Integration of Parents' Narratives in Creating a Culture that Is Holistic and Supportive towards Cognitive Learning Disability

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Abstract

The rationale for this anthropological paper is to present educational challenges faced by parents who are parenting children with a cognitive learning disability in rural schools of uMkhambathini. Through the qualitative research design, emic experiences were anthropologically recorded. The data collection was completed through life history and focus group interviews. Fifteen parents were purposively recruited from the community who had children with cognitive learning barriers and who attended mainstream schools. Research findings revealed that although some parents would eventually come to accept the natural being of their children, the socio-cultural and the South African education system in rural areas still need be prepared to accommodate these children. This paper has contributed a three-tier encompassing model as a solution that befits the lifespan of affected children with a cognitive learning disability and is also supportive of teachers thus caring for and supporting the educational needs of a child with a cognitive disability. This journey is filled with obstacles and a combination of emotions. Data analysis also revealed that this human rights issue excludes children from rural areas, which needs to be addressed. The theorized three-tier is contributed as a holistic consideration of learning disability culture. The solution model is also contributed as a monitoring tool which will monitor (i) the South African inclusive policy on education, (ii) the integration of parents to shape the future of their children with a cognitive learning disability; (iii) to ensure that children with a cognitive learning disability are treated and recognised as human beings who should be granted access to education without being compromised.

Keywords

Parent Narratives, Inclusive Support, Cognitive Disability, Learning Disability,

Experiences

1. Introduction

This paper focused on collecting the lived experiences of parents of children who have a cognitive learning disability (CLD). A reasonable amount of literature sources were reviewed. The rationale for this study is that while cognitive disability has been spoken about, very few anthropological studies have paid attention to the experiences of parents and their children in rural areas. Secondly, it was essential to illuminate stagnation or gaps in the South African inclusion policy, which does not integrate learners with cognitive learning disabilities. The paper argued that the South African inclusion policy, which is the mandate of the education sector, has not practicalized the inclusion of rural areas and children with cognitive learning disabilities; hence they are often excluded from the education system that befits their needs. In anthropology, empirical studies allow researchers to tap into the real world of the studied population.

The general impression that was gathered from all literature sources on the experiences of parents regarding cognitive disability was that the nature of life will always present daily challenges for most parents who provide care for affected children. The outside world, together with societal devaluation and exclusion of people who deviate from standardized norms, has not presented any opportunity for accommodating culture (Reid-Cunningham, 2009). In the abundance of writings addressing parenthood and parenting issues, there has been a lack of a comprehensive analysis of the experiences of parents raising children with cognitive disabilities and attending mainstream schools in rural areas. This paper aims to present possible solutions that could gradually introduce a supportive culture for parents in their journey of caring for children living with cognitive disabilities. This paper was approached with anthropological theoretical lenses and extensive use of research methodology in anthropology to gather the experiences of parents. This was for the purpose of extracting solutions as desired by parents for the betterment of their lives and children.

Ginsburg and Rapp (2013: p. 55) aver that anthropologists have focused on people with any mental disability from as early as 1960. Their writings and research focused on mental health. Their ethnographic studies told the stories of people in the United States and encouraged a longer-term focus on the subject by confirming that people had something to say. To date, their research contribution is regarded as foundational for its insights and attention to a historical trace of disability as a subject area in anthropology as a discipline and as the study of humanity. According to Albion and Henschell (2008), other scholars followed Edgerton's pioneering work in studying people with cognitive impairment. His ethnographic work is thought to have laid the groundwork for Nakamura's engaged research at Bethel House with a rural Japanese community of

people with psychiatric disabilities.

Since then, ethnographies in anthropology have enabled more studies to decipher personal stories and document knowledge that will inform solutions in all collective social realities (Taderera & Hall, 2017). Social relationships have been viewed as more than just individual tragedies, with families and communities also being understood to bear the burden of disability. The following section discusses cognitive disability as a reality that the parents in question face, as well as its broader impact on the lives of both children and their parents, as revealed by the literature.

