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ARE CHILDREN WITH DISABILITIES HEARD BY GOVERNMENTS? EXPERIENCES OF ACCESSING EARLY CHILDHOOD DEVELOPMENT SERVICES FOR YOUNG CHILDREN WITH DISABILITIES IN ZIMBABWE

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ABSTRACT

Children with disabilities are often overlooked, marginalized and most vulnerable members of communities in developing countries. This article explores the experiences of children with disabilities in accessing early childhood development services in Zimbabwe. Also, parents/caregivers' perceptions and experiences of bringing up children with special needs have been discussed. Photovoice and interview were used to solicit rich information from parents/ caregivers who had disabled children between the ages of four and five years. The findings related to parents who felt that they lacked knowledge and support, especially financial support. They also struggled with the daily challenges of raising a disabled child. Negative community perceptions and misconceptions were significant in this study. Although the government is mandated to provide services to children with disabilities, lack of resources and inadequately trained teachers were identified as inhibiting progress in schools and communities. Despite the existence of stipulated national, regional and international agreements on the disposition of inclusivity, the Zimbabwean education system has yet to implement these policies successfully. Zimbabwean education system should prioritize Early childhood development teachers for children with special needs and comprehensively training them with appropriate skills and empowers them with the knowledge to assist this special population. Further research should however explore the impact of cultural beliefs on the development of children with disabilities.

Key words: early childhood, accessibility, Early childhood development services, disability,

1. INTRODUCTION

Early childhood is a critical phase for growth and development. Experiences during early childhood can influence the development outcomes across the entire course of an individual's life (WHO, 2012). Development in the early stages of life is influenced by the personality of the child, the family, and the broader social environment, hence one can postulate that "what happens to children in their first days, months and years of life affects their development, the development of our society and the development of our world" (Bernard van Leer Foundation, 2004:3). Various ecosystemic factors have an impact on a child's development. These factors can be explained as mutual relationships in the society in which the child lives and can be found

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among people, communities, institutions and policies. Viviers, Biersteker and Moruane (2013) speculate that the provision of early childhood development (ECD) services can be regarded as a public good, based on the recognition that ECD services not only contribute to the development and outcomes of the child, but also to the growth and development of society as a whole. The provision of ECD services in Zimbabwe is fragmented; young disabled children may go to special schools, which usually are not free of charge, and only a small number of children may be eligible for government funds due to a strict evaluation system. This article explores perceptions and experiences of parents/caregivers of children with disabilities regarding the accessibility to ECD centres in Zimbabwe, focusing on the four- to five-year age group.

2. LITERATURE REVIEW AND THEORETICAL SYNOPSIS

Atmore (2013:3) highlights that young children deserve "the best quality care and education". Subsequently, the area of ECD has become a critical global research focus, underscoring, conceding, considering and meeting the unique needs of the young child (Storbeck & Moodley, 2011). Regrettably, as noted by Nyikahadzoi, Chikwaiwa and Mtetwa (2013), young children with disabilities contend with adversities that ordinary children do not generally experience.

Disability and the Social Model

Yeo and Moore (2003:572) view disability "as the loss or limitation of opportunities to take part in the everyday life of the community on an equal level with others due to physical and social barriers". Disability is viewed by more recent models as being constructed by the structures of society; thus, the effects of disability are inflicted upon people by their social environments (ACPF, 2014). There is some degree of truth in that the structures in the society exacerbate the disability woes of young children; for instance, a person is not disadvantaged by his or her disability or use of a wheelchair, but relatively owing to inaccessible buildings, toilets or play centres. Oliver (1996) elucidates that disability is everything found in the society that does not accommodate disabled people or exclude them, such as prejudice, inaccessible buildings, transportation systems, discernment and segregated education; thus, without these hindrances, there would be no disability. To this effect, children with some types of disabilities are susceptible and may be subjected to a diverse range of risks, such as poverty, stigma, discrimination, abuse and neglect, over and above limited accessibility of services. In a substance of truth, Haegel & Hodge, (2016) sum up that it is the way the society or caregivers are oriented that will determine their association with and involvement with persons with disabilities.

