

Support Services Available for Kenyan Learners with Cerebral Palsy in Aid of the Performance of Activities of Daily Living

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Janet Auma Odhiambo¹

¹Department of Special Needs Education, Jaramogi Oginga Odinga University of Science and Technology, Kenya

Email: odnette@yahoo.com

ABSTRACT

The study explored the available support services for Kenyan children with cerebral palsy in aid of their performance in the Activities of Daily Living. The study adopted an exploratory design. Sample size of the study consisted of 69 respondents which included, 26 learners with Cerebral Palsy, 10 teachers in charge of learners with Cerebral Palsy, 30 parents of learners with Cerebral Palsy, 2 Physiotherapists, and 1 Occupational therapist. Convenience and Purposive sampling procedures were used for selection of respondents. Instruments used for data collection included observation, interviews and Focus Group Discussions. The study findings showed that, learners with Cerebral Palsy depend so much on their peers with mild disabilities for survival. There were insufficient assistive devices such as wheelchairs, crutches, walkers and prosthetic devices. There were insufficient professional medical specialists such as Physiotherapists, Occupational therapists and Speech therapists to work with learners with Cerebral Palsy. Services provided by speech therapists was a significant deficit in the study. While the support systems in the institutions were not enough, those at home were worse. The study recommendations include: The government, Institutional Authority and Non Governmental Organizations should provide support services and Institutional support systems to learners with Cerebral Palsy. The parents of learners with Cerebral Palsy should be made aware of the available support services for their children and how to access them. More of Physiotherapists, Occupational therapists and Speech therapists should be trained and posted to schools for learners with physical disabilities.

Keywords: Cerebral Palsy, Support services, Physical disability, Activities of daily living, institutional support systems.

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1. INTRODUCTION

Cerebral palsy (CP) means paralysis of the muscles as a result of brain damage, often the parts of the brain which are most affected control movements of the arms, legs or facial muscles, resulting in limbs being either very floppy or very tight and tense (Rosenbaum, 2005). Cerebral palsy describes a group of disorders of the development of movement and posture, causing physical or motor activity limitations that are attributed to non progressive disturbances that occurred in the developing infant's brain. Many people with cerebral palsy have multiple disabilities. Most of the children with cerebral palsy do learn to walk several years later than their able bodied peers and do so in ineffective manner (Bigge *et al.*, 2006). The severely affected like the quadriplegic never walk. The children may not respond or react as other babies do due to floppiness, stiffness, lack of arm gestures and lack of face muscles. In most cases, children with cerebral palsy become frustrated while trying to learn new skills and as a result avoid participating in day today physical or motor activities (Pakula *et al.*, 2009). People with cerebral palsy have a wide variety of concomitant defects that when put together present a tremendous handicap in the performance of motor related activities. Cerebral Palsy is characterized by motor impairment that significantly interferes with a child's Activities of Daily Living (ADLs).

Globally, every 300 babies worldwide are born with or develop cerebral palsy and it is the most frequent cause of physical disability (Rosenbaum *et al.*, 2007). Motor disorders of cerebral palsy are often accompanied by epilepsy and secondary muscular skeletal problems. The condition affects muscle tone, which interferes with voluntary movement, and delays gross and fine motor development (Bigge and Best, 2005). This voluntary movement is crucial in the performance of activities of daily living such as dressing, toileting and cleaning among others.

2. LITERATUREREVIEW

Olaf *et al.* (2007) explored available support services for children with cerebral palsy in support to their functional abilities in America. The study recorded that there are a larger number of organizations, Government and non-Governmental that provide assistive devices to children with cerebral palsy. Early intervention and school services provided include special education, therapies, family support, parent education, parent to parent contact and assistance to the childcare center or kindergarten. Many other organizations such as Association for children with disability continue to provide assistance to school age children, although some are restricted to pre-school or early childhood intervention years.

The Bhasin *et al.* (2006) conducted a research on coping strategies among children with cerebral palsy in Europe. The study revealed that children with cerebral palsy within the European countries are provided with special services by the government. The Individuals with Disabilities Act (IDEA) requires that all children suspected of having a disability be evaluated without cost to their parents.

