

## ORIGINAL RESEARCH

# Beyond physical access: a qualitative analysis into the barriers to policy implementation and service provision experienced by persons with disabilities living in a rural context

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## ABSTRACT

**Introduction:** Persons with disabilities make up approximately 15% of the world's population, with vulnerable communities disproportionately affected by the incidence of disability. Research reflects that persons with disabilities are vulnerable to stigma and discrimination, social isolation, and have physical barriers to accessing support services, all of which serve to perpetuate a sense of uncertainty and vulnerability within their lives. Recently a number of policies and models of intervention have been introduced intended to protect the rights of those affected by disability, yet limited research has been conducted into the lived experiences of persons with disabilities, particularly in rural contexts. This implies that little is known about the impact of the rural context on the lived experience of disability and the ways in which context impacts on the implementation of policies and practices.

**Methods:** The current study employed a qualitative design underpinned by the principles of narrative inquiry and participant observation. Thirty adults with a variety of congenital and acquired disabilities (15 men and 15 women, ranging in age from 19 to 83 years) living in 12 rural communities in the Mpumalanga Province of South Africa were recruited through snowball sampling. Data collection comprised a combination of narrative inquiry and participant observation. Narratives were collected in SiSwati with the assistance of a SiSwati-speaking research mediator and were transcribed and translated into English. Data were analysed inductively according to the principles of thematic analysis.



**Results:** Findings confirmed that the experience of living with a disability in a rural area is associated with discrimination, social exclusion, and isolation and barriers to accessing services, underpinned by numerous context-specific experiences, including mortality rates, exposure to numerous and repeated forms of violence across the lifespan, and corruption and lack of transparency in the implementation of government policies and practices. These experiences are not currently reflected in the literature or in guidelines on the implementations of policies and service provision, and thus have the potential to offer novel insights into the barriers faced by persons with disabilities living in rural areas.

**Conclusions:** The results of this study suggest that barriers to service provision extend beyond physical obstacles, and include a variety of sociocultural and sociopolitical barriers. By failing to take these into account, policies and current models of service provision are only able to provide limited support to persons with disabilities living in rural areas. The findings reveal narrative inquiry to be a powerful and culturally safe tool for exploring lived experience among vulnerable populations and hold significant implications for both practitioners and policy developers. Furthermore, it emerges that one-size-fits-all policies are unable to meet the needs of persons with disabilities living in rural areas. However, the implementation of site-specific needs analyses with the use of flexible and culturally appropriate tools has the potential to redress the discrepancies in policy implementation and can be used to strengthen institutional ties and referral pathways.

**Key words:** context, disability, policy, practice, South Africa.

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## Introduction

Persons with disabilities make up approximately 15% of the world's population<sup>1</sup>, with research reflecting that those living in rural areas, those who are poor, and those with limited access to information, education and healthcare are disproportionately affected by the incidence of disability<sup>2</sup>. The combination of disability and poverty renders individuals vulnerable to a variety of forms of discrimination, perpetuating a sense of vulnerability and uncertainty in their lives and impacting on their ability to access basic services and make independent life choices<sup>3</sup>. These experiences serve to further marginalise and isolate these individuals from mainstream community life, and consequently poverty and social exclusion are seen to increase the severity of impairments<sup>4</sup>. By employing a qualitative methodology, this article will explore the lived experience of persons with disabilities living in a rural area of South Africa and investigate how these experiences impact on effective policy implementation and access to service provision.

In recent years there has been an increased awareness of the impact that disability has on social development<sup>5</sup>. Consequently a focus has been placed on establishing a culture of rights, with numerous policies and conventions being developed, intended to enhance quality of life and protect the rights of those affected by disability. These include the World Programme of Action Concerning Disabled People<sup>6</sup>, the United Nations Rules on the Equalisation of Opportunities for Persons with Disabilities<sup>7</sup>, and the United Nations Convention on the Rights of Persons with Disabilities<sup>8</sup>. Furthermore, in South Africa, a number of additional initiatives have been introduced, including the implementation of the white paper on an Integrated National Disability Strategy<sup>9</sup>, the African Charter on Human and People's Rights<sup>10</sup>, the Patient Rights Charter<sup>11</sup>, and the Batho Pele Principles<sup>12</sup>. The South African Constitution is considered to be one of the most inclusive constitutions in the world, with specific attention paid to protecting the rights of vulnerable populations, including women, children, persons with disabilities, people who are sick, and those without adequate access to nutrition, security, housing, health care and education<sup>13</sup>. The South African Constitution is complemented by the South African Bill of Rights<sup>14</sup>, which



