

PREVALENCE AND INCLUSION OF CHILDREN LIVING WITH NEURODEVELOPMENTAL DISORDERS IN KENYA

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ABSTRACT

Neurodevelopmental disorders are on the rise globally, especially in South Asia and sub-Saharan Africa. These disorders arise from impairments in the developing brain and/or the central nervous system and they affect the child's behavior and ability to learn. Examples of neurodevelopmental disorders include, but are not limited to, intellectual disability, autism, cerebral palsy, dyslexia, attention deficit hyperactivity disorder (ADHD), and learning deficits. Research shows that in 2016, 2.06% of the Kenyan population was affected by neurodevelopmental disorders. But unlike many developmental disorders, few people know about neurodevelopmental disorders in Kenya. Most of these disorders are still seen through the lens of misinformation countrywide. Consequently, neurodevelopmental disorders are largely ignored, and affected children continue to experience intolerance, bias, and marginalization in the education sectors. However, it is good to know that all children have unique strengths, talents, and interests. For some children, learning and developmental needs require special responses from the educational community and society at large. The researcher carried out a qualitative study using purposive sampling in Christ Is The Answer Ministries (CITAM) Kenya. The study involved semi-structured in-depth interviews and focus group interviews. Data was analyzed using Nvivo11 which revealed that 5-10% of the children in Sunday school lived with neurodevelopmental disorders.

Key terms: Prevalence, inclusion, neurodevelopmental disorders, disability

Introduction

Neurodevelopmental disorders such as intellectual disability, autism, cerebral palsy, and dyslexia were in the past referred to as “global developmental delays,” referring to delays in two or more milestones, or areas of development (Gupta, Gupta, & Ahmed, 2016, p. 5). However, this study has embraced the definition given by the “Diagnostic and Statistical Manual of Mental Disorders (DMS-5),” where all these disorders have been grouped together using the term “neurodevelopmental disorders” (American Psychiatric Association, 2013), hence the term used in this research. Neurodevelopmental disorders refer to conditions originating from “impairments

in the developing brain and/or the central nervous system” (Bakare, Munir, & Bello-Mojeed, 2014, p. 1) that upset a child’s social behavior, recollection, and learning capability.

Synopsis of Neurodevelopmental Disorders

Neurodevelopmental disorders and impairments are linked chiefly with the operational function of the nervous system and the brain. Some of these neurological disorders include, but are not limited to, autism, cerebral palsy, intellectual disability, and dyslexia. These disorders are recognized as a disability since they hinder the children’s full potential participation in daily life activities. The Kenya Law Act No. 14 of 2013 posits in section VI that children with special needs comprise those who are “intellectually, mentally, physically, visually, and emotionally challenged or hearing-impaired learners” (National Council for Law Reporting, 2017). The conditions display persistent deficits in “social communication and social interaction across multiple contexts” (American Psychiatric Association, 2017). Children living with neurodevelopmental disorders and impairments may exhibit problems with motor skills, conduct, recollection, learning, language and communication, or other nervous system functions.

The conditions displayed could inhibit the typical development and the child’s efforts to relate to the people in their spheres such as family and peers, thus delaying them in reaching the ordinary progressive milestones of independence and self-caring skills, relating with peers, and being able to learn in formal schools (Wills, 2014, p. 165). Diagnosis and treatment of these conditions can be challenging; management of neurological disorders and impairments usually comprise a blend of “professional therapy, pharmaceuticals, and home and school-based programs” (Mushtaq, Suman, & Terhuja, 2014, p. 1146). Although the symptoms and characteristics of neurodevelopmental impairments ordinarily change as a child develops, some infirmities are permanent.

The majority of the world’s children living with neurodevelopmental disorders live in the global South, “yet nearly all of the research on relations between the physical environments experienced by children and their cognitive and socio-emotional development has taken place within North America and Western Europe” (Ferguson et al., 2013, p. 31). This is unfortunate for many reasons. Foremost, the majority of the children living with neurodevelopmental disorders grow up outside of the affluent countries where most of the work has transpired. The

development of interventions to improve the educational and faith formation environments experienced by such children across the globe is thus warranted.

