Cerebral Palsy
Africa

Annual Report and accounts 2022

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Cerebral Palsy Africa

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 its work after the retirement of the founders. CPA-NL registered in March ’20; a renewed policy has since been developed.

We are Cerebral Palsy Africa

We aim to improve the quality of life of children with Cerebral Palsy (CP) - specifically the most severe cases - and their caregivers in low- and middle-income countries through better interventions and services provided by well-equipped staff working in (collaboration with) Community-Based Rehabilitation (CBR) programs.

- We support reputable local organisations and integrate new and proven approaches into existing Community-Based Rehabilitation (CBR) programs.
- We develop new training modules on an evidence based interventions for CP within existing curricula for training institutes and universities. Our approach focusses on functionality and family-centred care, aiming to improve the quality of life for the child with CP, the caregiver and the family.
- We help programs that we support to become more cost-effective.
- We support scalable service opportunities.
- We work with country representatives, ensuring local ownership and sustainability.
- We contribute to system change in the care and rehabilitation for children with CP and caregivers.

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CPA invests in a dream which is twofold

A) A national public health system that provides adequate support to prevent, early detect and adequately refer (complex) neurodevelopmental disabilities i.e. CP

- We work with local universities (e.g. medical, nursing and midwifery faculties), traditional birth attendants and the primary healthcare sector (public as well as private) to strengthen the prevention, early identification and early referral of children with neurodevelopmental disabilities.

B) A better quality of life for children with (complex) neurodevelopmental disabilities i.e. Cerebral Palsy, and their caregivers.

- We play a role in building the capacity of the (re)habilitation sector in low- and middle-income countries. This leads to improved competencies of service providers including rehabilitation cadre.
- Ultimately this leads to better functioning of children with complex neurodevelopmental disabilities i.e. Cerebral Palsy. It also leads to better daily functioning and better participation at home, in school and in the community as well a better quality of life of the child, caregiver and family.
- This is achieved through intersectional collaboration within existing CBR or Community-Based Inclusive Development programs, managed by reputable organisations in low-and middle- income countries

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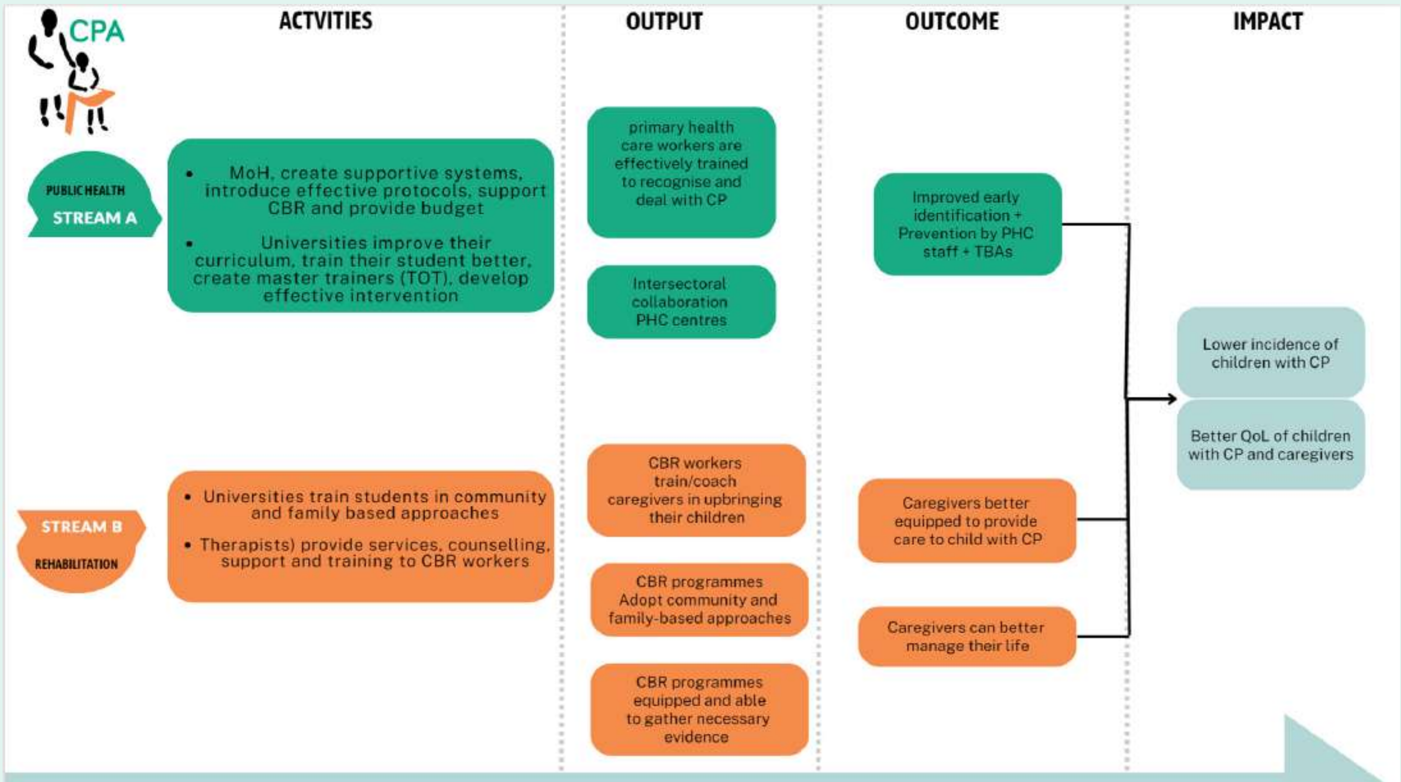
Theory of Change (ToC)



