Cerebral Palsy Africa: Multi Annual Plan 2020-2022

Vision

Children in Africa with Neurodevelopmental (ND)-related disabilities[1] will achieve their potential and be a valued part of their community.

Mission

In order for children with ND-related disabilities to achieve their potential, Cerebral Palsy Africa will:

- Provide targeted specialist training.
- Facilitate key trainees in African countries to become competent trainers themselves.
- Capacitate trainers to become coaches for caregivers, focusing on Quality of Life and coping, both for caregivers and for their child living with an ND.
- Support trainers in setting up appropriate assistive equipment workshops.
- Raise awareness among stakeholders and policy makers about early identification, referral and intervention.

Aims

1. To facilitate local and/or regional African ND-expert networks, working within the broader context of the ICF framework, and operating in line with the CBR/ CBID strategy.
2. To provide management staff and other specialists with functional rehabilitation training (including a focus on appropriate assistive devices) on ND. Such training will also target, amongst others, therapists, teachers, Community Based Rehabilitation (CBR) workers and caregivers of children with neurodevelopmental conditions.
3. To reduce the stigma attached to (having) children with NDs; to communicate and liaise with the government and other partners to promote the inclusion of children with NDs in their regular services, and when needed, to invest in special services.
4. To evaluate and research the effectiveness of training and the efficacy of assistive technical devices, and to disseminate findings.
5. To identify and support individuals with potential to become leaders in the field; to identify and support potential expert trainers and parent associations.

Wider context:

The World Health Organisation's (WHO) first world Report on Disability report[2] estimates that 95 million children worldwide have a disability, with 13 million children having a "severe" disability. In

[1] 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 many neurodevelopmental-related disabilities are often misdiagnosed. As such, we would like to broaden our scope to include, render visible and empower children with a variety of NDs. Hence, the text will thereafter refer to ND-related disabilities as opposed to Cerebral Palsy only.

[2] WHO (2011) World Report on Disability

https://apps.who.int/iris/bitstream/handle/10665/70670/WHO_NMH_VIP_11.01_eng.pdf;jsessionid=3C26DA38C79A0BC5D90AA62B1D251FE3?sequence=1

their overview of childhood disability and review of statistics, UNICEF[3] warns us about said data, in that varying definitions of disability, reduced access to services and lack of visibility highly influence the reliability of the data collection. In fact, the WHO's latest statistics on childhood disability stem from the Global Burden of Disease report[4] that was commissioned in 2004. Nevertheless, country specific studies and statistics show that the prevalence of childhood disability is higher in low- and middle-income countries than in high-income countries.

Child mortality is also higher in developing countries. In UNICEF's under-five mortality ranking[5] the countries where CPA works have relatively high mortality rates, Uganda is rated 26, Malawi and Zambia 31, Ghana 34, Kenya 38 and Tanzania 41 (out of 195 ranks). These numbers indicate a lack of services in countries where there are high numbers of children with health and disability difficulties.

In low-income countries, the prevalence of cerebral palsy seems slightly higher than in high-income countries. A study in Uganda (Kakooza-Mwesige et al., 2015) 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 – obviously - 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. In fact, CP has 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).

These children are some of the most marginalised 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 stigmatised 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.

Assistive appropriate technology such as chairs 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. Access to made-to-measure, sustainably produced wedges, chairs, and standing frames becomes possible and affordable where appropriate technology workshops are set up and run by trained and motivated people. Articles 4, 9, 20, 21, 24, 26, 29 and 32 of the Convention on the Rights of Persons with Disabilities (CRPD) make explicit mention of specific aspects of assistive technology[6] and describe it as a human right. According to World Health Organisation only 5-15% of people with disabilities are able to access assistive devices/technologies.

There are many approaches to the treatment of children with cerebral palsy. CPA training is primarily focusing on improving Quality of Life and building coping capacity for caregivers living with a child having an ND. An intervention package is developed, including training materials based on the LSTMH's Getting to Know Cerebral Palsy manual; proper assessment -, goalsetting - and monitoring tools; the

[3] https://data.unicef.org/topic/child-disability/overview/

[4] https://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf

[5] UNICEF(2013) The State of the World's Children
http://data.unicef.org/corecode/uploads/document6/uploaded_pdfs/corecode/SOWC_2013_75.pdf

[6] http://www.unicef.org/sowc2013/focus_assistive_technology.html by Johan Borg
http://www.who.int/disabilities/technology/activities/en/

RehApp CP and coaching of fieldworkers. The training package is framed within ICF and the related CBR/ CBID strategy. A recent evaluation study by the Liliane Foundation provides more information[7].

