*Preprints* (www.preprints.org) | NOT PEER-REVIEWED | Posted: 4 September 2020 doi:10.20944/preprints202009.0092.v1

*Article*

# 'I Waited for It Until Forever': Community Barriers to Accessing Intellectual Disability Services for Children and Their Families in Cape Town, South Africa

**Siyabulela Mkabile * and Leslie Swartz**

* Correspondence: s.mkabile@uct.ac.za

**Abstract:** 1) Background: Intellectual disability is more common in low- and middle-income countries than in high-income countries. Stigma and discrimination have contributed to barriers to people with intellectual disability accessing healthcare. As part of a larger study on caregiving of children with intellectual disability in urban Cape Town, South Africa, we interviewed a sub-group of families who had never used the intellectual disability services available to them, or who had stopped using them; 2) Methods: We employed a qualitative research design and conducted semi-structured interviews to explore the views and perspectives of parents and caregivers of children with intellectual disability who are not using specialised hospital services. We developed an interview guide to help explore caregivers' and parents' views; 3) Results: Results revealed that caregivers and parents of children with intellectual disability did not use the service due to financial difficulties, fragile care networks and opportunity costs, community stigma and lack of safety, lack of faith in services and powerlessness at effecting changes, and self-stigmatisation; 4) Conclusion: Current findings highlight a need for increased intervention at community level and collaboration with community-based projects to facilitate access to services, and engagement with broader issues of social exclusion.

**Keywords:** intellectual disability; children; South Africa; access to services; poverty; inequality

---

## Introduction

Intellectual disability (ID) is more common in low- and middle-income countries than in wealthier countries [1], and there are fewer services in these countries to support people with ID and their families [2–4]. An article setting global priorities for research into developmental disabilities [5] suggests, among other recommendations, that more needs to be done to make health systems more accessible to families of children with ID. Some research suggests, however, that even in contexts where health services are reasonably close by for families, there may be under-utilisation of these services by those who could potentially benefit from them [4].

Stigma and discrimination have contributed to barriers to healthcare in many parts of the world [6–11]. People with intellectual disabilities (PWID) still face social exclusion and discrimination more than those without ID [7,12–15]. As a result, more than the general population, they may face substantial difficulties in areas of health, education, housing and employment [16–19]. ID is widely known as a stigmatising condition, however, research in this area, especially in the Global South, is still very sparse [2,20]. Although South Africa is still the only country in Africa with inscribed constitutional rights for people with disabilities, implementation remains a major challenge because of lack of resources [2]. While studies have shown that public attitudes, stigma and discrimination can act as potential barriers to healthcare access for PWID and their families, it is not clear whether this contributes to people with ID not using services even when such services are available to them.

© 2020 by the author(s). Distributed under a Creative Commons CC BY license.

There is strong evidence from high-income countries with sound programmes and policies on ID suggesting that many PWID do not use specialised ID services although they are eligible. Records from hospitals and special services data show that there is a significant decline in numbers of PWID attending specialised services in the United Kingdom (UK) [21]. The failure to access specialised healthcare services can lead to poor health outcomes. Emerson [22] (p. 155) notes that 'as such, the poorer health status of people with intellectual disability can be appropriately described as an example of health inequity'. He further reported that non-users had higher health risks (exposure to material hardships, neighbourhood deprivation and smoking) compared to PWID who used ID services, although the difference was marginal (overall both PWID who accessed services and the 'hidden' PWID who were not known to ID services had high exposure to health risks/social determinants of health).

