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The Role of Parents in the Education of their Children with Disabilities in Sub-Saharan Africa: A Critical Review of the Literature

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ABSTRACT

Parents of children with disabilities (CWDs) play important and varied roles in their children's education. Policies, including the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD), underscore the need for parent-teacher partnerships to improve a child's learning environment. This paper explores the extent to which countries in Sub-Saharan Africa have integrated the UNCRPD's tenets on parental involvement in inclusive education into their own cultural contexts. To achieve this, the paper analyzes the literature written on parents of CWDs in the Sub-Saharan context to identify the different conceptualizations of the roles played by parents in the education of their CWDs. Findings of the literature review reflect consistent barriers faced by and responsibilities expected of parents of CWDs in educational settings. Future research should focus directly on parents of CWDs' experiences in schools.

KEYWORDS

children with disabilities, inclusive education, parental engagement, role of parents

Introduction

Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 43 of the 46 countries in Sub-Saharan Africa have ratified the convention (UNCRPD, 2006). However, the extent to which the document's tenets have been integrated within national policies differs depending on individual country contexts. Article 8 addresses the need for parental and community education on disabilities, either through creating public awareness campaigns about what disabilities are, emphasizing the importance of respecting the rights and lives of all individuals, or highlighting the harmful effects of prejudice against those with disabilities and their families (UNCRPD, 2006). The role of parents in the education of their children with disabilities (CWDs) is a topic that has increasingly been addressed in the realm of education research. In Sub-Saharan Africa, there was a trend to improve disability education programs after the ratification of the UNCRPD (Mulcahy-Dunn et al., 2020). The UNCRPD underscores the need for parent-teacher partnerships to improve a child's learning environment. The document views parents as assets to schools, as they have a wide array of resources and strengths to contribute to their child's education (UNCRPD, 2006). Article 5 states that children with disabilities have the right to reasonable accommodations in government schools, so parents and teachers must work together to determine how to identify and implement such accommodations (UNCRPD, 2006). If parents deem accommodations inadequate, Article 13 states they have the right to send their children to specialized

schools1 to support their child's needs (UNCRPD, 2006). In contrast, if government schools refuse to educate a CWD, parents have the right to seek and participate in legal proceedings.

This paper analyzes the literature written on parents of CWDs in the Sub-Saharan context to identify the different conceptualizations of the roles played by parents in the education of their CWDs. This paper also considers the effectiveness of the methods used and the questions asked by past researchers to understand the experiences of parents of CWDs in educational settings.

Method

To understand the conceptualizations of the roles of parents of CWDs, it is necessary to first consider who is considered a parent in the literature. The term "parent" can take on a host of different definitions depending upon the context the term is used in. In some communities, parent may refer to a child's primary caregiver, such as older siblings, aunts and uncles, or grandparents (Amos, 2013). Other settings may use the term collectively to refer to children's mothers and fathers (Cambridge Dictionary, n.d.). In the literature, when discussing individuals other than a mother or father who care for a CWD, the word parent is not used. Rather, it is exchanged for terms that reflect the connection of the caregiver to the CWD, including grandmother or sibling. Many of the included articles explicitly state that the mother is the parent that is primarily responsible for the upbringing of a CWD. A study in Nigeria interviewed 80 families to explore the quality of life of families of children with intellectual disabilities, and while 82.5% of the families included a mother and a father, 97.5% of the families saw the mother as the primary caregiver (Ajuwon & Brown, 2012). As studies primarily interviewed mothers or referred to mothers' experiences when discussing "parents," it is important to note that the conceptualizations of the roles of parents of CWDs reflected in this review at times refer only to mothers.

As the focus of the review is Sub-Saharan Africa, the selected articles highlight research conducted in the region, which included studies conducted in ten different nations in the region; Ethiopia, Ghana, Kenya, Malawi, Namibia, Nigeria, South Africa, Uganda, Zambia, and Zimbabwe. To reflect any changes made to national policies relating to disability education or the role of parents in the education of CWDs, the included articles were published after the adoption of the UNCRPD by the nation referenced in the literature, between 2006 and 2021. The final criterion was the inclusion of or reference to the experiences of parents of CWDs. These articles either directly referenced the experiences of parents raising CWDs or addressed the role of parents of CWDs within the context of inclusive education programs or other educational opportunities available to CWDs. The decision to include articles that highlighted parents' personal thoughts and experiences is because of the influence that parents' self-perception of their roles and responsibilities has on the roles and responsibilities that parents end up actually undertaking in their children's education (Lupiani, 2004). In total, 23 articles were included in this review.

