PATSOGOLO CP FOUNDATION

Our Programme Pillars

Clinical Care · Awareness & Advocacy · Training · Research

A narrative overview of Patsogolo CP Foundation's four programme pillars, prepared to support funding proposals and partnership discussions.

Mangochi District, Malawi· “No child left behind”

Introduction

Patsogolo CP Foundation organises its work in Mangochi District around four interconnected pillars: Integrated Clinical Care, Awareness and Advocacy, Training, and Research. Together, these pillars translate the Foundation's vision, a Mangochi where every child with cerebral palsy (CP) is supported by multidisciplinary care, empowered families and educated, inclusive communities, into a coherent set of activities that address the medical, social and systemic barriers facing children with CP and their caregivers.

No single pillar works in isolation. A child identified early through our awareness activities is referred into clinical care; the health workers who identify and refer that child were equipped to do so through our training programme; the caregivers who bring their children to clinic become, in turn, the advocates who reduce stigma in their own communities; and the data generated across all of this becomes the evidence base for our research, feeding back into how we design clinical care itself. This document sets out each pillar in turn, describing the components that make up each pillar and how they work together to change outcomes for children with CP in Mangochi District.

Pillar 1: Integrated Clinical Care

At the centre of Patsogolo CP Foundation's work is a model of care that did not exist in Mangochi District before 2023: a single, multidisciplinary clinic visit in which a child with CP receives physiotherapy, nutritional support, medical treatment and health education together, rather than being referred piecemeal between departments that rarely communicate with one another. This integrated model, built on the ICF (International Classification of Functioning, Disability and Health) framework, now runs across four sites: Malawi Children's Village, Mangochi District Hospital, Njereza Health Centre and Malembo Health Centre and reaches over 400 children and their families.

Physiotherapy and rehabilitation

Physiotherapy is delivered in partnership with each caregiver rather than to the child alone. Therapists and mothers set shared three-month goals whether that is more independent eating, improved sitting balance, or greater participation in social activities and progress is reviewed together at each visit. This caregiver-centred approach ensures that rehabilitation continues at home between clinic visits, which is essential given how few children can attend more than monthly. Where families cannot reach the clinic at all,

community rehabilitation volunteers are trained to carry out home-based assessments and follow-up, bringing intensive, individualised therapy directly into the household.

Medical care and management of comorbidities

Cerebral palsy rarely occurs in isolation. Across our clinic population, 42% of children present with epilepsy and the great majority have some degree of feeding or swallowing difficulty. Our medical component therefore places particular emphasis on identifying and treating epilepsy; many children arrive with seizures that have never been medically managed alongside general paediatric care for common illnesses. In 2026 this component expanded further with the introduction of a dedicated Autism and ADHD clinic, following specialist training of our multidisciplinary team, in recognition of the growing number of children presenting with co-occurring neurodevelopmental conditions.

Nutrition and feeding support

Malnutrition affects a large share of the children in our care: 40% with moderate-to-severe malnutrition, and 92.2% found to be wasted, 35 times the national average wasting prevalence. Children with disabilities who become malnourished face a substantially higher risk of death than their peers without disabilities. Every child is screened using anthropometric measurements, and those with moderate malnutrition receive food supplementation (including locally produced Likuni Pala), while severe cases are referred to district malnutrition programmes for Ready-to-Use Therapeutic Food. Because so many children with CP struggle to swallow safely, we have gone further than screening for malnutrition alone: in partnership with occupational therapy expertise, we translated and validated the EDACS (Eating and Drinking Ability Classification System) for the Malawian context the first tool of its kind adapted for this setting so that even health workers with limited specialist training can reliably classify a child's feeding difficulties and select appropriate recommendations. These recommendations, together with practical guidance on food texture, positioning and preparation, are now compiled in a CP-specific cookbook developed with caregivers, which has since been published internationally and adopted into UNICEF's disability feeding resource bank.

