Approaches for Inclusion of Children with Neurodevelopmental Disorders in Spiritual Formation Programs.

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ABSTRACT:
This study interrogates the approaches for Inclusion of Children with Neurodevelopmental Disorders in Spiritual Formation Programs in Kenya. Children living with neurodevelopmental disorders are categorised as special children. These children are at most times excluded from faith formation activities and decision-making, an aspect that greatly affects their development and self-esteem. Nonetheless, such children are likely to have their formation journey in faith halted for lack of participation. The study took an explorative qualitative approach and employed the social model of disability by Oliver (1986), Multiple Intelligence Theory by Howard Gardner (1983), Faith Development theory by Fowler (1981), and Ecosystems Theory by Bronfenbrenner (1979) in explaining children’s spiritual formation. The study was carried out among selected branches of a mega church in Nairobi. The Mega Church comprises a population of over 50,000 congregants. The accessible population comprised 93 individuals, and judgmental/purposive sampling was used to narrow the sample to 28 participants. The study's target population was formed by Christian education pastors, Sunday school teachers, senior pastors, children’s pastors, and parents. The process of collecting data was carried out through face-to-face in-depth interviews and focus group discussions and further analysed and presented in themes. The study findings indicate that in the inclusive spiritual formation of children living with neurodevelopmental disorders, various stakeholders ought to be involved in devising approaches for systematic change at all levels. These results contribute to the body of knowledge through publication and will help stakeholders such as religious institutions on strategies for inclusion of children living with neurodevelopmental disorders, especially as far as the curriculum, learning environments, and approaches to teaching for the formation of children with neurodevelopmental disorders are concerned.

Key Terms: Neurodevelopmental disorders, Spiritual formation, Learning environments, inclusive education.

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INTRODUCTION

Children living with neurodevelopmental disorders are categorised as special children. These children are at most times excluded from faith formation activities and decision-making, an aspect that greatly affects their development and self-esteem. Nonetheless, such children are likely to have their formation journey in faith halted for lack of participation. Neurodevelopmental disorders such as intellectual disability, autism, cerebral palsy, and dyslexia arise from impairments in a developing brain and/or the central nervous system. They were referred to as “global developmental delays”, referring to delays in two or more areas of development or milestones (Gupta et al., 2016), and they affect a child's behaviour and ability to learn.

Kenya has a policy on inclusion aimed at making education accessible so that all children with disabilities can go to school. This includes providing space, resources, and training in mainstream schools so that children with and without disabilities can learn alongside each other. Even though, as a matter of policy, Kenya recognises the right of individuals with disabilities to quality education, devoid of discrimination and on an equal basis with others (Ongeri, 2009), “what people see on the ground are integration and not inclusive education” (Villamero, 2017). Suffice it to say that inclusion policy in Kenya does not necessarily mean that inclusion happens in practice. For example, the spiritual formation of children living with neurodevelopmental disorders has been ignored and mainly trivialised in many Christian formation ministries. This neglect has created a literature gap and chasm between policy and the actual implementation of the faith formation programs.

In research conducted by Oliver (2015), evidence shows that the church, for example, is currently faced with lassitude, having a generation of children who are yet to obtain the knowledge of the gospel of Jesus Christ, introduction to the character of God, familiarisation with the scriptural teachings, and access to the wealth of Christian experience. Fisher (2011) rightly states that at the core, all humans are spiritual beings. However, as Todd (2009) enlightens us, no spirit travels through life “unformed”. Inclusion is only possible when Sunday schools are designed and administered so that all children can experience quality learning and recreation together (Baraza, 2018). This study purposes to address the literature gap and the policy gap in strategising Children's formation through church involvement, hence growing their faith. The study highlights how strategies for the inclusion of children with neurodevelopmental disorders in spiritual formation programs in worship congregations can be formulated.