In a similar vein, Boag-Munroe and Evangelou [23] conducted a systematic review on challenges related to service provision for hard-to-reach families in the Global North (UK, Canada, United States of America, Australia). The authors used various synonyms to define 'hard to reach' families, including hidden populations, vulnerable, underserved, fragile families, socially excluded, disengaged, marginalised, non- (or reluctant) user, high risk, at risk, families with multiple or complex needs, minority groups, minority ethnic, ethnic communities, and less likely to access services [23] (p. 213). They quote Landy and Menna (cited in Boag-Munroe and Evangelou [23]) who state that 'working effectively with families who might be labelled "hard-to-reach" involves a shift from perceiving the family as being "hard-to-reach" to thinking about what makes the service that is being offered hard to accept for a particular family'[23] (p. 180). In the literature reviewed, the authors identify three main organisational barriers to access for hard-to-reach families and hard-to-engage families. The barriers go beyond tangible physical access issues and include alienating attitudes and unwelcoming buildings. The authors acknowledge the latter two as being the most difficult to resolve, requiring money and time to overcome. Barrier 1 relates to communication, barrier 2 is about setting, and barrier 3 has to do with quality of service. They highlighted one of the key challenges with the setting as lack of awareness by services that families may have valid reasons for non-engagement and presupposing families' needs. Physical location is also mentioned as a setting barrier where hard-to-reach families face obstacles in accessing a service because it is spatially distant from where they are, and the authors suggest it might be useful to 'shift locus of provision towards the community' to increase visibility and improve access [23] (p. 218). The literature review findings also indicate that families might perceive settings and services as stigmatised or stigmatising.

As part of a larger study on caregiving of children with ID in urban Cape Town, South Africa [24], we became interested in a sub-group of families who had never used the ID services available to them, or who had stopped using them. We report here on interviews with this small group of families.

## Materials and Methods

### *Research design*

To explore the views and perspectives of parents and caregivers of children with ID who are not using specialised hospital services, a qualitative research design was employed [25]. Based on Kleinman's Explanatory Models (EMs) [26], we developed an interview guide to help explore caregivers' and parents' views.

### *Study setting*

The study was conducted in a predominantly Black[1] township in Cape Town, South Africa. The specialised ID services for this area are allocated in a nearby psychiatric hospital. The hospital was built during segregation laws to serve the Coloured community only. However, the hospital is now open to all service-users and most people from the neighbouring communities, including Khayelitsha, a large area of mainly informal dwellings, live in the catchment area of the hospital provides [27].

### *Recruitment and sampling*

As part of our larger study, we recruited eight Black isiXhosa speaking parents and primary caregivers of children with ID who were not using specialised ID services. Participants were sampled and recruited using purposive sampling methods. Through the help of those using the hospital services, participants were identified using principles of qualitative research. Potential participants were then contacted via telephone by the first author, who speaks isiXhosa as his first language, and this made it easier to build rapport with the participants, while remaining mindful of the possibility of over identifying with participants. We then contacted the parents or caregivers and requested to visit them at their homes to speak with them. As indicated above, participants lived in Khayelitsha and surrounds. Khayelitsha is one of the largest townships in South Africa, mainly impoverished with a high proportion of informal (shanty) housing in the Cape Flats in Cape Town.

### *Data collection*

We conducted the individual interviews between April and May 2018 at the participants' homes. Participants were not participating in any services the healthcare facility provides and they preferred to have interviews at their homes in Khayelitsha and surrounds.

Kleinman's [30] EM framework to develop a semi-structured interview guide was used and constructed in English. Following this the guide was then translated into isiXhosa by the language and communication centre at [anonymised for peer review] University. After the original translation the first author, who speaks and understands isiXhosa as his first language, did minor edits. The guide was then tested before it was administered to collect data. We recorded all interviews using an audio recording device and all the necessary permissions of the participants were sought. The data presented here concern questions about accessing (or not accessing) the nearby ID services.

### *Data analysis*

Once interviews were completed, we transcribed the audio recorded interviews in isiXhosa and the transcriptions were then translated into English by a language translator who also speaks and understands isiXhosa as his first language. Following this, the first author, who speaks isiXhosa as his first language, then checked the transcripts against the original recording to ensure accuracy. Thereafter, the first author performed an initial analysis of data which was then checked in collaboration with the second author for accuracy. When disagreements emerged, we vigorously discussed these until a resolution was reached. Following Braun and Clark's [31] guide, we used thematic content analysis to analyse the data and codes were categorised into themes.

---

[1] The use of 'racial' terminology in South Africa, as elsewhere, is highly politicised and contested [28]. We do not claim that any of the terms we use, such as 'White', 'Black', 'Coloured' or 'Indian', which are still terms used in contemporary South African equity legislation, and have strong social (if contested) meanings, have any basis as biological or scientific categories. They are social categories which have proven remarkably durable, even in a supposedly non-racial democracy [28,29]. The term 'Black' in South African terminology refers chiefly to people who speak indigenous languages; 'Coloured' refers to people of diverse origins, most having Afrikaans as a first language. Under apartheid, the Western Cape Province was deemed a preferential area for 'Coloured' labour and settlement, and 'Black' people, even those born in the province, were regarded as foreigners.

