

INCLUSION OF THOSE
MOST LEFT OUT

Hands-on

Learning from our implementing partners

Providing access to intervention support for rural children with cerebral palsy

Although there aren't reliable statistics about how many children have cerebral palsy (CP) in South Africa, figures from well-resourced settings suggest between 2-3 babies per 1000 live births will have CP (Himmelmann et al., 2010; Kragelow-Mann et al., 2009). Because of inadequate obstetrical and neonatal care, particularly in rural poor areas in South Africa, the number is likely to be higher (Couper 2002). Access to good early intervention services (physiotherapy, occupational therapy, speech therapy, and stimulation), and to supportive equipment, is essential to prevent children from becoming more disabled as they grow older. In South Africa, the lack of these services particularly in poor and rural areas, results in a population of children with CP who are generally very severely affected and disabled (Saloojee et al., 2003).

All children with CP, no matter how old, or how severe, have the potential to improve

their condition – with assistance, the child has possibilities for doing more for him or herself; but without help, the child's problems could get worse and deteriorate (arms and legs get stiffer and the child's body can become twisted with deformities and contractures). Most children with cerebral palsy living in well-resourced settings receive therapy from an early age and on a regular basis (usually weekly) and so they usually reach their maximum functional potential before the age of ten years (Rosenbaum PL et al, 2002). Ongoing therapy is necessary to maintain this level of functioning and to prevent deterioration and a loss of skills (Mayston 2004).

Malamulele Onward has pioneered a model of short-term intensive therapy interventions in rural areas for the last 7 years and has been able to demonstrate the enormous potential that short therapy interventions hold for children who do not receive regular therapy.

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Cerebral Palsy

Cerebral Palsy (CP) is a developmental disorder, the result of a young baby or child's brain being damaged whilst it is still developing.

There are many reasons for the brain damage that causes Cerebral Palsy and it could happen anytime during pregnancy, the birth process, or after the baby has been born. The condition is life-long and there is no cure. As a result of the brain damage, the hallmark of all children with cerebral palsy is that they have difficulty with moving their bodies, their arms and their legs which means that everyday activities like sitting, moving about, walking and using their hands is difficult. As the muscles of the face and head may also be affected, the children often have problems with swallowing, eating and drinking and with talking. Thus the disability is complex and multi-faceted and the burden of caring for a child with CP is high.

Malamulele Onward's Intervention support

Malamulele Onward aims to reach to children with CP and their carers living in the deepest rural areas of the country and to offer them the support and the services to which all children with disabilities are entitled.

Malamulele Onward achieves this by identifying hospitals and clinics in deep rural areas where there is an existing service for children with CP as well as local therapists who are interested in treating the children. Importantly they do not start a new service, but rather build on an existing service, no matter how small, and grow and strengthen it so that more children can be reached and a more



effective service offered to all the children. An annual outreach to these sites is offered, during which children receive a short intensive five-day course of therapy (physiotherapy, occupational therapy and speech therapy). Experienced therapists who have specialised in working with children with CP volunteer their time to treat the children. During the outreach, the children's caregivers are taught to continue the programme at home. The children are also provided with the equipment and assistive devices they need and their caregivers are trained in the use, care and maintenance of these devices.

Malamulele Onward also offers selected children from the outreach sites an additional intensive two-week course of therapy in their Johannesburg offices. Their new Mother-to-Mother training programme, trains mothers from each of the outreach sites, to run a series of workshops for parents of newly diagnosed children in their communities.

They have had positive outcomes in terms of the impact of the intervention on the children; their caregivers as well as the local rehabilitation staff.

The value of Malamulele's early interventions

Malamulele Onward has worked with nearly 400 children with CP at nine sites in Limpopo, the Eastern Cape and KwaZulu Natal. Using standardised outcome measures such as the

Gross Motor Function Measure (GMFM) and the Paediatric Evaluation of Disability Inventory (PEDI), Malamulele Onward has consistently demonstrated significant improvements in the children's scores before and after a five day intensive course of therapy, showing that it is possible to make a difference to a child's functional performance in a short time (see table below).

These changes are measured not only with standardised assessments but also by semi-structured interviews with mothers, asking them what, if any, changes they have observed and they need to be able to describe them. Some examples given by mothers include: "he can wipe his face with a towel when you wash him"; "he no longer spills when he drinks water"; "she is now chewing food, not just swallowing, she no longer requires that soft, soft food"; "he can now sit for five to ten minutes which he could not do before"

Videos and photographs are also used to record changes in the children, taking a baseline at the initial screening visit and then a follow up after two months, documenting very powerfully the changes.