According to Reid-Cunningham (2009), the disciplinary dimensions of social, cultural, and medical anthropology have enhanced our understanding of disability as a component of human living. According to reports, anthropological interpretations of disability have included concepts such as "the other", deviance, and stigma, which could inform our broader understanding of human behavior in the social ecology (Reid-Cunningham, 2009). According to the scholar, anthropology studies humanity and relies heavily on cultural relativity as an organizing principle. The current paper falls under the socio-cultural subfield of anthropology. This branch of anthropology examines human experience, including status, religion, law, stigma, and deviance (Reid-Cunningham, 2009). This paper is interested in integrating disability into social realities, particularly the perspectives of parents who care for and nurture children with disability.

In recent years, there has been a growth of evidence-based research on the impact of the family on parental social progression; some of these studies have analyzed the role of different household factors on student learning barriers (Robledo-Ramón & Garcia-Sánchez, 2012). The findings indicated that the household setting, parents' attitudes toward their children and parental involvement in education all play a role. Scholars such as (Pierangelo & Giuliani, 2008) argued that learning difficulties vary depending on the individual in a learning space, and the required specialized attention is spoken in different modes because their parents and teachers pre-empted their cases. In a study that sought parents' perspectives on mainstream and special school partnerships, (Frederickson et al., 2004) discovered that some parents perceived the absence of special schools in their community as jeopardizing the essence of inclusion and inclusive education.

2. Brief Literature Reflection

Ginsburg and Rapp (2013: p. 55) suggested that the anthropological focus on people with any form of mental disability was pioneered by Ruth Benedict (1934) as well as Hanks and Hanks (1948) and Edgerton (1967, 1993). Their writings or studies were concerned with mental retardation. Their ethnographic studies told the experiences of people in the United States and encouraged a more sustained continuation on the subject as they confirmed that people had something to narrate. Their publications drew largely on the emic perspectives,

that is, "the world/experience of the subject" instead of the etic "analysis by the other". Their research contribution is regarded as foundational for both its insights and attention to a historical trace of disability as a subject area in anthropology as a discipline and as the study of humankind.

Ethnographies in anthropology have since allowed more studies concerned with the embedment of disability in collective social realities. The rationale was to Taderera and Hall (2017). Families and communities endure the burden of having to care for people with disabilities. This is because identities have not been accommodated as accepted in the normative way as many see race, gender and other embodied identities in our societies. Taderera and Hall (2017) assert that cognitive learning barrier is a disability referring to children who experience learning challenges without presenting with obvious physical disabilities and who struggle with comprehension to a greater extent than the average child. Cognitive disability (CD) is also a learning disability caused by genetic and/or neurobiological factors that alter the brain functioning of school-going children and those who have completed their schooling journey. Cognitive disability is a type of disability involving various types of mental challenges. A person or a child that has experienced a cognitive disability presents with processing problems that can interfere with learning basic skills such as reading, writing and/or maths. These symptoms also come with an inability to demonstrate higher-level skills such as organization, time planning, abstract reasoning, long or short memory and attention (Willingham-Storr, 2014). Studies conducted by psychologists and psychiatrists have confirmed that parents barely accept this learning challenge because it may not be evident to them. Some parents saw symptoms from the early stages of their children's development. Other parents find it difficult to accept their children's cognitive disabilities because they probably did not experience it with their other children. However, psychologists admit that parents are not to be blamed because there is no bluebook for parenting, there is no perfect parent, and parents are heterogeneous by nature. Pierangelo and Giulian (2008) found that children with learning challenges symbolically tread and acclimatise with various difficulties compared to those with normal identities in an ordinary learning setting. Parenting a child with any form of disability is a task that is not easy for any parent on any day (Thwala et al., 2015). However, the parents of these children remain in admiration and live by the desire to see their children acquire skills and attain educational achievements. Parents are often referenced as punished by God and are mostly not supported by religious organizations and government and non-government agencies. Such pressures have resulted in the abandonment of children from birth as children were left at riverbanks in Ghana, hoping to be taken or killed by river floods. Kang et al. (2016: p. 2) observed that "the birth of a disabled child is said to provoke dispute and self-blame within the family and society because parents may be stressed and be faced with a responsibility to act in support of the born child. Parents encounter various demands and restrictions, which can

