

# PARENT-LED WORKSHOPS CAN CREATE A POSITIVE THERAPEUTIC ENVIRONMENT AND DISPEL MISPERCEPTIONS IN RESOURCE-CONSTRAINED SETTINGS



Misty Weyer, B.OT; Dr Gillian Saloojee, PhD; Lydia Ngwana, Parent

Malamulele Onward NPC

A non-profit organization offering innovative solutions to improve the quality of life of children with Cerebral Palsy and their caregivers in rural resource-constrained settings

## BACKGROUND

Whilst working with children with Cerebral Palsy (CP) and their caregivers in rural, low-resourced settings we observed that most were ill-informed and confused about CP, despite attending regular therapy. Consequently carry-over and care was sub-optimal and therapists were left feeling frustrated with caregivers who seemed to not care about their children.

To address this need for information and understanding of CP, a parent-led training programme comprising five workshops was designed in consultation with twenty parents from 10 rural areas representing five languages and cultures. These parents were then trained over a three week period as workshop facilitators. Workshop topics included "What is CP"; "CP as a way of life"; "Eating and drinking"; "Communication" and "Central Visual Impairment".



## AIM

To evaluate the impact of parent-led training workshops on caregivers of children with CP.



## METHODS

Over a two year period, trained Parent Facilitators from ten rural areas in South Africa and Lesotho ran a series of five workshops for caregivers in their own communities. Caregivers completed a questionnaire after each workshop. Following translation into English, the data was analyzed thematically.

A year later, the impact of the workshops was explored further through five focus groups with parents that had attended. This information was then transcribed, translated and analyzed thematically.

## RESULTS – WORKSHOP EVALUATIONS

During the two years 564 caregivers attended all five workshops, 41 of whom participated in the focus groups. Prior to the workshops, caregivers expressed being in a state of confusion, hopelessness and darkness. They struggled to accept their children believing that a child with CP "doesn't live very long", felt alone and blamed themselves.

After the workshops caregivers expressed feelings of confidence, pride and hope – "my heart is now relieved." Many caregivers expressed how the workshops helped them to overcome the struggle of accepting their child, which allowed them to love their child and feel confident to take them out in public.

Caregivers openly stated that two misperceptions: firstly that their child will not live for a long time and secondly that therapy would "fix" the child, resulted in them not listening to what therapists tell them. Furthermore caregivers wanted to help others and tell them that "their child is not sick."



## RESULTS – FOCUS GROUPS

During the focus groups the following themes emerged:

### THE CAREGIVERS' RELATIONSHIP WITH THE CHILD

- **Improved understanding of their child and of Cerebral Palsy –**
  - "I did not know what is the real problem with my child, but coming here and learning about CP and how to help my child helped change my relationship with my child."
- **Accepting their child and that they, as caregivers, are not alone –**
  - "It was difficult for me to accept my child but coming to the hospital and meeting these women helped me a lot to understand my child better and love my child like other children."
- **Learning practical skills which assisted with daily care activities**
  - ".....we could not handle and cope well, especially with communication, but since coming here for the workshop we understand he uses his eyes."
- **Perceived improvement and progress in their children**
  - "... because I have been taught how to work with my child at home, there is progress with my child and I am happy."



