

**CONCEPTIONS OF DISABILITY AND DESERT IN THE SOUTH AFRICAN
WELFARE STATE: THE CASE OF DISABILITY GRANT ASSESSMENT**

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ACRONYMS

AIDS	Acquired Immunodeficiency Virus
CSG	Child Support Grant
DG	Disability Grant
GIA	Grant-in-Aid
HIV	Human Immunodeficiency Virus
MDR	TB Multi-drug resistant TB
OAG	Old Age Grant
OT	Occupational Therapist
PHC	Primary Healthcare
PMG	Parliamentary Monitoring Group
SASSA	South African Social Security Agency
TB	Tuberculosis
TDG	Temporary disability grant

ABSTRACT

Disability is a universally difficult concept to define and assess for social assistance and social insurance purposes. The ways in which access to disability welfare rights are defined and allocated remain especially neglected in the Global South. This thesis examines the administration of the disability grant (DG) in South Africa, where unusually generous disability benefits exist alongside very high levels of unemployment and poverty. It focuses on the role of doctors, who must confirm that applicants for the DG are disabled, serving as gatekeepers, and thus as ‘street level bureaucrats’ within the South African Social Security Agency (SASSA).

Observations of doctor-claimant interactions in clinics and hospitals showed that disability assessments are sites of contestation between doctors, claimants and the state over how social security rights should be allocated. Doctors struggled to balance their roles and obligations as medical professionals, gatekeepers and moral agents, in a context where issues of employability and disability are hard to separate. In the face of heavy workloads and significant pressure from claimants to recommend grants, doctors employed coping strategies that distanced and objectified patients. Despite efforts by SASSA to curb their discretion, doctors inserted their own subjective understandings of disability and deservingness into the assessment process as they interpreted and applied DG policy in their interactions with claimants - bending the rules for people they thought were ‘deserving’ and rigidly applying the rules in ‘undeserving’ cases.

Variation in doctors’ decision-making reflects different ways of framing disability cases. The interpretive schemas that doctors used to organise and make sense of cases were shaped by their social background and dispositions, work environment, professional and personal norms and values, and ideas about distributive justice. Framing is also an interactive process and was influenced by claimants, who brought their own agency to bear on the assessment. The concept of framing contributes to street-level bureaucracy theory by capturing the pluralism of norms and ideas that ground street-level actions, whilst allowing us to observe and explain patterns emerging in street-level decisions. It is also useful in examining the relationship and potential conflicts between professional expertise, social norms and values, and bureaucratic rules. The study also shows the need for scholars of street-level bureaucracy to consider the influence of citizen agency on policy implementation. The challenges and pressures doctors faced in categorising disability, combined with patients’ misunderstanding of and resistance to these categories and related demands to be included in the system, demonstrate significant gaps in the design and application of social security and poverty alleviation policy in South Africa.

CHAPTER 1: Introduction

1.1 Introduction

Doctor Rahman stood at the door, calling out to the huddle of patients waiting outside in the passage: “Thobani Dlamini”. Shortly afterwards, a young man entered the consulting room. Dr Rahman and I were sitting in a shipping container attached to a small clinic in one of the small towns in the wine lands around Cape Town in the Western Cape Province of South Africa. Most of the people living in the area rely on unskilled, seasonal work on the surrounding farms during fruit-picking season. That day twenty of them, who were applying for a disability grant (DG), were waiting to see Dr Rahman. The South African DG is a non-contributory, means-tested cash transfer of R1420 (\$107) per month (as of April 2015), available on a permanent or temporary (6-12 months) basis to people deemed unfit to work as a result of functional impairment and who do not have sufficient other means of support. As of September 2015, 1.1 million people - approximately 3.4% of the working age population¹ - were receiving disability grants (SASSA, 2015).

Confirmation of disability by a medical doctor is a requirement for all DG applications. Dr Rahman was contracted by the South African Social Security Agency (SASSA) to conduct medical assessments to determine whether claimants were what the state considers to be disabled. He moved daily between clinics in the Western Cape, seeing dozens of patients applying for DGs, the care dependency grant (for parents of disabled children) or the grant-in-aid (a small grant given to elderly or disabled people in need of permanent care)². He was a medical professional, with his own private practice, but in the work he did for SASSA he acted as a bureaucrat of the state. Although medical doctors are professionals providing therapeutic care to their patients, in their role as disability assessors they become also (or even primarily) *street-level bureaucrats* (Lipsky, 2010); i.e. frontline workers who control access to public services through the ‘application’ – and interpretation – of government laws, rules and policies during their face-to-face encounters with citizens. These doctors are tasked with a gatekeeping rather than (or in addition to) their therapeutic role, as part of a bigger rule-bound bureaucratic process.

During the day I spent with Dr Rahman, he told me several times that he had fantasised a lot

¹ According to the 2011 Census, 33.2 million people are of working age (between 16 and 35)

² As of September 2015, 126,642 people received the Grant-in-Aid and 129,296 received the CDG (SASSA, 2015)

about developing a formula or algorithm that would help him standardise his decision-making. He described a computer programme that would allow him to put all the variables into a system, weigh them and produce a recommendation based on the patient's specific profile. Although removing what he called "the human element" or the discretionary aspect of decision-making would make his job easier, Dr Rahman knew that his imaginary system would be impossible and undesirable to implement because it would override individual experiences or circumstances (i.e. the very things that made his job difficult).

Thobani Dlamini provided an example of why Dr Rahman thought that a formulaic objective system like this could never work in practice. Although Mr Dlamini was only 31, his gaunt face made him look much older. He had been diagnosed with HIV in 2005 and should have started anti-retroviral treatment (ART) in 2008, but it was now 2014 and he had never taken any medication. His health was deteriorating, which was demonstrated by his low CD4 count and recent tuberculosis (TB) diagnosis³. He was evasive about why he was not taking ART treatment, but after some probing, he reluctantly admitted to Dr Rahman that he was receiving treatment from a *sangoma* (traditional healer) instead of taking ART, although he was taking his TB medication. Dr Rahman told me afterwards that an algorithm would never be able to account for a situation like this. By refusing an available form of treatment for his condition, Dlamini would be classified by a computer as ineligible. Dr Rahman thought not taking into account the specific context of the case would be unfair and that a human being therefore needed to make this decision. Dr Rahman felt that he could not discriminate against someone's belief system and that he needed to be flexible and open-minded in cases where people preferred to use alternative therapies.

Social security legislation and SASSA guidelines lay down specific rules and provide a set of eligibility criteria for DGs to ensure that DGs are equitably distributed to people who 'deserve' them. Although perhaps not as refined as Dr Rahman's imagined system, SASSA's guidelines actually provide fairly straight-forward directives on how to handle cases such as Mr Dlamini's. Where patients are non-compliant or do not properly adhere to treatment, the guidelines clearly advise against recommending a DG. Dr Rahman was familiar with these guidelines and it seemed that what he was really looking for in some objective computer system is a way for him to overcome his daily moral quandary: whether to err on the side of the patient

³ CD4 count refers to the number of CD4 or T-cells per cubic millimetre of blood and is a key indicator of the progression of HIV. A normal CD4 count is somewhere between 500 and 1,200.

or the state. Although many patients clearly do or do not qualify on a clinical basis alone, many others fall into a grey area, especially when socio-economic factors and actual employability are taken into account. Although SASSA does allow doctors some discretion in considering non-medical factors such as level of education in cases of moderate impairment (which it classifies as an abnormality that interferes with function), SASSA defines employability in terms of one's ability to participate in the *open labour market*, regardless of the availability of work (SASSA, n.d: 4). Considering that the DG is not intended to address poverty amongst the non-disabled population, this definition makes sense. For doctors, however, it is difficult to divorce a claimant's physical ability to work from the broader economic and social context. When considering the employability of individuals like Dlamini, Dr Rahman found it difficult not to consider how unlikely they were to find a job, especially given the paucity of skills development or re-training programs in surrounding areas. Why should belief-based non-compliance with treatment preclude an obviously sick man from being deemed disabled when compliance would probably not secure him a job?

The case of Dr Rahman and Mr Dlamini shows that despite rules and regulations that outline specific claimants' eligibility for DGs, decisions on eligibility are seldom clear-cut. This case of non-compliance related to cultural beliefs provides an example of one of the many moral and intellectual struggles that physicians like Dr Rahman face in making DG decisions in a context like South Africa. Dr Rahman was thorough in his work and made considered choices, but he struggled to balance his responsibility to individual patients with his responsibility to SASSA. All the exceptions he made for individuals based on what he thought was in their best interests made him a poor gatekeeper and he had been cautioned by SASSA about his high approval rates. Despite being reprimanded, he had really struggled to adapt to their approach. "The best approach is probably to be rigid, but then are you really doing justice to people? This is the problem I sit with."

This research explores these and other tensions in the DG system. Focusing on the use of discretion in the medico-bureaucratic work in DG assessments in the Western Cape Province, it focuses on how doctors like Dr Rahman interpret and apply DG policy in their interactions with claimants and explores the gaps between social policy, medical knowledge and practice. It shows how doctors juggle their responsibilities as medical professionals, gatekeepers and moral agents within a context of contrasting and unresolved discursive tensions relating to development and welfare, as well as regulatory and budgetary challenges brought about by an HIV epidemic, high levels of structural unemployment and poverty. This is grounded in

observations of the daily encounters between DG applicants and doctors and interviews with doctors about these interactions, which both shed light on the underlying factors that shape doctors' decisions. I argue that the pressures and constraints doctors face in working as gatekeepers for the state highlights important failures in both social protection and disability policy.

Not all doctors involved in this study approached DGs in the same way as Dr Rahman. As I will demonstrate, some were extremely strict and inflexible, some (like Dr Rahman) were happy to bend the rules to accommodate greater numbers of poor patients and some bent the rules for individual patients who they felt were particularly deserving, while enforcing the rules strictly in what they perceived to be undeserving cases. An article in the *Mail and Guardian* (Green, 2015), headlined *TB Man's Shirt Too Nice for a Grant*, illustrates the latter case well. It tells the story of Bongani Ngcobo from a rural settlement in the province of Kwa-Zulu Natal, who lost his job because of his multi-drug resistant tuberculosis, which requires two years of intense treatment. Despite MDR TB being a clear case of medical eligibility, the doctor assessing him refused to recommend a grant, telling him that he dressed too well to be poor and that others needed the grant more than him⁴. Doctors are employed to conduct medical, not financial assessments of claimants' eligibility (SASSA carries out formal means testing) and by making this snap judgement, the doctor concerned was clearly stepping beyond the boundaries of his assignment. I argue that this subjective decision-making by doctors should not just be treated as arbitrary bias to be eliminated by introducing more rules, reducing discretion and increasing bureaucratic oversight. Rather, the patterns that emerge in examining doctors' decision-making reveal important aspects of the institutional, organisational and professional logics that structure doctors' work, as well as the discourses and values that shape social development, health and disability policy in South Africa.

In examining the day-to-day interactions between physicians like Dr Rahman and DG claimants like Mr Dlamini, I show how doctors act as intermediaries between claimants and the state, working within the constraints of SASSA's rules and processes, but also using their discretion to insert their own ideas and values into this process. Using the concept of *framing* (Goffman, 1974) to understand doctors' decision-making, I show that as professional, moral and social agents, doctors bring different framings of disability to bear on assessments. I demonstrate how citizen-state interactions in administrative settings can be sites of negotiation

⁴ As a result of the publication of this story, Ngcobo was eventually awarded a grant

and contestation around entitlements to social welfare. The encounters between doctors and claimants reveal how ideas and values about distribution and social justice and conceptions of the deserving poor are constructed, and can influence social policy implementation. I argue that it is important to attend to the disability assessment process and the politics that emerge around disability assessment, not only for what it adds theoretically to the study of frontline workers in public services, but for its practical implications. Understanding the challenges and pressures doctors currently face in assessing disability will provide greater insight into gaps and inconsistencies in the current design and application of social security policy in South Africa.

In the first part of this introductory chapter, I present an overview of the programme and show how the universal ambiguity of the disability category and both the general and South African-specific difficulties in assessing disability make it an interesting case study of welfare policy implementation. I then present an overview of the comparative and South African sociological literatures on street-level bureaucracy and medical gatekeeping. This is followed by a discussion of my methodological approach in relation to other studies of street-level bureaucracy and studies of doctor-patient interactions and a brief overview of my research design. This chapter concludes with a roadmap of the remainder of this thesis.

1.2 The ambiguities of disability grants

The past two decades have seen the massive growth of social protection programs in the Global South (ILO, 2014). These have largely emerged in the form of direct cash transfers to the poor, which have been demonstrated to reduce poverty and promote development (DFID, 2011; UNICEF, SASSA & DSD, 2012; Samson et al., 2010; Hanlon *et al.*, 2010). South Africa has featured prominently in this story as a case study of success. South Africa's social assistance system comprises eight cash transfer programmes⁵. These cash transfers (or social grants) have been heralded (although perhaps begrudgingly) by the South African government as its most effective anti-poverty initiative.

The development of social assistance programmes offered in the form of cash transfers emerged much earlier (between the late 1920s and mid-1940s) and along a different path to the cash transfer programmes that have more recently emerged in other countries in Africa

⁵ South Africa has five social grants in addition to the three disability-oriented ones: Older Person's Grant (also known as the old-age pension, for people over 60); Child Support Grant (children under 18); Foster Child Grant (for legal foster parents); Social Relief of Distress (short-term relief, often in the form of food parcels); and a War Veterans Grant.

(Seekings, 2015). Although social grants are a legacy of South Africa's colonial and apartheid past, the post-apartheid government has overseen a massive expansion of social grants from 2.4 million beneficiaries in 1994 to over 16 million in 2015. South Africa's social assistance programmes have a very wide reach and two-thirds of households have a member with some sort of social grant income (Seekings & Moore, 2013).

This growth has not come without controversy and there have been extensive debates in the media, through which both the public and government have expressed concerns about possible perverse incentives associated with grants, as well as concerns about undeserving claimants receiving grants, particularly the Child Support Grant (CSG)⁶ and the DG. Although there is little ideological contestation around whether children or disabled people 'deserve' state assistance, there has been significant anxiety about whether these groups are targeted effectively; i.e. whether mothers who receive a CSG *for* their children spend it *on* the children and whether the people receiving DGs are genuinely disabled.

The DG has for many years proven extremely difficult to administer and target effectively (Graham et al., 2010). The main eligibility criterion for the DG (work disability) is considerably 'fuzzier' and more flexible than criteria used to identify 'deserving' categories of people as eligible for other types of grant. In order to apply for an Old Age Pension or CSG, claimants must provide SASSA officials with proof of their identity, age and financial means, whereas applications for disability-related grants also requires an assessment of disability⁷. As social security legislation requires that assessments be conducted by medical doctors, the South African government relies on the expertise, authority, and discretion of these professionals to assess whether an applicant is medically eligible for disability assistance and their gatekeeping work has been difficult to manage⁸. There are long-standing concerns amongst policy-makers, implementers and civil society that DG assessments are highly subjective and open to bias and fraud on the part of both doctors and patients (see Chapter 2)⁹. Whilst overt incidents of fraud (e.g. falsified documents and bribes to doctors) has been easier to address with the

⁶ The CSG, paid to the primary caregivers of children, has the largest coverage of South Africa's social grant programmes, reaching over 11 million children.

⁷ The Care Dependency Grant for disabled children and Grant-in-Aid also require a doctor to determine how disabled an individual is.

⁸ Attempts have been made to de-medicalise assessments by including other healthcare professionals and community representatives in the assessment process, but these have been unsuccessful. See Chapter 2.

⁹ Doctors also experience difficulties in determining children's eligibility for the CDG, which is equal in value to the DG. However, there is less demand for this grant and with the exception of one highly disputed media report about women intentionally disabling their children by drinking during pregnancy (Davis, 2013) there has been significantly less concern about this issue.

establishment of SASSA and introduction of new management procedures aimed at preventing fraud, regulating the more regular but often divergent decisions doctors make has been more challenging.

One of the reasons why DG assessments are so difficult to regulate is because disability is a complex and multi-dimensional concept. Ambiguities around the definition of disability and difficulties in making binary distinctions between disabled and non-disabled people mean it is difficult to use disability as an administrative category for allocating social rights. As a result, even countries in the Global North with well-established disability assessment systems struggle to target disability benefits (Bolderson et al., 2002). The South African context creates a number of additional difficulties in accurately targeting intended beneficiaries. These contextual problems include: unemployment, poverty, grant generosity (relative to earnings) inherited from the apartheid welfare state and the HIV epidemic which has greatly escalated demand for the grant.

Significant and longstanding debates exist in the disability studies, medical and social policy literature about how disability and impairment should be conceptualised. Much of this debate has been around the extent to which disability should be treated as an embodied, individual and medical problem or a fluid and relational concept determined by the interaction between the person and their environment and therefore social problem and human rights issue (Swartz & Schneider, 2006: 234; Oliver, 1996; Shakespeare, 2006). Although these theoretical debates have not been fully resolved¹⁰, it is now generally accepted that disability is a complex, multidimensional concept and the presence of disability may vary between individuals based on socio-economic circumstances, culture, environmental conditions and personal characteristics (Altman, 2001).

