

SPECIAL MOTHERS

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Project

<http://specialmothersproject.blogspot.com>
www.specialmothers.org

DRAFT POLICY SUGGESTIONS ON HANDLING CHILDREN WITH CEREBRAL PALSY

Cerebral Palsy (CP) is a neurological disorder that affects movement and sometimes speech of children; CP affects every child differently, so no two children with cerebral palsy are the same.

It is the most common physical disability in childhood and is also one of the least understood. There are over 17 million people living with CP and an estimated 350 million families, friends and supporters who care about them, according to the World CP Day organization

In Ghana, persons especially children with cerebral palsy face exclusion from society; they do not have access to education. Even with Ghana's Inclusive Education policy, most children with cerebral palsy are outrightly rejected and denied admission into schools, both public and private, under the excuse that the child is either not walking, nor talking or is not toilet trained and so cannot be in school.

Some schools give excuses such as other parents will withdraw their children if they admit a child with cerebral palsy or any disability for that matter. Yet others frustrate parents to the point where they withdraw the children from school due to stressful conditions.

Some parents are therefore compelled under the circumstances to lock these children up in rooms for long hours to enable them go and earn a living.

Most parents usually do not see any future for their children with cerebral palsy to the extent that some resort to killing these children.

Given that every child is different and should be handled in a unique way, many health professionals do not fully understand the diagnoses and treatment of children with cerebral palsy; they therefore resort to trial and error treatments which sometimes further worsen the condition of a child with cerebral palsy.

For the same reason, most of our hospitals use 'one size fits all' therapy tools; a system which does not help in the rehabilitation of children with cerebral palsy. The lack of assistive devices is also a major issue that parents are dealing with. Appropriate Paper Technology chairs and

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standing frames are sometimes not properly done and tend to further deform the child instead of correcting the disorder.

Finding an appropriate care giver who can understand the condition of a child with cerebral palsy and empathize with the child is also a very daunting challenge to many families

In the light of all these, at a National Conference on Cerebral Palsy held on the 20th and 21st of July, 2017, stakeholders including the SWEB Foundation, Special Mothers Project, (A Parents Advocacy Support Group), Presbyterian Inclusive Child Development programme, Multikids Foundation, Special Education Unit of the Ghana Educational Service, Representatives of the Department of Social Welfare and the Ghana Federation of Disability Organizations recommended the use of Community Based Rehabilitation (CBR) professionals to visit homes of children with cerebral palsy to help train parents and caregivers on basic handling techniques.

However, there is no concrete data on children with disability, so the lingering question is how does the CBR professionals even identify families raising children with cerebral palsy and other children with conditions needing rehabilitation.

We therefore respectfully call on the Government of Ghana to:

- absorb the trained CBR graduates to help with the handling of children with cerebral palsy in all government school setting, in line with the Inclusive Education Policy

Recently graduated teachers should also be trained and attached to selected schools and community centers to help with the handling of children with cerebral palsy.

- To engage unemployed nurses, to be trained in basic physiotherapy and assigned to selected polyclinics and schools to cut the distances mothers have to travel to the major hospitals for physiotherapy.

SHS Graduates who have could also be engaged to be trained and work as Caregiver support for families, some will identify with it as a passion and it will serve as an employment avenue for many youths.

The need for early identification and intervention of children with cerebral palsy should be prioritized. Most parents have had to contend with either the lack of diagnoses or late diagnoses of their child's illness which denies them the opportunity to seek early intervention; or push many of them to resort to spiritual help.

Most regular children enroll into crèche as early as six months, however a child with cerebral palsy is not allowed into school or an educational centre sometimes forever in their lives due to their disorder. We therefore appeal to the President to direct the creation of Inclusive Community Early Childhood Centers for CP children.

- We suggest that in line with the Inclusive Education Policy, every Government school will have a Special Unit attached where parents within the community could leave their

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children with cerebral palsy and other disabilities to enable them go and work and come back to pick their children.

The Special Mothers Project adopted the Madina Demonstration School Special Unit to draw attention to it and help make it a model for Inclusion. The Special Mothers project has successfully rehabilitated the Unit and has constructed a two-seater toilet with bio digester for the unit.

- We will appreciate if government employs National Service Persons who have studied Disability and Rehabilitation Studies and attach them to the unit to run an eight to five system that fits the schedule of most working parents

The Special Mothers will be happy to provide practical training to the National Service Persons if need be.

In the spirit of No Child Left Behind, and to put that scheme into ‘universal’ action, teacher training curricular should include the efficient handling of children with cerebral palsy.

Children with cerebral palsy are calling for their parents to be included in the access to the Disability Common Fund. Many of the parents, especially mothers are compelled to abandon career to take care of their children with cerebral palsy. Access to the fund could enable them engage professional caregiver services, buy assistive devices and afford education which tend to be very expensive for a child with cerebral palsy in Ghana.

It must be noted that even though some parents have been able to access the funds, there is no uniformity in the way the District Assemblies disburse the funds thus disbursement of the funds seems like a “whom you know” kind of system.

We will also appreciate if we are able to get a higher authority to report to when our rights as parents of children with cerebral palsy or disability are abused, for example where do we report when a school blatantly reject or refuse to admit our children on the basis of their disability?

Government should kindly capture in the nation’s budgets, teaching and learning devices needed by persons with cerebral palsy and **monitor the admission and retention of children with cerebral palsy in schools.**

- A Home based Caregiver programme run by the Department of Social Welfare could support parents of children with cerebral palsy with respite. A directory of professionally trained caregivers by the Department of Social Welfare could be a good resource for parents to get daily, weekly or monthly respite at affordable prices, possibly subsidized by Government.

A professionally run caregiver programme would also serve as a source of employment for the youth. It must be noted that Caregiving is considered a noble profession in other developed countries and that could be replicated in Ghana

- The National Health Insurance Scheme should absorb the cost of medications needed for children with cerebral palsy and also the cost of therapy such as physiotherapy,

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occupational therapy and speech therapy as well as the cost of seeing a counselor or psychologist for emotional support.

In Ghana, many people tend to lump all children with disabilities together, however, a child with autism may be entirely different from a child with cerebral palsy, a child with autism may have completely different needs from a child with cerebral palsy.

In developing a policy, care must be taken to address the uniqueness of each disability to ensure that no group of children with a specific special need is left behind in our attempt to achieve Inclusive development.

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