

LEARNING BRIEF



DEVELOPMENTAL PROGRAM FOR CHILDREN WITH DISABILITIES

Partners:



INTRODUCTION

Give a Child a Family, operational since 1996 as a Child Protection Organization, embarked on a capacity building program in April 2014 with an emerging Community Based Organization, *Ikhaya lethu Home of Love and Care*, registered as a Child and Youth Care Centre with the Department of Social Development. One of the key non-governance objectives is the provision of occupational and developmental programs for severely disabled children. A Memorandum of Understanding is in place between Give a Child a Family and Ikhaya lethu for a capacity building program and the Izingolweni Program has been contracted in to provide services to Give a Child a Family and *Ikhaya lethu Home of Love and Care* children with disabilities.

Ikhaya lethu is situated in KwaNzimakwe in the Ugu district of KwaZulu Natal and has capacity to admit 35 children in 2014 with an increase to 56 children planned for 2015. There are currently 30 children in care.

WHO ARE THE IKHAYALETHU CHILDREN?

Children with disabilities remain the most vulnerable group of society as their rights are often ignored. Children are marginalized and stigmatized which leads to neglect, abandonment, and often times, abuse. Children admitted to Ikhaya lethu are between the ages of 5 and 18 years old, who have been abandoned, orphaned or their families are unable to care for them.

85% of Ikhaya lethu children are severely and profoundly mentally and physically disabled and totally dependent upon care-givers to provide care and development. 10% of children are unable to sit unless supported by binding restraints. 4% are permanently bedridden due to

prolonged spasticity resulting in extreme deformity

13 children present with the symptoms of Microcephaly

14 children present with the symptoms of Cerebral Palsy

1 child presents with the symptoms of Proportionate dwarfism and developmental delay

1 child presents with the symptoms of a possible Near Drowning

1 child presents with the symptoms of Hydrocephalus

Total 30

1% of the children's life-spans will be truncated due to extent of disability and non- functionality. Intellectual disabilities are not illnesses; there are no cures available.

PROGRAMS

Care Plans

Care Plans have been developed for each individual child to ensure that they are assisted to achieve his/her full potential and to function at an optimum level. Care plans incorporate physiotherapy, a range of passive motion exercises to ensure that their muscle and skeletal problems will not be further compromised, supportive play, recreational therapy, cognitive therapy and music therapy.

The program is provided 3 times a week by the Izingolweni therapists and caregivers continue with the program on alternative days.

Physiotherapy

The individual passive physiotherapy regime promotes mobility and physical comfort of children. It is furthermore important for bedridden children who are prone to lung infections as well as maintaining skin integrity and preventing bedsores.



Occupational therapy equipment was donated by Give a Child a Family and the therapist of the Izingolweni Outreach Program and the Port Shepstone Department of Health provided wheelchairs and buggies. One room was allocated to set up the Occupational and developmental therapy unit. The rooms and living quarters of children were decorated to make it more child friendly and toys were provided.

Caregiver Training

Caregivers are trained and instructed on the basics of disability care and passive physiotherapy exercise routines by the Izingolweni Therapists. Focus is furthermore on the facilitation of movement and on safe moving and handling techniques which ensures that staff work in the best possible way, are aware of their own spinal posture and are able to physically manage the needs of the children.

In addition to physio and occupational therapy, the Give a Child a Family Nurse provides Healthcare and Hygiene training on a weekly basis to ensure that the physical and medical needs of children are attended to inclusive of keeping the children's immunizations up to date, the correct administration of chronic medication and referral to the nearby clinic for other illnesses.

Group Therapy

Group music therapy includes spinning, dancing and singing in which all children participate whether on mattresses, wheelchairs or mobile.

This therapy lifts the mood of children and allows caregivers and children to interact in a healthy way.



The program has grown to include “mini maths”, counting while reciting rhymes such as “One Two Buckle my Shoe. Three Four Knock at the Door” etc. Children love the rhymes and at the same time are learning something new.

Understandably children’s retentive skills are compromised and activities are therefore repeated regularly. The learning experience also leads to development of social skills and a remarkable improvement has been seen in a willingness to share and individual achievement with efforts to learn independence (“to stand on his/her own feet”). Although teaching at Ikhayaletu is only at kindergarten level, it is wonderful to see their willingness to learn and their devotion to complete the project they are working on.

