

There is always Sorrow: Risk Factors Faced by Parents of Children Presenting with Severe Intellectual Disabilities

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Abstract: *Background:* This study investigates the risk factors faced by parents of children with Severe Intellectual Disabilities.

Methods: This study used a phenomenological research design within a qualitative research approach. Six parents of children diagnosed with Severe Intellectual Disability at Learners with Special Educational Needs schools were purposively selected to participate in this study. Data were collected through semi-structured interviews and a focus group. Thematic data analysis was used to analyze data.

Results: The findings of this study revealed that parents of children with Severe Intellectual Disabilities faced risks that exacerbated negative outcomes. Psychological distress, social exclusion and isolation, financial burdens, and lack of access to formal education were risk factors that hindered their ability to care for and support their children.

Conclusions: Based on these findings, the study concluded that parents need access to multidisciplinary teams of healthcare professionals to support them in combatting the risk factors they face.

Keywords: Children, parents, severe intellectual disability, risk factors.

1. INTRODUCTION

The birth of a child typically marks the onset of a thrilling new chapter that is often accompanied by a myriad of emotions. Peer and Hillman contend that there are significant changes in the lifestyle and identity of a household brought on by a newborn. However, when a child is born with a disability, such as a Severe Intellectual Disability (SID), the experience of parenthood is altered as preconceived plans for the future need to be revised and expectations recalibrated [1]. The altered parental expectations and the need to adapt to caring for a child with SID impact the ability to parent. While the inherent value and rights of children with SIDs remain equal to those of other children, including the right to grow up in inclusive, protective family environments, [2] providing nurturing homes for children with SIDs is not always attainable. Families are burdened with unprecedented challenges, which may include access to quality education, financial constraints, and a lack of access to health facilities [1]. These unique challenges lead to an overall poor relationship between parents and their children with SIDs as a result of the negative impact on their ability to care for their children.

The risk factors of having a child with a disability have been widely studied [3, 4]. For example, Olsson, Larsman, and Hwang [5] conducted a comparative study on the well-being and quality of life of parents who had children with and without

intellectual disabilities. Datta, Russell, and Gopalakrishna [6] investigated characteristics that could predict a burden upon the parents of a child with an intellectual disability. In South Africa, studies have highlighted parents' experiences when navigating the health system and accessing disability services [7, 8]. However, there is a shortage of knowledgeable SIDs, both internationally and locally. Thus, this study focused on understanding the risk factors faced by parents who have children diagnosed with SIDs. Having witnessed the challenges faced by parents and the insufficient support system, the researchers aimed to delve more deeply into the risk factors of South African parents with children who have SIDs. The study's objective was to investigate these risk factors to provide interventions for parents of children who have SIDs. This study also sought to contribute to the knowledge base for parents in similar situations, raising awareness and humanizing the experiences of those affected by SIDs.

2. LITERATURE REVIEW

2.1. Severe Intellectual Disability

Intellectual Disability (ID) is defined by the Diagnostic and Statistical Manual (DSM-5-TR)[9] as a mental impairment that leads to an individual's inability to meet expected milestones in personal independence, social responsibility, and other aspects of daily living tasks. Given that there are varying levels of ID (Mild, Moderate, Severe, and Profound), this study focused on SIDs. Zoning in SID allows us to study an often overlooked and glossed-over disability,

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enabling us to promote inclusivity even in neurodivergence. The DSM 5 TR [9] defines SID as an impairment in different domains of functioning that leads to an individual's inability to meet expected milestones in personal independence, social responsibility, and other aspects of daily living tasks before the age of 18. An individual must also have an IQ level below 20–35, and their approximate mental age in adulthood must be between three and five years old [11]. Taylor and Stenberg¹² posit that, even in adulthood, individuals with SIDs struggle to achieve independent social and economic adjustment, even under the most favorable conditions. For one to meet the criteria for a SID diagnosis, there should be impaired functioning for both the socio-cultural context and the individual's age group [9]. There must also be a deficit in the conceptual, social, and practical domains. A deficit in the conceptual domain for individuals with SID implies that individuals have a limited understanding of the concept of time, numbers, quantity, and money [9]. Patel *et al.* [10] states that a limitation in the social domain results in the affected individual's inability to communicate socially beyond single phrases or words. Morrison [11] adds that the relationships formed by individuals are typically limited to caregivers or service providers. Individuals with SIDs also experience a deficit in the practical domain, implying the need for support and supervision for all activities of daily living [9]. Thus, the acquisition of skills requires prolonged teaching and ongoing support [9].

