

Upskilling

disability peer supporters –
The Manguzi Rehabilitation Team

**MALUMULELE ONWARD,
ADRI CRONJE, DR GILLIAN SALOJEE**

Distinguished Visitor Award

To assist the Manguzi Hospital in improving the outcomes in children and adults with moderate and severe disabilities and enable the peer support services in Manguzi to evolve into parent-led services.

Rehabilitation therapists at the deep-rural Manguzi District Hospital in northern Kwa-Zulu Natal, and beneficiaries of 40 years of trailblazing care, are building on a fundamental human truth about caregiving, 'nobody knows a child better than his or her parents'.

The other is, 'nobody can empathise, understand or win the trust of a disabled person like another person with that same disability'. This second fundamental truth is most effectively applied in rehabilitation of patients with spinal cord injuries. Occupational therapist, Adri Cronje, has devoted the past 12 years of her life to working with children with cerebral palsy and more recently, training and counselling their caregivers. Adri is a person the community has grown to trust and love. Quoting a grandmother at a recent peer training workshop, she says, "The Gogo said to me, 'this is nothing you haven't told us, but we couldn't believe you because you're not the mother of the child. You have all this book knowledge and theory and experience but mothers relate to mothers.'"

This experience cemented a belief long-held by Adri and her colleagues that training primary caregivers, especially mothers, significantly improves the quality of life and longevity of their patients.

"I realised my job was to guide and supervise, and let them get on with it by teaching and supporting each other. We believe they're the ultimate therapists," she says. That week-long workshop was led by one of her first trained peer-supporters and was aimed at mothers of children with cerebral palsy. Called the Carer-to-Carer Peer-Support-Club (C2CPSC), it has proved enormously successful. A powerful illustration of the value of parent-support of one another and of disabled people, emerges from the follow-up records of Manguzi's disabled outpatients. In 2015, when Discovery Foundation funding was first secured, the follow-up rate was 25%. Three years later it is 61%.

Carers and peer supporters in the community keep patients in touch with the hospital and identify and recruit new patients, many that suffered tragic neglect. Manguzi's team has built up a network of 183 children with cerebral palsy and their caregivers who are working with a "parent-facilitator" or "peer-supporter".



Sustained peer-supporter training kicks off

A Distinguished Visitor in the person of rehabilitation veteran and physiotherapist, Dr Gillian Saloojee, will begin visits to Manguzi Hospital in August 2019 (Gillian is the founder of the pioneering Malamulele Onward NPO that works with children with disabilities, in particular children with cerebral palsy living in rural, resource-constrained settings. Gillian and the Malamulele Onward team will make six week-long visits over 18 months. A Master-parent-facilitator trainer, Lydia Ngwana, and monitoring and evaluation specialist, Vutomi Ringane, will accompany the team.

Their aim is to improve outcomes in children and adults with moderate to severe disabilities and enable the peer-support services in Manguzi to further evolve into parent-led services. As Gillian says from bitter experience, "A short-term intervention is really quite meaningless". Her mortality data tragically illustrate this. Her recent research in the Nquthu district of Kwa-Zulu Natal revealed an alarmingly high mortality rate of 79 in each 1 000 children and adolescents with cerebral palsy. Additionally, only half the children needing rehabilitation were accessing it, while no teenager or young adult was receiving any kind of support. "Teenagers and young adults living with cerebral palsy are an invisible population," says Gillian.

In contrast, at Manguzi Hospital, Adri has cared for and organised trained parent care for cerebral palsy patients who've lived well into their 20s and 30s. Gillian's evolution and creation of Malamulele Onwards, (Malamulele meaning The Rescuer in Shangaan), began after working at Chris Hani Baragwanath Hospital in Johannesburg where she ran the cerebral palsy clinic, seeing some 300 children a month.

"I had to wonder what real difference I was making with so many kids and so few resources. So, I went off to research that and try and discover how one could improve on this seemingly hopeless situation. I spent two years interviewing parents attending public service hospitals throughout Gauteng and Limpopo, and saw just how desperate mothers were for services and support," she says. An unanticipated outcome was the non-profit organisation, set up to find innovative solutions and ways of providing effective rehabilitation to children. The organisation was named after the village of Malamulele in Limpopo where the project was first piloted. Much has changed since this first outreach with nine volunteer therapists who worked with 27 children over a five-day period.

"We've learnt that while therapy can result in amazing improvements over a short time, we cannot make a real, meaningful and lasting difference unless we adopt a comprehensive and holistic approach to create a nurturing and supportive environment. This includes the child's mother, family and the local rehabilitation services. Cerebral palsy is for life, it does not take a break and caring for a child needs to become a way of life. The ultimate therapist is the child's mother and we need to give her the skills, knowledge and confidence to understand and bond with her child, to do everyday things in a helpful way and to feel prepared for a lifetime of caring. We have discovered that the best way to do this is to train mothers as parent facilitators or peer supporters to train and support other mothers in their communities. A mother with the experience of caring for a child with a disability is a powerful game-changer – she speaks from her own experience and instantly connects with other mothers in a way that therapists will never be able to," says Gillian.



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Manguzi - a long and fortunate history

Manguzi Hospital is among the early beneficiaries of Dr Pam McLaren, an occupational therapist who pioneered rural rehabilitation services, winning the Lifetime Achievement Award from Rural Rehabilitation South Africa in 2015. She and one of the several current stalwarts of Manguzi, Jabu Ndlovu, (winner of the Rural Doctors of South Africa, Therapist of the Year Award in 2016), are responsible for Manguzi being one of the oldest, most effective rural rehabilitation departments in the country, having first visited in 1980.

Manguzi's rehabilitation chief, multiple-award winning veteran physiotherapist, Maryke Bezuidenhout, runs the spinal cord injury service. She works with occupational- and physiotherapists to strategise, network and provide psychosocial support, imparting critical wheelchair skills and providing a wheelchair repair service. "Not enough is known about the inputs, outputs and impact of peer-support work in rural areas and Dr Saloojee and her team will begin to address this," Maryke explains.

Another local innovation, Manguzi's High Risk Baby Programme, established in 2006, has 3 600 babies on its data base. The local rehabilitation team identifies high-risk babies before categorising them by disability (Downs syndrome, cerebral palsy or developmental delays). This information is included in the mother's maternity file, and coded red, orange or blue based on the risk. This improves nursing and doctor care, allowing the therapists to help out at the first sign of complications. Again, educating mothers, many of them teenagers (the highest defaulters on follow-up visits), is crucial.

Maryke skillfully negotiates the 16km of sand-dune roads from her home to the hospital on her scrambler motorbike, and uses it to conduct outreach visits. "The other day, some spinal cord-injured guys asked me if they could use a bike like mine to get around. I told them it would be physically impossible. But now I'm on a four-by-four quad bike fund-raising mission, because that would transform their lives," she laughs.



Unleashing skilled "Mom power"

Malamulele Onward founder, Dr Gillian Saloojee says, "We've pioneered the unusual concept of going straight to the parents so we can access kids with disabilities in remote areas where education and transport are major challenges. It's a problem-solving approach, not a systems approach. Rural women might be unsophisticated or even uneducated but they're amazingly resilient and strong, holding their families together. We want to turn them into leaders in their communities and unleash a huge amount of power. Generally, a cerebral palsy child in the public sector gets 35 hours of therapy in their lifetime. In the private sector it's 90 to 100 hours a year. Without increasing resources, we've found a way of tripling the therapy time in a public sector setting."