promises the right to non-discrimination, education, information, safety and housing. Furthermore, the National Health Plan for South Africa<sup>15</sup> undertakes to provide free health care to persons with disabilities. Persons with disabilities are also eligible for disability grants, issued monthly, provided they have proof of South African citizenship, undergo a means test and are assessed in terms of their levels of functioning by a medical doctor who decides whether or not the disability grant is warranted<sup>16</sup>.

The policies described above are incorporated into models of service provision intended to meet the needs of persons with disabilities. These models have changed over time from the medical model to the bio-psychosocial model, with current service provision being based on the WHO's International Classification on Functioning, Disability and Health (ICF)<sup>17</sup>. The ICF acknowledges that disability is more than 'something which a person has', but rather something which occurs in the interaction between the person, their ability and the environment, including the physical, social, communicative, informative and policy environments<sup>17</sup>. However, within the ICF model, contextual and cultural variables are viewed as universal. This implies that little attention is paid to the effects of subtle barriers, including the impact that the sociocultural context has on the implementation of policies and practices. This has resulted in policies and practices focusing more on the environmental determinants of health, as opposed to the social determinants, including the interplay between cultural and contextual influences on the lives of persons with disabilities.

Current research suggests that the experience of living with a disability is dominated by stigma and discrimination<sup>18,19</sup>, social exclusion<sup>20,21</sup>, and physical barriers to accessing services<sup>3,22</sup> including the provision of public transport and physical access to buildings. The majority of studies on the experience of disability have, however, excluded participants who are uneducated and illiterate<sup>19,22</sup> and those with cognitive-communicative impairments<sup>19,22-24</sup>, with few studies being conducted with those living in rural areas<sup>25</sup>. This implies that research into the impact of sociocultural contexts on the implementation of policies and practices has been

superficial. Thus, despite the fact that comprehensive policies exist, the limited attention paid to the ways in which contextual variables impact on lived experience has potentially affected the implementation of policies and practices. Furthermore, it is proposed that contextual barriers serve to perpetuate the socially embedded discrimination to which persons with disabilities are exposed and in this way prevent them from accessing civil, cultural, economic, political and social rights.

South Africa provides a unique setting in which to study the impact of context and culture on the lived experience of disability, and consequently to provide insight into barriers to effective policy implementation and service provision. South Africa is a diverse country, situated on the southern tip of the African continent, and is home to more than 51 million people<sup>26</sup>. The country is divided into nine provinces, with 11 official languages, and a variety of cultures and religions. Despite the fact that South Africa has been described as an upper-middle-income country, its distribution of wealth is uneven<sup>27</sup>, and the country continues to face enormous challenges imposed by poverty, limited access to services, low literacy levels and high levels of unemployment<sup>28</sup>, with many people continuing to live below the poverty line<sup>27</sup>. This is further impacted on by the influx of both legal and illegal immigrants into South Africa, which has impacted on the country's population growth and its socioeconomic status. These issues are further compounded by high levels of corruption infiltrating all levels of service delivery within the country<sup>29</sup>. Sub-Saharan Africa is estimated to have the highest incidence of disability in the world<sup>5</sup>, with an approximate prevalence of 13% in South Africa, 5% of who are severely disabled<sup>30</sup>. South Africa's history of inequality has resulted in an extreme spatialisation of poverty<sup>31</sup> reflecting the pervasive imbalance of political and economic power within the country. Current statistics suggest that 38% of the South African population live in rural areas<sup>32</sup>. These include but are not limited to former homelands established during the apartheid regime, tribal villages, homesteads and rural farmlands<sup>33</sup>. These rural areas are defined by their poor infrastructure, lack of basic service provision, low levels of literacy, high levels of unemployment, limited access to



healthcare and education, high incidence of communicable diseases and high mortality rates<sup>34</sup>.