The Department of Basic Education [13] states that many people with SID commonly exhibit sensory impairments and damage to the central nervous system. Gentile, Cowan, and Dixon [14] further note that they experience limitations in physical abilities, reduced life expectancy, and seizure disorders. Jacobson, Mulick, and Rojahn [15] contend that individuals with SID have a significantly higher mortality rate. The neurotypical population tends to live 15 years longer than individuals with SID, who have a mortality three times higher than that of the general population [15]. This is attributed to their decreased ability to care for themselves, generally inferior structures, and the higher prevalence of physical defects. Schalock, Luckasson, and Tassé [16] claimed that SID has unknown underlying causes. Historically, it was attributed to either biomedical origins or psychosocial factors (intoxication during pregnancy). Saulnier and Klaiman [17] point out that recent research has indicated that causes can be linked to multifaceted factors, including behavioral and educational. Pandya

[18] expands this perspective by emphasizing that timing (prenatal, perinatal, and postnatal) should also be considered within the factors. Although SID is generally considered to be non-progressive, Shogren, Luckasson, and Schalock [19] argue that certain genetic disorders exacerbate the condition. Inadequate family support, delayed intervention, and a lack of resilience in the affected families also contribute to the worsening of the condition of the individual affected by SID.

2.2. Risk Factors

Antony [20] describes risk factors as contributing to a higher probability of negative outcomes. They increase one's vulnerability and susceptibility to detrimental effects. Notably, Masten, Narayan, and Wright [21] add that risk factors also occur in multiple settings and categories and can be caused by individual, family, and environmental factors. Because of the limitations that children with SID have, their parents bear a heavy burden. Opoku *et al.* [22] report that they lack training in comprehending and catering to their children's needs. Anderson *et al.* [23] identify economic hardships such as poverty, coupled with the extra added expenses of caring for a child with special needs, as risk factors for the quality of life of these parents. Masulani-Mwale *et al.* [24] found that parents of children with SIDs had low expectations for their children to receive quality education and live a fulfilling life. Moreover, the adversities faced by children with SID add to the emergence of risk factors that threaten their parents [25]. As children with SIDs encounter difficulty in finding placements in schools that meet their needs, Peer and Hillman¹ believe that this predicament forces parents to forfeit any means of income to provide full-time care for their children. Their sacrifice contributes to heightened stress, frustration, anger, and depression [22]. In addition to various challenges, parents of children with SIDs experience an ever-increasing range of psychological disorders [24]. The frustration and stress brought about by the fact that their children's abilities fall outside societal norms and practices contribute to their emotional turmoil [25]. Consequently, there is reportedly a higher divorce rate among parents of children with SIDs in comparison to neurotypical children [26]. Bauman [27] adds that when neurotypical children reach development milestones, these serve as a reminder that their child with a disability will never accomplish the same achievements. This reminder persists throughout their lives, even though it may evolve and manifest differently in each stage of life.

Furthermore, Pandya [18] points out that access to childcare support services that are available for neurotypical children is lacking for children with SIDs. The lack of support services for children with SID leaves parents feeling isolated as their children require constant close monitoring [18]. In addition to facing disparaging stigmas and misinformation, Dammeyer [25] reports that parents of children with SIDs avoid social activities to evade negative attention. McKenzie [28] points out that despite initiatives by the Department of Social Development, children with SIDs still face marginalization and substandard living conditions. Moreover, families of children with disabilities not only lack fundamental knowledge about the diagnosis and management of their children's conditions but also face resource scarcity [29]. Consequently, families with children with SIDs rely on government social and disability grants, which frequently fall short of providing adequate education, transportation, or daycare services [29].

