

Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa

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Abstract

Background: Post-apartheid, understanding and management of intellectual disability remain poor in South Africa, complicated by various contextual and cultural explanations used to describe and conceptualize this condition.

Method: We conducted 20 semi-structured interviews with primary caregivers and parents of children with intellectual disability residing in Khayelitsha, a low-income setting in Cape Town, South Africa. We used Kleinman's Explanatory Models (EMs) of illness to explore terms used to describe and conceptualize this condition.

Results: Carers' explanatory models included biomedical causes, injuries during pregnancy or birth, as well as spiritual causes. It was reported that there were significant difficulties in accessing services and support, and difficulties with coping in the context of extreme poverty and deprivation.

Conclusions: Current findings highlight a need for collaboration between the biomedical and alternative healthcare systems in educating carers and parents regarding intellectual disability.

KEYWORDS

caregivers, explanatory models, intellectual disability, parents

1 | INTRODUCTION

The prevalence of intellectual disability in low- and middle-income countries (LMICs) is higher than in other regions due to risk factors largely associated with poverty (Tomlinson et al., 2014). Despite this, most information on intellectual disability has its origin in studies based in high-income countries (HICs) (International Association for the Scientific Study of Intellectual & Developmental Disabilities [IASSIDD], 2014; Robertson, Emerson, Hatton, & Yasamy, 2012; Tomlinson et al., 2014) and there are very few studies on caregivers originating from Africa (Aldersey, 2012; Aldersey, Turnbull, & Turnbull, 2014, 2016; Ajuwon & Brown, 2012; van der Mark, Conradie, Dedding, & Broerse, 2019; McKenzie & McConkey, 2016). The few studies conducted explored views, perceptions, support needs and quality of life of caregivers caring for individuals with intellectual disability in Africa. Findings revealed that most of the caregivers from various African countries were women, caring for their loved ones with intellectual disability in isolation, with very limited

support from other family members and the authorities (Aldersey, 2012; Aldersey et al., 2016; McKenzie & McConkey, 2016). These difficulties had increased the burden of care, and their quality of life was also significantly compromised (Ajuwon & Brown, 2012). A global priority-setting exercise concluded that the sparse existing evidence on intellectual disability coming from LMICs, especially Africa, is largely gender, culture, ethnicity and context insensitive (Tomlinson et al., 2014). In addition, similar studies coming from HICs are often irrelevant and not applicable for LMICs. A review of community-based rehabilitation services focusing on intellectual disability reports that the quality of evidence in this field is very poor; there simply are not enough rigorous, empirically sound papers published in this field (Robertson et al., 2012). This has led to calls for research priorities to be identified and set in LMICs in order to ensure that service provision and support in the field of intellectual disability is evidence-based (Aldersey, 2012; IASSIDD, 2014) and strikes "a balance between basic science, clinical research and public health research" (Tomlinson et al., 2014, p. 1122).

Although efforts to set research priorities have identified priority areas that need to be focused on in LMIC research on intellectual disability, the identified priority areas were largely biomedical and described intellectual disability as exclusively a medical condition, without sufficient regard for social contextual factors. According to Tomlinson et al. (2014), the identified five main research priority areas for intellectual disability research in the majority world are as follows: (a) advance identification, screening and early intervention; (b) improve awareness, prevention, and promotive interventions; (c) identify causes, prevalence, biomarkers, and risk and protective factors; (d) transform health systems to improve access and build human resource capacity; and (e) improve support to parents and families. In order for appropriate support for parents to be developed, in line with this last requirement for research, it is important to know what their experiences of raising a child with intellectual disability are, and how these experiences are shaped by their cultural beliefs about their children's intellectual disability.

A position paper by IASSIDD (2014), an organization that seeks to improve the understanding and lives of people with intellectual disability or developmental disabilities and their families and support systems, reviewed existing evidence on families of children and people with intellectual disability. The paper also set out research priorities for this area of study (IASSIDD, 2014). The Families Special Interest Research Group (SIRG), who authored the position paper, reported that research on parental characteristics of caregivers of children and people with intellectual disability was "relatively poor," but that research on contextual factors associated with families of children with intellectual disability showed that "families supporting a child with intellectual disability are more likely than other families to be exposed to poverty and a range of associated environmental adversities; though, the strength of this relationship will vary with the severity and cause of intellectual disability" (IASSIDD, 2014, p. 423). For instance, one study reported that families of children with disabilities had no formal sources of income and most of the families were fully dependent on the disability grant the government provides (van der Mark et al., 2019). The position paper further asserts that families of children with intellectual disability face more complex challenges than families of children who are developing typically. The Families SIRG underscore that, "for many families, and especially families in low- and middle-income countries, these challenges will be exacerbated by the absence of effective and appropriate services and supports" (IASSIDD, 2014, p. 425). In South Africa, it was reported that parents of children with intellectual disability struggled to afford specialized professional support services for themselves and their children with disabilities (van der Mark et al., 2019). In setting research priorities for studying families of children with intellectual disability, the position paper suggests that the focus should be on: taking a global perspective where research from diverse economic and cultural contexts is prioritized; building the evidence base to improve the current low levels of research focusing on families of children with intellectual disability; and considering contextual factors relating to how families of children with intellectual disability fare and cope in different cultures, and the impact thereof

on the well-being of families and how they relate and engage with services and their communities (IASSIDD, 2014).