Emerging Themes

Parents' Roles in Addressing Physical Barriers

Parents typically bear the burden of ensuring their children can access schools. However, for parents of CWDs in Sub-Saharan Africa, the literature highlights 3 barriers to accessibility: physical barriers, financial barriers, and attitudinal barriers. One of the primary roles of parents of CWDs in their child's education discussed in the literature was to ensure access to schools. A common barrier to education for CWDs was a lack of transportation options for parents to get their children to and from

1 Specialized schools, also referred to as special schools, are schools that cater to children with disabilities and/or special needs.



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school. In a study of the barriers faced by CWDs in schools in Zambia, one mother described the difficulty she faced transporting her child to the school building (Hansen et al., 2014). The mother shared that, by having to wheel her child across pothole-ridden roads due to a lack of accessible public transportation methods, it was rare for her or her child to leave their home (Hansen et al., 2014). Parents of CWDs in Ethiopia shared similar concerns, stating that finding transportation options to specialized schools in Addis Ababa that were affordable and convenient was nearly impossible (Aldersey et al., 2020). As the local schools would not accept their children, it was seen as parents' responsibility to find a way to transport CWDs to special schools (Aldersey et al., 2020). Students with physical disabilities, intellectual disabilities, and other conditions may not be able to independently travel to and from school, especially when the distance between communities and special schools can be tens of miles (Human Rights Watch, 2015). Without transportation support from educational or government entities, parents who want their CDWs to attend school may take on the responsibility of ensuring their children have access to educational spaces.

This dichotomy, where parents must identify school access for their children without the assistance of gravely needed public services, often results in CWDs simply not attending school. Developing the social and behavioral skills of CWDs is another responsibility that may fall on parents. Though social and behavioral skills may not initially seem like an issue of school access, studies reflected teachers asking CWDs that exhibit disruptive behavioral tendencies in social or classroom settings to leave school. Thus, without social skill and behavioral development and guidance, CWDs may not have access to local schools. Parents, then, are responsible for ensuring their CWDs exhibit appropriate behaviors for school environments, but many parents are unsure of how to address possible behavioral issues. A subsection of articles included in this review specifically addressed CWDs with behavioral and developmental disabilities. Masulani-Mwale et al. (2016) describe how a mother in Malawi was unsure of how to stop her son from pinching other students and acting aggressively during school activities. Similarly, a study conducted in Kenya expressed mothers' frustrations around not knowing how to handle their CWDs' behavioral issues, such as crying in class or speaking out of turn (Cloete & Obaigwa, 2019). This frustration can be exacerbated when parents lack information on how to support their children when they are exhibiting disruptive social or behavioral tendencies. To learn how to aid in their children's behavioral development, Zambian parents sought advice from therapists or medical professionals (Nyoni & Serpell, 2012). All but one of the 17 parents of children with Autism-Spectrum disorder included in the survey conveyed that the professionals they interacted with lacked sensitivity for their CWD (Nyoni & Serpell, 2012). One mother was told the cause of her children's behavioral issues was due to a lack of parental guidance (Nyoni & Serpell, 2012). Taderera and Hall (2017) reflected similar experiences, as parents in Namibia struggled to learn about how to support the social and behavioral development of children with different disabilities, as they lacked access to accurate information on available support services, behavioral therapy programs, social skill training, and other educational material.

Despite this, mainstream schools may still expect parents to independently find ways to improve their children's behavioral and social skills. In Ethiopian mainstream schools, teachers expelled students with autism due to their behavioral issues and parents struggled to find schools that would accept their children, even after offering to pay three to four times the typical school fee (Tekola et al., 2016). Similarly, Brydges and Mkandawire (2020) found that it is the responsibility of parents of CWDs in Nigeria to prepare their children to adapt to the challenges of learning in the same environment as their typically developing peers, rather than schools having the responsibility to make accommodations for CWDs. Without needed infrastructure and resource centers, parents find themselves



attempting to address the physical barriers that exist for their CWDs to participate in educational spaces.

