Reflections from South Africa



SEVERAL YEARS AGO I

was on the doctoral committee of a physical therapist, Dr. Gillian Saloojee, at the University of the Witwatersrand in South Africa. Her dissertation,

focusing on caregivers' perceptions and experiences of rehabilitation services for their children with cerebral palsy, was the best dissertation I had ever read. I loved her sensitivity to complex cultural issues in her country. I asked Gillian to share some of her professional experiences working in rural areas of South Africa. The following are Gillian's reflections:

While doing my dissertation I was confronted daily by the dearth of therapy and resources for children with cerebral palsy and their caregivers living in poor rural areas. I subsequently started Malamulele Onward (named after a small, rural village), a non-governmental organization. We are based in Johannesburg, South Africa, and we provide physical therapy, occupational therapy, speech therapy, equipment and caregiver training to poorly resourced rural areas of South Africa and other African countries.

Therapists volunteer a week of their time to join us on outreach projects to various sites (usually hospitals or clinics). Here we spend five days working with a group of 30 children with cerebral palsy and their caregivers. The children receive intensive daily "hands-on" therapy, equipment and assistive devices (e.g. standing frames and specialised seating), and their caregivers are trained in how to continue the program at home. The results of using this model have exceeded all our expectations!

Caregivers living in poor rural communities often live with little knowledge of what their children can do with a little help. Frequently little is expected of the children. The people do not understand disability, its causes and prognosis. So when the Malamulele Onward outreach team moves into the



Gillian Saloojee works with a young patient in South Africa, her native land, where she has created a program to treat children with cerebral palsy and work with their mothers to help the children be more independent at home.

area for an intensive five days with highly skilled clinicians and laden with equipment and assistive devices, it is an extraordinary experience for both the mothers and the children.

and attempted to roll over when we placed her in a vision box which we had made from a simple cardboard box.

To maintain these gains, we keep in touch with the mothers and children through annual visits, either at home or at the hospital or local clinics. During these visits, the parent liaison officer (herself a parent of a child with cerebral palsy) encourages mothers to start support groups and to start "doing it for themselves" rather than waiting for the circumstances in and around their lives to change.

We now have accommodations and a therapy room to bring children and their caregivers to in Johannesburg for additional intensive treatment that is comprised of both hands-on therapies for the children and caregiver training and empowerment. We lobby local health services and advocate for increased access to support services for children with cerebral palsy.

As funds become available, Malamulele

... Malamulele Onward will continue to expand to new areas, and we will continue to celebrate our achievements with mothers without forgetting that this is only the first step of a long journey together.

When one 3-year-old girl reached out to touch her mother's face, looked deeply at her mother and smiled, tears rolled down her mother's face. It was the first time her daughter had reached out to touch her and smiled.

Similar scenes are played out many times during our multidisciplinary outreach projects. I remember a mother yelling for joy and running around the room crying, "My child can chew! I never knew that my child can chew!" after her child bit into a piece of marshmallow and started chewing with the help of a speech therapist.

Also I recall the tears from an elderly grandmother, the main caregiver of her 8-year-old granddaughter with severe disabilities, when the little girl started to laugh Onward will continue to expand to new areas, and we will continue to celebrate our achievements with mothers without forgetting that this is only the first step of a long journey together.

For further information, please visit www.cpchildren.org or contact Dr. Saloojee at gsaloojee@icon.co.za. ■

Terry K. Crowe, PhD, OTR/L, FAOTA, was the founding director of the occupational therapy program at the University of New Mexico (UNM) and is currently a full professor in the department of pediatrics at the UNM School of Medicine in Albuquerque. She has worked in Bangladesh, Cambodia, Mexico, Thailand and Vietnam and traveled in 48 countries around the world. She can be contacted at tcrowe@salud.unm.edu.