Children with disabilities in a Zimbabwean society

In April 1980, Zimbabwe declared education a fundamental human right to all its citizens and the role of the government, by then, revolved around the reversal of all forms of inequalities that favoured the racist colonial establishment at the expense of the cultural choice and ethnic integrity of the local people within the country (Kanyongo, 2005). However, these same rights seem not to be extended to young children with disabilities as the Education Act does not stress the protection and provision of rights to this class of citizens, possibly implying that lawful protection is jeopardised. An observation made by The Marist International Solidarity

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Foundation (2011) observes that the Act fails to articulate the provision of education to persons with disabilities. It notes that even if the Act advocated for inclusive education and children having the choice to go to any school near them, there are few or no teachers in public schools with the necessary expertise to work with learners with disabilities. Sadly, as revealed by Nziramasanga (1999), in practice, there is only a handful of highly equipped schools in the country, which are extremely expensive; consequently, very few children with disabilities attend these schools (Marist International Solidarity Foundation, 2011). The need to redress inequalities is part of the broader agitation for the provision of educational services to all citizens of Zimbabwe, as far as children with disabilities are concerned (Marist International Solidarity Foundation, 2011).

Children with disabilities in the context of Bronfenbrenner's Ecosystemic theory

Bronfenbrenner's (1979) ecosystemic theory guided this article on the strength of his thoughts that societal factors influenced children's development. According to Bronfenbrenner, the various structures of the society influence everything up to the least details (Harkonen, 2007). Leonard (2011:991), points out that, "Bronfenbrenner's theory is an attractive one because it is expansive, yet focused; one eye is trained on the complex layers of the family and community relationships, and the other eye is sharply focused on the individual". Furthermore, Allen (2010:3) adds that Bronfenbrenner's ecosystemic theory is grounded on the assertion that "all individuals are part of interrelated systems that locate the individual at the centre and move out from the centre to include all systems that affect the individual". For the purpose of this article, the main focus will be on the microsystem where the parents/caregivers and the children with disabilities are centrally located, this said, other systems will also be referred to in passing.

Paquette and Ryan (2001) explain that the microsystem as the first and closest layer to the child, which is made up of structures that directly influence the child. Similarly, according to Hannaway (2012), the microsystem includes contexts such as the child's household, school, associates and neighbourhood. In the microsystem context, the child closely associates with parents, siblings, early childhood caregivers, baby minders, church members and class and playmates within the neighbourhood. In the context of this article, Chidindi (2010) adds that the interaction between the child and his or her immediate environment influences both participants either negatively or positively, depending on the prevailing circumstances. In this case study, at the micro-ecosystemic level the interrelationships among the child with a disability, his or her caregivers, parents, home, siblings, the ECD centre and neighbourhood are explored. Direct exchanges and connections with agents of socialisation transpire in this system; simultaneously, the growing child is not perceived as an impassive beneficiary of practices, but is viewed as someone who aids in the construction of the settings (Santrock, 2014). Hook (2009) points out that the nature of the influence is reciprocal; for instance, the child with disabilities can experience positive social relationships and support from a loving and caring family or negative social relationships when living with parents or caregivers who are not supportive. Suffice to note that, families that live in poverty often exhibit helplessness in fending for their children because poverty has disabled their capacity to realise this obligation. Though, in their study, Meintjies and Van Belkum (2013) emphasise the important role of parents and other caregivers,

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especially in observing the developmental process of their children, a study by WHO (2011) and the World Bank (2011), uncovered that households with children with disabilities have a high probability of experiencing higher levels of socio-economic shortcomings, compared to those without disabilities.