CPA role in activities to contribute to both strategies

1) Facilitate CP-expert networks on a country level.
2) Build the capacity of Experts in CP to become Trainer of Trainers (ToT) and to monitor the implementation of acquired expertise in existing CBR programs through reputable organisations.
3) Develop modules on CP management with universities and other (mid-level) training institutes.
4) Support key stakeholders in developing policies on prevention and early identification.
5) Support initiatives to promote parent associations and – initiatives, e.g. on day-care or producing locally available, appropriate assistive devices.
6) Evaluate and research the effectiveness and disseminate findings.

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In CPA programme countries we expect the following results in 2023-2025

- Train 50 CP experts as Trainers.
- Trainers train and coach 500 community rehabilitation workers and/or (mid-level) rehabilitation fieldworkers.
- 500 community rehabilitation workers and/or (mid-level) rehabilitation fieldworkers are responsible (each 30 on average) for the support of 15.000 children with CP and their families.
- These children live in a family of average 5 to 6, meaning that between 75.000-90.000 persons will benefit.
- Data collection and analyses will show evidence of (gradual) improved functionality, - improved quality of life and – participation[1].
- Scaling up initiatives will take place as soon as small initiatives allows for such to be done.
- CP-expert networks are active in CPA programme countries.
- CP modules are developed for 5 universities and/ or allied training institutions.
- Parent initiatives are active.

Conditions for results

1) Develop a solid CPA organisation in the Netherlands; we're in a process of merging with Enablement Ltd. (www.eneablement.org) and to establish the 'Enablement Foundation' second half of 2023; by the end of 2023. Good governance - and proper project management systems will be in place, as well as recognition by controlling bodies (CBF).

2) Develop strong bases for CPA in programme countries by contracting country representatives, and securing local management and expertise, which is characterised by an entrepreneurial drive for results 'on the ground' directed at the improvement of children with CP, their caregivers and families. In 2023 the functioning of current country representatives in Ethiopia and Ghana will be reviewed; options for contracting new ones will be explored in Malawi and Uganda See annexes 2,3,4[2].

1 specific outcome indicators to be defined Q1-2 '23.

2 In Annex 2 we present you with an overview of the key bottlenecks and system deficiencies regarding CP Further we explain further our strategic orientation in annex 3 on our twofold strategy and in annex 4 we specify our interventions to address the bottlenecks and deficiencies

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Activities & Results 2022

1) Training CP experts and establishing the African expert network on CP. One of the main ambition of CPA since its inception in the Netherlands in April 2020, is to establish an African network of CP-expert trainers. Objective is strengthening skills & coaching competencies of fieldworkers, aiming to improve the Functionality & QoL of children with Neurodevelopmental Disabilities and their families. A training (6-day curriculum) has been organised in November '22 in Ethiopia, with 25 participants from 5 Africa countries.
2) A CP module has been developed. This will be integrated in '23 into curricula for education of rehabilitation professionals (PT/OT) and - CBR workers in Ethiopia and Ghana; more countries will follow.
3) In Ethiopia and Ghana, country representatives were appointed. They'll be key in further developing CPA policies, and bridging with local contexts.
4) Related to training provided, CBR programs are supported in Ghana, Malawi, Uganda and Ethiopia, implementing the new approach for hundreds of children/ families.
5) Communication: the number of (funding) partners has grown further; Wild Geese Foundation (Stichting Wilde Ganzen) has supported the program in Malawi directly (therefore not reflected in our annual accounting report) with an additional amount of almost €7.000.