2.3. Contextualising the Study

Previous studies [30, 31] have focused on the experiences of children living with disabilities (including SIDs), while the risk factors of parents of children with SIDs remain a grossly understudied area. Given the complexity and the varied ways that SIDs present themselves, it remains an understudied area. Patel *et al.* [10] cite that the multifaceted nature of SIDs necessitates research that speaks to various inter-disciplines such as neuroscience, social sciences, psychology, and genetics. An additional barrier to the study of SIDs is that it is under-diagnosed. Mkabile and Swartz [8] state that seeking a diagnosis might be overlooked in favor of trying to explain away the symptoms using traditional beliefs. Moreover, there is a contextual gap in South African-based studies that address both the experiences of parents and the challenges that accompany raising a child with SIDs. Thus, this study explored the risk factors experienced by parents of children diagnosed with SIDs in a Learners with Special Education Needs (LSEN) school situated in Johannesburg, South Africa. It was essential for this research to consider factors specific to the South African population, including socio-economic conditions, cultural and spiritual elements, and access to resources. Consideration of these context-specific factors allowed for a deeper understanding, providing insights and interventions directly relevant to the local context.

3. METHODOLOGY

A qualitative approach enabled the researchers to gain insight into the participants' narratives. Pietkiewicz and Smith [32] state that this approach allows the researcher to pursue a holistic truth encompassing many voices, contexts, and experiences. Thus, the qualitative approach was appropriate for this study as it allowed the researchers to delve into the lived experiences of parents of children with SID, particularly regarding risk factors. This study also deployed a phenomenological research design. The emphasis was on people's perceptions and how they articulated events, experiences, and perceptions as opposed to merely describing them [33]. This research discussed and explored the first-hand experiences of parents with children with SIDs.

Using a purposive sampling method, these researchers aimed to explore and comprehend the risk factors faced by parents with children diagnosed with SIDs. Purposive sampling, as described by Ranjit, [34] involves selecting participants with the required information or the relevant knowledge the researchers seek. Given the limited understanding of the phenomenon being researched in this study, this method proved beneficial. The researchers deliberately selected parents of children with SIDs who experience adversity. The sampling criteria allowed for identifying six parents, male and female, whose children were diagnosed with SID and enrolled at an LSEN school in Johannesburg.

The researchers used a combination of individual semi-structured interviews and a focus group to generate data for the study. The interview questions were developed by the researchers and guided by the research question: What risk factors are faced by parents in supporting their children with SID? The interviews lasted between 30 to 45 minutes. With the permission from participants, the interviews were recorded and transcribed manually. One focus group lasting 60 minutes was also conducted. The interviews were conducted according to the parents' preferred medium of choice, either virtually or face-to-face, at a convenient time and place.

Thematic analysis is a common method used in qualitative research to analyze transcribed data in the form of interview transcripts. It was employed to analyze the collected data in this research. According to Bertram and Christiansen, [35] data analyses consist of transcribing data, assembling it, and drawing

inferences. This process begins with raw data, followed by pattern detection, and concludes by drawing inferences [35]. Similarly, the researcher identified common patterns, ideas, and themes. Clark and Braun [36] outline six steps in the process of analyzing data, which the researchers followed diligently. The first step, according to Clark and Braun [36], consists of familiarising oneself with data, which in this study included the transcription of data from the recordings by the researchers. This was followed by the second stage, which entailed generating initial coding, where the data was coded manually by the researchers [36]. In the third stage, meaningful phrases and sentences were assigned codes; codes with similar meanings were clustered and labelled as themes, which was the fourth stage [36]. This made it possible for the researchers to draw meaningful interpretations from the themes and thus summarise the content to compile a comprehensive report of the findings [36].

