



Kyanninga Child Development Centre

Annual Report 2014

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The Idea

Kyanninga Child Development Centre (KCDC) was the idea of Kyanninga Lodge owners Steve and Asha Williams in 2013, while they were trying to find help for their own son, Sidney, who has epilepsy and developmental delay. They realised that there were very few resources or specialists available in the area to help children with special needs and their parents, and they themselves had to travel long distances to Kampala to find help, at great personal expense.

They decided to expand the search for help and contacted a number of child development centres and physiotherapy networks in the UK, hoping they might be able to get in touch with a specialist therapist willing to come out to Uganda to help not only with Sidney, but also to establish a facility where other families in the area could also access affordable expert care.

It was in this way that Fiona Beckerlegge heard about the project. She has worked as a specialist paediatric physiotherapist for over 10 years in both the UK and Bermuda, and had previously worked in Tanzania, and was willing to come to volunteer with the family for 3-6 months. Fiona arrived in Uganda in October 2013 and immediately started working with Sidney, but realised very quickly that there were many more children with disabilities that would benefit from additional specialist services in the area, and so decided to stay and help bring Steve and Asha's idea to life.

The Need

In 2010 the African Child policy report acknowledged that children with disabilities in Africa are among the most neglected groups and that they and their families face enormous economic, political and social barriers that have an adverse impact on their physical, social and intellectual development and wellbeing.

In the 2005/6 household survey of Uganda 12% of the population reported having a child aged 6-17 living with a disability. Many of these children do not have access to the most basic needs such as health services and education. In the same survey 60% of people with disabilities had not received any form of rehabilitation and 46% of people living with a disability over the age of 14 had difficulty finding employment due to their disability. In the 2009/10 household survey the figures remained the same, although 90% of those with disabilities aged 6-24 reported that it affected their ability to attend school.

In Western Uganda there are several NGO's that provide support to children with disabilities and their families through community support networks, income generating activities and support towards education but there is no facility that provides specialist therapeutic intervention, including physiotherapy, occupational therapy and speech/language therapy as well as support, training and education to organisations, families and communities.

There is also a cultural and social stigma attached to families who have a child with a disability; they can be shunned by their own family and the community as people believe that a disability is contagious, a curse, witchcraft or a punishment from God for the sins of the parents. This isolation often causes increased family stress, financial burdens and a reluctance to seek help, often resulting in a disability becoming more debilitating as it remains untreated.

The Start

In January 2014 the process of setting up Kyanninga Child Development Centre began, with situational assessments, networking with district officials, other local community based organisations working with children with disabilities and other rehabilitation centres in Kampala and Mbarara. A board of directors was selected and a constitution drafted and signed into effect on the **16th June 2014**. Additional documents were also drawn up including a development initiative, 1 year and 3 year work plans and initial budget (see annex 1-5 for copies of all documents).

A dedicated website was designed and launched in April 2014 www.kyanningacdc.org and a facebook page www.facebook.com/kyanningacdc.org was started in July 2014 to highlight the recent activities of KCDC and continues to be updated on a weekly basis.

KCDC was accepted by the Uganda NGO board in October 2014, with registration number S5914/11444 (annex 6) and will now register with the Community Development Officer at the District and Sub-Counties of Kabarole.

Board Members

Bob Rubaale – Chairman
Steve Williams – Treasurer, Founder, Executive Director
Rehema Vedio – Secretary
Fiona Beckerlegge – Founder, Clinical Director
William Byaruhanga – Member
Asha Williams – Member
Edgar Rugamayo - Member

The Vision, Mission and Objectives for KCDC:

Vision:

To enable all children to reach their optimum potential so that maximal functionality is achieved, deformity prevented or reduced and the effect of disability minimised so that they may overcome many of the barriers that they and their families face.

Mission:

- To provide high quality, specialised and affordable physiotherapy, occupational therapy and speech therapy to children with disabilities and special needs in the Kabarole District, Uganda;
- To provide daily respite care for families with children with severe disabilities;
- To provide training, education and support to families, carers and communities in the care of children and young adults with special needs.

Objectives:

- To provide occupational therapy, physiotherapy and speech language therapy assessment and rehabilitation to children aged 0-16 to meet their developmental goals
- Develop a family-centred environment that can provide information, support, advocacy and networking for families and their communities

- Foster social equity by providing an accessible and affordable programme available to all
- Develop partnerships with local medical centre's and similar Non-Governmental Organisations to enhance our services
- To provide relevant information that will empower the community to make informed choices in relation to their health.
- To lobby and advocate for fair policies and laws that affect the daily life of the local community through research, networking and strategic alliance building.
- Maintain the financial and ethical integrity of the organisation through sound governance, record keeping and management practices.

