Annual Report
Malamulele Onward
1 April 2018 – 31 March 2019

Growth and regrowth
Vision and Mission

VISION: Our vision is to improve the quality of life of children with disabilities living in resource-constrained settings through innovative and sustainable solutions.

MISSION: We exist to enable each child with a disability, in particular, Cerebral Palsy to reach their best potential within a supportive environment.
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Tumi’s story

Tumelo “Tumi” Matlou has three children: Koketso (13), Kgomotso (9), and Tsepiso (8). She lives in Daveyton with her husband, Godfrey. But her life is not ordinary: she is one of Malamulele Onward’s Parent Facilitators, and like many of them, she has a child, Kgomotso, who has cerebral palsy and needs full time care.

“I had several scans during my pregnancy, and no problems were detected until, at my last check up, the clinic sister told me that the baby’s heart was not beating well. She then referred me to hospital, where they found cerebrospinal fluid inside my baby’s head. “I don’t remember anyone mentioning Cerebral Palsy (CP)” Tumi says. “They gave me the option to have a Caeser or to abort my baby. Well, I said I was a giver of life, not a taker.”

Kgomotso was born in June 2009. She appeared to be a normal child who sucked well and showed no sign of spasticity. “She did have the big head that indicates there’s water on the brain. As she grew, I noticed changes and became worried. She got more stiff, she wasn’t sitting.” Tumi says when Kgomotso had a seizure at age four, she took her to the hospital, and that’s the first time she heard the term CP.

Kgomotso started therapy at the Far East Rand Hospital. “I remember walking in and seeing different types of children, all different types of disabilities. I was shocked that there were so many people with different types of children, and that’s when I felt an acceptance: this is how my child is going to be. We joined in the therapies, but Kgomotso just kept developing complications. But, now it is easier because at least I could speak to someone about it.”

At some stage, Tumi heard about Malamulele Onward. “I remember feeling very happy. At Malamulele Onward, I’m getting the right tools to take care of my child. I learnt that there is no specific ‘therapy time’ in our lives. CP is a way of life. We don’t call our exercises ‘exercises’. It’s about constantly positioning and supporting your child, making sure they are well supported when lying down or sitting or standing. CP will always be there. But we can make our children’s lives better with our knowledge.”

Following three weeks of training at Malamulele Onward, Tumi is now a Parent Facilitator, training other parents as a peer supporter, a parent to parent caregiver working in the hospital environment. Tumi regularly visits and shares her knowledge with other families in her community affected by CP. She’s funded to work at Tambo Memorial Hospital in Boksburg once a week.

Tumi believes it’s easier for a parent to hear information about their children from someone who knows what it’s like from a personal experience. “Sometimes the therapists don’t have children or don’t understand CP as well as a committed parent or caregiver does. So let us teach one another,” she says.

Parts of this story were taken from the article about Tumi, CP and Malamulele Onward by Margot Bertelssmann, in the May/June 2019 edition of “Baba en Kleuter” magazine.
Malamulele Onward's relationship with Madwaleni Hospital in the Eastern Cape goes back to 2007 and a look at the current services for children with CP provides an excellent example of what is possible when there is a long standing partnership between the hospital rehabilitation team, Malamulele Onward and the funders, the Charlotte and Douglas Roberts Trust.

With few therapists and high numbers of children with CP, the structure of the clinic and the use of human resources have been reorganised in order to provide a more impactful service to the children and families.

The hospital offers a week-long intensive therapy and education programme every month called the Residential Therapy Programme (RTP) which compliments the weekly CP clinics to great success. Between 4 and 5 children and their caregivers are admitted to the rehab ward each month for the RTP. This programme enables children to receive more individualised therapy than many South African children are likely to receive in their life-time. Therapy combined with the workshops allows caregivers to have a greater understanding about CP and how to help their child at home. This effectively teaches caregivers how to carry over therapeutic strategies and techniques into their home-life – ensuring the child has continuous support, specific to their needs on a daily basis. The RTP compliments the CP clinic and Madwaleni hospital home visits and outreaches to outlying clinics, as caregivers who have attended RTP are able to share skills and knowledge informally to others and the CP clinics help them to practice skills, trouble-shoot problems and continue accessing excellent support.

