

## Disability and Shame Special Issue Forum: Research Article

### A Counter-Narrative to Shame in Namibia

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**Abstract:** Fewer than 20% of children with disabilities (CWD) in Namibia attend school. One meta-narrative proposes CWD are being hidden from societal spaces, including school, due to shame. This study foregrounds stories of CWD and their access to societal spaces. It interrogated meta-narratives and uncovered a counter-narrative that illustrates hybridity.

**Keywords:** Disability Studies; Namibia; Culture

### Introduction

There is no lack of stories and other evidence illustrating that children with disabilities are routinely excluded from all spheres of life in the so-called Global South. One marker of inclusion/exclusion is the school-attendance of children with disabilities in Namibia. Despite strides in the implementation of inclusive education, only about 18% of children with disabilities in rural Namibia attend school (Namibia Statistics Agency, 2016). In comparison, depending on the age of the student, between 66–89% of non-disabled children in Namibia attend school (Republic of Namibia & UNESCO, 2015). The literature reports that exclusion is fueled by complex factors, one of which is shame (Haihambo & Lightfoot, 2010, Zimba, Mowes, & Naanda 2007). While shame about a family member with disabilities may trigger reactions that entail limiting access to social, academic, and economic spheres, it does not tell the full, complex story. These study results agree that in some cases shame may lead to the exclusion or hiding of the family member, but as told from families of children with disabilities in rural Namibia, part of the exclusion comes from families' good intentions to protect their child.

The purpose of this ethnographically informed study was to listen to the voices of families of children with disabilities, and provide, via phenomenological interviews, a localized counter-narrative from individual vantage points as they relayed lived experiences. Throughout the study, families describe ways in which children were included in local contexts and how the desire to protect them from outside negativity and harm was a factor in the ways in which they lived their lives.

### Background

The Republic of Namibia has been legally free from apartheid since 1990. From the first contact with Portuguese explorers in 1488 until 1990, when Namibia became independent, the country had been wrought with oppression and murder of its people, international treaties, and armed struggles that finally led to UN-supervised elections (BBC

New, 2018).

Currently, the 2.3 million people in the thriving and diverse country sparsely populated it's mostly desert landscape. Over half of the people in Namibia identify as Ovambo, an ethnic group that is largely situated in the north-central region of the country. These individuals are the focus of the study. Additionally, about 80–90% of Namibians identify as Christians. Many live in rural areas and can be faced with challenges such as access to safe drinking water, electricity, and cell phone coverage.

About 98,000 citizens identified as having a disability that causes “difficulties engaging in any learning and/or economic activity” (Namibia Statistics Agency, 2016, p. xii). As with many societies, people with disabilities are more likely to experience poverty, marginalization, limited access to formal education, unemployment, and violence (Grech & Soldatic, 2016; Namibia Statistics Agency, 2016, pp. xii-xiii).

After gaining freedom from South Africa in 1990, Namibia has prioritized its growth and progress in all facets. In 2014/15 about 9% of its Gross Domestic Product (GDP) is allocated toward education (Republic of Namibia and UNICEF, 2017). In addition to putting money into the education system, the Ministry of Education, Arts, and Culture has created and adopted multiple policies that are paving the way for better access to quality education for children with disabilities.

The policies that provide a foundation for the development of inclusive education for children with disabilities began when the founders of Namibia wrote the constitution in 1990. The constitution puts forth in Article 20 that all persons shall have the right to education, and that primary education shall be free and obligatory for all children up to the age of 16. Building on that foundation, Namibia has adopted international covenants such as the 1989 UN Convention on the Rights of the Child, 1990 Jomtien World Declaration on Education for All, the Salamanca Statement and Framework for Action (UNESCO, 1994), Dakar Framework for Action (Dakar World Education Conference, UNESCO 2000), and 2006 UN Convention on the Rights of Persons with Disabilities.

In addition to being a signatory on international agreements, Namibians have crafted national laws and policies that guide the implementation of inclusive education. These include the 1997 National Policy on Disability, 2000 National Policy Options for Educationally Marginalised Children, 2000 Namibian National Plan of Action for EFA 2001-2015, 2004 Namibia Vision 2030: Policy Framework for Long-term National Development, 2004 National Disability Council Act, 2007 Education and Training Sector Improvement Programme (ETSIP), 2008 Education Sector Policy for Orphans and Vulnerable Children, 2012-2017 Ministry of Education Strategic Plan, and 2013 Sector Policy on Inclusive Education.