Multi annual budget 2023 - 2025

Main elements & activities	2023 in Euro	2024 in Euro	2025 in Euro	Results 2023
1) follow-up training master trainers; coaching on the spot	**30.000**	**40.000**	**50.000**	**20 masters/champions trained; 5 coaching trajectories CBR programs**
2) develop modules & conduct trainings at universities and related training institutes	**35.000**	**25.000**	**25.000**	**3 universities engaged in '23**
3) organisational develop-ment in NL, merging CPA and Enablement Ltd. into 'Enablement Foundation	**25.000**	**50.000**	**100.000**	**Merging CPA – Enablement**
4) country representatives working budgets	**45.000 (3 countries)**	**60.000 (4 countries)**	**75.000 (5 countries**	**Monitoring & evaluation implementation**
5) support structures & parent initiatives for children & families	**50.000**	**100.000**	**200.000**	**500 families & children**
6) assistive technology workshop	**65.000 (Ethi-opia)**	**45.000**	**25.000**	
7) monitoring & evaluation	**20.000**	**10.000**	**10.000**	**Disseminate evidence of re-sults re. quality of life, partici-pation & functionality of child & parent**
8) prevention, lobby & advocacy	**25.000**	**35.000**	**50.000**	**500 midwives, traditional birth attendants and health workers in primary healthcare are better equipped to recognise risks factors for CP and know where best to refer to.**
Total budget	**295k**	**365k**	**535k**	

Enclosures:

1) Report country activities
2) Context and problem analysis
3) Strategies implemented in programme countries
4) Key elements in CP programs

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1: Activities & Results Project countries CPA in 2022

1) Ethiopia CPA-country representative report

The CPA Ethiopia project is developed to address the two main CPA-issues in Gondar: 1. developing a system for early identification and referral of children with CP. 2. Strengthening the support and rehabilitation care provided to children with Cerebral Palsy (CP) through evidence-based rehabilitation services and support services for parents. The project began activities in August 2022.

Stream A. Prevention – Developing a system for early identification and referral of children with CP

Early identification: Most children with CP in Gondar are diagnosed (too) late, usually after the critical period when optimal neuroplasticity of the developing brain has passed. At present, there is no organised system in place in Gondar for the early identification and referral of CP, and health professionals lack the necessary skills and knowledge to do so. The establishment of such a system is therefore crucial to ensuring that all children at risk of CP are screened early and referred to appropriate services. A training was organised about the identification of Cerebral Palsy and intervention for health care workers around Gondar city. Health extension workers, nurses and midwives primarily from six health Centres and six health posts in Gondar Town attended the training. The training consisted of three sessions. The first session covered the manifestations, prevalence, prevention and treatment of CP. The second session was oriented on the importance of early identification of CP in order to mitigate the consequences of the health condition. Finally, a brief introduction to the International Classification of Disability (ICF) was discussed to provide the biopsychosocial perspective in understanding disability.

Participants learned about prevention strategies and early signs of Cerebral Palsy. All participants received the developmental screening chart and referral tools. Health workers are now referring children with CP signs to the UOG CBR program and hospital, and giving pregnant women health education about CP prevention. Within two months of the training, 20 children with possible CP diagnoses had been referred to UOG hospital by the training participants.

Stream B: Evidence-based rehabilitation services for children with CP and support services for parents

1. **Home-based services** for children with CP: Through this project, six CBR workers of the UOG CBR program in Gondar town were trained and supported to provide home-based functional therapy to children with CP. The support included training, technical support, and providing monthly transportation allowance. First, the CBR workers were given a 3-day training on rehabilitation interventions for children with CP as well as on how to use the CPA STEP tool for assessment and intervention planning. Since the training, the 6 CBR workers have been providing home based therapy for 47 children with CP in Gondar town in collaboration with the CPA country representative.
2. **Wheelchair services:** Most children with CP in Gondar don't have access to appropriate Assistive Technology (AT). Even those with access to AT have devices that are not fitted correctly or inappropriate. The use of inappropriate AT, such as a poorly fitted wheelchair, may further restrict instead of enhance function. Through this project, wheelchair modifications services for children with inappropriate wheelchairs were set up to to render wheelchairs appropriate and well-fitted. The establishment of a new AT centre is planned for 2023.
3. **Developing a CP module** for UOG BSC OT and BSC PT programs. According to collective experiences and observations, many therapists are not properly trained in the management of children with CP. Universities continue to teach outdated approaches and interventions for CP rehabilitation.
   To address this issue we have collaborated with the UOG BSC OT and BSC PT programs to develop a course on contemporary approach for rehabilitation for children with Cerebral Palsy. The course is being developed collaboratively by UOG experts from the OT and PT departments and CPA experts from the Netherlands. Upon completion, the course will be integrated into the current UOG BSc OT and BSc OT programs curriculum.
4. **Community Based services:** In Ethiopia, the majority of children with CP are invisible in the community, are not given the opportunity to socialise nor participate, and spend most of their time at home, hidden. Some parents hide their children because they are embarrassed to have a disabled child. Social isolation is detrimental to a child's cognitive, physical, and social development.
   To address this problem, a community gathering place/meeting place for children with CP and their parents was established in Gondar Azezo Youth Centre. Children with CP and their parents from that district meet up at the Youth Centre every week to socialise, play and share ideas.