Research by Fasoli (2008) found that children with cerebral palsy in Europe are provided with the early intervention systems which include the staff that works with the child's family to develop Individualized Family Services Plan (IFSP). The IFSP describes the child's unique needs as well as services the child will receive to address those needs. The IFSP also emphasized the unique needs of the family which helps the parents and other members of the family learn how to help their young child with cerebral palsy. Early intervention services are also provided as well as special education related services that includes, school staff that works with the child's parents to develop Individualized Education Program (IEP), special education services such as physiotherapy, occupational therapy and speech language pathology, which are provided at no cost to parents. All these are done on a sliding fee basis, meaning that the costs to the family depend upon their income.

According to research carried out by [World Health Organization \(2007\)](#) in America, early intervention services to support infants with cerebral palsy are given to infants before their first birthday. Special education and related services are also available through the public school system for children including pre-schoolers. Under the Individuals with Disabilities Act (IDEA) children with cerebral palsy are usually found eligible for orthopedic impairment. Children with cerebral palsy born in America are provided with early intervention services immediately they are born while those in Kenya might even stay for years before their conditions are diagnosed. This could happen when children are born at home and are never taken to hospitals in good time or lack of diagnostic machines available in government hospitals for early diagnosis and intervention.

[Eliasson et al. \(2006\)](#) assessed the intervention measures available to help children with cerebral palsy in Iran and came up with both older and newer interventions. The study recommended that the management of cerebral palsy requires a team approach with the parents, therapists, doctors, nurses and teachers who can all contribute to ensure optimal progress is made. The study further recommended pediatric therapists to play a key role in the management of movement problems experienced by children with cerebral palsy. Physiotherapists and sometimes occupational therapists are essential to provide a programme to encourage motor development for the performance of activities of daily living.

present study focused on the available services necessary to aid in the performance of Activities of Daily Living by children with cerebral palsy in a Kenyan context.

[Philip et al. \(2013\)](#) explored the management of cerebral palsy in England. The study findings recorded orthopedic surgery as a major management strategy of cerebral palsy. The surgery is mainly undertaken on the lower limb and occasionally in the upper limb. Physiotherapy is an essential part of post-operative management. Gait laboratories are useful in planning the surgical programme for children who are able to walk independently or with sticks or walking frames. The hip soft tissue surgery is often effective for children when the hip problems are detected at an early stage. Lengthening of the abductor muscles may all be that is required in younger children. However, when the problem progresses, and especially if it is neglected, more extensive surgery to the hip bones is required for a significant number of children.

[Rosenbaum et al. \(2007\)](#) conducted a study in Canada on the provision of educational services to children with disabilities. The study revealed that regional offices of the Department of Education in Canada provide information and resources about schooling for children with cerebral palsy. Schools may request assessment reports to establish a child's needs and a doctor or a therapist can ensure that the services are provided and made available to the schools. A small number of schools provide more specialized programmes for children with special needs. Workers who know the children well, such as the therapists, the teachers and the pediatricians are able to provide information and support during the process of choosing a school for such children. However, the final decision is left to the parents

[Townsend and Polatajko \(2007\)](#) assessed the therapies that are available to assist children with cerebral palsy in Victoria. The study findings revealed that therapy is often incorporated in an early stage intervention programme which addresses not only the movement problems but aims to optimize the child's progress in all areas of development. Movement in children with cerebral palsy is an important aspect in facilitating the performance of activities of daily living

[Panneth et al. \(2006\)](#) reviewed the available support services for children with cerebral palsy in Metropolitan, Atlanta. The study recorded that nurses provide assistance in various ways to children with cerebral palsy. Maternal and child health nurses monitor children's early development and provide support to parents. School nurses either in main stream or special schools are available to address everyday health issues such as bowel and

bladder management. Community nurses, whether in hospitals or community health centers may provide advice in areas of management. Nurses may also be helpful in liaising with and obtaining appropriate health care services.

Donald *et al.* (2015) assessed the provision of services necessary for children with cerebral palsy in three African countries. The study recorded various ways of helping children with cerebral palsy in coping with the activities of daily living which included, working with pediatric therapists who are skilled in working with children with cerebral palsy, provision of assessment, advice, and treatment by the medical personnel. The medical personnel may also work with children and their parents either individually or in small groups. The study observed that children with cerebral palsy are mostly assisted by physiotherapists, occupational therapists, and speech pathologists.