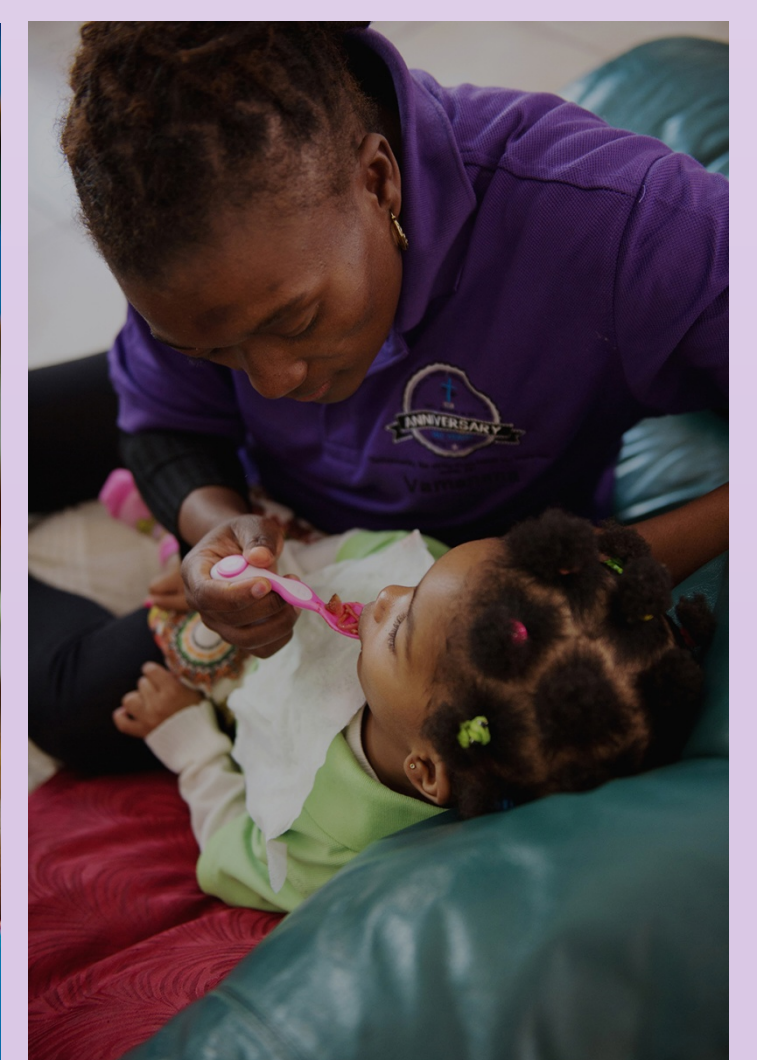
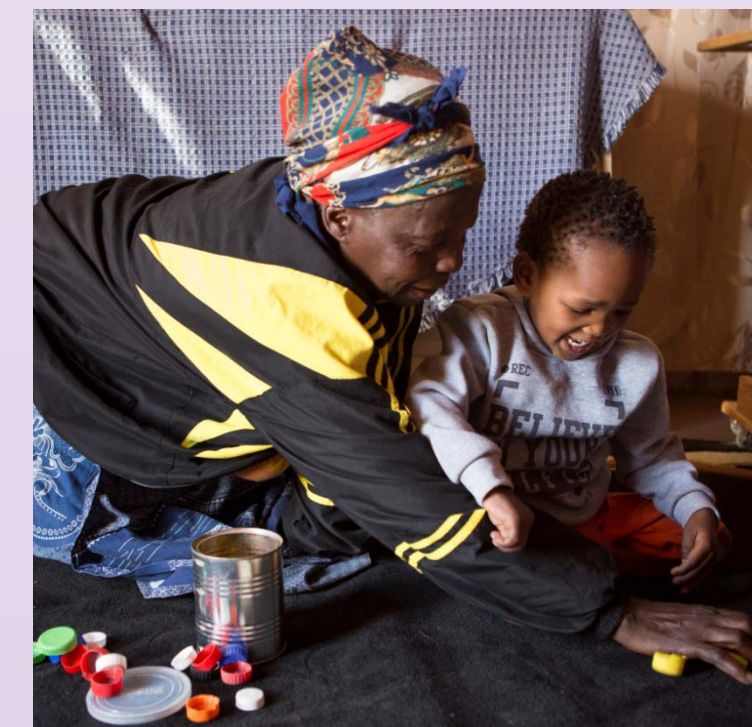
## RESULTS – FOCUS GROUPS

### THE CAREGIVERS' RELATIONSHIPS WITH THEIR FAMILIES AND NEIGHBOURS

- **Love and acceptance from family and neighbours**
  - "all those horrible things people used to say about my child was hurting, but after attending the workshops my life is easier and now those people are praising my lifestyle with my child".
- **Improved understanding of the child's condition**
  - "the relationship with my family is good because now they understand what is wrong with my child and that it was not a punishment"
- **Parents feel more confident**
  - "at first it was difficult with my neighbours not knowing what to say to them, but now thanks to the workshops it is better."

### THE CAREGIVERS' UNDERSTOOD THAT CARING FOR A CHILD IS A WAY OF LIFE RATHER THAN A SET OF EXERCISES AND CONSEQUENTLY VIEWED THEIR CHILDREN DIFFERENTLY

- **Caring for a child with CP is a way of life (rather than a routine of exercises)**
  - "Before attending the workshop I used to feed my child in any other way – like lying down – but coming to the workshop I learn about good positioning and our lives have changed."
- **As a result of parents understanding their children better, parents viewed their children differently – e.g. The child is now perceived as a person who has likes and dislikes as well as potential**
  - ".... Even with housework I let her try and help, I learned from the workshop to give her a chance."
- **Parents feel more competent as parents**
  - "....so the workshops helped me to change the things I did before to be a better parent."



## CONCLUSIONS

Providing caregivers of children with CP with information in their own language, presented in a way that is simple to understand and by a parent who has lived the same journey is a powerful tool in dispelling misperceptions and creating a positive environment for therapy.

The workshops help parents to understand their child's condition to the degree that not only are they able to explain CP to family, neighbours and even strangers, but they feel comfortable and competent to do so. This greater understanding of CP has helped parents and family to accept the child, to stop blaming, to start loving the child and this then leads to the child becoming more involved and included in daily life. Parents have also gained skills and knowledge in caring for their children and this has enabled them to feel more competent as caregivers.

As a consequence of the above, parents have come to view their children in a different light – they see their children as having the potential to do things, not matter how severely disabled he or she may be. This is a really exciting step forward, because parents start to have more expectations of their children and will start to notice small improvements.

### FUNDING ACKNOWLEDGEMENT

This programme is funded by the Unifor Social Justice Fund, the DG Murray Trust and Elma Philanthropies.