The importance of exploring and understanding what forms of care is used and how such care is sought and experienced is underscored by calls to re-examine dominant Western constructions of knowledge and practice and to endeavour to gain a deeper understanding of the relationship between mental health and culture (Swartz, 1998; Center for Mental Health Services, 2001; Kleinman, 1978; Kleinman, Eisenberg, & Good, 2006; Loewenthal & Lewis, 2011). There is growing recognition that on its own a biomedical approach to health and illness, including mental health and mental ill-health and disability, is limited (Swartz, 1998; Skinner & Weisner, 2007). Though the biomedical approach does at best allow for cultural variation, it remains true that the emphasis is still largely on the search for universals, with less attention given to local variation (Kpobi, & Swartz, 2019). The current authors acknowledge that biomedical definitions of intellectual disability attribute intellectual disability to deficits in intellectual as well as adaptive functioning, with onset during the developmental period of childhood (Schalock et al., 2010; Wehmeyer et al., 2008). However, intellectual disability might be viewed differently by various cultural groups. The current study conceptualizes intellectual disability from the perspective of the socio-cultural model, according to which impairment is not a pathology. This model views stigma and other environmental conditions as disabling to people with disabilities, including those with intellectual disability (Goodley, 2001).

In their review of socio-cultural studies, Skinner and Weisner (2007) demonstrated that calls for the consideration of culture in understanding intellectual disability began many years ago. As cited in Skinner and Weisner (2007, p. 302), Edgerton (1967) noted that "mental retardation is pre-eminently a human condition that is both cultural and biological" (p. 302). Skinner and Weisner (2007) further argue that the most important influence in the developmental pathway of a child with intellectual disability is as follows:

the sociocultural place...where that child is going to grow up. Place means not only the geographic locale and ecology, but the local community and its resources and ways of life, and its shared beliefs about development and disability...diagnosis, services, and biomedical interventions should be important, as will be community attitudes, family socialization and care, and many other features. Yet all of these will be shaped in large part by the cultural community and family circumstances into which that child is born.

(Skinner & Weisner, 2007, p. 302)

There is, of course, also a political dimension to this concern, especially in the South African context, where the current study was conducted. South Africa is a multilingual and culturally diverse country with 11 official languages spoken by various ethnic groups. Many of these groups were never fully recognized or acknowledged under apartheid laws. As a result of colonial and apartheid legacies, which

did not foster culture- and class-sensitive ways of practising and providing healthcare services, the current South African health system struggles to meet the needs of Black and uneducated citizens from low socio-economic backgrounds (London, 2008).

These reviews and research priority-setting exercises drive home the point that there is an urgent need for high-quality research, from LMIC contexts, utilizing qualitative and quantitative methods, and addressing research questions related to the experiences of families of children and people with intellectual disability, as well as the services and support systems available to them. The current paper seeks to make a small contribution to this knowledge gap, and to building the evidence base in this area of study by reporting findings from a qualitative study that sought the views and experiences of parents and caregivers of children with intellectual disability from a marginalized and impoverished area of the Western Cape, South Africa.

2 | METHODS

2.1 | Research design

We employed an exploratory qualitative research design using individual interviews to examine the experiences and perspectives of parents and caregivers whose children have intellectual disability. We were interested in exploring caregivers' and parents' individual views, ideas, experiences, beliefs about intellectual disability and accounts of caring for a child with intellectual disability in the local context (Babbie & Mouton, 2001). To this end, we developed an interview guide (see Appendix 1) based substantially on Kleinman's Explanatory Models (EMs) approach (Kleinman et al., 2006). EMs provide an opportunity to answer fundamental questions about cultural underpinnings of intellectual disability where biomedically informed interview models have traditionally been limited. Key aspects of the EM approach have now been incorporated into the DSM-5 Cultural Formulation Interview (Radhakrishnan, 2016). For Kleinman (1978), caregivers and parents are significant sources of information due to their first-hand day-to-day experience in dealing with children with intellectual disability. Some studies have reported on caregivers' views and experiences of caring for a person with intellectual disability. Their findings suggested difficult caring experiences, stigmatization, discrimination and negative cultural beliefs, all of which negatively affected their caring experiences (Aldersey, 2012; Aldersey et al., 2016; Ajuwon & Brown, 2012; McKenzie & McConkey, 2016). To our knowledge, there are very few studies that have explored views of caregivers and parents of children with intellectual disability from low-income areas using an EMs approach.