## Ethics

Ethical approval was sought and obtained from the [anonymised 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 Intellectual Disability Services (IDS), Lentegeur Hospital (LGH). Children of the interviewed participants were already known to the local department of social services and various social agencies operating in the communities providing social support and guarding against any form of abuse. They were also receiving care dependency or disability grants from the Department of Social Services.

## Results

Participants gave a number of reasons as to why they are not using the ID services close to them. These included financial difficulties, fragile care networks and opportunity costs, community stigma and lack of safety, lack of faith in services and powerlessness at effecting changes, and self-stigmatisation. We present data on each of these in turn.

### *Financial difficulties*

Though the high level of care available at the specialist ID services is offered free of charge to those who cannot afford to pay, there are other financial barriers which affect caregivers' ability to access services. One participant decided not to use the services anymore because she had no money to pay for the public transport. The whole family depended on the state-provided Child Support Grant of R420 (approximately $25) per month because the mother, who is a single parent, was not working and had no other source of income:

> *I stopped taking him there in 20 what? [20]16. I think in 2016 because I was not working that time, so I had to borrow money in order to go there and then I couldn't pay it back. That time my allowance [the value of the Child Support Grant at the time] was about R260, and with that amount I had to buy food and … so I was spending a lot on travelling fees to go there.* (GMCWID_02)

Other parents shared similar difficulties:

> *He receives the same grant that other children who do not have disability get. I mean there's nothing … He receives the same grant as other kids. Only that R420.* (BMCWID_05)

> *He does not receive Disability Grant … Yes, he just receives Child Support Grant of R400, he doesn't receive the Disability Grant.* (BMCWID_02)

The caregivers here are referring to a grant which is available from the state for care of children with disabilities, and this is the Care Dependency Grant of R1860 (approximately $110) per child per month, commonly referred to as a 'disability grant'. Despite being eligible to receive this grant, which is substantially bigger than the child support grant, parents were not accessing it for various reasons:

*Preprints* (www.preprints.org) | NOT PEER-REVIEWED | Posted: 4 September 2020 doi:10.20944/preprints202009.0092.v1

> *At his school they said they are going to call us … Last year we were called to come for a meeting at the school because people from SASSA [South African Social Security Agency, the agency which administers grants] will come and register children who does not receive disability grant. Till now they haven't [inaudible].* (BMCWID_02)

> *I'm waiting for transport that will fetch me and the child who was burnt [and disabled]. It never came. I waited for it until forever. Those ladies from social services said last time they called they said another child who was at hospital passed away so they went to that child's funeral. After the funeral they will call me back and inform me when they will come.* (GMCWID_04)

It appears that a combination of logistical challenges from government agencies, and transport costs to go to the relevant office to register to receive a Care Dependency Grants, are major barriers for our participants. In the absence of the Care Dependency Grant, the cost of getting to the hospital (and ID services) is unaffordable.

### *Fragile care networks and opportunity costs*

For some participants, a change in those acting as primary caregivers for the child affected their use of services. For example, one family stopped using the services because the primary carer of the child passed away. After the death of the primary carer, those who were left behind to care for the child did not take the child for his follow-up appointments because they were working and could not get time off work. They had no one else to assist with taking the child to ID services:

> *My mother used to take him to the hospitals that had children with the same condition as his. When she passed away I had no one else to help to take him for his appointments.* (SMCWID_01)

### *Community stigma and lack of safety*

Some caregivers stopped taking the children to ID services because of community stigma in the context of high levels of violence in the community. Some caregivers feared for the safety of the child, or worried that the child might be taken advantage of if she left the home. As one carer put it:

> *Eh, I think the reason why I didn't want her to go to school or hospital was because I was fearing that other people won't understand that she is a girl child with a disability. People outside are very cruel. And secondly, they will see someone and think that they are seeing a lady but they are seeing someone with [a] disability [this is a reference to the sexual maturity of the child, and a concern about gender-based violence]. And thirdly why I wanted to keep her indoors was because she seemed much more safe indoors than to be exposed outside.* (BSPWID_03)