### **Exclusion**

Despite the policies that guide Namibia toward providing education for all children,

including those with disabilities, most disabled youngsters are not accessing formal education (Namibia Statistics Agency, 2016). Educational exclusion is a complex construct that is fueled by cultural models, unquestioned ways of knowing, and systemic deficits such as the lack of resources. It is also an important signifier of inclusion in society. Cultural models (i.e. cultural beliefs about disabilities) and institutional deficits are driving forces that perpetrate notions of shame. Shame, or the pain that is caused by “disgrace” (“Shame,” 2018) in some cases may cause African families to ‘hide’ and not allow the individual with a disability access to social, educational, and economic spaces (Abosi, 2007; Abosi & Koay, 2008; Chireshe, 2013; Haihambo & Lightfoot, 2010).

Such hiding possibly stems from shared cultural assumptions, or cultural models, that are ideologies and cultural understandings that have become deeply embedded within people/society and leave no space for alternative thoughts about people with disabilities (Strauss, 2005). However, people can hold both positive and negative views, as well as, complicated perspectives that take into account for biological and indigenous ways of understanding (Danseco, 1997; Groce, 1999). The notion of hybridity, or a view of these ideas not mutually exclusive, allows us to see a more complex picture of exclusion. The mixture of the cultural models of families of children with disabilities holding a notion of shame, while simultaneously believing that children need protection from the outside world, demonstrates that it is not an either or dichotomy.

The meta-narrative in the small body of literature focused on Namibia is that the cultural models, or ways of thinking, typically evolve from spiritual, supernatural, and mythic ways that support peoples’ thoughts of shame. For example, witchcraft, punishment from God, a curse, missteps of the mother, and myths about disabilities have been noted as ways of thinking about children with disabilities (Haihambo & Lightfoot, 2010). Because “ideologies and cultural understandings have power over thought and expression,” these cultural models, or ways of thinking, and other complex factors, arrange for exclusion for children with disabilities (Strauss, 2005, p. 203). The discourse of belief in the supernatural that in some cases may lead to shame and exclusion, is a part of a complex picture. A picture that considers multiple barriers, beliefs, religions, and cultural models.

Other factors that lead to exclusion of children with disabilities from formal education are the attitudes of teachers and society, teacher training, perceptions of education, curriculum, financial resources, and materials (Zimba et al., 2007).

*The National Report of Namibia* (2008) identifies the main barriers to inclusive education as: 1) economic, 2) political, 3) after-effects of apartheid, 4) social, 5) teachers’ education, 6) physical, and 7) communication. In addition to these obstacles, and in spite of educational advances, children with disabilities continue to be relegated to the margins. “Despite the advances in the expansion and provision of basic education, a remaining major challenge is to address the needs of educationally marginalized children and young people” (Ministry of Education, 2013, p. 2).

Addressing the needs of children with disabilities relies on the notion of inclusion. Shame that leads to exclusion of children with disabilities in Namibia is a widely accepted construct. The study suggests, however, that in its small sample, families of children with disabilities did not hide offspring due to feelings of shame. In fact, the children were able to navigate the rural community and some attended school. By continuing to sustain the discourse of shame/stigma, without a reframing, allows people with disabilities to continue to be seen as separate and marginalized. The notion that shame leads to exclusion and hiding can be reframed to a discourse that posits, in some cases, that protection is the driving force in the perception that the child with disabilities is being hidden.

Such a counter-narrative is a different way of viewing the exclusion of children with disabilities in rural Namibia. While shame and hiding are still real and prevalent, they are not the only narrative.

### **Theoretical Framework**

This study is grounded in the use of critical global disability studies perspective (CGDS) and postcolonial theory. Both of these lenses explore the families' perspectives in non-binary, social, political, cultural and critical ways.