Kleinman's (1978) Explanatory Model of Illness framework informed the semi-structured individual interviews. Kleinman's EM model approach employs a particular interview technique to reconstruct, in a rigorous fashion, clients' conceptions of the cause and development of specific diseases. Good and Good (1981) describe the EM interview as one that elicits the patient's (or parent's)

perceptions of the onset of the disorder; its cause, symptoms, manifestation over time and appropriate treatment; and the values and emotions that are related to the disorder. In our context, where services are scarce it was also important to probe carefully the accessibility of services.

2.2 | Study setting

The study setting is a catchment area around a psychiatric hospital situated in the heart of the Cape Flats in Cape Town. Originally built under the apartheid system, Lentegeur Hospital (LGH) was originally built to serve Coloureds¹ only. With no mental health facility built specifically for them, Black African isiXhosa-speaking patients with psychiatric illnesses, including those with IDs, were compromised with regards to health services in the Western Cape, especially on the basis of language and culture (Swartz, 1998). Although LGH now prides itself as non-racial, non-discriminatory and community orientated (Drennan, 1999), Black African psychiatric patients, including those with intellectual disability, who reside in the Cape Flats catchment area, still have difficulty accessing mental health services. Because of the difficulties encountered by Black Africans in accessing health services in general, a particular focus was given to Black African isiXhosa-speaking participants living in an urban LGH catchment area to achieve the goals of the study.

The hospital is appropriate for identifying and recruiting participants focusing on parents and primary caregivers of children with intellectual disability, because hospital-based sampling is in accord with Kleinman's (1978) theoretical framework.

2.3 | Recruitment and sampling

Twenty Black African isiXhosa-speaking parents and primary caregivers of children with intellectual disability, using both outpatient and in-patient services, were recruited. The hospital is a public mental health institution, with Intellectual Disability Services (IDS) being one of the units. IDS is the only specialized public health service in the Western Cape for the treatment of mental health illness and skills training for children diagnosed with intellectual disability.

A purposive sampling method was used for recruitment and inclusion. Based on the principles of qualitative research,

¹In apartheid South Africa, four main racial classifiers were used. The majority population, or "Africans," were indigenous people largely speaking local languages; "Whites" were people of Caucasian origin; "Asians" were people largely of Asian (chiefly Indian) descent. The term "Coloureds" was used for a group of diverse and mixed origins, largely first-language Afrikaans-speaking residents in the Western Cape, where they remain the numerical majority to this day. Our use of apartheid categories does not imply that we ascribe any biological or scientific significance to such labels; one of the ironies of the post-apartheid era, however, is that such labels persist in order to assess progress towards equity in the country (Posel, 2001). For the context of the current study, it is important to note that, historically, under apartheid, the Western Cape was seen as a predominantly Coloured and White area; with substantial in-migration of African people, largely from the Eastern Cape, there is a rapidly growing isiXhosa-speaking population with compromised access to services (Benjamin, Swartz, Chiliza, & Hering, 2016).

participants were approached directly by the researcher, who is employed as a senior clinical psychologist in the service, and having worked there for 11 years, is familiar with the setup and speaks isiXhosa as his first language. The researcher (who is the first author of this article) is in fact the only isiXhosa-speaking psychologist in the service in the entire province. This made for easy rapport with participants, but it was also important to guard against any possible over-identification with participants. This was dealt with through discussions between the first author and the second author, who is a very experienced disability researcher who has written extensively on methodological issues in this research in the African context (see, for example, Swartz, 2014; Swartz & Marchetti-Mercer, 2018).

[The researcher] contacted the parents or caregivers by requesting to speak with them following their attendance at the out-patient programme or in-patient programme of the Psychology Department, or one of the other multi-disciplinary professions. In addition, folders of service users who had accessed services during the previous four months were used to compile a list of names of people who could be approached to participate. Participant characteristics are presented in Table 1. All participants lived in Khayelitsha, a large, predominantly impoverished community with a high proportion of informal (shanty) housing, situated within the catchment area of the hospital.

2.4 | Data collection

Twenty individual interviews were conducted by the first author between January and March 2018 at the hospital and at the participants' homes. For various reasons, the majority of participants preferred to be interviewed at their homes in Khayelitsha.

Using Kleinman's (1978) EM framework, the semi-structured interview guide was developed, constructed in English and then translated into isiXhosa by the language and communication centre at [anonymized for peer review] University. It was then edited by the first author who speaks and understands isiXhosa as his first language. Following the testing, the interview guide was then used to collect data. All interviews were audio recorded with the permission of the participants. Each individual interview session took between 60 and 70 min. Following each interview, field notes were written to capture the context, environment and non-verbal communication. These were reflected on after each interview and used to guide further interviews where appropriate.

