Cerebral Palsy Africa
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Annual report CPA 2021

History

Cerebral Palsy Africa (CPA) was founded in 2005 by two Scottish rehabilitation professionals with long working experience in several African countries: Archie Hinchcliffe, a pediatric physiotherapist, and Jean Westmacott, a special needs teacher who became the driving force behind training and the promotion of low-cost assistive devices, such as adaptive chairs and tables, functional toys, and equipment.

In 2019, the Scottish Board of CPA decided to facilitate the transition to a Dutch Non-profit Organisation that could continue and develop their work after the retirement of the founders. CPA-NL registered in March ’20; a renewed policy has since been developed.

Purpose

CPA aims to improve the quality of life of children with neurodevelopmental disability (NDD) - *specifically the most severe cases (such as large groups of children with Cerebral Palsy)* - and their parents through better interventions and services provided by well-equipped staff working in Community-Based Rehabilitation (CBR) programmes.

Justification

A large number of parents of children with NDD, 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.

While the needs of children with NDD and their parents are enormous and well documented, the tragedy is that (human- and material-) resources for appropriate services/interventions needed for these children and their parents are extremely scarce in LMICs. Albeit of progress being made there is still a shortage of knowledge about NDD in terms of causes, prognosis, and effective interventions. Despite some progress made over the past 40 years, the reality of these countries is that:

- there is often not a clear diagnostic policy or needed knowledge and equipment for accurate diagnoses to provide parents with accurate information about what a certain diagnosis means for the child, the child’s development, needed interventions and prognosis;
- often, interventions are not needs-based (i.e. person-centred and family-based);
- there is a serious shortage of competent rehabilitation professionals who work in the public sector and who are willing or able to provide quality services to this category of children;

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- 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;
- training of rehabilitation professionals is often outdated, due to limited access to finances for continued education, as well as not focussing on childhood disability nor contextualised;
- these countries seriously miss well-trained and sufficient numbers of (mid-level) rehabilitation field workers able to provide tangible support to parents and their children, early detection and timely referral for a continuum of care and quality care pathways;
- much needed – and even the most basic – appropriate assistive technology is not available nor accessible because of its high costs;
- this is a category of children – especially when referring to severely disabled children – not seen by politicians, policymakers and planners, and even not by organisations of people with disabilities. These children and their parents have a need and a voice that is not being heard due to not seeing these children as able to do something, which is then also attributed to their family.

Strategies

The strategies that CPA employs are directed at:

1) providing evidence of good practices on interventions and development of children with NDD in LMICs;
2) developing expertise on prevention, through providing training for professionals and fieldworkers to improve skills in the early identification of children with NDD or at risk of NDD;
3) offering training in a home-based and community-delivered functional rehabilitation intervention approach, including the development and provision of appropriate assistive devices for children with NDD and their families.

Training always needs to be connected with concrete and practical implementation in the field, with a focus on improving the participation of the child with NDD in the family- and community life. This helps to translate knowledge and skills into practice. Monitoring the impact of training and interventions is part of the entire process that we start together with host parties (usually NGOs and universities). Prevention and early identification strategies are integrated into the training and at the level of the implementation of fieldwork. This means that close collaboration with the (public) health sector is indispensable and much encouraged. As such, we expect from our partners that they play a significant role in local community lobby and advocacy as well. While lobby and advocacy are important we, however, wish to remain practical, realistic and most of all, emphasise ‘walking the talk’ to implement knowledge into practice through training- and coaching strategies.

Evidence from Uganda shows that – among the many causes of cerebral palsy (CP) – particularly cerebral malaria and other infections of the central nervous system account for 25% of cerebral palsy cases. However, lack of oxygen during birth, birth injuries, as well as prenatal causes related to the poor

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nutritional status of the mother are also among preventable causes. (Kakooza-Mwesige A et al, 2017). CPA intends to stimulate its partners to increasingly form networks with the (primary) health care sector and universities that train nurses and midwives and raise awareness about risk factors. Additionally, to develop necessary interventions to make sure that at primary care levels pertinent attention is given to the recognition of risks factors, and that necessary interventions take place to lower the incidence of cerebral palsy and optimise the course of the child's development. Specific attention will be given to the importance of informing traditional birth attendants, traditional healers, and religious leaders as well.

Activities

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 trainers of trainers and coaches on functional rehabilitation for parents/caregivers, focussing on improving Quality of Life (QoL) and coping and resilience, both of caregivers and their child living with NDD.
c) Develop a realistic policy 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 NDD in low-resource areas;
    2) the efficacy of low-cost assistive devices;
    3) the results of coaching parents to(mentally and financially) cope with life in supporting their child.
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 NDD 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 NDD.

