‘Five minutes earlier, you were giving hope’: Reflections from interviews with doctors conducting assessments for South Africa’s childhood disability Care Dependency Grant [version 1; peer review: 2 approved with reservations]

Zara Trafford, Leslie Swartz
Psychology Department, Stellenbosch University, Stellenbosch, Western Cape, 7600, South Africa

Abstract
Background: In South Africa, medical doctors functionally decide whether a primary caregiver can access state-funded social assistance cash transfers (‘social grants’) for the care of their disabled child. In this paper, we unpack the subjective experiences of doctors involved in conducting assessments for the care dependency grant, designed to support the cost of disabled children’s specific needs.
Methods: Individual in-depth interviews were conducted with five paediatric doctors who practice and regularly conduct assessments for the care dependency grant at three Cape Town public sector hospitals. Analysis was thematic and used deductive coding.
Results: The doctors we interviewed were aware that these grants were probably shared among household members but felt this was acceptable, as it contributed to the child’s wellbeing. Doctors seemed to be applying nuanced, individualised assessments but often felt the need to simplify the documentation of these assessments, sometimes even bending the rules, to ensure access for their patients. Doctors’ primary allegiance in these processes appeared to be to their patients. They identified more with their caring responsibilities than their bureaucratic gate-keeping role but nonetheless felt a heavy responsibility for decision-making, in the context of extremely strained public resources and a lack of guidance from the government’s social assistance implementation agency.
Conclusions: The hyperlocal practices and approaches that doctors described allows for perception of the messier – but also more accurate – details of the system that is actually in place. Doctors’ narratives also reflect long-standing inattention to the ‘trickle down’ of guidelines to frontline implementers of disability-related grants. This cadre is a valuable but under-utilised source of evidence and information about the real-world functioning of disability-related grants administration and they should be actively included in
implementation planning.

**Keywords**
care dependency grant, social assistance, children with disabilities, disability assessment, decision-making, paediatric doctors, South Africa

Corresponding author: Zara Trafford (ztrafford@gmail.com)

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Introduction

For most South Africans, the only access to income support for social protection is through a national, non-contributory social assistance programme. Various ‘vulnerable’ groups are eligible for poverty-alleviation or age- and disability-related unconditional cash transfers, known locally as social grants. The grants system is relatively progressive, well-established and impactful (Fragoso, 2022; Granlund & Hochfeld, 2020; Kidd et al., 2018; Satumba et al., 2017). However, it is also large and costly, raising the associated economic, political and emotional stakes. Studies about the grant system, from the perspective of its recipients especially, report widespread implementation issues relating to systems for its administration, consistency, monitoring and distribution (Du Toit & Lues, 2021; Granlund, 2022; Hajdu et al., 2020; Hanass-Hancock & McKenzie, 2017; Kelly, 2013; Lund et al., 2009; Patel et al., 2019). As a result, questions of appropriate expenditure, the ‘deservingness’ of recipients and whether or not grants are getting to those who need them most are often central to investigations of the grants programme. This is especially true for grants associated with a need for care due to age or impairment, as these are of a significantly higher value than poverty-alleviation grants. The ‘disability-related grants’ portfolio includes the care dependency grant (CDG), for the support of disabled children up to the age of 18, and the adult disability grant (DG), intended as income replacement for adults with long-term impairments or disabilities, as well as the small supplementary Grant-in-Aid (GIA). The value of the CDG and DG is the same and was at R1,980 (approx. USD112/GBP98) per month in September 2022 (SASSA, 2022).

There is a rich literature on the adult DG, partly because it has a large beneficiary base and is thus a productive site for investigation of state expenditure and the politics of redistribution. The DG is also closely associated with perceptions of and actual issues relating to fraudulent activity in the grants system. This focus loops in compelling discussions about the neoliberal undertones of state-funded social assistance, moral judgments about adults’ ‘willingness’ to work or ‘compliance’ with recommended action or treatment, and implications for citizenship and belonging in society (cf. for example Kelly, 2016a; Knight et al., 2013; Schneider et al., 2011a; Schnitzler, 2020). In other words, discussions about the DG tend to focus on adult labour market participation. Similarly, an extensive literature has thoroughly investigated the child support grant (CSG), the CDG’s counterpart for the support of non-disabled children, exploring everything from the CSG’s impact on redistribution to its affective dimensions for various role-players, in various parts of the country (cf. for example Gordon et al., 2017; Granlund & Hochfeld, 2020; Hajdu et al., 2020; Patel & Ross, 2022; Zembe-Mkabile et al., 2015). In conversations about social assistance for disability, then, the emphasis is on working-age adults. In conversations about social assistance for children, the emphasis is on non-disabled children. Even the Social Relief of Distress grant, instituted and extended during COVID-19, has received much recent attention due to its impact on adults without disabilities but under the eligible pension age (Gronbach et al., 2022; Köhler & Bhorat, 2021; Marx et al., 2022). In contrast, the CDG brings a rather different set of questions and focal points into view: the human rights of disabled children, the need to support their caregivers in accessing public services due to insufficient or inaccessible services and income replacement for parents forced to stay away from work because they must provide full-time home care for their child in the absence of alternate support systems.

The CDG has received minimal attention to date, compared with other grant types. The small literature available is focused on caregiver experiences (Dimhairo, 2013; Letsie, 2016) and desk-based analyses of policy frameworks (Khumalo, 2020; Martin et al., 2014), as well as one now outdated sociodemographic survey (De Koker et al., 2006). An additional range of research touches on or relates to the grant and its recipients, but this work does not explore its administration in great detail or from the perspective of implementers (a non-exhaustive list of examples includes De Sas Kropiwnicki et al., 2014; Elphick et al., 2015; Hall, 2022; Philpott, 2014; Philpott, 2018; Saloojee et al., 2007). No published research has investigated how health workers tasked with assessing eligibility for the CDG feel about the process, how they perceive potential applicants and actual recipients and how they balance their dual role as health workers and bureaucratic agents of the state. These questions are important because they must be contended with in trying to describe and understand the real-world implementation of policy in practice (Hoag, 2010; Hoag & Hull, 2017; Hull, 2012). This is especially critical in South Africa (SA), where pessimism about the achievement of policy goals suffuses the general public and many state administrators, who are well-aware of the limitations of and barriers to achieving these goals. In this article, we share findings from interviews with paediatric doctors who conduct CDG assessments in South Africa’s Western Cape province, as part of a broader multi-stakeholder qualitative study focused on the CDG.

