

Annual Report 2017

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Background

In Uganda, approximately 13% of children (2.5 million) are living with disabilities and access to healthcare is limited. The majority of disabilities are due to birth-related injuries, illness and congenital defects, resulting in severe disability. Many of these children are living in extreme poverty, meaning that most children have not seen a medical professional regarding their disability and as there are very few therapists working in Uganda, it is estimated that only 18% of children have access to specialized rehabilitation services.

Widespread local beliefs that disabilities are an untreatable curse cause disabled children and their families to be excluded from their communities, often cause increased family stress, financial burdens and a reluctance to seek help, in particular from educational institutions. The poor local understanding of disability is a huge barrier to the progress, learning, and independence of many children.

Kyanninga Child Development Centre is a Ugandan registered NGO (S5914/11444), founded in 2014 by entrepreneur Steve Williams and his wife Asha and physiotherapist Fiona Beckerlegge to create equal opportunities for children living with disabilities in Uganda. The extent of the problem faced by families was initially highlighted during Steve and Asha's own personal search for help with their son, Sidney.

Vision, Mission and Objectives

Vision: Equality for children with disabilities

Mission: Create equal opportunities for children with disabilities in Uganda

Objectives:

- Provision of specialist therapy services
- Promote awareness and education of disability amongst community members
- Give technical training to caregivers
- Integrate suitable social enterprises into the fabric of KCDC to economically empower participating families

Core Values

Development through Play – We are all on the same playing field

Child Focused – It's all about the kids

Transparent – We do what we said we would do

Empathy – We have understanding of family challenges

Inclusive – We respect everyone and do not discriminate

Efficiency – Things get done by doing them

Positivity – Always look on the bright side of life

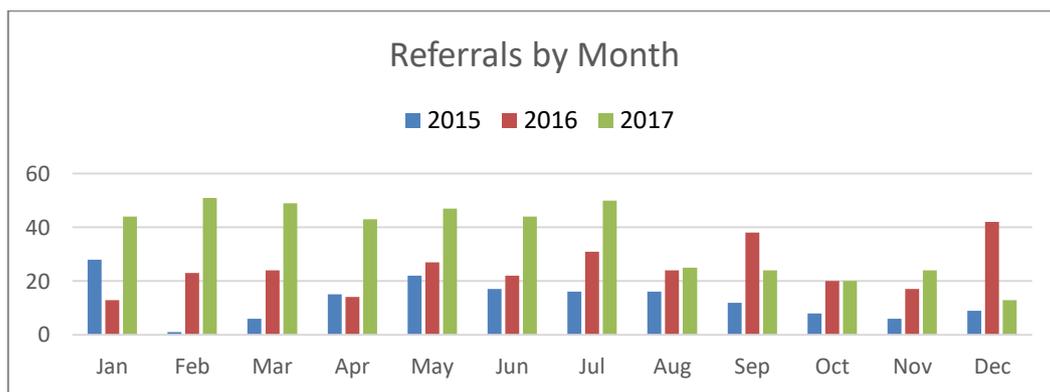
Achievements

Since opening in October 2014, we have:

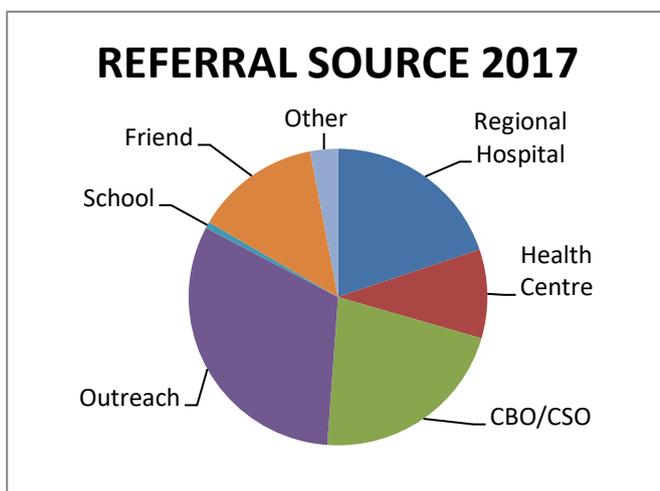
- Treated 917 children with a wide range of disabilities.
- Run 16 community outreach days in different parishes across Kabarole and Bunyangabu Districts, seeing more than 620 children and adults with a wide range of physical and intellectual disabilities.
- Worked regularly in 5 schools with 102 children with disabilities, promoting access to education and supporting both teachers and students with individual educational needs.