Parents' Roles in Addressing Financial Barriers

The second barrier that parents have a role in addressing is insufficient funding to make schools accessible to CWDs. CWDs in Sub-Saharan Africa who are enrolled in schools are either educated in mainstream schools, including public or government schools that serve typically developing children, or special schools (Geda et al., 2016). Though some mainstream schools offer inclusive education programs, most disability education resources, such as assistive learning devices and teachers trained in disability education, are found in special schools, in part due to a lack of funding (Walton, 2011). Ghanaian teachers in mainstream schools advise parents of CWDs to transfer their children to special schools, stating that CWDs could not learn sufficiently in their classrooms as they lack the resources needed to effectively educate CWDs (Botts & Owusu, 2013). In addition to a lack of funding for supplies to make classroom spaces accessible, a lack of funding for programs to adequately train teachers on inclusive education practices is referenced by Kenyan teachers as the primary barrier for CWDs in mainstream schools (Hunt et al., 2021). Though governments in the region have introduced policies to increase the number of CWDs in mainstream classrooms, including Ghana's Education Strategic Plan, Uganda's 2015/16–2019/20 National Development Plan, and Nigeria's 2008 National Policy on Education, few resources have been allocated to help achieve the inclusive education goals set out in these policies (Botts & Owusu, 2013, Bannink et al., 2020, Brydges & Mkandawire, 2020). Without the necessary financial support from governments and other stakeholders, parents are seen as responsible for providing resources to allow for CWDs to be included in mainstream classrooms (Magumise & Sefotho, 2020).

To make up for the lack of resources available in mainstream classrooms, parents who can afford to do so may offer to pay schools to provide extra support for their CWDs (Botts & Owusu, 2013). However, when offered financial support from parents, mainstream schools may still refuse to educate CWDs, sometimes due to a lack of training (Magumise & Sefotho, 2020). Furthermore, the ability of parents to financially support the education of their CWDs is often limited. Masulani-Mwale (2016) found that the vast majority of CWDs, upwards of 85%, reside in resource-poor countries. Research within this context, including a study that explored the relationship between disability and poverty in Kenya, suggests that households with a CWD are likely poorer than households without CWDs (Hunt et al., 2021). Special schools may also pose challenges for parents. Only a proportion of a communities' children have disabilities, so there are generally fewer special schools than mainstream schools in any given region. This means that, unlike mainstream schools, special schools enroll CWDs from various communities. To keep their children enrolled, parents of CWDs at special schools must either find ways to trek across long distances or pay for a service to transport their children to school (Soni et al., 2021).

Further, when parents cannot physically transport their CWDs to school or pay for transportation services, their children may have to drop out of school. Thus, funding both causes a barrier in accessing mainstream schools and special schools. In some cases, both the actual and the perceived costs of attending special schools in Malawi caused parents to forgo sending their CWDs to school (Soni et al., 2021). This means that parents may never attempt to send their CWD to school as they fear that the financial burden on their family would be too high. However, this also harms parents' financial situations, because CWDs that are not in school must stay at home during the day, sometimes causing parents to leave their jobs to care for their children (van der Mark et al., 2019). Parents who are single



mothers or mothers who do not receive financial assistance from their husbands are placed in arduous positions, often having to care for their CWDs with little to no money (Zuurmond et al., 2020). Just as with physical barriers, without additional resources, parents face financial barriers to enrolling and keeping their CWDs in schools.

Parents' Roles in Addressing Attitudinal Barriers

The third barrier that parents face while trying to include their CWDs in education spaces is attitudinal barriers from educators and community members. Described in nearly all the articles included in this review was the social stigma surrounding disability. Indigenous spiritual beliefs in Ghana and Zambia assert that those born with disabilities were cursed by God or deities to punish them or their mothers for wrongdoing (Washington-Nortey & Serpell, 2021). Doctors in Ghana and Ethiopia described how mothers often blamed themselves when they were told of their CWD's diagnosis, believing God had cursed their child on account of their bad deeds or past sins (Washington-Nortey & Serpell, 2021, Badu, 2016). Parents of CWDs, even those who did not subscribe to the belief that their child was cursed, were often isolated from their communities. Ethiopian parents recalled how neighbors would ask for their CWDs to not play with other children in the community and would exclude them from birthday parties and other community events (Tekola et al., 2016). In Malawi, parents were told their child's disability was due to careless parenting while working with community members to try to find services for their CWDs (Aldersey et al., 2020). Mothers are often isolated from their own family circles, as grandparents, aunts and uncles, and fathers will distance themselves once they learn a child has a disability (Masulani-Mwale et al., 2016). For parents of CWDs in many communities in the Sub-Saharan context, especially mothers, social isolation is a daily reality.

