



**FOUNDATION**  
**CEREBRAL PALSY AFRICA**  
**Annual Report 2023**

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## SUMMARY ANNUAL REPORT 2023

**As a cerebral palsy (CP) knowledge organisation, the foundation Cerebral Palsy Africa (CPA) supports community-based rehabilitation programmes in low- and middle-income countries, with a focus on improving the quality of life of children with CP. By 2023, through knowledge transfer and funding, we helped in reaching hundreds of children with CP, their parents and siblings with interventions that enabled them to function better as families and in their participation in their communities.**

Our 2023-2025 Multi-Annual Plan sets out objectives for the core elements and activities of CPA support. For each objective, we then defined the results we wanted to achieve in the three consecutive years. The results planned for 2023 were almost all achieved, and in some cases exceeded. In addition, important developments were set in motion during the year, which should lead to a broadening and strengthening of our support in the coming years, and thus indirectly to an increase in the number of children, parents and families with a better quality of life.

### Spending

In 2023, we spent a total of €197,410 to support projects for children with CP. Of this, €166,516 went to the 'programme countries' Ethiopia, Ghana and Uganda, where we work with 'country representatives'. On a smaller scale, we supported projects in Malawi, Vietnam, Nepal and Bangladesh.

### Programme countries

In **Ethiopia**, we spent €52,248 to support the CBR rehabilitation programme of the University of Gondar. This programme directly reached 573 people, including 87 children. We spent €24,606 to support the development of a social enterprise for the local assembly and production of assistive devices.

In **Ghana**, we spent €52,596. In the Winneba District, we supported CBR Africa's CBR programme and, with MultiKids Africa, enabled mothers of a child with CP to participate in a 100WEEKS programme: a cash giving programme. CBR Africa's project reached 60 children and around 300 parents and other family members. In 2023, 29 mothers started the 100WEEKS programme and 20 more mothers were trained in liquid detergent production.

In **Uganda**, a total of €37,167 was spent supporting projects at the Katalemwa Cheshire Home in the Kamuli District and the Angel's Centre for Children with Special Needs in the Wakiso District. In Kamuli, 147 children with CP and 535 parents and other family members were reached, while in Wakiso, 70 and 350 respectively were reached. Six parent groups were also established in Wakiso.

### Other countries

In **Malawi**, we provided 17,000 euros for a pilot of the hospital in Mangochi. 'Wilde Ganzen'<sup>1</sup> supplemented this amount with over another 8,000 euros. The pilot project transformed the

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<sup>1</sup> The Wilde Ganzen Foundation is a Dutch NGO with a mission to reduce poverty and inequality through community-led initiatives.

existing CP clinic in Mangochi, which offered almost only physiotherapy, into a multidisciplinary outreach clinic. As a result, many more children with CP are now reached. In addition, 80 staff from (14) health centres and (2) local clinics were trained and received health education from relevant stakeholders in five communities. 73 people participated in the sessions. A baseline measurement of perceived quality of life was conducted for 62 families of a child with CP. The pilot project also aimed to test whether Malawi can become a CPA programme country. No decision has been made on this by 2023.

In **Vietnam**, where CPA support is about to end, a modest amount was spent to finalise the programme. In **Nepal**, we funded a five-day training course in which rehabilitation workers from **Bangladesh** also participated.

### Organisational development

Exploratory talks were held in 2023 to merge CPA with Enablement Ltd, a not-for-profit training, consultancy and research organisation in the field of disability and inclusive development in resource-poor countries. CPA and Enablement already work together and share the same vision for rehabilitation. Discussions to merge the two organisations were successful:

from 1 January 2024, CPA and Enablement Ltd form the **Enablement Foundation**. Within the Enablement Foundation, CPA will continue its current work and Enablement Social Enterprise (ESE) will focus on capacity building through tool and e-learning development, research and consultancy. From 2024, the Enablement Foundation has a Supervisory Board and an executive director.

### Innovation

A major barrier to improving the quality of life for children with CP and their families is the way many professionals in Africa, including physiotherapists and physicians, 'see' children with neurodevelopmental conditions. They are seen as 'sick', which means they need to be 'treated'. This mindset among professionals leads to a one-sided focus on physiotherapy and other forms of physical correction, while little attention is paid to interventions that help children function better and participate in their environment. To help change this mindset, in 2023 we developed a serious game called 'Shifting Focus'. **Shifting Focus** is an experiential learning tool (ELT). A pilot of the serious game will take place in Ghana in 2024.

The **RehApp**, a mobile knowledge base for field workers working in communities with people with disabilities, has been developed within Enablement Ltd. Organisations can also use the app as a management information system. The app provides information on different disabilities in separate sections. The app is still being developed, but - among many others - the chapter on CP is already complete. Now that Enablement Consultancy is part of the Enablement Foundation, more field workers and organisations in programme countries are expected to use the RehApp.

### 2024

In 2024, we will continue our work as the Enablement Foundation. Strengthened, together with local partner organisations, we will build on the results achieved in 2023 for children with CP and their families in low- and middle-income countries. And with energy and confidence, we will continue to implement the developments for which the foundations were laid in 2023.

**Table 1** on page 6 summarises for the (3) programme countries the 2023 target and realised results.



*Field workers have a crucial role in the new rehabilitation approach for children with CP.*



*Field worker on route with equipment provided by CPA.*

### Intended and achieved results programme countries in 2023

| <b>Table 1: Summary objectives and results 2023 in the (3) programme countries</b> |  |
|--|--|
| <b>Objective</b>   | <b>1. Further training 'trainer of trainers' (master trainers); coaching in practice</b>   |
| <b>Intended result</b>   | 20 trained master trainers; implementation of 5 coaching processes within CBR programmes.  |
| <b>Result achieved</b>   | The objectives have been partially achieved. The formation of a network of potential master trainers (trainers of trainers) has started in the three programme countries. By the end of 2023, the network consisted of 10 professionals: 5 in Ghana, 3 in Ethiopia and 2 in Uganda. The three country representatives are driving the network forward and working to expand its capacity to train and coach field staff, including the use of the Shifting Focus experiential learning tool. The training of master trainers and then field workers has the ultimate goal of reaching more children with CP with the renewed approach. |
| <b>Ethiopia</b>  | 3 potential master trainers were identified; 6 CBR workers received follow-up training in 'paediatric rehabilitation' and were coached in the practice of their work.  |
| <b>Ghana</b>   | 5 potential master trainers were identified; field workers were advised on how to approach children with complex neurodevelopmental disorders and were coached in the field.   |
| <b>Uganda</b>  | 2 potential master trainers were identified; 8 staff were retrained to work according to the CBR model. They can now use this model in other communities.  |
| <b>Objective</b>   | <b>2. Develop modules and provide training to universities and related training institutes</b>   |
| <b>Intended result</b>   | 3 universities in low- or middle-income countries are committed to the programme.  |
| <b>Result achieved</b>   | This has been achieved. Collaboration with universities will be further expanded in 2024.  |
| <b>Ethiopia</b>  | In cooperation with the University of Gondar (UOG), an 'Enhanced Approach to CP' course has been developed and will be included in the curricula of all relevant courses at the university by 2024.  |
| <b>Ghana</b>   | CBR Africa works with the University of Education, in particular with Special Education and CBR departments. The University of Ghana provided a summer course.   |
| <b>Uganda</b>  | Cooperation with the Kyambogo University has not yet been formalised, but there are already good contacts.   |
| <b>Objective</b>   | <b>3. Organisational development in the Netherlands: merger of CPA and Enablement Ltd. into Enablement Foundation.</b>   |
| <b>Intended result</b>   | Realisation of merger of CPA and BV Enablement.  |