Although understandings of disability have become more nuanced and inclusive over time, policy makers need to translate abstract ideas about disability and resolve how to define, operationalise and measure disability for administrative purposes. As no single definition of disability is feasible or desirable that will fit all purposes of assessment or all contexts, disability determination subject to ideological, technical and administrative challenges and disputes (Gooding & Marriott, 2009: 691; Hicks, 2001). The standards used to measure disability are therefore typically more a function of their particular purpose and the political,

¹⁰ I will not address these debates because this thesis is not concerned with normative ideas of how disability should be defined, but with how disability has been and is defined and operationalised as a category of 'need' in the welfare state and how this shapes the distribution of resources.

economic and social context in which they are used than some objective, bio-scientific framework or universal truth about what disability ‘is’ (Jette, 2002, Stone, 1984; Møller & Stone, 2013; Anner et al., 2013; Andrews et al., 2006)¹¹. For example, in South Africa there are different operational definitions of disability for workmen’s compensation claims, social grants, employment equity policy, and education policy. Whilst in education a more inclusive definition of disability is appropriate to identify children in need of additional support, when disability is used as a categorical targeting mechanism for social benefits and assessments have financial implications, the definition of disability has to be more limited in scope (Albrecht, 1992).

People with physical, mental, sensory and intellectual impairments face impairment-related as well as social, economic and environmental barriers to participation in the mainstream labour market. In recognition of these difficulties, many states provide welfare benefits to people with disabilities who cannot be suitably employed. Identifying who should qualify for these benefits is however difficult, and countries with more developed welfare systems than South Africa, with much greater capacity and resources for assessing disability claims, still struggle with inclusion and exclusion errors in determining eligibility for disability-targeted welfare programmes (OECD, 2010). These difficulties are not new and concerns about how to define impairment and disability and the tendency of disability programmes to grow, date back to the first implementation of social insurance programmes in Bismarck’s Germany in the 1880s and social assistance offered through poor relief systems in England (Priestley, 2010; Stone, 1984).

There are numerous reasons for this. Firstly, exempting certain groups from participating in the work-based system and providing them with social aid requires making normative decisions about who can legitimately access support from the state. Given the expectation that people will attempt to avoid work, liberal welfare states (Epsing-Anderson, 1990) such as the United Kingdom (on which the South African system was modelled), guard the boundaries of categories of entitlement to social aid to exclude the ‘undeserving’. This requires that operationalising disability with specific eligibility criteria and measurement tools that include the population it intends to target and excludes those who are not considering deserving (Meershoek et al., 2012). Disability assessment is used to manage the number of people who

¹¹ Concerns about growing disability welfare rolls in Europe and North America have driven welfare bureaucracies to reform their systems to actively encourage labour market participation (De Boer, 2010; Prinz and Thompson, 2009). As a result, disability benefits are increasingly tied to work reintegration efforts and assessment tools and eligibility criteria have been adjusted to focus on functionality and residual work capability and medical criteria and measures of work ability have been tightened (Kalisch et al., 1998; Matheson, 2003).

are able to claim benefits and to root out people seeking to misrepresent themselves as disabled in order to make illegitimate claims (Stone, 1984). As medical impairment is relatively easy to verify, it has remained the predominant underlying factor in disability determination (Robinson, 2004) and the medical expertise of doctors is highly valued in the assessment process.

Although it is not easy to make binary distinctions between the disabled and non-disabled because of the relational and contextual nature of disability, in the case of welfare programmes like the DG a decision has to be made whether a person does or does not qualify (Swartz & Schneider, 2006). There therefore needs to be a balance between the measurable attributes that make someone disabled (e.g. medical or functional), more relational factors such as the environment that affect functioning and participation and more pragmatic concerns such as cost (Jette 1999). There is no one set of medical or other standards for assessing disability for social protection purposes and there is significant overall variation in how different welfare regimes have constructed the disability label and have used it to target disability welfare programmes (Anner et al., 2013; De Boer, 2007)¹². Tests of disability vary in their specificity and restrictiveness and consider medical evidence, functional capacity, and personal and social aspects of disability to different degrees. Impairment thresholds, for instance, can shift over time based economic and political factors and in the face of financial pressure medical evidence can be used a rationing device (Bolderson et al., 2002; Millward, 2014).

Furthermore, for the purpose of establishing eligibility for disability pensions or social assistance programmes, disability is generally operationalised in terms of work or earning capacity rather than in terms of other areas of social participation. As the definition of ability to work changes over time in response to political and economic circumstances, so does the threshold for what we consider to be disabling (Priestly, 2009). The plasticity of employability and work capacity further muddles the process of sorting people into or out of the disabled category (Garsten and Jacobsson, 2013). Periods of economic downturn can make it more difficult for people with mild and moderate impairments to work and can lead to growth in disability programmes, as has been seen in Europe and North America (OECD, 2010; Prinz & Thompson, 2009; Autor & Duggan, 2001).

Despite these complexities, disability policy has received relatively little interest from social welfare scholars internationally and relatively few scholars (Albrecht, 1992; Skocpol, 1992;

¹² Although the World Health Organisations' International Classification of Functioning and Health (ICF) guidelines present an attempt to create an international standard of disability measurement, they have not yet been widely adopted as a standard for disability testing in social security programming internationally.

Stone, 1984; Mashaw, 1983; Kohrman, 2005) have studied bureaucracies that are linked to the rubric of disability and that do the work of constructing the disability category. Kohrman (2005: 3) calls these organisations “bio-bureaucracies” because they are undergirded by and promote a set of biologically oriented “ways of conceiving of and responding to normalcy and abnormality, health and pathology.”

These complexities are multiplied in the South African context. According to the Social Assistance Act of 2004, someone is eligible for a DG if “he or she is, owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance.” Disability itself is not defined in the Act and the lack of a proper definition means that it remains open to interpretation. Eligibility is also strongly tied to the capacity to earn income from work, which means that in DG administration a clear link has to be made between disability and employability without conflating the two concepts. This is extremely difficult to do. In his analysis of the American disability welfare system, Mashaw (1983: 53) argued that there are no clear lines between being unemployed, unemployable and disabled. In a context of high unemployment such as prevails in South Africa, where even able-bodied people struggle to find work, these distinctions are even more difficult to make.

Although officially the government policy in the form of the Integrated National Disability Strategy (1997) and Draft National Disability Rights Strategy (2014) supports and promotes a social understanding of and human rights approach to disability, these models were not designed for social protection purposes. The South African government has struggled to develop a multi-dimensional model for assessment that is affordable and practical and the DG system remains predominantly medically focused.

The positioning of the DG within the broader social policy environment also complicates its administration. South Africa is unusual among developing countries for having such an established and relatively generous programme for disabled people (Gooding & Marriot 2009). Social assistance targeted specifically at disabled people is more common in developed welfare states, where lower levels of unemployment and absolute poverty are present, and which have better systems of support for sick and disabled people and more extensive social insurance coverage for the unemployed. In South Africa, disability grant policy has shown strong path dependency and despite a number of failed attempts at reform, the eligibility criteria and assessment process have not changed significantly since the grant was first introduced through the Disability Grants Act of 1946 in a very different political and socio-economic

context¹³. The South African system was initially designed to cater to the white population and was modelled on the British welfare model that targeted specific categories of the ‘deserving’ poor. The deserving poor are typically categorised as those who are not expected to participate in the labour market and cannot be blamed for their poverty – such as children (and their mothers), disabled people and elderly people (van Oorschot, 2000)¹⁴. This system is premised on the notion of full-employment and given the realities of the current South African post-apartheid context where many people other people are jobless and poor, this targeting system excludes large numbers of the able-bodied, long-term unemployed (Natrass, 2006).

Although South Africa has an extensive social grant system in terms of beneficiary numbers and there has been some parametric reform (Seekings & Matisonn, 2010) and extension of the social grant system (in the cases of the Old Age Pension and Child Support Grant), the South African state has resisted introducing new social grants for either the chronically ill or the able-bodied unemployed¹⁵. Although contributory unemployment insurance exists in the form of the Unemployment Insurance Fund, this is very limited and does not include informal sector workers or those who have not been recently employed (Bhorat et al., 2013).

In this context the DG has been in high demand from people whom the grant is not intended to target. The only grant paid to and intended for adults of working age¹⁶, it is relatively generous compared to the CSG paid to caregivers of children (R330 per month¹⁷) and the boundaries of inclusion and exclusion are unclear. As a result, many poor people in South Africa, including those without disabilities, have seen claims of disablement as means to access to financial support¹⁸. Health and social workers have repeatedly reported that large numbers of people apply for the DG because they see it as a form of stable income, considering even minor ailments as an opportunity to apply for grants and re-applying repeatedly until successful

¹³ Grants for the blind were introduced earlier (1936) and were administered separately from DGs until the passing of the Social Assistance Act of 1992.

¹⁴ These categories are based in the ‘moral economy’ - a set of collective and normative shifting ideas about need, distributive justice and ‘deservingness’ – the degree to which a person deserves the assistance of others (Stone, 1984).

¹⁵ It has also been reticent to provide financial support to the long-term unemployed outside of its Extended Public Works Programs, which reaches only a small proportion of the over 26% people who are unemployed (Stats SA, Q1 2015).

¹⁶ The CSG is paid to adult caregivers but it is intended for the child

¹⁷ Other social grants are valued as follows: CSG (R330 per child), Old Age Pension (R1420), Care Dependency Grant (R1420), Foster Care Grant (R860).

¹⁸ The government also provides support to the disabled in the form of indigent relief for rates and services, access to free healthcare, rehabilitation and support services and special education and training services and employment.

(Steele, 2006; Kelly, 2012). Although the DG is set below the minimum wage it can pay more than informal sector work and is not significantly less than the minimum wage in a number of sectors including low paid domestic work (R2,065 per month) and minimum wage work in the agricultural sector (R2,520 per month), contract cleaning (R15.66 per hour) or work in the retail sector (R15.95 per hour) (DoL, 2015)¹⁹.

The DG was designed to target a specific, particularly vulnerable section of the population. However, without adequate social security options for the chronically ill and able-bodied unemployed, the grant has become in some measure a *de facto* chronic illness grant, and even a general poverty grant. In some communities, the DG has been called *igrant yokuhlupheka*, translated as “the grant for the poor people” (Delany et al., 2005; Steele, 2006; Hansen & Sait, 2012).

The HIV epidemic in South Africa has also introduced particular challenges in targeting the DG, which will be discussed in Chapter 2. Although not corroborated in systematic quantitative or qualitative studies, several studies report anecdotal evidence of some people intentionally infecting themselves with TB or HIV/AIDS and some TB and HI/AIDS infected people being reluctant to take medication that will restore their health and make them non-eligible for the DG (Delany et al., 2005; Leclerc-Madlala, 2006; Natrass, 2006; Hardy & Richter, 2006; De Paoli et al., 2010; 2012; Woolgar, 2014)²⁰. This has been characterised as a “bizarre sickness-poverty trap” (Standing, 2008: 22). This also applies to other chronic diseases such as epilepsy (Segar, 1992), diabetes and hypertension.

Disabled people often have special resources dedicated to them to help them find work, to cover the additional costs they face or in the case of the DG, to compensate them for not being able to work. Disability therefore becomes a desirable category because it has the potential to offer some kind of social and economic inclusion. As I have argued elsewhere (Kelly, 2012), the disability assessment provides marginalised citizens access to a kind of “biological citizenship” (Petryna, 2002). Being disabled becomes a form of social advantage or a resource, creating a divisive, triage-based access to economic resources that can create conflict within communities.”²¹ These dynamics around the grant have provided fuel for the debate around the

¹⁹ These low wage workers may also spend a significant portion of their income travelling to work.

²⁰ Woolgar (2014) found that some respondents in her study had stopped taking ARVs to receive the grant but became so sick that they resumed taking them. However, this did not appear to be a common strategy.

²¹ Kolofanos (2010) terms this “biosociopathy”. This is an adaptation of Paul Rabinow’s (1992) concept of “biosociality” – a sense of collective identity that forms around biological categories. Kolofanos (2010) applies the

limitations of a social security system that excludes the majority of the unemployed and the need for a Basic Income Grant or Chronic Illness Grant, which I will also discuss in Chapter 2.

The state relies heavily on the cooperation of doctors to ensure that only appropriate claimants are able to receive DGs. Although SASSA, which is responsible for administering social grants, makes the final decision on DG applications based on a person's income and assets, doctors' medical assessments are the most significant factor in determining eligibility. Despite SASSA's emphasis on a medical model, disability can seldom be determined by medical diagnosis alone. Although in principle doctors should consult with other professionals (e.g. occupational therapists, vocational specialists or medical social workers) on non-medical aspects of assessments, the system is not geared for this. Both the health and SASSA system lack the capacity to properly investigate functional capacity and the more relational and contextual aspects of disability such as psychological, socio-economic and environmental factors. This means that doctors are left making decisions on employability based either entirely on a medical model or based on their own assumptions about the non-medical aspects of disability.

The ambiguity of the disability category, the amount of discretion that doctors have in carrying out assessments, and the lack of thorough professional training in disability assessment amongst doctors has opened up space for DG assessors to insert their own understandings of disability and deservingness into the assessment process. This implies that access to DG depends not only on the rules defined in legislation and regulations, but on doctors' interpretation and application of SASSA's medical guidelines to individual patients, which can be influenced by non-Weberian (i.e. subjective) factors and logics that undermine bureaucratic ideals (Lipsky, 2010; Keiser, 2010; Dubois, 2010; Prottas, 1979; Hasenfeld, 2000, 2010). These discretionary decisions are important because they have implications for how state resources are allocated. Although doctors have been criticised for many years by policy makers, social security administrators and academics for providing subjective and arbitrary assessments, existing studies on DG have not focused sufficiently on the nature of these subjectivities and how they influence the distribution of social benefits (Delany et al., 2005; Steele, 2006; MacGregor, 2006; Govender & Miji, 2009; Jelsma et al., 2008; Tumbo, 2008; Segar, 1994; Baron; 1992; Graham et al., 2010). By observing disability assessments and interviewing doctors about their work, this study aims to contribute to understanding the challenges doctors

concept of biosociopathy to the competition for food aid in Mozambique, where HIV positive status becomes a resource and means to access material benefits.

face in disability assessment and what motivates their decision-making.

1.3 Street-level bureaucrats

As the previous section has shown, doctors have played an important role in the DG system through their gatekeeping role in disability assessments. This thesis builds on the foundations of street-level bureaucracy theory to unpack and explain their decision-making and how their actions in the context of DG assessments shape policy implementation. Doctors are positioned as street-level bureaucrats to the extent that they work at the interface between citizens and the state and have an important role in the allocation of state benefits and are subject to the bureaucratic constraints and regulations of social security and health policy.

Street-level bureaucracy research is grounded in a theory of policy implementation that considers frontline state workers and the point of service delivery as key to understanding how policy works (Brodkin, 2003). The seminal works of Protass (1979) and Lipsky (2010²²) first introduced the idea that frontline public service workers form a part of the policy-making process due to their discretionary ability to apply policy in different ways through their daily practices at the ground level. Lipsky first called these workers “street level bureaucrats” and included a wide range of professional, semi-professional and white collar public service workers in this category. Somewhat confusingly, Lipsky described all street-level bureaucrats as “professionals”, which Evans (2010, 2011) argues glosses over the differences between white collar workers and those who would typically be considered professionals in a narrower sense (e.g. doctors). Although Lipsky’s intention was to focus on the common experiences of frontline work, Evans suggests that differences in occupational status are in fact important, reasoning that the idea that professionals (in the narrow sense) have discretion is fairly obvious. In this thesis I work with the narrower definition of professional, namely, the professional as someone belonging to an occupational with recognised professional status (Freidson, 1994).

Street-level bureaucrats translate policy into practice through their everyday interpretation and application of procedures, rules, laws and policies, often in ways that make their difficult work easier. The work of street-level bureaucrats draws our attention to how professional knowledge and experience is put into action through practical reasoning processes. It also, as Rowe (2012: 15) notes, “takes us further, to the context-dependent ethics of public service (the *phronesis*)”.

Lipsky (2010) argued that street-level bureaucrats effectively create policy through the ways in

²² Originally published in 1980.

which they exercise agency as they interpret policy and process and categorise clients in their daily work. The body of literature that has emerged around this concept focuses primarily on the tensions between the norms and goals of street-level organisations, the professional and individual values and goals of frontline workers, and broader policy goals and what this means for how policy is enacted (see Brodtkin, 2012, 2013; Dubois, 2010; Maynard-Moody & Musheno, 2003; 2012; Jewell, 2007; Møller & Stone, 2013; Harrits & Møller, 2013; Soss & Keiser, 2006; Soss, 1999; Rice, 2012).