- Provided sign language classes to 35 children and young people with hearing impairment.
- Increased our team to include 4 physiotherapists, 2 occupational therapists, 1 speech and language therapist, 1 speech therapy assistant/nurse, 1 orthopaedic officer, 1 disability support worker, 2 Street Business School coaches, 1 driver/maintenance officer.
- Partnered with 11 local health centres, providing monthly outreach clinics.
- Provided more than 350 pieces of specialist adaptive equipment, including wheelchairs, walking frames, CP seats and splints.
- Provided training in early intervention of children with cerebral palsy to 44 parents and caregivers

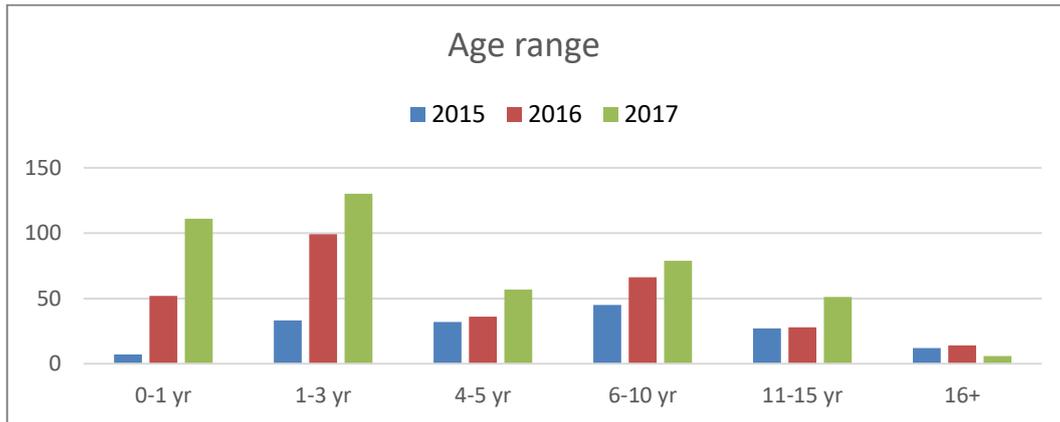
Data Analysis



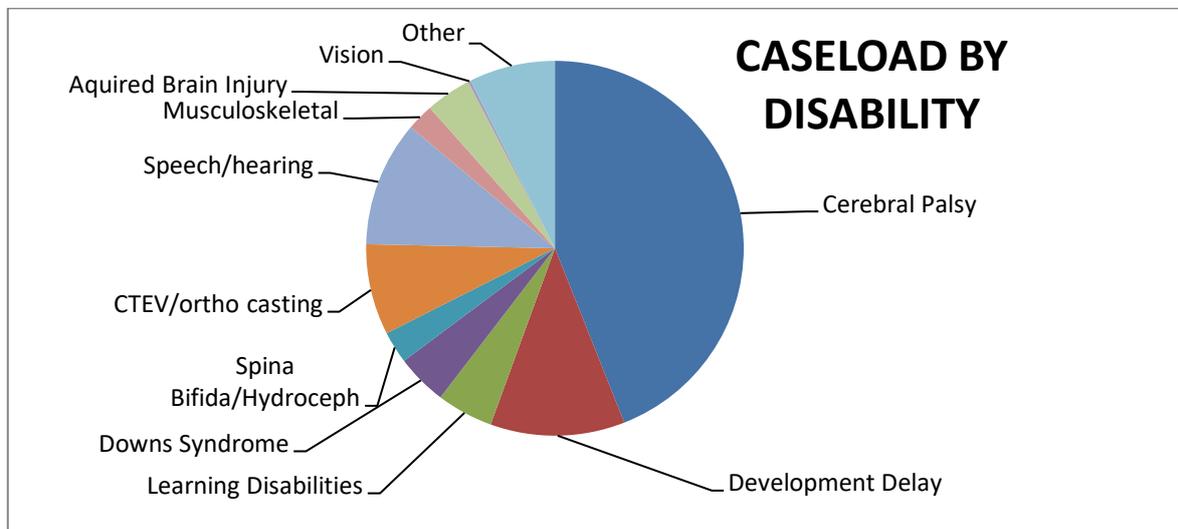
As with previous years, the greatest number of referrals are received in the first half of the year, with the months January to July averaging 47 per month, dropping to an average of 21 per month for the period August to December. Subjective review of this trend is unclear, as it crosses both dry and rainy seasons, and does not reflect a change in staffing levels. It may be related to training on identifying and managing children with disabilities for nurses and health workers in the local health centres in late 2016 and early 2017, generating an increase in referrals.



