Cerebral Palsy Africa
A van Leeuwenhoekweg 38 Unit A16
2408AN Alphen aan den Rijn
The Netherlands
☏ +31 6 28485083 (chair)
☏ +31 6 21913027 (secretary)

Strategic plan CPA 2022-2024

1. Our Dream

CPA has a dream which is twofold:

- to play a role - substantially and structurally - in building capacity of the (re)habilitation sector in Low- and Middle- Income Countries (LMIC's). This should lead to improved competencies of service providers including rehabilitation cadre.
  Ultimately this should lead to better functioning for children with complex neurodevelopmental disabilities i.e. cerebral palsy in their:
  1) daily functioning
  2) participation at home, school and community
  3) quality of life
  4) caregivers' wellbeing
- to closely work together with universities (medical, nursing and midwifery faculties), traditional birth attendants, and the primary health care sector (public as well as private) to step up its work on the prevention of childhood disabilities, early identification, early referral, and timely intervention of children with neurodevelopmental disabilities and coaching of caregivers (e.g. caregivers); as well as building a body of knowledge of contextually appropriate, good practices.

We recognize that this only can be achieved through intersectoral collaboration of various (public) sectors with and within existing Community Based Rehabilitation (CBR) or Community Based Inclusive Development (CBID) programs in Low- and Middle- Income Countries, through sharing knowledge, skills, and tools about contemporary, and where possible evidence-based rehabilitation practices. The key stakeholders involved to make this happen are organizations of persons with a disability, governmental ministries/agencies, the NGO sector, community rehabilitation workers, (mid-level) rehabilitation field workers, rehabilitation professionals, donor organizations and last but not least caregivers - ideally - caregivers of children with cerebral palsy (CP) as well as their children.

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1.1. Our Values

1. We support existing reputable local organisation. This implies that we don't fund the employment of their staff members. We thus integrate new approaches in existing programmes.
2. The approach which we plan to integrate into existing curricula and trainings focuses on functionality and family-centred care.
3. Whatever we do we ensure that it is cost-effective.
4. These principles contribute to a systems change within the countries where we work
5. We aim at scalable service development.
6. We work with local country representatives since we believe that ownership is vital to success.

2. CPA programme-countries

The selection of the 3 African countries - i.e. Ethiopia, Ghana and Uganda - is formed by the availability of resources (manpower as well as structures and systems), existing contacts and opportunities. However, we realise that within the history of CPA contacts exist with other countries as well: namely Malawi, Nigeria, South Africa and Zambia.

While concentrating on a number of African countries we are temporarily active in Vietnam since we took over the Butterfly basket a foundation which has been working in the same field in this country for 13 year. We developed a new relationship with the Friendship Foundation active in Bangladesh

3. Our mission

CPA aims to improve the quality of life of children with cerebral palsy - specifically the most severe cases - and their caregivers through better interventions and services provided by well-equipped staff working in Community-Based Rehabilitation (CBR) programmes.

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4. Context and justification of key elements in CPA's multi annual plan

4.1 Context

A large number of caregivers of children with CP born in Low- and Middle-Income Countries (LMICs), are struggling to come to terms with the challenges of managing their life and bringing up their children in the best way possible, especially while living in poverty and dealing with stigma and discrimination. This is often a lifelong challenge starting from birth to adulthood.

There is a substantial difference between the prevalence and severity level of CP among high- and low- and middle-income countries. According to a study in Bangladesh, the incidence rate of cerebral palsy in Bangladesh is more than double that of Australia (3.4 versus 1.4 per 1000). Almost two times more Bangladeshi children have significant motor deficits (GMFCS IV–V = 43.6%, as compared with 26% in Australia), and 78.2 percent receive no rehabilitation at all. This is undoubtedly related to a lack of access to preventive and rehabilitation services in low- and middle-income countries[1]. This demonstrates that investing on prevention, early detection, and proper rehabilitation services for children with CP in low-income countries such as Ethiopia and Ghana could have a significant impact on decreasing the incidence and severity level, as well as improving the quality of life of the affected children.