LITERATURE REVIEW

Inclusion in faith development is a relatively new concept (Patka, 2014), and very few studies address Neurodevelopmental Disorders among religious circles. Equally, the religious institutions that ought to be custodians of data of their congregants do not have the records of information on the representation of Neurodevelopmental Disorders. The literature gap is also highlighted as there is no data on Practical tools to support inclusion in learning institutions. These, coupled with a lack of policy on the inclusion of children living with Neurodevelopmental Disorders in faith communities, have rendered these children's spiritual formation ineffective. Thus, as has been observed by some empirical researchers such as Ouellette-Kuntz et al. (2012); White (2014); Anderson (2015); Lee (2014); and Baraza (2017), there is a loss of the relevance of the faith communities to the children with cognitive impairments.

This renders the clergy and their teams ineffective in the inclusion of children living with Neurodevelopmental Disorders in the faith communities, and hence, these children end up being ignored, as though they don't exist in
the community. Even though Peterson (n. d.) posits that many times the lack of inclusion in faith institutions may be due to “unconscious attitudes”, but “unconscious attitudes” are equally damaging and destructive to the children with neurodevelopmental disorders. The destruction is done largely when the leadership either ignore these children’s presence and uniqueness hence end up defining all the children in their midst chronologically and giving them the same learning scales (integration), or by defining children living with neurodevelopmental disorders as children who are incapacitated intellectually hence not able to learn (segregation).

Patka states that few studies have delved into addressing the understanding of cognitive impairments among religious circles and capture their opinions with regard to the inclusion of persons with neurodevelopmental disorders into faith communities (Patka, 2014). Few congregations have reliable information on how many of the children in their congregations are living with neurodevelopmental disorders and how these affect their learning and spiritual growth in the long run. The marginalisation of Children living with neurodevelopmental disorders is more pronounced even as they are often excluded from resources and decision-making, which trickles down to harming their faith formation journey (Baraza, 2017).

Even so, empirical research indicates that all children can thrive in sensitive and supportive environments to their unique needs. The social model of disability by Oliver (1986) posits that “disability “is socially situated and hence ought to be understood within the broader cultural construction, bearing in mind the prevailing attitudes and assumptions and not be narrowed to the disorder of the disabled person. Multiple Intelligence Theory by Howard Gardner (1983) states that all human beings have a unique combination of competencies (intelligence) within them that can advance ability, skill and solve problems. This intelligence relates to a child's distinct abilities and unique ways of demonstrating their intellectual abilities. The theory underscores various types of intelligence and aptitudes used by the human brain that permits children to learn and express themselves in diverse ways (Silveira, 2007).

Spiritual formation occurs within given ecological systems as grounded in Bronfenbrenner’s ecological systems theory, which views the child as developing within a complex system of relationships affected by multiple levels of the surrounding environment (Bronfenbrenner, 1979). This sentiment was equally upheld by the great theologian Alexander Campbell (1839) in the "Christian Systems", in which he postulates that the "Christian spiritual life is never lived apart from particular contexts". Once a child goes to Sunday school, his/her world broadens. Sunday school exposes the child to other cultures as he/she is surrounded by family members and teachers/leaders, peers, and members in their faith communities. These sub-groups in the sphere of the child's development can be classified as factors influencing the spiritual development of children. That is why this paper focused on Sunday school teachers and pastors as major factors influencing the spiritual development of children living with neurodevelopmental disorders in the selected assemblies.

If we realise that young children, including those living with neurodevelopmental disorders, are beginning their journey by being learners and experiencing life in all of its diversity and beauty, then perhaps any steps we make in helping them start that journey are valued. We don't necessarily have to do it all, but we can do part of it. There is no annotation embedded on a spiritual quest as a preserve for “people with heights over 5’7; 20/20 vision; ability to hear; IQ 100 or higher; acceptable public behaviour’… one’s mental, physical, or sensory condition is neither a help nor a hindrance in relationship to God” (White, 2014). Further, James Fowler’s theory, which has been very influential in
pastoral work, and spiritual guidance (Coyle 2011), theorises that all human beings have a spiritual quest.