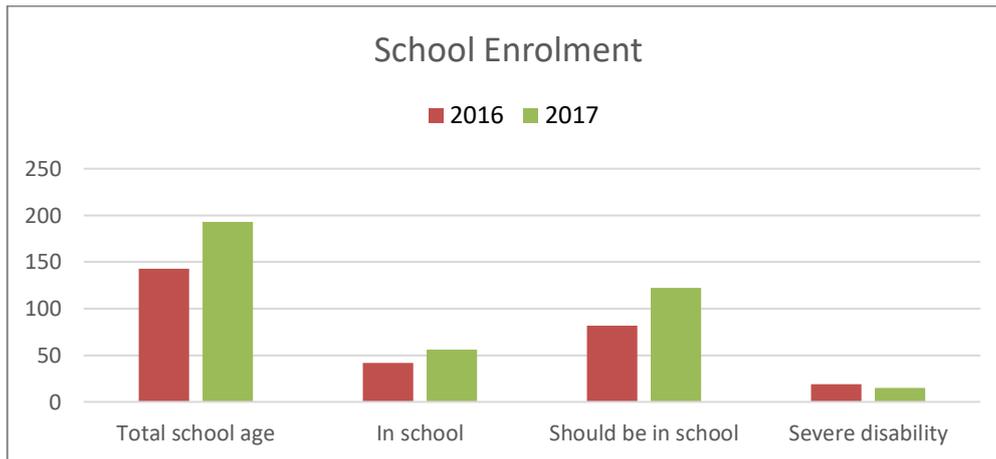
In comparison to 2016, a greater percentage of referrals were received from our extensive community outreach programme. This currently serves 11 health centres across the district, making therapy services accessible to many more families. The regional referral hospital and other health centres, where we do not currently run our outreach programme, also generate a large percentage of referrals, along with partner community organisations



Due to our early identification and intervention of young children with cerebral palsy programme, including training to nurses and healthcare workers, as well as a 10-part parent education and peer support group, the age range of has dropped, with 55% of referrals in 2017 under the age of 3 years. With earlier intervention, children with disabilities have greater positive long-term outcomes.



As with previous years, Cerebral Palsy (44%), Developmental Delay (11%) and speech and hearing disorders (10%) make up the largest percentage of primary disabilities. These are generally caused by non-progressive damage to the infant brain during pregnancy, delivery or the first few months of life and can be caused by infection, illness or oxygen deprivation during birth.



It is estimated that the national enrolment of children with disabilities into school is only 9%, so to have 29% of school-age children enrolled is certainly encouraging. We have employed a disability to support worker to support children in schools and to encourage more schools and families to enable children with disabilities to attend. Children are excluded for several reasons, including a lack of knowledge regarding a disabled child's right to education, mobility/accessibility limitations, financial constraints or the schools' unwillingness to accept a child with a disability.

Work Plan Objectives 2017

1. Provision of specialist therapeutic services for children with disabilities

Achieved:

- **434** new children with a wide range of disabilities have been assessed and received treatment in 2017, in addition to the children that are continuing to be seen from previous years, taking the total number of children that have received therapy intervention to 917.
- Monthly visits to 11 local health centres, 5 local schools and individual homes provides accessible therapy and rehabilitation to those who need it most. This community outreach programme now reaches more than **56%** of our clients, with **26%** attending the outpatient clinic in Fort Portal and **14%** being seen at school. As a team, we have provided more than **4500** individual therapy sessions in 2017.