While the needs of children with CP and their caregivers are enormous and well documented, the tragedy is that (human- and material-) resources for appropriate interventions needed for these children and their caregivers are extremely scarce in LMICs. Albeit of progress being made over the past 40 years, there is still a shortage of knowledge, adequate skills and available information about CP in terms of prevention, identification, causes, prognosis, and effective interventions in these countries. The reality of these countries is that:

- there is often not the needed knowledge and equipment for early and accurate diagnoses to provide caregivers with accurate information about what a certain diagnosis means for the child, the child's development, needed interventions and prognosis about the future.
- often, interventions are not needs-based (i.e. person-centred and family-based);
- there is a serious shortage of available and competent workforce (such as community rehabilitation workers and/or (mid-level) rehabilitation field workers) who work in the

[1] van Zyl C, Badenhorst M, Hanekom S, et al. Unravelling 'low-resource settings': a systematic scoping review with qualitative content analysis. BMJ Global Health 2021;6:e005190. doi:10.1136/ bmjgh-2021-005190

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public sector and who are willing or able to provide quality services to this category of children. Very limited opportunities are available for specialisation especially with regard to paediatrics.

- even if there are rehabilitation professionals available, they often use outdated, non-needs based, and/or painful or harmful intervention methods while working with these children due to lack of (continuous) professional education.
- they seriously miss well-trained and sufficient numbers of community rehabilitation workers and/or (mid-level) rehabilitation field workers able to provide tangible support to caregivers and their children, early detection and intervention and timely referral within a network of stakeholders to ensure strong care pathways and continuum of care, because such type of care and rehabilitation is often not available e.g., in remote areas.
- much needed – and even the most basic – appropriate assistive technology (AT) is not available nor accessible often because of its high costs involved in getting such technology. When there is AT available, it is often imported, of limited sizes to provide good support. Personnel from AT workshops are inventive, but wish to increase knowledge, skills and material resources to provide appropriate support.
- these children - especially the severely disabled children – are not seen and heard by politicians, policymakers and planners, and even not always by organisations of people with disabilities since they may be more interested in quick results.
- in addition, there are serious barriers to acceptance of the idea of investing in self-care by service providers and planners. These could for instance be based on vested interests from the side of professionals. They may see such an approach as being against their own financial/economic interests. Besides, it requires (drastic) changes in power structures i.e. the therapist not on top of the rehabilitation process but serving the interests of caregivers

4.2 Key Elements

4.2.1 Prevention

Although CP in many cases cannot be prevented, there are established and evidence-based prevention methods for certain causes of Cerebral Palsy [2]. However, their applicability has been limited to high-income countries because of a lack of awareness and services in low-income countries. In CPA programme-countries like Ethiopia, Ghana and Uganda, health professionals

[2] Namaganda LH, Almeida R, Kajungu D, Wabwire-Mangen F, Peterson S, Andrews C, et al. (2020) Excessive premature mortality among children with cerebral palsy in rural Uganda: A longitudinal, population-based study. PLoS ONE 15(12): e0243948

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and the public are often unaware of these prevention efforts. One of the key areas for CPA to work on is raising awareness and advocacy on the prevention of CP. Some activities to address this could include.

- Providing training for health care professionals (formal ones and informal ones such as traditional birth attendants) on prevention methods of CP.
- Educating community health and community rehabilitation workers and/or (mid-level) rehabilitation field workers about prevention
- Work with primary health centres in the community
- Raising awareness through mass media and local information sharing systems.
- Influencing curricula of relevant training programmes at universities and training colleges.

4.2.2 Early identification, diagnosis, and treatment

Unfortunately, most children with CP in low-income areas are diagnosed (too) late: usually after the critical period when optimal neuroplasticity of the developing brain has passed or when timely intervention is not provided for health issues, leading to worse e.g., with meningitis, jaundice, malaria, epilepsy. The first 1000 days of life are critical for neurological development. During this time, the brain is developing at rapid speed making it the ideal time to harness neuroplasticity. Evidence shows greater benefit from early versus later intervention in CP. Early detection and intervention are therefore crucial for optimizing both motor and functional outcomes of children with CP.

There are several ways to promote early intervention and detection for children with CP. In low- and middle-income counties such as Ethiopia, Ghana, and Uganda, with proper training and support, CBR programmes, community centres and primary health care centres could play a very important role in this. One of the areas for CPA work will be to facilitate and promote contextualized and efficient early identification and intervention for children with CP and to strengthen networks and referral pathways for early identification and – intervention.