Activities & Results 2021

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1) MultiKids Academy Africa in Ghana

Ghana was first visited in June 2021, for an assignment as (final) part of the UK-AID funded programme on Inclusive Education for children with CP. This visit was done on behalf of Cerebral Palsy Africa (CPA) Scotland. During this visit, contacts for follow-up CPA activities were established with Multi Kids Academy (MKA), the Heart, Hands and Voice Foundation (HH&VF), the University of Education Winneba (UEW) and the CBR programme of the Salvation Army in Duakwa.

2) Establishment of an African network of trainers in NDD

The main ambition of CPA since its inception in the Netherlands in April 2020, is to establish an African network of Neurodevelopmental Disabilities (NDD)-Master trainers, connected to existing CBR programmes. The main objective is to ultimately strengthen skills & coaching competencies of fieldworkers*, aiming to improve Functionality & QoL of children with Neurodevelopmental Disabilities and their families*. A first NDD Master training (6-day curriculum) was originally planned for October '21 in Ethiopia, in collaboration with Light for the World (LftW) and the University of Gondar (UoG). Due to the civil war in Ethiopia, this had to be postponed. The Salvation Army in Ghana offered to take over the lead in organising the event on October 4-9, 2021, co-hosted by the University of Education Winneba (UEW), Multi Kids Africa (MKA) and the Hearts, Hands &Voices Foundation (HH&VF).

- *Goal: establish an African network of NDD Master Trainers.*
- *Objectives: change the narrative and mindset on the management of severe (level 3/4/5) CP within CBR programmes.*
- *Key elements: functionality; mindset change to evidence-based, contemporary approach, versus old-style 'fixing the impairment' routine (an orthopaedic focus with passive exercises and massage); the central role of parents (including attention for parent support groups and daycare facilities) and a focus on results related to Quality of Life.*
- *The majority of the 29 participants (22) came from various CBR programmes and Universities (Disability Studies & CBR) in Ghana, 3 came from Uganda, 3 from Ethiopia and 1 from the Democratic Republic of Congo.*

Criteria to participate:

- *Professionals with field experience in working with NDD in CBR programmes. Participants were supposed to be familiar with working with children with NDD and CBR.*
- *Being ready for a shift in thinking, open-minded to reflect on own practices and open to changing and accepting more evidence-based practices, aiming for better results 'on the ground', both for parents and the child; be ready to stop certain old-style practices especially harmful routines such as prescribing non-functional devices and applying useless routine massage and non-functional passive stretching, which, in most cases, is not helpful and can even be harmful.*

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- *Capable of coaching and influencing colleagues on contemporary, evidence-based management of children with NDD (within the International Classification of Functioning, Disability and Health (ICF) Framework).*
- *Commitment to start a pilot (within their organisations) after the training, with 20-25 families, starting with a baseline; ensure proper documenting of results; use the outcomes of the pilot for further up-scaling.*

Results:

- *The various support tools resulted in lively sharing of experiences and debates, with consensus on a crucial point: the importance of always starting with an in-depth, empathic dialogue with the caregiver about the well-being of the family and the child.*
- *Two Ghanaian Universities (Winneba and Kwame Nkrumah University of Science and Technology) are committed to developing a special module on NDD, supported by CPA, as part of their Disability Studies and CBR training.*
- *The overall atmosphere was positive; people were eager to learn and enthusiastic, also on a WhatsApp group which was formed during the training. Field visits, taking into account safety measures with regards to COVID through protection measures and testing, were an important part of the programme: assessments and action plans for 10 children/ parents were made, using a problem-solving logbook based on the ICF. Presentations and reflections were essential in the learning process.*
- *An African Network of NDD Master Trainers was established, with a moderator from Ethiopia (Mr Zelalam Demeke) and a vice moderator from Uganda (Mr Martin Kayima).*
- *Participants employed by a CBR organisation committed themselves to developing small pilots to apply the newly introduced contemporary approach. Implementation of these pilots in 2022 will be the real proof of results 'on the ground': without implementation and evidence building, this training would end up being just another talk show.*

Lessons Learned from this training:

1) ***Stick to the criteria for admission to participate in the ToT training:***
   - ***a.*** *Only for professionals with proven broad experience on NDD in CBR programmes;*
   - ***b.*** *Being open-minded for applying an evidence-based, contemporary approach on NDD;*
   - ***c.*** *Being capable of organising ToT (Training of Trainers) sessions in their region.*