Parents meeting in Gondar Azezo Youth Centre

5. **Services for parents:** Gondar town has a high rate of poverty and a low rate of employment for parents with children with CP. Through this project, startup funds were provided to start with 5 income generating businesses for mothers of children with CP.
   Sharing experiences, knowledge and skills can be an important strategy not only to relieve burden and feel supported, but also to strengthen the voices of the parents in their lobby and advocacy for quality services, inclusive education (from early childhood to higher education). Through this project, technical and material support were provided to establish the Gondar Association of Parents' of Children with disability. The association has 47 members, selected seven committee members to function as representatives for all the parents and is currently awaiting a government registration certificate.

Ghana CPA-country representative report

Fifteen children (9 males and 6 females) with Cerebral Palsy ranging from 2-15 years of age in Winneba community were selected for a pilot. Most training sessions and interactions took place in the children's home settings using the local dialect of Effutu and Fante. Field visits, follow-ups and interactions with families were done 2 to 3 times a week (Wednesdays and Saturdays, and occasionally on Fridays) by the 2 employees of HHV, Grace and Gladys. Collaboration with the University of Winneba CBR program resulted in the posting of 3 CBR students to the centre from November 2022 till date. All in all, 51 visits were made from January to May 2022, and 119 visits were done from June to November 2022.

The Ubuntu manual and logbook were the main tools used in the field. Parents were engaged in discussions and activities on functional activities of daily living skills, socialisation, identifying and building on child's strengths, encouraging a more child-friendly environment and provision of locally-sourced relevant assistive devices.
In December, field visits were intensified to three times a week: Tuesdays, Thursdays and Fridays. 20 home visits were done in December before the Christmas holidays. In total, 120 regular home visits were done in 2022.

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The outcomes from the interventions as evidenced from the data in the logbooks and observations from fieldworkers are:

- Improvement in parent-child relationship; caregivers have observed that their relationship with their children have improved, leading to a lighter atmosphere in homes. They are able to focus on realistic goals and celebrate any progress the child or the family makes. Due to the constant presence of the fieldworkers in the homes, neighbours are taking an interest in the child as well resulting in improved social relationships and behaviors and decreased attitudinal barriers. Parents who were overprotective of their children are also opening up to more support from the fieldworkers, resulting in improved participation as a family in community activities such as attending church activities or taking the children out into the community generally.
- The Parent Support Group meetings and trainings have created a sense of belonging, especially for caregivers who were feeling alone and neglected prior to its inception. The group actively refer new children and caregivers to the foundation for support
- This pilot has succeeded in connecting children to their fathers, who were otherwise absent in their lives prior to the field visits. Regular field visits, follow-ups, education, counseling, trainings, opinion leaders' involvement coupled with the changes/progress they witnessed in their children, encouraged these fathers to take up their role in the children's lives. Ten out of the 15 children selected for the pilot currently have their fathers in their lives.
- Through support from CPA, all the children and caregivers on the pilot have had their National Health Insurance policies renewed, lessening the burden of healthcare.

In December, the foundation collaborated with a local NGO (With God Cerebral Palsy) in Winneba that offers free therapy services for children. CPA-Ghana hopes to work with this NGO in the future to facilitate good practices and ensure that services rendered are truly beneficial to the children.
In the latter part of 2022, the economic climate in Ghana was truly challenging, with inflation rate up from 37.2% in September to 50.3% in November 2022. This resulted in an increase in prices of goods and services across the country. As a result, these already poor families were driven further into poverty, struggling even more to provide basic needs of their households and managing transportation costs involved in taking the children to the centre so they could go out and work. Through CPA's support, in December, all the 15 children on the pilot were given nutritious food blends recommended by a dietician, that were easy to prepare, swallow and digest.

Through lobbying, the Member of Parliament for Winneba municipality donated GHS500 to each family in the centre to help in income-generating activities on December 23rd ,2022.
Further collaborations with Project Ten, a locally-based NGO bringing volunteer rehab therapists from Israel to Ghana in February 2023, will help families access these services through field visits made by these professionals.