In some cases, though there may be opportunities for their CWDs to partake in community activities such as schooling, parents may opt for their child to remain isolated. Negative experiences with community members led some Kenyan parents to purposefully exclude their children from local schools to protect them from discrimination or hatred (Cloete & Obaigwa, 2019). Similarly, some parents in Guyana chose to keep CWDs in the home environment due to their community's negative perceptions of disability (Cloete & Obaigwa, 2019). By not enrolling their children in schools, parents may believe they are preventing their CWDs from facing these challenges. CWDs and community members may criticize these decisions but, as a parent in Malawi shared, they believe their CWDs would have been excluded from the community either way (Brydges & Mkandawire, 2020). As well as social stigma, parents may choose to not enroll their CWDs in schools due to both an actual and perceived lack of resources in schools, preventing their children from having to experience inaccessible learning environments (Nelson et al., 2017). These decisions, though they sometimes lead to a life of solitude for parents and CWDs, are perceived by parents as acts of protection from prejudice. South African mothers of CWDs shared that caring for their children in isolation was, in part, by choice, as it allowed them to raise their child without judgment from others (Torgbenu et al., 2021). Thus, social stigma can both cause educators to discriminate against CWDs in educational spaces and lead parents to keep their CWDs confined to the home environment. These three barriers, physical, attitudinal, and financial, pose significant challenges to the inclusion of CWDs in schools in the Sub-Saharan region and place additional responsibilities on parents.

Critical Analysis

The Nature of Parental Roles

The literature conceptualizes the overall role of parents of CWDs in education systems in the Sub-Saharan context as the key to whether their child is enrolled in school. If parents do not find ways for



CWDs to access schools, their CWDs may not have the opportunity to attend schools. Additionally, if parents do not find ways to keep their CWDs enrolled in school, by providing financial support or locating external community resources, their children could be turned away from schools. Conversely, if a CWD is not enrolled in school, it may be due to their parents wanting to protect them from unsuitable learning environments or community stigma.

The final sections of the articles included in this review typically included suggestions on program, service, or policy changes to help parents fulfill these roles. To aid parents in keeping their CWDs in school, a study in Namibia proposed training more social workers to support parents when local schools provide only fragmented disability support services (Zuurmond et al., 2020). Taderera and Hall (2017) suggested that, in Ghana, parents should attempt to cultivate relationships with their CWDs' teachers to help streamline the process of solving problems related to education accessibility. A study in the Kenyan context supported the development of education programs for parents, to empower them to enroll their children in schools rather than isolating them from society as a means of protection (Botts & Owusu, 2013). However, these three examples underscore the literature's tendency to position parents as the solution to their own problems. The first example, rather than making school access easier for parents of CWDs, provides support for parents outside of the formal schooling space. Instead of addressing the larger issues within inclusive education programs or special schools, including a lack of trained teachers, inaccessible learning spaces, or absence of public transportation services, the literature still expects parents to find ways to keep their children in schools. Furthermore, efforts to educate parents on new interpretations of disability fail to change the community's social stigma towards CWDs and parents still feel compelled to play the role of protector. Without addressing the structural, financial, political, and cultural barriers that exist for CWDs in both mainstream and special schools, parents bear the brunt of the responsibility when it comes to educating their CWDs.