School Program

More children have now been brought into the school room and surprisingly, some are those we originally did not think would make Children are enjoying the disciplines of school and the results have been astounding.

Some children (in wheelchairs) limbs are severely spastic; it never ceases to amaze how they find the most effective posture or position for themselves, to hold a crayon and colour in the picture in front of them.



Hand eye coordination is improved by means of block building and stacking of rings. Reaches, grasps, holds, and releases are perfected during these games. The transfer of an object from one hand to another and from one place to another markedly improves hand eye coordination. It is during these games that preferential handedness is assessed.

At present we have Colouring-in, Flash Cards, Numbers, Colours, Alphabetical Letters and Finger-painting. Toy play, arts and crafts, block building and stacking rings. Cognitive Therapy (picture recognition and verbalization of picture names) was implemented and is being enjoyed by the children and the caregivers alike.

There is no way to make the transition to school, discipline and routine a painless one but there are ways of making it less painful by making learning fun. School hours are from 8:30 to 12:30, followed by singing and musical therapy after the lunch break. School is a big step in improving cognitive abilities and curbing inappropriate behaviour, no matter what level these children are currently functioning at.



PROUD ACHIEVEMENTS

A child with Hydrocephaly has had a specific occupational therapy for neck and head control to get her mobile by crawling. Protruding teeth and difficulty in chewing compromised her nutritional status and her diet was changed to a soft diet to ensure that she grows and develops to her full potential.



An eighteen year old girl, presumed to be mute is speaking for the first time. Not just words, but meaningful words. She can name all her facial features, count to twelve and despite the severe physical disability she suffers, takes the time to colour in with new perfect precision. This is a result of speech therapy and training the caregivers on the importance of communicating with children.

A boy who had no interest in anything and just sat in a corner where placed Now wheels his own wheelchair ... gets off and although on his knees, he delights in the music therapy and traditional dancing. He is a joy to watch.



Four of the extremely spastic children who were completely bedridden have once again joined the other children outdoors propped up and seated in buggies. This achieved only by ongoing and continuous Physiotherapy - Sensory stimulation and range of motion regimens to reduce the severity of spasticity and increase their mobility and movement. This wonder can only lead to a longer and healthier life.

Two bedridden children are now propped up by means of cushions and are seated in their beds where they can reach toys and amuse themselves, albeit one handed.

The Ikhayaletu Choir

New techniques were explored to cultivate and energize a learning, developmental and planned recreational environment for the children. Our choir may not know all the words yet, but joined by the staff they make a joyous sound together.

Bonding Sessions

The children have benefited greatly from the bonding sessions which improve social skills and decreases frustration, defiance and aggressive behavior.



Raising Awareness

What a delightful day it was when members of the local community together with Induna and other visitors brought various groceries and gifts for the children, including toys made by the local community.



WHAT HAVE WE LEARNED?

Challenges

Emerging CBO's like Ikhayaletu are faced with various challenges such as a lack of funding, governance and other skills. After the transfer of children to Ikhayaletu it became evident that staff required assistance and training on the care of children with profound disabilities. Children's activities were non-existent except for placing the children in front of the television or carrying them outside for short periods during the day as the only input into the children's wellbeing.

The prolonged absence of occupational, physio and developmental programs for children living with disabilities prevent them from enjoying quality of life and reaching their full potential.

Positive Outcomes

- Since the commencement of the program in May 2014, there has been a marked improvement on the mood, behaviour and wellbeing of children
- Individual care plans address the specific needs of each child
- Attention is given to specific dietary needs of children
- Through the physio and occupational therapy mobility is improved and further regression of physical ability is prevented
- Through the developmental program (School) the first steps are taken for future protective workshops.
- Dancing and music therapy increases flexibility, agility, coordination, and spatial awareness. At the same time, it develops children's expressive, musical, motor, and auditory skills. And dance offers a noncompetitive alternative to sports — one in which visually, mentally, and physically disabled children can easily engage.
- The program is sustainable as caregivers can continue with the program after they are fully trained to implement the programs on their own.



"Being disabled should not mean being disqualified from having access to every aspect of life."
Emma Thompson