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Intellectual disability: Indigenous and Western systems of care with Professor Leslie Swartz

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Introduction

Intellectual disability (ID) is experienced globally, with significantly higher prevalence rates in impoverished environments (Maulik et al. 2011). Despite this, most of what is known about ID comes from higher-income contexts. Thus, it is important to explore the identities and experiences of families with children with ID in a wider range of contexts. These experiences are largely shaped by cultural meanings and social institutions.

In South Africa, limited studies have been conducted in the ID field, possibly because of the shortage here of specialist professionals working in the field, although these professions are better represented than elsewhere in Africa. Whereas South Africa reportedly has 0.32 psychologists and 0.28 psychiatrists for every 100 000 health care users, for the African continent as a whole, there is usually less than one person representing either of these professions per million people (Lund et al. 2010; Njenga 2009).

Professor Leslie Swartz's work has included exploration of the understudied, marginalised population of people with ID, including children, their families and communities. In my work with him, first as a doctoral student and later as an academic in the field, I have been interested in exploring this topic, with a special focus on the lived experience of black, low-income primary caregivers of children with ID, locating these experiences within the context of their health care seeking behaviours and access to health and social services for their children. I have also been interested in exploring and then testing interventions that would bridge the gap between Western systems of care, that is the biomedical health system and indigenous care systems, such as those provided by traditional healers and faith healers. In both areas of interest, Prof. Swartz has been instrumental as a guide, a mentor and a friend. Below, I discuss in greater detail the studies Prof. Swartz and I conducted on this topic.

A global perspective on intellectual disability

A significant population-based investigation in a rural region of South Africa found significant links between mild ID and socio-cultural factors, suggesting increased ID prevalence in lower socio-economic settings (Kromberg et al. 2008). In a prior study involving children aged 2 to 9 years in the same underprivileged region of rural South Africa, it was suggested that the results were representative and thus applicable to other rural areas of the country. It was argued that mild ID was strongly associated with: (1) poverty; (2) poor diet and nutrition; (3) inadequate 'intellectual stimulation'; (4) medically unsupervised home-based child birth; and (5) other aetiological factors such as maternal alcohol use during pregnancy, human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) (Christianson et al. 2002).

Along with these correlations, there is also documented evidence of parents and caregivers of children and adults with ID experiencing high levels of stress. This suggests a need for mental health interventions for children with ID, adults with ID and their families. Evidence suggests that social conditions such as poverty and material deprivation exacerbate parental stress for caregivers and families of children with ID (Blacher & Hatton 2001; Brannan & Heflinger 2001; Eisenhower & Blacher 2006; Heller, Caldwell & Factor 2007; Smith, Oliver & Innocenti 2001).

Some studies have reported that informal family support can provide effective coping mechanisms, playing a protective role against caregiving burnout over time (Le Roux & Fourie 2023; Modula 2022). However, Emerson's distinction between proximal and distal

Note: The manuscript is a contribution to the themed collection titled 'Growing disability studies on the African continent: The career contribution of Prof. Leslie Swartz' under the expert guidance of guest editors Prof. Brian Watermeyer and Prof. Lieketseng Ned.

causes provides a more comprehensive and nuanced understanding of the complex interaction between different familial psychological stresses (Coetzee 2016; Emerson & Hatton 2009). Proximal causes relate to those factors that are directly related to the challenges of caring for a child or adult with ID, in the context of poor access to quality health and social services. Distal causes relate to the underlying factors associated with ID that aggravate the stress of being a carer or a parent of a child or adult with ID, such as the lack of income to pay for basic things like transport to take a child to appointments, as in areas like Khayelitsha that do not have any specialised health and clinical services for ID. Other distal factors include poor living conditions such as a lack of adequate housing, clean water and sanitation, which make it all the more difficult to care for someone with ID. Social capital is another important distal factor for carers and families of people with ID as it denotes the extent to which they are able to draw support and experience connection with their immediate and community environment (Putnam 1995). By characterising proximal variables as mediators of various types of behaviour, recent studies have provided important insights that enhanced the understanding of the connection between the child's behaviour and the distress experienced by parents. For instance, the link between parenting stress and socio-economic status is worsened by various neurological factors like severe ID and autism spectrum disorder. However, these direct causes should not overshadow significant indirect, underlying factors (Emerson & Hatton 2009).