Paediatric doctors who undertake CDG assessments work within the context of the extremely strained social sector health system, which serves around 85% of the population with a tiny minority of the country’s human resources for health (Burger & Christian, 2020; Coovadia et al., 2009; Mayosi & Benatar, 2014; Rispel, 2016). The situation is even more dire for disabled people and their caregivers, who face additional barriers to access and affordability (Fourie, 2017; Sadiki et al., 2021; Saloojee et al., 2007; Vergust et al., 2015). In order to try to manage limitations in the public sector health system, doctors have developed a range of practices around grants assessment, along similar but also contrasting patterns to those previously reported in a study of assessors for the adult DG (Kelly, 2016a; Kelly, 2016b; Kelly, 2017; Kelly, 2019). These bottom-up practices seem to have been influenced more by paediatric doctors’ own medical expertise and insights from colleagues than by any formal guidelines from the country’s official social assistance...
implementation agency, the South African Social Security Agency (SASSA). This cadre of health workers’ ‘informal’ solutions to the problem of operating within a highly dysfunctional system represent a valuable knowledge base that is often hidden because doctors do not necessarily have much time or the space to reflect on their practices. There is also no universally-applied, formal approach to how doctors should work with SASSA. In our small study, we aimed to understand and interpret what a group of doctors based in SA’s Western Cape province do in their daily practices of CDG assessment, how they react to patients and their families in the process and what their understanding of CDG policy and interactions with SASSA looked like. As we shall show, when these doctors working at the coalface of grants implementation have the opportunity to reflect with interlocutors on the complexities of their work at the interface between health care and the social development system, they provide interesting and important information.

Background: The grants system in South Africa

In SA, the distribution of social grants is governed by the Social Assistance Act (SAA) 13 of 2004. CDGs are currently disbursed to a primary caregiver a child with a long-term disability from the time of approval until the child turns 18. Access is contingent on 1) a means test to determine the income of the applicant, and 2) a (medical) assessment of their child’s impairment and level of independence, to gauge whether their disability entails a ‘need for permanent care or support services’ (South African Parliament, 2004). All grants are legislated by the national Department of Social Development (DSD) and managed and administered by DSD’s implementing agency, SASSA. SASSA’s slogan is, ‘Pay according to the right person, at the right time and place. Njalo (every time)!’ This reflects SASSA’s primary intention: that grants are awarded appropriately i.e. to ‘deserving’ applicants. However, decisions about approval for disability-related grants are in most cases made by medical doctors (Kelly, 2016a), especially for the CDG (Trafford & Swartz, 2021). In all but one of SA’s nine provinces, doctors are directly contracted by SASSA. In the Western Cape province, SASSA directly contracts a small group of doctors but most work for the Western Cape provincial Department of Health (WCDoH) and conduct assessments under the auspices of a service-level agreement between WCDoH and SASSA’s regional office.

Although these relationships are official, there is a conspicuous lack of guidance available from SASSA regarding the various thresholds that affect how doctors perceive the eligibility of applicants. This is partly because SASSA officials characterise themselves as administrators and bureaucrats, not as disability practitioners, and thus say that they do not feel equipped or appropriately positioned to guide the assessment of disability (Trafford & Swartz, 2021). After various attempts circa 2008-2012 to redesign or make disability-related grants assessments less subjective, more comprehensive and with greater community impact (Kelly, 2016a; Schneider et al., 2011b), the system defaulted back to doctors being tasked with making these decisions on their own. Most notably, governing legislation contains no explicit clarity on where thresholds for inclusion or exclusion for the CDG lie. In addition, the use of the word ‘severe’ in the DSD’s Social Assistance Act description of eligibility was technically removed in 2004, in order to bring the law into alignment with more contemporary understandings of disability (Martin et al., 2014). However, this did not formally carry through into the redesign of forms or communication with implementing partners (SASSA and assessing doctors) and by 2008, the word severe had reappeared in an amendment to the law but only in one part of, rather than throughout, the Act (Martin et al., 2014). More recent amendments to the Social Assistance Act (promulgated in May 2022) define a ‘care dependent child’ as one who, ‘due to his or her physical or mental disability, requires and receives permanent care or support services’, from which a loose outline of eligibility for the grant can be drawn (DSD, 2022). However, in contradiction of the Act, SASSA’s website and public hand-out brochure indicate that only children with ‘severe mental or physical disability’ (emphasis added, SASSA, n.d.-b; SASSA, n.d.-a) are eligible, which is echoed on the national government website (South African Government, n.d.) and the Western Cape government website (Western Cape Government, n.d.). Thus, the already difficult work of defining the eligibility of an applicant (Kidd et al., 2018; Moodley, 2021) functionally falls to individual doctors, who are not given formal instructions about whether or not to include severity as a metric for access, nor what the threshold for severity should be.

Methods

Ethics

Ethical approval for this research with human participants was obtained through the Stellenbosch University Research Ethics Committee: Social and Behavioural Research (REC: SBER). Initial approvals were received on 28th November 2019 (PSY-2019-13097) and renewed annually until data collection had concluded. Procedures were in accordance with the ethical standards of the REC: SBER, as well as the 1964 Helsinki Declaration and later amendments. All interviews were remote so additional ethical permissions including relevant safety and data storage procedures were gained prior to data collection. Written informed consent was obtained from each participant prior to our interview. Data were stored on password-protected cloud storage and backed up weekly to an external hard drive. Only the first author has access to these data.

Participant demographics and recruitment

Permission to conduct interviews was obtained from line managers or heads of department prior to recruiting participants. Recruitment was conducted by the first author by means of direct email contact using email addresses gathered from the websites of the health facilities where they worked or the academic institutions where they had joint appointments. In one case, an earlier participant suggested additional possible participants. Suggested participants

Page 4 of 17
were then approached independently by the first author, without including the referring participant in the recruitment invitation. Potential participants were sent an email which summarised the goals of the research, as well as what would be expected from them in terms of time commitments and related arrangements. A one-page description of the overall research project was also included.