2. Promote awareness and education of disability amongst community members

Achieved.

- In 2017, we ran a pilot parent education and peer support programme, using the London School of Hygiene and Tropical Medicine programme – 'Getting to Know Cerebral Palsy'. We completed 5 groups in 2017, which involved **31 parents** of children under 2 years. This programme is led by a KCDC facilitator and an 'expert mother' and includes interactive sessions on understanding disability, communication, feeding, positioning, play and everyday activities.
- We have also run **2 nutrition groups for 10 parents** caring for children with severe malnutrition, and started a fathers group, to encourage more fathers to become engaged in their children's care and therapy intervention. This also involves education sessions and peer support through shared experiences and challenges. So far, 19 fathers have engaged through the group.

- We have developed various information posters to be displayed in the local health centres, and includes management of club feet, developmental milestones and information on cerebral palsy. We also produced a series of posters for World CP day in October that were displayed in hotels and restaurants around Fort Portal, showing children with CP and a statement of what they want the world to know about them.

3. Give technical training to caregivers

Achieved.

- We have provided training workshops to **31** healthcare workers from **16** local health centres, **10** community workers and to **20** Village Health Team workers to improve their understanding, management and care of children with disabilities. This has helped increase the number of referrals of children with disabilities to our outreach programmes and to the clinic in Fort Portal. Monthly mentoring and supervision at 11 of the health centres, where outreach programmes are conducted, has ensured that learning has continued. The other 3 health centres will be included into the 2018 monthly outreach programme and mentoring will be introduced to healthcare workers there.
- We have also provided individual training sessions to health centres on various topics, including Club foot management to **6** health centres.
- We ran a 5-day training course on running the Early Intervention parent education and support group to 3 KCDC staff, 3 NICU nurses and 2 parents to become programme facilitators and start running groups.

4. Integrate suitable social enterprise into the fabric of KCDC to economically empower participating families

Achieved.

- This year we trained 2 mothers of children with disabilities to be lead coaches for Street Business School. This programme, developed by Bead for Life, trains women in business and entrepreneurial skills, teaches market analysis, book-keeping, savings and marketing so that women living in poverty can set up and run their own small business. The first cohort of **22** women began in October 2017 and will complete their weekly training programme in April 2018.

Staffing

Fiona Beckerlegge continues to run the day to day operations at the centre, supported by Steve Williams who also focuses on fundraising and networking for the centre. Matt Cooper has been a great support working on grant applications throughout the year. In August 2017 we increased the team to include Charles Remo Joseph, a Speech and language therapist, Nsamba Arnold, a physiotherapist and Swaib Matovu as a disability support worker. All three have fitted in well into the team. In addition to the full-time staff, we also have Alimpa Jackline and Kabasinguzi Moreen as Street Business School Coaches and Agnes and Peluce as expert mothers for the Early Intervention groups. This make the total staffing levels to be 9 therapists and 17 staff in total.

Volunteers

- In January we welcomed Tim Lyons, an accountant from the UK through Accountancy for International Development, who worked with us to improve our financial systems and reporting procedures. We also welcomed Anne Shipsey, a paediatric physiotherapist from the UK who spent 4 weeks with us, developing the knowledge and skills of the entire team. Anne returned for a 2nd time in November 2017 to be a part of the Inclusive sports day and work again with the team
- In February, we welcomed Kaitlin Murphy, a special educational needs teacher from the USA to provide training and awareness of inclusive education for local teachers as well as support for individual students
- In March, we welcomed Dr. Maya Kholi-Lynch as part of the early intervention pilot project, and Alexandra Hejazi, a physiotherapist, both of whom stayed with us until early August and had a huge impact on service development and training to local community and healthcare workers.
- In August, we welcomed Jaya Simpson, a speech and language therapist for 3 weeks of intensive training with Charles and Rehema, our speech and language team. This was followed by Alex Rymer, a SLT student from London who continued working with Charles and Rehema.
- In October, paediatric physiotherapist Sheila Bryson spent time working with the physio team of David, Brenda and Arnold, as well as the rest of the team.
- In November, District Nurse Jane Reynolds spent a month working with our community outreach programme, focusing on the general health and well being of many of the children we see. Her friend, Kay Pritchard was volunteering as a midwife at a nearby community health centre.
- We also continued to offer student placements to physiotherapy students from Mbarara University of Science and Technology as well as the continued partnership with Knowledge for Change, where we offered physiotherapy, occupational therapy and integrated nursing and social work placements