3. METHODOLOGY

A qualitative approach was adopted in this research article on the strength of its universality, humanistic and person-centred standpoint in understanding human-subsisted practices devoid of the specific insights (Field & Morse, 1996). The approach was applied to this article as a means to appreciate the experiences and perceptions of parents/caregivers of children with disabilities and gain their lived experiences with regard to accessibility to ECD services in Zimbabwe. This is in line with Creswell's (2012) view that qualitative research is educational research in which the researcher depends on the viewpoints of the members participating (emic view) and an investigative procedure of appreciating societal and human complications grounded on distinct methodological traditions. As mentioned before, the aim of this article was to explore experiences and perceptions of parents/ caregivers on the challenges they faced in accessing ECD services for their children with disabilities in Zimbabwe. Purposive sampling was used for selecting information rich participants, who we felt, possessed the specific attributes the research study aimed to secure (Teddlie & Yu, 2007). With that in mind, ten parents of children with disabilities between the ages of four and five years were asked to participate in the study.

Data collection

The photovoice method was used to solicit data from parents. We opted for this technique on its strength as an instinctive photography (Olivier, Wood & De Lange, 2009). According to Olivier et al (2009), the photographs are idyllic in gaining insights from participants, their commitment in the research study is almost guaranteed as they feel and become involved. Nykiforuk, Vallianatos and Nieuwendyk (2011) add that, the photo voice method is ideal in merging narration with snapshots in exploring community issues that may be difficult to delve into ordinarily, in this article, being challenges faced by children with disabilities. The approach constructs deep, sociological foundations of people and communities fusing captured pictures and words to communicate needs, cultural issues, hitches, and aspirations. Parents involved in the study were asked to capture snapshots of scenes depicting their experiences and perceptions in accessing ECD services for their children with disabilities. There is belief that photographs ignite a "chain reaction" which triggers people to reminisce, cogitate and acquire new standpoints, highlights, Banks (2001), in Kamper & Steyn, 2011:286). Interview as an adjustable tool used for collecting data that enables multisensory processes was employed, we understood that the most common understanding is that there is a considerable rate of information exchange between the researchers and participants (Cohen, Manion & Morrison, 2011). Thematic approach in analysing data to identify, evaluate and report emerging themes was utilised in this article.

4. RESEARCH FINDINGS

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The findings from the study reveal a number of factors. The analysis is presented as portrayed by each participant regarding their experiences and perceptions regarding the accessibility of ECD services to their young children with disabilities. The key photographs selected were titled as a way to depict the views and experiences of the participant. A brief narration is given and, in some instances, this is substantiated by verbatim quotes, solicited through interviews. Pseudonyms are used to protect the identities of the participants.



Photograph 1 – **Knowledge is power**

Participant A expressed her concerns through the captured photograph, on what she perceived as lack of empowerment through access to information. Knowledge is a strong tool to freedom, depicted in photograph 1, many families with children with disabilities are deprived of vital information regarding disability issues. The participant indicated that many parents have no access to relevant and adequate information on childhood disabilities and, thus, grapple with their demanding situations naively. With the advent of technology, parents feel dissemination of vital information could be expanded extensively for their benefit and social media platforms could be utilised.

Participant B captured a picture (photograph 2) of a staircase to portray his perceptions and experiences of challenges in accessing some ECD services. He underscored the dilemma people encounter because of inaccessible structures. Participant views the access to many services as being hindered by unaccommodating environments.

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Photograph 2 **Distant but near**

The physical setup of many service providers were exclusively designed and developed without consideration for children with disabilities. It is difficult to access because the child can neither climb a staircase, nor use a wheelchair, and thus has to be lifted by the caregiver. The participant revealed that the captured photograph elucidated challenges he faced when taking his child to the local paediatric hospital. In expressing his predicament, he said:

"Though the local housing authority is rolling out a programme in assisting build ridges (ramps) in homes with disabled children so as to help them to move around in their wheelchairs easily, still my challenge is that I am renting this house and even if they want to help me, I cannot make changes to a house that is not mine.