Another carer who preferred to keep the child away from others said:

> *Some people sir tease this girl saying she is a creature [an animal]. Because she walks differently. I go outside to fight with whoever is teasing her. I tell them that it's not this child's fault that she is like this.* (GMCWID_04)

Stigma affected relationships within the family, and even where caregivers and children could live:

> *I just moved in to my stepmother's house but my stepmother started gossiping about my child's disability to her neighbours and colleagues. I was then forced to move out of the house and came here. I couldn't continue staying with them having a child with this condition.* (BMCWID_02)

There were also concerns that as a result of the child's disruptive behaviour, others were not tolerant, which exacerbated stigmatisation and led caregivers to be more careful to keep the child out of public view:

> *He doesn't play with other children, he fights with them. So that is why I'm saying, it's because of the teasing that is happening around him. Because of this he doesn't play much with children of his same age, he plays with children that are younger than him. He hits children that are the same age as him, but plays well with children of two to three years that are younger than him.*

> *Every day I receive reports about him from the community and sometimes I don't know how to handle those situations although they know what kind of a child he is, you understand. So when their parents come to my house to confront me, it becomes difficult for me to explain his condition to them.* (BMCWID_02)

### *Lack of faith in services and powerlessness at effecting changes*

Not taking the child to ID services was part of a pattern, for some, of not taking the child to school or other services, consequent, it appears, of the belief that these services could not help and would just add to stigma:

> *He does not go to school because there's nothing he's going to learn because he is just sitting … I've never … maybe I'm not ready because you know people, they like to judge others. So I don't want them to go there and I don't … They know I have a son because I talk about my son but they never came here to see him. It's few of them that do come but I don't go around encouraging people to come*

> *and see him. So, when you hear things that come out of people's mouth you would weigh what they say. And then for you to not get hurt you stay away from them.* (BMCWID_06)

One mother believed that her child's ID was caused through preventable birth trauma, and she blamed the hospital where she delivered the child for this. She had, however, decided not to claim compensation from the hospital, on the advice of another doctor who told her the attempt could be enervating and fruitless:

> *So that doctor said suing the hospital is going to take your time and energy and you won't have time for your child. It's better to love your child and accept his condition. Because the moment you go up and down you are going to chase after money and forget about your child.* (BMCWID_06)

This generalised, for her, to a lack of faith in whether services could be trusted to help her and her child.

*Self-stigmatisation: Feelings of incompetence and guilt*

Some caregivers felt unequal to the task of caring for the child, and feared being exposed if they went out with the child. One mother, for example, mentioned her young age and those of other parents:

> *A child with disability is an everyday challenge. That's why I don't blame mothers who neglect their own children. So that's why other mothers decide to give up on them. More especially when you're young. I'm also young; don't be misled by this doek I'm wearing. But having an experience of a child … Because I had my child when I was only 17.* (BMCWID_06)

Guilt was also a factor keeping parents away from services:

> *I felt bad because he was my first child. So bad because first time I have a child and have a child with this problem. I was feeling very guilty.* (BMCWID_02)

> *I'm also to be blamed for what went wrong, I always punish myself with that. I think I'm punishing myself for my mistakes. So I always blame myself that I'm the cause of his disability, you understand. I feel guilty and blame myself because I did not accept him at first.* (BMCWID_05)

## Discussion

Despite living reasonably close to specialist ID services, these caregivers were not using the services. A striking feature of the data, consistent in almost all of what parents said, is the multidimensionality of urban poverty in a middle-income country. Most fundamentally, caregivers could not afford the transport costs to take their children to services. An aspect of their inability to afford transport is the fact that, in the absence of any general social security unemployment grant in South Africa, and in the context of endemic unemployment, whole families in South Africa subsist on meagre old age pensions, disability pensions, and child grants [32,33]. We can see in the data a vicious cycle of poverty – despite these caregivers being potentially eligible to receive a Care

Dependency Grant, due to the cost and logistics of registering to receive the grant, they could not attain the grant. This fact in turn seems to have been a barrier to using the ID services, as the Child Care Grant, often the only income in the household, was so meagre.