Critical global disabilities studies, coined by Grech (2015), has its base in disability studies and critical disability studies. The foundation of these theories is to understand the lived experience from the perspective of the person who experiences it (Linton, 1998). Additionally, power issues must be explored and problematized. Specifically, in terms CGDS, Grech posits that, in the past, scholars have often transferred and applied their epistemological underpinnings to a multitude of contexts—even when the contexts have different ways of knowing and being (2015). Thinking through such a frame means problematizing transference of “discourse, epistemologies, and methods” (Grech, 2015, p. 384). It also means that working in the Global South, the histories of oppression and colonialism, and neocolonialism must be remembered. More specifically, honoring the cultural complexities and identities; and seeking to understand and conveying ways of interpreting and knowing “their own world” (Grech, p. 384, 2015).

This study is also influenced by postcolonial hegemony including its political and economic effects that have marginalized people, cultures, languages, and indigenous ways. In addition, a primacy is set for the essential need for people—indigenous and/or people with disabilities—to claim their rightful place in society.

In postcolonial theory, hybridity, as described by Bhabha (1994), speaks about the complex, mutually constructed ways of being that were inherent when colonization occurred and continue to be lived vis-à-vis imperialism and diffusion of western thought. The resulting space of intersection produces a tangle of thoughts, beliefs, behaviors, policies, languages, and ways of schooling, which are negotiated by local actors. In this study, a tension between indigenous ways of knowing and being with western ways illustrates a hybridity of existence.

## Methods

Ethnographically informed qualitative field research was used to uncover the cultural complexities of shame and protection as they relate to exclusion. Methodologically, interviews were used to gain an understanding of the interplay among cultural models and human motivations that arrange for children with disabilities to be excluded from societal spaces and opportunities. An overlay of analysis methods were employed to mine the breadth of data. First, analysis began with uncovering phenomenological themes and then moved to discovering deeply held cultural models vis-à-vis non keyword analysis (Seidman, 2006; Strauss, 2005).

### Participants

The current study, part of a larger study, foregrounded the life stories of five children and one adult, in which the five families living in rural northern Namibia shared the lived experiences of disabled family members with openness and candor as participants names have been changed. Mrs. Ipinge (age 38), the mother of Armas (age 7), shared her son's story through her lenses as a teacher and mother. Ms. Elago (age 27), the mother of Indila (age 8), shared her daughter's story through her lenses as a retail worker and mother. Mr. Angula (age 62), the father of Toivo and Magano (age 8), shared his twin children's stories through the lenses of a farmer and father. Mrs. Haufiku (age 38) relayed her thoughts about her daughter Ndahafa (age 16). Tangeni's (age 36) story was shared from the view of his aunt Mrs. Paulus (age 62).

A purposeful sampling method was utilized to "intentionally select individuals and sites to learn or understand the central phenomenon" (Creswell, 2013, p. 194). Connections were made within the researcher's network that allowed recruitment of participants. After contact was initiated, consent was provided, and the interviews commenced.

The actual number of participants was an important decision. First, logistical transportation was taken into consideration to accommodate the ability to travel during the rainy season. Because travel during the rainy season, either by foot and/or truck, to different parts of the region is difficult, if not impossible. Therefore, the sample had to be accessible. Additionally, when considering an *n*, Seidman (2006) hesitates to establish a number that indicates "enough" participants (p. 55); while Creswell (2013), suggests a variable number between "3 to 4 individuals to 10 to 15" (p. 78).

This study purports to be counter-narrative that is representative of the participants. While generalization is not the aim of the work, opening a space that leads to discussion about possible alternative and complex views of shame and exclusion is a focal point.

### The Interview Process

The three-part unstructured interview session/s engaged the participants in telling the stories of their family members with disabilities. The method utilizes a storytelling approach

about lived experiences and how they, themselves, interpret it (Seidman, 2006). As Seidman (2006) says, “individuals’ consciousness gives access to the most complicated social and educational issues, because social and educational issues are abstractions based on the concrete experience of people” (p. 7). Therefore, listening to the stories of people allows for insight into a phenomenon based on the interviewee’s experiences. Furthermore, the meaning of the words and experiences is a co-construction between the interviewee and interviewer.

Interviews included three parts, in which some were carried out over three sessions while others took place in one session. Each of the three interview parts are distinct in structure, as advocated by Seidman (2006). The first part one of the interviews captured the focused life history. Next, interviewees were asked to share the details of daily lived experiences. The third part or final portion of the interview explicitly asked the participants to reflect on the significance of their experiences (Seidman, 2006).