cause the family unity to collapse. Parents suffer from endless sorrow, a sense of loss and hope, depression and guilt for their children". Parents with disabled children are mostly not supported by the government, especially in ensuring that every rural community has a special school that children with any disability can access and progressively develop. Taderera and Hall (2017: p. 1) indicated in their study that "challenges faced by parents of children with a cognitive learning disability are exacerbated by factors such as community attitudes, cultural beliefs as well as institutional challenges. Because of the superstition that evil spirits, witchcraft or a mother's improper relationships cause learning disabilities, women are often abandoned by their husbands to have to bear the burden of caring for the child alone". Oti-Boadi (2017), argued that "raising a child with any type of disability has tremendous psychological problems, often turning into depression, anxiety, and somatic symptoms for parents". Parents of children with disabilities try more and devote more free time to solving their child's problems. It is expected that parents will try, for personal and financial changes, to adapt to new roles to meet the child's unique needs. Siddiqua and Janus (2017) added that parents are often worried about the transition from pre-school to higher education levels because children with cognitive learning challenges need specialised school systems that are often unavailable in rural areas. Bingham (2017: p. 12) asserts that "in South Africa, many children with disabilities experience exclusion from health and education services, amongst other support infrastructure, which is crucial for their development". The position paper of the United Nations Children's Fund (2013) advocates for the right of children with disabilities to education and an approach to inclusive education based on human rights. The report contains the slogan "Education for All" (EFA), which is an international commitment to ensure that every child and every adult receives good quality basic education based both on human rights and on the generally accepted belief that education is the basis of individual well-being and national development. In the position paper, inclusive education systems have developed schools based on "a child-centred pedagogy capable of successfully educating all children, including those with serious disadvantages and learning disabilities. Furthermore, the merit of schools is not only that they are capable of providing quality education to all children; their establishment is a crucial step in helping to change discriminatory attitudes will create welcoming communities which is holistically inclusive. Findings by Moen et al. (2012) revealed that parents are always in fights with educators who do not seem to accept their children in mainstream/formal learning schools. Their children are constantly reminded that they will never make it to the next grade without providing the necessary support that they need. To have a learning/cognitive barrier does not mean that one is totally not a capable learner, but the problem is that the disabled learner may need extra support to work on the completion of their tasks. Bornman and Rose (2010) observed that it is not teachers who are unwilling to support learners with learning barriers, most South African schools are still without a cur-

riculum that accommodates the variety of learning patterns of different learners. There is a general lack of support and resources from higher structures and a prevailing negative attitude towards disability which contribute to the general bewilderment in South African schools. Mak and Kwok (2010) conducted a qualitative study in China where 188 Chinese parents with children living with autism were recruited to participate in a study which confirmed that the stigma attached to learners with autism does not only affect the discredited learners but extends to the individuals that are closely related to the stigmatized children. Parents were listed as the closest to falling on the receiving end, where societal misconceptions blame them for giving birth to disabled children.

UNICEF's (2012) position paper calls for a radical change within the school system and argues that if teachers' values and principles are incorporated, the world's most vulnerable and deprived children will realise their fully deserving right to education. This ongoing goal of the UNICEF has a holistic approach of dedication and incorporates the values involved in the education process. The envisioned goals as listed by UNICEF (2012) to help promote the education of children with disability included, giving equal value to every being; Helping everyone to experience their own existence; Promote learning and participation in education; Eliminate the exclusion and discrimination and barriers which inhibit education and participation; Develop cultures, policies and practices to promote equality and equality for all; Learning comprehensive ways to share comprehensive lessons; Realize the difference between children and adults in the forms or modes of learning. Recognize the right of children to high-quality education locally, improve staff and parents as well as children's schools and emphasizing the value of building positive school communities.

3. Theoretical Framing

This paper employed Ecological Theory, Identity Theory which allowed an inductive understanding of how micro, meso, exo and microsystems as stages of progressive social life which can create and influence identities and shape one's experience. These theoretical frameworks befitted the study. Through them, we were able to record the experiences of parents in rural areas of uMkhambathini whose children are excluded from mainstream education because of learning cognitive disabilities. Through these theoretical lenses, parents experience multi-dimensional parenting issues because of having given birth to a child with a cognitive learning disability. The paper recorded identity, communal and familial related experiences.

4. Methodology

This anthropological paper drew mainly from the qualitative interpretive research paradigm. This paradigm permitted the successful collection of personal "emic" experiences through personal engagement such as through life-history interviews and focus groups with only parents who were affected by the particular topic and volunteered to participate in the research. As discussed by Ormston

et al. (2014) qualitative research is mostly employed to record the overall sentiments of human life in relation to their socio-cultural surroundings. The paper analyzed in pouring personal experiences from parents. This prompted the use of a qualitative approach to achieve this paper's purpose.