**Table 1: Summary objectives and results 2023 in the (3) programme countries**

|                        |  |
|------------------------|--|
| <b>Result achieved</b> | The goal has been achieved. From 1 January 2024, CPA and Enablement Ltd continue together as the Enablement Foundation.  |
| <b>Objective</b>       | <b>4. Working budgets country representatives</b>  |
| <b>Intended result</b> | The working budgets total €75,000.   |
| <b>Result achieved</b> | The operating budgets were significantly higher  |
| <b>Ethiopia</b>        | In Ethiopia, €76,754 was spent; €52,248 went to the Community-Based Rehabilitation programme (CBR) at the University of Gondar, €24,606 to (the development of) Grand Assistive Technology, a social enterprise for local assembly and production of assistive devices; over €20,000 of the budget was spent on training in South Africa.<br>The country representative himself raised funds for the development of parent initiatives. He received \$50,000 from Queens University in Canada. |
| <b>Ghana</b>           | In Ghana, €52,596 was spent; this supported (mainly) CBR Africa's projects and, in cooperation with MultiKids Africa, the participation of 29 mothers of a child with CP in a 100WEEKS cash giving programme.  |
| <b>Uganda</b>          | In Uganda, €37,167 was spent; of which €24,667 went to programmes of the Katalamwa Cheshire Home and €12,500 to a project of the Angel's Centre for Children with Special Needs.   |
| <b>Objective</b>       | <b>5. Supporting support structures and parent initiatives</b>   |
| <b>Intended result</b> | 500 families with a child with CP receive appropriate help and guidance.   |
| <b>Result achieved</b> | This objective has been achieved.  |
| <b>Ethiopia</b>        | In Ethiopia (Gondar), 87 children with CP and (about) 435 parents and other family members were supported. Through the revolving fund of the parents' association of children with CP set up in Gondar, 15 mothers were able to set up their own businesses.   |
| <b>Ghana</b>           | In Ghana (Winneba), 60 children with CP and (about) 300 parents and other family members were supported; 29 mothers of a child with CP were included in the 100WEEKS programme; 20 mothers received training first in making cleaning products and then tools and ingredients to start a home-based business.  |
| <b>Uganda</b>          | In Wakuli, 147 children with CP and (about) 535 parents and other family members were supported, in Wakisa 70 children with CP and (about) 350 parents and other family members. Support included home visits by <i>Village</i> Health Teams, parent training, income-generating activities, medical care and food. in Wakisa 6 parent groups set up; 15 children attended weekly early childhood education and play programmes.   |
| <b>Objective</b>       | <b>6. An 'assistive technology' workshop</b>   |
| <b>Intended result</b> | Starting a social enterprise for local production of assistive devices for children with CP. In all three countries, there is a severe lack of proper assistive devices.   |

**Table 1: Summary objectives and results 2023 in the (3) programme countries**

|                        |  |
|------------------------|--|
| <b>Result achieved</b> | Preparations for the launch of the first social enterprise have been completed: the Grand Assistive Technology (GAT) Centre has been developed in Ethiopia with support from CPA and Shonaquip Social Enterprise in South Africa.          |
| <b>Objective</b>       | <b>7. Monitoring and evaluation</b>  |
| <b>Intended result</b> | Evidence of achievements in functionality, participation and quality of life of children with CP and their parents are brought out and disseminated.   |
| <b>Result achieved</b> | Important steps have been taken in gathering evidence. From 2024, results will increasingly be communicated externally.  |
| <b>Ethiopia</b>        | In Ethiopia, the impact of the implemented interventions on children's participation levels was measured.  |
| <b>Ghana</b>           | The CPA logbook is used systematically. Both the initial data of families (to be seen as a baseline measurement) and the results of interventions are recorded here. This provides information on the functioning of the renewed approach. |
| <b>Uganda</b>          | Village Health Teams (VHTs) enjoy the trust of parents and determine interventions with them. Decisions, findings and outcomes are recorded and shared with stakeholders.  |
| <b>Objective</b>       | <b>8. Prevention, lobbying and advocacy</b>  |
| <b>Intended result</b> | 500 (traditional) midwives and primary care workers are better equipped to help prevent CP, recognise symptoms and refer parents and children appropriately  |
| <b>Result achieved</b> | This target was not achieved in 2023. Work on this will continue in 2024 and the following years.  |
| <b>Ethiopia</b>        | 3 awareness campaigns were conducted with programmes on a local radio and a regional TV station. In 5 public sessions on disability and children with CP, 45 people from the community participated.                                       |
| <b>Ghana</b>           | Family members and neighbours of the children in the programme were educated about (living with) CP.   |
| <b>Uganda</b>          | Investment has been made in contact and collaboration with relevant <i>stakeholders</i> in the community such as health centres, schools, banks, churches and the police to make additional support accessible to children and parents.    |



## 1. INTRODUCTION CPA

**Foundation Cerebral Palsy Africa (CPA)** is a knowledge organisation in the field of cerebral palsy (CP). Children contract this neurodevelopmental disorder due to brain damage before or around birth or in early childhood. In low- and middle-income countries, CP is much more common than in wealthier western countries. Also, the rehabilitation of children with severe CP still often relies on outdated practices. Partly because of this, children's quality of life falls far short of what is proven to be achievable with the fundamentally different approach in which CPA has expertise. Helping to improve the quality of life of children with CP and their parents in low- and middle-income countries is CPA's core goal. That is why we share our know-how with local partners.

As CPA, we do not run our own programmes, but 'feed' existing CBR<sup>2</sup> - or DID<sup>3</sup> - programmes of well-established local organisations with our knowledge and experience. CPA only supports programmes of which rehabilitation of children with CP is an integral part.

### History of CPA

The Dutch foundation is a continuation of 'Cerebral Palsy Africa' (CPA), which was founded in 2005 by two Scottish rehabilitation professionals. Archie Hinchcliffe and Jean Westmacott had both worked for years in several African countries. They joined forces to raise awareness in low- and middle-income countries in Africa and Asia of their ideas on local manufacturing of affordable assistive devices for children with CP and the importance of physiotherapy.

To ensure that the work of the founders would continue and develop further, the Scottish board decided in 2019 to transfer CPA's activities to a Dutch non-profit organisation. On 13 March 2020, CPA Netherlands was established. The policy has since been renewed, deepened and broadened.

### Work area

CPA is now mainly active in Africa, more specifically in Ethiopia, Ghana, Uganda and, to a lesser extent, Malawi. Occasionally and on a modest scale, we also provide support in a few other countries.

To realise our ambitions, we decided to merge in 2024 with Enablement Ltd, an organisation that specialises in CBR and DID in low- and middle-income countries and is widely recognised as an expert in capacity building, research and innovation, especially when it comes to the rehabilitation of children with CP. From 1 January 2024, we will jointly form Enablement Foundation or Enablement Foundation.

### Governance model

So far, CPA Foundation is governed according to the following model: there is a general board consisting of three people and a daily board formed by one member of the general board.

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<sup>2</sup> Community-Based Rehabilitation.

<sup>3</sup> Disability Inclusive Development.

The general board consists of:

Mr H. Cornielje: president  
Mr C.J. van den Broek: executive secretary  
Mrs Y.E. Cox-Vleeshouwers: treasurer

The chairman and executive secretary both have extensive expertise in rehabilitation. They have both worked frequently and sometimes for longer periods of time in various African countries and have extensive experience in the rehabilitation of children with severe CP. Mr Van den Broek serves as the day-to-day management. This means that (mainly) he deals with day-to-day business and policy implementation.

The board members are not remunerated. Mr Van den Broek receives a small fee for his executive work.

### ***Change of governance model***

It is planned that after the merger of CPA and Enablement, the present governance model will be replaced by a Supervisory Board model<sup>4</sup>.

### **Future**

Our ambition in the coming years is to grow as a knowledge partner of organisations in low- and middle-income countries working in a family- and community-oriented way to improve the quality of life of children with CP and their parents. To provide broader and better support to these organisations and their programmes, we aim to expand our range of services, including the development of new trainings and innovative practical tools, and by coaching and facilitating local organisations in evidence-based<sup>5</sup> work.

### **Employees**

CPA has no paid staff so far.

### **INGO and ANBI**

Foundation Cerebral Palsy Africa is an international non-governmental organisation (INGO). CPA is a recognised 'Algemeen Nut Beogende Instelling'<sup>6</sup> (ANBI) in the Netherlands. After the merger of CPA and Enablement Ltd. into the Enablement Foundation, the ANBI status is maintained.

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<sup>4</sup> In the Supervisory Board model, a managing director is responsible for running the organisation, developing policies and day-to-day operations. The Board approves policies and oversees their implementation.

<sup>5</sup> To make its own programme, as well as other similar programmes, increasingly effective, it is very important that each organisation systematically collects and records 'evidence' of how interventions, methodologies and tools work. Analysis and evaluation of this 'evidence' allows conclusions to be drawn at a level that transcends individual programmes about what works well or less well and when and why this is so. Based on the outcomes, improvements can be made and shared. In this way, the effectiveness of programmes is constantly improved. Evidence-based working is also necessary to demonstrate the effectiveness and efficiency of the chosen approach in contacts with decision-makers and policymakers.