Financial Considerations

For a comprehensive review of the finances please see the Financial Report 2014.

Both Steve and Fiona agreed to a personal input of \$5000 each to help get the ball rolling, and to enable them to begin the process of registering KCDC as an NGO, looking for suitable premises, getting hold of equipment, linking with schools, orphanages and health centers throughout the district and recruiting staff and volunteers.

In May 2014 Fiona met with trustees of Accomplish Childrens Trust, a UK based organisation that supports the work of 2 organisations working with children with disabilities in Kasese District. They were looking to expand their support to other organisations in Uganda and an application was submitted in June 2014. A positive outcome was received in September 2014 for the sponsorship of 2 qualified Ugandan therapists. It was agreed with them that these additional staff would be hired in early 2015 once KCDC was established and functional.

Kyanninga Lodge hosted the Kyanninga Triathlon in May 2014 and Fiona offered all competitors sports massages after the race at a cost of 20,000 shillings each, raising a total of 630,000 for KCDC as well as being able to raise awareness of the organisation in its early stages.

Premises were found and rented from August 2014, with time needed to purchase furniture and equipment



before clients could be welcomed to the centre. The first clients attended in September 2014, although physiotherapy activities were conducted in the community prior to this. Fiona was also accepted as a member of the Uganda Allied Health Professions Council in September 2014 (annex 7).

Kyanninga Child Development Centre premises

The budget summary for the period Jan – Dec 2014 is shown, with a conversion rate of 1 USD = 2900 UGX:

<u>Expenditure</u>	UGX	USD
Rent of Premises	5,000,000	1724.14
Premises Renovations	1,807,200	623.17
Equipment Costs	8,437,120	2909.35
Utilities	280,000	96.55
Insurance		
Maintenance of building and equipment		
PO Box Rental	130,000	44.83
Staff Wages (Local)	1,050,000	362.07
Salaries (PT, OT & SLT)	0	0
Volunteer Expenses (in kind)	10,000,000	3448.27
Grass Cutting	132,000	45.52
Communications	0	0
meeting and general office		
Vehicle Maintenance		
Fuel for generator and vehicle	20,000	6.89
Other Travel	3,252,740	1121.62
Office Costs (incl. Stationary)	653,040	225.18
General Overheads	288,000	99.31
Legal Fees	1,207,000	416.20
Seminars/Training		
Networking		
	<hr/>	<hr/>
	32,257,100	11,123.13
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	32,257,100	11,123.13

<u>Income</u>	UGX	USD
Cash Donations	629,000	216.90
Donations via PayPal	3,300,500	1138.10
MRFC Donation	1,250,000	431.03
Fundraising Activities	730,000	251.72
Treatment sessions	200,000	68.97

6,109,500 2106.72

Excess of expenditure		
over income	<hr/> 26,147,600	<hr/> 9016.41

Contributions from the founders	22,886,560	7891.92
to 31st December 2014		

Staff

Once the premises for KCDC were confirmed, security personnel were hired, for nights only initially and once daily activities were being conducted a day guard was also employed. Fiona continued to work in a volunteer capacity throughout 2014, developing the organisation programmes, fundraising and writing grant proposals, and carrying out physiotherapy interventions. Steve and Fiona met Rachel Lassman, an occupational therapist conducting research in Mulago Hospital, Kampala in April 2014. She expressed interest in joining KCDC and was employed in September 2014, due to start work part time at the centre in January 2015. The positions of junior physiotherapist and junior occupational therapist (sponsored by Accomplish Childrens Trust) were advertised through the Ugandan Association of Physiotherapy network, and through the Uganda Institute of Allied Health and Management Sciences - Mulago in November 2014. There were 5 applicants in total and interviews will be conducted in January 2015 (annex 8).

Toro Babies Home



In January 2014 Fiona began working with Toro Babies Home, an orphanage in Fort Portal which is home to nearly 40 children, including 7 with disabilities. She conducted physiotherapy assessments on all 7 children and provided specialist training to the house mothers, staff and volunteers in the care and management of a child with a disability. Fiona also taught one member of staff and 4 international volunteers on year-long

placements therapy and exercise programmes for these identified children and advocated for the care and development of all other children living in the orphanage, teaching about normal development and play to promote this. Fiona attended the orphanage twice a week throughout the year and will continue to provide this support in the coming year, along with the additional staff at KCDC.