The South African government has prioritised the needs of persons living in rural areas, with increasing attention being paid to social and economic development<sup>35</sup>. Despite this prioritisation, little research has been conducted into the experiences, needs and challenges of those living in rural areas, particularly among the disabled population. Based on the above, this article will explore the lived experiences of persons with disabilities in a rural area of South Africa and in so doing will contribute towards the development of a theoretical understanding of the complex variables that impact on policy implementation and service provision.

## Methods

The present study took place in 12 rural villages located in the Nkomazi East Municipality in the Mpumalanga Province of South Africa. These villages are typical examples of rural communities ravaged by the effects of poverty; burden of disease; limited access to healthcare, education and information; and high prevalence of disability. The research site was selected as an appropriate place to conduct the current study, given that the first author had worked as a speech-language therapist within the Nkomazi East Municipality for more than a year, and had previously conducted research into the experiences of caregivers of children with disabilities within the surrounding villages<sup>36</sup>. This provided a sense of insight into the challenges experienced by persons living in a rural area and also allowed the researcher to become familiar with many of the persons with disabilities living in the communities, the local beliefs pertaining to the onset and management of disability, and the barriers facing persons with disabilities and their caregivers.

Thirty participants (15 men and 15 women, ranging in age from 19 to 83 years) with a variety of disabilities were sampled using snowball sampling. Sixteen of the participants had physical disabilities; two had sensory disabilities; one had a cognitive disability; and 10 had multiple disabilities,

including combinations of physical, communicative, cognitive, psychiatric and sensory disabilities. Seven of the participants had congenital disabilities, while 23 had acquired disabilities, ranging from 5 months to 43 years from time of onset. Twenty-one of the participants were recipients of disability grants at the time of data collection and one participant received an old-age pension. The remaining eight participants relied on their families and the community to support them financially.

A qualitative design was adopted, underpinned by the principles of narrative inquiry, participant observation and researcher reflections. A research mediator who is a local resident of one of the villages in the Nkomazi East Municipality was employed to assist in overcoming the challenges of working cross-linguistically and cross-culturally. The research mediator was chosen based on the fact that she and the first author had worked together previously, both clinically and conducting research; she has a physical disability, and she works as a community-based rehabilitation worker within the community and therefore has a vested interest in disability and the lives of those affected by disability. The research mediator acted as both a cultural and linguistic broker, and assisted in identifying potential participants, accompanying the first author to the homes of these participants, conducting narrative interviews with the participants, reflecting on her own responses in relation to the elicitation and content of interviews, and providing insight and contextual information into the interpretation of observed events and narrative interviews.

Narratives were collected in SiSwati (one of South Africa's 11 official languages) and recorded on a digital audio-recorder by the first author and a SiSwati-speaking research mediator. Data collection took place over a period of 3 months. Participants were visited in their homes over a period of 2–3 hours on a minimum of two occasions, and were asked to 'tell their story'. Based on the themes that emerged, Flick's approach<sup>37</sup> to guiding questions was adopted in order to probe the participants for additional detail on their experiences. Once data had been collected, narratives were



transcribed and translated from SiSwati into English by a SiSwati first-language research assistant.

In order to triangulate data and ensure trustworthiness of findings, narrative interviews were combined with participant observations and researcher and research mediator reflections. Participant observations were conducted concurrently during narrative interviews, as well as by spending time with the participants during daily activities on at least two occasions, lasting between 2 and 3 hours each, during the period of data collection. This was done in order to establish how the individuals interacted with their environments and how other people related to the person with a disability. Observations were recorded using Spradley's guidelines<sup>38</sup> for participant observation. Researcher and research mediator reflections were documented in order to account for subjectivity and bias.