<sup>6</sup> A Charitable or Public Benefit Institution.

## 2. MOTIVATION

**If you are or have a child with a severe form of CP in a low- or middle-income country, it is usually disastrous for your quality of life. Especially if children and parents are deprived of appropriate support. And unfortunately this is very often the case. We know it can be done differently and what is needed to do so. That's why we take it for granted that we use our expertise to contribute to concrete improvements in the quality of life of children and parents and to a structural transformation of the way rehabilitation of children with CP is currently organised and handled.**

The brain damage that leads to CP in unborn or very young children is caused, for example, by a disposition disorder, oxygen deprivation, haemorrhage, infarction or injury. There are wide variations in the degree, effect and impact of CP. A child with a mild form of CP will experience relatively few impairments. However, more severe forms of the disorder often cause significant limitations: difficulty sitting, standing or walking, but sometimes also swallowing, speaking, eating, hearing, seeing and learning. Some children with CP have seizures or pain. Intelligence may also be reduced to a greater or lesser extent.

### Increased risk

A child cannot be cured of CP. It is a permanent condition. CP does not get worse, but if children and their parents do not get the right support and resources, or do not get them at all, then the physical, mental, emotional and social effects of CP will reduce their quality of life. The risk is greatest if a child with CP is growing up in a country with high levels of poverty, a weak health system and limited institutional capacity. Countries such as Ethiopia, Ghana, Uganda and Malawi have these characteristics.

In rich countries, CP occurs in 2 out of 1000 live-born children. In low- and middle-income countries, it can be as high as 10 out of 1000 of live-born children. In these countries, there is less focus on prevention and early recognition, referral and treatment. The living situation of many families also increases the risk of CP: pregnant women and young children are especially vulnerable to the harmful influences of poverty, poor nutrition and lack of access to health care. Other factors that make children in low- and middle-income countries more susceptible to CP than their peers in richer countries are infectious diseases such as tuberculosis, but also malaria, for example. These diseases can also lead to CP.

Once children have CP, their functioning and wellbeing become highly negative affected by poverty (again), but also by lack of knowledge among parents and health care workers and by poorly functioning rehabilitation care in rural areas and urban slums. In addition, ignorance in society about the causes and consequences of CP as well as about the abilities of children with CP often leads to misunderstanding or even stigmatisation and exclusion of these children, their parents and their families.

### Renewed rehabilitation approach

Because in low- and middle-income countries CP in children is often diagnosed late, parents remain uncertain for a long time about what is wrong with their child and do not receive the early support that is so important for them and the child. Subsequently, a diagnosis of CP, whether

given at a very young age or only after many years, does not mean that children receive the help that is appropriate to their form of CP and to their living situation. The therapies prescribed are often based on outdated practices that have been shown not to produce the desired effects and can sometimes even be harmful to the child's development.

In most low- and middle-income countries, rehabilitation of children with CP has so far a predominantly orthopaedic perspective. The emphasis is on correction of impairments caused by the condition. 'Rehabilitation' then often involves passive stretching of spastic body parts. Especially for children with severe CP, such treatments can be painful and stressful, while the results are minimal.

Renowned international research has now conclusively demonstrated that a new approach leads to much better results. This approach focuses on functional improvement of children with CP, broadening their activities and participation in family life, as well as on acceptance, inclusion and participation in the local community. Children with CP, their parents and families learn to cope with the resulting situation as best they can and are supported in doing so. Tools, adaptations and other interventions tailored to their specific circumstances enable children and parents, both at home and in the community, to live a less restrictive life. The quality of their lives increases as a result.

### Motivation CPA

What drives us is the conviction that the new approach is more appropriate, more effective and more cost-efficient in low- and middle-income countries, and the realisation that we are there to help make it happen. We have the expertise, the tools and the network. By sharing our knowledge, skills and tools with local partners, we can work with them to ensure that the quality of life for children with severe CP and their parents is greatly improved. And, of course, we want to do this.



*In all countries where CPA supports programmes, there is a great need for day care or schooling for children with CP.*

### 3. GOALS AND STRATEGY

**By contributing to the introduction, implementation and mainstreaming of the new approach to the rehabilitation of children with CP in low- and middle-income countries, we aim to achieve two ultimate goals. To do this successfully, we are pursuing a two-pronged strategy.**

Both the goals and the strategy are driven by the ambitions and needs of inspired and knowledgeable local organisations who, like us, are convinced of the need for a fundamental change in the way their countries help children with severe CP and their parents. They see in the practice of their work where the current approach falls short. This is why they are advocating an approach that recognises that the rehabilitation of children with CP is much more than a mere physical process in isolation from their environment. Their rehabilitation is also, and even primarily, a social process that must take place within the family and the community to which the family belongs. It is about achieving a situation in which children with CP, their parents, but also their siblings, can function as individuals and as a family as best they can, in which they are visible in their community and their participation in it is natural, and in which they are also accepted by the community and supported where necessary.

#### Ultimate goals

Together with our local partners, we want to contribute to achieving two ultimate goals in the longer term:

- A. Through improved health policies, (complex) neurodevelopmental disorders, such as severe forms of CP, are prevented where possible or at least detected early, and children with CP are referred to appropriate support at an early age.**
- B. Through an improved rehabilitation approach, (parents of) children with a (complex) neurodevelopmental disorder, e.g. a severe form of CP, experience a significant improvement in their quality of life.**

#### Strategy CPA

To bring us closer to achieving both end goals, we are working with a dual strategy:

- A. To achieve policy focus on prevention of preventable neurodevelopmental disorders, early detection of these types of disorders in children and adequate referral of young children with CP, for example, our partner organisations work with local universities, especially with faculties of medicine, nursing and obstetrics; with primary health care organisations; with traditional midwives; with religious leaders; and with (local) policy makers.
- B. To achieve widespread implementation and embedding of the improved rehabilitation approach in low- and middle-income countries, we are helping to build the capacity of the local rehabilitation sector. In part through our efforts, rehabilitation professionals and other involved care and service providers can develop and strengthen the skills needed for the new approach. Ultimately, for children with CP and related conditions, this leads to improved functionality, progress in daily activities and increased participation at home,

school and in the community. As a result, (parents of) children with severe CP, for example, experience a significant improvement in their quality of life.

### Trickle-up approach

Of course, improved (national) policies will ultimately have the greatest impact. At the same time, we know that it takes time to adapt policies and health systems. Decision-makers and policymakers need to be convinced of the need for and feasibility of the proposed changes. And in low- and middle-income countries, lack of priority, minimal budget, lack of facilities, resources and capacity slow down progress considerably.

Recognising that the desired policy change will not be easy to achieve, we are working with a trickle-up approach. This assumes that successful local application of the new rehabilitation approach (our second strategic goal) will be a powerful advocacy and lobbying tool that will ultimately contribute to the level at which policy is made and decided. For a trickle-up approach to be effective, it must be accompanied by effective lobbying of decision-makers and policy-makers.

### Concrete implementation of strategy

We concretise our strategy with the following activities:

- We support well-established local organisations and help them to integrate new approaches that have been shown to work into existing CBR or CBID programmes.
- Within existing curricula for training institutes and universities, we develop new training modules on interventions for children with CP that are proven to be effective and based on the latest evidence. These interventions focus on functionality and family-centred care, with the aim of improving the quality of life of the child with CP, the parents and the family as a whole.
- We help the organisations we support to make their programmes more effective.
- We look for and support service initiatives that have the potential to be scaled up.
- We work with country representatives to ensure local ownership, continuity and sustainability.
- We contribute to fundamental and sustainable changes in the systems in which children with CP are rehabilitated and in which they and their parents are cared for and supported.

### ICF as a guideline

The World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) guides CPA's objectives and strategy. The ICF looks at people's health and functioning from a physical, individual and societal perspective. You always function within a context, which helps to determine whether you have problems in functioning and offers insight into the interventions that are needed.