The University Of Johannesburg Faculty Of Education Ethics Committee (SEM 2-2021-151) provided ethical permission to undertake this study. The researchers also obtained permission from the Gauteng Department of Education to conduct this study in an LSEN school. Additional permission was sought from the school principal and the school governing body. The participants consented to be part of this study by signing informed consent forms. They also signed an additional consent form for audio-recorded interviews. During data collection, the participants were reminded that participation was voluntary and that they could withdraw their participation at any point. Confidentiality was maintained by keeping personal and sensitive information safely stored to be destroyed only after the study had been completed. Furthermore, the participants were given pseudonyms as a way of keeping them unidentifiable.

4. RESULTS

Data analysis revealed a range of risk factors faced by parents of children diagnosed with SID. The emerging four themes are discussed under the headings: psychological distress, social exclusion, isolation, and financial burdens. Parents indicated that they grappled with psychological disturbances and were ostracized from social gatherings. Moreover, they experienced heavy financial burdens and difficult yen rolling their children in special schools. Quotations from the transcribed data collected from the semi-structured interviews and a focus group supported these themes.

4.1. Theme 1: Psychological Distress because of SID Diagnosis

Psychological distress that ranged from emotional to mental disturbances surfaced as a risk factor for parents of children with SIDs. The findings of the study revealed that parents grappled with feelings of guilt, hopelessness, and depression following their child's SID diagnosis. To illustrate, Participant 3 shared their profound emotional journey:

Upon diagnosis, I thought my life was over. That first day was very, very dark. I wanted to put the nightmare behind me and pretend it didn't happen. I was terrified. They drugged me up to help with the shock, and within a couple of hours, there was a psychiatrist at my bed to help with the shock and discuss what lay ahead.

Participant 2 elaborated on the depth of the emotional roller-coaster ride the diagnosis took her on: *"I felt hopeless! In the year before I went for therapy, I felt like the worst mom in the world! I felt helpless, clueless, depressed, I felt that God robbed me of the one thing that I wanted so badly, a healthy, perfect child"*. Participant 4 contemplated this as being the cause of her current depression: *"I think that is when I started getting depressed; I still am depressed 19 years later. I didn't know how to deal with it"*. Participant 1 said: *"I did grieve for a time, and I did accept his diagnosis ... but yes, there's always sorrow, every day. People's reactions to him make me very upset and would take me back to the grief I first experienced when he was younger"*.

4.2. Theme 2: Social Exclusion and Isolation

Parents of children with SIDs encountered social exclusion that resulted in social isolation. The parents expressed a decline in social invitations, and if they were invited, they were not accommodated; they felt unwelcome, and this led to their subsequent withdrawal from social activities. Furthermore, they dealt with discomfort caused by the unwanted attention and stares that were directed at their children. For example, Participant 5 reflected on the difficulties and adaptations they had to make to go out as a family:

It wasn't easy going anywhere with him. Simple things like going to the mall -I remember the first time we found out about his diagnosis. We went to the

shopping mall, and he was screaming in the mall, hitting people. I didn't know by then that too many people, the change of environment, the noise, and the lights affected him. Once we realized that we had to avoid going to places like that with too many people, too much noise and lighting. Visiting friends as well was also affected because he couldn't stay for long in any environment that he was not familiar with. So, our social life was severely affected.

Participant 6 lamented about the negative and often unwanted attention that came with going out: *"It was difficult to go out with her in public because people would stare, and some people would ask questions, and some people would be ugly. So, as a person, it affected me a lot; I didn't know how to deal with it".*

Participant 2 spoke of the decline in social invitations:

The circle of friends became much smaller over a short period of time ... my opinion is that people would rather not see and experience disability in their circle of friends because it makes them uncomfortable, and they do not know how to respond and support you. Some just stopped visiting and communicating over time.

This is a point that Participant 3 agreed with and expressed as follows: *"Many people didn't want to communicate or acknowledge our son. We also had conversations with friends stating they would like to invite us but didn't want to inconvenience my son by taking him out of his environment".*

4.3. Theme 3: Financial Burdens

Financial Implications that encompassed a lack of affordability and accessibility to special services for individuals with SID emerged as a risk factor in this study. Despite some participants having medical aid, certain specialist practitioners charged out-of-medical aid rates that led to financial strain. Being on medical aid did not alleviate financial burdens, as most parents had to supplement medical costs by tapping into their savings. This was evidenced when Participant 3 pointed out the following:

Medical aid did not cover most of the costs. Before being referred to a

neurologist, Carlos [1]¹ Saw many other specialists first to rule out other diseases. He was assessed by a psychologist, audiologist, occupational therapist, speech therapist, and neurologist, then referred for an MRI of the brain, blood tests, and EEGs! We used all our savings and went into debt to pay for speech therapy and occupational therapy after diagnosis.

