

**SOCIAL
INNOVATION
IN HEALTH
INITIATIVE**



KYANINGA CHILD DEVELOPMENT CENTRE

CONTINENT

Africa

COUNTRY

Uganda

HEALTH FOCUS

Primary Health Care

AREAS OF INTEREST

Child Health, Community Mobilisation

HEALTH SYSTEM FOCUS

Community Service Delivery

KYANINGA CHILD DEVELOPMENT CENTRE, UGANDA

Kyaninga Child Development Centre provides rehabilitative and educational services to children living with disabilities and their families, through an entrepreneurial, holistic and community-embedded model contextualized for a rural resource-poor setting

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ABBREVIATIONS

ACPF	African Child Policy Forum
CwDs	Children with Disabilities
KCDC	Kyaninga Child Development Centre
NSSF	National Social Security Fund
UGX	Ugandan shilling
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund.
USD	United States Dollar
WHO	World Health Organisation

CASE INTRODUCTION

Kyanninga Child Development Centre (KCDC) is a non-governmental organisation, seeking to improve the lives of children with disabilities and their families. The organisation currently operates in both urban and rural mountainous areas of the western region of Uganda.

The organisation was established in response to the inadequate care and management of disabilities and limited opportunities for Children with Disabilities (CwDs) in Uganda. Generally, there is poor understanding of disability and inadequate numbers of trained therapists to provide children with physical and developmental difficulties with sufficient rehabilitation services to meet their needs.

KCDC provides a holistic community-embedded approach, involving a qualified multidisciplinary team of therapists who provide various rehabilitative services, such as physiotherapy, occupational, and speech language therapy, assessment, educational services and peer support programmes. KCDC also provides entrepreneurial business training to enable carers to earn money to provide support for their children. Additionally, inclusive sports activities are organised to provide a platform for families with disabilities to meet and share experiences. To address gender dynamics, KCDC encourages trained fathers to be role models to other men with children with disabilities.

Since the organization was founded in 2014, KCDC has assisted more than 1350 CwD and their families. Over 5000 individuals -- parents, carers and other community members -- have been sensitized on disabilities and trained to give the necessary therapeutic services. More than 425 items of specialist adaptive equipment have been provided to CwDs and 30% of school-age children registered with KCDC have been enrolled in school.

This case shows that strong support systems that incorporate community involvement and community-based rehabilitation can lead to better physical, psychological and social outcomes for children with disabilities and their families. It highlights the need for offering comprehensive training to therapists such that they can provide basic occupation, physiotherapy, orthopaedic and speech therapy services in order to increase the availability of care amidst the challenge of limited rehabilitative therapists in Uganda.

When we are looking at that child (CwD) we are looking at the whole family's point of view ...It's not just the fact that we are teaching children to start sitting, stand or walk.... but it's to strengthen the bond within the family and within the community, and really looking at the whole big picture. (Fiona Beckerlegge Co-Founder of KCDC)

1. INNOVATION PROFILE AT A GLANCE

Organisation Details

Organisation name	Kyanninga Child Development Centre
Founding year	2014
Founders	Fiona Beckerlegge, Steve Williams, Asha Babu Williams
Founder nationality	British and Ugandan
Current head of organisation	Steve Williams
Organisational structure	Non-governmental organisation, Social enterprise
Main value proposition	Through an entrepreneurial, holistic and community-embedded model contextualized for a rural resource-poor setting, KCDC provides rehabilitative and educational services to children living with disabilities and their families.
Organisational stage	Organisational growth and scale
Size	Total 34 employees across 2 centres
Main income streams	Donor grants and revenue from product sales and recreation activities hosted
Annual expenditure	\$120,000

Operational Details

Country/countries of operation	Uganda
Local scope	2 centres: One in Fort Portal and one in Kasese
Type of beneficiaries	Primary beneficiaries; Children with disabilities aged 0-18 & parents / carers of children Secondary beneficiaries; Healthcare workers, schools and teachers and community leaders
Number of beneficiaries (annually)	1350 children and 6345 family members annually
Cost per client	Therapy services are freely offered to clients, but carers are asked to contribute between \$1.5 and \$15 for adaptive equipment and additional medical expenses such as surgery and hospital bills.
Local engagement	Partnerships with local public health centres, village health teams, local community organizations and schools
Innovative elements	Utilising a holistic approach to make care for disabilities affordable and accessible and to reduce stigma <ul style="list-style-type: none"> ○ Holistic community embedded model delivering rehabilitative and educational services to children and families of children with disabilities in a resource poor rural setting ○ Community capacity building through awareness raising & skills ○ A revenue generating enterprise supporting organizational sustainability