Data were analysed using the principles of thematic analysis<sup>39,40</sup>. Data analysis proceeded according to the four cognitive processes described by Morse (pp. 73–81)<sup>40</sup>. These included comprehending, synthesising, theorising and re-contextualising the data. Once data had been collected, transcribed, translated, and validated for accuracy of translation, a significant amount of time was spent dwelling on the data, reading and re-reading transcripts, field notes and research reflections. During this period, notes, memos and journal reflections were kept in order to develop analytic thinking, which was later used to explore and explain the underlying patterns and processes within the data<sup>41,42</sup>.

The procedures used in identifying themes were recursive in nature<sup>39</sup>, and involved becoming familiar with the data set, generating initial codes across the data set, searching for themes by collating similar codes into potential themes, searching for unique and recurring themes, and searching for linkages and associations across and between themes. Initially themes were identified at a semantic level; however, as data analysis progressed, these semantic themes merged into latent themes, which were more interpretive in nature<sup>39</sup>. By labelling and categorising emergent themes, the data were reduced to a manageable entity, and verbatim quotes that

highlighted the various themes were preserved in order to maintain the voices of the participants<sup>41</sup>. Themes that emerged were inductively assigned to categories. These themes were then further analysed in order to identify the ways in which context impacts on policy implementation and the accessibility of services for persons with disabilities. Within each of these categories, subthemes emerged, providing insight into the reality of living with a disability in a rural area.

A number of measures were taken in order to ensure trustworthiness of findings. Employing a research mediator who was a local woman with a physical disability implied a degree of shared knowledge between the participants and the research mediator, and allowed for detailed descriptions of personal and often traumatic narratives to emerge. In addition, trustworthiness was ensured by sustaining a prolonged presence in the field prior to, during and after data collection; triangulation of data collection methods; member checking of transcribed interviews; using audit trails in the form of reflective journaling and audio-recorded reflective conversations between the researcher and research mediator; and using verbatim quotes in documenting the findings. Furthermore, a third of the transcripts were verified by an independent researcher with experience in qualitative research in order to verify both the accuracy of the transcription of interviews and the analysis of findings. Some differences in translation were noted, for example, 'bath' compared to 'clean', and 'it was painning me' compared to 'it was so difficult' or 'my heart was painful'. None of these differences appeared to change the meaning of the narratives. In a few instances, some inaccuracies in translation were noted, but these pertained mainly to the omission of redundant words.

Given the fact that data collected reflected a combination of interviews, observations and reflections, and the independent researcher was not familiar with the research site, no formal method of determining agreement between findings was applied. Instead, the independent researcher was provided with a third of the transcripts together with the tables reflecting the process followed during data analysis and asked



to verify the processes undertaken in order to identify the emergent themes. The authors then met with the independent researcher in order to discuss the nature of the findings that had emerged. Stemming from the independent researcher's lack of familiarity with the research site, questions arose regarding the ways in which physical and sociocultural environment impacted on the participants' interpretation of experiences. However, the independent researcher was in agreement about the ways in which themes had been identified and assigned categories.

### **Ethics approval**

Permission to conduct this study was granted through the University of the Witwatersrand Non-Medical Ethics Committee (protocol number H090612).

The participants in this study were viewed as a vulnerable population given their disabilities, their dependency on others, their socioeconomic status, and their lack of formal education, all of which impacted on their understanding of their rights when participating in research. A number of measures were put in place to protect the rights of participants, including adapting the informed consent process to include a detailed verbal explanation in SiSwati, augmented by the principles of supported conversation: repetition of significant points, the use of closed-ended questions and by requesting recall and feedback from the participants on the nature of the study and what their involvement would entail.

Despite the fact that many participants had cognitive-communicative and psychiatric disabilities, they were all capable of producing a personal narrative and of providing informed consent. This was measured by their ability to engage in and maintain a conversation of mutual interest with a conversational partner. In addition, permission to include these participants was obtained from family members and caregivers, in order to protect them from potential violation during the research process. In this way, a shared decision-making process was implemented to obtain informed consent by engaging with the individual, the family and, where necessary, members of the community.

## Results

In line with findings from previous studies, discrimination, social exclusion and physical barriers to accessing services all emerged as prominent themes.