This was supported by Participant 4, who referred to the lengths to which they had to go to cover medical costs:

Medical aid didn't cover everything, so for the first five years of Nancy's life, we worked to pay medical bills and go from one doctor to the other. Eventually, we had to sell our house because we couldn't keep up with the payments and try to pay all our medical bills. All her Doctors she sees are specialists, so most of them are charging more than the normal medical aid rates. Which means I end up paying for it out of my pocket. Most of her tablets the medical don't cover, so that's a cost out of my pocket. My medical aid is usually exhausted before June every year, so I pay for most expenses out my pocket.

Participant 1 reflected on the difficulty in finding an affordable school after getting retrenched:

Definitely a lot of financial implications because we had to see quite a few specialists; we had been to the neurologists who started medication for him, which he has to fetch monthly. We had to see speech therapists and occupational therapists.

Participant 2 described some of the many medical expenses acquired:

George's 74-day hospital stay cost over R1 million. Once he was released from the hospital, things became more expensive for us as he had to be on a special type of formula due to his sensitive stomach; we had to get him onto a lot of supplements

¹All children's names have been changed for anonymity purposes.

as well as physiotherapy and speech therapy, which we started as soon as we could. We have never qualified for any kind of disability grant or funding from the government for anything, so in that sense, our expenses were a lot higher than with our other two sons. Also, George was in nappies for a lot longer than his brothers, and nappies are also costly.

4.4. Theme 4: Lack of Access to Formal Education

Another concerning factor for parents of children with SID was the poor formal education that their children were subjected to. They reported limited schools, long waiting lists, and high school fees. Parents also expressed disappointment in the quality of education that their children received. Participant 5 pointed out the lack of government institutions, especially formal education:

South Africa doesn't provide enough schooling options for children living with special needs. Private schools, therapy, or any kind of assistance costs are astronomical. As a matter of fact, there are no government institutions properly catering to special needs adults (compared to Western countries). No government assistance. Knowing that my hands were tied pushed me over the edge until I just could not cope!

Participant 3 echoed these sentiments:

The main thing that was the issue was the education and school for as a child with SID. There are not many government schools that specialize or cater primarily to kids with SID, but there are quite a few private schools, obviously, that charge an arm and a leg. So Ronald attended one for 3–4 years as we were on a waiting list for a government school.*

The long waiting lists seemed to be a common experience for parents of children with SID. This was supported by Participant 2, who concurred:

It was a painful journey - a journey I don't wish on any parent. From his creche, we had to look for schools and I didn't find any – so he was placed on the waiting list. Not finding a public school meant that we

had to put him in a private school, which was very expensive. I had to pay 6.5k monthly fees. There was a time he spent about a year at home the reason being I got retrenched and couldn't afford fees from the private school.

Securing placement for a child with SID at a government school posed its own set of challenges. To this effect, Participant 1 stated:

The process of finding a school for Nancy was tedious, painful, and frustrating because of her size and her disability. When she finally got a place in a school, we were told that she was very disruptive and could not learn anything. They told us to either get a private nurse who would tend to her during school times in class or look for an alternative school.*

5. DISCUSSION

Although the participants sampled in the study had children who had been diagnosed with SID, they came from different cultural backgrounds with varying socio-economic status and beliefs. One would assume that varied status would account for contradictory experiences; however, the risk factors encountered by parents remained the same. The researchers found this especially notable considering the longstanding class divide in South Africa. The risks experienced by parents of children with SID transcended both class and socio-economic status.