2.5 | Data analysis

All the audio-recorded individual interviews were transcribed in isiXhosa and then translated into English by an isiXhosa-speaking

TABLE 1 Participant profile of parents and primary caregivers of children with intellectual disability

Interviewee identification	Relationship to the child with intellectual disability (CWID)	Age	Marital status	Employment status	Age of child with intellectual disability (CWID)
PA001	Separated biological mother of a CWID (SepBMCWID)	44 years	Separated	Unemployed	11 years
PA002	Separated biological mother of a CWID	40 years	Separated	Unemployed	13 years
PA003	Single biological mother of a CWID	40 years	Single	Unemployed	17 years
PA004	Widowed biological mother of a CWID	61 years	Widowed	Unemployed	18 years
PA005	Single biological mother of a CWID	39 years	Married	Unemployed	11 years
PA006	Single biological mother of a CWID	40 years	Single	Unemployed	11 years
PA007	Single biological mother of a CWID	45 years	Single	Unemployed	12 years
PA008	Single biological mother of a CWID	40 years	Single	Unemployed	10 years
PA009	Single foster mother of a CWID	33 years	Single	Unemployed	13 years
PA010	Single biological mother of a CWID	41 years	Single	Unemployed	16 years
PA011	Remarried biological mother of a CWID	M - 38 years	Remarried	M - Unemployed	14 years
PA012	Single biological mother of a CWID	55 years	Single	Unemployed	14 years
PA013	Married biological father of a CWID	58 years	Married	Employed	12 years
PA014	Married biological mother of a CWID	53 years	Married	Employed	12 years
PA015	Stepfather of a CWID	46 years	Married	Employed	14 years
PA016	Married biological father of a CWID	39 years	Married	Employed	11 years
PA017	Single biological mother of a CWID	40 years	Single	Employed	15 years
PA018	Single biological mother of a CWID	48 years	Single	Employed	15 years
PA019	Single biological mother of a CWID	38 years	Single	Unemployed	14 years
PA020	Single biological mother of a CWID	44 years	Single	Unemployed	16 years

translator. The translation was checked against the original recording to ensure accuracy by the isiXhosa-speaking first author. Qualitative data software ATLAS.ti (v.8) was used to analyse the data. Initial data analysis was done by the first author and then checked in collaboration with the second author. Disagreements were vigorously discussed by both authors until they were resolved. Data were analysed using thematic content analysis where each transcript was first read through, then manually coded, and repeated codes were categorized into themes (Braun & Clarke, 2006).

3 | ETHICS

Ethical approval was sought and obtained from the [anonymized for peer review] University Humanities Research Ethics Committee and the Western Cape Department of Health Ethics Committee before the data collection process. Formal permission was also sought from Lentegeur Hospital Research Committee.

Following ethical guidelines, participants who showed signs of distress following the interviews were referred for individual psychological support or to a parent support group at IDS, LGH. All the children of the interviewed participants were already known to the local department of social services and various social agencies operating in the communities to provide social support and to guard against any form of abuse. They were also receiving care dependency or disability grants from the Department of Social Services.

4 | RESULTS

Results of this study are presented narratively in themes. Five main themes emerged from the analysis of data:

1. Recognizing and labelling intellectual disability.
2. Consequences of intellectual disability.
3. Explanations of the causes of intellectual disability.
4. Difficulties in accessing care.
5. Use of various intervention/healing options.

We shall now discuss each in turn.

4.1 | Recognizing and labelling intellectual disability

All participants reported on how they initially recognized their children as having intellectual disability. They used both biomedical and socio-cultural terms to refer to their child's condition. Most of them did not make a distinction between intellectual disability and mental illness. There were also respondents who indicated that they did not know what their children's condition was, because they were never told by the doctors. Socio-cultural terms seemed to be associated with negative and offensive labelling. They used normative terms such as "mentally ill," "autism" and "special needs." For example, one parent stated that:

Since I have attended support groups and doctors' appointments, I believe she has autism.

(PA002, separated biological mother of a CWID)

Socio-cultural terms included "uphambene," "isidenge" and "ukhubazekile-engqondweni." These words directly translate to "mad," "stupid" and "intellectually disabled." When asked about the words they use to recognize intellectual disability, all participants showed high levels of discomfort, embarrassment and shame. They reported that these are the labels used in their communities by others when referring to their children with intellectual disability. These labels were common across most participants. All participants felt that it was neither appropriate nor acceptable to refer to their children with these labels. These labels were reported by most participants regardless of whether they were a primary carer or a biological parent of a child with intellectual disability. The carers' and parents' discomfort with these labels are indicative of their appreciation of the stigma and discrimination associated with them.

4.2 | Participants' description of the consequences of intellectual disability

The participants also reflected on the consequences and/or impact of raising a child with intellectual disability in their lives. Consequences were reported in three forms; that is, on the child, the carer or parent and on the family.