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Budumburum Camp

Pureheart Centre is located in the heart of Budumburum Refugee Camp in the Central Region. The centre is managed by 6 caregivers who engage in petty trading such as the sale of drinking water alongside, as children do not pay for the services in the centre. The centre currently has 15 regular children with a range of neurodevelopmental disorders, about 70% of which are Cerebral Palsy. Families living in and around the camp are currently beneficiaries of this service.
Being based in a classroom of a local government school, the caregivers try to engage the children in educational activities such as story time, art and writing where possible, as well as functional skills. Caregivers have no formal training in education, but try to support the children based on similar activities teachers in the school do.
With CPA's support, training was organised for these caregivers using the Ubuntu manual to equip them with more skills to address challenges they had in caring for the children. The sessions were interactive and focussed on their realities and challenges. Caregivers felt empowered and requested for further support from educationists in navigating that terrain. Following the training, caregivers regularly contacted the trainer for support (phone calls and videos). From September 2022, due to the economic crunch in Ghana, the number of children in the centre drastically reduced, as families living outside the camp could not afford the transportation costs that had significantly increased.

Curriculum Development

As planned, initial contact was established virtually (phone calls and zoom) with instrumental people from the University of Ghana, Accra and University of Education, Winneba. These include the Head of Department for the Physiotherapy Department in University of Ghana, Dr. Gifty Nyante and the Program Coordinator for the CBR program in University of Education, Ms. Rabbi. In-person meetings followed the calls/emails, and Country Reps were able to garner support from these key players.
Currently, Dr. Gifty Nyante, who is also the tutor for the Pediatric Physiotherapy course, has demonstrated active interest in a module for the undergraduate program as well as extending the reach with time to practicing professionals. She has taken part in the review of the first draft of the module and is keen to collaborate even further as needed.
Ms. Rabbi has shared her interest in further collaboration and is in talks with the Head of Department to make the collaboration with CPA per the University's policies official, in order to take the development work to the next level.

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Malawi: Project report Mangochi District Hospital

Introduction:

Mangochi district hospital serves a population of approximately 1.4 million and an estimated six to seven thousand children with Cerebral Palsy and neurodevelopmental disabilities (NDD). However, only less than 5% of these children manage to receive (hospital-based) rehabilitation services. There is late identification of the CP and NDD children for commencement of rehabilitation.

In March 2022, physiotherapy department from Mangochi district hospital in collaboration with Dr Bente of family Medicine department from Kamuzu University of Health Sciences (KUHeS), started Cerebral Palsy awareness trainings to health workers at Mangochi district hospital. The aim was to alert health workers on the risk factors of Cerebral Palsy and the importance of early identification for rehabilitation. In collaboration with the maternity department, weekly health talks are organised with mothers of new born children with Cerebral Palsy risk factors. The talks focus on Cerebral Palsy risk factors and developmental milestones. This proved to have increased our monthly Cerebral Palsy statistics with 35% on average. Furthermore, parents are able to bring their children for rehabilitation from as early as three months once they note missing developmental milestones in their children. A start was made to use a record book specific for children with Cerebral Palsy.

From the 1st August to 5th August 2022, with the help of a Dutch medical doctor and Cerebral Palsy Africa (CPA) country representative in Ethiopia, a training was organised on the fundamentals of rehabilitation for children with Cerebral Palsy. The participants were Physiotherapists and rehabilitation technicians from Mangochi district hospital physiotherapy department, Tiyende Pamodzi group in Namwera Mangochi and Nsanje district hospital. This has changed the approach to a family-based approach in which no longer 'treatments' with routine passive movements are given. The logbook that was developed by CPA for every child that visits the physiotherapy department has been introduced. Results are that there is more initiative coming from the parents and that they are more involved in the treatment. It is observed also that this way of (functional instead of non-specific task) therapy is helping children a lot more in ADL.

Training of CPA on interventions and on the use of the problem solving logbook.

During the training, nutritionists of the Mangochi District Hospital were involved. They are applying new knowledge about positioning and preparation of foods to all children that are admitted in the malnutrition ward and who are in the outpatient malnutrition program. They have also started to do a weekly food demonstration session.

Food demonstration in the malnutriti-on ward.

After this training, the awareness was extended to health workers from three of the five health zones of the hospital in September 2022. After this exercise too, a rise in the number of children being referred for rehabilitation was observed. During this training, talks were held with cli-nical officers, nurses and health surveillance assistants about what CP is and how to identify a child with CP in an early stage.
In October a meeting was held with all the different departments in the hospital that will play a key role in the integrated care clinic that will start early 2023.
From 29th November to 3rd December 2022 there was a training at the University of Gondar in Ethiopia that aimed at building a network of African Master Trainers in Neurodevelopmental Disabilities. This training was conducted by CPA and a representative from Magochi Hospital Malwi and one senior lecturer were invited to attend.
In December, community stakeholders meetings were started. During these meetings, talks were held with different stakeholders including: chiefs, religious leaders, traditional healers and teachers to get a better understanding of the attitudes, beliefs and perceptions of the communities towards families with children with Cerebral Palsy.
During these meetings, there were in depth semi-structured questionnaire focus group interviews, with health education after the interview. The data will be analysed in January '23 but the already received feedback about the health education is that there is a big knowledge gap in the communities and that such health education will really help in early identification. During these meetings, home visits were also conducted to get a better understanding of the situation of the children living in these communities and the problems they are facing.

