

Preschool Education for Children with Disabilities in Sub-Saharan Africa

[Harvey Pressman's Note: Among the most disadvantaged and deprived children in the world are poor Malawi preschoolers with disabilities. Malawi is the poorest country in the world, clinical and educational services for young children with disabilities are few and far between, no training programs for special educators of young children exist, food insecurity is endemic throughout the nation. This is a situation that exists throughout sub-Saharan Africa, but perhaps nowhere on the continent are the prospects for young children with disabilities as dire.

Against all odds, one notable exceptional program for such children has emerged in Blantyre, Malawi's second largest city. The Able Kids Foundation (AKF) School and Clinic has begun to demonstrate a pioneering approach to the needs of preschoolers with disabilities. AKF's founder and director, Victor Musowa, has become a leading national advocate for providing services to such children and, since founding AKF, has also been elected, by a historically large margin, as an MP in Malawi's Parliament. In the article that follows, Mr. Musowa tells the ground-level story of AKF's response to the needs of these preschoolers.]

Report By Victor Musowa, Malawi

After working with kids with special needs for almost five years at AKF, and working with both trained and on-the-job trained caregivers and teachers, I have a practical story to share about our preschool education program, which is solidly grounded on the practical trials we have experienced over these years.

We have experimented with several models over the past years, but the one which works better is the one I will share with you. We call it the AKF preschool model. It all starts by welcoming the kids from their parents and caregivers from 7:30am to about 8:00am. Upon arrival, they go straight into thirty minutes of supervised play and, from there, to breakfast (a nutritious soya porridge designed to fill important nutritional needs).



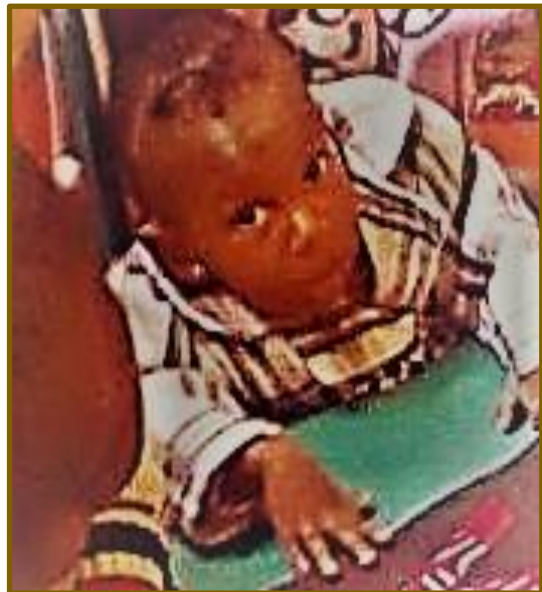
From breakfast they proceed to one hour of physiotherapy and occupational therapy activities, provided by a trained rehabilitation technician and a team of caregiver volunteers. Immediately thereafter, they move on to classroom activities, which range from eye-hand coordination, socializations skills, and a variety of needed educational supports. Many of the books and educational games that we use have been provided to us by the Central Coast Children's Foundation in California. From the classroom activities, the children move on to speech therapy, which bases its activities on a group therapy model. We then serve them a nutritious lunch, after which some of the babies are ready to go home, while an older group is left to take a nap and then finish up the day with activities of daily living, such as washing and dressing classes. This afternoon group gets picked up at 3:30pm.

About 65% of our pre-schoolers come to us from a hospital. They have a history of neonatal infection and other post-natal conditions, like seizures, jaundice, and cerebral malaria, which leads into Cerebral Palsy. At registration, the kids present with a variety of symptoms. Most notable are physical presentations, such as spasticity, no head and trunk control, not gaining milestones, feeding and swallowing problems, and zero to very little speech and delayed communication developed. Generally, the kids look under weight, and this is usually confirmed by their health pass book.