4.2.1 | The child

Most participants reported that children with intellectual disability were stigmatized (for example, subject to name-calling), had no friends, experienced both physical and sexual abuse in many cases, manifested challenging behaviours, and some were neglected and excluded from community activities as a consequences of having intellectual disability:

Most people understand her; it is only just this one lady who has a problem with her. In other houses when she wanders off to them they keep her and they call out to me to report she is by their house. But this lady she throws her out of her store.

(PA005, married biological parent of a CWID)

4.2.2 | The parent or caregiver

Most of the participants indicated that they were not supported by the extended family members or members of the community. As a result, they had to give up their employment because there was no one else to help with the child's care. In addition, participants reported that they themselves developed mental health problems as a result of caring for a child with intellectual disability:

I am unemployed and I rely only on his disability grant which only covers his needs.

(PA006, biological mother of a CWID)

...you are always tired, you are always anxious, you are mentally exhausted, and you are just staring into space exhausted, but I have to carry on.

(PA001, separated biological mother of a CWID)

There have been times when it has been so hard I have made a decision to kill myself and then think what would happen to [child's name] and then decide it is better just to die with all my children. Then my mother; I do not want to include in this then I think if I would go through with it, she would suffer the most, then I stop and find a way to go on.

(PA003, single biological mother of a CWID)

...it has adversely affected me; I had to go to the clinic because I had a relentless headache; I was diagnosed with depression. I was prescribed medication which I take dutifully but the headaches are still there.

(PA002, biological mother of a child with ID)

It is a lot of strain, I get so frustrated and I do not have anyone in my family to help relieve my stress. I have to find a way to encourage myself again and stand strong. It gets very difficult since I am sick as well, I am on ARVs [antiretrovirals]. I have to remember to take them every day and I have [child's name] who needs my constant attention...

(PA008, biological mother of a child with ID)

4.2.3 | The family

Most of the participants reported a number of family difficulties that were associated with raising or having a child with intellectual disability in the family. These included separation or divorce, poor family relationships and difficulties in caring for other children. Some participants poignantly talked about the difficulties of raising a child with intellectual disability with no support system, when they had their own challenging chronic illnesses such as HIV/AIDS, high-blood pressure, diabetes and other conditions to contend with. As one participant stated:

It changed it a lot when I got [child's name]. I did not know he was going to turn out with a disability. People loved him when he was younger (an infant), even his father's family loved him. When the disability showed out everyone turned their backs on us, even my family. When he was an infant, he was handsome and cute, everybody loved him and when he got older the disability showed;

they did not want anything to do with him. Even my own mother rejected us...

(PA008, biological mother of a CWID)

Often that they would not pitch in and help with the baby, even with the small things you would be told that the child has wet themselves or the child has done this or that and you find that the child is not fed because you were not home.

(PA001, mother of a CWID)

Caregivers who did not have a strong support system worried a lot about what would happen to their child with intellectual disability were they to die first. One mother stated:

I worry a lot about if I would die who would look after my child, what would happen to him? When they do not care about him while I am still alive how will they care for him when I am dead? No one even asks after his health, how he is or any reference. I often pray for God to take him first, not me, because I worry what would become of him should I die first.

(PA008, biological mother of a CWID)

4.3 | Participants' explanations of the causes of intellectual disability

Participants gave various explanations with regard to the causes of their child's intellectual disability. Their views were mostly concerning life events experienced, and biological or spiritual reasons for the child's condition:

There is something I have always found curious that my wife had food poisoning while pregnant, and my child came out with a mark on her leg, she was burnt/scarred by the poison. So, I have often thought of that incident for the reason that she is the way she has ID.

(PA005, married biological father of a CWID)

I believe her mother was highly stressed during her pregnancy and pregnant women should not be placed in a position of constant stress when they are expecting because it affects the unborn child adversely. I met her when she already had "xxx" and I accepted them even with her child's condition in my life. I married her with her child's condition. I did not have a problem with that, the child is already born like that there is nothing that can be done now.

(PA011, stepfather of a child with ID)

I believe it was caused by the seizures she experienced.
(PA002, single biological mother of CWID)

Some participants believed intellectual disability could have been caused by physical and/or emotional abuse they experienced during pregnancy. They reported that they were physically and emotionally abused by their spouses. They suggested that these fights and stress might have affected the foetus and resulted in the child developing intellectual disability after delivery. Some of these experiences were also coupled with lack of food or a proper diet during pregnancy:

It was a strenuous time during that time, I had gone (away) and got back to Cape Town to my ex and found him with a woman. I did not take it well and my high blood pressure shot up during that stressful time. I got into labour but I was turned back because I was still far off from my delivery date. I was in labour for two days and when...they discovered my high blood pressure was too high and doctors recommended an emergency caesarean.

(PA011, remarried biological mother of a CWID)

I believe her mother was highly stressed during her pregnancy and pregnant women should not be placed in a position of constant stress when they are expecting because it affects the unborn child adversely.