The importance of working with caregivers

Malamulele Onward recognizes that an important component of its work, which supports their success, is the work with the children's carers (who are mostly mothers and grandmothers). Children

SUMMARY OF CHANGES IN GMFM SCORES AT 4 MALAMULELE ONWARD SITES

Site	No. of children	Mean change in GMFM-66 score	Significance
Malamulele 2006	22	5.04	p=0.00
Butterworth 2007	30	1.46	p=0.02
Siloam 2009	20	3.09	p=0.00
Donald Fraser 2011	22	4.54	p=0.00

*any p-value<0.05 is statistically significant

The Gross Motor Function Measure (GMFM) is the standard for measuring change in the motor function of children with CP. Any mean change above 2.2 would be considered clinically significant, i.e. more than what would be expected over time. With the exception of Butterworth, all the children made progress far greater than what would be expected.



with CP living in deeply rural areas have little access to regular therapy or to education and their carers have no support systems to help them cope – not just with the daily care for their children but also help with dealing with their own feelings of guilt; the stereotyped attitudes of neighbours and friends towards children with disabilities and the traditional myths and misconceptions regarding the cause of the disability.

The impact of this is that mothers are often ignorant about their child’s condition and the possibilities their child has for change and improvement, given the right environment and opportunities. The Mother-to-Mother training programme has grown out of this need to give parents accurate information about a complex condition in a way that makes sense to them. There is a big gap in current service delivery for children with CP in that there is a need for parents to share their feelings, their hurt, their guilt and their pain in a safe space,

with other parents, and then to give them accurate information about the child’s condition and the lifelong implications.

A mother or grandmother who successfully cares for and raises a child with a severe disability in an adverse environment (poor rural areas, far from a clinic, no running water or electricity), possesses resilience and knowledge which needs to be harnessed, and can assist in addressing the unmet needs of children with severe disabilities in rural settings and support their caregivers.

Implications for broader systems and policy development

Malamulele Onward has found a way of providing specialised therapy services in rural areas that is having an impact despite limited contact time. Specialised services for children with cerebral palsy are only available in the bigger centres and costly for mothers to access. Searching for a cause (and cure) for the child’s condition places parents at the mercy of unorthodox healers, and at a cost they can ill-afford.

Thus any service for children with CP has to take cognisance of both the child’s needs as well as the caregivers’ need for information and support. In addressing these needs, the experience of Malamulele Onward has shown that there are three essential ingredients for success:

Actual “hands on” therapy by experienced physiotherapists, occupational therapists and speech therapists trained in working with children with CP is needed. There are few, if any, specialised therapists working in rural areas, and yet this expertise is essential as CP is a complex condition. Working alongside experienced therapists during the outreach visit, and attending the additional short courses of therapy offered to some children at our Johannesburg offices, is a practical way of passing on specialised skills to local therapists.

Children need to be **provided with the equipment and assistive devices**



This teenager spent most of her life lying on the floor, unaware that sitting by herself was a possibility. We gave her a bench and trained her caregiver in how to loosen her legs and help her to sit. Now she can sit in a wheelchair.



they need. Hands-on therapy and the provision of equipment go hand-in-hand. Effective management of CP involves addressing the daily needs of a child if you are to reduce or minimise the contractures and deformities which are an inevitable part of the condition as the child grows. Good supportive seating, lying and standing systems need to be introduced early and become a way of life for mother and child. Accessing equipment and assistive devices has proven difficult and waiting lists for buggies are usually a year or more in length. Despite an excellent array of equipment available on government tender, the processes for ordering and acquiring the equipment are often inefficient. Reliable and regular hospital transport to do home visits is another constant problem.

However, whilst equipment is essential, it needs to be continually maintained, adjusted and replaced

as the child grows. This presents a logistical problem in rural areas where just getting the equipment to the child's house in the first place is a challenge and as distances are far, follow-up visits to check on equipment are very time-consuming. There is no easy or ready solution to this challenge. Caregivers can be taught basic maintenance and adjustments, but the equipment is too heavy to carry back to the hospital or clinic, and so as the child outgrows the equipment, regular home visits are a necessary part of an effective service.

The **training of caregivers** is also essential. Caregiver training needs to go beyond teaching caregivers practical handling skills of how to care for their children, but needs to address the underlying ignorance and misconceptions regarding CP as a condition and find ways of supporting caregivers emotionally.

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This learning brief tells of the hands-on experience of:



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