Global Prevalence of Neurodevelopmental Disorders

Medical practitioners from the American Academy of Neurology say that neurodevelopmental disorders are common and affect 1% to 3% of children globally (Shevell et al., 2003, p. 367). As a matter of fact, neurodevelopmental disorders are likely to “account for more than 28% of years lived with disability and to be responsible for at least one in every nine deaths” (Kawakatsu et al., 2012, p. 2). Recent studies show that globally, 52.9 million children under 5 years of age had neurodevelopmental disorders in 2016 in comparison with 53 million in 1990 (Olusanya et al., 2018, p. 1100).

The prevalence of neurodevelopmental disorders defined by delay or impairment in motor condition, visuospatial, speech, language, and communication skills ranges from 0.4%-3% of the population across countries (Ritchie & Roser, 2018). While some scholars have stated that the occurrence of certain neurodevelopmental conditions has been increasing over the last four decades (Faras, Ateeqi, & Tidmarsh, 2010, p. 295), recent studies on universal statistics on children with neurodevelopmental disorders indicate insignificant improvement since 1990, signifying insufficient worldwide care on the developmental potential of children especially in sub-Saharan Africa and South Asia, which are resource-poor regions (Olusanya et al., 2018, p. 1112). The study undertaken of the prevalence of neurodevelopmental disorders globally from 1990-2006 indicated that the number of children affected by neurodevelopmental disorders increased by 71.3% in Sub-Saharan Africa, and 7.6% in North Africa and the Middle East (ibid.). In 2014, the regional distribution of neurodevelopmental disorders, based on continents, were as follows: North America and Europe 9.4%, Asia 7.5%, Africa 4.4%, and South America 33.4% (Bitta et al., 2017, p. 5).

Regional Prevalence of Neurodevelopmental Disorders

Neurological disorders are important and under-recognized reasons of morbidity in Sub-Saharan Africa (Meyer & Ndeti, 2016, p. 2). In fact, in 2016, the world data indicated Africa being the most affected by the neurodevelopmental disorders with Somalia topping with 3.25%,

Niger 3.04%, Democratic Republic of Congo 2.76%, and Eritrea 2.67% (Ritchie & Roser, 2018). This prevalence is expected to be high in under-developing countries because of the non-genetic factors such as malnutrition, poor healthcare and environmental factors (Iqbal et al., 2016, p. 28).

Very few studies have been carried out in East Africa on the statistics of neurodevelopmental disorders and published in peer-reviewed journals and papers. Thus, information on this area is very scanty. Among the few studies that have been made, findings indicate that in the year 2016, Uganda was affected by 2.32%, followed by Tanzania at 2.12% while Kenya was affected by 2.06% in 2016 (Ritchie & Roser, 2018).

National Distribution of Neurodevelopmental Disorders

Studies indicate that in the earlier years, Kenya had higher percentages of the prevalence. For example, Mung'ala-Odera et al. (2006, p. 3) posit that the neurodevelopmental disorders stood at 6.1% in 2006 in Kenya, and at 2.06% in 2016 (Ritchie & Roser, 2018). However, currently, there is inadequate data and information on the prevalence of neurological disorders in Kenya (Ministry of Health Kenya, 2015, p. 5).