The photo captured by participant C, (photograph 3) reflects her need and lack of access due to lack of assistive devices. In this study is was apparent that children with disabilities were often confined to, stuck or hidden in their homes due to a lack of appropriate services and sometimes shame. Very little opportunities exist for them to attend schools or play with friends. Participant C expressed the challenges she has to cope with on a daily basis. She has a child with cerebral palsy. She said the following:

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Photograph 3: Freedom of movement

"My child is five years old and I do not have a wheelchair for her to use. I am using this baby pram. She sits there and I push her around and when taking her for health check-up, I strap her on my back."



Photograph 4: **Disability is not inability**

In photograph 4, Participant D wishes people could see her child without her disability, the child was born disabled with no upper limbs. Participant D, a single parent, expressed her feelings after her child was born. She said: "It was painful.

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I cried, but went for therapy at the paediatric hospital." The participant disclosed that she has raised the child on her own as the father disappeared soon after the child was born. Through the photograph she wanted to portrayed optimism in the life of her child. She said that people were afraid of her, and they would just stare at her. The paternal family disowned her and accused me of being a witch. The captured picture symbolises the capabilities of her disabled child. It is evident in the photograph that there is a shortage of assistive devices. The mother had to improvise to provide a support seat for her child. Nevertheless, she described this photograph as positive, showcasing her daughter's ability and not disability. Although the presence of stigma and exclusion was widely acknowledged as a problem by most of the participants, Participant D felt it was possible to change attitudes if information on disability was disseminated timely and appropriately. The photograph is a reflection of a proud parent, that the child can write, unassisted, despite extreme disability. The participant highlighted the need for support of schools and caregivers in special institutions. The lack of support and marginalisation of children with disabilities lead to their exclusion from ECD services.



Photography 5: The ideal world

Participant E captured photograph 5 to express hope in the future for her child with a disability. She remarked: "...if my child is able to attend such an ECD centre and mix with abled-bodied children, I will be happy. I wish all ECD centres had such access ramps." The participant felt that if her child had a school with a ramp, she will be in a position to socialise with other children. The photograph therefore depicts an ideal environment for children who are physically challenged; however, many ECD centres are not child-friendly as they have been built with no consideration for disabilities.

Although the play centre is an ideal place for children to develop their gross motor skills and also to work off pent-up energy, Participant F felt that the play facilities have not been designed for children with disabilities.

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Photograph 6: **The onlooker player**

The photo reveals a perceived ideal environment where children can exercise their muscles. Sadly, this is only possible for children who are able to go up the slides, use climbers or roll tyres. The participant enunciated that if provisions were made available for children with disabilities to access such services within the communities, children could benefit. Many play centres are not adaptive to the needs of children with disabilities.



Photograph 7: **Down the road**

Participant G perceived disabled children as being costlier than able-bodied children. The captured photography 7 clearly illustrates how the parent wished there were ECD centres that

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could cater for children with disabilities in the community to reduce her transport costs. Expressing her experiences, she said:

"... the schools cost more and transporting my child from one place to another is very challenging. All the way from home to school I use public transport, and as a parent I have to be explaining to people that my child is disabled so that that they bear with me. I cannot carry the wheelchair. I have to pay for it as well."

The participant also indicated that an increase in awareness campaigns on issues of childhood disabilities was necessary for people to develop empathy and gain knowledge regarding the challenges parents face. She also felt that access to such information for parents of children with disabilities would help them to identify appropriate care facilities and support. There is also a need for the government to come in and help financially because, as she said, "We are challenged financially. There are a lot of funds needed".