Throughout the planning and execution of the interviews, language differences and interpreting/translating was a vital consideration. The researchers gave each participant was given the option to conduct the interview in English or Oshiwambo. Only one participant opted to conduct the interview in English. During the Oshiwambo language interviews, an interpreter or translator that was familiar with educational jargon was employed.

### **Data Analysis**

Data collected from interviews were analyzed with methods selected to expose cultural notions that have all emerged from Ovambo beliefs. According to Strauss (2005), there are multiple ways that cultural understandings and ideologies exert force on human thought and action. For example, a cultural model where beliefs that are so deeply internalized and these assumptions are so ingrained, that one is not aware of holding the belief and does not consider there to be any alternatives (Strauss, 2005). To uncover the intricate workings of culture embedded in talk, Strauss’ method was utilized to understand, “ways in which ideologies and cultural understanding have power over thought and expression” (2005, p. 201). Furthermore, cultural models exert power on how people think about children with disabilities, their school-going abilities, and how those beliefs manifest as participation in society.

To bare the shared cultural assumptions among a community, the data was mined for cultural models through thematic analysis using three distinct phases. In the first phase, data were reduced and summarized into individual profiles. In the second phase, profiles were compared for connections and themes. Third, profiles and interviews were analyzed with methods selected for the ability to expose cultural notions.

More specifically, the profiles were created to reduce and then shape the material “into a form in which it can be shared or displayed” (Miles & Huberman as cited in Seidman, 2013, p. 121). In this first step, individual profiles of each child with disabilities was created based on the interview with their family member. The profiles contained demographic information, health history, lived experiences of the child, and school experiences, if applicable. Once the



data were ready for analysis, the profiles were grouped, coded, and categorized based on themes (Seidman, 2013). The themes emerged to show connections and common understandings.

### **Trustworthiness**

Presenting research that allows the reader to believe in it, called trustworthiness by Lincoln & Guba (1985), was addressed in the study through the use of triangulation of data. The triangulation for corroboration or validation of data (Creswell, 2002) was done using multiple voices that all generally pointed to the same outcomes. In the larger study, multiple voices from parents, grandparents, childcare providers, and professionals working in nonprofit organizations were incorporated into the data set. Next, recent literature from other educational stakeholders and families was sought to determine whether it supported the findings. Finally, observational data were collected as the researcher conducted the study as a way to further corroborate the data.

The incorporation of trustworthiness through member-checking and peer debriefing also took place. Member-checking was done with two of the families, such interaction invited the families to read the data collected and correct for any misunderstandings and/or for clarity. Peer debriefing occurred at a Namibia international conference, this allowed for comments or questions from Namibian and international professionals working with children with disabilities.

## **Findings**

Throughout the research, two themes emerged that illustrate people with disabilities engage freely in rural and known locales, while families discourage navigation of more urban, populated spaces. In the study children with disabilities were able to access the local community and were not hidden from social spheres and in some cases had access to formal education. The children traversed to neighbors, school, and church, and conducted daily chores that required them to leave their homestead. In contrast, it also emerged that families were fearful of the individual navigating more populated areas (i.e. town, urban setting, roads).

### **Navigating Rural/Known Spaces**

As children were able and old enough, they would visit neighbors, play with other children, and interact with the local community. For example, Indila had built a relationship with her neighbors—adults and children alike. Her mother said, “In her community, especially the neighbors, they welcome her and she goes and plays with them. She go [sic] herself even. And can go ... and they welcome her anytime.” She played “with the children who are around ... [the] same game, like building small houses with sand and sometimes chasing one another.” During these play opportunities, Indila is constantly laughing and enjoying her time.

The welcoming and acceptance of Indila by neighbors, and her ability to make connections, illuminates the capacity of the community to be open and accepting of children with disabilities. Such receptivity was also demonstrated in Tangeni's village. Mrs. Paulus shared that at about age 10, he began to go out of the homestead alone, "to go visit neighbors sometimes ... just go and sit ... he sometimes didn't talk to them." She continues to explain that he also regularly interacted with people in the village community, "People know him, talk to him, and he likes [sic] people"

In addition to social spaces in the community (i.e. neighbor's house), the children with disabilities accessed more institutional settings such as church and school. These settings, especially schools, are not always a space of welcome and acceptance for children with disabilities (Haihambo & Lightfoot, 2010). However, in this study it was seen that some children and families found them to be a place for spiritual and educational growth.