2) ***Avoid pilots whose results are difficult to monitor:***
   - ***a.*** *Develop uniform and simple guidelines for action plans;*
   - ***b.*** *Develop uniform and simple outcome indicators.*

Next steps:

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- *Develop a module for CBR Master students at two Ghanaian Universities in Ghana (UEW and KNUST).*
- *Further facilitate the Network of African NDD Masters.*
- *Facilitate and support the implementation of the various pilots, applying the new contemporary approach in practice; monitor results on the ground.*
- *Develop a policy on the prevention, early identification and intervention of NDD in Ghana and integrate this aspect within the ToT training.*
- *Facilitate follow up (on – & offline) training.*
- *Facilitate initiatives for support structures for parents in the form of Day Care facilities.*
- *Coach key persons in the field.*

3) The Angels Day Care Centre Programme in Uganda

The Angels Day Care Centre Programme in Kampala, Uganda has been supported by CPA in their CBR work. Two of their staff participated in the Master training in Ghana.
This is the summary of the outputs, outcomes, case stories, lessons learned, challenges, future plans of the Community Based Rehabilitation (CBR) project implemented by Angels' Centre in partnership with Cerebral Palsy Africa in 2021.

Outputs

- 60 children and caregivers/families were reached through the home-based and centre therapy.
- 20 children have improved their health with evidence of reduced spasticity and mobility challenges.
- 50 children have been supported with assistive devices.
- 8 respite care sessions were held with caregivers of 20 children in which caregivers were given sufficient time for individual counselling and advice.
- 10 Children with complicated cases were referred to different health facilities.
- 4 caretakers were referred to Tecla, the founder of Weavana an organisation that equips caretakers with vocational skills to generate income. Three of the caretakers that already had the sewing skills and baking skills were provided with a sewing machine and oven, respectively.
- 4 caregiver groups were formed through which they received psychosocial support and referrals to 5 Village Health Teams were identified from the caretakers themselves to be the focal persons of children and families with neurological disorders.
- Two staff members (Rose Mary the Executive Director and Martin the therapist) from Angels' centre were equipped with more knowledge and skills in Community Based Rehabilitation through the training in Ghana.
- 40 families were supported with food hampers rich in nutrients and twice every quarter.

Outcomes

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- 49 caregivers can provide within the course of daily life activities that help their children to better develop.
- Increased utilisation of therapy and pediatric services offered at Angel's Centre to 49 children for this entire period.
- 3 caregivers were provided with sewing machines and an oven and are using them for income generation.
- Increased staff capacity and delivery of the CBR model.
- Increased staff capacity in data collection on filling and analysing the information in the CPA logbook and tools.

Case stories

Marion and her motoka

Marion is a 10-year-old girl with cerebral palsy, both sides of the body, dyskinetic component (= involuntary movements). She started speaking at the age of 7, which really impressed the family. Joan, her mother, and Marion were identified through referral by a fellow caregiver. Marion was then assessed and enrolled into the CBR programme. Joan and Marion were coached in how to manage activities of daily living such as holding a cup, self-feeding, walking by using a homemade walker made by the caregiver.

"Of recent, she has started refusing to be fed porridge. She tells me to let her feed herself and I only help her when her hands are tired. Even then she makes the gesture to ask for my help because she is also committed to her development. In addition, she can now wear a blouse and trouser,s which was not the case before. We count these small steps and big victories. My family and I are happier than before," narrates Joan.

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"Marion calls these parallel bars 'motoka' meaning a car and so every morning she wakes up early in the morning going to drive her 'motoka'," **says a very happy and proud Joan.**

Marion is now able to fold her arms around the bars and can now make steps which was not the case before.

Marion happily drives her 'motoka' as a proud Joan watches her

A healthier Abdul

''*I am a single mother and Abdul is my firstborn born. After a few months, I realised he was getting thinner and thinner each day. I suffered stigma because people kept on telling me the child was bewitched. With COVID-19, my husband left me with no financial support. I thought to myself I wouldn't move on. It is after I came into contact with Angel's Centre that I got to understand that Abdul had cerebral palsy. Angels' centre supported me through providing a referral to Mulago hospital where we were admitted for 2 months while Abdul was being monitored. In addition, I have been provided with nutritious meals which have improved my baby's health. Being part of the care support group has also made me feel less stigmatised and I am able to share my experiences with fellow caregivers."* Salima Magezi the mother to Abdul.