The doctors interviewed for this study were all based at specialist hospitals in Cape Town, the capital city of the Western Cape province. Five doctors participated and indicated that CDG assessment was a daily task for them. All were neurodevelopmental paediatricians with at least a decade and as many as thirty years of experience each. All were cisgender, with four being women and one a man. However, we have used she/her pronouns for all direct quotes, to maintain a degree of anonymity. None of the participants identified as disabled and their ages ranged from 39 to 65 years old. Most had joint academic appointments in parallel with their clinical roles. Participant identifiers (Dr A, Dr B etc.) have been randomly assigned.

Data collection and analysis
Data were collected from June 2021 to May 2022 using semi-structured individual in-depth interviews (IDIs) of about 1.5 hours long. The first author conducted these remotely (due to COVID19-related prohibition of in-person research) and used videoconferencing software of the participant’s choice. Two participants selected Zoom and the others were interviewed using Microsoft Teams. All were also recorded using a ZoomH1n audio-recorder. The first author transcribed all recorded audio data verbatim, a process which served as initial data familiarisation. Transcripts were then reviewed multiple times for additional familiarity. For this manuscript, deductive codes were used to highlight common or unusual responses to our semi-structured interview questions. An initial version of this manuscript that comprised the results of a basic thematic analysis was drafted by the first author and shared with the second author, who suggested a narrower focus on the subjective experiences and practices of the doctors included. All findings were discussed with the second author, who was also involved in conceptualisation, edits to and approval of all drafts of this manuscript.

Trustworthiness
While these are not quoted in this article, interviews with other role-players (caregivers, SASSA staff, civil society representatives etc.) were also included in the parent study, allowing for a degree of triangulation. We have also included thick (detailed) descriptions of our setting and the administrative arrangements at play in our participants’ context, to allow for a degree of transferability (Korstjens & Moser, 2018). By including limitations and other reflexive considerations throughout the Results and Discussion, we have tried to make explicit the ways in which our interpretations or participant narratives may be affected by bias or lack of direct observation. However, this work was intended to be exploratory, rather than to aim for generalisability or widespread transferability. Our participants’ insights offer directions for future research, aim to create more conversation in this under-researched area and add to the growing international understanding that frontline worker perspectives are critical for gaining a deeper understanding of the real-world functioning of complicated bureaucratic systems.

Results
Doctors’ feelings about CDG applicants
Doctors framed the CDG as useful for improving a family’s access to the means for early and ongoing intervention and support for their disabled child. This was because they felt that having an income would ‘get this mother or parents empowered… to access early childhood development services’ (Dr E). However, they also explained that in light of insufficient state support and service delivery, the grant was ‘not enough’ for the majority of caregivers, especially those who were very poor or had a child with multiple specific needs. Sometimes, this meant that when a child was assessed they might technically not qualify for the CDG but from the doctor’s perspective, their disability would inevitably develop into something more ‘severe’. They then approved the CDG, in anticipation of the child’s long-term prognosis and reasoned that the child would probably need this support at some point anyway, so they ‘would rather err on [the side of] offering [the CDG], even though you’re not sure’ (Dr E).

Some doctors said that their own emotional reactions to the desperate circumstances of patients and their families could make it more likely that they would approve the grant because ‘we all pander to the sympathy effect, where you can see a parent really struggling’ (Dr E). This was sometimes the case even when a doctor believed that the child’s disability might not strictly qualify for the CDG.

‘…there have been times when my judgment has been clouded by the way a person presents… when you get your heartstrings pulled… [and they say], “life is really hard” – I’ll [think], “Ugh, grant [approved]”’ (Dr D)

Having acknowledged the powerful emotional reaction she had to the difficult and economically perilous lives of her patients, Dr D also noted that she sometimes had negative reactions to potential applicants. This was particularly the case if, for example, caregivers had missed many months of appointments for their child and then arrived and asked the doctor to fill in a grant form.

‘…there are also people that I have rejected because I have a sense that there’s a very strong pecuniary interest in why [they’re] coming to see [me], and the child is secondary… I want to think that I’ve never gone, “You’re bad, you can’t get it”’. But it’s just that, for many, many grant applications, you just have to close your eyes and hope this isn’t going to meth[amphetamine]… and that someone’s going to care for the child’ (Dr D)
However, these negative reactions were usually based on wider social problems, rather than judgement of the person directly in front of them. Doctors tended to opt for more rather than less inclusion, even if this meant they sometimes had to, as Dr D put it, ‘close your eyes and hope [for the best]’.

Doctor participants expressed deep empathy for and sensitivity to the circumstances facing potential CDG applicants. Although uncertain exactly how CDG funds were spent, doctors felt that the CDG was probably often subsumed into the household income. One doctor noted that for poor parents, it was ‘very difficult to just keep [CDG funds] for one child when you have another child next to you who’s hungry’ (Dr C). Although this meant that the CDG was not necessarily used for the disabled child alone, Dr C went on to explain that ‘if the rest of the family is not ok, there’s no way that child is going to be ok’. As such, the use of these funds for the household was not framed as problematic and doctors drew a direct link between the stability of the household and the quality of care available to the child with specific needs. They felt that if caregivers were able to cover the costs of the household, the ‘wellbeing of the entire family and mostly, of the child who’s most vulnerable, would be improved’ (Dr E).

Severity thresholds: a moving target?

The subjectivity of severity thresholds was a prominent thread in conversations with doctors. An experienced doctor who had been in practice since the late 1980s also reflected on her shifting perceptions and depth of understanding of the need to consider each disabled child individually and the uncertainty surrounding severity. She noted that when she had first started doing assessments, she had rejected applicants if ‘the[ir] child was continent, could attend a mainstream creche, [or] was ambulant’ (Dr B). In other words, she had only approved the CDG if a child’s disability was so severe that they could not perform any functions of daily living. However, around 2008 Dr B had started to soften her approach as she realised that ‘you’ve got to see each case individually – just because a child can walk, doesn’t mean they don’t need a disability grant!’ The usually less visible demands of caring for neurodiverse children, in particular, were also highlighted by multiple doctors.