Armas's mother, after trying out a few churches, found one where her family and especially Armas was accepted and welcomed. After one Sunday of not going to church, she said Armas missed it and then imitated what his experiences were while in the church:

even [though] I failed to take him to the church last Sunday but I found him just starting to clap hands like in the church because the people in church clap hands, singing ... but there are many be memories and he can remember start clapping hands but cannot able to sing but to make loud noise[s].

In addition to church being a place of acceptance for Armas and his family, Toivo, Magano, and family have found acceptance at school. As the Namibia Statistics Agency (2016) notes it is highly unusual that children with disabilities, especially children with down syndrome, attend school, Toivo and Magano were learning alongside their non-disabled peers.

As Toivo and Magano are from a family with four other siblings, there was never a second thought by the parents to send the children to school. However, the children's performance in school was reported to be quite different from peers'. For example, Toivo "was able to play, [but] not ever able to use [a] pen." and away from school, Toivo "likes to be with goats and cattle." In contrast, his twin sister Magano can write her name, but is unsure of her use of basic information, also, "if asked which village [she is from], she doesn't know." Mr. Angula continues, "She is making progress, needs special education, encouragement, and support."

In the study, families expressed that their child/ren was able to be in the local, rural community in terms of visiting neighbors, going to church, attending school. They also noted that completing family chores that require the children to venture into the community are required and vital. For example, Tangeni cares for the family's cattle, in doing so, he walks them to the watering hole where other boys/young men take the cattle. Additionally, he fetches water at the local tap, thus illustrating that his disability and shame is not a powerful cultural model for the family. Toivo, as a boy, has the same responsibility that Tangeni has



and is able to pilot himself and cattle within his local community. Like many African cultures, Namibian families highly value the contributions the children make to sustain the household (Ingstad & Whyte, 2007; Marfo, Walker, & Charles, 1986; Reagan, 1996). Mr. Angula noted that his children with disabilities are “very supportive to the family,” he illustrated this by sharing how the children are, “responsible for the field, house, and tell if visitor come. [They can] relay message and can run errands.”

While this small sample illustrates children with disabilities are accessing their local, rural communities, it is also a demonstration that in these cases, they are not being hidden within that community. As the literature has shown it is a widely held belief that they are being hidden out of shame and embarrassment. The parents in the study paint a different picture (Abosi, 2007; Abosi & Koay, 2008; Chireshe, 2013; Haihambo & Lightfoot, 2010).

### **Exclusion from Urban/Unknown Spaces**

In accessing the wider community—moving outside the rural, local community, children with disabilities face greater challenges. While children with disabilities in the study traverse local communities, they are seemingly being protected from other spaces because of fear for their safety.

Toivo and Magano’s father, Mr. Angula, said the family has hope for each of the children’s future, yet still is fearful about each of them being in the urban and the less immediate community. Mr. Angula said there are “some challenges” to having children with disabilities, like “your heart is not free because we are worried [for them] to go out, for fire, getting lost, or doing something incorrect.”

Tangeni’s aunt agrees that being in the urban setting is worrisome for her in regard to how her nephew would be protected. While he moves freely around the village, he does not go to town because Mrs. Paulus is “afraid for him to be in town and hit by a car.” Mrs. Haufiku, Ndahafa’s mother, shares the same sentiment, “I fear for my child’s safety,” she goes on, “...many things to can happen to Ndahafa in a place that does not know her.” Mrs. Haufiku point of view concurs with what all families expressed, in spaces where the individual with disabilities is known, there is less opportunity for them to navigate safely. There is constant worry and fear that the children will be susceptible to harm.

All families of children and adults with disabilities shared stories that illustrate they were able to access the local community, but fear and protection is what kept them from being able to access the larger community (i.e. town).

## **Discussion**

In this study, counter to the meta-narrative of shame, participants did not hide family members from the rural community; in fact, all people with disabilities that were of an age to leave the homestead and travel to other homesteads and rural community spaces did so.