Pictures during the meetings with community stakeholders.

In December, there was also a meeting with 30 volunteers of Malawi Children Village (MCV) working in the villages of the catchment area of MCV, the organisation that we will work with in the near future to run the integrated care clinic. These volunteers identify children in their communities and follow up on these patients. A training was given about the principles of CP, early identification, and the clinic will start to run early 2023. In addition, an in-depth discussion was held with the leaders of these volunteers to hear their stories and experiences in the field.
The planning is to run an integrated clinic starting early 2023 at one of the outreach centres (Malawi Children's village) that currently provides physiotherapy services. The integrated clinic will ensure a multidisciplinary team approach in the management of CP-children to ensure that they are being helped holistically.
This integrated clinic is planned to start after doing a quality of life assessment for the children and their caregivers. This will be done through questionnaires and a few in-depth focus group interviews.

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Uganda: project report of Angel's Centre for Children with Special Needs Community Based Rehabilitation Program Summary report 2022

Njoki a mother to Jordan has always believed in therapy, she consistently applies therapy on her child and she has seen a great improvement, Jordan now tries to sit by himself for about a minute something she couldn't believe, she was selected to be the village health team member of Ganda village where she oversees all children with neurological disorders and reports to the community staff.

Introduction

Angel's Centre for Children with Special Needs collaborated with Cerebral Palsy Africa to build the capacity of caregivers and families of children with neurological disorders. 60 children with 60 caregivers and families have been supported through the coaching and mentoring of caregivers, health and nutrition activities, as well as project evaluation.

Coaching and mentoring of 60 caregivers: Angel's Centre supported 60 caregivers with children with NDD to participate in the project. Following each child's need, the Angel's Centre team carried out training and coaching of 60 caregivers, focusing on the relevant therapies. These included therapeutic exercises, using locally made assistive devices for standing and walking, using wheelchairs and standing frames, feeding and sitting, hygiene and nutrition, and play therapy, among others. Through the follow up conducted, at least 39 caregivers are adopting the therapies, especially with feeding and sitting a child in an appropriate position, proper hygiene and nutrition, as well as eye-hand coordination.

Provided health and nutrition support to 150 families: Angel's Centre distributed food hampers for 150 families. Items included cereals, milk, pulses, nuts and hygiene products.

Medical support to children: Angel's Centre also supported medical cover for 35 children to access basic medicines at Sebbi hospital and Bambi Children's Clinic. This enabled caregivers to cut down some of the health bills to meet other basic needs.

Early learning: the early learning program has been jointly implemented with several approaches including reading, writing, which has helped children with reading comprehension, letter recognition, manipulation and counting physical objects. 35 children have received early learning daily, which was also sustained with physio-therapy, occupational therapy, hydrotherapy, speech and language therapy.

Parents Focus Groups: 3 parents focus groups were established to help parents come together and discuss issues that press them in the journey of raising children with different special needs. Parents met up once a month to discuss challenges encountered, happy moments with their children and to share different ideas on how to deal with disability.

Partnerships and collaborations: Angel's Centre patterned with a Banda Health Centre to conduct four trainings in NDD and prevention strategies. Angel's Centre therapists facilitated training. 15 Community members and 10 health workers got more knowledge on the use of a Developmental Milestone Chart (DMC), handling different types of neurological disorders, referral pathways as well as feeding and nutrition. Furthermore, the training – on inclusion – was done at a local community at the (CBS 88.8) radio station for one hour. On 6thOctober 2022, Angel's Centre did an awareness match to celebrate the World Cerebral Palsy Day. Angel's Centre did this through a community match involving the parents, children, Angel's Centre staff and other likeminded partners such as Save the Children and Special Children's Trust. This further helped to raise awareness on neurological conditions and the need to support children and families affected. Furthermore, there has been a collaboration with Promise International and UWEZO microfinance where the caretakers are given loan on 1% to improve on their quality of life.

2: Context & Problem Analysis

Many 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.

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 countries3. 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.

3 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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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 limited 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) but focussing on the health aspect.
- 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 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 regarding paediatrics.
- if rehabilitation professionals are 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.