The theory of bureaucratic action put forward by scholars of street-level bureaucracy directly challenges rational-agent models of bureaucracy and theories of the policy-making process based on the notion that policy can be controlled from the top. Top-down theories of policy implementation (Pressman & Wildavsky, 1973; Sabatier & Mazmanian, 1980; Hood, 1976; Bardach, 1977), which first emerged in the 1970s, looked to the Weberian ideal of rational, hierarchically structured bureaucracy as the best way to achieve policy goals. The ideal Weberian bureaucracy is one run by neutral, rational technocrats, who carry out their work in a detached and uniform manner - “*sine ira et studio*” – without hatred, passion, love and enthusiasm. Their work is managed through codified rules and processes that ensure that policy implementation on the ground takes place as policy makers at the top conceived it. Recognising that policy is not always implemented as intended, top-down theorists have attributed policy goal failures to deviations from the ideal rational model caused by principal-agent problems (e.g. shirking or sabotage) that are created by asymmetries between governments (principals) and bureaucratic agents. They have offered solutions promoting greater bureaucratic compliance and control through managerial procedures and rules (Sabatier & Mazmanian, Hood, 1980).²³

On the other hand, bottom-up theorists, like Lipsky, opposed the notion of the ideal rational bureaucrat and the idea that implementation can be controlled from above through hierarchical compliance models. Rather than glossing over ambiguities and indeterminate aspects of policy, Lipsky and others (Hjern & Hull, 1982) started to explore what happens in the grey spaces between policy and practice (Brodtkin, 2003). Instead of treating street-level divergence as a function of the principal-agent problem, where self-interested bureaucrats take advantage of information asymmetries for their own benefit, Lipsky and others have argued that workers

²³ Principal-agent theory is based on the idea that asymmetries in information held by principals and agents incentivise deviations in policy implementation because agents act in their self-interest.

(agents) may just be employing “coping mechanisms” in response to environmental conditions, for instance, high demand for their time or the complexity of decisions they are faced with making. Although the concept of street-level bureaucracy emerged in and has been most commonly applied in Northern countries, its focus on the role of discretion and hence motives that underlie the decisional aspects of frontline work, provides an important frame for understanding the ‘problems’ that seem to interfere persistently with policy implementation in South African bureaucracies.

In his original exposition of the street-level bureaucrat concept, Lipsky (2010) used teachers, police officers and other law enforcement personnel, social workers, judges, public lawyers and other court officers and health workers (including doctors) as examples of street-level bureaucrats. Since then the street-level bureaucracy concept has been elaborated, extended and applied in a wide range of disciplines in a wide variety of different government programmes and services. Some examples include studies of caseworkers in welfare benefit and work activation programmes (Sandfort, 2000; Jewell, 2007; Soss, 1999; Watkins-Hayes, 2009), disability and illness benefit determination by welfare case workers (Møller & Stone, 2013; Gulland, 2011; Marston, 2013; Keiser, 1999, 2003), the gatekeeping and healthcare policy implementation work of nurses and doctors (Allen et al., 2004; Checkland et al., 2004), the work of teachers (Maynard-moody & Musheno, 2003), social workers in various social programmes (Evans, 2010; 2011; Sherz, 2011; Halliday, 2009), immigration work (Heyman, 1995, 2001), and legal and criminal justice work (Barnes & Prior, 2009). Despite differences in focus, these studies are all grounded in the idea that the agency of frontline workers and their interactions with clients are vital to understanding how policy is ‘made’ in practice (Maynard-Moody & Portillo, 2010; Rowe, 2012). Arguably, the actions of street-level workers are not always consistent or coherent enough to *build* policy– for the most part their actions are individualised and context-specific and the patterns that emerge in street-level settings may not necessarily ‘add up’ to policy, although it may influence it (Maynard-moody & Musheno, 2000, 2003).

There is now an extensive literature focused on the frontline public service workers who make the daily decisions about “who gets what, when and how” (Laswell, 1936) in European and North American welfare states. However, the role of frontline workers, how they interact with welfare claimants and make decisions about eligibility is understudied in Africa. In general, there have significantly fewer studies of how frontline public service workers contribute to how

policy is realised on the ground in developing countries. There is however growing interest in developing an *emic* or ‘insider’ perspective of African bureaucracies and using ethnography to explore the gap between official norms and rules and the behaviour of workers within them (Hoag, 2010; Bierschenk, 2010; Bierschenk and de Sardan, 2014; de Sardan, 2005, 2015; Blundo, 2006). In South Africa this has included studies of officials at the Department of Home Affairs (Hoag, 2010, 2014; Segatti et al. 2012), nurses (Le Marcis & Grard, 2015; Harrison, 2000) and nurses and doctors (Gibson, 2004) and policeman (Steinberg, 2008; Marks, 2004, 2005; Altbeker, 2005). There are a small number of studies that have applied the street-level bureaucracy concept more directly. These include studies of teachers in South Africa (Mutereko & Chitakunye, 2015) and nurses in South Africa (Walker & Gilson, 2004), Ghana (Ageypong & Nagai, 2011) and Kenya (Kaler & Watkins, 2001). There is also growing interest in the more general design and functioning of South African state bureaucracies, institutional dynamics and bureaucratic structures (Chipkin, 2011; Chipkin & Lipietz, 2012; Von Holdt, 2010), including public hospitals (Von Holdt & Maseramule, 2005; Von Holdt & Murphy 2007; McIntyre & Klugman, 2003) and the social grant system (Vally, 2014; Donovan, 2015). As this diversity of studies shows, the ‘street-level’ category is broad and inclusive. However, not all state workers can be considered street-level bureaucrats. Street-level bureaucrats are characterised by their **direct (frontline) interaction** with the public and the **high degree of discretion and autonomy** that they have in practically applying the benefits and sanctions of institutions to citizens (Maynard-Moody & Portillo, 2010)²⁴. They are linked by their common experience of working in resource-constrained settings where they have to make complex decisions quickly, with limited information and time.

Street-level bureaucrats generally also have significant autonomy in their work because their interactions with clients and citizens often take place in spaces where it is difficult to observe and monitor their performance: in schools and clinics, on the streets or in private consultations. Frontline workers have discretion because the complex, interpretive and situated nature of their work means they need some flexibility in how they respond to clients. Policy-makers (in the legislature or executive) cannot provide rules for every experience and every interaction between frontline staff and clients. At the organisational level, rules and goals are often ambiguous and even guidelines and rules that are designed to channel decision-making can be

²⁴ Front-office postal service workers (for example) interact with ‘clients’ on a daily basis, but their activities are highly routinised and they have little autonomy in their roles. There are of course also bureaucrats who never interact with clients.

open to interpretation (Sandfort, 2000). Møller & Stone (2013: 601) argue that “rules are abstract thinking that must be converted into meaningful actions” and that in this process street-level bureaucrats must reconcile policy norms with their prior beliefs and moral judgements as well as their own interests. Their ability to exercise discretion in their direct interactions with clients, whose engagement with bureaucracies is often non-voluntary, gives them significant power and the daily decisions they make affect citizens’ lives and their relationships with the state (Lipsky, 2010). This does not mean that street-level bureaucrats use their discretion all the time. In other words, they “do not do just what they want or just what they are told to want. They do what they can.” (Brodin, 1997: 24)

The outcomes of discretion are most visible in gatekeeping work that involves classifying people in ways that allows or denies people access to certain benefits, such as welfare or immigration service work (Heyman, 2001) or in social service case work (Scherz, 2011). However, discretion that is exercised in less observable ways can have equally large impacts on how resources are allocated or how policy is (or is not) implemented. One particularly relevant case put forward by Lipsky is of doctors working in the Veterans Administration (VA) hospital system in the United States in the 1970s. At the time VA hospitals did not offer outpatient services and feeling that this was an important aspect of care, doctors began to place patients in the “pre-bedcare” category. Patients in this category were allowed to receive medical services prior to admission. Placing patients in this category, but never actually admitting them, allowed doctors to informally offer outpatient care.

As the exercise of discretion can undermine policy intentions and lead to unequal treatment of clients and citizens, street-level bureaucracies typically aim to rationalise and standardise the decision-making of frontline worker by promoting accountability and constraining bureaucratic discretion. Some writers (most notably Howe, 1991) have argued that rising managerialism in the public services (what is referred to as New Public Management) in Europe and the United States and the increasingly intense control of frontline worker performance have significantly curtailed professional discretion and made Lipsky’s work irrelevant (Evans & Harris, 2004). However, Lipsky’s original work is sceptical about managerial control, arguing that reforms and complex protocols and rules can create confusion and require the use of more discretion or simply re-locate discretion. This has been shown to be the case in recent empirical studies, which have demonstrated that despite increased managerialism, discretion continues to be a significant factor in public administration and it can be very difficult for managers to change the way that street-level bureaucrats carry out their work (Ricucci, 2005). In South Africa,

Hoag's (2013) study of the Department of Home Affairs showed how managerial instructions and reporting requirements were treated with suspicion and often ignored by bureaucrats weary of the increasing and frequently changing demands on their time. Hoag (2014: 414) also argues that "rules can never be enforced enough, nor specific enough to direct action in context with precision, meaning that bureaucrats' interpretations are integral to their work – not a deviation from it."

Eliminating discretion is also not desirable as the ability of street-level bureaucrats to respond to individual circumstances is important and valued by citizens who can become trapped in the "iron cage" of inflexible bureaucracy. Dworkin (1978), Mashaw (1983), Evans (2010) and Maynard-Moody and Portillo (2010) therefore argue against dichotomising discretion and rule-based systems and instead focus on how discretion is nested within rule-based systems, treating control and autonomy as a "complex dialectic" (Brodkin, 2013: 946). In more recent work Maynard-Moody and Musheno (2012, 2015) have called for abandoning the "implementation-control-discretion narrative" that has been a primary concern in implementation studies in favour of focusing on agency and how frontline workers express their agency and make meaning in their work through pragmatic improvisation within the structure of laws, roles, institutions and practices.

No single factor or theory can fully explain the exercise of street-level discretion, which is rather shaped by a complicated set of overlapping and contradicting factors arising in the course of implementation. These factors can be broadly grouped as: 1) the organisational and regulatory environment that street-level bureaucrats work in; 2) their individual interests, personal norms, values and biases; 3) their professional norms and values; 4) the dynamics of their face-to-face interactions with clients; and 5) the socio-economic systems and institutions in which both they and clients are embedded (Meyers & Vorsanger, 2007). Whilst the first two groups have been well studied, the latter three have not been, but are of growing interest in the field. Using the concept of framing, this study shows how, in the case of disability grant assessments, these factors combine to pattern decision-making.

Street-level bureaucrats are often responsible for allocating state resources and implicit in their decisions are implicit or explicit conceptions about some categories of people 'deserving' state services whilst others do not. Lipsky (2010) argued that they use their discretion to simplify their work in response to environmental conditions. They do so by developing their own rules of practice and choosing to ignore or privilege policy directives depending on what makes the most practical 'sense'. When used systematically, their discretion and the unwritten rules they

develop in their daily practice become informal policies (Brodkin, 2012).

In order to manage large numbers of clients and ration access to services and benefits, street-level bureaucrats need to create patterns of simplification for processing information and categorising clients according to administrative categories. These simplifications can be both formal (e.g. triage in healthcare) and informal, based on personal biases and decisions on moral worthiness. Olivier de Sardan (2015) in his work on bureaucracies on the African continent refers to these informal and tacit rules of the game as “practical norms”. These routinised simplifications can lead to the institutionalisation of stereotypical tendencies that result in street-level bureaucrats treating different categories of people in different ways (Lipsky, 2010).

A number of South African cases provide useful examples of how organisational context and bureaucratic action shapes the way in which public services are delivered. Hoag’s (2010: 18) ethnographic study of the Department of Home Affairs (DHA) demonstrated that bureaucrats developed their own “systems of meaning”, as well as unofficial processes and ‘metacodes’ of conduct to stabilise their work environment. This context was characterised by poor communication, supervision and training and arbitrary and incoherent policy directives from above, where frontline staff needed to manage time constraints and cope with a public whom they deemed as untrustworthy and likely to ‘abuse’ the DHA system. He argued that the unsanctioned processes they employed made the DHA bureaucracy illegible to the public. Walker and Gilson (2004) explored the role of nurses as street-level bureaucrats, finding that negative effects of free healthcare on healthcare personnel workloads, attitudes and morale led to moralising and blaming of patients. A number of studies on policing work in South Africa also show how police officers’ discretionary decision-making is strongly influenced by both organisational and environmental factors (Steinberg, 2008; Marks, 2004, 2005; Altbeker, 2005).

Although Lipsky focused predominantly on the coping mechanisms used by street-level bureaucrats to secure their own survival within organisations, others have since highlighted the importance of the personal and professional identity and ethics of street-level bureaucrats in shaping their behaviour (Maynard-Moody & Musheno, 2003; Dubois, 2010; Evans, 2010; Eikenaar, 2015). As Walker (1993:151-152) argues, “street-level decisions and actions are guided less by rules, training, or procedures and more by beliefs and norms, especially beliefs and norms about what is fair.” Based on the stories told by frontline workers, Maynard-Moody and Musheno (2003) argue that street-level bureaucrats see themselves as citizen-agents rather than a part of state machinery (state-agents) and that they work with other citizens on an

individual basis, based on ideas about the 'right' thing to do rather than their own self-interest.

Before concluding this discussion on street-level bureaucracy, I will briefly highlight three gaps in the literature to which this thesis contributes. Lipsky included professionals who work within rule-bound situations in the street-level bureaucrat category, but paid little attention to the role of professional status, in structuring and informing discretionary practices. (Evans, 2010; Hupe, 2007). Much of the empirical research on street-level bureaucrats has focused largely on non-professional groups like welfare workers (Evans, 2010) and by focusing on doctors, this thesis makes an empirical contribution to our understanding of the work of more professionalised groups, who have more discretion and may associate more strongly with a set of professional values and norms than bureaucratic rules.

Although the fact that frontline workers come face-to-face with citizens is a crucial part of the street-level bureaucracy concept, the dynamics of how bureaucrats and citizens communicate and relate to one another in these encounters have not been well studied (Bartels, 2013). It is important to look at the performative, interactive aspects of street-level encounters, both because the nature of these interactions shape decision-making, and because it highlights the agency of citizens and the role that citizens play in shaping policy implementation. This has largely been neglected in international studies of street-level work (see Barnes & Prior (2009) and Dubois (2010) for some exceptions.) This is also the case in the South African literature, although Steinberg (2008) does show that South African policemen may avoid situations and interactions where their authority is likely to be challenged.

While the concept of street-level bureaucracy has proved useful as a micro-level concept that reveals aspects of policy implementation that are hidden by a top-down approach, few efforts have been made to link street-level work to wider systemic, organisational, institutional factors and other parts of the policy process. For example, there are few studies on how street-level bureaucratic action and its divergence from official policy in particular, is interpreted higher-up the policy formation and bureaucratic hierarchy, and how this shapes further policy-making (Gofen, 2014; Moynihan & Soss, 2014). While the scholarship on policy feedback suggests that a dialogical relationship exists between politics, policy and administration (at the street-level) and that policy outcomes shape future policy development (Pierson, 1993, 2003; Skocpol, 1992; Soss et al., 2007), the vagaries of how and to what extent such dialogue indeed occurs, likely differs by policy domain and circumstance.

1.4 Medical gatekeeping and decision-making

Whilst the street-level bureaucracy concept is useful in structuring my analysis, its very broad focus does not capture some of the particular complexities and moral tensions attached to medical decision-making that have been written about in the sociological literature on medicine. As high-status professionals with considerable professional power and expert knowledge, doctors have more discretion and expect more autonomy than many other types of frontline workers. They are also more likely to resist outside control (Freidson, 2001) and their work is harder to manage through rules and managerial tactics. Whilst there is a degree of uncertainty and interpretation in decision-making in all street-level work, this is particularly pronounced in all medical decision-making, including treatment and diagnostic decisions, as well as the gatekeeping work that I focus on in this thesis.

Doctors routinely make decisions on how to allocate health resources to the public, using both their professional knowledge and guided by national health policy and organisational policies. As intermediaries between the state and its new citizens, health care institutions have historically been a crucial yet understudied site in which conceptions about cultural difference and ‘deservingness’ of public benefits are elaborated and deployed (Horton, 2004). The gatekeeping or rationing work of doctors in medical bureaucracies, both public and private, has been studied by medical ethicists and economists, but less by sociologists (Light & Hughes, 2001), who have focused on social categorisation in healthcare settings but have only recently connected this to micro-level rationing (Vassy, 2001).