Scaling Considerations	<p>Scaling this model is possible under the following conditions:</p> <ul style="list-style-type: none"> • A resource constrained setting with high numbers of people with disability • In settings with limited rehabilitative staff who can be trained as generalist therapists competent in basics of occupational, physiotherapy, orthopaedic and speech therapy
Sustainability Considerations	<p>KCDC sustains its operations through;</p> <ul style="list-style-type: none"> • Revenue generation from the Kyaninga dairy product sales • Fundraising from sports and social events • Engagement of expert volunteers to provide therapy
Health Systems Lessons (3)	<ol style="list-style-type: none"> 1. In rural resource poor settings, rehabilitative services can be effectively delivered in community settings such as homes, schools and community centers, as shown by KCDC. 2. In settings with severe shortages of rehabilitation staff, health worker training should be adjusted to train generalist staff competent in the basics of physiotherapy, speech and occupational therapy. 3. Through creative revenue generating models, providing rehabilitative services can become partially sustainable.

2. CHALLENGE

Globally, over one billion people live with some form of disability (WHO and World Bank, 2011). About 93-150 million children aged 0-18 years suffer from physical, developmental or communication disabilities (UNICEF, 2013). Low and middle-income countries (LMICs) contribute 80% to the 100 million Children with Disabilities (CwDs) under five years of age (UNESCO, 2010). The Lancet global health analysis on disabilities indicated that the risk of developmental disabilities among children younger than 5 years in LMICs is likely to exceed 350 million (roughly three in every five children) (Olusanya et al., 2018). In Africa, CwDs are among the most neglected in society, and with their families, they face enormous economic, political and social barriers with adverse impact on their physical, social and intellectual development and wellbeing. More than half of the disabilities are a consequence of illness acquired in the first five years of life, and most of these disabilities are preventable (ACPF, 2011).

Uganda, with a total population of around 44 million people (World Population Review, 2018), 2.5 million children live with some form of

disability (UNICEF UGANDA, 2015). Children aged 6-19 years contribute 53% to the nation disability burden (UBOS, 2012). The majority of the burden of disability in Uganda is comprised of physical impairment (34%), vision impairment (22%) and hearing impairment (15%) (UBOS, 2006). Developmental disabilities including cerebral palsy and spina bifida are reported to be more prevalent in Uganda than higher income countries (Sims-Williams et al., 2017, Kakooza-Mwesige et al., 2017).

The burden of living with disability in Uganda is intensified by inadequate access to basic service. Repeated household surveys indicate limited access to rehabilitation services with 60% of Persons with Disabilities (PWD) not able to receive any form of rehabilitation (UBOS, 2006, UBOS, 2010). In Uganda there are 2.5 physiotherapists per 100,000 population compared to 18 per 100,000 in South Africa and 59 per 100,000 in USA (World Health Organization, 2011). Parents in Uganda continue to carry their children with disability on their back as assistive devices are not always available or applicable for use in their setting (Bannink et al., 2016).

Further, children with disabilities in Uganda face high levels of violence and limited access to available child protection mechanisms compared to those without disabilities (Banks et al., 2017, Devries et al., 2014). In addition, communities continue to subject CwDs to various forms of discrimination and marginalisation, based on negative attitudes developed from superstition and cultural norms (UNICEF, 2014). A recent study from Uganda found that majority of people believe that disability is caused by witchcraft and curses, bad luck, use of family planning methods, divine intervention, and genetic problems in the family, which are believed to affect the baby before birth (Bannink et al., 2015).