The researcher recently carried out a qualitative study that used Straussian grounded-theory, single case with embedded units design with Christ Is The Answer Ministries (CITAM) as the case. The findings of the study were based on the interpretation and analysis of data obtained through the process of semi-structured, face-to-face, in-depth interviews and two focus group interactions. Key informants of the study were five Sunday school teachers, five senior pastors, five Christian education pastors, six children's pastors, and four parents from the selected assemblies of CITAM. The top church leadership from the Elders' council and the Deacons' board were equally interviewed. In total, the study collected data from 28 participants through in-depth individuals and two focus groups. The research examined the prevalence of children living with neurodevelopmental disorders in CITAM, and how these children were viewed and formed spiritually. In addition, strategies deemed effective in forming them spiritually were examined and explored. Data revealed that neurodevelopmental disorders existed among Sunday school children in CITAM. The neurodevelopmental disorders identified

to be in existence included cerebral palsy, autism, intellectual disability, attention deficit hyperactivity disorder (ADD), and dyslexia.

The respondents approximated the average number of children living with neurodevelopmental disorders in the various CITAM assemblies to be 10 to 20 children per assembly. In essence, therefore, the study indicated that about 60 to 120 (5% to 10%) of the Sunday school children lived with neurodevelopmental disorders within the selected assemblies of CITAM alone in comparison to the congregational attendance indicated to the chart below:

Sunday Attendance Numbers	Valley Road	Woodley	Ngong	Parklands	Karen	Buruburu
Adults	2,700	2,800	2,100	900	2,300	3,500
Children	1,300	1,200	900	300	1,200	1,500
Total	5,000	4,000	3,000	1,200	3,500	5,000

Relevance of the Study Findings in Respect to Empirical Studies

While consistent with the findings of the Kenya Ministry of Health, that currently there is inadequate data and information on the prevalence of neurological disorders in Kenya (Ministry of Health Kenya, 2015, p. 5), the respondents' feedback revealed that there was no tabulated data of the neuroatypical children in CITAM. When asked to give the exact number of neuroatypical children who attended Sunday school, one respondent said, "We have not taken the statistic but every now and then you come across one or two, but I guess that we are not very intentional, like to know how many they are." All respondents reported a lack of recorded/tabulated data to refer to for the neurodevelopmental disorders' statistics in CITAM including the Sunday school teachers and children's pastors who interact with such children on a weekly basis. Hence, the respondents worked with estimations of the numbers within their Sunday schools. This also confirmed Patka's findings that very few studies have delved into addressing the understanding of cognitive impairments among religious circles and captured their opinions with regard to the inclusion of persons with neurodevelopmental disorders into faith communities (Patka, 2014, pp. 1-2).

Few congregations have reliable information on how many of the children in their congregations are living with neurodevelopmental disorders and how these affect their spiritual growth in the long run. CITAM, for example, is a leading church in Kenya, and her target audience is the urban elite, the majority of whom are found in Nairobi, the capital city of Kenya. Nairobi is the second-largest metropolitan in the “African Great Lakes area with 3.5 million residents. With the suburbs included, Nairobi is Africa's 14th largest city with 6.54 million people” (Kenya Population, 2018). Unfortunately, no research has been done to determine the numbers of children living with neurodevelopmental disorders in CITAM, despite empirical studies indicating that in the earlier years, Kenya had higher percentages of prevalence. The findings of 5-10% distribution of neurodevelopmental disorders among the CITAM Sunday school children is consistent with the literature findings that there is an increase in neurodevelopmental disorders in children around the globe (Tatishvili et al., 2010, p. 250; Ministry of Health Kenya, 2015, p. 6; Ileri & Mwayo, 2017, p. 4244).

However, the study findings revealed that the lack of statistical as well as empirical data in CITAM concerning children living with neurodevelopmental disorders led to some knowledge as well as practical gaps in terms of their faith formation by the church. This confirms the findings of the empirical studies that neurodevelopmental disorders continue to be part of the main causes of children’s disability, forming the leading cluster of children who remain out of social and learning circles (Sæbønes et al., 2015, p. 4). The knowledge and practical gaps subsequently led to these children either being segregated and ignored in their faith formation journey in the CITAM churches, which is consistent with Donald, Samia, Kakooza-Mwesige, & Bearden's study findings that most children living with neurological disorders encounter many obstacles in the social, economic, and political arenas because they are often deprived of the basics of schooling, social interactions, and appreciation (2014, p. 31). Segregation of neuroatypical children was upheld by a number of respondents that were interviewed. One respondent said:

Personally... [they need to be] here with their own section as a church... a special church for them. (R19)

Another respondent said,

I think they should just be separated into a special school, a special class with a teacher with a special skill, to drive the point home. Because we are being pushed to finish a syllabus and they can't catch up. That's a fact. She even doesn't know how to write, so how would she understand the message. (R8)

Segregation is in conflict with the drive towards inclusion that was advocated for by the Salamanca Statement which was ratified by legislatures of numerous nations and international organizations in 1994; and later reinstated in 2000 at the World Education Forum in Dakar to a growing consensus that it is the right of every child to have access to communal education regardless of their circumstances, attainment or disability (UNESCO, 2000). The study thus indicates that the spiritual formation of children living with neurodevelopmental disorders has not been given much focus in CITAM.

A National Need

CITAM is a reflection of what is going on in Kenya as a whole. Being a developing country, neurodevelopmental disorders impose a substantial burden on the family and on the affected individuals in Kenya. The Kenyan educational system, for example, is characterized by insufficient structures and facilities that are capable of responding to the numerous challenges that are confronted by learners with disabilities (Fioravanti, 2016, p. 4). In theory, children living with neurodevelopmental disorders in Kenya can either join an integrated school which should allow them to learn together with the “regular” children or join special needs schools which are tailor-made for their specific conditions (Villamero, 2017). In reality, however, special needs schools are few in number, and even the few that are available are very expensive for people with a middle-class socio-economic status.

As a matter of policy, Kenya recognizes the right of individuals with disabilities to quality education, devoid of discrimination and on an equal basis with others (Ongeri, 2009, p. 21). However, as Villamero remarks, “What people see on the ground are integration and not inclusive education” (2017). Integration systems and models, on the one hand, have an underlying assumption that there is something wrong with the learners that must be fixed to fit into the existing structures and systems. Therefore, the provisions of support that are given are to force the learner into an existing classroom situation. The learner is required to “fit in” to what already exists in the school. The child with learning disabilities must adjust to these adaptations

or fail. Successful systems or models of inclusion, on the other hand, are built on the idea that every child is unique, and every child is capable of learning. There is really nothing about children that requires “fixing” in order for them to fit into the given structures and systems. As a whole, the school system is transformed so as to meet the individual and unique requirements of all learners. As such, there is a commitment from all stakeholders to remove every obstacle that inhibits the involvement and participation of every child as equally valued and distinct persons in the community (Stubbs, 2002, pp. 24-25).

At times, we also see in Kenyan scenarios what scholars like Cologon (2015) would term as “macro” and “micro” exclusion, which occasionally are erroneously taken for inclusion. As explained by Cologon, macro exclusion is when a learner with a disability is put “into a separate classroom, unit, or school,” while micro exclusion is when a learner with a disability is registered in a typical setting but is “isolated into a separate area of the classroom or school for all or part of the day.” This child is only allowed to join the rest of the children partly, and only probably to do a presentation, but not participate in the activities along with the other children. Such a learner is regarded as a burden to the school community, rather than a valued member of that group.

The Kenyan reality is that special needs schools are very few in number, and quite expensive for the average person, rendering the Kenyan national education system to be characterized by insufficient facilities and structures necessary in responding to the challenges encountered by learners with neuro-impairments. “Disability” is widely perceived as a barrier to accessing learning (Villamero, 2017). Significant policy makers in Kenya are rarely persuaded to think about and involve the children living with neurodevelopmental disorders in educational programs when they think and plan for the rest of the children. Similarly, we have scenarios where some families reject or desert their children living with neurodevelopmental disorders. Therefore, we can assert that responses toward the circumstances of children living with disorders are mostly restricted to rejection or desertion (Munyi, 2012). Children with neurodevelopmental disorders and their families are commonly left out from the social order of life due to stigmatization. This renders the aspect of the inclusion of the children living with neurodevelopmental disorders in Kenya a nationwide crisis.