Abdul and his mother being enrolled into the programme

Abdul and his mother during CBR

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Lessons learned

- Equipping caregivers with knowledge and skills needs to be ongoing at least for some time, and recurring throughout the different life phases.
- It is important to be aware of the different conditions and environments in homes so that the support given is relevant. With this, we mean that when living in a small house or in poor conditions, there is less room to move for the child and parent and, for example, for the use of assistive devices.
- Applying the CBR model is a continuous learning process where lessons need to be documented, adapted and reviewed for better implementation. It is not a static model.

Challenges

- Limited income still bothers many caregivers and compromise their ability to take care of their children and families.
- Many caregivers have had proper hygiene management practices largely due to limited access to water, compromising the well-being of the family.

Future plans

- Angel's Centre will be putting its efforts into promoting livelihoods for caregivers so that children can have a better growth environment. Some of the efforts include entrepreneurship training, promoting the I-Save model as well as linkages with other service providers.
- Angel's Centre is developing its strategy to promote Water, Sanitation and Hygiene among the families.
- Angel's Centre is also putting efforts into creating and establishing strategic networks with like-minded organisations

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- Ronald and Diarah were among the few children so far that have received standing frames and they were so excited. The mother to Diarah narrates how the child could only sit in a wheelchair for quite a long time: *"all the child could do is cry because I didn't know it was uncomfortable for her until the therapist came and detected the problem and it was fixed, now my baby has a standing frame I am so grateful that she can now at least stand".*

A young boy fixing the locally made parallel bars that were no longer stable after many times of using them. Then that's Marion showing the mother how happy she is to have got the parallel bars as the siblings are on-looking.

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Sylvia, a mother of two special needs children, was excited to have received her daughter's new CP chair and she is excited that finally, Valencia has her own assistive device.

Communication

The means of communication of CPA has been improved by renewing the website which was developed in the year 2020 and now is being maintained by a member of our advisory board (see: www.cerebralpalsyafrica.eu). Additionally, a brochure – to be found at the homepage of the website - was developed to inform stakeholders and potential funders about the mission and vision of CPA.

The Future of CPA: Strategic Priorities for the period 2022-2024

1. *Facilitate the development of an African Network of Master Trainers on NDD*. Organise a follow up in 2022 for the October '21 training, combined with coaching during field visits. Focus on capacity building for ToTs.
2. *Facilitate support structures* for pilots and daycare facilities to support at least 100 families in 2022; monitor results and disseminate findings, build evidence as a base for scaling up to at least 1000 families in 2025.
3. *Develop a policy on prevention* of NDD, early identification, referral and intervention and integrate this aspect within the ToT training for rehabilitation professionals but also lobby for the inclusion of this theme within the undergraduate training of midwives and nursing personnel.
4. *Support initiatives in Vietnam in the area of children with disabilities and support of community workers and families in remote areas*, connected to the former Butterfly Basket Foundation (integrated within CPA as from early '21).
5. *Consolidate CPA* as an effective, reputable and sustainable organisation based in the Netherlands. Concentrate activities in a limited number (3-5) of countries. Seek future opportunities to partner with strategic partners.

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6. Finances

We're very grateful to donors who supported our work in the starting phase. Several new (institutional) donors were approached to support our work; some contacts are still pending and we're confident we will succeed in building a stable donor base in future.

Income	**In Euro**	**Expenditure**	**In Euro**
Donations	81.191	Executive costs	5.925,00
		General costs	2.841,00
Total spent	**84.086**	**programmes**	**75.320**

Multiannual budget

Main elements & activities	**2022 in Euro**	**2023 in Euro**	**2024 in Euro**	**Results 2022**
1) follow-up training Master trainers; coaching on the spot	**30.000**	**40.000**	**50.000**	**20 Masters trained; 5 coaching trajectories**
2) Day Care facilities supporting 100 children & families in 2022, 250 in 2023, 500 in 2024	**60.000**	**100.000**	**200.000**	**100 families & children**
3) M&E: collect & publish	**10.000**	**10.000**	**10.000**	**Published report: evidence of results related to the quality of life parent & child**
4) Prevention, lobby & advocacy	**25.000**	**35.000**	**50.000**	**Maternal centres, midwives and traditional birth attendants who are connected with primary health care programmes (at the community level) are better equipped to recognise risks factors for NDD and can refer appropriately**
Total budget	**125k**	**185k**	**310k**	

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