Data from 2010 show that although 90% of Ugandan children are enrolled in primary school, only 9% of children with disabilities are so

enrolled (Riche, 2014, UNDP, 2017, Ministry of Education and Sports, 2011). CwDs are more likely to drop out of school (Riche, 2014), and only around 6% of CwDs proceed to secondary school compared to the national average of 25% (USDC, 2014). This high rate of school dropout may be due to the inadequate provision of special needs education. In 2014, Uganda's National Council for Disability reported that there were 138 special education units in the country to cater for 2.5 million CwDs (National Council for Disability, 2014).

In Uganda about 80% of PwDs live in poor conditions (Riche, 2014). Having a child with disabilities has economic consequences on families when a family member needs to be a full time carer and hence cannot take up employment (ACPF, 2011). Other children in the family may also be removed from school to look after a disabled sibling.

3. INNOVATION IN INTERVENTION

Kyaninga Child Development Centre (KCDC) is a non-governmental organisation, established to respond to the inadequate care and management of children with disabilities (CwDs) in Kabarole district in Uganda. To increase opportunities for (CwDs) in Uganda, KCDC uses a holistic community-embedded approach to address the needs of children and families, living in rural Uganda. The key components of the intervention include: rehabilitative services, education and training.

3.1. REHABILITATIVE SERVICES

KCDC increases access to care and therapy by providing a combination of affordable orthopaedic services, physiotherapy, speech and occupational therapy in a resource constrained, rural environment. The organisation has therapists who assess and treat a wide range of injuries and disabilities among children and young people in the community. The physiotherapists address conditions such as cerebral palsy, paralysis, Down syndrome, developmental delay,

and orthopaedic conditions including limb deformity. The speech language therapists offer individual and group communication-aid sessions to children with communication difficulties such as language delay, speech sound delay, cleft palate, dyspraxia and social communication disorders. Occupational therapists work with children with disabilities and their families to help them perform skills such as writing, dressing and playing. KCDC also provides subsidised orthopaedic equipment such as splints and casts to restore movement and prevent lifelong disability among children.

3.2. EDUCATION AND TRAINING SERVICES

KCDC provides free training sessions to various categories of community members. The parents/family members of CwDs, community health workers, health workers at local health centres, school teachers, and members of community organisations are empowered to better understand disability and its management. The education outreach of the organisation increases awareness on disability, with the aim of

breaking down misconceptions that lead to discrimination of CwDs and their families. KCDC in partnership with BeadforLife organisation runs a street business school that seeks to end extreme poverty through small business ownership. Parents of CwDs receive practical business training to build up their enterprises and meet family needs. The training is designed as a 6-month module, after which successful participants are awarded certificates of completion, followed up by KCDC team and encouraged to start up their own small business

enterprise(s). By 2018, two beneficiary parents of KCDC had graduated and started coaching 20 other parents.

So many children have more severe disabilities than should be because of lack of intervention and lack of knowledge not just by parents but by health care providers as well.... we are providing training to health care workers, community workers, teachers, and parents and care givers in identification, understanding and management of children with disabilities (Ms. Fiona Beckerlegge, Co-Founder of KCDC).

4. IMPLEMENTATION

4.1. INNOVATION IN IMPLEMENTATION

KCDC's model of service delivery enables the centre to reach those in need of the services through the community-based programmes and stakeholder collaborations. KCDC is able to provide affordable therapy services by supplementing grants and donor funding with local revenue generated from Kyaninga dairy product sales and outdoor activities like triathlons.

Community-embedded model

KCDC provides services beyond conventional primary health care clinics, in order to increase access to care. Around 31% of services are offered at the KCDC clinics to families that can afford to make it to town centres. Therapists also visit individual homes to offer rehabilitative services, especially when the nature of disability makes it hard for caregivers to transport the child to a health centre. The organisation delivers 28% of the services at the individual homes. KCDC also partners with local health centres where it provides 26% of its services, in order to

strengthen rehabilitative services offered to families that seek care at those facilities. Further, KCDC extends 15% of its services to schools where school children with disabilities are

provided care and their teachers are equipped with skills to support them.

The organisation staff have working relationships with local health centres, such that KCDC therapists are able to offer monthly therapy sessions in the community. KCDC also collaborates with other NGOs offering rehabilitation, and schools which identify and refer disability cases to KCDC for assessment. Additionally, KCDC organises social events including sports and parties. Such events bring together families with a family member with a disability. They feel encouraged and supported when they interact with each other and with other community members and leaders.