Given their prevalence in the literature, the themes reflected in Table 1 were not particularly surprising. However, by employing a recursive method of thematic analysis<sup>39</sup> and through the process of re-contextualisation<sup>40</sup>, additional themes emerged which appeared to underlie the themes presented in Table 1. These themes included the experience of living in a community ravaged by high mortality rates, prolonged exposure to numerous forms of violence over the course of a lifetime, and exposure to corruption and lack of transparency in the implementation of government policies and practices (Fig1).

The underlying themes reflected in Figure 1 emerged as unexpected findings – they have not previously been reflected in the literature or in policies and guidelines for service provision and thus have the potential to provide a novel understanding of the lived experience of disability in a rural area and the ways in which context influences accessibility to services and policy implementation.

In the sections below, a description will be provided of the ways in which these underlying themes emerged and how they related to the overriding themes of dependence, discrimination and social exclusion, and physical barriers to accessing services.

### **Theme 1: Increasing mortality rates**

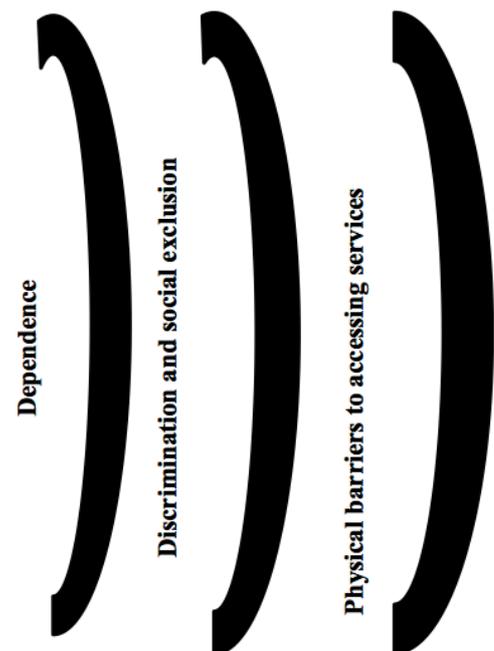
The ubiquitous presence of death within the community appeared to impose significant restrictions on the ability of persons with disabilities to participate in community life. The experience of living in an area ravaged by the effects of increasing mortality rates, coupled with the physical limitations imposed by disability seemed to magnify the sense of isolation, social exclusion, and barriers to accessing services that emerged in many of the participants' narratives.



**Table 1: Most common emerging themes and subthemes within the data**

	Dependence on others		Discrimination and social exclusion				Physical barriers			
	Physical dependence	Emotional dependence	Inability to develop intimate relationships	Exclusion from family activities	Loss of friendship	Feeling of isolation	Barriers to accessing health	Barriers to accessing education	Barriers to accessing information	Barriers to accessing employment
No. of participants who reported challenges	19	15	17	21	15	14	3	4	6	5
Total no. of reports in narratives	43	23	31	46	22	17	5	6	14	8

Overriding themes	Subthemes	Number of participants affected	Number of times theme emerged in narratives
Increases in mortality		16	32
Violence	Psychological	30	74
	Physical	16	20
	Sexual	14	15
	Deprivation	9	16
Corruption and lack of transparency in government policies and practices	Barriers to identity documents	19	38
	Barriers to disability grants	12	23
	Barriers to education	6	9
	Barriers to employment	8	17



**Figure 1: Themes and subthemes underlying dependence, discrimination and social exclusion, and physical barriers to accessing services.**

The enormity of the impact of increasing burden of disease together with high mortality rates became apparent during the second site visit. Over this period, 18 homes were visited, and every one of these households had experienced a death in the 3 days leading up to the interview. At times, interviews were set up, but days later when we arrived, the

participant had died, while in other instances locations of interviews had to be changed as a consequence of a death in the family. Thus, data collection took place under the ubiquitous presence of death, which although only spoken about incidentally, seemed to pervade the participants' stories and life experiences.



While many of the participants made reference to the death of loved ones, this was discussed in a matter-of-fact way with little reference to the emotional impact that these experiences had on both individuals and on the community as a whole.