As equally affirmed by Sachdev (2012), various perceptions regarding this topic converge at one fundamental point; the importance of spiritual education lies in fostering the children's 'holistic development and 'wellbeing'. In giving a definition that has been embraced by many Christian scholars as far as children's spiritual formation is concerned, Tolbert postulates that “Children's spirituality is the child's development of a conscious relationship with God in Jesus Christ, through the Holy Spirit, within the context of a community of believers that fosters that relationship, as well as the child's understanding of - and response to - that relationship” (Tolbert, 2014). Equally, Gangel and Wilhoit (1998) define spiritual formation in children as “the step by step and stage by stage process through which a child is guided, encouraged, nurtured, admonished, and disciplined to embrace Christ as Savior and be disciplined to develop as a Christian through the work and power of the Holy Spirit”. From those two definitions, we can simply state that children's spiritual formation is the process by which a child is guided, encouraged, and nurtured to embrace Christ as Savior and get disciplined through the Holy Spirit's work and power within the context of a community of believers that fosters that relationship.

This study agrees with Roehlkepartain et al. (2006) that the idea of spiritual formation adds a significant dimension, especially in the fact that it emphasises the process. Sunday school teaching is more than just meeting once a week with a small group of children and telling them religious stories. Rather, it is a construction business in which serious effort is made to build each child into a temple of the Living God (ECC, n. d.). To this end, Oliver (2015) affirms that the faith communities need to develop faith formation models that would enhance all-age learning and lead to greater commitment and spiritual growth of their members by allowing “knowledge grounded in solid pastoral practice and sustained by a conscious commitment to spirituality shaped by the curriculum, ethos, and activities of the programs” (Lesniak, 2013). Therefore, the paper thus addresses some of the approaches that can be put in place by the faith formation communities and worship congregations as a whole in order to ensure the upright and spiritual formation of children with neurodevelopmental disorders through inclusion. The next section highlights the methodology that was used in conducting the research.

METHODOLOGY

The research was an explorative qualitative study that used Straussian grounded theory (Muhaiyuddin et al., 2016), single case with embedded units design. This research design is suited to tasks that address a subject matter to which little is known (Shodhganga, 2007), such as this one because of its ability to entirely describe a phenomenon and give in-depth information to describe the situation within a context (Muhaiyuddin et al., 2016). Given the importance of this study, a Straussian grounded theory was considered the most appropriate approach to use "as it emphasises the processes in which participants engage as they attempt to manage a given problem" (Cullingworth, 2014). A grounded theory approach was also appropriate in an exploration of church leaders' perceptions toward the inclusion of children living with neurodevelopmental disorders due to its keen “appreciation for and attention to the data” (Feeler, 2012). Therefore, a mega church and its Branches in Nairobi, Kenya, was selected as a single case with embedded units instead of several different churches (Baxter & Jack, 2008).

Using purposive sampling, the accessible population had 93 members. This being a qualitative study, it could not interview all 93 members; hence the researcher resorted to judgmental/purposive sampling and chose 28 participants who were deemed “the appropriate number of
participants” (Asiamah, Mensah, and Oteng-Abayie 2017). The sample size was drawn from the six selected assemblies. The results of this qualitative study are based on interviews of five Sunday school teachers, five senior pastors, five Christian education pastors, six children’s pastors, three administrative leaders serving in the Deacons’ Board and the Elders’ Council, and four parents from the selected assemblies, which according to Asiamah, Mensah, and Oteng-Abayie (2017), refers to the group of individuals or participants with the specific attributes of interest and relevance. All respondents voluntarily participated in the study. Grounded Theory Tools employed were the semi-structured in-depth interviews, focus groups, field notes, and observation.

Coding
The analysis involved a three-step coding process described by Blair (2015): open coding, axial coding, and selective coding, using the NVivo11 computer program. The transcribed manuscript was organised in significant themes/nodes and categories with the aid of NVivo11 according to codes. As progress was made with the analysis, additional sub-themes were included to categorise significant connections, relationships, and trends. The qualitative analysis process was concluded by the description of thematic relationships and patterns of significance to the research. However, the qualitative process was a repeated venture and hence was approached in a spiral manner, rather than a fixed linear action to allow for exhaustive extraction of information, until data saturation was obtained which was the standard measure “for determining when adequate sample size” had been reached (Gentles et al., 2015).