The other doctors interviewed agreed and felt that as well as being more clearly defined, the severity threshold they perceived as being in place ‘could be lower’ (Dr A). They indicated that even children with moderate disability can have very high care needs and worried that enforcing very strict guidelines could have negative implications for the future prospects of a large proportion of children who might not be ‘severely’ disabled, but were nonetheless in desperate need and might actually benefit most from the therapeutic interventions that the CDG could facilitate.

‘...take the example of a child who’s got a very mild hemiplegia... [a] weakness on [the left] side of the body. They can walk... [their] language is normal. But... they’re clumsier, they can’t run as well, can’t manage stairs... And maybe they have some significant learning difficulties... In a [mainstream] class of 45 or 50 children, their difficulties are not going to paid attention to... The hand, which with the right kind of intervention could become at least moderately functional, actually has no chance... [but] they wouldn’t be eligible for a [CDG]... [That] gives you an idea of how the milder children can end up. They’re the ones that in a way, have the best potential of being able to [live] a relatively optimised, maximum potential life... but ironically, because they’re “too” mild, they don’t get anything, and so you get the worst outcome for them and we [end up only] supporting the very severest end of the spectrum’ (Dr A)

Despite the lack of official guidance from SASSA, participating doctors found most CDG judgments reasonably straightforward. However, all of them also indicated that there were always ‘grey areas’, which then required them to make personal judgments on the threshold for severity because of the lack of ‘clarity of definitions about what “severe” means’ (Dr A). The same doctor commented that ‘on [disability-related assessment] forms, it’s a zero-sum game [but] in reality, there’s a lot of grey’ (Dr A). Another noted that the process was often ‘very subjective, especially when it comes to moderate [disability]’ (Dr C).

In order to secure access for patients they had decided were deserving, doctors reported that they were sometimes compelled to be dishonest about the severity of a child’s impairment because of their belief that children with moderate disability would not be approved for the CDG. Based on their prior experiences with clients who in their view ought to have been approved by SASSA but were not, doctors felt the need to be very explicit or sometimes even to exaggerate. This was also because of the use of a specific form, as detailed further in the following section.

‘There is a big group of kids who may be moderate but... should get the CDG... [but] on the form it’s [only] “mild” [or] “severe”... I can honestly say I end up choosing severe just so they get that grant... [When] I was in general paediatrics I would write moderate, [but] the feedback was that they never got [the grant]’ (Dr C)

Doctors worried that a more accurate, nuanced approach to assessing impairment would not secure the grant for the applicant.

Once they had made their own assessment and had decided the applicant was deserving of support, they aimed to do what they could to ensure approval. A few doctors commented that contemporary understandings of disability (specifically neurodiversity) were not reflected in the systems and tools they used, which could again lead assessing doctors to bend the rules:
‘...a lot of my autistic [patients] will probably be able to do some of the mental tasks [on the form]... [so] now what do I do?! Because they’ve completed the test, but they can’t even have a conversation... then it gets down to, is this child really difficult to live with, and will they be able to get on a bus and go to school? Never! But I don’t have a tick box for that one. So I complete the form with an appalling precis of the child, for SASSA’s purposes... I have to have this absolute black paint, over the child’s assessment, to ensure that they’ll get the grant’ (original emphasis, Dr D)

These doctors saw this rule-bending as a necessary means to a positive end.

However, doctors were worried that caregivers would read and be discouraged by assessments that so strongly emphasised the severity of their child’s impairment, even though ‘five minutes earlier, you were... giving hope to that same mom, about their child who’s doing so well’ (Dr E). This conflicted with doctors’ medical and therapeutic intentions, which were reliant on the caregiver feeling hopeful about their child’s prospects.

‘I know that I’m not jacking the system, I’m just making sure that [they get the CDG for their child who can do some things but]... is [still] incredibly dependent... [So] I say [to parents], “Please don’t read this form, it’s not the truth about your child – I have to say these things, because if I don’t... you’re not going to get a grant”’ (Dr D)

In these instances, doctors aimed to communicate clearly with caregivers, to help them understand that these occasional exaggerations were there to secure their CDG access and ‘to explain who is processing the form... [and] that they’re not medically trained, so I need to spell it out in simple words’ (Dr E).

Doctors were required to serve, in these moments, at a difficult intersection between the emotionally weighty task of bolstering the hope of these parents while initiating them onto a grant that could be perceived as a marker of their child’s ‘hopeless’ future. It seemed much more important to these doctors that they deliver on their clinical role than that they follow (their perception of) SASSA’s rules to the letter. One noted that ‘experience... and being around the block as long as we have’ had taught them ‘which diagnoses fulfil [SASSA’s CDG] criteria’ (Dr E). Doctors were trying to address their bureaucratic partners in terms that would be understood, and to pre-empt or prevent additional expense or rejection for their patients. Rather than being unsure about how to gauge the impact or medical severity of the condition of the children they treated, they were aware that these assessments would be received by SASSA and aimed to ensure that when they believed an applicant was eligible, their access to the grant would be relatively straightforward.

The ‘white form’: reflecting on hyperlocal tools and processes

Participant doctors reported that SASSA and the DSD did not provide specific information about how to conduct assessments and whom to include or exclude. Instead, doctors had usually relied on a line manager or senior colleague within the health facility where they first did these assessments for guidance in gauging qualification for the CDG. Despite conducting CDG assessments since 1997, for example, Dr D commented that she had ‘never encountered anything official’ in terms of eligibility guidance. All of these doctors also had joint academic appointments, so they supervised medical students and taught them ‘how [the CDG] fits into care pathways and the management plan for children who fall under our care’ (Dr A). Tools and practices sometimes travelled from one hospital to another, but this seems to have happened informally, without an underlying structure or organising logic. As a result, institutionalised patterns regarding tools and procedures have sprung up, especially in relation to the CDG, with assessing doctors technically serving as key frontline implementation agents of social assistance for disabled children and their families.