4.1. Sampling and Subjects

Fifteen parents were purposively recruited to participate in this anthropological study voluntarily. Their relevance to the study was that their offspring were born with cognitive learning disabilities and had been excluded from the South African inclusive education policy hence they were deemed relevant. These participants (parents) had children who attended in the three local mainstream schools; Asizenzele, Inkanyezini, and Table Mountain Primary School who after few years of school attendance were excluded completely from the schooling system after having not met progression requirements for normal learners yet they had no school in the area to cater for their learning needs. The purposeful identification of participants started with an initial meeting between the researcher, school principals, governing bodies from the three schools and the parents.

4.2. Data Collection

Data collection took eight months where a series of life-history interviews and focus group discussions were held with the sampled population of fifteen parents whose children are affected by a cognitive learning disability. Du Plooy-Cilliers et al. (2014) opine that qualitative research is about adopting a worldview of the subject where researchers immerse themselves in an in-depth understanding of the phenomenon. Data collection was guided by a set of sixteen questions that were qualitatively worded. These questions permitted an open-ended interaction between the researcher and the subject.

4.3. Ethical Considerations

Parents signed consent for participation; there were two sessions for data collection from each school and data collection altogether lasted for over one week. Prior to data collection, we solicited gatekeeper clearance from local dignitaries. The University of KwaZulu-Natal Human Research Council issued study clearance. Participants in the study were guaranteed confidentiality of information, they were promised the use of pseudonyms to conceal their identities. Prior to data collection, participants were assured that their voluntary participation in the study was not going to be dishonored. They were also unconstrained to discontinue their participation should they see a need to do so at any given time. We take pride in reporting that data collection did not bridge ethical clearance stipulations.

5. Data Analysis

Data analysis was guided by thematic analysis which was deemed relevant to

analyze qualitative data. This method of data analysis placed parents of children at the centre of data analysis and interpretation. All stages of thematic analysis were followed hence this data set is contributed.

6. Results

Table 1 reveals that out of the sample of fifteen participants, only two married couples co-parented a child/learner with a cognitive learning disability. Ten participants were single parents who carried the responsibility to parent their children without being supported by fathers of cognitively challenged learners. Three parents were recorded to be rendering a caregiving responsibility to children with a cognitive learning disability. Their ages were between 25 and 50 years of age. Recording these parenting categories did not come as a surprise. Anthropologists have played a significant role in recording familial and their changing dynamics which came as a result of labour migration, HIV/AIDS and absent fathers in Africa (Levine-Rasky, 2009).

Parents' experiences revealed that giving birth is a blessing, being called a mom is a dream for most women but giving birth to a child who is not considered normal constitutes a traumatic experience. Parents proved to be overwhelmed not only by having given birth to an abnormal child, but their parenting journey is inhibited by socially-constructed identities and societal stigmas associated with their children's identities. Parents explained that giving birth to children with disabilities in rural areas brings many socio-economic challenges. This is because giving birth to a child with a cognitive learning disability in a rural area where there are no resources feels like being imprisoned by a plethora of issues, (i) you are categorized as a cursed mother, (ii) as someone whom god and ancestors do not accept which is a cultural-religious discrimination, (iii) your child is doubted by our maternal family let alone the child's paternal family, the extended family and the society at large. Data analysis further revealed that mothers' identities are given socially constructed labels which are demeaning and not supportive. These socially constructed identities are then inherited by children who have a right to be accepted for who they are, and be part of a loving, supportive family and a community at large. Parents also narrated that those that are not brave to face all the challenges of being stigmatized opt to isolate

Table 1. The outline of research participants in different categories of parenting and their marital statuses.

Parenting type	Number of research participants in that parenting type	Marital status ✓ Yes × No
Co-parenting (husband and wife)	2	✓
Single parenting	10	×
Caregiving parenting	3	×

their children. These narratives are not far from what Thwala et al. (2015), Kang et al. (2016) and Taderera and Hall (2017) concluded in their publications where they expressed the hardship which is coupled with painful exclusion and alienation that parents encounter daily.