Strategies to identify children with CP and those at risk of developing CP in the community.

- Train and provide tools to (health) professionals at rural primary health care centres to identify, diagnose and refer children with CP[3].

[3] Karim, T., Scherzer, A., Muhit, M., Badawi, N., & Khandaker, G. (2019)

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- Use of a Developmental Milestone Chart (DMC) to educate health care workers, community rehabilitation workers and/or (mid-level) rehabilitation field workers and stimulate referral for early diagnosis and intervention.
- Train and utilize health extension workers in countries like Ethiopia or community health workers, from existing structures, to identify and refer children and provide basic counselling to caregivers and basic intervention to the child, where needed with support of higher-level workers in primary health care or hospital. They mainly focus on awareness raising, prevention and referrals to primary level health care centres. While they do not provide treatment, they do deliver a range of other services to families. If properly trained, they can be very instrumental in early identification, referral, task shifting (e.g., after care or continued care from other professionals) services for those children and counselling and coaching of caregivers.
- Train and utilize staff from (local) early child development centres (or early childhood education centres) to identify and refer children and even improve their own services by being more disability inclusive.
- Utilize local community structures such as religious groups and social groups at the community level to identify and refer children.

The next step after identification is early intervention.

4.2.3 Community based early interventions

In countries like Ethiopia, people with CP often don't have access to specialized rehabilitation services due to many reasons including financial constraints, transportation problems, and centres being located in hospitals in urban areas. One of the most effective ways to address this lack of access to specialized services is a strong focus on community-based early intervention and rehabilitation programmes. A study conducted in Bangladesh found that a community-based parent-led comprehensive early intervention and rehabilitation programme delivered by community health workers resulted in a promising positive functional and motor outcome for children with CP[4]. Such community- and family- centred programmes will have a substantial impact on the quality of life of children with CP and their caregivers. Caregivers of children with CP often experience a poor (health-related) quality of life and feel overwhelmed by the economic burden and their caregiving role. Community based programmes can benefit caregivers in reducing their burden and providing them with the skills and knowledge they need to effectively

[4] *Karim, T., Muhit, M., Jahan, I., Galea, C., Morgan, C., Smithers-Sheedy, H., ... & Khandaker, G. (2021). Outcome of Community-Based Early Intervention and Rehabilitation for Children with Cerebral Palsy in Rural Bangladesh: A Quasi-Experimental Study. Brain sciences, 11(9), 1189.*

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support their children at home. The following paragraphs describe the types of services that CPA is focussing on for capacity building.

Support Services

Children with severe CP who are not accepted in school or who require more individual support, could benefit from support services such as day care, which are often lacking in the countries mentioned. In such a centre, they spend the day receiving therapy and participating in activities such as play, crafts, socializing and informal education. Such a centre should be the place where the caregivers or caregivers learn skills and knowledge to effectively support their children at home. They are also actively participating in the activities of the day care centre. CPA wishes to establish community-based early intervention and rehabilitation programs in countries such as Ethiopia and Ghana where such programmes are desperately needed, including these type of centres.

Early Childhood Development

Some countries have programs for early childhood development. Only few of these programs do include children with mild disabilities, but children with CP are usually not included or programs are not equipped (material and knowledge) to serve these children. However, there is an imminent need for capacity building of the staff of these centres by providing them with knowledge and tools in adequately including the child with CP in regular play and development activities.

Improving the Quality of Rehabilitation Services for Children with CP

According to collective experiences and observations of the CPA (advisory)board and their informal local representatives, many therapists are often not properly trained in the management of, and providing interventions for, children with CP. Universities teach outdated approaches and interventions for CP rehabilitation as they often don't have access to faculty members or specialists with knowledge and skills that follow up to date good practices and evidence-based practice. This problem can and should be addressed by providing continuous training and mentorship of professionals, university lecturing staff, as well as collaborating with universities and updating the curricula e.g. there are currently four physiotherapy and one occupational therapy training programme in Ethiopia; speech and language therapy training programmes are even more rare (mainly relevant because of nutrition and feeding issues). Professionals can become the trainers and coaches of the community rehabilitation workers and/or (mid-level) rehabilitation field workers.