Poverty, however, is more than the lack of income. It also has implications for social exclusion, exposure to climate and other negatively impactful factors, as well as to violence [34,35]. There are higher rates of mortality in poorer areas, which as the data show can have implications for caregiving. Part of the caregivers' lack of use of services seems to relate to a sense of a lack of agency as well as a lack of faith that institutions, such as schools or hospitals, have the potential to make a difference in the lives of the caregivers and the children with ID. In literature on access to biomedical services for families with a child with ID in Africa, cultural reasons are often cited as why people do not use services [36]. In our study, no caregiver cited religious or cultural barriers to using care. The focus was much more on social isolation, the cost and difficulty of accessing care, and the sense that services might not be able to help. Though this lack of faith in services may in part be explained by participants' explanatory models of ID as not changeable [24], there seems also to be a more general feeling of isolation and of being cut off from services.

This isolation is exacerbated by the pervasiveness of stigma within households and beyond. Though there is evidence for the stigmatisation of ID globally [37], the lived experience of stigmatisation may be more impactful in a context in which people live in very small dwellings, often with shared taps and toilets. There is no way to conceal taking a child to ID services in an area in which there is very high population density and much of life is lived on the street in view of neighbours. This is very different to a middle-class existence.

Studies from other parts of the world have shown that although many PWID and their families were eligible for specialised ID services, they did not all make use of these services [21–23,38,39]. It is difficult to establish the magnitude of under-utilisation of services, and in the South African context where there are no systems in place to track attendance, as well as non-attendance of the services users, it is not possible to generate comparative data from information readily available. Financial difficulties have been reported as potential barriers to healthcare access for marginalised population groups in a number of African countries [6,10,40,41]. However, none of these studies reported service users giving up permanently on using the services, as some of our participants seemed to have done. In South Africa, much work has been done on making services more affordable, but what is clearly needed is an integrated support system that goes beyond offering services at the point of care. Specialised services should consider the access needs of low-income primary caregivers of children with ID from the minute they step out of the home, not only once they reach the service. This finding also reinforces the point made by Boag-Munroe and Evangelou [23] regarding the need to shift services to communities where families with children with ID reside, in order to improve access.

## Conclusions

The challenge of creating services which people are able to use goes far beyond setting up services and waiting for clients to arrive. It must be possible to get to the services, and the services themselves need to be welcoming and not alienating [23]. These issues, as we have seen, go far beyond healthcare-related issues as narrowly understood. If children with ID are to receive the best healthcare they need, social changes far beyond the domain of the hospital are needed. The very social conditions which create a greater risk of ID in poorer communities act as barriers to receiving the best care available. It is noteworthy that priorities for research into improving ID services in low-income contexts tend to focus on the improvement of health services and systems [5]; our data suggest that broader social conditions are as important, or possibly even more important, as a focus of concern.

**Funding:** No external funding was received for the research reported in the paper.

**Author contributions:** Conceptualization, SM. and LS; Methodology, SM; Formal Analysis, SM and LS; Investigation SM; Resources, SM; Data Curation, SM. and LS; Writing – Original Draft Preparation, SM. and

LS.; Writing – Review & Editing, SM. and LS.; Visualization, SM.; Supervision, LS; Project Administration, SM.; Funding Acquisition, SM.

**Conflicts of interest:** The authors declare no conflict of interest.

## References

1. Maulik, P.K.; Mascarenhas, M.N.; Mathers, C.D.; Dua, T.; Saxena, S. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Res Dev Disabil* 2011, *32*(2), 419–436. doi:10.1016/j.ridd.2010.12.018
2. Adnams, C.M. Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. *Curr Opin Psychiatry* 2010, *23*(5), 436–440. doi:10.1097/YCO.0b013e32833cfc2d
3. Masulani-Mwale, C.; Mathanga, D.; Silungwe, D.; Kauye, F.; Gladstone, M. Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? *Child Care Health Dev* 2016, *42*(6), 871–880. Available online: https://onlinelibrary.wiley.com/doi/abs/10.1111/cch.12368 (accessed on 21 August 2020).
4. Njenga, F. Perspectives of intellectual disability in Africa: epidemiology and policy services for children and adults. *Curr Opin Psychiatry* 2009, *22*(5), 457–461. doi:10.1097/yco.0b013e32832e63a1
5. Tomlinson, M.; Yasamy, M.T.; Emerson, E.; Officer, A.; Richler, D.; Saxena, S. Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *J Intellect Disabil Res* 2014, *58*(12), 1121–1130. doi:10.1111/jir.12106
6. Ali, A.; Scior, K.; Ratti, V.; Strydom, A.; King, M.; Hassiotis, A. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS One* 2013, *8*(8), e70855. Available online: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3741324/pdf/pone.0070855.pdf (accessed on 26 July 2020).
7. Jahoda, A.; Markova, I. Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *J Intellect Disabil Res* 2004, *48*(8), 719–729. https://doi.org/10.1111/j.1365-2788.2003.00561.x
8. Scior, K.; Addai-Davis, J.; Kenyon, M.; Sheridan, J. Stigma, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups. *J Intellect Disabil Res* 2013, *57*(11), 1014–1026. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2012.01597.x
9. Spassiani, N.A.; Friedman, C. Stigma: Barriers to culture and identity for people with intellectual disability. *Inclusion* 2014, *2*(4), 329–341. https://doi.org/10.1352/2326-6988-2.4.329