Currently the Parent Facilitator team at Madwaleni hospital consists of Mama Nodutch, who has been a Parent Facilitator for many years, together with two new and recently-trained volunteers, Zikhona and Nontembeko. With over 167 children with CP on the database, the Madwaleni team can proudly say that they get to see at least 70% of the children each year through a combination of monthly CP Clinics, home visits, and the RTP.
Chair report – Dr Wiedaad Slemming

Dear Valued Stakeholders, Friends and Colleagues

This financial year has been a particularly challenging one for Malamulele Onward. We are emerging from a year that has seen the organization at one of its lowest points. The longstanding financial challenges, for organizations such as ours, had taken its toll and resulted in us taking a step back, assessing our position and making tough decisions to ensure that we can continue to exist, grow and be sustainable. This meant, sadly, that we had to streamline our activities to projects that were fully funded and only keep the staff essential to run these. We would like to thank our dedicated team of staff and volunteers who have shown great commitment to making a difference in the lives of children and their families affected by cerebral palsy and the work of the organization over the past 14 years. You will forever remain part of the Malamulele Onward family, no matter where you are.

We have spent most of this year rebuilding and now the organization is more resilient and financially stronger than it has been in a while. We are in the process of succession planning with the Founder of the organization, Dr Gillian Saloojee, handing over the leadership role to our new Executive Director, Matseliso Ntsoelikane. Matseliso has extensive experience in the non-profit sector, including in leadership positions, and we have full confidence that she is able take the organisation forward successfully.

Despite these many challenges, Malamulele Onward has continued to garner recognition and commendation for the valuable contributions it makes to the many children and families it serves. The organisation was awarded a Discovery Distinguished Visitor Award and a Rural Rehab South Africa (RuReSA) award as a Best Practice Community-based Rehabilitation (CBR) project.

We are very proud of our successful Carer-2-Carer Training Programme, run by our Parent Facilitators and trainers. This programme has earned recognition as an emerging best practice for South Africa and continues to strengthen and flourish. The Malamulele Onward Practical Training Courses continues to be a major part of our work, especially in equipping young therapists with the necessary knowledge and skills to provide quality care for children and families.

I would like to thank all our donors, supporters and volunteers who have collaborated with us over the past year. Without your help and support, we would not have been able to do the work that we do, and weather the challenges we have faced over the past year.

I would like to thank the staff and volunteers for their unwavering commitment and dedication and for all that they have achieved this year. And to my fellow Board members, a sincere thank you for all your time, expertise and support. We are stronger together.
Founder report – Dr. Gillian Saloojee

It is 14 years since our first outreach to Malamulele Hospital in September 2005. At the time we were not a formal organization, it was a one-off intervention to Malamulele Hospital called The Malamulele Project, so named by our Canadian supporters and funders, specifically Barbara Harrison, Tara Seon and Nazreen Garda. The success and impact of the Malamulele Project on both the therapists who volunteered and the Canadian friends who raised the funds led to the formalizing of the Malamulele Project and so Malamulele Onward was born and formally registered as a non-profit organization in 2006 with John Whitter as Chairperson of the Board and myself as Executive Director.

Our Annual Reports and newsletters over the years have documented the history of a growing organization – we had our first office in 2009 and our first staff members were employed in the same year. All our programmes were outreach projects to various sites, mainly in Limpopo and the Eastern Cape. Recognizing that if we were to increase our reach and create sustainability of our intervention, we needed to pay more attention to how we worked with parents. Hence in 2012, we pioneered the Carer-2-Carer Training Programme where we developed a training programme for rural parents to become Parent Facilitators, able to train other parents in their own communities. 2014 saw the start of our Practical Training Courses on CP, aimed at young therapists working in rural communities. In this way we were strengthening both the family support systems as well as the health systems caring for children with CP.

By 2016, we were working at 31 sites (in Limpopo, Eastern Cape, KZN, Mpumalanga, Gauteng and Limpopo), with 40 Parent Facilitators working at 24 of these sites. We were reaching approximately 1500 families a years and a full time staff of 12.