A study by the Day (2010) on services for children with cerebral palsy in South Africa records that every region has specialist children's services department with an early childhood intervention services. The team assists families in finding other services and on how to use the services. Children aged six years and over who have an intellectual disability in addition to a physical disability are eligible to receive services from disability client services. The disability client services provide access to a range of services for children and their families including assessment, case management and respite care.

Levit (2010) explored the available service providers for children with cerebral palsy in Ethiopia. The study revealed that therapy services were provided through some hospitals in Ethiopia. The hospitals also assist families of children with cerebral palsy by providing medical and surgical services at various clinics and through other departments such as social work and psychology.

Research by Philip *et al.* (2013) in South Africa on coping strategies of children with disabilities showed that tremendous progress has been made in South Africa in the field of cerebral palsy habilitation. State subsidies and voluntary associations have been able to establish schools equal to the best in the world in various parts of the republic with suitable curriculum for the pupils. Provisions are further made for retarded cerebral palsied children in the schools. There were also diagnostic and assessment clinics which operate in many schools. Provincial hospitals are also expanding clinical services for children with cerebral palsy.

A study by Amy *et al.* (2012) similarly revealed that the United Cerebral Palsy Association of South Africa provides children with cerebral palsy with quality nursing care and stimulation in form of creative occupational therapy. Eliasson *et al.* (2006) in agreement records that in a year round programme of planned activities for children with cerebral palsy based on various themes with active exploration being key to various projects are in place in South Africa, of great significance in the year being the importance of self feeding, stimulation of fine and gross motor skills through aqua-hydrotherapy and communication strategies through speech therapy to children with cerebral palsy.

A study conducted by Ogunlesi *et al.* (2008) in Nigeria, showed that children living with cerebral palsy in poor rural areas in Nigeria were particularly neglected. Although they qualified for assistance by the government, children with cerebral palsy involved many additional costs not associated with non disabled children to trips, clinics and hospitals, special foods and disposable nappies. The children remained dependent on their mothers for feeding, dressing and toileting, placing a heavy burden of care on their mothers. Mothers therefore reported feeling isolated, lonely and depressed in coping with day today living.

Research by Hartley *et al.* (2005) which was conducted in Uganda, revealed that cerebral palsy is a huge but hidden problem in most African countries. Most of the parents and caretakers of children with cerebral palsy were ignorant of the available support services for such children and therefore the children are hidden in the homes.

A study by [Summer *et al.* \(2008\)](#) in three African countries recorded important factors for consideration to help children with cerebral palsy. The findings of the study recorded the use of assistive devices such as wheelchairs with straps, use of occupational therapists who train on the activities of daily living, the physiotherapists who train on the exercises of muscle strengthening, and speech therapists who trains on speech.

A study carried out by [Geere *et al.* \(2012\)](#) on caring for children with disabilities in Kenya revealed that in low-income families, many careers of children with disabilities contend with poverty, limited public services and lack assistive devices. In these situations coping becomes very difficult and care giving may become more of a physical work than in high -income families and so carrying out the activities of daily living among children with disabilities may be a greater risk resulting into secondary complications.

According to the reviewed literature, available support services for children with Cerebral Palsy in the developed countries are accessed from a number of Organizations which include. Government, and Non-Governmental Organizations. They provide assistive devices to children with Cerebral Palsy. Early Intervention and School Services provided such as Special education, therapies, family support, parent education, parent to parent contact and assistance to the child care center or kinergarten. While in developing counnries there were quite a number of challenges experienced in accessing support services for children with cerebral palsy.

According to the available literature, while the developed countries provide a variety of support services and institutional support systems to children with Cerebral Palsy, the Kenyan situation appear to be different. The current economic crisis has led to lack of essential social services like that of persons with disabilities.

3. METHODOLOGY

3.1. Design

An exploratory design was used. Both quantitative and qualitative approaches were applied. Quantitative data was collected first, followed by qualitative data, then interpretations done. The strategy was suitable for confirmation, cross-validation, and corroboration of findings within a study ([Creswell and Plano, 2007](#)). Figure 3.1 below is a figurative representation of the design used in the study.