10. Tilahun, D.; Hanlon, C.; Fekadu, A.; Tekola, B.; Baheretibeb, Y.; Hoekstra, R.A. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC Health Serv Res* 2016, *16*(1), 152. doi:10.1186/s12913-016-1383-9
11. Werner, S.; Roth, D. Stigma in the field of intellectual disabilities: Impact and initiatives for change. In *The Stigma of Disease and Disability: Understanding Causes and Overcoming Injustices*; Corrigan, P.W., Ed.; American Psychological Association, 2014; pp. 73–91. https://doi.org/10.1037/14297-005
12. Ali, A.; Strydom, A.; Hassiotis, A.; Williams, R.; King, M. A measure of perceived stigma in people with intellectual disability. *Br J Psychiatry* 2008, *193*(5), 410–415. doi:10.1192/bjp.bp.107.045823
13. Baffoe, M. Stigma, discrimination & marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research* 2013, *3*(1), 187–198. doi:10.5901/jesr.2013.v3n1p187
14. Edgerton, R. *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded.* University of California Press: Berkeley, 1967.
15. Kakuma, R.; Kleintjes, S.; Lund, C.; Drew, N.; Green, A.; Flisher, A. Mental health stigma: What is being done to raise awareness and reduce stigma in South Africa? *Afr J Psychiatry* 2010, *13*(2), 116–124. Available online: https://assets.publishing.service.gov.uk/media/57a08b0de5274a31e000093a/Mental_Health_Stigma.pdf (accessed on 27 July 2020).
16. Anderson, R.; Wynne, R.; McDaid, D. Housing and employment. In *Mental Health Policy and Practice Across Europe: The Future Direction of Mental Health Care*; Knapp, M., McDaid, D., Mossialos, E., Thornicroft, G., Eds.; Open University Press, 2007; pp. 280–307.
17. Cichello, P. *Hindrances to Self-Employment Activity: Evidence from the 2000 Khayelitsha/Mitchell's Plain Survey.* Centre for Social Science Research: University of Cape Town, Cape Town, 2005. http://hdl.handle.net/11427/19374
18. Dickinson, R. Parenting a child with disabilities: the intersection of education and cultural perceptions in Southern India. *J Hum Rights Soc Work* 2018, *3*(2), 72–80. https://doi.org/10.1007/s41134-018-0053-8
19. Gibson, S. Narrative accounts of university education: socio-cultural perspectives of students with disabilities. *Disabil Soc* 2012, *27*(3), 353–369. https://doi.org/10.1080/09687599.2012.654987

*Preprints* (www.preprints.org) | NOT PEER-REVIEWED | Posted: 4 September 2020 doi:10.20944/preprints202009.0092.v1