The participants of this study unanimously reported experiencing psychological distress upon the diagnosis of their child with SID. Scherer, Verhey, and Kuper [37] define psychological distress as symptoms of anxiety, stress, and depression that compromise mental health. Moreover, the negative emotions and feelings associated with psychological distress negatively impact their daily lives and their interactions with others [38]. The authors ruminated on the extent to which the psychological distress affected the participants' ability to parent their children. Given how mental health is downplayed in our society, it is no wonder that parents spiral into compromised physical health and minimal self-care. The participants confessed to experiencing shock, denial, and depression. Similarly, in a study conducted by Taderera and Hall [39], they observed that parents battled to cope owing to being overwhelmed by increased parental responsibility. In line with the current findings, a study conducted by

Nordlund [40] revealed that parents of children with disabilities underwent an explicit deep sorrow that was compounded by guilt and emptiness that they perceived as insurmountable. Interestingly, the manifestation of psychological distress can be likened to chronic sorrow, a term introduced by Olshansky [41] to describe the pervasive, enduring, and cyclic nature of grief that parents with children diagnosed with SIDs face. Over time, researchers have expanded on this term and concurred that parents grapple with ongoing grief throughout their lives as they are daily reminded of shattered expectations that they had for their child (see [40]). Attributes linked to chronic sorrow, such as recurring grief and resurgence of sorrow over time, were apparent in the findings of this study. The findings of the study also revealed that participants experienced a resurgence of sorrow when they realized their children's unmet developmental milestones. A study conducted by Coughlin and Sethare [42] supports these findings and reports that parents were retriggered by milestones. Life events such as enrolment in Grade 1, the onset of puberty, matric year and 21st birthday, transitioning to adult health care, and consideration of possible guardianship in case the parents died showed the discrepancies between the child with SID and their siblings [42].

Moodley and Ross [43] suggested that the financial burden that parents of children with SIDs experience transcends class, income levels, and rural geographical boundaries. Participants in the study unanimously reported heightened stress levels brought about by the financial challenges they faced. This finding aligns with Hassan, Hamid, and Eltayeb, [44] who noted that the parents of children with SIDs experience higher financial stress than parents of typically developing children. As many as 42% of the participants with children who had SIDs mentioned that they were overwhelmed by financial burdens [43]. In this study, the participants revealed that medical bills contributed to their financial burdens. Leonard *et al.* [45] argued that in the case of children with severe disabilities, families often have to have separate medical emergency savings in addition to their medical aid contributions to cover medical. This aligns with the findings in this study in which participants mentioned being on their medical aid's highest option but exhausting the available funds midyear or having to pay cash and claiming for reimbursement. Moreover, participants noted that they worked reduced hours or did not work at all as their children required extensive caregiving. Hassan *et al.* [44] supported these findings and explained that the loss of income and increased

expenses contributed to how most parents of a child with SID found themselves on the financial backfoot.

The findings of this study further indicated that parents of children with SIDs often avoided public spaces and social engagement because of the negative and upsetting reactions of the general public. Adding to the emotional burden, friends would suggest leaving their children at home. These reactions that are rooted in myths and stigmas became all too exhausting for parents to address. In line with the present results, previous studies such as Masulani-Mwale *et al.* [24] and Tryfon, Anastasia, and Eleni [46] have demonstrated that parents of children with SID find it challenging to relate to parents of neurotypical children. Currie and Szabo [47] reason this is due to unrealistic expectations imposed by cultural and traditional parenting norms. This is exacerbated by the emotional and behavioral challenges of their children, opening them up to shame and judgment from onlookers [47]. It is possible, therefore, that a lack of understanding and acceptance from people in social settings leads to exclusion and, ultimately, isolation. This study also uncovered a typically overlooked risk factor that further added to the social exclusion of parents, which was inaccessibility to public spaces. Aktan, Orakcı, and Durnalı [48] view this lack of social inclusion as a deliberate attempt to discourage the participation of differently-abled people in society. SID is often comorbid with a physical limitation, and thus, narrow doorways, staircases with no options for ramps, and limited disability parking bays deter social engagement and participation [49]. Another finding was that participants always had to find a reliable carer to look after their child before honoring invitations, and the unavailability of carers further exacerbated their isolation. Consequently, parents had to forego previously enjoyed interactions and usually decline invitations to mix socially, leading to ever-shrinking social circles [50].