Research findings further revealed that they were always caught between trying to address their children's identity conflicts and working to gain a normal identity, which would seem to be unattainable. Engaging with data analysis revealed that the rural community of uMkhambahinini has many school-going children who were born with cognitive learning disabilities and are attending mainstream education because there are no schools to cater for their disability needs. Other parents narrated that they enroll their children in mainstream schools because they had been subjected to the lack of support from their families to accept the situation of their children hence, they burdened educators. For them, sending them to mainstream school was a therapeutic relief because they will not be judged by families and the society for having given birth to a non-progressing child, however, they would fight with educators when their children are not being passed to the next grade. Other parents were adamant that their children qualify to be sent to mainstream schools, but the problem was with teachers who are not equipped to teach them. During focus groups, the sadness on their faces revealed that giving birth to a child that would not strive academically was seen as a curse. Parents were disappointed in themselves because every child becomes the hope of their parents. They were mostly concerned about the future which will not be bright as their children will not be able to strive like all other educated children. They even expressed that their parenting expectations have become gloomy. Their heartfelt concern was that their excluded children will not become anything in life and they do not qualify to access education. This means that they will not be able to compete like all other classified capable children who are assigned with the responsibility of fending their parents when they grow up. This is due to the lack of all-encompassing support which was narrated and described by parents as constant prevalence in identity construction and isolation of families who have children living with any form of disability through stigmas and failure to recognize. Ben-David and Nel (2013) agree that the macro-system which is the family is not always supportive hence it then becomes difficult for the child and the mother to accept their cognitive status and find other ways of coping.

It was also interesting to note that parents have built coping resilience. They confirmed that the first acceptance must come from within, which means that, it was their responsibility to accept their children before they could expect others to accept them as normal. Other parents accepted that this was a generational lineage which they had inherited from their ancestors. In this context, children with cognitive learning disabilities were then considered to be special and mostly loved by their ancestors. They hope that their ancestors will use them to communicate important messages through these special children. Others coped by accepting that you do not choose a child; God does; this is a religious resilience

that enabled them to negotiate their identity as mothers and the identity of their children with cognitive learning disabilities. Others believed that this cognitive impairment is a result of a child being born prematurely and, according to them was another of God's plans. They celebrated that it is better to have a child with this type of a disability rather than pointing to a grave with a child that did not get to live. They expressed that they would not have coped if they were to bury their children. One parent expressed that no parent should bury one of his/her offspring. Coping strategies brought a cluster of expressions. Other parents proved not to cope with the situation because they feared that when they die, who will cater for the needs of their children who will not be able to advance their education and become economically independent? But they still would prefer not to have buried their children either at birth or later in their stages of development. Their other coping strategy was the hope that will be realized by God and their ancestors simply because the South African education sector has not catered for the educational needs of their children.

Other parents expressed that their hope has been diminished by the South African Education sector which enacted an inclusive policy which does not include rural areas. One parent expressed that the education section has plunged them into great misery simply because it has not provided an education that is equivalent to the learning needs of their children. They further narrated that white parents and their children are well catered for because their children are able to attend well-resourced schools that met their learning abilities. In these schools, children with a cognitive learning disability are able to progress with vocational skills that they use to earn decent jobs. They narrated that these white-resourced schools are inaccessible especially to them because they are poor parents from rural communities. What saddened them is that those that can afford to access these expensive special schools are able to earn acceptable identities and statuses in the community because they become bricklayers, carpenters and fashion designers. This is because they become direct beneficiaries of the inclusive policy which is not benefited by a child in the rural area. Their plea was that government should make equal provisions to close the gap between a white and a black-skinned child who were both born with a cognitive learning disability. If this democratic expectation is not realized, to them, democracy will then be a panacea and the exclusion of their children from streams of education thus remains a human rights issue. To them, the South African Education sector is mandated by the South African Constitution to treat and make provisions for South Africans equally; hence they want to see their children tapping into the same privileges that children of other races enjoy.
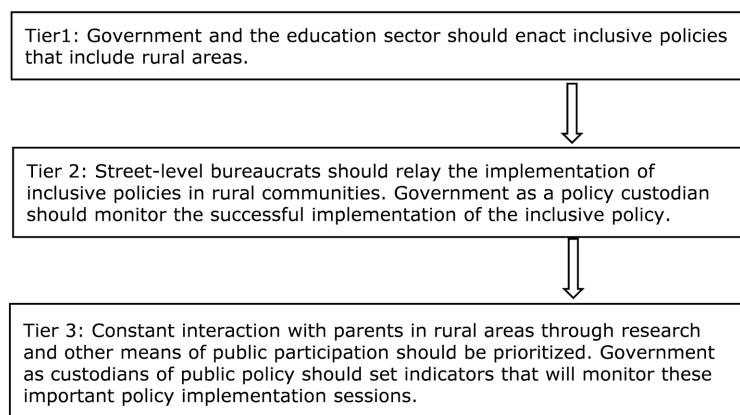
7. Discussion