Doctors decide when to provide and withhold treatment and to whom, often in life or death situations. There are a number of different reasons for gatekeeping in healthcare: ensuring patients receive appropriate care (neither too little nor over-treating), budget constraints and preventing overuse of the system (moral hazard) and justice in distributing care (need to ration care to avoid disadvantaging others) (Willems, 2001). One such gatekeeping mechanism is the referral system, which rations access to medical specialists. Patients are generally seen first by lower-level or more generalised care providers at what is known as the primary healthcare level and only if the health problem requires more specialist input or inpatient care will they be referred to a specialist. Admissions criteria to hospitals follow a similar logic. Another well-known example is triage – the principal of prioritising some patients over others based on the severity and urgency of their medical problem. Other forms of medical rationing include organ transplant lists (Elster, 1992), patient discharge policy (Dill, 1995) and determining who has entry into treatment programmes in settings where resources are limited and where specific

eligibility criteria have to be established to ration access, for instance TB treatment in India (Harper, 2005) and HIV treatment in South Africa (Human, 2011). Rationing can be explicit (as is the case with a list of treatments covered by a health insurance) or implicitly through healthcare workers' decisions (Schmidt, 2004) and can also take the form of treatment delays, less desirable treatment or denial of care (Vassy 2001).

Whilst the relationship between a doctor and a patient is often thought of as dyadic, it is actually mediated by multiple actors and contextual conditions, including organisational, regulatory and professional (May, 2007). Studies in the United States and Europe have shown that as doctors are co-opted into corporate and state healthcare structures, the role of doctors and the space of the clinical encounter have become increasingly regulated, standardised and dominated by evidence-based models of practice and protocols and service-oriented and rules and guidelines (May, 2007). In the process, doctors' professional discretion has been eroded (Moreira, 2005). This forms part of a general trend towards bureaucratising professional action and increasing accountability through rules and procedures (Berg et al., 2000; Freidson, 1994). As a result, physicians have become "agents for many masters as they try to meet the demands of patients, hospitals, utilisation review committees, insurance companies and government agencies" (Zinn & Furutani, 1996: 525). This bureaucratisation of medical practice in Europe, has led a number of scholars to position doctors as street-level bureaucrats, using street-level bureaucracy theory to explore the tensions between doctors' professional role and their institutional and legal responsibilities (McDonald, 2002; Checkland *et al.*, 2004; Meershoek et al., 2007; Eikenaar et al., 2015). These studies showed how doctors mediate between outside bureaucratic pressures to adhere to guidelines and their own daily professional practice and how they used existing processes and procedures to re-shape how and to whom services were provided. They also highlight how important professional expertise and socialisation are in shaping how doctors approach the rules and policy structures.

A crucial problem of medical gatekeeping work is that the logic of clinical judgement and cost-effectiveness, are radically different from the logic of justice (Willems, 2001: 26). There is a high degree of incommensurability in medical decision-making, and how to prioritise certain factors over others is not always clear. The practice of medicine therefore requires a degree of judgement or wisdom or *phronesis* (Montgomery, 2006). There is a literature on micro-rationing and resource allocation in healthcare which bears many similarities to the street-level bureaucracy literature (Allen, 2004; Mizrahi, 1985). These studies show that doctors' decisions on how to allocate their time and other resources or social benefits were influenced by similar

factors to those found in the street-level bureaucracy literature. They show how doctors often become caught in moral dilemmas and are required to juggle the principals of justice, economics and their individual obligation to the patient and reach some sort of equilibrium (Willems, 2001). More generally, the field of medical sociology has shown that medical decisions and resource-allocation in healthcare are not based solely on an objective clinical assessment, but are socially complex processes shaped by social and cultural context (Nurock, 2009: 504).

Doctors are ethically obliged to treat all patients equally and doctors aspire towards objectivity in how they approach patients, trying to 'separate' themselves from their biases. However, doctors are also human agents who also have the capacity for extreme bias and moral failure – clear examples of which include the racism of doctors in apartheid South Africa apartheid (most notably Wouter Basson, who developed chemical and biological weapons for the apartheid government) and doctors working for the Nazi regime.

In the South African healthcare system healthcare workers are overburdened and resources are limited and in this context clinicians have to make decisions that are not always ideal (Gibson, 2004). As a result, decisions have to be made as to who is more 'deserving' of support, which can lead to moralizing about certain categories of people (Le Marcis & Grard, 2015; Walker & Gilson, 2004; Fassin, 2008). Le Marcis and Grard's (2015) work in a public hospital in the midst of the AIDS epidemic showed that nurses' efforts to cope in this environment shaped the development of a set of practical norms and ethics that determined how patients were treated and the quality of care they received. Another South African study showed that healthcare workers also made decisions on the basis of who was most likely to comply with or benefit from treatment (Schneider, 2010). Mizrahi (1985) argued that doctors in the US developed a Getting Rid of Patients (GROP) mentality and in order to make quick decisions about how much energy to spend on patients, doctors placed patients into medical and moral categories. Those labelled self-abusers, system-abusers and troublesome or difficult patients received minimal attention. Studies of the medicalisation of deviance also illustrate how professionals create the 'problems' they own and treat, and they make moral judgments both in the technical language of the profession and in the language of popular moral meanings (Waitzkin, 1991; Schneider, 1985).

As well as their gatekeeping work within the health system, doctors also play a gatekeeping role for welfare and private insurance, deciding who has access to sickness and disability benefits. However, theoretical and empirical work on the sociology of doctors' work, medical

knowledge and medical encounters has typically focused on therapeutic medical encounters. The role of doctors as third-party assessors and gatekeepers in social security medicine (disability and illness benefits) and the doctor-patient relationships that form around non-therapeutic medical assessments has not been well-studied or theorised (Meershoek et al., 2007).

There is a small cross-disciplinary social science literature focused on decision-making in social insurance and occupational health medicine that focuses on the application of medical knowledge within bureaucratic frameworks internationally (Berg et al., 2000; Dodier, 1994; 1998; Meershoek et al., 2007; Wilde, 2014; Eikenaar et al., 2015; Meershoek et al., 2012; Stone, 1979, 1984; Mashaw, 1983; Wainwright et al., 2015; Cheraghi-Sohi and Calnan, 2013)²⁵. This research has also shown the conflict that physicians experience in their simultaneous roles of patient advocate, physician and medical expert in gatekeeping access to these benefits and how they struggle to determine whose interests they should be protecting or promoting (Wynne-Jones et al., 2010). There has also been limited exploration of doctors' views on DGs in South Africa by anthropologists (MacGregor, 2006; Segar, 1994) and medical doctors themselves (Baron, 1992; Tumbo, 2008). These studies recognised the subjectivity of DG assessments and highlighted the difficulties and frustrations that doctors experienced in dealing with patients seeking grants and in conducting assessments.

1.5 Research methodology and design

As this review of the literature has shown, problems in fairly allocating welfare or health resources or targeting social programmes are very often located in the spaces where citizens interact directly with state workers. Hypothesising that this also the case with the DG, the methodological approach taken to this research is qualitative and interpretive, driven by a desire to attend to the situated and interactional nature of the DG application process and the relationships between the actors involved in the implementation of DG policy: SASSA, medical doctors and those seeking DG benefits.

This research is divided into two parts: 1) the history and politics of DG policy making; and 2) the implementation of DG policy by provincial SASSA staff and local healthcare workers. The

²⁵ Most studies concerned with the gatekeeping and role of doctors in social insurance medicine and sickness benefits care found in the health sciences literatures (Wynn-Jones et al., 2010; Overland et al., 2008; Steenbeek, 2011; Schellart et al. 2011; Ydreborg *et al.*, 2007; Werner et al., 2012; Slebus, 2007; Soklaridis, 2011).

first component, largely presented in Chapter 2, traces the development of DG policy in post-apartheid South Africa and how this was tied to the politics of administration and discourses around who ‘deserved’ state benefits. This analysis was based on existing literature and primary data sources, which included: reports and documents from the Department of Social Development (since 1990) and SASSA (since 2006); DG legislation since 1946, when the grant was first introduced; minutes from meetings of the Parliamentary Portfolio Committee on Social Development (previously, Welfare and Population); and the record (Hansard) of debates in the National Assembly since 1998 (when they are first available online). Key-informant interviews were also conducted with government officials from the Department of Social Development, SASSA and the Department of Health, as well as with disability experts working in the non-profit sector and academia (list of interviews can be found in Appendix B).

The second component of this research entailed a study of the everyday work of administering DGs. Given that I intended to study the implementation of DG policy from the bottom-up, an ethnographic approach seemed most appropriate. As a non-medical person, with limited knowledge of inner-workings of the healthcare or SASSA bureaucracies, the only way I could possibly imagine understanding the context in which assessments took place was to physically observe them myself. This is not uncommon in studies of street-level bureaucracy, which are very much focused on the daily realities of organisations and the interactions and relationships between bureaucrats and their clients. This complexity is not easily captured through quantitative methods and many of these studies are explicitly ethnographic or use a mixture of in-depth interviewing and directly observing frontline workers at work on the streets, in cop cars and ambulances, medical wards, behind desks in offices or in clients’ homes.²⁶

Direct observation is useful in understanding the gaps between policy design and practice and for unpacking the “black box” of policy implementation by exposing the material effects of policies and revealing their unforeseen and unintended consequences (McKee, 2009). “In doing so it aims to reveal the messiness and complexity involved in the struggles around subjectivity, and offer a more nuanced and finely grained analysis of governing *in situ*.” (McKee 2009: 479). There are a number of excellent ethnographies of frontline workers in welfare and immigration bureaucracies in Europe and the United States (Dubois, 2010; Hays, 2003; Tickin,

²⁶ There are some scholars (Keiser, 2010; Tummers & Beckers, 2012; Riccucci, 2005; Brodtkin & Majmundar, 2010; May and Winter, 2009) engaged in research on street-level bureaucracy who have used quantitative methods to develop and test theories of decision-making and relationships between discretion and street-level behaviour. Although arguably there is a need to test more of the tenets of theory and effects of street discretion (Tummers and Beckers, 2012), qualitative methods seemed most appropriate in answering my specific set of research questions.

2006; Fassin, 2005; Heyman, 1995, 2001) as well as a growing number of ethnographies of developing country bureaucracies (Gupta, 2012; Hoag, 2010; Bierschenk, 2008, 2009; Olivier de Sardan, 2008; Fuller & Bénei, 2000; Von Holdt & Maseramule, 2005).

Narrative analysis is an approach that can be usefully combined with direct observation to understand the motives that underlie street-level action (Ospina & Dodge, 2005; Borins, 2011, Møller & Stone, 2013). An excellent example and detailed account of this approach is presented in Maynard-Moody and Musheno's (2003) book *Cops, teachers, counsellors: Stories from the front lines of public service*. In addition to observational work, researchers in this study asked frontline-workers to develop written stories which then became the basis for further in-depth interviews. This allowed the authors not only to observe workers in action but to understand how they made meaning of their interactions with clients. Although not capturing doctors' stories as formally, I paid attention in my analysis to how doctors constructed meaning and framed their interactions with claimants through narrative.

Although they may act as street-level bureaucrats in the case of DGs, doctors are first and foremost medical professionals and the particularities of the medical setting also needed to be considered in my approach. Participant observation has also been extensively used by medical sociologists and anthropologists to understand social life within clinical settings and studies on disability, chronic and terminal illness, and medical ethics and decision-making have relied heavily on ethnographic methods (Charmaz & Olesen, 1997; Kohrman, 2012).

Three ethnographies, Goffman's *Asylums* (1961), based on participant observational work in mental asylums, Roth's (1963) ethnography of patients' negotiations of treatment regimes in TB sanatoriums and Strong's (1979) documentation of the relationships between doctors and patients in paediatric consultations have become classic sociological studies.²⁷

There have been a number of studies of healthcare workers in South Africa that employ an ethnographic approach: Fassin (2001, 2008, 2009), Le Marcis (2014), Le Marcis and Gard (2015), Gilson (2004) and Human (2011). Macgregor (2006) and Segar (1994) both studied doctor-patient relationships in the context of the DG using an ethnographic approach. Although there is not a large sociological literature on medical decision-making in social security medicine specifically, existing studies have used either interviews with doctors (Waingwright

²⁷ Other notable medical ethnographies include Glaser and Strauss's (1965, 1968, 1975) works on chronic illness and palliative care, Atkinson's (1995) study of medical knowledge construction amongst haematologists and Mol's (2002) study of the multiplicity of medical practice based on observations of the daily work of diagnosing and treating atherosclerosis.

et al., 2015; Wynne-Jones et al., 2010; Eikenaar, 2015) or a combination of these with direct observation of encounters between doctors and claimants (Meershoek et al., 2007; Macgregor, 2006; Dodier, 1994, 1998). Medical studies of decision-making in social security medicine typically have taken a more quantitative approach, using surveys or asked multiple doctors to assess the same patient's case, asking them to explain the reasons for their decision-making and quantifying the results (Zinn & Furutani, 1996; Soklaridis, 2011; Baron, 1992). While useful for comparative purposes (these studies showed significant variations in doctors' decision-making), these studies do not capture a key aspect of decision-making – the interaction between claimants and doctors.

There is also a large medical literature on doctor-patient and nurse-patient interactions (see Ong et al., 1995; Waitzkin, 1984; Roter & Hall, 2006; Casey, 2004; Ventres et al., 2005) that uses the observation or the recording of doctor-patient interactions as a method to understand the formation of (or lack of) inter-personal relationships between doctors and patients, information sharing and medical decision-making. Many of these studies focus on process, quantifying doctor-patient interactions through coding, operationalising and measuring and predicting behaviour and communication in relation to socio-demographic, psychosocial, appearance and health factors (Ong, 1995; Clark et al., 1991). This overlooks not only the content of the interaction, but the complexities of the broader context in which doctor-patient interactions occur. Conversation analysis, which pulls apart and analyses the structure of 'talk' between doctors and patients has also become a popular method of examining doctor-patient communication (Heritage and Maynard, 2006). It seeks to bridge the problems of quantifying the doctor-patient interaction and the problems with ethnographic approaches. Although this approach is valuable, it requires videotaping or audio-recording doctor-patient interactions which was not feasible in this study²⁸. Besides, my main intention was to understand the decision-making of doctors. Analysing the conversation between doctors and patients would not shed more light on this than talking to doctors about their decisions as they made them, and was determined to be a more useful approach for this study.

²⁸ The feasibility of recording or videotaping interactions was discussed during my PhD proposal presentation to the Sociology Department, both as a way to reduce the influence that my presence as a researcher might have on the interaction and to more fully-capture the nuances of interactions. However, given the legal aspects of disability grant assessment, I suspected that both patients and doctors would be warier of having very sensitive conversations recorded than of having me in the room taking notes.

1.5.1 Data Collection

Data collection was carried out over a period of eleven months in the Western Cape Province of South Africa. The first phase of data collection was focused on understanding the structure and operations of the DG system in the Western Cape Province. Information on SASSA's operational structures and processes was provided by the Disability Management Unit at SASSA's regional office who helpfully shared documents, medical guidelines and management statistics, and answered my detailed questions over on SASSA's management processes and allowed me to observe two medical assessment training sessions run by SASSA staff. I also interviewed staff from the Disability Management Unit at SASSA's regional office and the medical doctor who worked as SASSA's quality assurance officer in the Western Cape, conducting audits on the forms completed by other doctors.

The Western Cape SASSA branch utilises the Department of Health's facilities to conduct DG assessments. These facilities therefore became the site of the observations, interviews and focus groups conducted for this study. The Western Cape Department of Health provides services to the 78% of the population who are uninsured and likely to use public health services, in six districts – Cape Town Metro, Cape Winelands, West Coast, Overberg, Eden and 32 sub-districts in the province (DoH, 2015). Healthcare services in the City of Cape Town are managed by both the City of Cape Town and the Metro District Health Services (MDHS) of the Western Cape Department of Health. The metro district is divided into the eight districts: the Northern, Tygerberg, Western, Southern, Mitchell's Plain, Klipfontein, Khayelitsha and Eastern districts, which are managed by four sub-structure offices. Primary healthcare (PHC) is provided at community health centres and clinics, more specialised and in-patient care is provided by secondary and district-level hospitals, and quaternary and tertiary care is provided at three large teaching hospitals²⁹.

The state of the health services in the Western Cape is considerably better than in many other provinces in terms of staff to patient ratios, the number of facilities available and the conditions of these facilities, but the system still faces considerable pressure from the high burden of infectious diseases, non-communicable disease, traumatic and violent injuries and maternal, perinatal and nutritional problems (DoH, 2014). HIV/AIDS and tuberculosis are the two leading causes of death in the province (Groenewald et al., 2013) and the Western Cape has the

²⁹ In 2014, there were 280 PHC facilities across the Province. At the secondary level, there were 34 district hospitals, five regional hospitals, four psychiatric hospitals and two sub-acute psychiatric centres as well as six specialised TB hospitals and one specialised rehabilitation services centre.

third highest rate of TB infection in country with 746 cases annually reported per 100 000 people (DoH, 2014).