Street Business School

This is an exciting project, designed by Bead for Life Organisation, that aims to create sustainable opportunities for women to lift their families out of poverty. They partner with organisations such as KCDC, and smart but impoverished women to help them get the skills and confidence they need to become successful entrepreneurs. They provide practical, relevant and hands on business training through a train the trainer immersion workshop, that is then shared over a 6-month period to other women to help start their own small businesses.

KCDC recruited 2 of their own mothers of children with disabilities to become lead coaches, and attended the immersion workshop in Kampala in September 2017. They are now working with their first cohort of 22 women, all mothers of children with disabilities and they are due to graduate in April 2018, when a 2nd cohort will be recruited.

Fundraising and Community events

Inclusive Sports

Changing people's perception about disability is about breaking down socially imposed barriers, and one of the most successful methods in achieving this through inclusive sports activities. These provide a perfect opportunity for people from all abilities and backgrounds to come together and participate in an enjoyable,

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fully integrated sporting activity. We use this approach on a weekly basis at our KCDC sports club where we invite children and their families, and siblings to come together and try different sports at our main centre in Fort Portal, as well as during sports afternoons at 3 of the local integrated schools.

On a larger scale, where we hope to have an impact on the wider community, we organise an annual inclusive sports and family fun day which takes place on Fort Portal's main playing field with games such as football, tag-rugby, tennis, boccia and simple games to develop skills. This really heightens the profile of disability within Fort Portal whilst offering an opportunity for integration amongst different sections of society and was held on a very wet Sunday in November!! 55 children and their families attended and made the most of the dry spells in the day to get involved in different activities, though in the end the day had to be abandoned because of heavy rain.

End of Year Parties – Our annual end of year party was a wonderful day of community spirit, shared experiences, celebration and support for children and their families. 202 children, along with 242 parent, siblings and community members attended the day in Fort Portal, while 34 children and their families attended in Kasese. The parents shared their children achievements over the past year, including learning to sit, stand, walk, talk and even graduating nursery school and class promotion in school.

Kyanninga Triathlon – Kyanninga Lodge hosted the 7th and 8th triathlons in April and November 2017, with all proceeds going to KCDC. This remains an extremely popular event, particularly in April when more than 100 competitors take part in the challenging event – a 750m swim across the crater lake, a 16.5km cycle around the local villages and a 4.5km run around the crater rim, or double distance for those that really like a challenge. KCDC co-founder Steve Williams successfully participated in his first triathlon in April to raise money for a Hydrotherapy pool for the centre, raising £1200. In total, the 2 events raised more than 15 million shillings (\$4340/£3390).

Running the Rift Marathon – The 2nd Running the Rift was again held in November, with 27 international runners participating in the 6-day event, including the race itself and the inclusive sports day. This is a fundraising event for KCDC and in addition to the 27 international entrants, there were just over 100 local runners from Uganda and East Africa taking part in the full or half marathon and 10km races, making the event another huge success, and raising more than 16 million shillings (\$4400/£3475)

Kyanninga Dairy

Kyanninga Dairy, a goat's cheese manufacturing project, was established in October 2016, with the expert support and guidance of Neal's Yard Creamery in the UK. As a sustainability project for KCDC. It now produces some of the finest goats cheese you will ever find. Although still in its infancy, the response and demand from high-end restaurants and deli's in Kampala has been incredible and it is hoped that as the dairy increases in size and production it will be able to support KCDC. Following the Kids for Kids campaign in December 2016, we were able to purchase 40 goats to begin production, and with an additional 26 goats in September, the dairy is now producing around 250kgs of cheese a month.

The dairy also has a community inclusion programme, providing employment opportunities for young people and adults living with disabilities. With over 60 goats in the dairy, and no mechanical milking, there is a lot of work that needs to be done. Not only does this challenge local beliefs that disability means inability, but it provides a platform from which to advocate for more inclusive employment opportunities.