Nobody (KCDC client) is complaining, because most of these therapy sessions are free of charge and we get to go to their homes and visit them, we do outreaches and come near to them. (Ms. Mutoni Vedastine Rehema, a nurse and speech therapy assistant of KCDC)

Equipping staff with generic rehabilitative skills

To facilitate increased availability of rehabilitative services in Uganda, KCDC commits to train their staff to have multiple therapy skills. KCDC organises workshops where their employees are

capacitated as generalist rehabilitative staff competent in basics of physiotherapy, speech, orthopaedic and occupational therapy skills needed. Additionally, the organisation partners with Ugandan universities to offer internships for students of physiotherapy, occupational therapy and speech therapy to gain additional experience and skills in working with children with disabilities.

Peer support

Parents are trained as expert mothers and fathers to educate, encourage and support other families with a child with a disability through KCDC's Early Intervention Programme. The programme uses the empowered expert parents to educate and support others to look after their children with disabilities. It is designed so that it can be run without specialist therapy services, so that the needs of children with disabilities can be met at low cost and in a highly effective way, regardless of the level of service provision. To encourage men's participation in care, KCDC established a fathers' forum where fathers who are actively involved in the care and therapy of their children are sensitized on disability. They are encouraged to mobilise other men to get involved and be supportive to improve the management of disability and to advocate for their families within district forums.

4.2. ORGANISATION AND PEOPLE

Kyaninga Child Development Centre was founded in 2014 by entrepreneur Steve Williams, his wife Asha, and physiotherapist, Fiona Beckerlegge. Their vision is to provide children with disabilities in Uganda with equal opportunities. The extent of

the problem faced by families was initially highlighted during Steve and Asha's search for treatment services for their son Sidney, who has cerebral palsy. Because of the limited access to rehabilitative services in Uganda, particularly in Fort Portal, the couple initially took their son to the UK for treatment. On return to Uganda, they

sought an alternate approach that entailed a physiotherapy volunteer coming out from the UK (Fiona). Following six months of treatment that Fiona provided to Sidney, they realized the need

that exists in the area. To support more children, Steve, Asha and Fiona founded KCDC.

I saw an advert for a volunteer position to come and do some intensive therapy with one child here in Fort Portal (Uganda) because the family was struggling to get any therapy for the child.... So, I came and lived with the family... for six months doing intensive therapy for the child, with the family. The family opened up the idea, wouldn't it be great to be able to create something that helps more children than just Sidney but they didn't have the clinical knowledge, we had to put it together. (Ms. Fiona Beckerlegge Co-Founder of KCDC)

The clinic was initially set up in Fort Portal, but Steve, Asha and Fiona soon realised that meeting the needs of the community required more than just operating in a clinic. Families who need care often live in hard-to-reach areas with poor transport, and may additionally be constrained with poverty, making it especially hard for them to reach health facilities in towns. This led KCDC to start the community based rehabilitative programme.

You see Kyaninga helps us because they come here (to the beneficiary's home), they put in their transport and come here to look for us. We would not have managed if these people were not here. (Ms. Esther Ategeka, KCDC Beneficiary)

By 2018, the organisation had a multidisciplinary workforce of 34 employees: the founder, an entrepreneur who spearheads creation and implementation of business ideas of KCDC, occupational therapists, physiotherapists, orthopaedic and speech therapists, nurses, special needs teachers, business coaches and expert parents, who combine efforts to offer holistic care and the management of disabilities.

4.3. BUSINESS MODEL

Kyaninga Child Development Centre has adopted various income generating initiatives to assist with operational costs. The creation of the business initiatives was developed by the KCDC co-founder, Steve Williams, who had sufficient business skills. Steve had prior experience in dairy

farming and this led him to encourage the team to start a goat dairy farm. With the Kyaninga goat dairy, 100 goats are bred to produce milk that is turned into high quality goat's cheese, which is marketed and sold across Uganda. This generates revenue to support the centre. All profits from the dairy go to the Kyaninga Child Development Centre. Kyaninga dairy also supports CwDs and their families, who come to the farm to learn skills such as farming and animal husbandry, in order to use these skills to earn a living. The dairy is also a source of employment for young adults living with disabilities, 25% of the total employees are PwDs.