From the analysis, it was observed that:

a) Children with neurodevelopmental disorders existed in all the assemblies that were sampled,

b) There was no tabulated data in the church concerning the numbers of children living with neurodevelopmental disorders in Sunday schools,

c) There were varied perceptions towards the support of the children with neurodevelopmental disorders in their spiritual formation journey,

d) There were no programs that had been designed and ran for the spiritual formation of the children with neurodevelopmental disorders in all of the assemblies researched.

DISCUSSIONS ON DATA
The main objectives of this study were to explore perceptions, prevalence, and strategies of inclusion in spiritual formation programs of children with neurodevelopmental disorders. Three themes emerged from the categories, namely; prevalence, perceptions, and strategies.

Prevalence of children with neurodevelopmental disorders in Sunday schools
The respondents’ feedback indicated that there were cases of cerebral palsy, ADHD, Autism spectrum disorder, and dyslexia in the Sunday schools. They approximated the average number of children living with neurodevelopmental disorders in the various assemblies to be 1% to 2%, confirming the literature findings by other researchers that neurodevelopmental disorders are common and affect 1% to 3% of children globally (Shevell., et al. 2003). For Kenya, being a developing country, the neurodevelopmental cases are certain to be high because of non-genetic factors such as malnutrition, poor healthcare and environmental factors (Iqbal, Baig, Bhinder, and Zahoor 2016).

Perceptions towards children with neurodevelopmental disorders in Sunday schools
There were varied perceptions by the church leadership towards the inclusion of the children with
neurodevelopmental disorders in the spiritual formation programs. Some respondents preferred segregation/isolation from the programs. Others advocated for segregation plus integration at the same time. Still, others advocated for integration alone. But a few others advocated for the inclusion of children with neurodevelopmental disorders in the spiritual formation programs in the church.

The Sunday school teachers’ focus group interviews revealed that most of the Sunday school teachers struggled with the approach of inclusion of these children in the available programs. One parent narrated her ordeal:

“Sunday school teachers have difficulties in identifying children [with neurodevelopmental disorders]. (R20)"

Another respondent echoed the same, stating:

“We have children in many of our assemblies, and pastors and the workers have no idea how to treat them (R9)"

Respondent R19 stated:

“The curriculum that we have is not engaging enough for these children; the teachers don’t have prerequisite skills in dealing with these kinds of children; the curriculum that is there is not meeting the needs of these children.

These eventually led to a lack of proper responses to the needs of children living with neurodevelopmental disorders in Sunday schools, a sentiment that several respondents seemed to affirm, noting that they did not know how to treat children with neurodevelopmental disorders in the Sunday schools.

Strategies for inclusion of neurodevelopmental disorders

This theme addressed the approaches toward inclusion of children with neurodevelopmental disorders in the spiritual formation programs and highlighted;

a) Church Policy on the inclusion of children with neurodevelopmental disorders

b) Awareness of neurodevelopmental disorders

c) Training of the personnel on neurodevelopmental disorders,

d) Inclusive Curriculums

e) Budgetary allocation

Some respondents said that the teachers gave very minimal attention to the children with neurodevelopmental disorders in Sunday school classes. The teaching methodologies employed by most teachers were suited for the typical/regular children as posited by respondent R11, “The teachers give them only like 20% support because there is a lack of one-on-one interaction with the teachers since there are other children who take the rest of 80% support”. Therefore, it emerged that the Sunday school teachers and pastors were not putting into consideration the learning styles and pace of children living with neurodevelopmental disorders.

One respondent noted, “We are sold out to the majority because these cases are very few and tend to be neglected or ignored”. An observation equally noted by Villamero (2017) when he states that in Kenya, there is a tendency to emphasise or focus on sensory impairments such as visual and hearing impairments, and missing out on some disabilities, especially ‘invisible disabilities’ such as autism, cerebral palsy and intellectual disability. Equally, an empirical study by Carlson et al. (2006); and Vettiyollil (2015) indicated unreachable expectations that the church places on its members. Religion is largely interpreted as a language game, and therefore it is dependent on the ability to socialise. One respondent explained, “We do not have any platform that allows them to be involved in service”.

