

Hidden in Full View: The Untold Story of Cerebral Palsy Caregivers in Nairobi

A 2016 perception survey on Cerebral Palsy in Kenya reveals that there is general low awareness of the condition, often resulting in neglect, social isolation and lack of adequate health care for affected children, placing even greater responsibilities and challenges on families and care givers.

Introduction

Cerebral Palsy is the most common cause of physical disability in children worldwide. There are about 1.5 to more than 4 per 1,000 children with Cerebral Palsy. Most of them have been struggling with various disabling conditions due to the Cerebral Palsy. These include physical deformities, impaired speech and mobility, limited mental capabilities and autism. In Kenya, it is unclear what the statistics are.

Children with Cerebral Palsy, like all children, need family love and care, and societal acceptance, to enable them to live a dignified life and develop to their full potential. However, owing to the low levels of public awareness about the condition, parents and caregivers often find themselves in a delicate and complex situation while attending to children with Cerebral Palsy.

In early 2016, a perception survey was carried out within Nairobi City to understand the challenges faced by families and caregivers of children with Cerebral Palsy, including access to health care and education. The survey — carried out by The Orion Foundation in collaboration with the Breakthrough Consulting — sought the perceptions of parents, therapists, doctors and teachers who attend to or interact with children with the condition.

Summary Findings

- There is a general poor public understanding of the impact of Cerebral Palsy on children and their families and caregivers.
- On the other hand, caregivers and families of children with Cerebral Palsy, especially among low-income households, lack relevant information and guidelines on the disabling conditions to enable proper care and attention.
- As a result of low awareness of the condition, many parents only got to know that a child had Cerebral Palsy when they noticed delayed milestones in child growth, rather than at the early stages when timely interventions were needed to manage the condition. In many instances, interventions for children with special needs were often applied in the late phase, which impairs child growth and development.
- Families' lack of understanding, or in some cases even denial of the special needs deriving from Cerebral Palsy, often leads to the postponed start of therapy and to an increase in family difficulties to deliver care to children with special needs.
- The extent of social stigma around Cerebral Palsy suggests that there are many children who are hidden away, probably neglected, with inadequate love and care, and excluded from opportunities for child play, social interaction and schooling.

- Mothers comprise the bulk of caregivers and shoulder a disproportionate responsibility in attending to the daily care, health and education of children with Cerebral Palsy. Besides the social stigma encountered, many mothers also sacrifice opportunities to lead normal life, such as employment, yet shoulder most of the financial costs for health care and education.
- Basic health care is limited by the poor availability of diagnostic facilities or medical personnel with experience and expertise in managing Cerebral Palsy. This situation is exacerbated by lack of available interventions such as medication, surgical procedures or therapy.
- Facilities such as special hospitals, rehabilitation centres, special schools, special staircases/ramps, special lifts, special seats/toilets and parking are not available or accessible to the Cerebral Palsy community and their caregivers.

Recommendations

- Families and caregivers, especially mothers in low-income households, need societal support and acceptance to enable them cope with the responsibilities and challenges of taking care of affected children.
- This calls for improved public awareness and understanding on the impact of Cerebral Palsy on families and caregivers, and a supportive environment that prioritizes care planning, based on the needs of each child and family. Parents of children with disabilities need more information about caring for them.
- Specific attention should focus on improved health care for children with Cerebral Palsy. These include specialised health facilities and treatment/therapies, insurance cover, medical subsidies and increased para-medical support.
- Special attention should also focus on improving the availability and access to specialised schooling facilities and teachers for children with Cerebral Palsy, as well as other supportive public infrastructure that cater for their needs.
- Also needed is a supportive policy framework that caters for the needs of affected children, families and care givers.



About The Orion Foundation

We are a non profit making organization whose sole purpose is promoting the well being of children with Cerebral Palsy and by extension, other special needs; creating awareness about the condition by initiating national dialogue on multiple platforms and channels; as well as a combination of advocacy and strategic legislative direction that results in policy change. We provide a platform for research on physical and social factors of cerebral palsy. Further, we play a pivotal role in disseminating pertinent information and referrals on therapy provision; counselling services; assistive devices and equipment; and other support services.

About Breakthrough Consulting

Breakthrough Consulting is a full service agency providing Market and Social Research, Management Training and Strategic Planning services for enterprises.

With a presence in Kenya, Uganda, Tanzania, South Sudan and Rwanda, industry leaders in Financial Services, FMCGs, NGOs and SMEs continue to trust our expertise to guide investment decisions, venture into new markets, evaluate growth, assess impact of social investments, implement market and brand positioning, develop products and gauge customer and staff satisfaction.

We serve the needs of medium and large for profit and non-profit organization. We enable organizations establish deep connections with their target audiences and offer solutions that foster strong emotional connections that enhance internal and external customer experiences.