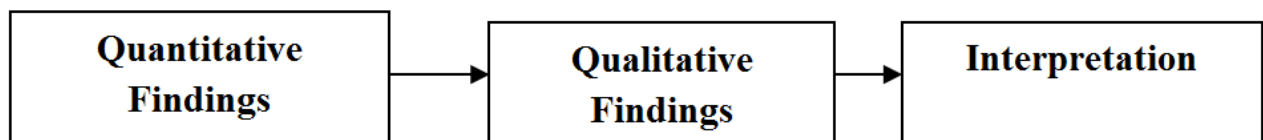


Figure-3.1. Sequential Explanatory Design

Source: [Creswell and Plano \(2007\)](#)

Quantitative Data was Collected first Followed by Qualitative Data Then Interpretations Were Done Concurrently.

Adopted from [Creswell and Plano \(2007\)](#).

3.2. Population

A total of 450 learners with physical disabilities, 64 teachers of learners with physical disabilities from three special schools, 900 parents of learners with physical disabilities, 2 Physiotherapists, 2 Occupational therapists and one Speech therapist were targeted for the study. The participants in the study included 26 learners with Cerebral Palsy, 10 teachers of learners with cerebral palsy, 30 parents of learners with cerebral palsy, 2 Physiotherapists and 1 Occupational therapist.

3.3. Sample Size and Sampling Technique

The sample size was twenty six (26) learners with cerebral palsy in three special schools for the physically disabled selected through purposive sampling technique, Thirty (30) parents of learners with cerebral palsy were selected through convenience sampling procedures based on their interest and availability for the discussion, two (2) physiotherapists were purposively sampled as key informants based on their medical knowledge on the available support services that can aid children with Cerebral Palsy in the performance of Activities of Daily Living, Ten (10) teachers of the learners were purposively sampled based on their knowledge on the existing support systems in the institutions, the curriculum and the level of performance of the pupils.

3.4. Research Instruments

The primary source of data in the study was through the use of observations. Supporting data was collected with the use of interview schedules for the teachers, physiotherapists, and Occupational therapist, and a Focus Group discussion with parents of the learners.

4. DATA ANALYSIS

Quantitative data was analyzed using descriptive and inferential statistics. The study followed [Creswell \(2005\)](#) step-by-step guidelines.

Qualitative data was analyzed through thematic analysis to determine the themes, trends and opinions from the participants.

4.1. Findings of the Study

Cerebral palsy places individuals at some form of disadvantage in the performance of Activities of Daily Living. However, the extent which it affects an individual may be determined by the support services available for use. The findings of the study show that learners with cerebral palsy in the learning institutions depended so much on assistance from their peers with physical disabilities who were not severely disabled in the performance of the Activities of Daily Living. They got other assistance from teacher aids, class teachers, social workers on attachments, and house mothers. While at home, the pupils with cerebral palsy were assisted by their parents particularly their mothers and siblings. The parents were able to cope with the condition of their children through family support, spiritual support, training, and through fellow parents in the same situations. Although many parents (mothers) coped well despite the added challenges of caring for a child with cerebral palsy, there were cases whereby demand of their children's challenges impacted negatively on their financial stability, physical fitness and emotional wellbeing.

5. CONCLUSIONS

It was concluded that while at the learning institutions, learners with Cerebral Palsy depended so much on their peers with mild disabilities who were their friends and room-mates for survival. There were insufficient assistive devices such as wheelchairs, crutches, walkers and prosthetic devices. Due to lack of enough medical specialists who can work with children with cerebral palsy such as Physiotherapists, occupational therapists, and Speech therapists in Kenya, accessing such services was not easy. Generally what stood out was that, while support services available at the institutions were insufficient, those at home were not better.

6. RECOMMENDATIONS

The government, institutional authority and Non Governmental Organizations should provide support services and institutionalized support systems for children with cerebral palsy.

The parents of children with Cerebral Palsy should be made aware of the available services and how to access them. More of physiotherapists, occupational therapists and Speech therapists should be trained and posted to schools for children with physical disabilities.

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