One example of how these hyperlocal, institution-specific practices have emerged, multiplied and carried over from one doctor (and their students) to others is the use of the so-called ‘white form’. Official barcoded SASSA forms for disability-related grant assessment, rolled out around 2008, were not being used in the settings where participant doctors worked. Instead, they used the white form, an older version of the CDG assessment that had been used in their hospitals for many years. Some participants had ‘never seen’ an alternative form but even when doctors were aware of the official form, they preferred the ‘white form’, with one doctor succinctly explaining why this was the case: ‘all I’d really like to do, at the end of my work, is just press the green button – failing that, the ability to quickly complete a form is a godsend’ (Dr D). Having seen some of the newer forms, Dr A explained that they were ‘much more woolly (unclear) with respect to what a child can and can’t do... I think [because] it’s been designed by somebody who isn’t necessarily medical?’). Dr E indicated that after moving from a tertiary hospital to a different hospital, she had ‘told SASSA that I would be using the same form I use at [my other hospital]’ and they had accepted this. With a wider view of the shortages in the system and an awareness of how few doctors are willing to conduct grant assessments, it is also likely that SASSA may be trying to make things as easy as possible for these doctors, in order to ensure they keep participating in assessments and are retained as a resource in the grants system.

Although doctors who had also seen or used the newer SASSA form opted for the white form, they nonetheless considered it ‘far from ideal’ (Dr E). In cases of ‘obviously severe’ (Dr C) disability, the white form’s questions felt unnecessary. Simultaneously, the form could not capture the
nuances of impairments that were medically moderate but might still be having a considerable effect on the child’s independence and on the scale of care and attention required from their caregiver. The white form was favoured only because it was efficient and reasonably well-aligned with their diagnostic approach, as captured in the following reflection:

‘I use it because I can do it in my sleep. Our speciality is very paper-labour intensive… [but] you can still use the white form as part of your normal consultation… [so] it’s user-friendly [because] you can just scratch [irrelevant questions] out… And for uniformity, because state patients largely get their [CDGs] from [specialist hospitals], which use the white form’ (Dr E)

Ultimately, doctors used the white form because it allowed them to achieve more quickly what they felt was their most important function: ensuring that their patients obtained social assistance so that they could best support their disabled child’s needs.

Doctors seemed able to assert themselves with SASSA and SASSA, in turn, appeared to be lenient with doctors’ use of the form they preferred. One of the implications of this looseness and flexibility, however, is a profound lack of support. In order to manage their task, doctors were effectively taking advantage of the gaps and loopholes they knew existed in the system to obtain support for needy families. Knowing that there were huge problems with the overall functioning of the system, they operated as well as they could within these constraints, used the forms that were most efficient for them (and their patients) and applied thresholds on the basis of their own historical and practice-based knowledge, rather than a clear guideline from the entities actually responsible for administering and managing the grants system. Doctors were forced into developing their own mechanisms for balancing the demands of their clinical work with the need to connect patients to income support as a key pathway to care. In the absence of proper guidance, they had established various pragmatic approaches that worked well for them in the context of their day-to-day work.

Between a rock and a hard place
Doctors appreciated the flexibility that the white form gave them and were unabashed about this. However, they did express conflicted feelings about the wider implications for fairness, consistency and state expenditure nationally. For example, one doctor was insistent that although it was difficult to see patients in desperate circumstances, she would never have approved the grant on the basis of poverty alone because in this role, doctors ‘are responsible [not just to their patients but also] to the state and to the government, [so they] have to fill [grant assessment forms] in with integrity’ (Dr B). In personal communications subsequent to our interview, Dr D noted that she would value seeing ‘an expanded vocabulary or debate on what constitutes ‘enough” dependence to warrant a [CDG] in this country in the 2020s’. The same doctor added that although this debate might be happening in policy or legislative contexts, ‘the trickle down [to the frontline] hasn’t happened… in the real world of my clinic, I just don’t see [policy] driving practice’.

To varying degrees, doctors seemed concerned about consistency within their own and across other doctors’ judgments, mostly because of the known weaknesses in monitoring and uniformity across the disability-related grants assessment system. In our interview, Dr D had eloquently and movingly noted the weight of responsibility for ensuring fairness in the social assistance system, as well as her concerns about the public fiscus.

‘It’s a really hard space to be in… Sometimes I’ve just kind of prayed for some protection there. And most of us, because we’re softies, will just kind of [approve the grant] but you can see how that plays out in millions and billions… When I started training, there was always a sense that there was a SASSA doctor who vetted the forms… [so] that we weren’t the final arbiter of whether a child got a grant or not. It was always a recommendation. But I have not had any contact with anything resembling a SASSA doctor who’s actually pushed back against an application… It does worry me that there is a massive bill… But I don’t see anyone pushing back at me, even though I’ve written my telephone number there for twenty years! … I would really appreciate that, just once, to tell me that someone out there is listening and watching a system that must cost the state… a lot of money… This morning I had a phone call with a parent whose child… [has] Down syndrome [with] moderate intellectual disability… his heart is fine and he’s just beetling around like any old five-year-old, with clear intellectual disability but not of a type that warrants a family to suspend life and do inordinate amounts of caring, I don’t think that child should get a grant, but I know there will be an internal consistency within [my assessment history], because I’ve probably completed grants for 95% of children with Down syndrome… that oversight [from SASSA]… is missing’ (Dr D)

This participant (and others) actually seemed to be craving more and much clearer guidance from SASSA, so that they could worry less about fairness in each assessment and could also share the responsibility for this enormous task. They were happy to advise on impairments and their impact, as this was a task they felt equipped for and agreed was not SASSA’s speciality, but it certainly felt wrong to them that it was their responsibility alone. Without proper support from the actual implementing agency, doctors were forced to try and balance giving people help while being aware that state resources were extremely strained, a process that Dr A described as ‘a wicked problem’.
When asked how they thought the system’s limitations might be addressed or improved, doctors expressed a willingness to adjust their own behaviours but did not have much hope that the country’s ‘thin administrative capacities’ (Dr D) and lack of human resources for health would offer much scope for improvement. Doctors also worried about the perceived lack of commitment at SASSA, as reported by their patients. They especially noted that officials tended to be ‘anonymous’ (in contrast with named, treating doctors who regularly had contact with their patients), leading to poor accountability and transparency.