(PA011, married stepfather of a CWID)

On the other hand, others attributed the causes of intellectual disability to challenges they encountered during delivery:

I think it is a result of two things, the first one I draw it from what his father said that there is someone with a similar disability in his family. The second thing is when I was set to give birth, I stayed an entire week after my water broke before I delivered him. So, I believe it is between those two things he developed his condition.

(PA008, single biological mother of a CWID)

I think it is because she was a premature baby. I delivered her at 29 weeks and she weighed only 1.8kg when I brought her home... That is what I think is the cause of her disability because she was very sick earlier on.

(PA001, separated biological mother of a CWID)

During delivery she did not get enough oxygen to her brain so that needed to be under the doctor's observations at all times.

(PA003, single biological mother of CWID)

Some participants suggested that another potential cause for their child's intellectual disability could be genetics. These participants believed that the reason their children had intellectual disability was because there was another family member in the family who had intellectual disability:

I think it is a result of two things, the first one I draw it from what his father said that there is someone with a similar disability in his family.

(PA008, single biological mother of a CWID)

Finally, apart from life events and biological causes, some respondents believed that they were either bewitched or that their ancestors were not happy with something in the family:

Shortly after that [child's name] suffered a seizure and her mother said it was probably bad spirits. So, I said she ought to take her to places that deal with bad spirits, which she did. She got medication from there...

(PA009, single foster care mother of a CWID)

4.4 | Difficulties in accessing care

Most of the participants expressed their difficulties and frustrations regarding accessing specialized intellectual disability services for their children. These difficulties included problems with access to transport, special schools, hospitals, specialized care centres, group homes and language difficulties in hospital settings. They indicated that specialized hospital services for children with intellectual disability were a long distance from their communities. They detailed the difficulties regarding travelling with a child with intellectual disability using public transport, including extremely high costs. Each appointment requires two to three taxis travelling to and from the hospital. In many cases, when these participants finally reach the hospital, they find that the services are offered either in English or Afrikaans, languages that they are not fluent in or comfortable speaking:

Hospitals are far and it is hard to access service which is not all that adequate as well... [the English and Afrikaans] are both not a language I readily understand but because I am in the Western Cape and it is predominantly White and Coloured people's province. Although we were taught English at school back in the Eastern Cape, I struggle to understand it most times... They do not know how to speak my language

(separated biological mother of a CWID)

It is expensive, because from home to Mitchells Plain the fare is R10 and another from Mitchells Plain to the hospital that tallies to R40 a return trip.

(PA001, separated biological mother of a CWID)

4.5 | Participants' description of the use of various intervention options

Most of these participants have reportedly resorted to various options to manage their child's intellectual disability. In addition to the mainstream hospital services, participants reported that they also seek advice from churches and traditional healers. The alternatives are used by the participants for various reasons. These include prayers, seeking a cure for intellectual disability, support for carers, everyone does it, seeking for answers and cleansing. One participant shared:

I also went to St John's (faith healer) where they asked me to go fetch soil from [child's name's] grandparent's house; he will only get better if I go and take soil from there or if I take him to go and live there.

(PA006, single biological mother of a CWID)

I get a lot of support from the church; even through December they often gave us money for us to buy food... He enjoys it, he enjoys the dancing at church – we are a Pentecostal church; we dance at church... The people from church always say he will be healed, and they are always laying hands on him and praying for him.... They always made sure I take him a cup of holy water to drink.

(PA006, separated biological mother of a CWID)

Some participants talked about first seeking help from traditional healers, but after being dissatisfied with the treatment, abandoning this alternative service:

Initially when we were at a loss of what was happening to her, so we consulted them (traditional healers) for answers but realised they do not know what is the matter as well so we stopped... She was given some medication but she would just drink and there was no improvement.

(PA005, married biological parents of a CWID)

Two years ago I went home to the village to carry out a ritual for him to introduce him to our ancestors as a way of introducing him to the family. It did not do anything for him. I thought he would calm down after that but he did not. I guess it is in him, in his veins; it would never come out.

(PA007, single biological mother of a CWID)

5 | DISCUSSION

Caregivers and parents seemed to employ a wide range of EMs to the causes of intellectual disability in their children. These included biomedical and socio-cultural explanations where they believed

witchcraft, bad spirits and bewitchment may have caused the intellectual disability. In addition, most of the participants admitted using both Western-trained doctors as well as traditional healers. These participants further reported a number of general barriers related to financial constraints and family dynamics that made it even more difficult to care for the child with intellectual disability.