Unexplored Parental Advocacy

Lack of support from teachers, community members, and service providers, as emphasized in the literature, is a major barrier to the education of CWDs. One way to address these barriers could be to engage parents in advocacy efforts in their communities, to ensure schools are accessible for CWDs. However, the articles included in this review did not reflect parents engaging in advocacy in local schools and communities. A handful of articles, though not explicitly conceptualizing parents as advocates, referenced moments of parental advocacy. Cloete and Obaigwa (2019) focused on the lived experiences of caregivers of CWDs in Kenya and stated that a group of caregivers banded together to both educate community members on disability and advocate for their children. A mother in South Africa, interviewed on her perceptions of inclusive education, shared that though she initially enrolled her CWD at a mainstream school, she successfully advocated to have her child placed in a mainstream school (Cloete & Obaigwa, 2019). Parents, aware that inclusive education and related services were more common in contexts where parents, teachers, and community members were educated on types of disabilities, may wish to see education programs on disability offered in their own communities (McKenzie et al., 2021, Amponteng et al., 2019).

References reveal that parents may have experience or interest in advocating for their CWDs' education. However, none of the articles included in this review specifically asked parents about their perceptions or experiences on advocating for increased inclusion with local teachers and school leaders. By not exploring parents' experiences or perceptions on trying to remove barriers for their CWDs in schools, both researchers and parents in these regions lose the opportunity to learn from the past



challenges and successes of parental advocacy. Moreover, these experiences and perceptions could expand researchers' understandings of the barriers that parents face in their attempts to advocate for CWDs, informing politicians, researchers, and educators of issues to address in the future. For many communities in the Sub-Saharan context, where a lack of resources and relevant services places pressure on parents to ensure their CWDs are educated, identifying methods of parental empowerment, and emphasizing the role that advocacy can play in acquiring these resources could positively impact CWDs' access to education.

Parents of CWDs in Education: Reframing the Research

When searching for articles on the role of parents of CWDs in education in Sub-Saharan nations, I struggled to locate articles that discussed parents of CWDs specifically in reference to their child's education. Of the 23 articles included in this review, only two directly considered this topic: one focused on the perceptions and experiences of parents of CWDs in inclusive education programs in Nigeria while the other discussed the utilization of family-teacher partnerships to support CWDs in South Africa. The remaining 21 articles mentioned parents' roles in their CWDs' education while answering other questions. These questions explored four themes: the coping mechanisms or stress of parents of CWDs, the daily lives of parents of CWDs, parents' perspectives on disability, or the barriers to inclusive education. Though some of these studies referenced other articles on the role of parents of CWDs in education, they often cited studies undertaken outside of the Sub-Saharan context. For example, Amponteng et al.'s (2019) study on parental perceptions of inclusive education practices in Ghana reviewed past research, but when creating a framework with which to contextualize their work, they only referenced one other study written in the Sub-Saharan context. The remaining studies were conducted in Australia, Singapore, the Netherlands, Greece, and Macedonia.

However, it is important to recognize the limitations of this review. As only 23 articles were included in this review, this paper cannot fully reflect the diverse experiences of parents of CWDs and the various differences cultural contexts present in the Sub-Saharan region. To further understand the roles of parents in the education of CWDs in Sub-Saharan Africa, researchers need to shift how and what they are studying. Rather than making inferences about the roles of parents of CWDs in schools from research in other regional settings, where the bulk of research in parental involvement in schools is being published, future research could focus specifically on nations within Sub-Saharan Africa. To identify how best to support parents of CWDs and their children in the Sub-Saharan region, researchers should invest in research that reflects the realities of the communities where these parents live (Buckler, 2011). Studies that center the importance of parents in their CWDs' schooling, particularly those that highlight parents' direct experiences with teachers and in school environments, should be a focus of future research. Investing in this type of research and making it accessible to governmental leaders can help further the need to invest in educational resources and infrastructure to meet the needs of parents of CWDs.

Conclusion

Parents play an important role in the education of their CWD, though the roles of parents may vary depending on the community where they live and the resources made available to them. The literature on parents of CWDs in the Sub-Saharan context conceptualizes parents' roles as addressing the barriers to their CWDs' education, whether they be physical barriers, financial barriers, or attitudinal barriers. These barriers both highlighted the lack of resources and necessary infrastructure to include CWDs in schools and the additional responsibilities that parents often must take on if they want their CWDs to be included in educational spaces. As most of the articles included in this review focused

on questions outside of the role of parents in their CWDs' education in Sub-Saharan Africa, it could be beneficial to parents and researchers to further explore this topic in future research.

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