’SASSA… [is] a big, grey hole, isn’t it? We don’t know who we’re dealing with. We hear anecdotal stories – true of most government departments in this country – of people who are rude, and people who are inaccessible, and people who are incompetent… [it’s] not a user-friendly service for already strained parents in this country who… [have] a child who has hugely specialised needs and they are struggling financially, emotionally… having to get into this massive… queue, only to get to the front to be chased away because you didn’t bring this and you don’t know that. It’s not streamlined, there’s no open lines of communication’ (Dr E)

They all also worried about a single, cash-based intervention being used in place of more substantial and varied interventions for the social protection of disabled children and their families, such as educational subsidies for children who might be able to access mainstream schooling with appropriate support.

The connection between SASSA and CDG-assessing doctors employed by the WCDoH is clearly mostly logistical, rather than based on shared goals. This may differ somewhat in the country’s other provinces, where directly contracted doctors are the majority of the assessing workforce and might be provided with more formal ‘nudges’ by means of the official SASSA form. But in the Western Cape, no formal guidelines or training are systematically provided to these assessing doctors. Investigations of bottom-up practices, such as this study, capture some of the realities ‘on the ground’ and show how critical concepts (such as ‘severity’), which are at the heart of this conversation about public benefits, are not agreed upon or shared by the key role-players involved.

Discussion and conclusions

Besides one notable study that specifically focused on the experiences and opinions of adult DG assessors in the Western Cape (Kelly, 2016a; Kelly, 2016b), there been little insight into the perspectives of doctors who conduct disability-related grants assessments. Specifically, there is no previous research that reports on doctors’ narratives about conducting CDG assessments. The Cape Town paediatric doctors we interviewed seemed to be applying a nuanced and highly individualised approach to CDG assessments. They were keenly aware that while (medical) severity can correlate with higher care and support needs, this was not necessarily the case for all disabled children. They were also aware that, as is the case with most grants in the country (Gutura & Tanga, 2017), the CDG was probably distributed among household members rather than being used exclusively for disability-specific needs. Doctors felt that this was an appropriate use of the grant, as improving the overall wellbeing of the family would help their disabled child by extension. Further, they explained that children with conditions that were medically moderate might none-theless have substantial therapeutic or other support needs. Doctors knew that if these children did not gain access to the larger CDG, their families would likely only be able to find similar support through the much smaller child support grant. They would then be less able to present at hospital for medical care, pursue other therapies or assistive devices and pay for regular accessible transport or specific nutritional support, with negative implications for the child’s health and happiness.

In contrast with the aforementioned study with doctors working in the same province and conducting adult DG assessments, the doctors we interviewed did not talk much about the ‘worthiness’ of potential CDG applicants. Kelly (2016a; 2016b) theorised that doctor participants were affected by a range of factors including their environment, relationship with SASSA and other patterns including the rapid growth in DG beneficiary numbers when treatment for HIV had not been available in SA, the high incidence of fraud and ‘malingering’ associated with the DG and experiences that doctors had had with threatening applicants. As a result, many of the doctors Kelly interviewed adopted an apparently quite stringent approach to grants assessment. This was not without exception; some of the doctors that Kelly worked with were lenient, emphasising the importance of empathy in considering their patient’s social circumstances. These ‘two extremes in the way that doctors frame[d] and deal[t] with DG assessment’ were described by one of Kelly’s participants as ‘hard’ and ‘soft’ doctors, respectively (Kelly, 2016a). This was echoed in our study with Dr D’s contention that ‘we [i.e. paediatric doctors working in specialist hospitals] are softies’. Indeed, most of the doctors we interviewed seemed to tend toward the latter ‘extreme’. They were concerned about those most in need gaining access but also said that they preferred to make inclusion errors than to exclude potentially deserving children. They explained their concerns about expenditure and limited state resources, but these were never their primary focus. Instead, doctors were profoundly – sometimes painfully – aware of the fact that the CDG was the only predictable, steady source of support from the government for these families and their disabled children.

Doctors’ narratives about feeling obliged to bend what they perceived as the rules shows how, in the moment of assessment, they would have to try to make complicated calculations about need, deservingness and the (unlikely) possibility that these children and their families would find sufficient support elsewhere. Some also worried that because of their perception that severity was the primary...
condition for access, the CDG might only be functioning for most recipients as a survival mechanism, rather than genuine social protection. They also knew that SASSA could desk-reject these applications if they explained the child’s disability in accurate terms that another disability practitioner would understand but which did not meet the box-ticking approach. As such, similar to some of the hospital-based DG-assessing doctors previously interviewed and observed, this involved ‘selectively applying and ignoring guidelines as it made practical sense’ (Kelly, 2016a). Paediatric doctors simplified their CDG assessments because they understood that there were no health practitioners checking the forms and did not feel that non-clinical administrators were properly equipped to understand more nuanced assessments. Individual doctors bore the weight of this decision-making but also felt unable to be accurate in their assessments, because of the spectre of SASSA’s potential rejection. Doctors would not have been satisfied applying assessment processes that did not incorporate proper knowledge of child disability but also did not want to have to be solely responsible for the fair and equitable distribution of needs-based grants. In other words, they were caught between compassion for their patients’ circumstances and a wider commitment to fair, distributive justice.