Although there are no other studies which we are aware of conducted on isiXhosa-speaking caregivers of children with intellectual disability, the current findings are consistent with previous studies from other groups in LMICs on the terminology used for people with intellectual disability. For instance, studies conducted in countries in other parts of Africa revealed that different population and cultural groups have also used various terms, words and idioms for intellectual disability (Brocco, 2015; Kisanji, 1995; Masulani-Mwale, Mathanga, Silungwe, Kauye, & Gladstone, 2016; McKenzie, McConkey, & Adnams, 2013; Stone-MacDonald, 2012). In the current study, intellectual disability is referred to as "ukugula ngengqondo," "ukuphazamiseka," "uphambene" and "autism." Referring to intellectual disability as illness was consistent with findings from a scoping review on intellectual disability rights and inclusive citizenship in South Africa (Capri et al., 2018). In the review, Capri et al. (2018) identify a common problem in South Africa where people with intellectual disability are commonly regarded as mentally ill. In addition, similar isiXhosa names used for intellectual disability were also reported for psychiatric disorders in other studies (Ngqoboka, 1998). These findings are indicative of potential confusion and shadowing of intellectual disability with psychiatric disorders. In addition, "uphambene" is a Zulu word which directly translates to "you are crazy," and this was also used for intellectual disability. These results are reflective of various spoken languages in South Africa, where there are eleven official languages. According to Keikelame and Swartz (2015), challenges in communication in a multilingual society may lead to difficulties in accessing care and support. Most participants referred to a person with intellectual disability as "isidenge," which was expressed with significant discomfort. These caregivers and parents explained that this was the term used by people in their communities when referring to their children with intellectual disability. They revealed that "isidenge" means "someone who does not know anything" or "crippled" and it is a derogatory term. The unwillingness to use certain words could be suggestive of stigma surrounding disability, including intellectual disability, in these communities (Jahoda & Markova, 2004).

In addition to biomedical explanations, participants gave socio-cultural reasons as the causes of intellectual disability, these including bad spirits, witchcraft, poisoning and bewitchment. Other studies reported similar findings where supernatural reasons were reported as causes of intellectual disability (Goodey & Stainton, 2001; Kromberg et al., 2008; McKenzie et al., 2013; Scior, 2011). Goodey and Stainton (2001) describe witchcraft as the act that involves use of magic to harm others or their property. Similarly, in our study some of these parents and caregivers believed intellectual disability could be caused by evil spirits from jealous neighbours.

The other important finding in this study is that caregivers and parents of children with intellectual disability have used both biomedical and alternative care systems for intellectual disability. This finding is consistent with other studies (Peltzer, 2009). There was very limited access to specialized biomedical services for children with intellectual disability and their parents' or caregivers' mental health needs. Although the status of mental health services in South Africa has improved, mental health services are still marked by discriminatory divisions established in the apartheid era when access to healthcare facilities for Blacks in the Western Cape was severely compromised. Black people living in Cape Town are still required to travel long distances to access basic mental health services in institutions where service providers often do not speak their languages, and where, as a result, they struggle to express themselves and to understand what is being said to them Benjamin et al., 2016). This is important in terms of the EMs framework referred to earlier. The findings suggest that the provision of services in a language that is not well understood by patients and their caregivers can frequently lead to the perspective of the clinician/healthcare professional and that of the patient/caregiver being at odds, with the clinician or healthcare professional not being aware of the EM of the patient/caregiver. Swartz (1998) warns that "the job of the clinician is not only to understand the patient's explanatory model, but also to negotiate between the professional explanatory model and that held by the patient, so that there can be some common ground and a basis for treatment which will be acceptable to both...a common understanding is likely to increase the extent to which the patient participates in treatment by following the advice, taking medication and so on" (p. 15). If the very language spoken by service providers is not well understood by caregivers and parents of children with intellectual disability, there is little chance that the understanding and common ground Swartz (1998) referred to above can be achieved.

In addition to cultural explanations, the inaccessibility, both physical, intellectual and psychological, of formal healthcare intellectual disability services, as experienced by participants in this study, may have contributed in large part to their seeking alternative healthcare systems in order to manage their children's intellectual disability. The findings in this paper show that caregivers and parents sometimes "resorted to" traditional healing to seek help, with some dually accessing both Western formal health systems and traditional healers. Other studies have shown that it is common practice for people to make use of both Western medicine and traditional medicine in South Africa (Peltzer, 2009). More specifically, both mothers and caregivers in various studies have often admitted using both indigenous as well as Western health services within the South African context (Kromberg & Jenkins, 1997).

From the limited available evidence base, it also appears that South African families of children with intellectual disability react differently based on various belief systems. These may determine their behaviours towards a family member with intellectual disability. Similar to our study, in a review by Mckenzie et al. (2013), traditional beliefs about intellectual disability in South Africa were

more rooted in negative feelings such as bewitchment and fear of the ancestors. As a result, some families would take their children with intellectual disability to traditional healers seeking a "cure" and performing rituals for the ancestors. However, this was not the case in other African countries, such as Tanzania, where some beliefs encouraged positive behaviour towards those diagnosed with intellectual disability. Furthermore, some religious beliefs in Tanzania had more positive views and encouraged more coping strategies (Kisanji, 1995).