A study (Emerson et al. 2006) involving 6954 mothers of children with or without ID, found elevated levels of stress, unhappiness and poorer mental as well as physical health among mothers whose children had ID. However, when statistical analysis controlled for socio-economic position (SEP), household composition and maternal characteristics such as general health and educational levels, statistical differences between the two groups were nullified. Approximately 50% of the increased probability to develop lower self-esteem and self-efficacy was attributed to the same three controlled variables, that is SEP, household composition and maternal characteristics. In fact, SEP on its own reduced differences between the two groups to non-significant levels (Emerson et al. 2006; Emerson & Hatton 2009).

A second large population-based social study examined the association between parental distress and SEP among 4953 Australian parents of children with and without ID. Parenting stress was associated with broader parental psychiatric symptomatology. Socio-economic position, hardship, adverse life events and inequitable or inadequate social support were related to increased maternal distress. Poverty amid children who were vulnerable to developing disability increased the odds of having maternal distress by 50%. The relationship between poverty and maternal distress was mediated through higher probabilities of experiencing adversity, lower health status and limited social and human capital. Remaining risk factors of

maternal distress were linked with the child's behaviour, social abilities and emotional development (Coetzee 2016; Emerson & Llewellyn 2008).

Perhaps the most decisive evidence on the relationship between socio-economic status and ID, the resultant compounded psychological impact on carers and families of people with ID, is corroborated by a third epidemiological study of 12 689 3-year-old children in the United Kingdom (UK) (Emerson et al. 2010). Families who had children with developmental delay were significantly worse off on all the socio-economic measurements than families without children who displayed suspected delay. Socio-economic adversity and higher levels of psychiatric illness were attributed to poorer personal capital because of lower levels of education and therefore lower-remunerative work, implying increased material hardship (Coetzee 2016; Emerson et al. 2010).

The imperative to focus on intellectual disability in South Africa

Intellectual disability affects both those diagnosed with it and those caring for them. The reported high prevalence of ID in Africa is of concern given the scarcity of biomedical health services to respond to the needs of both children and adults with ID and their families (Adnams 2010). Studies that have investigated mental health services for individuals with ID in low- and middle-income countries, including South Africa, have reported several social factors as contributing to poor mental health outcomes and access to care. A scoping review on services for children with disabilities in low- and middle-income countries (LMIC) (Magnusson, Sweeney & Landry 2019) indicates the paucity of services and consequent impact on families. It is clear that access to rehabilitation services in Africa is a challenge (Morris et al. 2019; Mkabile et al. 2021). While significant contributions and strides have been made in the literature on caregivers' and parents' experiences in various contexts, little is known about the experiences of black African caregivers and parents of children with ID in Africa, where specialised services for people with intellectual disability (PWID) and their families are limited or non-existent (Mkabile et al. 2021). My work has sought to respond to this evidence gap, through conducting studies that focused on: (1) the lived experiences of black African primary caregivers of children with ID in an urban township in Cape Town (Mkabile & Swartz 2020); (2) black African primary caregivers' explanatory models of ID and healthcare-seeking behaviour; and (3) exploring ways of bridging the gap between biomedical health professionals in ID and indigenous ID community support systems (traditional and faith healers).