Health education within the clinic

Every clinic day includes structured health education sessions in which caregivers, most of them mothers, discuss a specific theme: communication, positioning, feeding, or another aspect of daily care facilitated by a trained health worker. Beyond the transfer of knowledge, these sessions create a rare space for peer contact among women who often feel isolated by their child's condition, and caregivers consistently report

feeling more confident, both in caring for their child and in explaining the condition to family and community members who do not understand it.

Assistive devices

Many children with CP require positioning or mobility equipment simply to sit, feed or move safely and independently. Working with a local carpentry and welding workshop, and now formally partnering with Malawi Against Physical Disabilities (MAP) to strengthen artisan training, we produce tailor-made CP chairs, standing frames, rollators and modified feeding utensils. Devices are custom-fitted to each child, since an ill-fitting device can cause new deformities rather than prevent them, and to date well over one hundred devices have been distributed across our clinic sites, with additional devices now shared with the CP clinic at Queen Elizabeth Central Hospital.

Monitoring and patient information systems

To manage a growing caseload across four sites, we use an electronic patient records system that flags missed follow-up appointments, tracks which children require food supplementation, and gives health workers immediate access to a child's history and background information strengthening our ability to monitor individual progress and to demonstrate the collective impact of our clinical work over time.

Pillar 2: Awareness and Advocacy

Clinical care alone cannot overcome the stigma, isolation and late identification that shape the experience of children with CP in Mangochi. Cerebral palsy is still widely misunderstood in our communities, at times attributed to curses or wrongdoing during pregnancy, and children affected by it are frequently excluded from family, school and community life. Our second pillar works to change these attitudes, to reach children earlier, and to give caregivers themselves a voice in that change.

Early identification at the point of birth

Because most cerebral palsy in our setting results from complications around birth asphyxia, prematurity, or early infection, we have taken our awareness work directly into the maternity and nursery wards of Mangochi District Hospital, which sees roughly 1,200 deliveries every month. Weekly health talks equip new mothers, particularly those whose babies are at higher risk, with the knowledge to recognise early warning signs and to know where to seek help. Since the effect of rehabilitation is greatest before the age of five, this early-identification work is among the most consequential of all our activities.

Caregiver-led dramaplay

One of the most distinctive components of our advocacy work is a dramaplay group formed and led by caregivers of children with CP. What began as a small group has grown to twelve mothers, trained in performance skills, who write and perform their own plays depicting the realities of raising a child with CP. Six productions to date have been staged physically in communities and broadcast as radio drama, each followed by a facilitated community conversation. Beyond its public impact in reducing stigma, the group has become a source of mutual support for its members, who describe feeling less isolated, more confident, and better able to advocate for their own children as a direct result of their participation.

Radio and social media campaigns

A monthly radio programme on CP, broadcast twice weekly across eight districts of Malawi and archived as a podcast, reaches a far wider audience than our clinics alone ever could — an estimated one million people. Alongside the caregiver-led radio drama, this programming addresses both early identification and the beliefs that sustain stigma. We complement this with an active social media presence, sharing stories and updates from the programme, and mark World CP Day each year with a larger public event in which children and caregivers themselves help shape the celebration — now in its second edition.

School-based inclusion

Access to education is one of the clearest markers of inclusion, and one of the areas where children with CP are most often left behind. We have begun assessing daycare centres and primary schools in Mangochi Boma, training teachers and caregivers in the practical steps needed to accommodate children with disabilities, and playing an advisory role at a newly opened special-needs daycare. Beyond the direct benefit to the child, school enrolment gives caregivers, most of whom are mothers, time to pursue income-generating activities of their own.

Networks and policy engagement

We are building networks with government and other institutions, working toward national standards for CP care. We are founding members of a national Neuro-Developmental Disorders Network, formed together with Kamuzu University of Health Sciences, Queen Elizabeth Central Hospital, Zomba Central Hospital and other partners, which is working to become a national resource and training centre for neurodevelopmental disability care. Evidence generated through our clinical and research work is shared through this network and through direct engagement with the Ministry of Health, the Ministry of Gender,

Community Development and Social Welfare, and the Mangochi District Council's disability department, with the long-term aim of contributing to national standards for CP care.