At the time of fieldwork, DG assessments in the Western Cape were conducted at all levels of the healthcare system by both treating doctors (in hospitals) and dedicated SASSA assessors (in community clinics). At the PHC level I worked in twelve different community clinics: eight from the Cape Town Metro district and four clinics in two rural health districts in the Winelands (3) and West Coast (1) regions of the province. In Cape Town, I selected clinics from each of four Cape Town Metro health district substructures, covering seven of the eight sub-districts. There remain large socio-economic and racial divisions in the Cape Town population and attempting to maximise geographic variation when selecting clinics allowed me to observe doctors working with patients from different racial and class groups. In order to preserve the anonymity of the doctors and claimants I worked with, I have used pseudonyms throughout this study (including for the names of health facilities).

I also conducted fieldwork at three different hospitals: a tertiary hospital (Whitney Hospital), a district hospital (Welgemoed Hospital) and a psychiatric hospital (De Waal Hospital). I have also used pseudonyms to refer to these facilities. Within hospitals I attempted to work across a range of medical disciplines and worked with the departments of cardiology, neurology, neurosurgery, orthopaedics, psychiatry and infectious diseases, which generally received larger numbers of DG requests. Data on healthcare worker's role in the assessment process was collected through observational work in clinics and hospitals; in-depth interviews with doctors, occupational therapists and social workers; and focus groups composed of nurses and social workers. Interview questions for doctors were not standardised and were based on my observations and evolved as I learnt more about the DG system and the work of doctors, social workers and nurses within it, however I made sure to cover the following topics: how the DG system worked in the facility, their professional background, their individual approach to DG assessment, factors they considered in making decisions, contextual factors influencing their work, their familiarity with and views on the guidelines and SASSA, challenges faced in making decisions – both medical and non-medical, their personal views on social grants and their experiences interacting with patients.

Ethical approval to work in healthcare facilities was received from the University of Cape Town Human Research Ethics Committee and permission to work in these facilities was granted by the Department of Health, the City of Cape Town and managers of individual facilities (see Appendix A).

Observing doctors while they conducted DG assessments was central to my research design and formed the largest component of data collection. Twenty-four doctors were involved in the study, who conducted DG assessments during the course of their work as treating doctors (12) or as dedicated SASSA assessors (12). I directly observed the work of seventeen doctors over one or two days, where I would sit in for the entire duration of the clinic opening hours (four to eight hours). In cases where direct observation was not appropriate or not possible, I conducted in-depth interviews with doctors. In total, I observed 216 consultations, of which 196 were disability assessments. A total of twelve social workers, nurses and occupational therapists participated in interviews or focus groups about their involvement in and perspectives on the DG system. Data was also collected in less formal ways, when doctors were casually talking amongst themselves or consulting with one another on cases and in the corridors when I was talking to patients, who were often eager to share their experiences with me.

Although I made notes on each patient's age, race, gender and presenting complaints, my observational work was otherwise unstructured and I focused on capturing the interaction between doctor and patient in as much detail as possible. On meeting a doctor for the first time, I would begin by discussing the study with them before the clinic started. This generally led to a discussion about their views on the social grant system, during which time I would take notes. During the course of the day, the doctor and I would discuss patient cases and the rationale for their decision-making, usually between patient consultations. At the end of the day I would conduct a more formal interview to reflect on the cases seen and address any remaining questions I had about their decision-making and general approach. Combining interviewing with observation allowed me to probe doctors' reasoning and understand how they understood eligibility and deservingness.

Watching doctors perform the work of disability assessment and interacting with patients was useful for learning how organisational, medical, social and cultural factors shape doctors' decision-making and how the process of patient classification was "enacted" (Heyman, 2001). Observing the doctor-patient interaction created opportunities to learn how the assessment process was structured, how assessment tools were utilised and forms were completed, how doctors engaged with and examined patients, what questions they asked and what information was available in patients' medical records. It is important to look at these material aspects of bureaucratic worlds because it "helps us to attend to bureaucratic practice without fetishizing the bureaucratic decision and without dissolving the rule in a 'bath of context.'" (Hoag, 2010: 85, quoting Mull, 2008: 504) The "material organisation" (Dubois, 2010: 42) of the assessment

also sets claimants' expectations, thus framing the encounter between doctor and patient. I was also able to see how patients presented both their medical and social cases to doctors and how doctors responded to patient behaviour and characteristics. Direct observation also allowed for non-verbal forms of communication and interaction to be taken into account.

Direct observation was also useful in stimulating discussions with doctors that were grounded in the concrete particularities of real cases and provided opportunities for me to probe their understanding and experiences in a different way than if I just heard second-hand accounts of their work. This decreased the likelihood that doctors would just present the official version of their work or simply describe the professional ideology of medicine. Le Marcis and Grard (2015) note that this can be a difficult part of interviewing healthcare professionals. It is however, important to note that my presence in the room may have influenced how doctors made decisions and treated patients because doctors may not have wanted to be seen as making decisions that were not objective and may have been 'harder' or 'softer' on patients than they otherwise might have been. The depth and nuance of data that emerged during my observational work also allowed me to get "below and behind the surface of official accounts" (Bevir & Rhodes, 2006: 101) and combining interviews and observation enabled me to compare what doctors said they were doing with what they actually did. Brodtkin (2003: 159), for instance, found that street-level bureaucrats often described themselves as taking a hard-line (being 'tough') or being 'soft' in their application of the rules, but their actual practices were very different. Observing and participating in the collegial and casual encounters between doctors, nurses, administrative staff and SASSA staff who visited the clinics, deepened my understanding of the system. By speaking with claimants while they waited for the doctor to arrive, I gained more perspective on how claimants understand and navigate their way through the assessment process.

Although I did not take on participant observer status for an extended period of time, combining the rich material and thick description allowed by direct observation with interviews, and documentary analysis, allowed me to understand the material reality of the DG system. It also helped me to develop an account of the pressures, opportunities and constraints of the health and welfare systems that doctors work in.

Further details on the process of selecting research sites, data analysis, ethical considerations and reflections how my chosen research design and positioning as a researcher in the field shaped the quality of research is provided in Appendix A. Additional quotations not included in the main body of the text, but which support my argument, are referenced throughout and

included in Appendix C.

1.6 Outline of thesis

The next chapter provides a historical overview of the development of a legal and regulatory framework around DGs since the end of apartheid. Using government documents, legislation and parliamentary records, I document the government's struggle to develop a coherent strategy on how to manage DGs the post-apartheid policy space. The new government elected in 1994 perceived that doctors had been one of many impediments to fair access to DGs by black South Africans. The chapter documents the state's subsequent attempts to break down barriers to access and reduce its reliance on medical doctors in determining DG eligibility, which quickly created a perceived (and unintended) 'leniency' in the system. In the context of the HIV epidemic and high poverty-driven demand for the grant, doctors and newly introduced 'multidisciplinary assessment panels' responded to the poor socio-economic conditions of claimants. Recognising the mismatch between social protection policy and the experiences of the patients they encountered, doctors responded by recommending the grant in cases which previously might not have been considered eligible on medical grounds. This resulted in "policy drift" (Hacker, 2004) as the grant become a *de facto* poverty and HIV grant rather than one targeted at people whose disabilities were caused by physical impairments. As the number of grants paid escalated in the early 2000s, the state became concerned with the fiscal sustainability of the system and moved towards a more medical model.

Examining policy discussions around how to address the growth in DG numbers, I show how doctors' supposed failure as gatekeepers and alleged fraud by claimants were highlighted as major contributors to DG growth. Seeing the extension of the social grant system as an undesirable way of addressing poverty among working-age adults, but unable to solve the high levels of unemployment driving demand for the grant, policy makers focused on the more tractable problem of targeting. They did this by developing assessments tools and guidelines, attempting to tighten the definition of disability and eligibility criteria and introducing a waiting period between re-applications. Although government ultimately failed to achieve consensus around a definition of disability and tools to assess it, SASSA developed its own systems and processes to "rationalise" the DG system. These new limits on access led to a significant decline in the number of social grant recipients. However, ignoring the systemic issues that doctors were responding to with their over-generosity has not made them disappear. Although their discretion has been constrained by the introduction of new management systems,

disability remains poorly defined within legislation and SASSA guidelines. As a result, contestations around the meaning of disability continue to play out in the disability assessment process through the micro-level interactions between doctors and patients, which I focus on in the remaining chapters of this thesis.

Continuing from the previous chapter, Chapter 3 describes the regulation and assessment of disability grant within the framework of SASSA's Disability Management Model (DMM), the bureaucratic system put in place by SASSA to reduce beneficiary numbers, eliminate fraud and manage the medical assessment process. The chapter provides a detailed description of the structure of this system in the Western Cape Province as it existed in 2014. I provide the details of the relationships between doctors, the Department of Health and SASSA and explain how this differs at different levels of the healthcare setting (primary, secondary and tertiary). I consider the role of SASSA's Disability Management Unit and explain how the DMM process works from claimants' first visits to a SASSA office through to the medical assessment process, and finally to the administrative processing and award or rejection of the grant. I also describe the management and oversight systems and training, and guidelines, which SASSA has implemented to standardise the assessment process and reduce doctors' discretion within the assessment process.

In the fourth chapter, I consider the position of South African doctors as medical experts in the DG system and their role in legitimating access to the disability category. Drawing on the extensive sociological literature on the medical profession, the nature and practical application of medical knowledge and the doctor-patient interaction, I highlight the particular challenges that DG assessment presented to doctors. I discuss the nature of the doctor-patient relationship in South Africa and show how the role of the doctor in the DG assessment - that of "fraud detective" - differs from the work that doctors typically do in treating settings. Given that treating doctors are able to conduct assessments within the context of their outpatient clinics, I also reflect on the dilemma this created for doctors and what this meant for the doctor patient relationship. My fieldwork showed that there was a marked absence of trust in patients' intentions, which left many doctors (especially those in a treating role) feeling unsatisfied and discouraged in their work. SASSA's medical impairment guidelines were inadequate for conducting assessments in cases of moderate impairment where employability could be exclusively medically determined. As much of medical practice is based on tacit, experiential knowledge - what doctors described as "gut feel" - SASSA's attempts to codify disability assessment did not fit with the logic of medical judgement and many doctors therefore found

them limiting, and ignored them. Without proper training or guidelines that they found useful, doctors were left with an undesirable combination of discretion and uncertainty when considering whether and how to consider factors such as age, education or work history in their assessments. As a result, doctors frequently made subjective and often normative decisions on claimants' employability based on their own experiences and ideas about disablement and deservingness.

In Chapter 5, I show how doctors navigate between their role as medical doctors and their bureaucratic role as assessors for the state within the DMM system described in Chapter 3. I demonstrate how the organisational arrangements, tools, standards and guidelines put in place by SASSA, in combination with the organisation of the Western Cape healthcare system, structured doctors' work. Doctors improvised ways to cope with the demands, constraints and frustrations of both these systems in the clinics and hospitals where they worked. Despite organisational and regulatory impingements, doctors were able to find spaces of discretion in their work. The informal rules and practices they developed to simplify their decision-making undermined and impeded SASSA's attempts to standardise assessments. Doctors' attitudes towards and use of assessment guidelines and processes were based on their level of engagement with SASSA and their previous experiences of DG policy and processes. Unlike doctors contracted specifically to do assessment work, treating doctors were unwillingly drawn into the system and felt alienated from SASSA and DG policy. Their participation in the system was largely undirected, often leading to refusals to fill out assessment forms for patients or decisions made in the interest of the patient rather than the state.

Chapter 6 continues the discussion of personal and professional conceptions of disability raised in Chapter 4. Focusing on social categorization, I show how personal and professional norms, values and notions of justice shaped decision-making. Drawing on Goffman's theory of framing (1974) and Giddens' (1984) notion of schemas and structuration, I argue that doctors make sense of a claimant's situation and justify their choices in categorising claimants through the interactional and intersubjective process of framing. Doctors used the active process of framing to arrange medical knowledge, SASSA's rules and standards and professional and personal norms and values, as well as their own experiences and those of their colleagues, to answer the question of eligibility in individual cases. I propose that four frames patterned doctor's decision-making behaviour: the *bureaucratic frame*, the *clinical frame*, the *moral frame* and the *social frame*. Although shifting and flexible, the sets of practical rules that doctors created for themselves within the framework of existing rules created an orienting

structure from which to operate. They managed their bureaucratic ‘thought-work’ (Heyman, 1995) in ways that allowed them to exercise professional, social and moral agency. Doctors’ adoption of certain frames depended on their medical specialty and training, institutional environment, social and cultural background, gender, approach to patient care, previous experiences with patients requesting the grant and their political views. I show how these frames either aligned with and reinforced, or undermined formal DG policy and shaped doctors’ attitudes towards formal eligibility criteria, inclining them to be either “harder” or “softer” on particular types of patient.

Chapter 7 focuses on the disability assessment and the interaction between doctor and claimant as a site of negotiation and contestation over social security rights. I discuss the power relations that developed in the interactions between doctors and claimants and how these interactions shaped doctors’ decision-making. Drawing on Foucault (1977) and the work of Scott (1985, 1990), de Certeau (1984) and Barnes & Prior (2009) on subaltern agency and defiance, this chapter discusses the micro-politics of resistance and subversion that emerge during face-to-face encounters between doctors and DG claimants. I show that far from being passive participants in the assessment process, patients exercise agency to resist the objectifying process of disability categorisation and express their own subjective understandings of disability. Although doctors tended to dominate the assessment because of their professional and social status and decision-making power, some patients resisted this dominance and attempted to assert their personhood and demands for inclusion in the social security system during the assessment process. Some claimants used narratives and physical performances of disability and suffering or verbal and physical threats to coerce doctors. Although seldom effective, these small acts of resistance disrupted the assessment process. This points to the important, but often neglected, role citizens can play in shaping policy through their interactions with frontline workers and how they are also shaped by their experiences within welfare organisations. I also show how doctors coped with what they perceived to be attempts to pressure and manipulate them and what these strategies mean for policy implementation. The coping strategies they employed to protect themselves emotionally (and sometimes physically) from the demands of patients created distance and hostility between doctors and patients. These experiences and attempts to protect themselves made doctors more likely to take a hard-line bureaucratic approach to assessments.

The concluding chapter summarises the evidence presented in other chapters on the difficulties of allocating DGs in South Africa. It shows how doctors’ decisions were driven by their

interpretations and pragmatic application of formal rules and processes in response to the pressures and constraints of their work, the macro economic and social context, their personal and professional values and norms and their social interactions with claimants. Their work, and attempts by the state to regulate it, shows how important the actions of policy implementers can be in shaping policy outcomes and further policy development. Claimants' strategies to gain access to the DG shows that the agency and motivations of the people targeted by policy (in this case, DG claimants) also shaped policy outcomes. This is an important contribution to the street-level bureaucracy literature that (until recently) has primarily focused on the agency of frontline workers. I also argue that my findings illustrate the importance of considering professional values and ideas about the 'right' way of implementing policy in studies of street-level bureaucracy. More practically, it shows that professional values and sense of purpose may not be easily ceded in the face of bureaucratic rules and public management initiatives, and that other more collegial forms of engagement are necessary to manage professionals' work. I argue that the disjuncture between policy design and its implementation by doctors reveals the limitations of the DG system and fault-lines in social welfare and disability policy. I conclude by discussing some possible policy options for addressing problems in DG administration.

CHAPTER 2: Regulating access to the disability grant in South Africa, 1990-2013

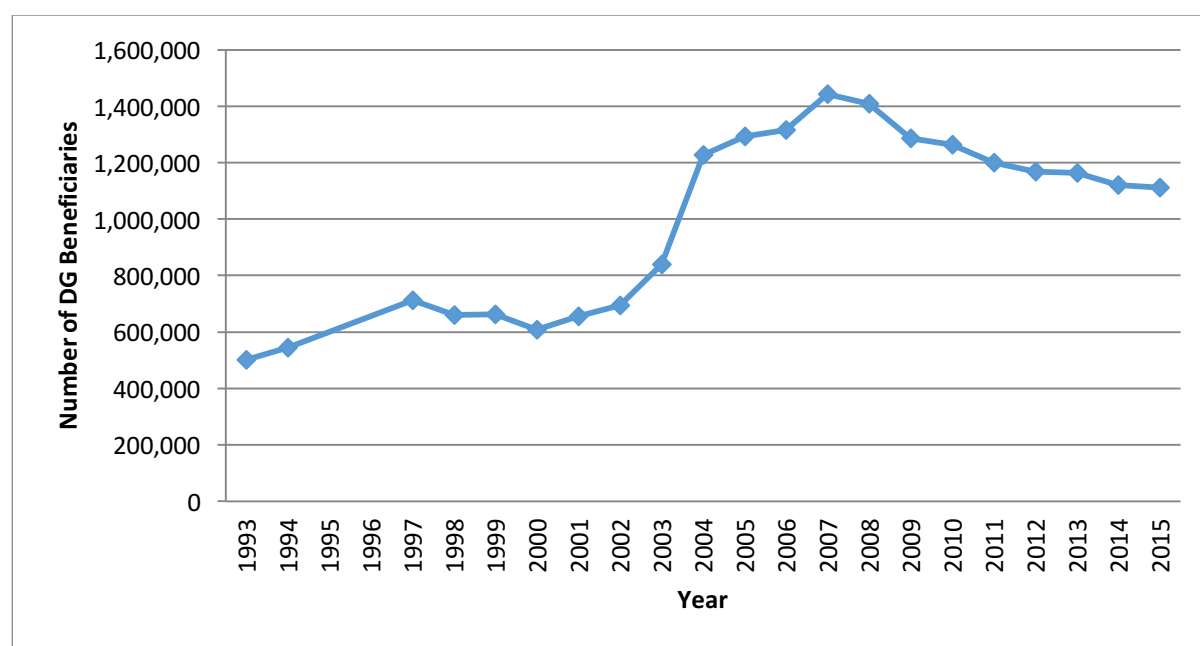
2.1 Introduction

Over the past 15 years, the South African disability grant (DG) has received significant attention in academic, civil society, media and government circles, largely because it has raised major questions about social development and poverty alleviation strategies that extend well beyond concerns about disability. This chapter sets out to examine the development of DG policy and regulations in post-apartheid South Africa and in doing so, explore understandings of disability, as well as how the rights of the sick and disabled to social security have been negotiated and decided by policymakers and legislators in government.

