

Disabled children's childhood studies in South Africa: Challenging deficit-centric perceptions



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Dates:
Received: 19 Feb. 2025
Accepted: 23 May 2025
Published: 30 Nov. 2025

How to cite this article:
Trafford, Z., 2025, 'Disabled children's childhood studies in South Africa: Challenging deficit-centric perceptions', *African Journal of Disability* 14(0), a1693. <https://doi.org/10.4102/ajod.v14i0.1693>

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Introduction

In South Africa, social assistance programming was originally instituted for only the white minority population. Welfare benefits focused on poverty alleviation and support for disability and old age but functionally excluded most of the population. In 1992, as apartheid began to dismantle, eligibility for these programmes was extended to the whole population, and the number of people potentially eligible for support increased quickly and exponentially (Delany et al. 2005). Today, the population groups eligible for such social assistance cash transfers include war veterans, pensioners, children living in very low-income families, and adults and children with disabilities.

The South African Adult Disability Grant (DG) may be particularly familiar to scholars in African disability research, as it has been thoroughly investigated and reported on, including in publications in this journal (Hanass-Hancock & McKenzie 2017; Hanass-Hancock et al. 2017; Hansen & Sait 2011; Kagee 2014; Kelly 2013, 2016; Knight, Hosegood & Timæus 2013; Schneider et al. 2011; Schnitzler 2020). Also well-documented in a substantial literature is the Child Support Grant (CSG), which was first initiated in 1998 (Granlund & Hochfeld 2020; Hajdu et al. 2020; Oyenubi 2021; Patel 2011; Patel, Hochfeld & Chiba 2019; Patel, Knijn & Van Wel 2015; Zembe-Mkabile et al. 2015, 2022). Much less prominent in the social protection literature, however, is the Care Dependency Grant (CDG), the childhood counterpart of the adult DG.

This gap motivated a central focus on the CDG for my doctoral research, which was a qualitative study of the perspectives of multiple stakeholders including South African Social Security Agency officials, medical doctors who conduct eligibility assessments for the CDG, caregivers in receipt of the CDG and key informants from national government, academia and civil society. I used semi-structured in-depth interviewing to gain insight into varying understandings of the purpose of the CDG, as well as issues around access to and the administration of the CDG. These data were complemented with an extensive desk-based review of legislation and relevant literature from 1977 to date. I conducted all data collection, verbatim transcription and analysis myself. Thematic analysis was supported by a combination of inductive and deductive coding. Further details of the methodological and ethical procedures used in this study were documented in prior publications (Trafford 2023a; Trafford 2023b; Trafford & Swartz 2021, 2022).

Recipients of the CDG report its considerable value to the beneficiary child and their family (Dimhairo 2013; Letsie 2016; Trafford 2023a). This seems an obvious area for urgent intervention and potentially, the expansion of benefits for this group, which could have a powerful effect on supporting disabled children's developmental potential, as is well-documented for the CSG. Instead, research over the last three decades has consistently reflected comparatively very low beneficiary numbers and insufficient change in the prospects and circumstances of children with disabilities in South Africa (Chataika & McKenzie 2013; Kleintjes et al. 2022; Martin, Proudlock & Berry 2014; McKenzie & Chataika 2017; Philpott 2014; Philpott & Muthukrishna 2019; Sadiki 2022; Saloojee et al. 2007; Shung-King et al. 2019, 2000; South African Government 1996).

In trying to understand details of the administration and distribution of the CDG, I also researched wider dynamics around this cash transfer including disability stigma, socialisation in disabled children's lives, and the wider landscape of service provision, access and participation for these children and their families in South Africa. These investigations raised an important question: why are disabled children and their caregivers in low-resource environments still so neglected and excluded, despite their obvious and relatively uncontroversial need for state support? Next, I describe the role that Leslie played in my professional development, before closing with a short discussion based on my doctoral research that reflects on why access is still so difficult, why

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. Liekieseng Ned.

necessary change has happened so slowly, and why disability-related service provision is still deeply exclusionary despite strong ideological commitments.