Photograph 8: The balance sheet

According to Participant H, photograph 8 portrays a balance sheet that is hard to balance. The participant expressed economic challenges, but was still hopeful that if funding was available, life would be better for his child. The participant expressed the importance of stimulation therapy for his child when he lamented –

"I have only managed to pay first-term fees. I am in so much debt, but I cannot just let him sit at home because when he is at home his condition is worse. It is better when he is among others and sees them play though he cannot take part."

The photograph further illustrates struggles they endure to transport the child to school; it is also inadequate for the child's needs. The participant highlighted that the child has been in an ECD facility for the past four years, exacerbating their financial challenges. He pointed out that they hire a kombi to transport him, at a cost of US\$10 a week.

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Photograph 9: **Inclusion in a special**

"The school uniform is the closest to inclusion with normal children for my grandchild with cerebral palsy", lamented Participant J. The participant captured her child in a situation that depicted what she would have wished her child to be (photograph 9). The participant stated that there are limited educational support facilities for children with multiple infirmities. Where such services are available, the costs are very high. The participant acknowledged the support they received from the school; however, she expressed concern about the unavailability of specific backing and assistance by the government to sustain the exceptional needs of children with disabilities.

5. DISCUSSION

Although the adage that says "it takes a village to raise a child" is true in many societal settings, viewpoints in this article pointed to situations where children with disabilities were disadvantaged due to a lack of capacity against high demand – there are many children needing these services, but only a few centres to accommodate them, coupled with bureaucratic systems that are not child-friendly. General feelings in this study were that there was a lack of priority in matters of access to ECD services for young children with disabilities. Support at family and community levels were not experienced as positive in many instances. Participants seem to face hostility and rejection in communities where they would have hoped to gain support and information on the survival of their challenged children and on the availability of ECD services. The parents of these children, in many circumstances, were not proactive due to their demanding schedules in taking care of their children; thus, they may be left out of programmes that could be aimed at bolstering them with both information and financial resources.

Participants expressed their concerns regarding the lack of knowledge on disability issues. Inadequacy in information dissemination and persistent ignorance by parents on disability issues

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perpetuates exclusion and further promotes lack of access to critical ECD services. They felt that if information was properly communicated to them in a way that could make them appreciate it, that could assist in minimising the stigma and shame they had to cope with. One participant shared what she went through as she tried to get an explanation for her child's disability, spending huge sums of money on traditional healers who were promising to rectify the anomaly. In expressing their sentiments, the participants also indicated that the government has failed in its mandate to provide free or affordable support services in the areas of health, education and general social life for their children with disabilities. The reactions from the participants revealed that inaccessibility of many ECD service providers was a result of, among other things, the unaccommodating environments and infrastructure. It has been disclosed during the interactions that many buildings (in schools or hospitals) are inaccessible to children with disabilities as some of the facilities had either staircases or elevators, and no option of ramps for wheelchair users, which provides a challenge to many children. The participants also lamented the high transport costs as the centres that enrol such children were not available in their communities. Indications were that the few available centres were financially out of reach to many families as either the fees charged were too high or they were not reachable due to prohibitive transport costs. The transporters had no provision to accommodate children in wheelchairs and had no modifications to support unaccompanied children; hence, the parents had to pay double fares as well as for the wheelchair. Thus, the participants hinted a need to have more centres offering critical services as a way to mitigate the hardships faced by children with challenges. The participants also raised concerns about the lack of government-sponsored general funds to sustain their children with disabilities. They highlighted that the nature of their children's needs means that they are always stretched financially. Many of the parents cannot be fully employed as their children need constant assistance. High costs of facilities for children with challenges were seen as hindering access to ECD services by these vulnerable young children.