Hansen and Sait (2012) argue that the process of conceptualising disability in South Africa can be divided into two distinct phases. The first of these was a period of reconciliation (1994 - 2001) when discrimination and subjective experiences of disabled people came into play and the focus was 'extending grants to those in need rather than to ask the question of who was in need' (2012: 96). The second phase (2001 onwards) represents a period of controlling access to the grant when the discourse of dependency was invoked along with a narrower biomedical conception of disability and a focus on who is disabled. However, this analysis overlooks the fact that in 2001 disability assessment was in fact adapted to incorporate a more social understanding of disability. This led to an unprecedented growth in DG beneficiaries until 2007, where a narrower, strictly biomedical model of disability was reintroduced.

This chapter offers a different periodization to Hansen & Sait (2012). I argue that there have been three phases in DG management by the post-Apartheid state, which have coincided with two major shocks to the social welfare system. The first came because of the seismic political, economic and social shifts that occurred at the end of apartheid. The new African National Congress (ANC) government recognised the urgent need to address massive poverty and social inequality that existed in South Africa. This led to a period of extending and deracialising access and overcoming administrative barriers, supported by a 'rights' and administrative justice discourse. This was followed by a period of growth and generous access (2001 – 2007), which, in the wake of what emerged to be one of the fiercest HIV epidemics in the world, led to a rapid increase in the number of people applying for and receiving the DG. The way in which DG assessors interpreted and applied DG policy in the context of the HIV epidemic created what Hacker (2004: 246) calls policy drift - the "changes in the operation or effect of policies that occur without significant changes in those policies' structure". The DG became,

in effect, an HIV grant and a general poverty alleviation grant, serving a purpose beyond the one for which it was designed. The massive increase in beneficiaries over this period resulted in growing concern about over-generosity and fiscal sustainability of the DG system. This culminated in a set of actions by the state that placed new limits on frontline worker discretion and access to the DG and a period of decline in the number of social grant recipients from 2007 onwards.



Source: Department of Welfare, DSD and SASSA Reports 1997-2015, SA Statistics, 2001

Figure Changes in DG beneficiary numbers 1993-2015

Crucial to policy changes over all three periods was the way in which ‘higher-ups’ interpreted and responded to street-level action and how this shaped further policy development. The relationship between the design of DG policy and its implementation provides an excellent case for thinking about the policy-making process as a feedback loop rather than a top-down process (Skocpol, 1992; Pierson, 1993; Hacker, 2002). In particular, it highlights the importance of administrators in not only shaping policy outcomes, which the literature on policy implementation tends to focus on, but also future policymaking.

2.2 Disability grant policy at the end of apartheid

Cash transfers specifically targeted at people with disabilities have a long history in South Africa. Social assistance for disabled people was first introduced through the Blind Persons Act of 1936 and the Invalidity Pension Scheme, which the Department of Welfare offered to

white South Africans from 1937 onwards. The Disability Grants Act of 1946 formalised this scheme in the form of a means-tested disability grant made available to all South Africans, but with the value of the grant and the details of the means-test differing by race (and urban/rural location), as was the case with old age pension.

From the 1970s, racial discrimination in the value of benefits was reduced. The real value of pensions for black people rose whilst they fell for the white population. By 1990, white people accounted for only 23% of welfare spending, whilst coloured and Indian people received 24% and black people 52% (Kruger, 1992; Terreblanche, 2003; Van der Walt, 2000 in Visser, 2004: 5). Discrimination in benefit levels based on race was finally eliminated and equal benefits were extended to all DG beneficiaries in 1993 (Ardington & Lund, 1995).

At the end of apartheid, the system of grants and pensions was in a state of ‘organisational chaos’ (Matisonn and Seekings, 2003: 58). The system was racially segregated and administered by seventeen different departments, serving different racial groups including Africans in the ten *bantustans*³⁰; four provincial administrations that served Africans outside of the *bantustans*; and three different administrations for whites, ‘coloureds’ and Indians under the tri-cameral parliament system (Department of Welfare, 1997a; Van Der Berg, 2002). Eligibility and means testing criteria, and grant payment amounts were racially discriminatory and payment periods varied significantly across these administrations (Lund, 1992). Data on beneficiaries were held by these various administrations, rather than centrally, and some were not computerised. The result was that there were few consolidated statistics on beneficiary numbers or expenditures by programme (Lund, 1992). Lund (1992) analysed estimates of expenditure, auditor general reports, parliamentary debates and policy speeches and interviewed members of various government departments, finding significant discrepancies in the information on social grants provided by these sources, estimating a total expenditure of R828 million in 1990 based on the best available data. No accurate data on the number of DG beneficiaries over this period appears to exist.

Between 1991 and 1995, the welfare budget grew faster than any other government department (23% per annum) as a result of equalising benefits (Ardington & Lund, 1995).

³⁰ Territories set aside for the African population. Four of these territories - Transkei, Bophuthatswana, Venda and Ciskei (TBVC states) - were declared fully-independent and self-governing.

As a result, there was concern about the growing welfare ‘burden’ and social security reform was informed by a need to manage costs leading to a push to ‘rationalise’ the social grant system (Department of Welfare, 1994) and increase administrative efficiency.

In January 1992, the *New Social Welfare Dispensation for the Republic of South Africa* document outlined the development of a new welfare policy that would incorporate welfare policy under a number of umbrella Acts, increase the allocation of social welfare services from 1.6% to 3.2% of GDP and achieve full parity of social grants by 1 April 1996. This led to the promulgation of the Social Assistance Act 59 of 1992.

The Social Assistance of 1992 repealed existing social welfare legislation, including the Social Pensions Act of 1973, the Disability Grants Act of 1968, and various welfare acts promulgated by the formerly independent homeland states. The 1992 Act used the same definition of disability as was used in the Disability Grants Act of 1968 and read as follows:

“Disabled person” means any person who has attained the prescribed age and is, owing to his or her physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance. (Social Assistance Act 1992, Section 1)

Other than eliminating racial disparities and increasing the age of eligibility from 16 to 18, the 1992 Act changed little in the way that DGs were managed. As in previous legislation, a disabled person was defined as someone with a physical or mental disability. However, as I will discuss in Section 2.3.3, the concept of ‘disability’ or how to assess it was never properly defined in the Act or its regulations.

2.3 Attempts by the post-apartheid government to extend access and overcome administrative barriers: 1994-2001

When the ANC government took power in 1994, poverty and inequality were significant problems. The poorest 52% of the population accounted for less than 10% of total income, whilst the richest 6% captured 40% of income (Taylor Committee, 2002). Grants were awarded to only 2.4 million out of a total population of 40 million people (Seekings & Matisonn, 2010).

On coming to power, the new ANC government committed itself to building a social welfare system that promised “the attainment of basic social welfare rights for all South Africans, irrespective of race, colour, religion, gender and physical disability, through the establishment of a democratically-determined, just and effective social delivery system” (Republic of South

Africa, 1994: 2.13). Although the ANC was committed to achieving racial equality in the social grant system, which at the time reached few Africans relative to other racial groups, it was also concerned about developing a welfare state that promoted dependency rather than development. The Reconstruction and Development Plan White Paper (1994) presents an early example of this discourse:

Co-ordination of programmes alleviating the needs of people living in poverty and marginalised circumstances will be essential to maximise individual potential and minimise the extent of dependency on the State... It is unfortunately true that many communities and families depend almost entirely on the cash from social grants. (RSA, 1994a: 3.12)

2.3.1 Difficulties in managing a messy system

The administrative complexities of the previous system, and poor capacity for delivering social security services, especially in more rural areas, made extending access to social grants an extremely challenging task. The social security system it inherited was fragmented, inequitable and administratively inefficient, and was designed to serve a minority of the population. In the case of the DG, existing administrative difficulties were compounded by the complicated nature of identifying and targeting beneficiaries who were particularly marginalised and were doubly discriminated against by the apartheid system in terms of both race and their disabilities (Nkeli, 1998). The new government therefore faced the daunting task of both consolidating and extending the complex and discriminatory administrative structures inherited from the previous regime.

Given low levels of unemployment in the white population, the apartheid social security system was focused on providing unemployment insurance to white people working in the formal labour market, with social assistance only forming a residual 'safety net' function for specifically targeted categories of people considered vulnerable to poverty, namely disabled people, children and the elderly (Seekings & Natrass, 2005; 2015). This design did not take into account the large numbers of previously excluded poor and unemployed black people (Woolard *et al.*, 2010). Service delivery structures of the social welfare system were based on the British and American models, which were inappropriate to the South African political, economic and socio-cultural context (Patel, 1992: 46). However, budget constraints made re-imagining a new system fairly challenging for the ANC government. In the six years after apartheid a series of commissions were assembled to examine how to re-structure the existing system: the Chikane Committee for Restructuring Social Security (1996), the Lund Committee on Child and Family Support (1996), the Public Service Commission

Investigation into Social Security Services (1998) and the Taylor Committee on Comprehensive Social Security for South Africa (2000).

The draft White Paper for Social Welfare, published in 1995 and adopted by cabinet in 1997, outlines the creation of a developmental social welfare system in-line with the goals and strategies of the government's Reconstruction and Development Programme (RDP). The White Paper was aimed at guiding the consolidation of welfare policy. Apartheid legislation was largely developed in an ad hoc fashion, reflecting reactions to particular issues and the White Paper for Social Welfare attempts to set the tone for more comprehensive and consultative welfare policy: "A comprehensive and integrated social security policy is needed to give effect to the Constitutional right to social security." (Department of Welfare, 1997a: 55)

The White Paper acknowledged that welfare services were underfunded and sought to increase welfare spending and the number of social grant beneficiaries over time, reintroducing promises of a universal social security system.

There will be universal access to an integrated and sustainable social security system. Every South African should have a minimum income, sufficient to meet basic subsistence needs, and should not have to live below minimum acceptable standards. The social security system will also work intersectorally to alleviate poverty (Department of Welfare, 1997a: Section 7.27).

However, at the same time, like the RDP White Paper, it expresses a reticence around building a paternalistic welfare state, promoting the idea of *developmental social welfare* instead. It suggests a number of strategies that would promote the 'sustainability' of the social security system by increasing the self-reliance of the poor and the vulnerable, effectively reducing their dependence on the state. These strategies included public works programmes, active employment policy, more stringent eligibility testing and employment and training programmes that would "divert people from the welfare system" (Department of Welfare, 1997a, 6.22).

There was also concern about the growing costs of the social grant system and the need to address the wasteful expenditure caused by the inefficiencies, confusion and fraud within the highly disjointed existing system. To this end, in 1995 the Department of Welfare began a project to amalgamate and clean up social grant records of the 17 different systems into one national database.

In 1997, the Cabinet instructed the Department of Welfare to undertake a national re-registration drive intended to reduce fraud and discrepancies in the system and a national

social security system was phased in from 1 April 1998. The clean-up process included removing deceased beneficiaries (ghost beneficiaries) and duplicates from the system as well as Temporary Disability Grants (TDGs) that had not been cancelled. Prior to 1998, disability pensions could only be terminated after an annual medical review and if the person concerned was less than 100% disabled. In 1998, amendments to the Regulations of the Social Assistance Act 59 of 1992 provided for the automatic lapsing of temporary DG granted before 1998.

As a result of these efforts, the number of DG recipients dropped 14.6% from 711,629 to 607,537 between the end of March 1997 and the end of March 2000 (see Figure 1). Although the clean-up process resulted in significant savings for the Department of Welfare, administrative problems in carrying out the re-registration – poor communication about the process as well as the lack of identity documents of many beneficiaries – caused financial stress for those whose grants were suspended or cancelled, especially in rural areas. The blanket cancellations of temporary DGs and the grants of ‘suspect’ beneficiaries without notice over this period also resulted in litigation by beneficiaries in which judgment was given in favour of the applicants (Olivier & Mpedi, 2009).

2.3.2 Poor coverage of the population eligible for the disability grant

Although the efforts to improve administration were effective in reducing the number of illegitimate beneficiaries in the system, in 2001 the Director of Social Grants in the Department of Social Welfare, Fezile Makiwane, acknowledged that the number of social grant beneficiaries was only a small fraction of the total number of eligible individuals (PMG, 2001a). There were also additional barriers to access specific to the administration of the DG that needed to be addressed, such the difficulty disabled people had accessing medical facilities and a shortage of medical doctors to conduct assessments. This is recognised in the post-apartheid government’s initial proposals for social security and disability issues in South Africa – the White Paper on Social Welfare (1997) and the Integrated Disability Strategy White Paper (1997), which the quote below is drawn from:

People who receive social security benefits in South Africa tend to be totally dependent on them for their survival. The majority of people with disabilities, however, receive no grant at all. ... The present social security legislative framework, its administration and allocation systems, tend to be discriminatory, punitive, insensitive to the specific needs of people with disabilities, uncoordinated, inadequate and riddled with high levels of fraud (Office of the

Deputy President, 1997).

As shown in Figure 1, in 1994 less than 600,000 people received the DG. This represented 1.6% of the total population (38.38 million) and around 30% of the people with disabilities based on survey estimates that disability prevalence at the time was around 5% (CSS, 1995). Although not all disabled people would necessarily be eligible for the grant, it is likely that uptake of the grant was low relative to the number of disabled persons living in poverty, largely because of punitive means testing and medical assessment processes (Department of Welfare, 1997a).

Coverage of black South Africans with disabilities was low compared to coloured and Indian people, despite a higher prevalence of disability and high likelihood of unemployment within this group (see Table 2 below). This is likely because of discriminatory practices during apartheid as well as spatial discrimination because of lower literacy levels and poor access to welfare services within rural areas.

Table 1 DG Coverage by population group

Population group	Number of DG recipients per 1000 people in population (1997)	% Disability in population (1999)	% of disabled people employed full-time (1999)
White	8	5.7%	19%
Indian	23	4.7%	9%
Coloured	31	4.5%	4%
Black	12	6.1%	6%

Source: Van Der Berg, 1997 and Schneider *et al.*, 1999 in Bredenkamp, 2001.

2.3.3 Problems of accessibility

The social grant system in the early 1990s was both difficult to access and “ironically over-administered” (Lund, 1997: 9). In 1997, the Community Agency for Social Enquiry (CASE) was commissioned by the Department of Welfare to research social security policy options for people with disabilities. CASE convened a task team that included representatives from the disability sector and the Department of Welfare. The report, based on data collection in five provinces, found that administrative inefficiencies presented a serious barrier to accessing the grant (Schneider & Marshall, 1998). Beneficiaries reported that the application process was frustrating and complex and that the success of an application frequently depended on being lucky enough to find a sympathetic official (Schneider &

Marshall, 1998). Healthcare workers pointed out the challenges disabled people faced in navigating the DG application process:

“We’ve joked in the past at our hospital that if you can actually get through the whole system, get to all the places and see all the people, you probably aren’t disabled enough to qualify.” (Medical assessor quoted in Schneider & Marshall, 1998: 50)

The Black Sash, which provided paralegal advice on social security issues, reported that DG enquiries constituted 60% of the advice given by their paralegals (Black Sash, 2000a). This was likely a result of high demand for the grant, challenges faced by those seeking access to the grant and the suspension of DGs without notice.

At the time, all DG forms were filled out by Medical Officers (MOs) and assessed by Pension Medical Officers (PMOs) employed by the state to oversee the administration of DGs from a medical perspective. This practice was criticised for creating significant backlogs (Baron, 1992) and for allowing PMOs to make important decisions affecting patient welfare without actually examining patients (Simchowitz, 2004). The shortage of medical doctors available to perform assessments in rural areas also lead to significant assessment backlogs in some provinces. The Department of Welfare estimated that in 2000 there was a backlog of 86,951 grant applications across the country (see Table 3 below). The Eastern Cape and Northern Province faced the largest backlogs.