Finally, this study also revealed the adversities experienced by parents trying to find a suitable school for their children with SID. Despite the global awareness that a child with an ID may not be considered ineducable, education for children with SID remains a privilege and not a right. Considering the policies and the Bill of Rights that govern the South African Constitution on the rights of the disabled, this is a travesty of justice.

When taken to task by the Western Cape Education Department in 2010, the government still contended

that resources were scarce and these children would most likely not benefit from any education [51]. As a result, educational initiatives proved to be scarce, with long waiting lists, and facilities provided often did not meet the needs of learners. This was consistent with the findings of this study, as parents reported feeling that their children were a low priority and evidently a burden to society. A study conducted by Mabuza [52] reported similar sentiments expressed by parents of children with disabilities who lamented that the basic education ministry did not provide educational opportunities and that there was no place for them to go after completing school. Wood et al. [29] proclaim that the creation of equal access to education and the learning and participation of children with SID has remained a pipe dream in the wake of the ambitious plans of the Education White Paper 6. [53]

Engelbrecht et al. [51] add that there are currently over half a million children with disabilities not in school despite the 2010 court proceedings that ordered that relevant organizations should be funded to ensure that every child—no matter the disability—has access to quality basic education. Available literature reveals that children with SID are often excluded from educational opportunities because of financial barriers and strenuous enrolment processes [53, 55]. Parents lamented that they were repeatedly referred to different local, provincial, and sometimes national departmental levels and placed on numerous waiting lists. They were also sometimes denied admission owing to the lack of facilities and space. In a study conducted by Wegner and Rhoda, [56] parents felt that policies favored people without disabilities. The parent's concern about the education of their children with SID being a low priority was echoed by Chitiyo and Chitiyo [57], who revealed that in addition to being understaffed, many teachers in African special schools lacked relevant qualifications to teach. De Sas Kropiwnick et al. [54] point out that inadequate financial means influence how parents search for a school - this is in line with the findings of this study in that the participants were at the mercy of the district officials as they could not afford the school of choice for their children. Although the number of special schools has increased from 295 to 489, none of them are no-fee schools [49]. The access to basic education for all children has not been made equal.

CONCLUSION

The current study investigated the risk factors faced by parents of children with SID. This study revealed

that parents of children with SID encounter risk factors such as psychological distress, social exclusion and isolation, financial burdens, and lack of access to formal education. To combat the identified risks, multidisciplinary teams - encompassing mental health practitioners, the Department of Education, LSEN schools' staff and management, and community members - need to intervene to support parents of children with SID. In alignment with the findings of this study, we recommend that parents' mental health practitioners provide interventions, such as therapy, workshops, and programs, to deal with psychological distress, social exclusion, isolation, and other risks associated with SID diagnosis. Furthermore, the services of specialists such as Speech Therapists and Occupational Therapists to assist with developing home programs that are readily available in clinics and online to support parents in fulfilling the daily life activities required for children with SID are recommended. It is also critical that services and interventions provided to parents of children with SID be tailored to their needs and be culturally appropriate. Hence, we propose the use of 'parent mentors', individuals who have raised and supported children with SID who will now serve the role of guiding and supporting the parents of a newly diagnosed child.

In line with guidelines offered by the Department of Education (DoE), [53] LSEN schools should function as resource centers for nearby parents, communities, and schools. They could offer SID awareness programs, communal support groups, and empowerment weekends. As parents reported limited access to formal education, the DoE should consider investing in developing more schools in different parts of the country to cater to the needs of children with SID. The Department of Social Development stakeholders need to investigate the financial constraints faced by parents of children with SID and implement interventions to support them. In conclusion, this study enhances the current body of literature by identifying the risk factors for parents of children with SID. It was imperative to undertake this study to provide insights into the risk factors faced by parents to suggest interventions to be used to assist them in navigating these risks. Further studies in other contexts should be considered, as this study serves as a basis for future studies.

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