However, in 2018, we hit a speedbump and no longer had the funding to continue with all our projects. With a heavy heart, we stopped and scaled down our activities and staff, continuing only with projects that were fully funded. Thanks to the support of the Board, our volunteers and our long time funders, we have been slowly able to regroup and as we come to the end of 2019, we find ourselves in stronger, wiser and financially more secure than we have been in a long time.

A leaner and more resilient Malamulele Onward now starts a new chapter and it is my delight to pass the leadership baton onto our new Executive Director, Matseliso Ntsoelikane, who, with her background and experience in the non-profit sector, is well qualified to take the organization forward. As the Founder of Malamulele Onward, I am not “fleeing the field” but will remain involved in an advisory and technical capacity.

Without the support and commitment of our Board, under the guidance of Wiedaad Slemming as Chairperson; our long term funders and partners, our Parent Facilitators and all our friends and volunteers, our growth and achievements would not have been possible. I owe a debt of gratitude to everyone of you who believed our potential, in the potential and power of the parents we work with, and ultimately in the potential each child with CP we encounter has for change. Thank-you.
Executive Director Report – Matseliso Ntsoelikane

Director’s Message

The year 2019 was a challenging year for the organization, however we strived on to ensure that for children living with Cerebral Palsy (CP) their quality of life has improved, they reach their potential as much as possible and they live their life to the fullest.

In general non-governmental organizations are always struggling to have sufficient resources in order to be in a position to fully implement their planned activities. The organization started the year with 1 therapist unlike other years when it had 5 or more therapists. This meant that not all the children living with CP could be reached and those who could be reached were not visited as many times as we had wished for. Therefore, less visits meant less therapy provided to the children, which implies that the progress in relation to the health and well-being of such children is delayed or would never be realized.

However, through partnerships with Parent Facilitators based in Lesotho, Kwazulu Natal, Mpumalanga, Limpopo, Western Cape and Gauteng, these continued to assist the organization to reach children living with CP, to be provided with much needed therapy and training for their parents in order to build their capacity to enable them to effectively and efficiently take care of their children. These Parent Facilitators work for almost free and yet they themselves are the parents of children living with CP. Therefore, they provide real life experiences of looking after such children. Furthermore, the training they continuously receive from Malamulele Onward, provides them with advanced and up to date information on the management of CP. These Parent facilitators have visited children at their own homes to assist with real daily activities. They also helped the parents to accept their children’s condition, without blaming themselves or thinking that they have been bewitched or cursed. They further helped therapists at the local CP clinics in various local hospitals to provide children living with CP with proper and professional therapy in order to improve their health and well-being. They also conducted workshops for the affected parents on CP and its management.

The organization provided private therapy and training course for therapists, caregivers, parents, lawyers, health workers, teachers etc throughout the year in order to deepen their understanding on CP and its management. These activities also helped to provide the much need financial resources to supplement the ones that the organization received from the donors, and thus played a major role in ensuring sustainability of the organization’s activities.

We would like to thank all our development partners, board members, staff members and volunteers who have always supported us and continuously made sure that we provide the best services to the children living with CP under any circumstance.

Looking forward, Malamulele Onward will still continue through the support of its current and potential development partners strive to provide the best services to the children living with CP and their families in resource constraints rural areas. We will intensify our efforts on advocacy activities to prevent and eradicate high level of discrimination and stigmatization levelled against those who are living with any kind of disability in our communities. People with disability have fundamental human rights just like those who are able bodied. At the end we are all human beings with dreams and aspirations to live a better and fulfilling life as much as possible.
Our impact

18 sites where we work (South Africa and Lesotho)

207 CP clinics run (1024 hours)

168 home visits undertaken (608 hours)

2980 - number of hours worked by PFs

307 CP workshops run (1059 hours)

9 RTTP run with 26 children (640 hours)

7 site visits undertaken

24 active parent facilitators
Thank you Europcar for your complimentary vehicles that got us to our site visits this year.
Some of our key highlights and achievements this year:

- We won the Discovery Distinguished visitor award for our partnership with Manguzi Hospital, the only non-medical NGO to do so.
- We won the RuReSa award for best community health NGO this year.
- One of our APT (Appropriate Paper Technology) volunteers Mpho Mohlolo, based in Mpumalanga, won the SAB Foundation’s social innovation for disability empowerment award. Read more about APT further in this report.
- An ongoing calendar of training activities were run, including workshops in Uganda and Georgia, covered in the Training write up in this Annual Report.
- We continued to develop and strengthen our Parent-led services at the various sites we work in, which we detailed the successes of in the Parent Led Services section.
Further highlights of the year

Further highlights include:

• We recruited a new Executive Director with extensive experience working in NGOs – Matseliso Ntsoelikane.
• The birth of Bophelo Day Care – more on this later in the report.
• We undertook site visits to our Parent Facilitators at Nquthu (KwaZulu Natal), Mohales Hoek (Lesotho) and Madwaleni (Eastern Cape).
• Rebuilding staff and volunteers, and recruiting an AVI marketing volunteer, Andrew Milnes, from Australia, and a volunteer physio Maureen Ryles from Scotland who volunteered with us for a working holiday.
• Successful events we ran for World CP Day in October (in conjunction with the Tokelo Foundation) for CP children and their families and for Mandela Day in July.
• A sewing workshop for Bophelo and Malamulele staff, run by staff from Anglo American as part of their community leadership program.
• A team of Malamulele Onward staff took part in the 702 Walk the Talk marathon to raise funds and awareness, thanks to our sponsors Europcar.
• A thank you lunch for long-serving ex Chair, John Whitter.
• A working bee with volunteers from Africa Tikkun, and successful end-of-year jumble sale.
Training

Although we had to scale back on some of our programs this year, we were able to continue to offer training courses, and in fact this aspect of our work grew in that we were invited to run training courses outside South African, namely in Iganga in Uganda and in Ozurgeti in Georgia. We also introduced a new training course – “CP 101 – Understanding the Basics”, for professionals working with children with CP who were not therapists (e.g. psychologists, dieticians, lawyers and teachers etc.).

Lydia Ngwana, our Parent Facilitator has been promoted to Master Trainer and she now runs five day courses for paid caregivers. One such course was run at Malamulele Onward for 13 caregivers while another course was run at Ezibeleni School for children with Special Needs on the East Rand for the hostel mothers and fathers, classroom assistants and drivers. Currently our therapists courses are oversubscribed, which demonstrates the increasing demand for this type of training.
Training

These are the numbers of trainees we have in the past year:
For our March 2019 Therapist course: 23 attendees
For our May 2019 Therapist course: 27 attendees
For our August 2019 Therapist course: 27 attendees
For our Caregivers course: 13 participants
For our Ezibeleni caregivers course: 20 participants
For our CP101 course for non-therapists: 6 participants

For our Training in Uganda, 18 participants, this included:
Therapist course participants: 5 therapists, 5 occupational therapists
Carer-2-Carer Training Course participants: 6 caregivers
APT Course Participants: 2 participants

For our Ozurgeti (Georgia) course: 18 participants (13 parents, 3 therapists, one special needs teacher, and one psychologist)

67 SA Therapists trained
33 SA caregivers Trained
18 trained in Uganda
18 trained in Georgia = 136 trained
Parent Led Services

Insufficient funding meant that just 17 of our 29 Parent Facilitators were active this year. Long term donor support and investment by the International Development Relief Foundation (IDRF), the Charlotte and Douglas Roberts Trust; Malamulele Onward Canada, the Paige Project and the Jabulani Rural Foundation has enabled the Parent Led Services to grow in the Nquthu area as well as at Madwaleni, Zithulele and Tambo Memorial Hospitals and at four sites in Lesotho. Thanks to the support of the therapy team at Tintswalo Hospital in Mpumalanga and the rehabilitation department at Manguzi Hospital in Kwazulu Natal, the Parent Led Service in these two areas also remains active.

Our site visits to the areas where Parent Facilitators are working have shown us that their impact goes beyond assisting therapists at CP Clinics and running workshops for parents. We have always known that one of the main impacts of the Carer-2-Carer Programme has been that parents felt empowered through receiving accurate information about their child’s condition from another parent who was on the same journey and that they realized that they were not alone. Information and practical advice about day to day living with their child helped parents to connect more meaningfully with their children and to accept their child’s condition and diagnoses.