Table 2 Backlogs per province as of May 2000

KwaZulu-Natal	10000
Eastern Cape	30000
Mpumalanga	6000
Gauteng	2951
Northern Cape	400
Western Cape	500
North West	7000
Northern Province	30000

Free State	100
Total	86951

Source: Department of Welfare, 2000a

Based on the policy that no one should wait longer than three months for a grant application to be processed, payment of arrears was restricted to three months regardless of how long an applicant in fact waited to receive their grant (South African Federation for Mental Health, 1999; Black Sash, 2000a). Although this policy was meant to incentivise administrators to speed up the application process, long delays in administering grants were common. Another study by CASE found that only 27% of DG applicants received their grants within the stipulated three months (Schneider et al., 1999).

Physical access and transport to welfare offices for applications and collection of payments was often challenging and expensive for disabled or very ill people who had mobility issues and for whom the costs of transport or the time spent in long queues proved physically difficult. People who had moved from their hometowns had to travel back to these towns to collect their grant money (Schneider & Marshall, 1998).

Temporary DG applicants were often not told that their grants were temporary and their records were often deleted completely from the system without notice, forcing recipients to apply and wait without support for several months whilst their new applications were processed from scratch. The right to appeal grant refusals or cancellations was poorly understood by many applicants and beneficiaries. The appeals system itself was also deeply faulty and inconsistent and significant backlogs existed in the appeals process (de Villiers, 2006).

Inefficiencies and inequities in grant administration such as those discussed above undermined the constitutional requirement of lawful and reasonable administrative action outlined in Section 33 of the Bill of Rights in the Constitution of the Republic of South Africa Act 108 of 1996 and the Promotion of Administrative Justice Act 3 of 2000 that expanded on this right. This led to litigation by the Legal Resource Centre and the Black Sash against the Department of Social Development on behalf of applicants and beneficiaries facing delays and cancellations (Black Sash, 2000b; PMG, 2000a; Department of Welfare, 2000a)³¹. One of the most prominent cases over this time was the class action

31 The Department of Social Welfare (2000a) reported that litigation against the department at the time included

brought forward by the Legal Resources Centre on behalf of Ngxuza and two other defendants as well as 37,000 other temporary grant beneficiaries in the Eastern Cape, who had their DGs suspended or cancelled without proper procedure or notice (Department of Welfare, Eastern Cape v Ngxuza and others 2001 (4) SA 1184 (SCA)).

2.3.4 Problems in DG Assessment

The DG assessment process has been the most problematic and contentious aspect of regulating access to the DG. In the 1990s difficulties in the assessment process included: the lack of a proper definition of disability for social assistance purposes; a lack of standardised assessment tools; inconsistent and subjective application of assessment tools; the medical focus of the assessment process, which did not take social or environmental factors into account; and a shortage of medical doctors to perform assessments, especially in rural areas.

Although Section 9 of the Social Assistance Act of 1992 outlined the criteria for eligibility for DGs, there was no clear definition of what classified as “physical or mental disability.”

In fact, since the introduction of DGs in 1946, the concept of *disability* had never actually been formally defined in any of the social assistance legislation and related regulations. Although the definition of disability was vague, the Act required that an applicant’s disability be confirmed by a medical report, meaning that the assessment of disability was heavily biased towards medical diagnosis and the medical model of disability.

In the 1990s, a person was eligible for a grant if the degree of their disability was certified as greater than 50% on an open labour market and was expected to last longer than one year (Brown, 1990: 31; Guthrie & Sait, 2001). The assumption that there is a norm of physiological and mental function and that deviations from this norm can be measured in terms of a percentage of disability does not take into account social and economic factors that may act as barriers to people’s ability to participate in productive work (Schneider & Marshall, 1998; Kimani, 1999). Whilst the Workmen’s Compensation Act 30 of 1941 and the Compensation for Industrial Injuries and Diseases Act 130 of 1993 that later replaced it provided impairment tables (sometimes referred to as ‘meat charts’)³² to categorise the

a class action of approximately 30 000 cases in the Eastern Cape (Ngxuza) and another 150 cases in the Gauteng.

³² A meat chart assigns a value to each body part and assists in categorising the severity of an injury. The current DG system uses impairment tables.

degree of anatomic loss in workplace injuries, no such guidelines existed in the case of the DG (Lund, 1997). This meant that the judgment of what constituted 50% disablement was left to the discretion of medical officers. A general assessment of 'fitness to work' also did not take into account whether an applicant was able to carry out the type of work they were specifically trained for (Bredenkamp, 2001: 198) and it was not clear to what extent medical officers could or should take highly variable economic factors into account in assessing disability (de Villiers, 2002). This very one-dimensional assessment also left no room for self-representation by people with disabilities in the application process (Guthrie & Sait, 2001).

In addition, the 1992 Act referred only to physical or mental disability, excluding people with intellectual and sensory impairments, often causing administrative problems for deaf or sight-impaired applicants (Guthrie & Sait, 2001). There was also no clear definition of and delineation between temporary and permanent disability, meaning that these decisions were often made arbitrarily. Attempts to address this were made in 1998 through amendments to Social Assistance Act regulations which distinguished between permanent disability grants and temporary disability that lasted no more than six months or no more than a year. The temporary classification was frequently misapplied by officials and doctors and used as a "convenient half-grant" (de Villiers, 2006: 3) where they felt a permanent classification was not justified or where insufficient supporting evidence was supplied. There were also cases where people with temporary disabilities received permanent grants for conditions such as epilepsy, which are in theory manageable but remain stigmatised (Dr Jacobs, interview, 2013 October 24).

In the 1990s, given the spectre of a growing HIV epidemic and the lack of widely available anti-retroviral therapy, the White Paper on Social Welfare (1997) predicted an increased demand for disability benefits and there was growing concern in government about the possible burden that AIDS-sick people would have on the DG system (Department of Welfare, 1997a). Although DGs were not technically available to people with chronic illness, people who were functionally disabled by illness were eligible, making it difficult to establish at which point someone with a chronic illness such as HIV should receive a grant. Given inadequate definitions and vague and unclear guidelines, state doctors struggled with conducting DG assessments and were recommending the grant to people of varying levels of health and disability, creating confusion amongst applicants about who was eligible for grants (Baron, 1992; Segar, 1994; Schneider & Marshall, 1998).

Although not well documented, it appears that clinics and the hospitals had, during apartheid, been sites where rights to social benefits were negotiated and settled in ways that were often very different to official state policy (Jehoma, interview, 2014 August 11). Qualitative research conducted into the DG application process in the 1990s (Baron, 1992; Segar, 1994) as well as government documents and parliamentary discussions in the 1990s all reveal concern about the pressure placed on doctors by the growing numbers of people seeking DGs.

Although a national grants system was created in 1998, the nine provincial governments remained responsible for administering grants and implementing grant policy. Without national guidelines, provinces operated their own systems very differently and used different application and medical forms and guidelines for the DG application process (Black Sash, 2000a; de Villiers, 2002). In most of the provinces for assessing disability were inadequate or did not exist at all (Lund, 1997)³³. Without proper training, a clear definition of disability or clear universal guidelines for disability assessment, the system was subjective and arbitrary, resulting in confusion and inconsistency (Schneider & Marshall, 1998: 49; Swartz & Schneider, 2006; PMG, 1999; Department of Welfare, 2000b; 2000c).

As already overworked medical officers were conducting assessments in addition to their regular workload, medical officers generally did not have time to properly consider each case and thus made rapid assessments (Schneider & Marshall, 1998; Kimani, 1999). This meant that those with more obvious disabilities were more likely to receive grants. Schneider et al. (1999) found that people using assistive devices were significantly more likely to receive a DG than to not receive one. Given that the doctor had such influence over access to the grant, the process was further undermined by bribery, fraud and threats to doctors by people demanding the grant (PMG, 2000a).

In a context of high poverty levels, it is difficult to distinguish between disability-related poverty and other generalised poverty and there was often confusion as to whether someone was receiving a grant because they were disabled or unemployable (Schneider & Marshall, 1998). This was often the case amongst applicants over the age of 55 who were not yet eligible for the Old Age Pension and were awarded temporary DGs because they were no longer able to carry out manual labour but lacked the education or skills to do other work (Schneider & Marshall, 1998).

³³ This came under criticism in *Msiza v Director of Social Security, North West Province Bophuthastswana HC 702/2001*

There were also emerging concerns that in a context of high unemployment people were using temporary DGs as a 'ticket' to an income (Segar, 1994). Segar's (1994) ethnography of patient compliance to epilepsy medication in the epilepsy clinic of an Eastern Cape day hospital, indicates that patients were strategically using the illness to access the DG. In the case of her study, patients and doctors became "locked into a kind of negotiation where the issues of disease and therapy may themselves become of secondary importance." (Segar, 1994: 295) In a letter to the South African Medical Journal, a tuberculosis researcher focusing on patient compliance raised concerns that it was "financially advantageous for the indigent TB patient to remain in the 'sick role' for as long as possible" (Dick, 1995), affecting adherence to treatment. In recommendations to the Department of Welfare, Schneider & Marshall (1998) recommended the elimination of the temporary DG for this reason. This strategic use of the DG placed healthcare workers in a position of acting as both detectives and judges (Baron, 1992: 428), roles that were beyond the scope and training of their medical role.

2.4. A new strategy on disability

Although the Integrated National Disability White Paper (1007) and the White Paper on Social Welfare (1997) recommend changes to improve and extend access to DGs, government took little action to change policy, legislation or regulations around the DG until 1999/2000 when Zola Skweyiya became minister of the Department of Welfare in 1999 (which soon changed to the the Department of Social Development). In response to the obvious need to improve DG administration, the Department of Welfare convened a Disability Task Team including legal experts, academics, civil society and government representatives from the nine provinces to look at the existing legislation, regulations and implementation challenges (Department of Welfare, 2000c; Black Sash, 2000a). In June 2000 the Department of Welfare presented a new strategy on DGs to the Welfare and Population Development Portfolio Committee in Parliament (Department of Welfare, 2000b).

The strategy attempts to address the concerns and difficulties with administration of social grants in respect of disability and attempts to involve the disability sector in the assessment panels, to assess applications for a social grant. The strategy proposes a clear definition, clear assessment criteria and uses a combination of the medical and social model in the assessment process. Applicants will no longer be forced to go to a medical officer of health for a medical report but can obtain a report from any doctor who is familiar with his/her medical history (Department of Welfare, 2000a).

This strategy proposed amendments to the DG system which included: creating a new

definition for disability, reducing reliance on medical officers who were often not present in rural areas, creating a timeframe for temporary disability and specifying an appeals process for those claimants opposing suspensions and rejections. The medical assessment process was considered time consuming, expensive and duplicative³⁴ and the document recommended that this process be relaxed to allow any physician, psychiatrist, psychologist or optometrist of the applicant's choice to make recommendations on grant applications. This report would however only form part of the process and multi-disciplinary adjudicating panels would perform the actual assessment. The multi-disciplinary nature of assessment panels (APs) were expected to move disability assessment away from a biomedical understanding of disability by incorporating more social considerations into assessment of applicants' ability to work. This would bring the DG process in-line with the INDS White Paper (1997), which advocated a social model of disability. Including community members and the disability sector in the panels was expected to break the bias towards physical disability inherent in the medical examination.

Practitioners other than medical practitioners, and community members who have had the opportunity to observe applicants over a long period of time, may, it was hoped, be better placed to detect 'invisible' disabilities' than would a medical practitioner forced to undertake a quick assessment, with limited resources (Swartz & Schneider, 2006: 239).

Given the shortage of medical doctors, especially in more rural areas, the DSD hoped that APs would help to reduce the large backlog of DG applications and reduce the growing threat of litigation against backlogs and unclear or improper processes for DG cancellations or classifications or permanent and temporary disability. Based on these proposals, amendments to the Social Assistance Act 59 of 1992 were introduced in September 2000, with the main purpose of the amendments explained by the Department of Social Development (DSD)³⁵ as follows:

To remove constraining factors towards administrative justice. Remove incentives for unscrupulous individuals to enrich themselves. Regulation to be aligned with a more developmental approach to empowering people with disabilities to become self-sustaining (DSD, 2000).

³⁴ The grant had to be approved by both a medical officer and a pension medical officer

³⁵ In July 2000 the Department of Welfare was re-named the Department of Social Development. At the beginning of 2001 the Welfare and Population Development Portfolio Committee in the National Assembly was re-named the Social Development Portfolio Committee.

The DSD also hoped that introducing APs would decrease the individual discretion of doctors, whose decision-making was seen as subjective, bias and open to corruption. As the DSD Chief Director of Social Security, Fezile Makiwane, explained, “panels were mooted to shift the process of decision making from one individual to a group of persons” (Makiwane, 2001b).

Mr Makiwane did, however, agree with the Chair that the problem of fraudulent claims is a critical one and calls for a multisectoral approach. Capacity building by the government is needed to stamp it out. He hoped that with the setting up of the panel system the problem would abate to a considerable level (PMG, 2001c).

The multi-disciplinary nature of APs was expected to increase the reliability and validity of assessments. According to the 2000 proposal APs consist of a senior social security official, a rehabilitation therapist (nurse, social workers, psychologist, occupational therapist or audio-visual therapist) and either a representative from the disability sector or other reputable community member.

The idea, she underscored, was to incorporate people with the *locus standi* to testify to the applicant's disability status. The panels, she said further, are poised to inject some efficiency and reliability in the disability assessment process. The current set up is inadequate since it involves a single medical officer of health (PMG, 2001c).

Discussions around amendments of regulations to the Social Assistance Act highlighted the need to create a clear definition of disability for social grant purposes:

The MP pointed out that the definition of disability needs to be made clear. Because of high unemployment, people are using this avenue to obtain money, especially by claiming temporary disability benefits. In terms of the definition of temporary disability, how would one differentiate gout from arthritis? (PMG, 2000a).

Amendments made to the Regulations of the Social Assistance Act (Act 59 of 1992) in July 2001 removed the role and regulatory function of the Pension Medical Officer, allowing assessors to function independently of their oversight. This amendment also introduced Assessment Panels (APs) as possible substitutes for Medical Officers (MOs) in areas where there were no medical officers. Further amendments were made in November 2001, which allowed APs to be used in all areas and for Care Dependency Grant assessments. According to the Regulations as amended in November 2001 an assessment panel was defined as “a group of individuals appointed by the Director-General in accordance with regulation 2(4), who have the relevant experience and expertise to assess

disability and care dependency.”

However, despite an obvious need to clearly define disability, no definition of disability was included in the amendments to the regulations.

2.5 A period of unbridled growth in DG beneficiaries: 2001 – 2007

In a 1997 paper, Van der Berg commented that given the extent of unemployment in SA, the take-up of benefits such as the DG are likely to be as great as administrative leniency allows (Van der Berg, 1997: 494). This proved to be the case when 2001 amendments to the Social Assistance Act increased the leniency of DG administration, contributing significantly to the massive increase in DG beneficiaries from 655 822 in 2001 until 2007, when this number peaked at 1,442,808 (see Figure 1).

As a result of the amendments, which came into effect in December 2001, provinces had two available routes for assessing disability for social grant purposes. Provinces could either continue to use medical officers without PMO oversight, or assessment panels could be used to make a final recommendation to social security officials. Although new regulations were aimed at improving DG administration, the removal of the PMO oversight function and the lack of training or guidelines for APs in fact further reduced the control the DSD had over the assessment process and created what one provincial official described as a “free for all” (Delany *et al.*, 2005). Although panels were meant to include medical professionals such as occupational therapists, physiotherapists, doctors and nurses, two APs in the North West Province observed in a study conducted by Goldblatt (2009) did not always include these professionals and panellists often did not understand medical reports (Goldblatt, 2009: 376). Based on legal casework, de Villiers (2002) also reported that APs worked off scantily detailed, poorly explained and often illegible medical reports. Without the presence of MOs to explain their reasoning, the assessment panels were not able to establish the severity of medical impairment. APs also struggled to weigh medical factors in relation to the psychosocial and economic circumstances of applicants (de Villiers, 2002). Goldblatt’s (2009) research found and the Director of Disability and Retirement Benefits, Dimakatso Pooe reported that the panels they observed in the North-West province were ‘unprofessional’, lacked confidentiality and panellists were unclear on their roles or what model of disability to apply (Pooe, interview, 2014 September 10).