Conclusion

All children are important and valuable. Equally, all children have a right to education and if embraced and supported, all children can learn. Let the policy makers and all stakeholders in Kenya combine efforts to create and implement learning programs and learning strategies that address and remove barriers that marginalize children in order to achieve Vision 2030 which advocates for equality for all.

The study revealed that inclusion of the children living with neurodevelopmental disorders is a neglected aspect in the church and the country. The researcher proposes that there has to be a cultural dimension about this study that has not been addressed. There is something inherently within the culture that impacts people's orientations and perceptions. Therefore, future studies can further explore the underlying cultural underpinnings that prevent the church and the nation from thinking about and including neuroatypical children.

Interventions would also offer tremendous research opportunities to examine how environmental and general learning improvements can change developmental trajectories in the lives of these children. Future studies may also be able to better link the effectiveness of initiatives of spiritual formation of neuroatypical children with the construction of rich virtual learning environments that create whole learning experiences for these children. Thus, establishing instructional strategies and fertile learning environments that address the entire range of children's learning likes, needs, and concerns could help address the major methodological weakness in most faith formation programs for such children. The variety of ways in the faith formation journey for children living with neurodevelopmental disorders should involve as many senses as possible:

- Sight – Keep things visual. Use visual aids in teaching, as well as color in worship. Using colors enables children to easily restate God's plan of salvation (Jarvis, 2016).
- Sound – Stimulates the children living with neurodevelopmental disorders into learning through music, audio stimulation, motion, and dancing. Their different senses are thereby developed, which in essence enlivens and enhances worship (Islam & Leshkova, 2003).
- Smell – Smell is one of the keenest senses in the body and can be a great enhancement for worship. Some churches have a familiar smell of incense or wax. Consider other ways of involving this important sense but be sensitive to children with allergies or asthma.

- Touch – Hugging, embracing and handshaking are becoming more and more familiar in worship but be sensitive especially with children and cultural orientations.

- Taste – Sharing in Communion or Eucharist. Children who have confessed the Lord Jesus Christ as Lord and Savior should be welcomed to participate in the sharing of the Eucharist. Other opportunities include other social and fellowship events where children living with neurodevelopmental disorders should be embraced and be involved in accordance to their capacity.

Both Hussein (2012) and Baraza (2018) affirm that having multi-sensory environments in the learning institutions that embrace children living with disabilities is beneficial as it provides a two-way learning process for both the teachers and the learners. As such, it is highly recommended for teachers to employ personalized goals and values suitable to their teaching and individual learner needs. If this is done, no child would be left out of the spiritual formation. Fowler (1981) rightly pointed out that faith development is a universal quest. Every human being, regardless of their religious affiliations, age, abilities or background, does have a spiritual quest.

In order to better understand the effects of marginalization on neuroatypical children's spiritual development, the church in Africa must engage a holistic, multidisciplinary approach that incorporates the complex interactions between biological, physical, and psychosocial factors impacting children's faith development. Such work should be led by an interdisciplinary, global team of researchers, educators in collaboration with local and nation-wide administration, church agencies and community members, including the individuals living with neurodevelopmental disorders and their primary caregivers. This approach will allow the church to more effectively intervene in the spiritual formation process of the children living with neurodevelopmental disorders within the faith communities.

This research covered the qualitative aspects of children living with neurodevelopmental disorders in the church; prevalence, perception and structure. Further research on the same should be conducted quantitatively to determine the statistics based on the recommendations that emerged from this study. Also, similar research should be conducted in other church denominations and findings compared to this research. Lastly, the researcher recommends for empirical studies to be conducted that will inform monitoring and evaluation indices that can be

adopted in any church to measure the effectiveness of inclusion of neuroatypical children in the church.

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