What we have seen this year as the Parent Facilitators saw more children at home was the plight of older children who no longer attended therapy, mainly because it is too difficult for parents to find transport to attend therapy. In some cases, therapists have discharged the child from therapy, or the child, now a young adult, has finished schooling and there is no where for them to go. Without having Parent Facilitators on the ground in rural communities, this group of teenagers and young adults would not be receiving any support.
Parent Led Services

Despite the financial challenges, the Carer-2-Carer Programme has grown in that an additional two workshops have been developed – one on “Play” and one on “Getting ready to move”. Twelve Parent Facilitators have been trained in how to run these two new workshops. Thanks to funding from Modular Mining, seven of our sites have Smartphones with an app which combined with WhatsApp will be used to assist with mentoring, monitoring and evaluation. We are finally making use of technology to assist with remote support!

The Parent Led Services continue to be the heart of Malamulele Onward as it is thanks to these remarkable women that we are able to offer support, advice and information to hundreds of hard to reach children in remote areas. Without a doubt, our goal for next years is to secure sustainable funding which will enable all trained Parent Facilitators to actively serve and work in their communities.
This year, we had two daughter projects/organisations that became successes in their own right, and of which we are proud.

Bophelo Day Care Centre was started in March this year by ex employees of Malamulele, many of them are parents of children with CP. The Centre is housed on the Malamulele Onward site, and runs 5 days a week. The number of children it regularly cares for has grown now to more than 12, and in 2020 the Education Department and Department of Mental Health look to be keen to support on an ongoing basis, so hopefully the organisation will be able to stand soon independently on its own.

As well as that, the Recycle for Rehab organisation, which trains people in APT (Appropriate Paper Technology – making suitable and affordable equipment for children with CP out of recycled materials) had some successes. Jane Worsley, a volunteer from the UK, came to help support with further training. We currently have four active APT volunteers in Lesotho and South Africa working in this area providing chairs; one of them, Mpho Moholo, won the SABC Foundation Award for Social Innovation and Disability Empowerment for his work, which was well deserved. Well done both Bophelo and Recyle for Rehab!
Remembering Luli Confidence Ngwana

by Lydia Ngwana

Born: 07/01/1997 to 04/04/2019

He was born with Cerebral Palsy.

He had been the light and teacher of his mum, family therapists and families with children who have a disability due to Cerebral Palsy.

His happiness and well-being empowered so many parents that there is life even if there is a child with CP. Love, respect and dignity he lived till he’s where God wants.

Despite all the challenges he was the light to so many lives, professional and unprofessional. A great loss to the Malamulele Onward community, and all therapists that have worked and learned through him. Thanks to all the medical practitioners and rehab teams who knew him. Deeply missed by his family, may the soul of our Hero rest in peace.

Tribute to Luli Confidence Ngwana

by Gillian

6 January 1997 - 4 April 2019

Deep down we all know that at some point we are going to say goodbye to the children we work with and serve, but we are never ready for the final farewell to those we love so deeply.

I remember the first time I met Luli. Lydia would bring him for therapy at Stretford Clinic where we would sometimes work under the tree outside as there was no space inside the Clinic. I got to know Luli better when he started attending the Kopanang Centre in Orange Farm, he must have been about five or six years old. I remember this little boy sitting on the floor in the middle of the playroom, always beautifully dressed, always happy and always on the go. But he never had any shoes on. His favourite activity was sitting on the floor going around and around on his bottom. He would then lift up one foot to his head and take his shoe off and laugh. And if you put his shoe on again, he would simply do the same thing again – it was a favourite game for him.