Research project 1

Research project 1 explored meanings and explanatory models of intellectual disability for families to whom children with ID were born in low-income settings in South Africa. Thus, it was imperative for Prof. Swartz and me to investigate:

[*H*]ow the birth of a child with ID affects the family system in a complex low-income African context. In order to address this need, we conducted a narrative synthesis of qualitative studies on the subjective experiences of caregivers and parents of children with ID regarding their caregiving experiences in order to identify gaps in the literature regarding caregiver or parent and family experiences in Africa. (Mkabile et al. 2021)

We turned attention to qualitative research owing to the paucity of information and the lack of validated quantitative instruments in the African context (Christianson et al. 2002). Qualitative research in this work has proven able to provide detailed in-depth descriptions on which further work can be based (Mkabile et al. 2021). We conducted studies with caregivers and biological parents of children with ID, who were often black African mothers in Khayelitsha, as well as community leaders in the form of traditional healers and faith healers who gave us an understanding of community perspectives on ID and the role of traditional medicine and spirituality in supporting families of children with ID. Our primary aim was to review what is known about the experience of being a family caregiver for a child with ID in Africa. We believe that the imbalance of knowledge between developed and developing countries regarding disability, and specifically caring for a child with disability, requires more careful and thoughtful consideration, especially given the fact that disability is more prevalent in low-income contexts (Mkabile et al. 2021; Swartz 2014; Swartz & Marchetti-Mercer 2018).

Following the narrative synthesis, it became clear to us that in South Africa, post-apartheid, the understanding and management of ID was still poor. This was complicated by various contextual as well as cultural explanations used to describe and conceptualise this condition. We then investigated explanatory models of parents and caregivers of children with ID in Khayelitsha, Cape Town. Our aim was to gain insight on how caregivers understand the condition that their children were diagnosed with. Results revealed that carers' explanatory models included biomedical causes, injuries during pregnancy or birth, as well as spiritual causes. These explanatory models significantly shaped care-seeking behaviours among primary caregivers of children with ID, with many caregivers seeking care and support from both the biomedical health system in the form of clinics and hospitals and local support systems including traditional healers, faith healers and churches.

Research project 2

The second project explored healthcare-seeking behaviour of primary caregivers of children with intellectual disability and barriers to accessing care. We also focused on access issues related to accessing disability services within the biomedical health system. Primary caregivers reported significant difficulties in accessing services and support while having to cope in the context of extreme poverty and deprivation (Mkabile & Swartz 2020). The most important access issues include transport costs and difficulties with travelling to disability services, since none of the services

were located in the local community where the research participants lived. Further contributing factors are language challenges in many disability services, which mainly use English and Afrikaans as the medium of communication, in a context where black African caregivers mostly speak and understand isiXhosa, as well as the lack of local disability services that were accessible and relevant for black African caregivers. As a result, in this study, we concluded that, in addition to the urgent need to make biomedical ID services more accessible, both in terms of cost and quality (Mkabile & Swartz 2022a), there was a need for collaboration between the biomedical and alternative healthcare systems in educating and providing support to carers and parents regarding ID (Mkabile & Swartz 2020).

Research project 3

Research project 3 explored the role of indigenous care systems in supporting primary caregivers of children with ID and their families. As an extension of research project 3, Prof. Swartz and I decided to conduct interviews and focus discussions with traditional healers and faith healers, to get their views on how they conceptualise ID and the causes of ID, as well as their experiences of providing care and support to primary caregivers and families of children with ID in their communities. The findings that emanated from this study highlighted very similar ways of defining and understanding ID and its causes between traditional healers, faith healers and primary caregivers of children with ID. In other words, similar to the caregivers, traditional healers and faith healers understood and framed ID both in terms of biomedical conceptualisations and African belief systems (Mkabile & Swartz 2022b).

Research project 4

This project leveraged indigenous knowledge and care systems to provide better support and care to primary caregivers of children with ID and foster collaboration with biomedical intellectual disability services. The results from research projects 1, 2 and 3 formed the basis of the research idea behind research project 4, which constitutes my current postdoctoral work. Research project 4 is thus based on the main findings of my doctorate, as it relates to the ways in which black African primary caregivers utilise the services and support of indigenous systems of care vis-à-vis the Western health system. As cited above in discussing research project 3, my PhD study found that caregivers, indigenous healers and spiritual healers shared similar views about the causes of ID in children. They all reported biomedical causes, injuries during pregnancy or birth and cultural views such as ID resulting from the failure of the parent to perform a certain cultural ritual or rite, as well as spiritual causes, such as retribution from God or unhappy ancestors who may be displeased with the intellectually disabled child's parent. In addition, I found that there were significant difficulties in accessing services and support, difficulties with coping in the context of extreme poverty and deprivation among those living in very low socio-economic environments. All of these findings meant that the local indigenous systems of care