As discussed by Ginsburg and Rapp (2013), Ettekal and Mahoney (2017), the experiences of parents of children with cognitive barriers in learning have been overlooked yet it requires a contextual understanding of ecological and identity

experiences that are borne by people living with disabilities, their parents or by their caregivers. This helps to normalize their own feelings and experiences, and in some situations can lead to healing. These are all the fundamental considerations made by this paper to support the idea that the role and provisions for parents must not be overlooked in evidence-based policy formation, particularly when it comes to care giving and education of children with cognitive learning disabilities. Cognitive disability is multifaceted and complex. Some parents can read their children's behaviour and take the required measures to accept and make the best decisions for their children's cognitive development. Other parents, on the other hand, find it difficult to accept and finance the required assistance for their children. The point of convergence is that parental experiences with a cognitive disability will always differ and will remain a topic of interest to many parents in relation to a specific condition as this was evident in different parental experiences.

Parents had hoped for their children despite children with cognitive learning difficulties and argued that they could aspire to a prosperous life. They were, however, saddened by the hurdles, particularly those caused by a lack of support in their society. There were also fears about their children's future, mostly since they had learned about the recurring cycle of exclusion, as education beyond high school was uncommon in uMkhambathini. According to Leonard (2011), a necessary synergy for assistance should offer and center around the fundamental interlocking cycles that determine communal relationships between families, schools, community involvement, and teachers or educational authorities. According to Thwala et al. (2015: p. 214), parents are more familiar with their children and can advise teachers about their children's learning difficulties. They can assist teachers in better understanding their students, providing advice on particular behaviours, and assisting in the design and implementation of joint learning support initiatives.

8. Contribution of the Paper

This paper thus contributes a Three-tier model of solution (TTMS) (Figure 1).

Tier1: Government and the education sector should enact inclusive policies that include rural areas.

Tier 2: Street-level bureaucrats should relay the implementation of inclusive policies in rural communities. Government as a policy custodian should monitor the successful implementation of the inclusive policy.

Tier 3: Constant interaction with parents in rural areas through research and other means of public participation should be prioritized. Government as custodians of public policy should set indicators that will monitor these important policy implementation sessions.

Authors: Zondi and Gwala (2022).

Figure 1. The three-tier encompassing model of solution.

This paper theorizes that the South African education sector should ensure that children with any learning barrier are not excluded from education because it is their immediate human right. Children in rural areas should also benefit the successful implementation of education policies. This also means that government should take full responsibility to monitor that more children fall in between policy cracks. Education anthropologists should constantly conduct ethnographic research with parents every five years to ensure that their parenting experiences and the educational needs of their children are met or addressed by public policies. The contributed Three-tier Model of Solutions (TTMS) is also contributed to support the 2063 Agenda which is a response to issues of human rights to basic education and equality of educational opportunities in Africa. We argue that the exclusion of children with cognitive learning disabilities will set Africa's education progress back; hence, we urge all heads of state in Africa to champion the successful implementation of the inclusive policy incorporating the voices of affected parents.

9. Conclusion

This paper concludes by noting that parents are psychosocially affected by the exclusion of their children because of a cognitive learning disability. The theorized three-tier is contributed as a holistic response to the discussed phenomenon. Our argument invites the government a policy custodian, the education sector and policy implementers to heed the inclusion call of children with a cognitive learning disability in the education agenda. Every child deserves to attend any form of schooling and rural communities should be prioritized. This solution model is also contributed as a monitoring tool which will monitor 1) the South African inclusive policy on education; 2) the integration of parents to shape the future of their children with a cognitive learning disability; 3) to ensure that children with a cognitive learning disability are treated and recognized as human beings who should be granted access to education without being compromised. We conclude this paper by emphasizing that no child should be excluded from education because of their disability. Education is a basic human right for all.

Acknowledges

Conflicts of Interest

The study has not bridged any conflict of interest

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