### Theory of Change

The *output*<sup>7</sup>, *outcome*<sup>8</sup> and *impact*<sup>9</sup> we want to achieve as CPA and the way we are working towards it have been visualised and described in a Theory of Change (see page 15)

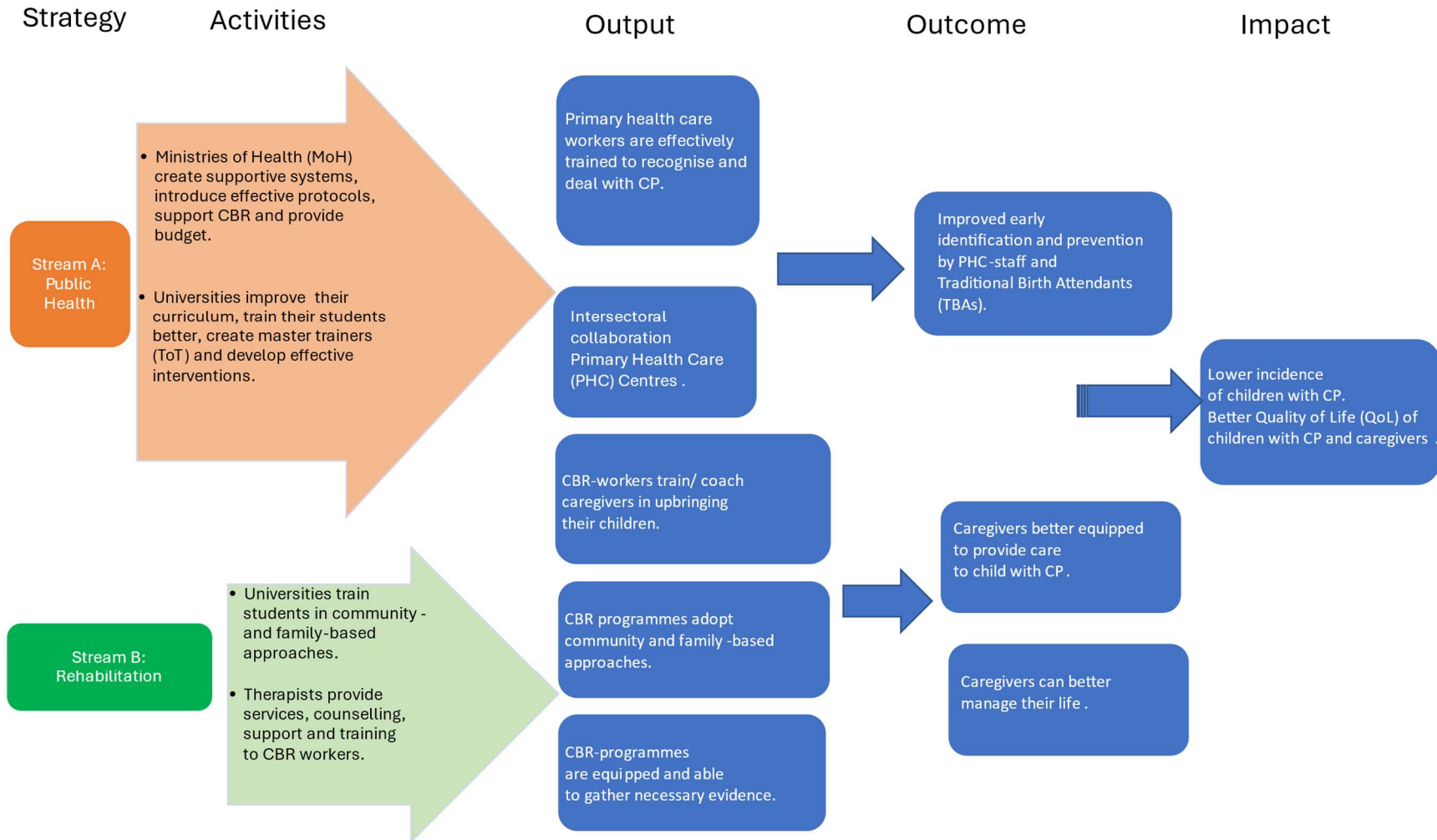
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<sup>7</sup> The direct (quantitative) result of activities carried out.

<sup>8</sup> The effects the *output has* on (the behaviour of) people.

<sup>9</sup> The longer-term change(s) that the *outcome* brings about in society.

## Theory of Change Cerebral Palsy Africa (CPA)



## 4. RESULTS PROGRAMME COUNTRIES 2023

In 2023, we spent a total of €197,410 on supporting projects in (7) countries. Of this, €166,516 went to the 'programme countries' Ethiopia, Ghana and Uganda where we also work with 'country representatives'.

Our 2023-2025 Multi-Annual Plan sets for each year concrete targets for the core elements and activities of CPA-supported programmes. For the programme countries, the results targeted and achieved in 2023 are summarised in **Table 1** on page 6. Chapter 4 'colours' this summary information with a breakdown of results and a description of the context, impacts and challenges of the projects in Ethiopia, Ghana and Uganda.



*Field workers explain to parents how they can support their child's rehabilitation at home.*

### 4.1. ETHIOPIA

In Ethiopia, a total of €76,754 was spent in 2023. With this we supported the community-based rehabilitation programme of the University of Gondar (UOG), income-generating activities of the parents' association founded within this programme<sup>10</sup> and the development of a social enterprise for local assembly and production of aids. CPA's country representative in Ethiopia is Zelalem Demeke.

The University of Gondar (UOG) in the Amhara region of northwestern Ethiopia runs a community-based rehabilitation programme in several locations, including the university town itself. Within the Gondar programme, UOG has been working with us since 2022. UOG strives to innovate its services, particularly in supporting and empowering children

<sup>10</sup> Gondar Association of Parents of Children with Cerebral Palsy.



with CP and their families.

#### Four focal points

UOG's rehabilitation programme has four focal points: parent *empowerment*, advocacy, capacity development and service delivery.

#### Empowering parents

In 2023, the Association of Parents of Children with Cerebral Palsy in Gondar was officially recognised as an NGO. The aim of the association is to empower parents and strengthen their position. From the project budget, the association received start-up capital to enable members to set up businesses. In 2023, the association, together with CBR field workers, has selected 15 parents to be the first to benefit. The parents' association will use the income generating fund as a revolving fund. It is planned that the parents' association will also engage in advocacy activities.



*Meeting of the Association of Parents of Children with Cerebral Palsy in Gondar.*

#### Advocacy

The taboo on physical, intellectual and multiple disabilities is high in Ethiopia. This is largely due to the still strong influence of traditional and cultural beliefs, but ignorance also plays a role. As a result, people with disabilities and their families are often shunned and even excluded. In 2023, the CBR programme in Gondar launched three awareness campaigns. Through a radio station<sup>11</sup> in Gondar and a regional TV station<sup>12</sup>, 'spots' were broadcast on the following topics: causes of disability; support needs of children with disabilities and their families; barriers for children and parents; available services; and opportunities for individual or community support for families with a child with CP.

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<sup>11</sup> Fana FM 98.1 Gondar Brach.

<sup>12</sup> Amhara Mass Media TV.

### Capacity development

- **Training of CBR workers**

CBR workers play an important role in the rehabilitation programme in Gondar. They provide rehabilitation and support to children with CP and their parents. They do this in the children's homes or at least in the neighbourhood. CBR workers are trained in the new approach to the rehabilitation of children with CP. They are advised and coached in their work in the community by experts from UOG.

- **Curriculum change**

In 2023, CPA, UOG and paediatric rehabilitation teachers developed an 'Enhanced Approach to Cerebral Palsy' course. This is a practical CP course from a holistic, community-based approach that enables therapists to work meaningfully with children with CP, their parents and their families. The course is planned to become an integral part of the curricula of relevant training programmes at the University of Gondar in 2024.

### Effects training and coaching

CBR workers in Gondar no longer use outdated interventions for children with CP, but have started using holistic, empowering interventions.

### Services

- **Rehabilitation and psychosocial support**

By 2023, 6 CBR rehabilitation workers have implemented interventions to 87 children with CP, mainly aimed at improving their functioning and increasing their participation in family and community life. Parental education and training is central to the revised therapy programme. Parents also receive psychosocial support.