were not being leveraged to the maximum to provide appropriate and scientifically accurate information and support to families of children with ID, in ways that would both recognise and uphold the place and importance of indigenous systems of care, as well as bridge and fill the gap between the Western health system and local community support systems so that relevant and appropriate care could be provided to this marginalised population. The findings highlight a need to work with parents, traditional healers, spiritual healers, community leaders, civic organisations, non-governmental organisations (NGOs) and community based organisations (CBOs) working in Khayelitsha and surroundings on developing a common understanding of intellectual and developmental disorders, as well as setting up collaborative ways of leveraging knowledge and information about ID in ways that would benefit children with ID and their families and primary caregivers. To this end, we have, for the past two years, been running an intervention study in Khayelitsha to respond to the research gaps highlighted previously.

The aims of this project are to:

- Increase awareness and knowledge about ID among marginalised, low-income communities.
- Reduce stigma around ID in Khayelitsha and surrounding areas.
- Engage spiritual leaders and healers with a view to developing ways of cooperating to improve the lives of children with ID and their families.

This work has been funded by the National Research Foundation and involves intervention workshops, qualitative interviews and focus group discussions. The body of work presented here, comprising research projects 1, 2, 3 and 4, has been presented at multiple national and international conferences, has produced six publications, and two honours thesis projects, as well as fostered collaborations with local and international scholars, specifically from the United Kingdom (UK) and United States (US).

Final reflections and conclusion

Here are final words on the influence and contribution of Prof. Leslie Swartz on intellectual disability research in South Africa. Professor Swartz is a beacon of light and hope in the academic field of disability and mental health in South Africa. While he has made immense contributions to science in this field through his many outputs, also in terms of fundraising for research projects, publications and teaching, his most important contribution may very well be his dedication to raising a new generation of black scholars in South Africa. When I first met Professor Swartz, I was lost and frustrated with my PhD topic. I knew I wanted to establish my academic career in ID and to advance knowledge and understanding in this area, but I did not know where to start and how to narrow my doctoral topic in a way that would add knowledge to the field, as well as contribute to my growth as a scholar. Professor Swartz gently, but firmly, took my hand and helped me see

the forest in spite of and as well as for the trees within the field of ID. I was able to identify a topic that was both understudied and resonant with my ideals of social justice and serving the most marginalised in society. Having been stalled and stuck with my PhD studies for years before meeting him, I was now able to refine my research topic and produce a PhD protocol, implement the PhD research project and publish my findings within set time frames. We met regularly, sometimes weekly, sometimes at 06:00 am in his house in Mowbray, and we would go through my drafts line by line, until we were both satisfied. He never tired of me and my questions, was exceedingly patient, always made time for me and made me feel as though I was the only PhD student he had, even though the truth was that I was only one of the many students to whom he was offering the same level of guidance and support! The many hours of guidance and support he poured into my work and development resulted in my becoming the first African intellectual disability psychology scholar to earn a PhD in 2021 when I completed my studies. Multiple publications and book chapters, local and international conference presentations and collaborations with leaders in my field, both nationally and abroad followed. I now lead a programme of work that seeks to develop culturally sensitive and congruent models for providing services and support to children with ID and their primary caregivers and families in South Africa and abroad, and similar to Prof. Swartz, my commitment to scholarship in this field is equally matched by my commitment to lifting as I rise, by teaching, guiding and mentoring, the next generation of scholars who come after me. Prof. Swartz's unwavering commitment to social justice and transformation in the field through teaching and mentoring young black scholars has brought vitality and recognition of the importance of disability services in the context of mental health in South Africa and similar settings. As a white male, born and raised in apartheid South Africa, he has given hope and modelled the way for transforming the academic landscape in South Africa.

Acknowledgements

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