*My two sisters and my brother are dead. So now it is just me.*  
(participant 2)

*My husband passed away, followed by my sister, and then my mother followed, so I think I had a lot of stress.* (participant 10)

Despite the fact that the participants spoke about death in a matter-of-fact way, the impact that this had on their quality of life and ability to participate in daily activities was obvious. It emerged that increasing mortality rates had a direct effect on ability of persons with disabilities to be socially and emotionally independent, creating additional barriers to access as support systems seemed to vanish, children were orphaned and breadwinners were lost. This appeared to result in significant emotional and financial strain, with decreased opportunities to access healthcare, education and information, thus deepening the participants' sense of isolation. In this way, the stigma and social exclusion associated with disability appeared to be magnified because there were a lot of deaths in the community.

*I have a problem going for check-ups because my mother is dead and she was the one assisting me to go to doctors or hospital. I did not get any care after she died.* (participant 3)

*They are all dead. My mother, my mother-in-law, my husband, and my sister. So it is just my grandmother and me and the small children. So we are suffering. There is no money for food or transport to the hospital. Even the children are not attending school now because there is no money for transport.* (participant 20)

Participants seemed to attribute increasing mortality rates primarily to sociocultural causes as opposed to biological and

medical causes, including generational conflict, emotional strain, and lack of adherence to social and cultural norms.

*My mother died because my father was married to two wives.*  
(participant 3)

In many cases links appeared to be drawn between cause of death and the onset of disability.

*The father of my child died in 2001 and I got disabled in 2006. They said it was because we did not do all of the preparations when he died the way that we were supposed to.*  
(participant 6)

*I became disabled because my father died without finishing to pay lobola [payment in cattle or cash by bridegroom's family to the bride's family shortly before marriage].*  
(participant 12)

These examples highlight the ways in which relationships are drawn between death and disability, suggesting that cultural attributions have the potential to manipulate the psychosocial needs of individuals and influence the reasons behind help-seeking behaviours.

## **Theme 2: Violence**

Violence emerged as a prominent theme, with numerous references to physical, sexual and psychological violence, as well as violence by means of deprivation, with most participants being exposed to numerous and repeated forms of violence across their lifespan. In this way, the combined impact of violence, poverty and social exclusion was shown to be profound amongst adults with disabilities, and highlighted the ways in which violence serves as a form of social oppression, preventing persons with disabilities from accessing appropriate services and limiting individual expression.

Psychological violence was a prominent theme which emerged as a disabling barrier to social inclusion.



*People in the community, they look at you like you are an animal. Some, when you are crawling, they are laughing and pointing, like it is the nonsense thing ... (participant 30)*

*When I am home alone, I need to move on the floor like a snake to get to the toilet and they (neighbours) are laughing and pointing at me. (participant 19)*

Additional forms of psychological violence emerged where female participants discussed the ways in which they were treated at the clinic, specifically during pregnancy.

*At antenatal classes others were saying 'if I were you I would not do that' and others were coming to me and saying 'don't do this again. Look at you!', like I had done something wrong. (participant 3)*

In addition to psychological violence, numerous references to sexual exploitation were made either in outright statements or in metaphorical ways.

*I was young and the men in my community were doing anything they liked to me. So I became a victim. (participant 3)*

*This one neighbour was helping me, giving me food, but afterwards he was saying I was not thanking him properly – I must go inside the house to thank him. (participant 6)*

Vulnerability to sexual exploitation was further impacted on by the fact that many persons with disabilities are dependent on others for assistance with activities of daily living, resulting in the formation of asymmetrical relationships. In this way, reporting these experiences of violence may result in losing a caregiver or support network.

Reports of physical violence pertained mostly to recollections of being beaten at school by teachers when unable to cope with the demands of the classroom, being physically punished for being disabled, or being attacked with knives and sharp instruments in order to release the demons which were believed to be causing the disability.

*... to learn together with normal people was stressful. When I didn't know the answers the teacher would beat me and the other children would laugh. (participant 21)*

This experience had a negative impact on participant 21, as evidenced where he states 'so then I was always isolating myself, feeling afraid, like I was not a human being' and where participant 27 reported, 'My father beat me because I was disabled. He said I was bewitched and he beat me and tried to cut me with a knife.'