### Effects renewed approach

Measurements of their level of participation after the intervention(s)<sup>13</sup> show that children with mild forms of CP in particular have improved in performing 'activities of daily living' (ADLs) such as eating by themselves, dressing and going to the toilet, and have started to participate more in family and community life. They now eat with the rest of family more often, watch television with them, and help with chores around the house. They play more with other children, both indoors and outdoors, and sometimes they go shopping or to church with their family. After the intervention(s), it was also measured<sup>14</sup> whether the supported parents now feel more empowered and better able to support their child's development and well-being. The results show that this is indeed the case. This is partly because parents have gained more confidence in themselves and in their child.

- **Other forms of support**

The majority of families in the CBR programme in Gondar live in poverty. CBR workers therefore also budget for material support for the poorest families. These include mattresses, blankets, clothes and cleaning materials.

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<sup>13</sup> The Child Engagement in Daily Life instrument was used for measurement.

<sup>14</sup> The Family Empowerment Scale (FES) was used for this purpose.

- **Community awareness raising**

Awareness raising is also part of the CBR programme. For example, CBR workers organised several coffee ceremonies at the home of a child with disabilities. Community members were invited to these ceremonies, where disability was also discussed. Both the mothers of a child with CP and the guests from the community seemed to appreciate the meetings.



*Various aspects of 'disabilities' are discussed during a coffee ceremony.*

### **Follow-up steps**

There are two other barriers that prevent parents from living a normal family and community life with their child with CP. Children with severe CP need intensive full-time care. This breaks many mothers. Day care for their children would help them, but there is a lack of such facilities. A second obstacle is the lack of resources. To help parents overcome these obstacles, the CBR programme will create two facilities by 2024: a day care centre for children with CP and related disorders, and a centre for the assembly and production of appropriate assistive devices.

### **Grand Assistive Technology Center**

With the support of CPA and in collaboration with Shonaquip SE, 2023 has prepared the establishment of Grand Assistive Technology (GAT), a social enterprise for the assembly and production of assistive devices such as standing frames, wheelchairs, adapted furniture, adapted eating utensils and grips to improve grip. The primary purpose of all assistive devices is to enable children with CP to function and participate better at home and in their environment. To ensure that the equipment is properly adapted and used, the GAT centre will also carry out outreach work. It is planned that GAT will also provide training in the use of assistive technology and develop a curriculum. GAT will also work on awareness raising. The aim is for GAT to be a self-sustaining organisation within five years. Profits will be reinvested to increase GAT's social impact.

### Summary results 2023

The UOG programme in Gondar targets several groups, some of which are reached directly and others indirectly. **Table 2** provides an overview of outreach in 2023.

| <b>Table 2: Outreach and impact programme UOG Gondar</b>   |  |
|--|--|
| <b>Direct reach</b>  | <b>Indirect reach</b>  |
| <p><b>573 people</b> were reached directly:<br/> <b>87 children</b> were supported in their rehabilitation at home; <b>435 parents/family members</b> received home counselling and education;<br/> <b>15 mothers</b> received financial support to start or expand a business;<br/> <b>6 CBR workers</b> did follow-up training on child rehabilitation; <b>45 community members</b> participated in 5 information sessions on disability and children with CP.</p> | <p><b>The 3 media awareness programmes</b> have reached many people in Gondar and in the region. Exact number are not known.</p> |

## 4.2. GHANA

**In 2023, our spending in Ghana totalled €52,596. We supported CBR Africa's community-based rehabilitation programme in Winneba, the resulting 100WEEKS programme in collaboration with MultiKids Africa, and the development of an updated CBR curriculum at the Pentecostal University in Accra. Our country representative in Ghana is Juliet Magyan.**

In Winneba, a fishing town of about 60,000 people in south-eastern Ghana, CPA supports a CBR programme run by CBR Africa. The activities will be supervised by MultiKids Africa in the coming years. This NGO is committed to inclusive education and the welfare of children with special educational needs.

### 4.2.1. CBR programme in Winneba

The CBR programme in Winneba started as a pilot project. By the end of 2023, 60 families had been supported. Each family is visited at home twice a month by a field worker. CBR field workers systematically record details of each family and all interventions in a logbook developed by CPA. CPA coaches them in their work. This is done during monitoring visits, but also regularly online. In 2023, the field workers also received support from TEN, a programme run by a Jewish NGO that allows professionals to volunteer for a month on projects in a number of African countries, among others, helping to build local expertise.

#### **Target group**

Analysis of log book data collected in 2023 has provided a good picture of the families involved in the programme: The children with CP are on average 10 years old, their mothers are often young and single; 41% of the children have a mild form of CP, 25% a 'moderate' form and 34% a severe form; more than half of them also have epilepsy, for which the vast majority have no medication; parents perceive the quality of life of themselves and their children as fair to good, but also express their needs, especially for better health, more income and more support in caring for their children.

Based on the results of the analysis, recommendations for the programme were made: to focus more on the mental health of both parents and children; to provide training and social, financial and economic support for parents; to improve children's access to health care and education; to teach them skills appropriate to their abilities; and to provide education to reduce stigma and promote inclusion.

### Local cooperation

CBR Africa also sought local cooperation and support in 2023, particularly for activities aimed at empowering mothers of children with CP to become self-sufficient while still being able to stay close to their child. A total of 44 mothers or caregivers participated in training or programmes that enabled them to increase their income (see 4.2.2. and 4.2.3.).

**Table 3** summarises the results and findings of CBR Africa's programme in Winneba.

### Results and findings CBR rehabilitation programme

| <b>Table 3: Results and findings CBR rehabilitation programme in Winneba 2023</b>   |
|---|
| <b>Output</b>   |
| There is a registry of 120 children with CP in Winneba. Experienced physiotherapists worked through TEN 3 x 1 month in the programme. Family and neighbours were educated about CP.   |
| <b>Outcome</b>  |
| The register enables outreach workers to reach parents of children with CP earlier. They are also trained locally to work with families. Parents see improvements in their child's home and living environment.   |
| <b>Scalability</b>  |
| To reach more families, work more cost-effectively and increase community impact, CBR Africa focuses on establishing and supporting special schools and nurseries and setting up parent groups.   |
| <b>Sustainability and exit strategy</b>   |
| To ensure sustainability, CBR Africa will work with the special education and CBR courses at the University of Education. Local organisations will be approached to address other needs such as nutrition and psychosocial support.   |
| <b>Cost-benefit ratio</b>   |
| <b>Costs:</b> supporting 60 families cost \$10,320 or \$172 per child/family.<br><b>Benefits:</b> children's access to a new rehabilitation approach leading to better functionality and increased quality of life; alleviation of parents' burden resulting in reduced stress and improved mental health; increased self-reliance of parents through participation in income-generating projects; increased community involvement leading to greater acceptance and inclusion of children and parents. |
| <b>Lessons learned/ dilemmas</b>  |
| The current skills of practitioners are inadequate for children with highly complex forms of CP. There are too few assistive devices to further improve functionality. Because their children cannot attend school, mothers in particular bear the full burden of caring for their child around the clock. This leaves them exhausted and unable to earn an income. Many parents find the CPA logbook 'complicated'.  |

#### 4.2.2. 100WEEKS programme

The 100WEEKS programme helps women living in extreme poverty to escape it for good. 100WEEKS uses a three-pronged approach: weekly cash transfers via mobile phones, training by local coaches, and savings and self-help groups. A 100WEEKS group consists of 20 women. Diversity is sought in the composition of the groups. Local partners select participants based on criteria. The 100WEEKS approach has been proven to be effective: it not only improves the lives of the women and their families, but also has a positive impact on the community as a whole. 100WEEKS has been working in Ghana for some time. When 100WEEKS partnered with MultiKids Africa in July 2023, a programme was also launched in Winneba. Through CBR Africa, mothers of children with CP were able to participate for the first time. Twenty-nine (29) women were enrolled in the programme, divided into five 100WEEKS groups. Their participation was mainly funded by CPA and MultiKids Africa.

#### Programme activities

Each 100WEEKS group meets weekly to receive training from local coaches on topics such as empowerment, budgeting, entrepreneurship, sustainable agriculture and life skills. All participants receive €8 each week through a mobile money system. Each of them has been given a mobile phone. Part of the money they receive is paid weekly into the Village Savings and Loans Association (VSLA), a communal fund within each group. VSLAs allow participants to withdraw larger amounts to invest in their businesses.