In the African countries where we work there are either physiotherapists or occupational therapists or both but they are very few in number.

Country	***Population[8] 2019***	***PTs[9] 2019***	***Ratio per no population***	***OTs***	***Ratio per no population***
Ghana	31,072,940	*165*	*1 per 188,320*	*22*	*1 per 1,412,406*
Zambia	18,383,955	*79*	*1 per 232,708*	*6*	*1 per 3,063,993*
Kenya	53,771,296	*2161*	*1 per 24,883*	*800*	*1 per 67,214*
Malawi	19,129,952	*65*	*1 per 294307*	*8*	*1 per 2,391,244*
Uganda	45,741,007	*70*	*1 per 653442*	*165*	*1 per 277,218*
Tanzania	59,734,218	*85*	*1 per 702756*	*128*	*1 per 466,674*
Nigeria	206,139,589	*690*	*1 per 298740*	*20*	*1 per 10,306,979*

These therapists have very limited opportunities for specialisation especially with regard to paediatrics. They are poorly paid, and in most countries, there is little or no career structure to motivate them to develop their profession.

The organisation

How it started.

After many years of living and working in Africa as a paediatric physiotherapist, Archie Hinchcliffe (Scotland) realised the need for children with cerebral palsy to have good therapy early in their lives. She also recognised the potential amongst African physiotherapists to meet this need if they could be given the necessary specialist skills.

She met Jean Westmacott (UK), who introduced the concept of Appropriate Paper-based Technology (APT) to enable people in:

- developing countries to establish sustainable production units; an
- manufacturing assistive equipment from recycled cardboard for children with disabilities.

Having discovered that 'rehabilitation' is not considered a priority by neither governments nor (inter)national development- and aid-organisations, and knowing that there was insufficient local expertise (though a great deal of willingness to learn) to help children with cerebral palsy, Archie and Jean decided to set up Cerebral Palsy Africa in the early 2000s. This was an attempt to close this gap and enable local people to master the competencies to support children with cerebral palsy and their families to have a better life.

[7] https://connect.lilianefonds.org/step/project+information/1447803.aspx?t=Reports

[8] https://www.worldometers.info/world-population/population-by-country/

[9] https://www.wcpt.org/countries

In 2019, the Board decided after 2 years of discussions to hand over the organisation to 'Enablement', a Dutch consultancy firm that has 35 year of experience in the field of CBR. Early 2020, a registration process was started, and the activities were taken over by a new Board as of April 2020.

Board CPA-NL as from 01-04-2020
The Dutch Board of Cerebral Palsy Africa consist of the following persons:

- Chairperson: Mr. H. (Huib) Cornielje
- Executive Secretary: Mr. C.J. (Kees) van den Broek
- Board member: Mrs Yvonne Vleeshouwers

Overseas partners
The overseas partners consist of:

- Short-term African trainers in childhood rehabilitation
- Individual volunteers from the UK & other countries:
- Project managers from partner organisations
- Individual rehabilitation professionals

Strategic Priorities for 2020-2022

1. *Establish an effective, reputable and sustainable organisation based in the Netherlands with initially its area of operation in African countries[10].*

2. *Focus, within the ICF framework, on capacity building and organising local ND-expert networks, equipped to train CBR fieldworkers and rehabilitation professionals to be coaches for caregivers.*

3. *Promote the availability of appropriate services and equipment to children with NDs. Promote functional rehabilitation, the manufacturing and use of appropriate equipment through training allied health professionals, teachers, families and community based rehabilitation workers.*

4. *Promote public awareness-raising activities, in order to contribute to reducing the negative stigma attached to NDs; including the support of lobby activities to (N)GO's.*

5. *Seek opportunities to work in partnership with IDDC members such as CBM, Motivation, Able Child Africa, Light for the World, NAD and the Liliane Foundation.*

Priorities for 2020:

1) Transparent communication to establish/ revitalise contacts with ND-experts, Southern partners and funding-partners.

2) Transition of on-going CPA activities and reporting to donors involved.

3) Focus of activities on a package (training material, tools, App) for the capacity building of expert-ND trainers (ToT) in a limited number (3) of countries.

[10] We may consider working in Asian countries as well if there are request for such an involvement.