Fifteen Years of Obstacles: Tales of Disability Outreach in Tanzania

Pamela L. Follett, MD, MPH

Co-founder, Chief Operating Officer, Lewis Rhodes Labs, Inc

In 2009 I traveled 25 km south from Dar es Salaam to a medical dispensary in the coastal region of Tanzania. The multistory buildings of (what was then) the capital city disappeared abruptly, replaced by crude huts scattered across grasslands laced with walking paths and chaotic clusters of roadside vendors. At the time I was a Child Neurologist in Boston focused on basic neuroscience research while secretly captivated by the plight of children with disabilities in East Africa. Since 2005 I had been sneaking off whenever possible to assist a pediatric surgeon in western Kenya, whose growing clinic of children with seizures and other developmental disorders had no neurologist.

There were even fewer medical resources in rural Tanzania where I was headed. The main highway south dropped quickly to one lane, morphed from asphalt to dirt, and became marginally passable. Later discussions at a covered picnic table - the office - swirled around improving the lives of children with disabilities by introducing specialized medical services in remote areas poorly served by regional health centers.

We expected to encounter a paradoxical scarcity of children with disabilities. While data indicates an over 7 % disability rate for children, mothers in Tanzania are blamed for their child's birth defects and disorders. We successfully strategized finding children hidden by families wary of stigma and shame. What we did not foresee was the impressive range of obstacles that would emerge as we increased awareness and availability of specialized care. The realities facing disabled children seeking health services demanded a much less myopic perspective than we anticipated.

We sent an infant with club feet to the free clinic in town for serial casting. Free, except for transportation costs and a surgeon who required private payment on the side. The casting never happened. The father abandoned them when the boy struggled to walk, putting his wife and son out on the street, relegating them to homelessness and extreme poverty. That's when our community outreach program began.

We referred a child with hydrocephalus from a distant village to the regional hospital in Dar es Salaam for evaluation. Amazingly, the village contributed bus fare for their travel across Tanzania. The child was evaluated and told to come back in 2 weeks for a shunt placement. There was no means to stay in the city, so they returned home. With no additional funds for another trip the child never received the

needed shunt. We conceived and built a dormitory adjacent to the clinic that provides food, housing, and transportation to and from the surgical referral hospital in Dar es Salaam. Comprehensive care happened.

A delightful 7-year-old girl with congenital finger anomalies learned to hold a pencil and write but was still denied admission to public school due to her visible deformity, as were several other children successfully treated for hydrocephalus but with large heads. We added ramps, accessible toilets, additional staff, and tuition support for children with physical disabilities at our onsite school. Increasing numbers of village children began listing children with disabilities among their friends. Lives changed.

Fifteen years later we rarely meet at the picnic table anymore. The Disability Office in the new clinic is available, but we typically gather in the open-air classroom at the physiotherapy building, surrounded by toys and mobility aids, where the half-height walls are brightly painted with animals and alphabet letters and mothers and children are ever-present. And when the team travels south to more remote villages there is no need for strategies to find children, the community brings them to us.

Dr. Pamela Follett is a pediatric neurologist and neuroscientist who is Co-founder and COO of LRL, a neuromorphic computing company in Concord, Massachusetts. Her basic research focused on modeling aspects of developmental brain injury and recovery resulted in multiple publications and patents, including key insights on the brain's capacity for rapid information processing at very low power that are foundational to LRL's neuromorphic search technology. Dr. Follett is a graduate of Rensselaer Polytechnic Institute (BS, BME), New Jersey Medical School (MD), and Harvard School of Public Health (MPH). She is the founder and medical consultant for Wezesha Kupaa, an outreach program in rural Tanzania providing medical care, community psrograms, and accessible education to children with disabilities.