As Lydia and I started working together, doing some field work and research in Orange Farm, I would often go to Lydia’s house and there I would sit with Luli for a little while. I remember what a thrill it was for me when I realised that Luli recognised my voice. He would hear my car pull up outside the house, and when I said hello, he would greet me like a long lost friend. He really made me feel really special and important. In later years, when Lydia and I travelled a lot together, and she would phone home – I always enjoyed listening to him greet her when he heard her voice over the phone. He would make his own sounds, he had his own language and he and Lydia would have a long, happy conversation.
Thank you to all our supporters –

We want to thank our donors and others who have supported us through the past year. Without your support, whether financial or in-kind, we would not be able to do what we do. From the bottom of our hearts, we say thank you for believing in what we do and for making it possible.

- Africa Tikkun
- Alma Bramble
- Andrew and Barbara Harrison
- Andre and Kabi Krige
- Anglo American Chairman’s Fund
- Anglo American Community Project Team
- Apricot Tree
- Barry Dawes - CMI
- Beryl Ansley
- Carolyn Brady
- Charlotte and Douglas Roberts Trust
- Clive and Anita Green
- Cynthia Alter
- Dave and Dianne Henderson
- Discovery Foundation
- Dot Murray
- EdgeData Technologies
- Elsie Schleffer
- Fhumalani Nengwenani
- Gillian Saloojee
- Geert Tom Heikens
- Heather Angilley
- Ingrid Wormsbaecher
- Israel Magane
- Itekeng Batswaphong Disability Association
- Jabulani Rural Foundation
- Jacqui Bessenger
- Jacqui Brown
- Jacqui Robinson
- Jane Worsley
- Jean McJarrow
- Jean Sparks
- Jean Westmacott
- John Whitter
- Kim Rosslee and Tsavo
- Lauren Davies
- Lynette Lourens
- Mandy Young
- Marie Bester
- Maureen Ryles
- Mary Murray
- Melba Parmite
- Malamulele Onward Canada
- Maryke Bezuidenhout, RuReSA
- Modern Electric
- Modular Mining Systems
- MySchool MyVillage MyPlanet
- Onnyx Holdings
- OWL Daycare Centre
- Pat Larther
- Priscilla Powell
- R B Hagert Trust
- Rob and Shirley McKechnie
- Rose Zillen
- Rusty Haynes
- RB Hagert Trust
- Samanta and June Bartlett
- Shonaquip
- Tara Seon
- Terry O’Donoghue and Morne Fourie from Halfway Toyota
- Timion
- Tokelo Foundation
- Tshepang Seothaeng
- Zelda Kruger – Sophiatown Counselling
### Detailed Income Statement for the year 31 March 2019

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<tr>
<th>Description</th>
<th>2019</th>
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<td><strong>Total income</strong></td>
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To view our full audited annual financial statements, please visit our website at [www.cpchildren.org](http://www.cpchildren.org).
<table>
<thead>
<tr>
<th>Project Description</th>
<th>Direct Project Expenses</th>
<th>Malamulele, Limpopo</th>
<th>Dilokong Hospital, Limpopo</th>
<th>Butterworth, Zikhulele &amp; TakaTlefe, Eastern Cape</th>
<th>Other Southern Africa projects</th>
<th>Silvan Hospital, Limpopo</th>
<th>Tshivhidi, Mpumalanga</th>
<th>Donald Fraser Hospital, Limpopo</th>
<th>Charles Johnson Memorial Hospital, Nqutu, KwaZulu-Natal</th>
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The Malamulele Onward Team

Gillian Saloojee

Matseliso Ntsoelikane

Vutomi Ringane
Lydia Ngwana
Andrew Milnes
Taryn-Zoe Gurr
Keith Viljoen
Tobias Mushroom
Victoria Zwane
The Malamulele Onward Board

Wiedaad Slemming
Gillian Saloojee
Kobus Snyman
Theresia Ralintja
Pulane Baloyi
Postal address:
PO Box 52641
Saxonwold 2132
South Africa
Street Address:
Malamulele Onward Training and Therapy Centre
Gate 10, 13 Joubert Street Extension,
Braamfontein, Johannesburg
Website: www.cpchildren.org
Email: info@cpchildren.org
Telephone/fax: +27 11 484 9456
NPO Registration number 056-807
PBO No 930025084
Facebook: https://www.facebook.com/CPchildren/
Twitter: https://twitter.com/MO_cpchildren
Instagram: https://instagram.com/malamulele_onward/