Professor Swartz's influence on my entry into disability studies

I met Prof. Swartz in 2019, when I had decided to pursue a research career but felt uncertain about which direction to take in a saturated field. Prof. Swartz gave a 'whistlestop' introductory lecture on disability studies. Through his linking together of diverse methodological and conceptual approaches to disability research, I realised that I could make a real contribution in this field. His lecture helped me to see that disability studies was an ideal place to deepen my persistent interest in equity and marginalisation, as well as social constructions of normality and abnormality, and investigations of the immense power these constructions have in shaping people's lives and opportunities.

In our early discussions about my doctoral work, Prof. Swartz suggested that the CDG would be an ideal focus for the exploration of my research interests at the intersection of childhood, wellbeing, disability and economic poverty. He understood that I wanted to use my professional research skillset to contribute directly to policy making, stronger implementation of policies and human rights advocacy, and knew that there was a notable gap in the social protection literature. He also realised that while pursuing a career in practical and applied research, I also wanted to think more deeply about the underpinnings of the patterns I observed. His detailed and long-term knowledge of the field of disability studies both globally and in South Africa was an invaluable resource, and one which he shared graciously. The opportunity to rapidly produce findings on the CDG (including documenting its full legislative history), to translate this work into reflections and insights that are useful to people working in policy and to advocate for the increased visibility and recognition of this especially marginalised group, would not have been possible without Prof. Swartz's perspicacious guidance.

In the sub-section that follows, I present reflections from my doctoral research, which highlight the ways in which the narrow and inaccurate beliefs of non-disabled adults tasked with making decisions can limit the possibilities available to children with disabilities in contemporary South Africa. These ideas were influenced by the field of disabled children's childhood studies and psychoanalytical frameworks for unpacking disability stigma.

Reflections on lessons from disabled children's childhood studies and psychoanalytical approaches to disability exclusion

Early in desk-based research towards the PhD, it occurred to me that although the CDG represents a key opportunity for

the state to ameliorate the excessive direct and indirect costs of disability, in-depth investigations of disabled children's needs and situation were relatively absent from discourses in social protection policy, legislation and secondary literature. There is a body of research focused specifically on the rights of disabled children in South Africa, particularly in relation to their healthcare needs. Within the *mainstream* literature on education, health access, and social protection, however, disabled children usually only feature as one of a list of 'vulnerable' groups. In many instances, these investigations into areas relevant to all children's lives do not engage more deeply with the experiences of disabled children beyond noting their need for additional support. The CDG has also been overlooked in quantitative assessments of the re-distributional effects of the overall cash transfer programme in South Africa, with the rationale for this usually being its comparatively low beneficiary numbers.

This pattern recurred during my data collection, when stakeholders from all groups commented on the systemic neglect of disabled children and a notable lack of progress in service delivery for this group. One key informant participant in my PhD study who had worked in social protection in Africa since the late 1980s reported that CDG recipients were 'a largely invisible group in [social protection] debates [and] scholarship'. Another key informant with a long history of working with government to support disability grant implementation and research commented that because beneficiary numbers were low and there was so much concern about high adult DG beneficiary numbers, 'the conversation was never around the care dependency grant'. This participant further explained that the CDG 'was always a little on the fringes' of such discussions. These and other participants argued that disabled children do not appear to have received sufficient or sustained attention in social protection programming, especially when compared with economically marginalised non-disabled children and disabled adults.

