children and their families are often stigmatized and caregivers struggle to cope physically with children as they grow older and heavier. The whole family, including the non-disabled children are often thrown into poverty, as the adults spend more time caring and less in economic activity.

Therefore, the intervention package also pays attention to environmental factors to optimize participation of the child with NDD in family-life, school and community. *If parents do better, the child will do better.*

### 3) **APPROPRIATE ASSISTIVE DEVICES** (focusing on activities and participation)

Appropriate assistive devices and technologies such as NDD-adjusted (wheel) chairs, sitting devices and standing frames can help reduce adverse effects of static positions by increasing a child's independence for life with sitting, standing, mobility and feeding themselves. It can reduce the numbers of children dying during feeding by holding the child in a good position. In LIMCs, only 5-15% of people who require assistive devices and technologies have access. The CPA - intervention package includes practical information about assistive devices. Appropriate paper-based technologies (APT), strongly promoted/ developed in the early years of CPA Scotland, is one of the options.

### Strategic Priorities for 2021-2022

1. Pool of African Master Trainers on NDD will be formed. Focus, within the ICFY framework, on capacity building for ToT's. Organize local NDD-expert networks, equipped to train CBR fieldworkers and rehabilitation professionals to become coaches for caregivers; a 10 days- training program, planned for September/ October '21, will be developed in collaboration with University of Gondar in Ethiopia and Light for the World.
2. Promote the availability of appropriate services and equipment to children with NDDs.
3. Integrate the activities of the Butterfly Basket Foundation: a Dutch NGO, highly specialized on NDD and with a strong track record in Vietnam. This organization became part of CPA as from January 2021.
4. Establish an effective, reputable and sustainable organization based in the Netherlands with initially its area of operation in a limited number (3-5) of countries. Seek future opportunities to work in partnership with IDDC members such as CBM, Motivation UK, Able Child Africa, Light for the World International, NAD and the Liliane Foundation.

World Health Organization's (WHO) first world Report on Disability:

<https://www.who.int/teams/noncommunicable-diseases/disability-and-rehabilitation/world-report-on-disability>

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Kakooza-Mwesige A et al.. Prevalence of cerebral palsy in Uganda: a population-based study. *Lancet Glob Health.* 2017;5 e1275–82. [http://dx.doi.org/10.1016/S2214-109X\(17\)30374-1](http://dx.doi.org/10.1016/S2214-109X(17)30374-1).

Disability report Uganda. <https://www.developmentpathways.co.uk/publications/harnessing-their-potential-the-state-of-disability-in-uganda-summary-report/>

Division of Birth Defects and Developmental Disabilities 2017; <https://www.cdc.gov/ncbddd/>