- Lack of appropriate assistive technology (AT). When it's available, it is often imported, of limited sizes to provide functional 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 (visible) results rather than in 'lost cases'.
- 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

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3: Strategies implemented in programme countries

CEREBRAL PALSY AFRICA OVERVIEW	
Main Strategies for project implementation: advocacy, community mobilisation, 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 caregivers
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 healthcare 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 expert- 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.	• Curriculum changes in universities.
• Health education, especially for adolescent girls, Improvement of nutritional status in community, Improvement in pre - and postnatal care.	• Provision of functional therapy services for children with CP.
	• Enabling participation and inclusion of children with CP in daily life activities.
	• Socio-economic empowerment and support for parents (IGA, parent association establishment and psychosocial support for caregivers).
Main Stakeholders PART A	**Main Stakeholders PART B**
Ministry of Health, primary healthcare cen-tres, hospitals, traditional and faith healers, healthcare 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, and rehabilitation professional associations.

Cerebral Palsy Africa

4: Key elements of the CPA programme

Strategy A: Prevention, early identification and referral

Prevention
Although CP in many cases cannot be prevented, there are established and evidence-based prevention methods for certain causes of Cerebral Palsy4. However, their applicability has been limited to high-income countries because of a lack of awareness and services in low-income countries. In CPA program-countries like Ethiopia, Ghana and Uganda, health professionals 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 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.

Early identification and referral.
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 a rapid speed making it the ideal time to harness neuroplasticity. Evidence shows greater benefit from early versus later intervention in CP. Early detecti-on and intervention are therefore crucial for optimising 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 particularly important role in this. One of the areas for CPA work will be to facilitate and promote contextualised and efficient early identification and intervention for children with CP and to strengthen networks and referral pathways for early identification and – intervention.

4 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

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 CP5.
- 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 utilise 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 utilise 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.
- Utilise local community structures such as religious groups and social groups at the community level to identify and refer children.

Strategy B: Evidence Based Rehabilitation services for children with CP and support services care givers

Community based early interventions

In countries like Ethiopia, people with CP often do not have access to specialised rehabilitation services due to many reasons including financial constraints, transportation problems, and centres located in hospitals in urban areas. One of the most effective ways to address this lack of access to specialised 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 CP6. 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 support their children at home. The following paragraphs describe the types of services that CPA is focussing on for capacity building.

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

6 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.

CPA focusses on 5 services for capacity building:

1: Support Structures

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, socialising, 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 types of centres.

2: 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.

3: Improve the Quality of Rehabilitation interventions

According to collective experiences and observations of CPA, 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.

4: Facilitate and Build 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.

5: 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 Organisation (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. [7] 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. Options to include the concept of 'Direct Giving' will be explored further.

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

Cerebral Palsy Africa

Stichting Cerebral Palsy Africa

Annual Accounts 2022

Cerebral Palsy Africa

2. General

2.1. Establishment

According to the deed dated March 17, 2020, the Foundation Cerebral Palsy was founded as of March 13, 2020
The foundation is registered with the Chamber of Commerce under file number 776.270.32

2.2. Objective

The objective of the Foundation Cerebral Palsy Africa (abbreviated: CPA) can be described as follows:
an INGO with as main objective improving the Quality of Life of (parents of) children with a brain damage (Neuro Developmental Disability - NDD)

2.3. Board

In 2022 the Board consisted of the following persons

Mr. H. Cornielje	Alphen aan de Rijn	Chair
Mr. C.J. van den Broek	Geldermalsen	Executive Secretary
Mrs. Y.E. Cox - Vleeshouwers	Rosmalen	Treasurer

2.4. Other information

The foundation does not (yet) employ any employees and is therefore not affiliated with a variety of formal bodies such as the Tax Authorities, Employers Association, Pension Fund and other insurances.

The foundation is qualified and registered with the Chamber of Commerce (KvK). The KvK numer is 77 627 032
The RSIN number is 86 10 70 641.

The IBAN account number of the Foundation is: NL 39 RABO 0354 0724 39

The Foundation originated from the Scottish CPA. The Scottish has transferred its activities to the Dutch Foundation CPA at the beginning of 2020.

The audited annual accounts of the year 2022 were discussed and approved by the Board in its meeting March 23th 2023. The 2022 annual accounts have been audited and approved by an independent auditor.