Respondents seemed to agree that even though the church had not yet embraced the aspect of involving the children living with neurodevelopmental disorders in the church service ministry, however, given the opportunity, there is value in involving the children with neurodevelopmental disorders in the service ministry of
the church. For example, respondent R2 stated, "I think is a way of telling them you have something to offer that will validate them," a sentiment that several other respondents supported.

Relevance: The study findings are relevant to the wider study of the spiritual formation of children living with neurodevelopmental disorders as they highlight their place in religious circles and society. The importance of the religious circles to understand the need for the spiritual formation of children living with neurodevelopmental disorders is crucial and cannot be overemphasised. This is so that those who are not personally or directly affected by neurodevelopmental disorders can still understand and appreciate the fact that these children affected by neurodevelopmental disorders are human and with a spiritual quest like any other person.

THE EMERGENT THEORY AND ITS APPLICATION
Inclusive spiritual formation is a function of and influenced by prevalence, perceptions, and strategies employed, thus requiring a systematic change at all levels; pastors, teachers, Sunday school children, the church assembly communities, policymakers, decision-makers, families, and society at large.

The study revealed that inclusion of the children living with neurodevelopmental disorders is a neglected aspect in the church and the country. Below are some approaches that would be helpful for the Sunday school teachers, the pastors, as well as the parents of children with neurodevelopmental disorders as approaches for inclusion of children with neurodevelopmental disorders in spiritual formation programs:

Suppose we are to include children with neurodevelopmental disorders in our worship congregations. In that case, we need to start acting and thinking in terms of an inclusive "we" and move from seeing them as "apart from" to a "part of" the congregation (White, 2014). In addition, we need to consider and relook at the curriculum, learning environment, and approach to teaching for children with neurodevelopmental disorders.
The Curriculum

Inclusive education and formation perceive learning and formation as a process—not content-based (Mugambi, 2017). The curriculum refers to the course of study the learner embarks. A spiritual formation curriculum would have an underlying philosophy that is based on drawing people unto the obedience of God. Every curriculum has an objective of attaining mastery of the subject within the context of a given worldview.

The goal of a spiritual formation curriculum is to discover the truth concerning the matters of faith. However, a curriculum for the spiritual formation of children with neurodevelopmental disorders should be lively and appropriate to their needs and the community's needs as a whole (Ferguson, 2008).

Factors to be borne in mind when designing a curriculum for children with neurodevelopmental disorders include, among others:

- The objectives to be achieved by following it,
- The personnel involved, that is, teacher and learner (every child living with neurodevelopmental disorders is unique and special and should be treated as such),
- The scope of what is to be taught or content,
- Process (all elements that facilitate learning); method, teacher, learner, etc.;
- The context or environment where it will be applied,
- Finally, the timing, when it will be implemented (Ferguson, 2008)

Ferguson states further that a curriculum should be based on the mission and vision of the faith community. The following qualities should characterise a good curriculum:

- It must be based on Scriptures as the only rule of faith and living;
- It must revolve around the person of Christ;
- It must relate to the pupils for whom it is intended (Ferguson, 2008)

An all-inclusive curriculum should provide all children with a learning experience filled with activities that involve various senses of learning within the learning environment.

The learning environment

Children with neurodevelopmental have the same needs all the other children. Empirical studies indicate that all children benefit from warm, secure and nurturing environments. They need acceptance with their personal patterns of weaknesses and strengths. Inclusive learning environments should promote the use of all senses allowing children with neurodevelopmental disorders to:

- To hear language appropriate to them to understanding
- Have extra time to learn and practice new skills
- Have tasks simplified
- Know that their efforts are valued
- Access a variety of ways to learn, such as touching, looking and listening.