Pillar 3: Training

Every gain made through clinical care and community awareness depends on having enough people, at every level of the health system, who know how to recognise cerebral palsy and respond appropriately. Our third pillar builds this capacity, from community volunteers to specialist clinicians, and addresses the reality that staff turnover in Malawi's health facilities is high, making training a continuous rather than one-off undertaking.

Early identification and referral training

The foundation of our training work is equipping Health Surveillance Assistants, maternity nurses, clinicians and community volunteers to recognise the early signs of CP and other neurodevelopmental disabilities and to refer children promptly into appropriate care. To date this has reached health workers across twenty health centres and several community hospitals in Mangochi. Because staff rotate frequently, refresher sessions are built into the programme rather than treated as exceptions.

Specialised clinical training

Beyond general awareness, our own clinical team and partner health workers receive in-depth training in specific tools and conditions: the EDACS feeding and swallowing assessment; identification and management of autism and ADHD; and the use of our electronic patient records system. This specialised training has already been extended beyond our own facilities to health workers at Queen Elizabeth Central Hospital and to partner organisations such as Tiyende Pamodzi, multiplying the reach of the expertise we have built in Mangochi.

Training the trainers

To extend our reach sustainably, we are training maternity nurses and clinicians themselves to become trainers of caregivers at the point of birth, and are developing a translated "serious game" tool intended to shift how community health workers and volunteers approach the management of neurodevelopmental disabilities. As each of these trainers goes on to train others, the knowledge base needed to identify and support children with CP spreads well beyond what our own team could deliver directly.

Caregiver training

Caregivers are trained as well as consulted. Structured caregiver curricula are used to guide monthly sessions on topics such as communication, positioning and feeding, and a growing number of caregivers, including members of the dramaplay group, are being trained specifically to lead these sessions themselves and to co-create materials adapted to the literacy levels and needs of other families.

Building local production capacity

Our partnership with Malawi Against Physical Disabilities is extending formal training to the local artisans who produce our assistive devices, improving both the quality and the durability of the chairs, standing frames and feeding equipment we distribute, and building a local skills base that will outlast any single funding cycle.

Pillar 4: Research

Every clinical decision at Patsogolo is backed by data we have gathered ourselves. Our fourth pillar turns the experience of caregivers, the results of our clinical work, and new academic partnerships into evidence that strengthens the case for CP care in Mangochi District and informs practice more widely — from a 2023 baseline study to our first PhD trajectory, launched in 2026.

Qualitative research

In-depth interviews and focus groups with caregivers and stakeholders capture lived experience alongside our clinical data, shaping how we design programmes such as our drama play and caregiver-support initiatives.

Tools

Development and validation of practical tools: the CP Quality of Life questionnaire, our CP cookbook, and the EDACS feeding and swallowing assessment turn research findings into instruments that health workers and caregivers can use directly.

Nutrition

Research into malnutrition prevalence among children with CP, alongside prevalence data from our Nutrition Rehabilitation Unit (NRU), continues to shape how we screen for and respond to malnutrition across our clinic sites.

Electronic patient file

Our electronic patient records system gives us structured, longitudinal data across all four clinic sites, allowing us to track outcomes over time rather than relying on a single point-in-time snapshot.

PhD collaboration

Our first PhD trajectory, undertaken in collaboration with academic and hospital partners, examines our district-level CP care model in depth — strengthening the evidence base behind it and connecting Mangochi's data to national and international CP research.

Conclusion

Clinical care, awareness and advocacy, training, and research are, in practice, a single system rather than four separate programmes. A caregiver reached through radio drama becomes a mother bringing her child to clinic; a health worker trained in early identification becomes the reason a two-year-old, rather than a six-year-old, receives their first physiotherapy session; a caregiver supported through health education becomes, in time, a co-facilitator training the next group of mothers; and the data generated across all of this becomes the evidence base for our research feeding back into how we design clinical care itself. It is this interconnection more than any single activity that Patsogolo CP Foundation believes offers the most durable path to improving the quality of life of children with cerebral palsy in Mangochi District, and, in time, across Malawi.

> ***"No child left behind" isn't a slogan added later. It's the reason the clinic changed shape in the first place.***
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