Finally, reports of violence by means of deprivation emerged in relation to food or money being withheld from persons with disabilities.

*At home my parents won't share food with me. They say I must buy food for myself and cook and eat by myself. (participant 7)*

*My family were always discriminating against me, treating me different. But then when I started getting the grant they were getting close to me, wanting money from me. (participant 20)*

The most significant effect of multiple exposures to violence over extended periods of time appeared to be the internalised belief that violence and abuse were an expected part of one's life.

*I was always feeling afraid, like I was not a human being. (participant 21)*

*I was always thinking that love was not for me. It was only for normal people to love each other. (participant 30)*

Similarly, participant 3 recalls her response to the sexual abuse she endured, coupled with the nurses' responses to her when she was pregnant, saying, 'I was always afraid of myself, the way I was'.

This data highlights the ways in which those who are most vulnerable in society are targeted, given that they are more easily bullied or bribed into silence, less likely to report



experiences of violence, and are unlikely to be believed if they do lodge complaints<sup>43</sup>. This suggests that the oppression and devaluation experienced by persons with disabilities, together with the lack of attention paid to the various manifestations of violence, serves to promote barriers to agency, and enables the continuation of abuse. In this way, violence, together with social exclusion and dependence on others, appears to result in the perpetuation of physical, socio-emotional and financial barriers to accessing adequate service provision.

### ***Theme 3: Corruption and lack of transparency in government policies and practices***

Evidence of corruption and lack of transparency in the implementation of government policies and practices manifested primarily in relation to accessing identity documents (IDs), obtaining disability grants, barriers within the education sector, and challenges in finding employment, all of which served to intensify a sense of competition for minimal resources among community members.

One of the most prominent subthemes that emerged was the challenges to obtaining IDs, even for participants who had been born in South Africa and had never left the country. Of concern were the numerous suggestions that government officials in the Department of Home Affairs purposefully do not process the applications of persons with disabilities in order to prevent them from obtaining disability grants.

*The problem is if you are disabled then you are nothing. You are the last thing to think of. Even the ID people don't follow up because they think 'wooo ... this person will get a disability grant and I won't'. (participant 1)*

*I have been trying to apply for an ID at home affairs. They say they don't help adults, only children, so up until today I am still using the pass book [containing personal information and required under apartheid laws designed to control the movement of young African men]. I think the government is throwing me away because they don't want to give me an ID. Even sleeping at night is*

*difficult because I am always thinking about the ID. I can't do anything without it. (participant 9)*

The impact of not having an identity document appeared to have far-reaching physical and emotional implications. According to South African legislation, individuals need to show proof of identity in order to qualify for a disability grant<sup>16</sup>, to qualify for free healthcare<sup>15</sup> and to be admitted into a school or to qualify for employment<sup>14</sup>.

*I couldn't go to school because I did not have a wheelchair. You see the problem was that I didn't have an identity book so (at the hospital) they said they could not give me the wheelchair. I had to wait for my sisters to come home from school so they could teach me. (participant 25)*

*I cannot work because I don't have the ID book. Nobody cares about you if you don't have the ID book. (participant 9)*

In addition, many of the participants reported challenges in obtaining disability grants. For some of the participants this was linked to the long periods that they needed to wait in order to have their identity documents issued, while for others it seemed that a lack of consistency in the methods used to assess whether individuals qualify for disability grants and the ways in which these processes are communicated were problematic.

*... from the time I applied it took two years for the ID book to come back. (participant 2)*

*It took a long time for me to get a wheelchair, even to get a pension took long. The problem was that I did not have an ID or even a birth certificate. (participant 25)*

*The problem that breaks my heart is that I don't receive the grant. I go to doctors, fill the form, but when I go to the social work offices to check they say 'sorry, it failed'. It hurts me a lot because if I were not sick you would not find me here. I would be working. (participant 7)*



*I made follow-ups for getting a grant for nearly a year, but it was not successful.* (participant 12)

The barriers to obtaining identity documents, together with challenges in accessing disability grants, had a direct impact on food security and the participants' sense of resilience to continue the fight for equal rights and opportunities under such dismal conditions. In addition, alarm was raised regarding community perceptions in relation to the provision of disability grants. It emerged that many community members believed that persons with disabilities should be content to live off the disability grant and that employment opportunities should be reserved for able-bodied members of society.