This is important for the development of self-esteem, which builds confidence for learning new skills. Many children with neurodevelopmental disorders will need extra help in one or more areas of their development. Equally, if equity and equality are to be experienced in the faith formation programs, ease of access to the learning environments must be enhanced for children living with neurodevelopmental disorders. This would call in for safe and supportive environments. Safe and supportive environments are very significant for any formation programs. The principles of safe and supportive environments apply to all aspects of the educational setting, be it in church or elsewhere. A safe and supportive environment normally pays attention to fundamentals in the physical environments such as:

- The quality of the relationships shared in the educational environments both from the teachers and the peers.
- The approach is taken to programming and planning for individuals and groups.
- The decisions about the physical layout of space, aesthetics and structure of the day
Social relationships are the interactions between the child and the various individuals or groups in their surroundings.

The teachers, policymakers, and all stakeholders should be willing to advocate for children living with neurodevelopmental disorders (Baraza, 2018).

Physical surroundings of the children's social environments such as facilities for education, open space for recreation, restrooms and all the physical environments to eliminate any hazard. These environments should be rich in interesting activities that arouse curiosity and offer moderate challenges hence providing a warm, responsive, and supportive environment that encourages exploration, stimulate curiosity, and provide play and learning materials that accelerate the children's intellectual development (Schunk et al., 2010).

Another critical factor to consider is that children living with neurodevelopmental disorders need environmental stimulation. Learning for children with neurodevelopmental disorders may be facilitated by interactive multi-sensory systems. Therefore, it would be worth it if the Church explored the idea of "Virtual Environments ", also referred to as "Virtual Reality", in the faith formation process of children living with neurodevelopmental disorders. Considered from the cognitive and sensory psychology points of view, learning for children with neurodevelopmental disorders "may be facilitated by interactive multi-sensory systems" (Dionne-Dostie et al., 2015).

One of the most attractive characteristics of virtual environments is their ability to bring the outside world into the classroom. Virtual environments can be used for communication, expressing "ideas,” and learning about communication through guided training and rehearsal in simulated social” situations (Cobb, 2007). This is in tangent with the prevalent theory of Gardner's Multiple Intelligences. A wide variety of visual, auditory, and sensory experiences will help promote brain connections.

Responsive environments for children living with developmental delays are key contributions toward their learning outcomes. This virtual reality method of learning is ideal for learners with neurodevelopmental disorders since it provides the learner with the opportunity to experience the subject matter that would otherwise be difficult, if not impossible, to illustrate or describe with conventional methods. In addition, a wide variety of visual, auditory, and sensory experiences will help promote brain connections for children living with neurodevelopmental disorders.

**Approaches to teaching**

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 colour in worship. Using colours enables children to easily restate God’s plan of salvation (Jarvis, 2016).
- **Sound** – stimulates the children living with neurodevelopmental disorders into learning through music, visual stimulation, motion, and dancing and thus stimulating and developing of their different senses, which in essence enliven and enhance 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 to 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 with 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 personalised 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. Regardless of their religious affiliations, age, abilities, or background, every human being does have a spiritual quest.

CONCLUSION

Inclusive education systems are an important part of inclusive societies. Inclusive education requires that a mainstream school considers all learners in its area as fully belonging to the school and its varied activities (Mugambi 2017). Every child has the same right to access education and spiritual formation. The “goal of inclusive education is rooted in policy initiatives developed to ensure that good quality education is accessible for all” (Heezen 2017). According to Metts, the ideal disability approaches to consider should be comprehensive with a combination of rehabilitation approaches that maximise the functional capabilities of children with neurodevelopmental disorders. In addition, the inclusion and empowerment approach facilitate their active participation in the spiritual formation programs and the society at large (Metts, 2000). The pastors, teachers, Sunday school children, the worship congregations, policymakers, decision-makers, families, and the society at large need to realise that children with neurodevelopmental disorders are gifted differently in the aspect of intellect; hence, they also “learn differently and grasp ideas at a different pace from their peers” (Baraza, 2018). That notwithstanding, it is for everyone concerned to consider that limitations in individuals often coexist with strengths. An individual level of life functioning improves if appropriate personalised supports are provided over a sustained period (Riou et al., 2009). Ultimately, inclusive systems for learning can only be created if ordinary learning institutions become more inclusive and become better at educating and forming all children in their communities irrespective of their abilities and disabilities (Mugambi, 2017).

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