Additionally, KCDC organizes four fundraising events each year such as triathlons and marathons, with each event generating funds to cover a month's operating costs of about US\$ 6500 from both Ugandan and international participants.

KCDC still depends mainly on grant and donor funds to run its projects. It has support from various funders including Accomplish Children's Trust (UK), Kyaninga CDC Trust, Spring of Hope UK and The Elma Foundation, volunteers' contributions, Kyaninga lodge (the primary hotel business that initially financed KCDC) and carers contribute between \$1.5 and \$15 for adaptive equipment and additional medical expenses such as surgery and hospital bills. KCDC has an annual expenditure of approximately US\$120,000, mostly for recurrent expenses. A significant proportion of the budget, around 42%, is spent on salaries. Other budget items are office running costs (18%), rent (14%), vehicle maintenance and fuel (9%), financial contribution for adaptive equipment and surgery (8%), community outreach and educational material (4%), and therapy equipment (5%).

5. OUTPUTS AND OUTCOMES

5.1. IMPACT ON HEALTHCARE DELIVERY

Since KCDC began in 2014, a total of 1350 CwDs have been reached with therapeutic and rehabilitative services and by 2018, about 6345 family members were benefitting annually. KCDC is currently partnering with 17 government health facilities and one private health facility to provide monthly outreach clinical services. Additionally, KCDC is working with 15 schools and seven local community organisations to provide rehabilitation. From these interactions, so far 265 medical staff, 30 teachers, 50 community workers and a total of 3500 caregivers have greater understanding in the identification, management and understanding of disability and therapy intervention. KCDC has also conducted 15 community outreach days in various parishes across the district, and through this initiative, more than 490 children and adults have been sensitized on disabilities.

More than 425 items of specialist adaptive equipment -- wheelchairs, supportive seating,

walking frames and splints -- have been provided to CwDs, and 30% of school-age children registered with KCDC have been enrolled in school.

The KCDC social activities attract over 200 people per event including CwDs and their families. The KCDC parent education and peer support programme promotes empowerment of families and caregivers through sharing experiences, increases knowledge and skills of caring for a child with disability, and promotes the advocacy of and steps to realise the rights of CwDs. Alongside increased awareness, knowledge and understanding, families have reported reduced stigma and isolation, leading to their improved confidence in integrating into local daily life and greater acceptance of children with disabilities by families and communities.

More than 23% of referrals are coming through word of mouth and friends and family ... because

that is mainly coming from parents who have had a positive experience and they're telling other people. (Ms. Fiona Beckerlegge, Co-Founder of KCDC)

5.2. ORGANISATIONAL MILESTONES

The organisation has been recognised for its work. In 2016, the co-founders were selected from more than 200 start-up companies to participate in a training organised by the Unreasonable East Africa organisation, where they were provided with financial and strategic planning skills from experienced entrepreneurial mentors. In 2017 KCDC won the regional National Social Security Fund (NSSF) -Towards Overcoming & Receiving Community Hardships (TORCH) award, which recognises community organisations that have transformed communities and made a difference through their projects, in Uganda.

5.3. COMMUNITY PERCEPTIONS

KCDC beneficiaries include children with disabilities, their caretakers, school teachers, healthcare workers, community workers and adults with disabilities. The experiences of beneficiaries reflect that KCDC is creating an

environment that enables families with disabilities to change their perspectives, manage disabilities, and improve the quality of life of CwDs.

I thought my son was the worst but I see that I am lucky, and I have hope that he will continue to improve..... I felt so alone but I have met people who have problems and difficulties like I do and we can support each other now. (KCDC Beneficiary)

KCDC has and continues to establish good working relationships with various stakeholders in the community. This increases its impact through receiving more referrals from the broad network.