Chimedza (2008) supports such an idea, as he claims some Africans with disabilities actually experience more acceptance in home-based, local communities in comparison to the communities where the individual is not known. In locales where the individual is not known, literature supports the assertion that shame and embarrassment does play a role in exclusion. One international aid organization published, “disabled children may be hidden away by their families who have little to no understanding of disability and in some cases, they are considered by being ‘cursed’” (Leonard Cheshire Disability, n.d.). A previous study on Namibian teachers’ beliefs reported that children with disability most often did not come to school because their parents were ashamed and hid them at home (Bartlett, 2003).

Contrasting evidence presented here suggests that people with disabilities are not being hidden, but are being protected by family members. It is evident that children with disabilities do have access to rural community spaces and have limited access to other spaces. From the discussion with the participants, it was not out of shame and embarrassment that the family member with disabilities was not taking transportation to/from the rural areas to urban spaces, or grocery shopping in town, or going to school; family members wanted to protect the person with disabilities from harm, stigmatization, and harassment.

Mrs. Ipinge described what challenges that she and Armas encountered when they went to the hospital, “sometimes he wants to play with them [the other people in waiting room] ... and touch them ... but you have to explain, this one is somehow [sic][because] some people can say, ‘hey ... what is wrong with these people’” (Armas and mother). Therefore, out of fear of what he may do, others’ interpretations of him, and any other negative backlash they may experience, “when we go to the hospital, we only keep him in the car just to avoid...maybe one of us in the queue while the other staying in the car with him until I join the queue to the doctor and then I become the second or third to go in, I have to come back to get him.” Ingstad and Whyte (2007) discussed reframing of the hiding of children with disabilities to a more probable reason of protection and care for the child; and this study supports that assertion.

It is not a binary notion that either people with disabilities are able to access public spaces or are hidden due to shame. The idea has a hybridity of influences and actions. The space of hybridity allows for a “third space of enunciation’ (Bhabha, 1994, p. 37), a space where multiple histories and influences arrange for different and new cultural understandings and actions. In the case of Namibia, many things must be considered: its colonial past, European and South African influences, and the current state that includes influences from international aid organizations. Such a discussion must also consider the inequity of power—power among which voices are elevated, which voices are not, and which voices are actively silenced.

The mutuality of influences have arranged for children with disabilities to be seen and taught in different ways over the years. Chimedza (2008) documents that education existed before colonization, but we do not always recognize that, “indigenous knowledge seems to have potential as a solution to some problems of great magnitude experiences in Southern

countries” (Mkosi, 2005, p. 89).

Yet, hybridity suggests that the space in which culture exists as it has become ‘mixed’ with the influences from the colonized and colonizer. However, as Abagi (2005) argues, Africa’s development and schooling “must be reconceptualized and redefined by Africans - based on Africa’s environment, experiences, and needs” (p. 297). The complexity of the exclusion of people with disabilities in Namibia is rooted in a past and present that posits shame is the driving force for exclusion. However, the families in this study did not hide the person with a disability. Instead, the individual was embraced by the local community. It was when they went into the urban setting that stigmatization occurred.

## Conclusions

Social realities illustrate that people with disabilities are coming out to freely navigating within local societies. This study demonstrates that some individuals with disabilities in rural communities in Northern Namibia are accessing their regional communities. More importantly, the results posit why they are not accessing more of the wider community. Protection and care, not shame and embarrassment, keep people with disabilities from freely accessing the urban environment in rural Northern Namibia.

Furthermore, the findings speak to the need for interrogation of the meta-narrative around children with disabilities allowing for the hybrid nature of influences to be recognized, while continuing to honor and respect different ways of being as people with disabilities step out from the margins and into societal spaces. Culture is dynamic and is changing, albeit slowly, in Namibia as it relates to children with disabilities. This is evidenced from the national policies and actions that are occurring as a product of the policies. One of these policies led to a pilot project of implementing ‘inclusion education’ in a few select schools. The actualization of creating a more inclusive communities and demonstrating progress for children with disabilities demonstrates progress. As progress for children with disabilities continues, we hope that one day the meta-narrative becomes one of acceptance and inclusion that leads to high quality education for all learners.

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