SASSA has expressed concerns about the bias and subjectivity of doctors, framing this as an impediment to standardisation and fairness across the disability-related grants portfolio (Kelly, 2016a; Kelly, 2017; Mitra, 2010). In addition, SASSA officials in the Western Cape and at national level are clear that although they tell clients that SASSA is deciding whether the grant will be awarded, the decision is actually being made by doctors, whose CDG recommendations are generally accepted by SASSA (Trafford & Swartz, 2021). While we can only theorise the reasons for their relative lenience, this may be partly because there is much less public concern about CDGs being fraudulently accessed and the existing beneficiary numbers are relatively low. In addition, in contrast with the DG, which is very well-known in the general population and is regularly requested by hopeful but ineligible applicants, CDG assessments were generally initiated by doctors and patients did not often request the CDG. Finally, a key difference between prior research with assessors and this study was that in the former instance, some of the doctors conducting assessments for adult disability grants were contracted by SASSA and were not necessarily providing treatment at the same time (Kelly, 2016a). For those who were also treating the patient they assessed, the context was less objective but ‘treating doctors were more likely to feel a sense of responsibility towards their own patients’ (Kelly, 2016a). Doctors also have direct and ongoing care relationships with many of these patients, which may be affected by inducing doctors into the position of judge and jury. Similarly, our participants usually bundled their CDG assessments into a consultation or diagnosis session, which may, for them, have foregrounded their clinical role and increased their sense of commitment to care. Whatever their reasons, the doctors who participated in our study seemed most attached to their primary identities as clinicians providing medical and pastoral care to the patient sitting in front of them, not as bureaucratic administrators focused on limiting inclusion errors or policing access.

Although they may have done disability-related grants assessments throughout their careers, these already overloaded doctors did not volunteer for this role and nor was it one of their goals when they chose to train in paediatric medicine. They have been inserted into a large bureaucratic system that is focused on monitoring the boundaries of grants eligibility and administration, but they have no specific interest or training in social security or social assistance. In this study, doctors expressed their discomfort with their positioning, at the interface between a huge, unwieldy bureaucratic system and enormous questions about redistributive justice and what the country can afford. This is partly a reflection of the potency of doctors’ perceived power, particularly in the process of validating claims on public and private benefits. There is an implication that doctors can ‘do anything’ and as a society, we have given them the power to make these decisions but have not ensured that they have the necessary skills or insights to deliver upon them. These doctors do have significant actual and symbolic power, but the impact of this power may be significantly diluted by broader socioeconomic forces, inequities and the medical intractability of the impact or some forms of disability (Watermeyer, 2013). Our participants also felt disempowered by the structural conditions surrounding their patients, which limited the impact their medical knowledge could have. On top of this, their voices were and are not formally included in conversations about policy and implementation, limiting their capacity to feedback and influence policy from the bottom up.

Strengths and limitations of the research

Importantly, this research relied upon self-reporting in one-on-one interviews. The initial study design included ethnographic observation, which were prohibited due to COVID-19 lockdowns. These intended observations might have allowed for the identification of differences between doctors’ self-presentation and actual behaviour. Although it is possible that a social desirability bias was operating, it is doubtful that any of them intentionally obfuscated the truth and the in-depth, semi-structured approach to interviewing offered opportunities to repeatedly interrogate their feedback. While there is always a chance that participants felt the need to represent themselves in a positive light, it is unlikely that the position of the interviewer – a younger, less educated person with no clinical knowledge – held much sway over them. Participating doctors were also honest about bending the rules when they felt they had to, as well as about doubting whether they were protecting state resources sufficiently. They also eagerly agreed to be interviewed and often ran over the time they had committed to, sometimes continuing our conversation in writing. Their willing participation and candidness suggest that doctors felt comfortable enough to share their limitations openly. One of the strengths of
this research is that it makes an initial contribution to an as yet unresearched area. Further, only a short time has elapsed since data collection, so this paper offers up-to-date evidence. We recommend that additional research be done across the country, especially in rural settings, to complement this study and deepen our understanding of how these practices and beliefs might differ in other settings. This may be particularly important in provinces with high beneficiary numbers, such as KwaZulu-Natal and the Eastern Cape (Hall, 2022). Award of the CDG has increased most in the Western Cape in the last decade, but the absolute numbers of beneficiaries is significantly higher in these other provinces, which are also home to large rural populations with poor access to specialist care.

**Conclusion**

Those who work at the coalface must be included in any adjustments to bureaucratic and service delivery systems or the state will forever be trying to apply perfect policies to imperfect situations. First, those most closely involved in implementation ought to be the key and primary informants for improvements. Second, deep changes are needed to strengthen intersectoral relationships, in this instance between SASSA and the relevant health department or assessing doctors in general. In the most substantial prior attempt at revising disability-related grants assessments, the process of harmonising the tools used for grants assessment with the country’s commitments to disabled people faltered, apparently because of resource limitations and clashing priorities at SASSA and the Department of Health. These previous revision attempts hold valuable lessons that could and should be drawn upon to inspire improvements on the current system (Schneider et al., 2011b). Far more important than the tools used for assessment, perhaps, is proper collaboration and mutual respect, as well as the ensuing process of informing, reorienting and retraining. Finally, a deeper and more contextually aware definition of disability should also be applied in assessments, but this also has to be flexible enough to be used operationally in our current context. It should be broad and ambitious – but not impossible or naïve.

As expressed by doctors and SASSA officials alike, SASSA cannot be solely responsible for setting disability thresholds because they do not hold the relevant expertise. At the same time, however, it is unfair to shift this responsibility onto doctors who are already carrying a huge workload. As Kelly argues, this is also unlikely to be successful because attempting to standardise and homogenise individuals to a narrow set of categories (e.g. mild, moderate and severe) will be resisted by doctors who are aware that disability cannot be reduced to these classifications. They may then ‘side-step protocols’ and favour their own professional and experiential knowledge over ‘top-down control’ in the form of overly restrictive guidelines (Kelly, 2016a). Instead, a set of practical and pragmatic guidelines should be co-created, with doctors and SASSA collaborating more closely to find an agreeable approach that takes both perspectives into account. These guidelines must acknowledge the reality of scarcity in all public sector institutions (especially the health system) and the importance of careful relationship management, open communications and a shared understanding of purpose and eligibility in the delivery of this important intervention. Doctors’ narratives are the most direct representations of how assessments for the CDG happen in practice rather than in theory, but these doctors are not in regular contact with SASSA. It is critical that their understanding of factors including severity thresholds (qualification for award of the CDG) and eligibility guidelines, as well as their perspectives about the appropriate way to use the CDG, are captured and understood.