#### Results and findings 100WEEKS programme

| <b>Table 4: Results and findings 100WEEKS programme Winneba 2023</b>   |
|--|
| <b>Output</b>  |
| 29 out of 60 mothers/carers of children with CP in the CBR rehabilitation programme participate in the 100WEEKS programme.   |
| <b>Outcome</b>   |
| Participants in the programme have access to the VSLA to set up or expand their own businesses. Through the cash money women receive, they can better meet the nutritional needs of their families.  |
| <b>Scalability</b>   |
| Parts of the 100WEEKS programme can be transferred to the CBR rehabilitation programme. 100WEEKS teaches that women themselves know best what is needed in their situation. The combination of a little extra money, coaching and confidence building gives women a new perspective on their future and the courage to make it happen. |
| <b>Sustainability and exit strategy</b>  |
| The aim is to enable more mothers or caregivers of children with CP to access the 100WEEKS programme. The aim is to raise at least part of the money needed through fundraising from local businesses, preferably in collaboration with the 100WEEKS Ghana office.   |
| <b>Cost-benefit ratio</b>  |
| Participants in the 100 Weeks programme did not receive their first payment until November 2023. A cost-benefit analysis will not be carried out until 2024.   |
| <b>Lessons learned/ dilemmas</b>   |
| Many mothers or caregivers in the CBR programme do not meet all the criteria to participate in 100WEEKS: for example, they are over 50 (the grandmothers) or single. An exception was made for some in 2023, but this remains an issue.  |

### 4.2.3. Training in the production of detergents

CPA funded a three-day training course for 14 mothers/caregivers and one young person with CP on the production of detergents: liquid soap, bleach and disinfectant. Detergents were chosen because the ingredients are readily available, production is simple, start-up costs are low and they are always in demand. The training took place in Winneba in October 2023 and was conducted by an experienced expert. After the training, participants were given raw materials and tools to make and sell products at home, thereby increasing their income. The total cost of the training was just over €4,000.

After the training, the participants were followed up and coached. Almost all of the women had been able to increase their income, enabling them to feed their children better. One lesson learned is that technical support is still needed after the training to solve problems in the production process.



*Food and detergents for sale*



### 4.3. UGANDA

**In Uganda, we spent a total of €37,167 in 2023. We supported projects at the Katalamwa Cheshire Home (KCH) in the Kamuli District (€24,667) and the Angel's Centre for Children with Special Needs in the Wakiso District (€12,500). Cerebral Palsy Africa's country representative in Uganda is Kenneth Nangai.**

By transferring know-how, the projects in Uganda aim to ensure that children with CP, their parents and families receive support within their own communities that actually improves their quality of life. In both Kamuli and Kamisa, Village Health Teams (VHTs) play a key role. These village-level teams are part of Uganda's public health system.

### 4.3.1. The project in Kamuli

The Kamuli District in eastern Uganda is one of the poorest regions in the country, heavily dependent on sugar cane. Families there are large and their incomes low. There is virtually no support for children with CP and their parents in the villages of Kamuli. KCH's project focuses on filling this gap by transferring the expertise of KCH and CPA to Village Health Teams (VHTs) and through them to parents of children with CP. In Wakuli, 5 VHTs have been selected, trained and equipped for their work in the villages. They were also coached on home visits to children with CP.

### Results and findings project in Kamuli

Including a six-week pilot, the project in Kamuli was implemented from June 2023. The results and findings for the first seven months are positive. For a summary, see **Table 5**.

| <b>Table 5: Results and findings project Kamuli</b> |   |
|---|---|
| <b>Output</b>                                       |   |
| <b>VHTs</b>   | <b>5 VHTs</b> were trained and provided with materials and equipment such as measuring tapes and scales, development charts, CPA logbook, flash cards on CP and a telephone with credit and bundles to facilitate communication and information exchange. The VHTs now visit families with a child with CP every week in <b>6 villages</b> .  |
| <b>Children and parents</b>                         | <b>147 children</b> have been identified and supported with interventions such as supplementary feeding, the ability to grow their own food, home modifications, epilepsy medication, an income-generating activity, assistive devices, exercise materials, referrals, and sleeping materials. <b>210 parents/caregivers</b> have been trained to provide rehabilitation for their child.   |
| <b>Community</b>                                    | <b>9 staff of 2 health centres</b> received information on disability and rehabilitation; one centre was supported with rehabilitation equipment and materials; <b>2 local organisations</b> integrated activities for women with disabilities into their programmes.   |
| <b>Outcome</b>                                      |   |
| <b>VHTs</b>   | <b>4 VHTs</b> can decide on interventions with parents/caregivers independently; one team needs additional coaching; coaching continues for all five teams  |
| <b>Children and parents</b>                         | More children with CP are now accessing health services. Of the children receiving functional therapy, 40 per cent have achieved new developmental and growth milestones. Of the children started on anti-epileptic medication, 70 per cent now have fewer seizures or no seizures. Medication and assistive devices enabled 5 children to attend school for the first time. Almost all of the 30 severely malnourished children were able to start therapy after three months of nutritional support with nutritional supplements. Children who were often ill are now less or no longer so. |
| <b>Community</b>                                    | In the communities involved in the project, CP is more often detected early. Parents seek help for their child earlier. There is more focus on prevention. Parents and communities experience more ownership because they are involved in plans and decisions.  |



| <b>Table 5: Results and findings project Kamuli</b>  |
|--|
| <b>Scalability</b>   |
| To ensure that the new rehabilitation approach is embedded in the communities, KCH focuses on working with and between health services, schools, village organisations, churches, the police and local leaders, among others. It is also important to set up parents' groups. They will play an important role in mobilising communities.  |
| <b>Sustainability and exit strategy</b>  |
| If existing facilities better tailor their services to the needs of children with CP and their parents, this will help ensure continuity and embedding of the new approach and appropriate interventions. KHC will train staff at the mainstream facilities and advocate for a rehabilitation unit at Kamuli Hospital. Parents will be encouraged to demand better services for their child. |
| <b>Cost-benefit ratio</b>  |
| By 2023, a lot has been achieved at a relatively low cost. Investing in VHTs has a long-lasting impact on communities and the local health system.   |
| <b>Lessons/ findings and dilemmas/ challenges</b>  |
| <p><b>Lessons/findings</b></p> <p>It is important to manage the expectations of both parents and VHTs.</p> <p><b>Dilemmas/ challenges</b></p> <p>In the last quarter of 2023, the number of enrolments increased; due to limited financial resources and staff capacity, this overwhelmed the VHTs.</p>  |

#### 4.3.2. The project in Wakiso

Since May 2023, CPA has been supporting the Angel's Centre for Children with Special Needs project in the Wakiso District in Uganda's Central Region. The main aim of the project is to provide parents and families of children with CP with knowledge and skills to enable them to provide better care and developmental support for their children at home. The Angel's Centre seeks to collaborate with organisations and institutions in the health and education sectors for knowledge sharing and advocacy.

#### Results and findings project Wakiso

In order to ensure that parents and other caregivers of children with CP have the knowledge, skills and resources to properly support the rehabilitation of their children at home and in the family environment, the Angel's Centre has implemented various interventions and activities. The main outcomes and findings are summarised in

**Table 6** on page 26.

**Table 6: Results and findings project Wakiso**

**Capacity building of parents and other caregivers/family members**

**Training and coaching**

So far, the project has reached **70 families**. In these families, both the parents and siblings of the child with CP have been trained. They have learnt how to better guide the children in their rehabilitation and involve them in family life. They were given information on how to get a child into a good position, play, hygiene, nutrition and help with learning. As siblings were also trained, they became more involved in the life of the child with CP. This gave the primary caregivers, usually the mothers, a little more time for other responsibilities or to rest.

**Access to specialist care**

A number of children in the project had serious health problems (heart problems associated with Down's syndrome, malnutrition, nutritional complications). Their families did not have the money to pay for specialist medical care. Angel's Centre provided referrals and cost sharing. The centre now works with two health facilities. Parents can bring their children here. In 2023, **22 children** received emergency medical care.

**Tools and training materials**

In 2023, **15 children** received new equipment. This included sensory play materials, standing frames, ankle-foot orthotics and CP chairs. Existing equipment was repaired. Equipment is essential for the functionality and independence of children with CP.

**Livelihood support**

Through parent groups, **20 parents/caregivers** received training in vocational skills, budgeting, saving and entrepreneurship, enabling them to start their own small businesses and increase their income. The parents were given start-up capital to start a small business - in soap making, agriculture or retail.