Outreach Day to Karagutu



In September 2014 KCDC team members Fiona and Rachel joined local CBO's and health service providers at an outreach day at Karagutu Health Centre, Ntoroko District. There was a large turnout, with around 100 families attending and receiving a medical review from one of the visiting specialists. There were a large number of children with cerebral palsy and developmental delay, and parents who had not been taught how to carry or care for children like this, with increased spasticity, poor head control, unable to sit or stand and difficulties with eating and drinking related to their disability.



There were also a number of children with untreated club feet, who were walking around on the borders of their feet. Club feet can be corrected without surgery and the larger referral hospital in Fort Portal offers this treatment, however families were unaware that such a treatment exists or cannot afford to travel from the villages to Fort Portal. This outreach day made us aware of the great need for rehabilitation services in the Western Region of Uganda, and that there are many more



children in need than we can reach at this time. Follow up for these children who attended the outreach day will be conducted by OURS centre in Mbarara and Rwenzori Special Needs Foundation, with appropriate referrals made to KCDC. Further outreach to Ntoroko district by KCDC is not possible at this time due to budget constraints and the current focus is on the children and families living with disabilities in Kabarole District.

KCDC clinic



Individual physiotherapy sessions began at the centre in October 2014, with most clients being referred through friends and community networking. The number will continue to increase with advertising and community sensitization activities. To December 2014 a total of 18 children and 6 adults had been assessed and are receiving regular treatment.

Connections with local community based organisations

KCDC has fostered links with a number of local community based organisations, including Good Shepherd Special Needs School, where 3 of the children with disabilities from Toro

Babies Home are enrolled and follow up visits were made to liaise with the teaching staff. Rwenzori Special Needs Foundation (RSNF) supports families through establishing income-generating activities, educational support to children with learning difficulties and financial support to families seeking assistance for their children with disabilities and has worked closely with KCDC since meeting in early 2014, with regular visits into the community for situational assessment and support during the initial planning phase. This partnership will continue into the next year as RSNF will refer a number of the children with disabilities that they support to KCDC for assessment and rehabilitation.

Twerwaneho Orphans Community Initiative (TOCI) is a locally run community initiative working with HIV/AIDS affected orphans, child-headed households, children with disabilities and special needs to lead healthy, sustainable and successful lives. KCDC has also been involved with community visits with this organisation, providing assessments and rehabilitation to identified children.

KCDC will continue to generate links with other community organisations within the Kabarole District to provide a holistic approach to their programmes and support all children and their families.

Activities for the coming year 2015

Kyanninga Child Development Centre will host Camp Kuseka in partnership with US Peace Corps in January 2015. This is a 5 day camp for 30 children with disabilities, with 40 volunteer counselors and community members to provide sports, art and craft and educational activities each day. The aim of the camp is to empower children with disabilities and their families to be advocates for their future. A 2 day parent programme will also be run alongside the kids camp, with the aim of providing health education, setting up parent support networks and to showcase the camp and the success of the children.

Activities to the community will start in January 2015 with in-reach to 2 schools; Canon Apolo Demonstration School and St. Peter and Paul Primary School, both government-aided and identified to accept children with



disabilities. Support will be provided to the teaching staff and assessment and rehabilitation programmes for the identified children with disabilities enrolled. Teaching seminars to parents and teaching staff will also be offered.

The District Health Centre IV's will also be approached, with assistance from the District Health Officer and District Community Development Officer, to establish regular outreach clinics run by KCDC. These clinics will allow families who have children with disabilities, but are unable to travel to the centre in Fort Portal, a chance for assessment, rehabilitation and support.

Rachel Lassman will begin working for KCDC in January 2015 and interviews for the junior physiotherapist and occupational therapist will be conducted in January 2015. Advertising for a volunteer speech therapist will also commence in 2015, with funding proposals being submitted for this to become a paid position.

Health Education activities will be conducted through radio programmes, community events, seminars at schools, church and community meetings. We will also work with TOCI and RSNF to establish parent/community support networks.

Funding proposals will also be submitted as opportunities arise to support the schools programme, community and health centre outreach and general running costs. Funding will also need to be sourced in order to purchase a 4WD vehicle and motorbike for the centre to enable us to travel into the communities and provide our outreach services.

Media campaigns will be conducted to raise the profile of Kyanninga Child Development Centre through national magazines and online platforms.