In most countries today, citizens' access to their human rights are often contingent on a set of implicit or explicit 'responsibilities' that are defined by the ideological, historical, and socio-political landscape of that country. Citizenship has traditionally been 'universal for the minority rich, regulated according to market inception for the working class and middle class, and denied to the majority of poor and marginal populations' (Biehl 2001:136). When adults do not participate in the labour market, they can be framed as deviant or 'irresponsible', making their claim to state support tenuous in a pattern which has been documented in relation to disability in both India and South Africa (Chaudhry 2019; Schnitzler 2020). The conscious or unconscious belief that disabled children may never be able to be 'responsible' citizens or join the economy 'in exchange for' their rights may contribute to the lack of public investment in opportunities for their support and development. In turn, both education and employment are profoundly disability-exclusionary. As key thinkers both internationally and in South Africa have argued, these

exclusions further fuel the perception that disabled children have little developmental potential, thereby denying their 'imagined futures' (Chataika & McKenzie 2013; Curran & Runswick-Cole 2014; Goodley & Lawthom 2013; McKenzie & McLeod 2012; Runswick-Cole & Goodley 2018; Runswick-Cole, Liddiard & Curran 2018).

The sharp distinction between the value of non-disabled and disabled children's lives – and the resulting effects on service provision and investment – is not unique to South Africa. In 2022, it was reported that 'only 2% of the estimated US\$79.1 billion invested [globally] in early childhood development [from 2007 to 2016] ... was spent on [children with developmental] disabilities' (The Global Research on Developmental Disabilities Collaborators 2022). Although the same report showed that the chance of a child being disabled is now 'at least ten times higher than that of dying before the[ir] fifth birthday', there appears to be little investment in what happens after these children are born. Both globally and nationally, there appears to be more of an emphasis on ensuring disabled children's survival at birth than on the quality of their lives once they are born (Moodley 2021).

These patterns are not necessarily intentional or malicious. However, when non-disabled adults who design and implement policy for disabled people look at (or 'gaze upon') children with disabilities and their families, their own projections of fear and fascination may prevent them seeing beyond the supposed tragedy of these children's lives. One of my participants summarised this phenomenon well, sardonically explaining that 'a disabled child is not a child'. When children with disabilities are only seen as inherently separate from non-disabled children, their child identity is obscured by their disabled identity – but both dimensions of their identity are important, and they are intertwined. When perceived only through the lens of the (still dominant) deficit model of disability, disabled children are looked at but never really *seen* (Garland-Thomson 2006, 2009; Lourens & Swartz 2016; Watermeyer 2006, 2018; Watermeyer & Swartz 2008). Perceptions of disabled children's lives as exclusively tragic are informed by the widely-held societal belief that healthiness is necessary for living a good life, and conversely, that the lives of 'people with "errant" bodies ... are not worth living' (Watermeyer 2013:18). Such beliefs may make it harder for decision-makers to see disabled children as whole people, to feel empathy for their experiences, and consequently, to mobilise sufficient resources for closing persistent gaps in access and inclusion.

Conclusion

We need to think more deeply about how to improve the *quality* of the lives of disabled children and young people in South Africa. Viewing a disabled child only through a lens of assumed infirmity and tragedy, both their 'child-ness' and their 'humanness' are obscured. This distances the country from our stated goal of embedding awareness of environment,

impairment, and life-stage into any view of disability, and particularly, any intervention aimed at equitable service provision. As Goodley, Runswick-Cole and Liddiard (2016) note in their 'analysis of the affirmative possibilities given by attending to the lives of disabled children' (p. 770), we must work to understand how structural forces constrain the optimal development of disabled children, especially those who are also living in low-resource environments. However, this can unintentionally lead to false binaries, as epitomised by dominant media and sociocultural portrayals of childhood disability. The latter tend toward so-called 'pity porn' or 'inspiration porn': exaggerated depictions of disabled children as either extremely and inescapably tragic, or superhuman in their capacity to transcend impairment 'despite the odds'. Obviously, there are many non-disabled people who do not engage with disabled people in homogenising and invisibilising ways. But while sociocultural phenomena may not apply to each person within a society, they will certainly affect general perceptions of marginalised or non-dominant groups.