As a result of the aforementioned historical difficulties in South Africa and other African contexts, such as Western-centric health systems, and the impact of belief systems on understanding illness, it should be expected that people may seek a variety of ways to respond to the child's disability. For decades, the biomedical model has been viewed as the only way of understanding and treating all illnesses. In a multicultural context where other belief systems and explanations do exist, conflicts and confusion between Western-trained doctors and patients are observed. Masasa, Irwin-Carruthers, and Faure (2005) warn that different belief systems may impact on rehabilitation. Fadiman (1997) graphically demonstrates the potential tragic consequences of a poor cultural fit between health systems and the beliefs of users of those systems. Given this evidence, our findings provide important implications for an intellectual disability-specific health policy that will draw in traditional healers and other alternative forms of care utilized by parents and caregivers of children with intellectual disability in order to learn from these alternative models and to facilitate their use to ensure that services that are in the best interests of children with intellectual disability are provided. The formal health system has to recognize the "interconnectedness of health care sectors in the context of culture" (Kleinman, 1978), and to appreciate that traditional healers, or "folk healers," in Helman's (2007) terminology, have as a strength the fact that they come from the same world, in terms of community, culture and values, as the people they provide healing services to. They also employ a holistic approach to the treatment of ill-health, considering a patient's relationships with others, the natural environment and the spirit world in diagnosing and treating a condition (Helman, 2007).

6 | CONCLUSION

The current study explored EMs, the understandings and conceptualizations of intellectual disability, and the perspectives and experiences of having a child with intellectual disability of Black African isiXhosa-speaking parents and primary caregivers living in poor, marginalized settings in the Western Cape. It is important to acknowledge that our sample has not been assessed to determine the extent to which it is representative of the situation of all such families. This said, though, the findings resonate with the 11 years of clinical experience of the first author as the only isiXhosa-speaking psychologist to work in intellectual disability mental health services in the entire Western Cape Province of South Africa.

The findings shed light on recognizing and labelling intellectual disability, consequences of intellectual disability, explanations of the causes, and difficulties in accessing care, to the use of various intervention/healing options available to them. Although to a large extent parents and caregivers reported negative experiences, they reported some very positive experiences. For instance, one participant reported that the community understood her child with intellectual disability and assisted in bringing her home. This finding is indicative of the community support and acceptance of individuals with intellectual disability in some communities. This also reflects the spirit of *ubuntu* (spirit of togetherness) common and popular among Black African families (Nyengele, 2014).

While these findings add to the sparse body of evidence on how families of children with intellectual disability experience living with their children in contexts of poverty, they also indicate a desperate need of support for both carers and children with intellectual disability in low resourced environments. Furthermore, they demonstrate that structural factors add to the challenges of accessing services and support, that families and children with intellectual disability experience isolation and stigma in their communities and that parents and caregivers use both biomedical and socio-cultural terms to describe and make sense of their children's intellectual disability. The use of both biomedical and spiritual interventions for their children is indicative of the need for advocacy for the recognition of the alternative healthcare practitioner within the health system in South Africa. In addition, there is a need to transform and to reform intellectual disability services in order to ensure that these services are accessible to families and children with intellectual disability who are living on the margins of society, who speak a different language to that spoken in the professional setting, and who have belief systems that are different from those espoused by the formal health system.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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APPENDIX 1

TOPIC GUIDE—SUB-STUDY 1

Individual interviews with users of Intellectual Disability Services (IDS) (Hospital Services)

Semi-structured in-depth interview topic guide:

1. What is your understanding of the condition that your child has?
2. What do you think caused your child's condition?
3. Why do you think your child has this condition at this particular time?
4. How do you think this condition works inside your child's body and mind?
5. What does this condition do to you? What does it do to your child?

6. How have your lives as a family been changed by the diagnosis of this condition in your child?
7. What was your first response when you heard/discovered that your child has this condition?
8. What are some of the challenges of having a child with condition?
9. How do you cope with having a child who has this condition? Probe for prayer/church support, cultural practices, and community services.
10. When did you start using IDS services?
11. Why did you start using IDS services? (Probe for presenting issue) – this could be the first question.
12. How easy or difficult is it to access IDS services for your child? (Probe for transport problems, waiting times).
13. What has been your experience of using IDS services? Probe for perception of IDS staff attitudes, treatment by IDS staff.
14. If non-English and non-Afrikaans speaking: How have you experienced receiving IDS services in English/Afrikaans?
15. What do you think of the services you are accessing for your child here at IDS?
16. What, if any, other services/help outside IDS have you sought for your child? Probe for traditional and spiritual healers, probe for homoeopathy/alternative medicine, non-prescribed medicines, social grants.
17. What, if any, would you change about the services you receive here at IDS for your child?