In the society, both the family and the child with disabilities face isolation and stigmatisation. They are discriminated against and the participants pointed out that they are indirectly excluded from ECD services when the children cannot participate. This also includes indirect costs they face when they have to buy assistive devices. The participants also disclosed their fear for their children with disabilities when they revealed that there were members of the community who believed that children with disabilities were a source of wealth as traditional healers misled people into believing that using the children's body parts could heal ailments and bring them victory. One participant also brought in the dimension of the negative attitudes of the community in situations when they did not understand the child's disability. He revealed how his congregation members scorned them, citing their failure to contain and discipline their child, as to these members, the autistic child's behaviour was weird and seemed lacking guidance. Male parents were also found not be very committed in the event of the birth of a child with disabilities. Some participants expressed despair as they had to raise children with no assistance from the fathers, while others pointed out that the male parents did not share the burden of raising the child with disabilities.

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Societal norms and values grounded on cultural beliefs and customary practices can strongly influence the acceptance or rejection of children with disabilities and, hence, have an impact on their access to and taking part in educational activities. Some participants expressed a general feeling that some parents of children who have some form of disability felt embarrassed by their children's condition. This was attributed to cultural beliefs regarding the existence of witchcraft which still remain common among many people and where disability is viewed as supernatural, subsequently someone has to bear the blame. In many cases, such oversights lead to parents locking up and hiding their children as they suffer from stigma and humiliation in the communities. The stigma they have to contend with was partly ascribed to the beliefs that the society held. Examples of such beliefs are that disability is seen as a curse, a bad omen or a form of punishment to the family of the child, resulting in some parents hiding or locking their children away from the scorning and prying eyes of the society. The misconception is passed on from one generation to another, repudiating the young child with disabilities his or her full rights to access ECD services, among other needs. However, one participant was positive and made indications that with the advent of development, there are people who seem to have accepted that disability is inherent and cannot be a result of witchcraft. From this perspective, cultural beliefs are not always encumbering.

Participants also concurred that there was an indispensable need for financial resources if the goals for the provision of ECD services for children with disabilities were to be achieved. They iterated that the success of many other services regarding the welfare of the challenged children was hinged on the availability of financial, human and physical means. An area of concern that was raised was the matter of ill-equipped ECD teachers, who appear not to have the proficiency to deal with their challenged children. Although qualified to teach children in the ECD phase, where the four- to five-year-old children with disabilities are found, ECD teachers are not accorded skills to manage this group of children. Although some participants acknowledged the ease of use of some materials in special schools, most of these resources were not tailor-made for their children with disabilities, hence, rendering the resources not very useful to the growth and development of the children, thus rendering life very difficult for the children and unmanageable for the parents.

Limitations

The study had targeted parents, however there were only two male participants, which was mainly attributed to the fact that male parents or partners refuted responsibility or disappeared in the event of the birth of a child with disabilities. This was a challenge as some mothers, despite the rejection, feared repercussions if they gave consent to participate in the study. We were unable to solicit a comparable sample of male parents; however, it is our belief that the information garnered gave us a broad picture of the plight of children with disabilities.

Recommendations

In light of the findings the following recommendations are made: The Ministry of Health and Child Welfare could initiate and institute an intensive programme for parents of young children

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from birth to five years old that focuses on the early identification of any indicative peculiarities in children's growth and development. It is pertinent that the programmes takes on board parents as the primary caregivers of children and equips and prepare them extensively on the nature, possible causes, and management of different disabilities. Caregivers indicated how they were emotionally drained, socially and morally isolated and economically incapacitated, it is recommended that parents could be empowered through sustainable income-generating projects and support groups.

6. CONCLUSION

As researchers, we were saddened by the fact that has very few people in society acknowledged the existence and rights of children with disabilities. The practical truth lies within the misinformation, misconceptions and myths regarding disabilities and how these have a negative impact on developing children. We realised that as children are nurtured by nature and socialised to uphold certain values, norms and customs, growing up in an environment and society full of negative attitudes, prejudice and beliefs regarding disabilities meant they had to copy and imitate the same attitudes, which are embedded in the fabric of the African society, and so the vicious circle of injustice is likely to continue. It is, therefore, hoped that people will appreciate that disability is not inability, and bestow in children with disabilities the rights they deserve.

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