

Family care group model By Ruth Nakalembe

In the last couple of months, we have been very busy at CFU. 8 Medical staff, 6 lead/expert mothers and 4 Community Health Workers (CHWs) were trained in rehabilitative skills to support children with Cerebral palsy in the Family Care Groups (FCGs). They were also trained how to screen children in the community for Cerebral palsy and refer them for detailed evaluation at the CFU. Based upon the degree and types of their disabilities, multiple children and mothers are placed into Community Family Care Groups led by CHWs and Lead Mothers who have been trained using the Ubuntu teaching modules for childhood disabilities to improve caretaker care of their children with Cerebral Palsy and provide peer support. Multiple assessment tools are administered at baseline (Caregiver and Nutrition Clinical Assessments, PEDQoL, MDAT, GMFM, Family Inventory & Satisfaction questionnaires using REDCap apps) and periodically through the three-year program to evaluate progress. Community educational programs are established to overcome cultural stigmas about CP.

To date a total of 50 children with Cerebral palsy have been enrolled in the program. 65% of the caregivers said they were not accepted in their communities; 75% were unemployed and separated from their husbands.

The common medical conditions faced by these children are malnutrition, malaria, pneumonia and diarrhoea.

5 Family care groups have been formed within the different parishes with improvements observed in the care/function of the children and community awareness. Enrolled mothers have gained confidence, identified many additional children with Cerebral palsy and have become more involved in their communities.

In these different family care groups, the care takers are taken through a number of modules. Below are the modules that are implemented in the family care groups



"I have shared my experiences and through sharing, others have trusted me, and they share with me their experiences and this gave me hope my child will get better. The experience and interaction with other mothers and their disabled children gives me confidence. I have been able to relate freely with others and it has reduced my stigma "(Lead mother from one of the Family care group in Kilokole, Kawempe division, Kampala district.)

It gave me confidence and I got to know what happened to my child and I appreciated the fact I was not alone." (One of the caketaker from katoogo Family care group)





In the above photo, katoogo FCG during the session of learning how to position the child.

Thank you for your support.