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Facilitating and Building the Capacity of Parent Associations

Sharing experiences, knowledge and skills can be an important strategy not only to relief burden and feel supported, but also to strengthen the voices of the caregivers in their lobby and advocacy for access to quality services, access to (health) information, inclusive education (from early childhood to higher education) and livelihood support. There are examples of successful parent associations in other parts of the world who even run their own day care centres.

Income Generating Activities

Compared with other children, children with disabilities are less likely to receive education, less likely to be employed as adults, less likely to start their own families and participate in community events, and more likely to live in poverty. This certainly applies to the target group of CPA: children with cerebral palsy. In many countries, the poverty gap between people with and without disabilities exceeds 20 percent. Further, when poverty is measured not merely by income but by multidimensional poverty measures – including health, living conditions, assets, education, employment, and various forms of social engagement – the gap is even larger. When the gap between what people with disabilities earn, and what they would be expected to earn if not disabled, is summed over all people with disabilities, the result is a measure of the loss in Gross Domestic Product (GDP) caused by disability. A report by the International Labour Organization (ILO) estimated that the loss in GDP in the countries they studied count up to 7% of the GDP. While those estimates are the result of lower earnings among adults with disabilities, many of whom acquired their disability after childhood, they do not account for the fact that people without disabilities might also be working less to care for family members with a disability. [5] It is therefore that CPA wishes to address not only the quality of life of the child but also that of the family and in particular the caregivers. We believe that this ideally should be an integral part of the establishment of small community day care centres where children can develop, learn, connect, enjoy life (see the section on day care centres) and caregivers/relatives are giving the freedom and opportunities to become involved in income generating activities. We wish to intensively collaborate with general community development programmes to help caregivers/relatives to raise an income, but it may be very well that we need to become even more active in this area of work.

5. General Strategies

The strategies which CPA employs are directed at:

A) prevention of CP; and
B) improvement of functioning and quality of life of children with CP and their parents (see next page for details).

[5] Combatting the Costs of Exclusion for Children with Disabilities and their Families, United Nations Children's Fund (UNICEF), New York, 2021.

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CEREBRAL PALSY AFRICA
OVERVIEW OF CPA ETHIOPIA AND CPA GHANA PROJECTS

Main Strategies for project implementation: advocacy, community mobilization, capacity building, coaching, service provision, research, and documentation.

Main project activities

Part A	Part B
Prevention, early identification, and referral	**Evidence Based Rehabilitation services for children with CP and support services for parents**
Main Activities under part A	**Main Activities under part B**
• Establish a system for early identification and referral	• Train local Master trainers in the contemporary approach for rehabilitation for children with cerebral palsy
• Provide health care providers with the knowledge, skills, and tools they need to be able to identify children with cerebral palsy and provide education on prevention strategies.	• Provide ongoing mentorship, and capacity building of the master trainers
• Educate traditional and faith healers on the health condition of children with cerebral palsy and the importance of early referral to appropriate services.	• Support, coaching and mentorship of CBR workers
• Health Promotion • Health education, especially for adolescent girls, Improvement of nutritional status in community, Improvement in pre, peri and postnatal care.	• Curriculum change in universities • Provision of functional therapy services for children with CP • Enabling participation and inclusion of children with CP in life activities • Socioeconomic empowerment and Support for parents (IGA, parent association establishment and psychosocial support for parents)
Main Stakeholders PART A	**Main Stakeholders PART B**
Ministry of Health, Primary Health Care centers, hospitals, traditional and faith healers, health care professionals such as physicians, midwifes, nursing staff, health officers and traditional birth attendants.	CBR programs Academic institutions Rehabilitation Professionals, Occupational Therapy, Physiotherapy, and Speech and Language therapy. Rehabilitation Professional Associations

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6. Activities

The following activities will be employed:

a) Facilitate CP-expert networks on a country level, operating in line with the Community-Based Rehabilitation/ Community-Based Inclusive Development (CBR/ CBID) strategy; support initiatives to promote parent associations, and access to (early) education; support initiatives to make locally available and appropriate assistive devices.