**Data availability**

**Underlying data**

The data from this research are not publicly available due to ethical restrictions regarding anonymity and confidentiality. Transcripts and audio data contain identifying information that would compromise the privacy of our research participants. Due to the specificity of these doctors’ roles and the limited number of specialised facilities locally, it would be impossible to completely anonymise the data. Readers may be able to identify hospitals or specific doctors who participated, comprising their confidentiality. Additionally, these data were generated by a specific interaction between the first author and the study participants and was affected by our respective positionality, meaning the data cannot simply be reanalysed by other researchers in the way that survey data might. The data that support the findings of this study are available from the corresponding author and further analysis or collaboration can be requested, in discussion with the authors.

**Extended data**

Figs hare: Semi-structured interview guide for in-depth interviews with decision-making doctors in Cape Town, South Africa

https://doi.org/10.6084/m9.figshare.21262875.v1

This project contains the following extended data:

- Doctors IDI guide_2020-2021.docx (Semi-structured interview guide for in-depth interviews with decision-making doctors in Cape Town, South Africa).

Data are available under the terms of the Creative Commons Zero “No rights reserved” data waiver (CC0 1.0 Public domain dedication).

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Marie Schnitzler

Institute of Research in Social Sciences, University of Liège, Liège, Belgium

This paper offers an interesting insight into the ambiguity of disability-related social assistance cash transfers in South Africa. More specifically, it shows the intertwining of medical and functional approaches of disability, together with more circumstantial element, when doctors take administrative but very impactful decisions. As such, it probes into the technical dimension of the assessment as well as the conflict of values doctors have to resolve when advising for the delivery of the care dependency grant.

A few modifications or further details might help improve the paper:

1. Providing some information on the number of CDG could help the reader better understand some arguments of the paper such as the actual economic importance of the grant, or the difference in terms of recipients with other grants such as the CSG or the DG grant. This information is easily retrieved from SASSA reports.

2. Some clarity on what the authors mean by “worthiness” and “deservingness” might be needed to avoid any confusion. Indeed, the authors estimate that recipients’ “worthiness” is not much discussed by doctors (which differs from the DG assessment, see p.9), but these doctors still comment on the emotional reactions steered by patients’ condition and circumstances, both negative and positive (p.5). Is taking into account these elements not partly estimating the deservingness of some in front of other? Or is the discussion on worthiness more related to identifying fraudulent applicants?

3. When limitations are discussed, the question of selection is never mentioned. Indeed, the fact that doctors “eagerly agreed to be interviewed” (p.10) interrogate the participants’ profile. Can we assume that all paediatric doctors are “softies” or are the data putting this profile to the front because doctors who participate in the research were the ones the most concerned with providing care for their patients and just assessments? A few information on the number of requests for interview and some cautions around the results could help bring a more nuanced tone. This however does not mean that the results are invalid, only that the method of recruitment might have favour certain type of participants’ profiles.
4. Somehow linked with the previous comments, when the authors underline the need for further studies in rural areas, adding other types of medical personnel providing CDG assessment beyond neurodevelopmental paediatricians could be useful.

5. In the conclusion, the need to review the actual system is not really contextualised. What is shown in the paper is a system that ensures flexibility, although it puts a lot of responsibilities and doubts on doctors. But why should this system be revised is not completely clear to me. Is this in link with SASSA desire to standardise the access to the grant and thus is SASSA already planning to modify the system of assessment? Or is there a real call from doctors to change the way they provide assessment, not only during interviews but publicly voiced?

**Is the work clearly and accurately presented and does it cite the current literature?**
Yes

**Is the study design appropriate and is the work technically sound?**
Yes

**Are sufficient details of methods and analysis provided to allow replication by others?**
Yes

**If applicable, is the statistical analysis and its interpretation appropriate?**
Not applicable

**Are all the source data underlying the results available to ensure full reproducibility?**
Yes

**Are the conclusions drawn adequately supported by the results?**
Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Anthropology, social sciences, disability studies

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

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© 2022 Kelly G. This is an open access peer review report distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.
Thanks for the opportunity to read this well crafted article. I feel that you have addressed many logistical, bureaucratic, medical, social and interpersonal issues that make it so difficult for doctors to conduct their assessments "objectively". The article could be strengthened in the following ways:

1. Making it explicit in the methodology that your sample are all treating doctors (you indicate upfront that they are all at specialist hospitals but not that they are treating patients). This is not the norm in SA or elsewhere. For those readers that don’t understand the MoU between DSD and SASSA it might be helpful just to make this clear upfront as there are obviously differences between their approach and those that those hired specifically as disability assessors will have, which you have touched on in your analysis but I think should come earlier. You should probably also highlight this as a limitation as you only have the perspectives of a very specific group of specialists with relationships with their patients who are being seen at a higher level of the health system. This is not to say that the perspectives of these doctors are not tremendously useful or important, but I do think you need to position them upfront - I know you are not trying to generalise, but it is still important.

2. I think you need to reflect on the implications of doctors work on policy implementation. You have noted that they should be involved in implementation planning, which I fully agree with. But what might be the consequences of their current practices? Street-level bureaucracy theory posits that bureaucratic practice "creates" policy - even if you don't employ this theory directly, it would be useful to reflect on what doctors' behaviour and gatekeeping role means for access to the system. It's a big question and you may not have space to do this in detail, but I think at least pointing to some of the practical implications of their practice and some of the established thinking and literature in the area of policy implementation and how your research extends or contributes to this would be very helpful.

3. I think you also need to highlight that these struggles are by no means a local problem. Disability assessment is notoriously difficult and doctors are notoriously bad at doing it all over the world. Socio-economic issues aside, the medical model is very limiting and doctors are not trained to assess function. The South African case is so interesting because it takes place in a context where there are much higher levels of poverty than in many other countries with disability programmes and it accentuates the challenges. While disability benefits for children are less politicised than for adults, some of this research has focused on disability benefits for children in the American context. I think that linking it to broader international challenges and political debates might bring your article to a broader audience.

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
No source data required

Are the conclusions drawn adequately supported by the results?
Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Social protection, disability grants, care for older persons

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.