At registration we also do a general Head-to-Toe assessment which focuses on areas that require additional evaluation by a Doctor and/or Dentist. These medical appointments are scheduled by a visiting nurse, who takes the kids to and from the hospital and is then able to advise us about their medications.

When all assessments are completed, we share the results with parents, after which we develop an individualized program for each specific child, which is agreed upon by the parents. Then we ask the parents to sign a commitment to therapy and all appointments. A majority of the parents in this group are new young mothers who are sometimes single mothers, therefore, counselling also becomes a part of the treatment plan. Allowing parent-to-parent discussion becomes a good support mechanism to promote regular therapy attendance.

Again with support from the Central Coast Children’s Foundation, we provide each family with a locally-constructed supportive Cerebral Palsy “therapy chair,” to ease sitting challenges and to help the Mom seat the child and concentrate on other activities at home. The “therapy chair” also helps to facilitate feeding and swallowing, enables the kid to sit upright and also helps to facilitate head and trunk control.



One very important component to the services we provide to these children is the feeding program, which provides good and nutritious meals while they are with us. This program element provides a good environment for the kids to concentrate on activities, and allows therapy staff to implement what has been planned. Over time we have seen that the nutrition status of our children has improved dramatically, both as observed by their appearance as well as checking progress in their health passbooks.



All in all, I believe we have set up a program that is providing not just appropriate education and therapy, but also medical interventions, nutritional support, psychosocial services and a holistic approach to the comprehensive preschool education that children with special needs require to learn and grow.

Case Example: Meet Emma B at age 5 years



Eighteen months after she was born, Emma B was diagnosed with Cerebral Malaria, a severe malarial condition affecting over half a million children in sub-Saharan Africa every year.* Doctors at Queen Elizabeth Central Hospital in Blantyre treated Emma for a month and then discharged her to her home on medications..As a result of her illness, the doctors discovered that Emma had lost all her development milestones. She had no head or trunk control, no ability to sit, no hand function. She could only communicate by crying.

An assessment by the doctors and our team at AKF confirmed that Emma suffered from cerebral palsy and severe malnutrition, and also experienced seizures, which we observed during the assessment. Emma was then referred back to the hospital to meet with a pediatrician, who managed the seizures. The hospital also provided support with nutrition advice. Immediately after all her medical issues were taken care, we enrolled Emma in the full day program at AKF, which allowed her to benefit from the program and to be seen by the

whole team. This also enabled her single Mom time to start a small income-generating activity, so she could manage her house as a breadwinner.



With good family support, Emma has been able to attend school with reduced absenteeism. After a year of school, we have seen marked improvement on many of her developmental milestones. Emma is able to sit in a chair with minimal support; her hand function has improved; and she is learning to use a spoon and cup. With respect to communication, she is able to sequence two cards to communicate, and she tries hard to vocalize. We are working to help her make longer sounds and to improve her breath support. Emma now spends more time with her teacher, goes to speech therapy and then to

physical therapy. Despite her rocky start in life, Emma is now making good progress, and, in a year's time, she should be able to go to primary school. We have been able to enable her to use adapted chairs at home as well as at school, but when the time comes to upgrade this equipment, we may not always be able to do so.

We also worry about her progress on the education side because our local primary schools have very high student/teacher ratios (Malawi primary schools average about 60 per class), and sanitation is also quite difficult. As a result, many of the kids are failing to cope up with primary school life and end up dropping out. Our future goal is for our children to be able to attend primary school classes with us, and then move to a government sponsored primary school as soon as the child is ready.

*[Harvey Pressman's Note: Cerebral malaria is the most severe neurological complication of infection with Plasmodium falciparum. With over 575,000 cases annually, children in sub-Saharan Africa are the most affected. Surviving patients have an increased risk of neurological and cognitive deficits, behavioral difficulties and epilepsy, making cerebral malaria a leading cause of childhood neuro-disability in the region. If parasite-filled blood cells block small blood vessels to the brain (cerebral malaria), swelling of the brain or brain damage may occur. Cerebral malaria may cause coma.]

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