



CEREBRAL PALSY: IMPACT ON FAMILY & DAY-TO-DAY LIVES

Cerebral Palsy (CP) is defined as a neurological disorder caused by a non-progressive brain injury or malformation that occurs while the child's brain is under development. This condition persists to older age and leads to lifetime disability. (Source: My Child Center)

The common manifestations of CP includes but not limited to; lack of muscle coordination when performing voluntary movements, stiff or tight muscles and exaggerated reflexes (spasticity), walking with one foot or leg dragging, muscle tone that is either too stiff or too floppy, excessive drooling or difficulties swallowing or speaking and shaking (tremor) or random involuntary movements. (Source: My Child Center)

Cases of CP are thought to be higher in Africa compared to Europe or United states; higher incidence major contributors are birth asphyxia and neonatal infections. Further, there is a challenge of structured and consistent screening policy for developmental disabilities amongst infants and preschool children hence, many children with disabilities are unrecognized and lack appropriate intervention. Stigmatization is rife among children with disabilities and their families denying them the basics such as health care, education, socialization and recognition. Information gaps and lack of skilled personnel challenge management of children with CP.

In Kenya, information about CP is scarce hence Orion Foundation in partnership with Breakthrough Consulting, conducted a study aimed at gaining deeper understanding into the lives of children with Cerebral Palsy and the social impacts to families/caregivers and day-to-day lives.

The study, which was conducted in Nairobi, targeted parents, mainly mothers of children with CP sampled at rehabilitation centers/ hospitals and schools / daycares and the general public randomly sampled at household level.

Study findings revealed that only 14% of the general public interviewed is aware of cerebral palsy. On awareness of special schools or rehabilitation centers, about 38% said they were not aware.

For most schools, facilities are not accessible to people with disabilities. 43% of parents cited special schools as the most available to parents with children with CP.

"Facilities for people who suffer from cerebral palsy are not readily available. Special schools and rehab centers are the most available and accessible amenities." Parent, child with Cerebral Palsy

"Our schools facilities are not accessible to people with disabilities despite the affirmative action taken by government. Information is also not accessible." APDK informant





On treatment, the cost of therapy is very high especially in private hospitals who charge up to 3,000/= per session while government hospitals charge 500/= or slightly less per session. In most cases, CP kids require therapy thrice a week. Insurance companies do not cover cerebral palsy and hence caregivers are forced to dig deeper into their pockets every time they take the children for therapy.

*“On average, I spend about Kes 20,000 per week on my daughter for therapy and transport alone, I have yet to consider food and help at home, it is very expensive since my insurance cover does not include this for my child.” **Mother of a child with Cerebral Palsy***

*“I take her for therapy sessions thrice a week and each time I am charged Kshs.500 at a government hospital” **Parent of a child with Cerebral Palsy***

Diagnosis of a child with cerebral palsy presents numerous challenges to the parents/ caregivers. These include: strained marriages, psychological problems and even quitting jobs to concentrate on bringing up the child. Stigma is rife where the parents and the child suffering from this condition are alienated from the society.

Only 3% of marriages of the people sampled improved when the child was diagnosed with cerebral palsy compared to 44% which have suffered negatively. There are also instances of open discrimination at household levels where some fathers refused to buy anything for the child with cerebral palsy while others opt to leave the house.

*“My marriage has suffered hugely and lead to a near divorce because my husband is unable to cope with our autistic child, I don’t know how to fix this but it is a challenge for families living with children with disabilities.” **Mother of a child with Cerebral Palsy***

When it comes to support from the government, 94% of the sample felt that it wasn’t doing enough/giving enough resources for cerebral palsy towards treatment and prevention. There were suggestions that the beyond zero campaign should also help in the awareness of cerebral palsy.

There is a big challenge when it comes to schools as not all areas have special schools and most parents cannot access facilities that cater for children with special needs. There is also the challenge of trained teachers to deal with special needs education and most of them end up in regular schools.

The challenges are not only in schools but also in hospitals as nurses in public/ government hospitals, in most cases do not give mothers/caregivers the correct advice especially, when a child has delayed milestones as they lack knowledge in this area. There are also issues of lack of adequate personnel in clinics. This is especially on Tuesdays when a lot of children are coming for the therapy sessions. Hospitals also face the challenge of insufficient facilities for therapies; in some hospitals, therapies are done in a container outside hospital structures.



Public places are unbearable places for people with such conditions. Stigma from general public who stares and asks questions is annoying and depressing. In few occasions, the people with disability are manhandled especially at the time of boarding matatus, and most public places are not conducive for people with wheelchair due to lack of appropriate facilities.

Parents/caregivers of children with disability face challenges in terms of having to do everything for them, regardless of their ages. A person with such a condition has to be washed, dressed, fed, taken to toilet, helped to board and alight from the bus. They constantly have to protect their children from rejection/ stigmatization by neighbors/ general public. They have to be there for their children when house helps and most family members are hesitant to assist hence limiting their freedom to travel.

To ease the burden on parents/ caregivers and also offer the child with cerebral palsy, a number of interventions are crucial. This include: lobbying insurance companies to cover disabilities to help ease the burden of medical cost for parents. Also, there should be subsidies on bills for children with disabilities, facilities should be increased for treatment/ therapies, medical practitioners should be lobbied to pay more attention to signs of cerebral palsy and advice parents accordingly.

Concerning information, there is need to increase awareness about such disabilities and provide information both for the general public and people living with children with disabilities. It is also important to provide more information to parents of children with disability about caring for them.

On education, the relevant stakeholders should be lobbied to increase institutions offering special needs education and improve facilities of existing institutions, call for increase in the number of teachers trained on special needs education and provide facilities required by children with disabilities.

The government should be pushed to implement policies that ensure that the needs of people with disabilities are catered for in infrastructure and such other facilities.