20. Mckenzie, J.A.; McConkey, R.; Adnams, C. Intellectual disability in Africa: Implications for research and service development. *Disabil Rehabil* 2013, *35*(20), 1750–1755. Available online: https://www.tandfonline.com/doi/abs/10.3109/09638288.2012.751461 (accessed on 27 July 2020).
21. Guzmán, J. Health beliefs and access to services in an ethnic minority population. *Learn. Disabil. Pract.* 2014, *17*(4), 30–33. doi:10.7748/ldp2014.04.17.4.30.e1504
22. Emerson, E. Health status and health risks of the "hidden majority" of adults with intellectual disability. *Intellect Dev Disabil* 2011, *49*(3), 155–165. Available online: https://meridian.allenpress.com/idd/article/49/3/155/1535/Health-Status-and-Health-Risks-of-the-Hidden (accessed on 27 July 2020).
23. Boag-Munroe, G.; Evangelou, M. From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Res Pap Educ* 2012, *27*(2), 209–239. https://doi.org/10.1080/02671522.2010.509515
24. Mkabile, S.; Swartz, L. Caregivers' and parents' explanatory models of intellectual disability (ID) in Khayelitsha, Cape Town, South Africa. *J Intellect Disabil Res* 2020, *33*(1). doi:10.1111/jar.12725
25. Creswell, J.W.; Creswell, J.D. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* Sage Publications: London, 2017.
26. Kleinman, A.; Eisenberg, L.; Good, B. Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Ann Intern Med* 2006, *88*(2), 251–258. doi:10.1176/foc.4.1.140
27. Drennan, G. Psychiatry, post-apartheid integration and the neglected role of language in South African institutional contexts. *Transcult Psychiatry* 1999, *36*(1), 5–22. https://doi.org/10.1177/136346159903600101
28. Jansen, J.; Walters, C., Eds. *Fault Lines: A Primer on Race, Science and Society.* AFRICAN SUN MeDIA, 2020.
29. Posel, D. Race as common sense: Racial classification in twentieth-century South Africa. *Afr Stud Rev* 2001, *44*(2), 87–114. doi:10.2307/525576
30. Kleinman, A. Concepts and a model for the comparison of medical systems as cultural systems. *Soc Sci Med B* 1978, *12*, 85–93. https://doi.org/10.1016/0160-7987(78)90014-5
31. Braun, V.; Clarke, V. *Successful Qualitative Research: A Practical Guide for Beginners.* Sage: London, 2013.
32. Braathen, S.H.; Vergunst, R.; Mji, G.; Mannan, H.; Swartz, L. Understanding the local context for the application of global mental health: A rural South African experience. *Int Health* 2013, *5*(1), 38–42. https://doi.org/10.1093/inthealth/ihs016

33. Schneider, U.A.; Havlík, P.; Schmid, E.; Valin, H.; Mosnier, A.; Obersteiner, M.; Böttcher, H.; Skalský, R.; Balkovič, J.; Sauer, T. Impacts of population growth, economic development, and technical change on global food production and consumption. *Agric Syst* 2011, *104*(2), 204–215.
34. Alkire, S.; Apablaza, M.; Chakravarty, S.; Yalonetzky, G. Measuring chronic multidimensional poverty. *J Policy Model* 2017, *39*(6), 983–1006. https://doi.org/10.1016/j.jpolmod.2017.05.020
35. Lund, C.; Kleintjes, S.; Kakuma, R.; Flisher, A.J.; Consortium, M.R.P. Public sector mental health systems in South Africa: inter-provincial comparisons and policy implications. *Soc Psychiatry Psychiatr Epidemiol* 2010, *45*(3), 393–404. doi:10.1007/s00127-009-0078-5
36. Mkabile, S.; Swartz, L. Traditional healers' explanatory models of intellectual disability in Cape Town. Under review.
37. Mitter, N.; Ali, A.; Scior, K. Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Res Dev Disabil* 2019, *89*, 10–21. doi:10.1016/j.ridd.2019.03.001
38. Cortis, N. Overlooked and under-served? Promoting service use and engagement among 'hard-to-reach' populations. *Int J Soc Welf* 2012, *21*(4), 351–360. https://doi.org/10.1111/j.1468-2397.2011.00825.x
39. Emerson, E.; Hatton, C. *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England.* Institute for Health Research: Lancaster University, Lancaster, 2004.
40. Saloojee, G.; Phohole, M.; Saloojee, H.; IJsselmuiden C. Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child Care Health Dev* 2007, *33*(3), 230–235. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2214.2006.00645.x
41. Sen, E.; Yurtsever, S. Difficulties experienced by families with disabled children. *J Spec Pediatr Nurs* 2007, *12*(4), 238–252. https://onlinelibrary.wiley.com/doi/full/10.1111/j.1744-6155.2007.00119.x