What is missing in these homogenised and binary representations of disabled children is what Prof. Swartz has called '[the reality] of disabled people leading ordinary lives ... neither abject nor miraculous, but both complex and mundane – like the lives of most people' (Swartz 2018:282). With Prof. Swartz's support, I tried to push back against the dominant deficit-centric narrative by presenting novel data in my final PhD chapter that reflected the narratives of caregivers who had shared their experiences with me so generously. I asked questions about their best memories with their disabled child, their hopes for this child's future and what they loved about being together. This revealed stories of close bonds, caregivers' determination to communicate and connect despite rigid barriers, and children with clearly defined personalities and strong desires and opinions. Seeking out and sharing these more diverse, real and human portrayals of children with disabilities (Maronga-Feshete, Pilusa & Dreyer 2024), while still sounding the alarm about their material deprivation, may help to challenge the over-simplified portrayals of their lives that dominate non-disabled people's perceptions.

In his own research and in the work he has supervised, Prof. Swartz has taken a clear ideological position on the importance of fairness and social justice (Hlongwane et al. 2022; Swartz 2012, 2023), and the value of locally specific, relevant research (Keikelame & Swartz 2019; Ned, Dube & Swartz 2022; Ned, Johannah Keikelame & Swartz 2022; Swartz 2014, 2018, 2022). He has centred the voices and experiences of disabled people themselves, at different life-stages and in different contexts (Bantjes et al. 2015a, 2015b; Lourens & Swartz 2016; McDougall et al. 2006; Mkabile & Swartz 2020; Schneider et al. 2011; Vergunst et al. 2015; Watermeyer & Swartz 2008). Prof. Swartz has pursued applied research, working closely with policymakers and those involved in implementing policy and developing programmes across the continent, but has balanced this with philosophical and psychoanalytical theorisation about the root causes of social exclusion and how we might address these.

This volume will demonstrate the enormous breadth and depth of Prof. Swartz's intellectual engagement, but his work has also been consistently honest, accessible and pragmatic. These qualities are uncommon and, to me, particularly impressive. As a supervisor and colleague, his thoughtfulness, efficiency and generosity of time and intellectual insight have been invaluable. I intend to build a long-term career in African disability research and in the process, try to emulate Prof. Swartz's remarkable approach. *Halala*, Leslie, and thank you.

Acknowledgements

The author would like to thank their PhD supervisor, Leslie Swartz, for his guidance and support through all stages of the research reflected upon in this article. The author would also like to acknowledge the energy and openness of all of their participants, who gave generously of their time during the highly stressful coronavirus disease 2019 (COVID-19) lockdowns and beyond.

This article is partially based on the author's thesis entitled 'Invisibility, informality and impropriety: Multi-stakeholder perspectives on the implementation and administration of South Africa's Care Dependency Grant for children with disabilities' submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy in the Faculty of Arts and Social Sciences at Stellenbosch University, South Africa with supervisor Prof. Leslie Swartz in December 2023.

Competing interests

The author reported that they received funding from Wellcome Trust which may be affected by the research reported in the enclosed publication. The author has disclosed those interests fully and has implemented an approved plan for managing any potential conflicts arising from their involvement. The terms of these funding arrangements have been reviewed and approved by the affiliated university in accordance with its policy on objectivity in research.

The author, Z.T., serves as an editorial board member of this journal. Z.T. has no other competing interests to declare.

Author's contribution

Z.T. is the sole author of this research article.

Ethical considerations

Ethical permission to conduct this study was obtained from the Stellenbosch University Research Ethics Committee for Social, Behavioural and Education Research (REC: SBER) (Project number: 13097).

Funding information

The research that informed this reflective article was supported by the Wellcome Trust (grant number: 217821/Z/19/Z).

Data availability

The data that support the findings of this study are available on request from the corresponding author, Z.T. The data are not publicly available because of restrictions imposed during data collection, which guaranteed anonymity for participants.

Disclaimer

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