

<u>Activity Report – Visit to Kitonzi village, Buheesi Sub-County</u>

On Thursday 5th March 2015, Kyaninga Child Development Centre physiotherapist Fiona Beckerlegge was invited to join YAWE Foundation public health worker Kagaba Stephen in a visit to Kitonzi village to assess the needs of 4 identified children with disabilities.

We were greeted at the village by a member of the Village Health Team, Kagonda George William. He has worked as part of the team for many years, and knows the community well. His role is to monitor the health of the community, support their health needs and liaise with local health centres when necessary.

The first child we saw was approximately 2 years and had multiple joint abnormalities. There was fixed flexion deformities in his elbows, wrists, knees and ankles, with minimal active movement in his fingers and or arms. He was unable to sit on the floor but was able to sit independently on his parents' knee. The family reported that they had never been to see a doctor at the regional referral hospital as they were unable to afford the transport. This boy would benefit from receiving a special chair to support him correctly at home and he will need a wheelchair as he grows as it will be difficult for his family to carry him as he gets older. Advice was given regarding care for his joints and prevention of further injury. Unfortunately there is no cure for disabilities like this but careful management is extremely important. A follow up visit is recommended.

Our next visit was to a family whose daughter is 32 years old. She has epilepsy and when she was 12 years old she had a seizure next to the fire and burnt her leg badly. She needed a below knee amputation of her left leg. They tried to teach her to walk with crutches but the family fear that she will have another seizure and injure herself again so she now crawls around the house and compound but never goes out. She spends her day weaving mats and baskets with her mother. We offered to teach her to use crutches again but the family remains reluctant, they would prefer to have a wheelchair for her which she could propel herself and stay safe. We have a shipment of equipment coming from the UK in the next couple of months and I will set aside a wheelchair for her. She is otherwise independent and no further input was indicated.

We then moved on to a single mother whose 14 year old daughter has epilepsy and mental retardation. She continues to have seizures regularly during the week. Her mother gives her diazepam after a seizure but she is not on any regular anti-epileptic medication. Her mother reported that she used to say a few words and be able to help with the household chores but this is no longer the case and she spends most of her days sitting under the tree outside the house or wandering around the area. Her mother is concerned for her safety. We advised the mother that regular medication should reduce or stop the seizures and that she should take her for assessment at the local health centre. Once she has stabilized on the medication and stops having regular seizures a further assessment can be done to see if we can help teach her the tasks of daily living.

Our final visit was to a 16 year old boy who fell ill with Malaria at the age of 4 and now remains in bed every day. He is unable to sit independently, though can change positions in the bed. He cannot feed himself and has very limited communication, though he enjoys listening to the radio during the day. As he has spent

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most of the last few years curled up in bed, on his right side so he can look out of the door, his joints have become restricted in the same position, with severe fixed flexion deformities at his hips, knees, elbows and shoulders. He does have some movement in his wrist and fingers bilaterally, enough to move the sheets, rub his face and adjust the radio while lying but when up in support sitting he struggles to hold his head up against gravity and to lift his hands. His mother feeds him in a semi reclined position. He was also severely underweight, though no signs of skin breakdown on his pressure areas. We discussed how different positions throughout the day were important for him, to protect his skin and to be able to move different parts of the body. He occasionally lies outside the house, but again this is on his right side, curled up. A further seating assessment would be good for this young man so that he is able to join the world around him.

This was an extremely interesting and informative experience, though also emotionally very difficult as I felt unable to make the necessary changes for these families. It brought home to me how difficult it is for families in the rural areas to reach the level of medical care their children need, and that without it their children suffer greatly. I will make a return visit to this village to provide further support to the Village Health Team and the children that I met, with wheelchairs and other equipment that they might need.

Fiona Beckerlegge
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On Wednesday 20th May I made a return visit to Kitonzi village to supply a self-propelled wheelchair to the lady with the below knee amputation. The family were all extremely grateful for the opportunities that this will open up to them, being able to include her in community activities. We will continue to monitor the other families until further services become available.



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