The most enjoyable part of the dairy's community inclusion programme is the weekly farm day. Here we invite parents and their children to come up to the farm and help with bottle feeding the baby goats, collecting grass for the adult goats, planting herbs and learning about caring for animals. They also have opportunities to interact and pet the animals at the farm, which includes pigs and donkeys.

Financial Considerations

For a comprehensive review of the 2017 finances please see the KCDC Financial Report 2017.

Accomplish Childrens Trust (UK) continues to support both Mumbere David and Ariho Patrick in their employment with KCDC, for which we are very grateful. We welcomed some of the Accomplish Trustees to KCDC in March 2017 and were able to share with them the work and activities that David and Patrick are involved in and the impact they are having.

Individual donors and supporters continue to provide most of the financial support for KCDC, along with the fundraising events.

Income	UGX	USD (*3600)	GBP (*4600)
Kyanninga CDC Trust	127,700,000	35,472	27,761
Kyanninga Dairy	5,335,000	1,482	1,160
Accomplish Children's Trust	18,215,000	5,060	3,960
Royal College of Paediatrics and Child Health	14,800,000	4,111	3,217
Friends of Shelby Newstead Trust	2,300,000	639	500
NSSF Torch Award	15,000,000	4,167	3,261
Individual Donations	56,410,500	15,670	12,263
Fundraising activities	33,085,200	9,190	7,192
Other income (loan repayments)	19,834,000	5,509	4,312
Treatment contributions	1,996,500	555	434
Total	294,676,200	81,855	64,060

Voluntary Contributions	UGX	USD (*3600)	GBP (*4600)
Consultants (legal/financial)	69,750,000	19,375	15,163
Directors unpaid	151,200,000	42,000	32,870
Volunteers (Therapists/Accountants)	253,000,000	70,278	55,000
Marketing and Social Media	25,000,000	6,944	5,435
Work Permit	1,800,000	500	391
Event Hall	15,000,000	4,167	3,261
Vehicle Hire	1,200,000	333	261
Total	516,950,000	143,597.22	112,380.43

Expenditure	UGX	USD (*3600)	GBP (*4600)
Salaries	109,114,150	30,309	23,720
Rent and accommodation	29,722,000	8,256	6,461
Office and Programme running costs	44,450,850	12,347	9,663
Therapy equipment and medical support	9,071,600	2,520	1,972
Vehicle fuel and maintenance	21,933,900	6,093	4,768
Community events	8,330,100	2,314	1,811
Website and marketing	3,868,000	1,074	841
Legal and Professional	3,416,000	949	743
Early Intervention project (RCPCH)	14,789,500	4,108	3,215
Hydrotherapy Pool (FOSN)	2,300,000	639	500
Street Business School	6,295,000	1,749	1,368
Capital Expenditure	5,707,850	1,586	1,241
Other	35,256,500	9,793	7,664
Total	294,255,450	81,738	63,969

Activities for 2018

- We have a large number of volunteers coming in the first few months of 2018, including physiotherapists, a speech and language therapist, an accountant, a doctor and a neonatal nurse.
- We have secured funding for a 1 year project to scale up the Early Intervention project, which will provide training to 70 more healthcare workers across 4 districts, train 10 more parents to become group facilitators and also improve small and sick newborn care in the 3 regional special care baby units.
- We will be opening our 2nd centre in Kasese district in January 2018. Mumbere David, our senior physiotherapist will be leading a new team there, providing the same high-quality services available in Kabarole district.
- We will be increasing the community outreach programme to include 3 more health centres in Kabarole, 4 health centres in Kasese and 1 each in Kyenjojo and Kamwenge districts
- We will expand the inclusive education programme to an additional 5 schools within the region
- The 9th Kyanninga Triathlon, 3rd Running the Rift Marathon and the Inaugural Ride the Rift Sportive will be held as fundraisers throughout the year.
- Funding proposals will be submitted as opportunities arise, in particular for additional staff and a mobile health unit for the Kasese clinic, and a social worker and special educational needs teacher for both centres.
- Our hydrotherapy pool will be up and running and will be used for a range of children and disabilities but will have a focus on those with a severe disability and movement impairment.