*When I'm looking for a job my neighbours are asking me why because I am getting the disability grant.* (participant 14)

*I met other people who asked why I was selling (fruit) if I was disabled.* (participant 20)

While it is acknowledged that, for many individuals, disability grants do serve as a financial safety net, the data suggest that they may also force individuals to become reliant on the state. In this way, social exclusion of persons with disabilities and exclusion from participating in entrepreneurial endeavours result in the perpetuation of negative attitudes towards persons with disabilities with society continuing to view these as dependent.

## Discussion

The results of this study suggest that barriers to service provision extend beyond physical obstacles, and include a variety of sociocultural and sociopolitical barriers which do not appear to be accounted for in current policies and models of service provision. The anxiety and uncertainty that the participants revealed suggests that in the rural South African context, the experience of disability may evoke a heightened sense of vulnerability pertaining to increasing mortality rates and the disintegration of the extended family, as well as

violation of human rights. Thus, while it is acknowledged that current models of service provision based on the ICF<sup>17</sup> recognise a relationship between the individual and their environment, this model fails to adequately take context and culture into account and in so doing perpetuates cycles of inaccessibility.

While the findings of this study are not necessarily specific to the South African context, they highlight the juxtaposition between democracy and 'a better life for all' with a heightened sense of fragility in the experience of everyday life. Increases in mortality and the burden of communicable diseases, violence, poverty, unemployment, sociopolitical instability and corruption have become dominating influences and have resulted in inequitable service delivery<sup>44</sup>. Thus, despite the fact that South African policies reflect the government's prioritisation of the needs of persons living in rural areas, many individuals are unable to access these services, and service providers, particularly those working in the public sector, continue to face the challenge of transforming the human, economic and social rights into tools of empowerment.

Based on the findings presented, it is suggested that an understanding of both context and culture is fundamental to the development of appropriate interventions that address the needs of people living with disabilities in rural communities. This implies the need for a critical awareness of the influences that context has on policy implementation and service provision prior to engaging in a debate regarding the rights of persons with disabilities. The ability to do this relies on the use of flexible and culturally appropriate tools which allow for the emergence of various interpretations of experience. In this study, narrative inquiry, together with the collaboration with a cultural broker, appeared to be a culturally safe way to explore lived experience among this vulnerable population and to reveal authentic evidence. It is therefore incumbent on the South African Government to acknowledge this evidence and to review the success of the implementation of its policies.



## Conclusions

The findings of this study create a sense of discomfort because they do not only challenge our understanding of what it means to live with a disability in a rural area, but they expose ruptures in societal morals and values. Furthermore, the findings draw attention to the limited insight that both clinicians and researchers have into the ways in which death, violence and lack of monitoring and evaluation of state practices affects the implementation of policies and the provision of services to those affected by disability. These findings raise questions regarding the ways in which service providers are complicit in perpetuating cycles of human rights violations.

While the results highlight a number of instances where policies fail the most vulnerable in society, it is acknowledged that the responsibility to redress these issues cannot be placed on one body but rather on the relationship between government institutions, healthcare providers and individuals. It is therefore necessary for the South African Government to review the ways in which policies and models of care are applied, acknowledging that care extends beyond personal relationships to the ways in which governments show that they value their people<sup>45</sup>. This entails examining the political imperatives of what care actually means, and considering how these concepts can be applied by taking into account the contextual and cultural needs of individual communities.

Given the vast disparities in the South African context, it follows that not all vulnerable groups can be considered as equitable, and therefore a one-size-fits-all policy to address the needs of persons with disabilities is unlikely to be adequate. However, site-specific analyses using culturally appropriate tools, together with needs evaluations, have the potential to redress the discrepancies in policy implementation and can be used to strengthen institutional ties and referral pathways.

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