b) Capacitate Master-Trainers to implement acquired expertise and become practical trainers of trainers and coaches on functional rehabilitation for community rehabilitation workers and/or (mid-level) rehabilitation field workers who in return should be the coaches of caregivers, focussing on nurturing care, improving quality of life, coping and resilience, both of caregivers and their children living with CP.

c) Where needed support governments in developing realistic policies on prevention, early identification and intervention and integrate this aspect within the training, - lobby and advocacy, and – the implementation of fieldwork.

d) Evaluate and research:
   1) the effectiveness of functional interventions in the lives of children with CP in LMIC.
   2) access to and the efficacy of low-cost assistive devices.
   3) the results of coaching caregivers to (mentally and financially) cope with life in supporting their child.
   4) the impact of parent associations on the quality of life and on access to health and education services.

e) Disseminate findings on concrete and practical evidence on our website, in newsletters and in publications in relevant journals.

f) Contribute to raising awareness on the position of children, youth and young adults with CP among local and international stakeholders and policymakers; create attention for these children; improve the availability of appropriate services; and reduce the stigma attached to (having) children with CP.

g) Build linkages for the participation of young adults with CP in livelihood activities.

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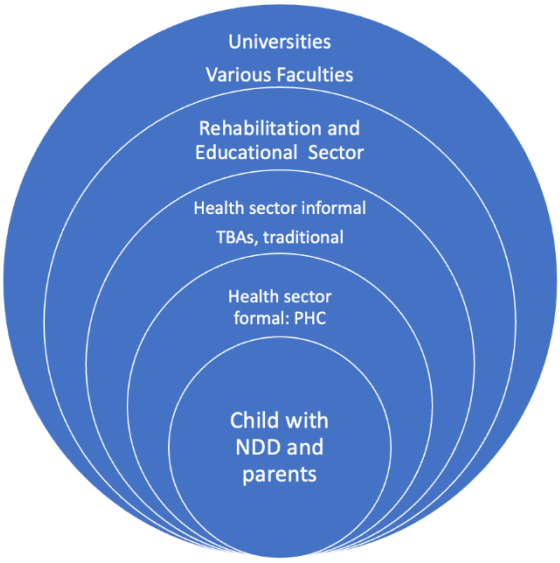
Major Stakeholders



Outcomes: improved

Structural and sustainable essential services directed at prevention, early identification and rehabilitation

Influence policies	partnerships	Improve curricula
Prevention Early identification Rehabilitation	Government (MoH) Health sector (in) formal Rehabilitation sector Universities Education Sector Parent Associations	Faculties of: - Medicine - Nursing - Midwifery - Physiotherapy - CBR
Establish day care centres	**Scalable implementation of pilots**	**African network of trainers**
Offer: - Day care - Childhood development - Income generation for parents	Robust pilots Show evidence Lobby/advocate	Invest in training Training of Trainers Training of coaches

Building blocks

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7. Conditions

While the above is our dream we realize that some conditions need to be in place within CPA as well and therefore we:

1) Develop a strong base for the CPA organization in the Netherlands, focus on the niche of neurodevelopmental disability only and securing continuity in management of programmes and funding.
2) Develop a strong base for CPA in programme countries, securing local management and expertise to coach and influence stakeholders, characterized by an entrepreneurial drive for practical results on ground-level (children and caregivers) within the comprehensive scope of Primary Health Care and CBR.
3) We will start working with country representatives in Ethiopia and Ghana as from the 1st of July 2022; contextualized country action plans are currently being developed.
4) Develop a solid judicial and steady financial situation for CPA.

Projected Outputs

We expect that in 3 years' time the following outputs will be achieved:

- Training 20 Master Trainers in CP for 2 countries (Ethiopia and Ghana)
- 20 Master Trainers train and coach 100 community rehabilitation workers and/or (mid-level) rehabilitation field workers.
- 100 community rehabilitation workers and/or (mid-level) rehabilitation field workers are responsible each (on average) for the support of 30 children with CP and their families
- These 3000 children live in a family of which at average the 5 to 6 people live in each family.
- In each of the 2 countries 25 support services and parent groups will be initiated taking care of 15 children each meaning 750 children with CP (with approximately 3750 family members) will benefit.

7. For more information, background and history

see our website: www.cerebralpalsyafrica.eu