**Village Health Teams (VHTs)**

**3 Village Health Teams (VHTs)** have been trained to provide psychosocial support to programme participants. The VHTs also follow up with families at home. They support parents with home treatment and arrange referrals when necessary.

**Learning and playing**

**17 children** with CP were able to take part in the early years programme and play activities at Angel's Centre.

**Cooperation with local partners**

Angel's Centre worked with the Rotary Club of Wakiso to raise awareness of the need for inclusion of children with CP. With other local partners, it advocated for health facilities to have more resources to screen for CP and related conditions.

**Challenges**

It is still difficult for parents to get a good education for their child with CP. Inclusive education is very expensive. More aids are also needed. Many children in the project have outgrown their wheelchairs and CP chairs. This hinders their mobility.

## 5. RESULTS OTHER COUNTRIES 2023

**On a smaller scale than in the programme countries Ethiopia, Ghana and Uganda, CPA supported projects for children with CP in Malawi, Vietnam, Nepal and Bangladesh.**

In Malawi, CPA provided 17,000 euros for a pilot project in the southern district of Mangochi. The 'Wilde Ganzen' Foundation<sup>15</sup> matched this amount with a further 8,000 euros. The pilot was also intended to test whether Malawi could become a programme country with a country representative. For the pilot, CPA worked with the hospital in Mangochi.

In Vietnam, where CPA support is coming to an end, a modest amount was spent to complete the programme. We also funded a five-day training course in Nepal, attended by rehabilitation workers from Bangladesh. The training provided knowledge and skills to work with a holistic approach to improve the quality of life for children with CP and their parents. In 2023, CPA spent a total of almost €14,000 in Vietnam, Nepal and Bangladesh.

### 5.1. Malawi

Many children with CP in Malawi, including in the Mangochi District, remain without care and support. Their condition goes undetected or is detected very late, mainly due to a lack of knowledge among health workers and relevant stakeholders. Mangochi Hospital developed a project plan to change this. A pilot of the planned project was implemented in 2023.

The pilot project focused on six activities: training of health workers; health education for community stakeholders; baseline measurement of the quality of life of children with CP and their parents; transformation of the existing one-sided physiotherapy-based CP clinic into a multidisciplinary outreach clinic; establishment of parent groups; and production of assistive devices.

#### Results and findings pilot Malawi

The main results and findings of the *pilot* are shown in **Table 7**.

| <b>Table 7: Results and findings pilot project Malawi 2023</b>  |
|---|
| <b>1. Training of health workers</b>  |
| A total of <b>80 staff</b> from the 14 health centres and the 2 local clinics in Mangochi were trained. The training focused on improving knowledge. In the next phase, the trainees will be coached in their work environment. |
| <b>2. Health education of stakeholders in communities</b>   |
| Health education sessions were organised in <b>5 communities</b> , targeting key stakeholders. A total of <b>73 people</b> participated in the sessions.  |

<sup>15</sup> The Wilde Ganzen Foundation is a Dutch NGO with a mission to reduce poverty and inequality through community-led initiatives.

|   |
|---|
| <b>3. Baseline measurement quality of life</b>  |
| The baseline measurement was carried out using a validated questionnaire based on the ICF model and interviews with (parents/carers of) <b>62 children</b> with CP. The preliminary data show that CP always reduces quality of life, but the negative impact increases with the severity of the form of CP. The final analysis will be available in 2024.  |
| <b>4. Pilot integrated multidisciplinary care and support for children with CP</b>  |
| The existing CP clinic, which focused solely on physiotherapy, has been transformed into a multidisciplinary outreach clinic where children with CP can receive not only physiotherapy, but also medical care, malnutrition support and health education. The clinic visits two sites in the Mangochi district every week. Now that the clinic has a new shape and approach, many more children are coming. |
| <b>5. Production of assistive devices</b>   |
| With a local carpentry workshop, assistive devices have been developed for children attending the clinic. Existing designs have been improved and device are customised. 10 CP chairs, 14 standing frames, 16 rollators, three tricycles and three wheelchairs have been delivered.   |
| <b>6. Setting up parent groups</b>  |
| The original plan was to start parent groups in 2023. It was then decided to find out what the primary caregivers needed most. These turned out to be income support and day care or schooling for their children. So in 2024, other parties will be involved in the initiative, especially organisations with expertise in setting up small business models.   |

### Evaluation

Periodic evaluations in 2023 showed that all stakeholders were positive about the functioning and results of the new multidisciplinary outreach CP clinic. However, chaotic situations sometimes arose due to the large influx to the clinic. In February 2024, the clinic will be operational for one year. A comprehensive evaluation will then be carried out, including a satisfaction survey and an impact measurement based on the logbooks kept by each child.

In 2023, Malawi's status as a programme country and whether or not to appoint a country representative has not yet been decided.

### 5.2. Nepal and Bangladesh

From 20 to 24 November 2023, **10 rehabilitation workers** from Nepal and Bangladesh attended a five-day training at the CBR School in Bhaktapur, Nepal. The training was funded by CPA, supported by Enablement Netherlands and organised by Enablement Nepal. The aim of the training was to equip participants with up-to-date knowledge and tools to contribute more effectively to improving the quality of life of children with CP and their families.

The training used a variety of learning methods including home visits, practical sessions, discussions and group work. Topics included integrating interventions into families' daily routines, highlighting children's strengths, and the importance of a holistic approach to improving the quality of life of children with CP and their families.

### 5.3. Vietnam

CPA has decided to end its activities in Vietnam. To enable the local partner to properly complete the supported programme, a further amount of over €7,000 was spent in Vietnam in 2023.



*Participants in the five-day training in Nepal.*

## 6. MAJOR DEVELOPMENTS

**By 2023, CPA has developed strongly. We have taken important new steps to increase our capacity to strengthen local organisations, particularly in low- and middle-income African countries, that are committed to improving the quality of life for children with CP and their parents.**

In this chapter, we look in turn at the substantial strengthening of our organisation, a serious game from which we have high expectations, access to the innovative 100WEEKS programme for women caring for a child with CP, and a mobile knowledge application for field workers.

### **Stronger together: CPA and Enablement Ltd.**

Since we, the Dutch Cerebral Palsy Africa Foundation (CPA), took over the activities of the Scottish CPA, we have adopted a new approach. The focus is now on knowledge transfer. For example, in places around the world where the quality of life of children with CP, their parents and their families is affected by poverty, stigma and barriers to action, we want to enable an approach that enables them to function optimally with each other and in their communities. In some countries, we do this by supporting programmes run by local organisations. Because we see that this support 'works' and has a life-changing effect on children with CP and their families, we want to strengthen our knowledge organisation and expand and secure our activities.

Enablement Ltd is a not-for-profit training, consultancy and research organisation working in the field of disability and inclusive development in low-resource countries. Since its inception 25 years ago, Enablement Ltd. has been committed to empowering people with disabilities to participate fully in society, be accepted by others and have access to services that improve their quality of life. In the world of development cooperation in particular, Enablement Ltd. has built a great reputation.

CPA and Enablement Ltd share the same convictions and approach. In 2023, intensive discussions were held on the possibility of developing the existing cooperation into a structural link. The talks were successful: as of 1 January 2024, CPA and Enablement Ltd. will together form the **Enablement Foundation**.

### **Structure**

Within the Enablement Foundation, CPA will continue its current work and Enablement Consultancy will focus on capacity building through *tool* and *e-learning* development and research and consultancy. The Enablement Foundation will have a Supervisory Board and an Executive Director during 2024.

### **A practical knowledge tool: the RehApp**

Within the Enablement Foundation, field workers in supported programmes have access to the RehApp, a mobile rehabilitation knowledge base created by Enablement Ltd and further developed by Enablement Consultancy. The RehApp is first and foremost a practical tool that enables users to be more effective in their work with people with disabilities in the community.

With the help of the app, which is based on the International Classification of Functioning, Disability and Health (ICF), field staff always have a knowledge base at hand. The RehApp provides basic information on possible causes, signs and symptoms of specific impairments, as well as options for intervention. The app already has several chapters, each dedicated to a specific disability. One of the chapters already in the app concerns cerebral palsy. New chapters are being worked on energetically, together with experts in the field of disability. Once downloaded, the app can be used in any environment, even without access to the internet.