Cerebral Palsy Africa

3. Balance sheet

ASSETS	31.12.2022		31.12.2021	
Liquid assets				
Cash (340 USD)	462		322	
Rabobank Current account	62.202		50.925	
Rabobank Savings account	-		-	
TOTAL ASSETS		**62.664**		**51.247**

LIABILITIES	31.12.2022		31.12.2021	
Equity				
Capital as per January 1	18.247		16.142	
Result fiscal year	16.775-		2.105	
Capital as per December 31st		**1.472**		**18.247**
Facilities and designated reserves				
Destination reserve Ghana	10.000		15.000	
Destination reserve Ethiopia	10.000		-	
Destination reserve Vietnam	6.192		18.000	
Destination reserve Malawi	10.000		-	
Capital - Continuity reserve	25.000		-	
		61.192		**33.000**
TOTAL LIABILITIES		**62.664**		**51.247**

Cerebral Palsy Africa

4. Income statement

Description	realised 2022	2021
Income		
Funds	112.714	81.091
Private donors	1.270	100
Interest	-	-
Total income	**113.984**	**81.191**
Expenses		
Programs Uganda, Kampala	11.500	32.800
Programs Ghana	21.590	39.044
Programs Ethiopie	28.969	3.476
Programs Vietnam	10.007	
Programs Bangladesh	6.630	
Programs Malawi	12.460	
Executive work (programs, fundraising, communication)	5.850	5.925
Other costs (bank, travel, communication & fundraising)	5.561	2.841
Total expenses	**102.567**	**84.086**
Balance of Income and Expenses	**11.417**	**-2.895**
Result destination		
Equity	-16.775	2.105
Destination reserve 2022 Ghana	-5.000	15.000
Destination reserve 2022 Ethiopia	10.000	-20.000
Destination reserve 2022 Vietnam	-11.808	
Destination reserve 2022 Malawi	10.000	
Capital - Continuity reserve	25.000	
Total	**11.417**	**-2.895**

Cerebral Palsy Africa

5. Explanation to the balance

5.1. Accounting policies for balance valuation and determination of the results

General

5.1.1. Business address

The Foundation 'Cerebral Palsy Africa' registration number Chamber of Commerce (KvK): 77.627.032 and RSIN number 861.070.641; business address: c/o Enablement, Antonie van Leeuwenhoekweg 38
2408 AN Alphen aan den Rijn. The Netherlands

5.1.2. General basis for the preparation of the annual accounts

The financial statements have been prepared in accordance with the provisions of Part 9, Book 2 of the Dutch Civil Code.

5.1.3. Accounting policies for Assets and Liabilities

Liquid assets

Cash and cash equivalents are valued at nominal value and are at free disposal of the Foundation.
It concerns immediately due and payable receivables from credit institutions.

Current liabilities

Short-term debts concern debts with a term of less than one year. Unless stated otherwise, these are valued at nominal value.

5.1.4. Principles for the taxation of the results.

Result determination

The result is determined with due observance of the aforementioned valuation principles

Income

Income includes subsidies received

Cerebral Palsy Africa

5. Explanation to the balance

5.2. Liquid assets

	31.12.2022	31.12.2021
Cash	462,01	301,00
Rabo bank, NL 39 RABO 0354 0724 39	62.202,47	50.925,00
Balance 31.12.	**62.664,48**	**51.226,00**

5.3. Equity

	31.12.2022	31.12.2021
State of affairs beginning of reporting year	18.247,00	16.142,00
Result fiscal year	-16.775,00	2.105,00
Balance 31.12.	**1.472,00**	**18.247,00**

5.4. Reservations/ amenities

	31.12.2022	31.12.2021
Destination reserve Ghana	10.000,00	15.000,00
Destination reserve Ethiopia	10.000,00	-
Destination reserve Vietnam	6.192,00	18.000,00
Destination reserve Malawi	10.000,00	-
Capital - Continuity reserve	25.000,00	-
Balance 31.12.	**61.192,00**	**33.000,00**

In 2022, the above designated reserves were formed:

Designated reserve Vietnam

The designated reserve for Vietnam was formed for projects in Vietnam, initiated by the Butterfly Basket Foundation (BBF). This Foundation was liquidated in '20 and taken over by CPA.

The remaining special-purpose reserve for Vietnam for 2023;

€ 18.000 - € 1.800 (10% general costs) -10.007,26, spent in 2022 = € 6.192 left as reserve for 2023

Cerebral Palsy Africa

6. Notes to the Income statement

6.2. Target spending

	2022	2021
6.2.1. Programs		
Uganda	11.500,00	32.800,00
Ghana	21.589,78	39.044,16
Ethiopia	28.968,61	3.476,00
Vietnam	10.007,26	-
Bangladesh	6.630,14	
Malawi	12.460,00	-
Total Programs	**91.155,79**	**75.320,16**

	2022	2021
6.2.2. General costs		
executive work (programs, fundraising, communication)	5.850,00	5.925,00
travel - and other costs	1.152,00	1.256,75
Communication & Fundraising costs	4.119,01	1.334,88
Bank costs	289,18	248,92
Total general costs	**11.410,19**	**8.765,55**

Cerebral Palsy Africa

Cerebral Palsy Africa
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The Netherlands

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Website: www.cerebralpalsyafrica.eu
Bank account: NL39RABO 0354072439