We are having clients who are being referred to us from people around... for example with other organisations like schools, other health centers, we are really working in partnership with them because they send us children, we go to their centers to do our work from there, some of our work we do it from churches, so the relationship is really good and people are appreciating that is why they have been referring children to us. (Ms. Golden Chariot KCDC orthopaedic officer)

6. SUSTAINABILITY

Financial support for Kyaninga Child Development Centre comes from donor funding, fundraising events and crowd funding. The dairy produce contributes 10% of the income and 5% income comes from the social events, but KCDC aims at becoming more self-reliant with limited dependence on donor funding through setting up more business enterprises.

To minimize costs on service delivery, KCDC finds expert volunteers who offer knowledge and skills

development for the KCDC team and make financial contributions to the organisation. Additionally, KCDC is able to sustain its community-based programme through partnering with community organisations like Youth and Women Empowerment (YAWE) foundation, Rwenzori Special Needs Foundation, Ambassadors of Great Hope and health facilities which provide the KCDC team with resources like space to conduct rehabilitation sessions, thus reducing home visits and associated costs.

7. SCALABILITY

KCDC continues to offer more services to meet the needs of the community. As most rural families with CwD in Uganda do not have access to any physical or social rehabilitation services, there is need to scale up this approach country wide. In early 2018 KCDC opened its second field office in Kasese, to offer the same holistic services as in Kabarole district. In the second half of 2018 it aimed to expand the community outreach programme to health centres in three neighbouring districts -- Kyenjojo, Kamwenge and Bundibugyo -- to enable families in these areas to have more accessible services, rather than travelling to the clinic in Fort Portal. It plans to set up other rehabilitation centres in Kasese, Kyenjojo, Kamwenge, and Kampala. In Kampala, it intends to set up a private clinic which would be able to generate revenue to facilitate the free

services offered to those who cannot afford to pay for care.

KCDC plans to expand services by increasing the number of therapists within the two centers, to include social workers and community health workers as well as physiotherapists, occupational and speech therapists. It also plans to open further satellite centres in the western region, to reach more children with disabilities and their families. Additional street business coaches and expert parents will also be trained to meet the needs of a wider regional impact.

We want to consider this (KCDC) as a center of excellence and then repeat it in each district so we would really want to recreate what we have here in all other centres. (Ms. Fiona Beckerlegge Co-Founder of KCDC).

8. KEY LESSONS

8.1. IMPLEMENTATION LESSONS

The process of setting up Kyaninga Child Development Centre began with situational assessments, and networking with district officials, other local community-based organisations working with children with disabilities, and other rehabilitation services. This enabled KCDC founders to understand the need for services and helped them to plan and strategize accordingly. This also enabled them to make constructive collaborations which have supported the implementation of programmes at a wider scale in a cost-effective manner.

Health care programmes need to be adjusted according to the prevailing need, and what works in a given context. The KCDC team initially thought that establishing a rehabilitation clinic in Fort Portal town would help to address the problem of inadequate care and management of disabilities among children. However, the challenge was far greater: there was a limited number of rehabilitation centers and other inhibiting factors, including poor transport from rural to urban settings, lack of awareness of services and interventions, and poverty. In

response, KCDC had to develop an integrated bundle of services to meet the prevailing demand. Rehabilitation services need to be delivered beyond clinics, delivering services in local communities and homes to increase accessibility and affordability of services to those who need them most.

Venturing into entrepreneurship activities can facilitate the delivery of affordable services to the community. KCDC is in position to offer cost friendly services and to operate broadly because some of the revenue is from sources other than donor funding.

8.2. PERSONAL LESSONS

Two of the KCDC co-founders have a child with a disability and were unable to find appropriate treatment for their child. With a volunteer physiotherapist, they worked to create an enabling environment to provide care for and manage disabilities in their community. The family also provides strong peer support to other families, thus reducing the stigma attached to having a disability.

So, we knew there was a bit of need.... when Fiona (physiotherapist from England) arrived she also

realized that there was a massive need, so then we started off (rehabilitation centre) slowly.
(Steven Williams KCDC co-founder)

CASE INSIGHTS

1. In rural resource poor settings, rehabilitative services can be effectively delivered in community settings such as homes, schools and community centers, as shown by KCDC.
2. In settings with severe shortages of rehabilitation staff, health worker training should be adjusted to train generalist staff competent in the basics of physiotherapy, speech and occupational therapy
3. Through creative revenue generating models, providing rehabilitative services can become partially sustainable

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