### ***Different packages***

The basic version of the RehApp is and will remain free of charge. To ensure the sustainability of the app, a fee structure is being developed for more extensive packages. This has been decided to cover maintenance costs. Any remaining funds will be used for further development and content updates. Tariffs will vary according to the size and capacity of the customer.

All the more comprehensive packages (Light, Advanced and Premium) include online RehApp training and troubleshooting support. The Advanced package also gives users access to the app's Management Information System (MIS) and training on how to use it. The Premium version offers the features of the Advanced package, plus e-learning material on rehabilitation processes.

### **'Shifting Focus': an experiential learning tool and *serious game***

CPA's core aim is to improve the quality of life of children with CP and their parents in low and middle income countries through better interventions and services delivered by competent, well-equipped local people working with CBR programmes. One of the biggest barriers to achieving our goal is the way many professionals in Africa, such as physiotherapists and doctors, still 'see' children with neurodevelopmental disorders. They are seen as 'sick' and that means they need to be 'treated'. This attitude leads to a one-sided focus on physiotherapy and other forms of physical correction, while little attention is paid to interventions that help children function better and participate in their environment. The 'treatment' of CP rarely has the intended result, and the neglect of practical functioning hinders children's development. Taken together, this leads to the marginalisation of children with CP both at home and in the community.

In order to contribute to a shift in focus in the rehabilitation of children with CP towards an inclusive approach, in 2023 we developed an experiential learning tool (ELT) in collaboration with Salsaparilla, a specialist in game-based change projects. The tool is a training of trainers (ToT) tool and is aimed at professionals who play an important role in coaching (mid-level) rehabilitation and CBR workers. A financial contribution to the development of the ELT 'Shifting Focus, a *serious game*' is provided by the Phelps Foundation<sup>16</sup>.

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<sup>16</sup> The Dr W.M. Phelps Foundation, particularly in the Netherlands, is committed to improving the quality of life of children with spasticity.

### **Main goals**

Designed as an experiential learning tool, also known as a serious game, 'Shifting Focus' allows trainees to practice both mindsets and skills in a 'playful' and 'experiential' way. The main objectives are that the participants will

- interactively learn about a modern, outcome-focused rehabilitation approach embedded in the CBR strategy, and what this means for approaching children with CP and their families;
- experience the difference between thinking from the paradigm of 'disease and cure' and thinking from an 'inclusion, acceptance and functional development' paradigm;
- become aware that the intended 'shift in focus' requires a different way of thinking and acting, and a different way of organising support for children with CP, their parents and their families.

We have high expectations for the new experiential learning tool as it will enable us to effectively transfer knowledge - even at a distance - in a way that fits the local context. A pilot of the serious game will take place in Ghana in 2024.

### **Continued participation in 100WEEKS programme**

The 100WEEKS programme, developed in the Netherlands, is an innovative, 'revolutionary' approach to poverty alleviation: it enables women living in extreme poverty to lift themselves out of it in 100 weeks. '100 weeks' was chosen because it seems to be a good average for making lasting changes in one's life. The key features of the 100 WEEKS programme are:

- providing a weekly cash allowance for women to spend as they see fit; in the beginning, the money is spent mainly on things like food, clothes, medicine, children's schooling and debt repayment; once the daily stress of surviving has subsided, space is created to focus on the future;
- training to give women the knowledge and skills to plan for the future and start implementing it;
- after a few months, women are able to save and invest; they start businesses or know how to generate income in other ways; after 100 weeks, they are physically, mentally and economically stronger;
- 100WEEKS is proven effective: investing in women benefits not only their families, but the whole community.

### **Unique opportunity**

For mothers or other primary caregivers - often grandmothers - of children with CP, participating in a 100WEEKS programme is a unique opportunity to make a lasting difference to the quality of life of their child with CP, their family and themselves. Although their situation is usually even more difficult than that of other women living in poverty due to the care of their children, their confinement to the home and the stigma of the community, they rarely have the opportunity to participate in a 100WEEKS programme. With the support of CPA and in partnership with MultiKids Africa, Ghana has succeeded in enrolling 29 (grand)mothers of children with CP in the Winneba District 100WEEKS programme in 2023. This is a significant development.



In Ghana, and in other countries where we support organisations, 100WEEKS programmes are being implemented in several locations. Our aim is to enable many more women caring for a child with CP to participate in one of the programmes in the coming years. If the (grand)mothers do not quite meet the eligibility criteria due to their specific circumstances, we try to make an exception for them.



*Mothers of a child with CP participating in the 100WEEKS programme.*

## 7. Plans 2024

**In 2024, we will build on the results and developments achieved in 2023. We will do this with a strengthened organisation and a new name: the Enablement Foundation.**

The outcomes we want to achieve in 2024 for the core elements and activities of our work and the budget available for this purpose are shown in **Table 8** on page 37.

### Operationalising the Enablement Foundation

**Table 8** also shows the development of the organisation in the Netherlands.

From 1 January 2024, CPA and Enablement Consultancy will together form the Enablement Foundation. In 2024 we will make this new organisation operational. This includes the appointment of an executive director with a small professional staff. The Foundation will also have a Supervisory Board. The establishment of this board is also on the agenda for 2024

### Training master trainers and field workers

In Ghana, the serious game 'Shifting Focus' will be piloted in the training of master trainers and (eventually) field workers. Lessons learned from the pilot will be used to further develop the game. It is also planned to use the RehApp in several programme countries as a mobile knowledge base for field workers and possibly as a management information system for their organisations..

### Support for parents and children

Our aim is to provide increasingly effective support for programmes aimed at improving the quality of life of children with CP, their parents and their families. Providing a future for the mothers of children with CP is critical to improving the quality of life for all involved. Their participation in a 100WEEKS programme or income-generating activities 'works' for the whole family and promotes the integration of the family and the child with CP into the community. We will therefore strongly support efforts in this area in programme countries.

### Funds

Donor support is needed to achieve the results planned for 2024 in the programme countries. As the Enablement Foundation, we remain committed to raising financial support. We do this primarily by demonstrating - increasingly - the impact of our evidence-based programmes on the lives of children with CP and their parents in low- and middle-income countries, particularly in Africa.

**Table 8: Summary of targets and results 2024**

|                        |   |
|------------------------|---|
| <b>Objective</b>       | <b>1. Further training 'trainer of trainers' (master trainers); coaching in practice</b>  |
| <b>Intended result</b> | 20 trained master trainers; 50 trained field workers in coaching programmes within 5 CBR programmes.  |
| <b>Budget in euros</b> | 20.000  |
| <b>Objective</b>       | <b>2. Develop modules and provide training to universities and related training institutes</b>  |
| <b>Intended result</b> | 3 universities in low- or middle-income countries are committed to the programme.   |
| <b>Budget in euros</b> | 15.000  |
| <b>Objective</b>       | <b>3. Organisational development in the Netherlands</b>   |
| <b>Intended result</b> | Operationalisation of the Enablement Foundation; implementation of a new governance model.  |
| <b>Budget in euros</b> | 50.000  |
| <b>Objective</b>       | <b>4. Working budgets country representatives.</b>  |
| <b>Intended result</b> | Working budgets total €60,000 (4 countries); implementation of monitoring & evaluation.   |
| <b>Budget in euros</b> | 60.000  |
| <b>Objective</b>       | <b>5. Supporting support structures and parent initiatives</b>  |
| <b>Intended result</b> | Supporting 1,750 children and parents.  |
| <b>Budget in euros</b> | 225.000   |
| <b>Objective</b>       | <b>6. Assistive technology</b>  |
| <b>Intended result</b> | Further development of social enterprise(s) for local assembly/production of assistive devices for children with CP.  |
| <b>Budget in euros</b> | 150.000   |
| <b>Objective</b>       | <b>7. Monitoring and evaluation.</b>  |
| <b>Intended result</b> | Disseminate proven results on quality of life, participation and functionality of children and parents.   |
| <b>Budget in euros</b> | 10.000  |
| <b>Objective</b>       | <b>8. Prevention, lobbying and advocacy</b>   |
| <b>Intended result</b> | 250 midwives, traditional midwives and primary health care workers are better equipped to help prevent CP, recognise symptoms and refer parents and children appropriately. |
| <b>Budget in euros</b> | 15.000  |