As the administration of grants was neither centralised nor standardised across provinces, different provinces introduced APs at different times and used them to varying degrees and

in various combinations with MOs and PMOs. For instance, Mpumalanga introduced three APs to work with MOs and retained an oversight role through a senior social security official. The Free State and KwaZulu-Natal eliminated the PMO role and ran dual systems that allowed either MOs or APs to make assessments. The North West and Limpopo provinces were most organised in implementing APs but also implemented quite different systems. The North West province introduced 26 APs linked to social security offices that worked alongside MOs in the assessment process and were the only province to provide trainings for panel members. Limpopo situated APs within hospitals where they worked alongside the Medical Officer to recommend the grant, with the MO conducting the medical assessment component. On the other hand, the Western Cape and Gauteng never introduced APs. Gauteng abandoned the PMO function while the Western Cape retained it, although they could no longer override an MO recommendation. The Eastern Cape and Northern Cape briefly piloted APs but abandoned them for logistical reasons (Simchowitz, 2004), with the Northern Cape retaining its original system (with the PMO) and the Eastern Cape using MOs exclusively (Delany *et al.*, 2005).

Medical assessment forms and the criteria used to define AIDS-related disability also differed widely across provinces, with some provinces offering the DG very generously and others having no HIV/AIDS guidelines available until 2004 or later (Delany *et al.*, 2005; Simkins, 2005; Natrass, 2007).³⁶

The unexpectedly large increase in the number of DGs from 2002 onwards has been largely attributed to the 2001 regulatory changes (Simchowitz, 2004; Delany *et al.*, 2005; Simkins, 2005; Natrass, 2007). Delany *et al.* (2005) reported that between October 2001 and September 2004 the number of permanent DGs increased by 143% and temporary DGs increased by 61%, whilst the CDG uptake increased by 119%. By 2007 over 1.4 million people accessed the DG, up from 600,000 in 2001. SOCPEN data demonstrate that the percentage of rejected/not recommended applications dropped significantly from 8% in 1997 to less than 1% in March 2005 (Steele, 2006). In addition, of those who registered as rejected in March 1999 and who reapplied later, 60% were successful in claiming a DG (either a PDG 5% or TDG 55%) by March 2001 (Steele, 2006).

³⁶ Northern Cape and Mpumalanga did not develop any guidelines and left assessment of HIV positive patients to the complete discretion of MOs.

In 2004, driven by anxiety about the budgetary implications of the growth in DG numbers, the DSD commissioned the Community Agency of Social Enquiry (CASE) to carry out new research into the increase in DG uptake (see Delany et al., 2005). This and other studies have attributed this growth to relaxation of grant assessment criteria, the reduction in oversight brought about by the elimination of PMOs and introduction of APs, the lack of a framework for assessments, the increase in the prevalence of HIV/AIDS and TB and high levels of unemployment (Delany et al., 2005; Simchowitz, 2004; Steele, 2006; Natrass, 2007). According to these studies, the social aspects of disability applications became the strongest factor in applications and the DG was often awarded more out of sympathy on the basis of poverty than actual physical capability (Simchowitz, 2004; Delany *et al.*, 2005; Simkins, 2005; Natrass, 2007). The confusion between medical diagnosis and actual functional capacity also meant that disability grants were often awarded to people who may have been able to work. HIV positive patients were particularly likely to be given the grant on the basis of their positive status rather than their actual ability to work and the popular perception emerged that people with HIV/AIDS would automatically qualify for the DG (Schneider & Goudge, 2007; De Koker et al., 2006), in some cases even promoted by politicians to encourage people to test (Oppenheimer & Bayer, 2007: 185). The willingness of doctors to recommend DGs for HIV positive patients may also have been driven by a sense of hopelessness and nihilism created by the lack of available treatment for the disease (Oppenheimer & Bayer, 2006). As HAART was rolled-out from late 2003 and people with HIV/AIDS were able to recover their health, awarding the grant to PLWHA became increasingly complicated and created further confusion around eligibility criteria. Based on an analysis of assessment forms, Delany et al. (2005) found that in 2003, 41% of new permanent DG beneficiaries received the grant because of their HIV status, up from 27% in December 2001.

It should also be noted that temporary DG numbers increased as a result of the reinstatement of 35,529 temporary DGs, mainly in KwaZulu-Natal and the Western Cape, following the Mashishi³⁷ class action in May 2003 as a result of inappropriate lapsing procedures for TDGs (Steele, 2006; Delany et al., 2005). The Mashishi ruling also halted further lapses of TDGs until correct review procedures were instituted. Given that most provinces only instituted these procedures between late 2004 and 2005, many TDG beneficiaries received their grants longer than initially intended.

³⁷ *Mashishi and others v the Minister of Social Development and others*, unreported Transvaal Provincial Division case number (4239/03) 2003.

2.6 Tightening the assessment process

As the result of such massive increases in the number of DG beneficiaries, all provinces except the North West Province abandoned the experiment with APs by 2004. Assessment Panels were formally removed from the regulations to the Social Assistance Act of 1992 when the social security system was centralised through the new Social Assistance Act of 2004 and South African Social Security Agency Act 9 of 2004. Regulations to the Act in 2005 and subsequent amendments in 2008 required that disability be exclusively determined by the medical assessment of medical officers and confirmed by a medical report. However, the oversight role of the PMO was never reintroduced.

The purpose of the Social Assistance Bill [B57-2003] and the South African Social Security Agency Bill [B51-2003] was to consolidate the administration of social grants under one national agency (SASSA) and undo the assignment of social assistance functions to provinces, which had struggled to administer social grants. Both bills were introduced at a time when the report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa (known as the Taylor Committee) was still being considered by cabinet. This committee had been commissioned in 2000 to evaluate and propose a new design for the social security system in South Africa. As no clear policy framework for social security reform (including reform of the DG) had yet been developed, civil society organisations suggested in submissions to the Social Development Portfolio Committee that the introduction of the bill was premature and would do little to reform the existing system.

Although the 2002 Taylor Report is best known for the controversy raised by its recommendation to introduce a Basic Income Grant, it also raised some major issues related to the administration of the DG and the definition and assessment of disability. It made a number of recommendations on radically reforming the DG system, none of which were included in the Bill and few of which have informed actual policy change. Selwyn Jehoma, former Deputy Director General of DSD, attributes the “lopsided levels of success” in implementing recommendations to: controversy around the Basic Income Grant proposed in the report distracted policymakers and civil society away from many of the other valuable recommendations in the report; a lack of support for some recommendations; DSD’s focus on creating the South African Social Security Agency; and in the case of the DG, the lack of a ‘champion’ within DSD to take the disability recommendations forward (Jehoma, interview, 2014 August 11). Many of its recommendations, such as the implementation of a multi-disciplinary assessment panels, extending the grants to people with HIV/AIDS and other

chronic illnesses and taking a less medical approach may have also seemed unpalatable in the context of growing DG numbers and the perceived failure of attempts to move the system towards a more social model.

Although the new (2004) Social Assistance Act did not address problems in DG administration, the DSD quickly began to investigate ways to contain the growth of the grant. In order to contain the use of the DG as a poverty alleviation tool, the CASE report discussed earlier (Delany et al., 2005) recommended the introduction of standardised assessment tools, clear eligibility criteria and educating frontline staff about the rules of disability management. These recommendations were focused on ensuring that the DG was given exclusively to the people with functional impairments that limit their ability to participate in the labour market. However, by focusing on what Natrass (2007: 184) describes as a “narrow set of managerial solutions” and not the underlying social reasons for the growth in DG applications and the overgenerous awarding of grants by assessors, the state ignored an important message about the gaps in the social security system made obvious by demand for this grant.

The spike in DG recipients as well as concurrent rumours that people were intentionally defaulting on their anti-retroviral medication to avoid recovering their health and losing their grants, led to significant discussion of the DG in parliament and the media. This was used by academics as an illustration of the limitations of existing the social protection system (Leclerc-Madlala 2006; Hardy & Richter, 2006; Natrass, 2006; Venkataramani et al., 2010; Sogaula et al., 2005). It also raised serious questions about who should be considered disabled and the purpose of social security in the context of chronic illness (MacGregor, 2010). In parliament, however, the focus of discussions was on the role of doctors, whose actions were framed as fraudulent, as was the behaviour of those who malingered or defaulted on their medication.

The issue of subjectivity in the medical assessment process raised in 2000 in the proposals for DG reform had not been solved by APs and the DSD therefore remained concerned that the process allowed personal views on who ‘deserves’ social assistance to influence decision-making around DGs. Although the DSD put out a tender for the development of a tool for DG assessment in 2003, piloting showed that the tool was too complex and theoretical for practical use (Margie Schneider Interview, 2013). Although APs were removed no useful tools, standardised guidelines or proper oversight yet existed for medical assessment by MOs and reports presented to parliament by the Special Investigating Unit in 2006 indicated that sympathy felt by doctors for their patients lead to overgenerous, even fraudulent

behaviour on the part of the doctor.

Referring to the disability fraud cases, he said that one of the main concerns were doctors who certified people as disabled even though they were not. Many of them get paid to do this. This was organised crime and was one of the focus areas at present. There were cases as well where doctors classified people as disabled because the case was not very clear and they felt sorry for them. People with AIDS were a problem as classification depended on their CD4 count and these counts could fluctuate (PMG, 2006).

The *Report on Incentive Structures of Social Assistance Grants in South Africa*, produced for the Department of Social Development in 2006 to investigate the possible unintended effects of grants, also noted that the increase in grants was not only driven by applicants but those referring or assessing them for DG applications:

It is sometimes not the potential recipients themselves that respond in unanticipated ways to incentive structures. It may, for example, be gatekeepers such as doctors or social workers, or even social security staff, acting in the perceived best interests of their client (Steele, 2006: iii).

2.6.1 The Harmonised Assessment Tool and Chronic Illness Grant Proposal

In 2003, the Department of Health (DoH) introduced a Policy of Free Health Care at Hospitals for People with Disabilities, which offered free services to those with moderate to severe disabilities of a permanent nature. The need for doctors to assess patients' eligibility for these free services led to growing irritation amongst healthcare professionals who were already struggling under the pressure of DG assessments. To simplify this process and overcome the ongoing lack of tools and guidelines for disability assessment, the DSD and DoH jointly developed a Harmonised Assessment Tool (HAT), which was piloted in 2006. The HAT was based on a definition of disability specifically created for determining eligibility for the DG and FHC, which was approved by Cabinet in May 2005. This definition described disability in terms of the limitations in daily functioning and activities that a person is able to perform and reads as follows:

Disability means a moderate to severe limitation in a person's ability to function or ability to perform daily activities as a result of physical, sensory, communication, intellectual or mental impairment. The definition clarified that disability is neither a medical condition, nor the symptoms or impairments arising from a medical condition (DoH and DSD, 2009).

The HAT was designed to assess what activity or participation restrictions exist for each

individual. The tool has two components, a medical assessment and an Activity Limitation (AL) assessment. The medical assessment component would act to confirm the existence of a particular health condition, whilst the AL component assesses disability by measuring activity limitations in terms of specific categories of impairment through observation, information gathering through interviews and testing (DSD, 2010)³⁸. The AL assessment would be undertaken by a registered health professional who had received specific training in use of the tool and related assessment guides (DoH and DSD, 2009)³⁹.

This focus on activity limitations over medical diagnoses promised to shift the responsibility for assessment from doctors to other healthcare professionals better trained in assessing functionality than doctors. This focus was expected to ensure that only genuinely disabled people received the grant and also make the assessment process more sensitive to hidden disabilities than had not been possible through medical assessment alone. The introduction of HAT would also bring the assessment process more in line with international guidelines such as the World Health Organisation's International Classification of Functioning, Disability and Health (ICF).

The DSD hoped that the introduction of the tool would “ensure uniformity in the assessment of disability, thereby contributing to more efficient management of disability benefits” (Parliament. National Assembly, 2007). As well as reducing access to DGs by the chronically ill, which was seen by the DSD as a ‘major error of inclusion’ (DSD, 2010: 10), it was hoped that a more standardised process would also reduce the number of appeals against decisions and reduce the threat of litigation by applicants. The HAT was to be implemented in conjunction with SASSA's plans for a Disability Management Model, which was also aimed at standardising provincial procedures for disability assessment.

The disability rights movement, which promotes a multi-disciplinary approach to disability assessment and which had long opposed the use of medical doctors who are trained to focus on medical conditions rather than functionality, favoured the introduction of the HAT. Disability activists argued that DGs should be specifically targeted at the permanently disabled rather than those with chronic diseases. ANC MP Henrietta Bogopane-Zulu,⁴⁰ a

³⁸ It uses Global Assessment of Function tool to assess social, psychological and occupational functioning.

³⁹ Audiologists, occupational therapists, physiotherapists or speech therapists would perform most AL assessments, but clinical psychologists, optometrists, orthotists and prosthetists or registered nurses would also be able to perform assessments if necessary.

⁴⁰ Bogopane-Zulu was appointed Deputy Minister of Social Development in 2015.

vocal disability rights activist, made this argument in a number of debates in parliament and the parliamentary Portfolio Committee:

Ms Bogopane-Zulu said that they had told the DSD many times that doctors should not be used to certify disabled people. A doctor could be used for a chronic illness, which was not a disability. She requested SASSA to address this. A disability was permanent normally and a panel should be used to certify disabled people. Those with AIDS should be classified as chronic and not as disabled (PMG, 2006b).

With its strong emphasis on functionality, implementation of the HAT would imply that a significant number of people who had been accessing the grant based on their chronic illness would lose their grants when they were restored to health, for example in the case of HIV patients who received ARV treatment. HIV positive people technically did not qualify unless serious complications were present, or the patient was classified as Stage 3 or Stage 4 (AIDS-sick) according to World Health Organisation HIV guidelines, but many relatively healthy people still continued to receive disability grants. These and many of the other people with chronic illnesses who were not in fact functionally disabled would be excluded by the new definition of disability and the HAT. Given that so many people were likely to lose their grants, the Department of Social Development acknowledged that some provision needed to be made for the chronically ill living in poverty. This was based on the argument that although with treatment many chronic illnesses such as HIV may live very healthy lives, without an income to support adequate nutrition and transport to healthcare facilities for ongoing care, some might struggle to maintain their health. In 2007 the DSD commissioned the Human Science Research Council (HSRC) to investigate policy options to provide social security benefits to people with chronic illnesses. Research was based on a desktop review of national and international literature on the provision of social security for chronic conditions as well as a review of existing data sets on the prevalence of chronic conditions in South Africa.

The HSRC report recommended two policy options: 1) the introduction of the HAT alongside a Chronic Illness Grant (CIG) for people with chronic illnesses not eligible for the DG; and 2) the roll-out of the HAT and provision of a coordinated set of general poverty alleviation programmes (Schneider & Goudge, 2007). The introduction of a Chronic Illness Grant (CIG) had already been recommended in the National Strategic Plan on HIV/AIDS drafted by the South African National AIDS Council (SANAC) and then approved by cabinet in 2007. The CIG was a popular option amongst AIDS activist organisations such as the Treatment Action Campaign and National Association of People

Living with AIDS.

The DSD initially appeared supportive of the CIG option and according to Parliamentary Monitoring Group minutes, “it was felt that perhaps there was a need for a special chronic illness grant, or, as another option, the provision of food vouchers by the Department of Health” (PMG, 2009). The DSD presented the CIG as a policy option to the Social Transformation Committee at the 2007 ANC Policy Conference, but this proposal was rejected. Although the committee acknowledged “the need to provide some form of safety net for those people, who do not have any income and are not eligible for any form of social grant under the existing policy framework”, the discussion was “characterised by a realisation by both commissions that the ANC in government should discourage dependence on social grants and therefore should seek to develop comprehensive measures to fight poverty” (ANC Social Transformation Committee Minutes, 30 June 2007). As a result, the committee decided that the chronically ill should continue to be excluded from the definition and that no social grant would be issued to the chronically ill. Instead responsibility for the chronically ill was seen as the mandate the Department of Health (DoH) and the Integrated Food and Nutrition Task Team (PMG, 2009). A decision was made that food vouchers rather than grants would be provided to the chronically ill to ensure that they had adequate nutrition to ensure they would be able to adhere to their medication. The Department of Health was unsupportive of the idea of a CIG, arguing that the need for a CIG was related to poverty rather than health issue and that a CIG would not be an appropriate tool. As Dr Yogan Pillay and Deputy Director General of the Department of Health noted, both in parliament and in an interview: “poverty cannot be treated with a health intervention” (Pillay, interview, 2014 September 9). The proposal was also unsuccessful at the Social Cluster level⁴¹. Selwyn Jehoma, argued that this lack of support for the CIG was based on territorialism and concern about the possible diversion of resources from the DoH to DSD (Jehoma, interview, 2014 August 11)⁴².

The lack of support for the CIG outside of its advocates in the DSD also shows up some of the conflicts within government around social grants. While Zola Skweyiya (DSD minister 1999-2009) understood social grants to have developmental as well as poverty alleviation capacities and advocated for social grant expansion and reform, other sectors of government, especially

⁴¹ Clusters are formed through inter-ministerial committees that focus on specific policy areas and involve multiple departments.

⁴² He shared similar sentiments in a 2010 interview with Goldblatt and Rosa (Goldblatt & Rosa, 2014).

the treasury had been less enthusiastic. Skweyiya reflected on ideological contestations within government in a lecture he gave in 2011 after the end of his term as Minister.

As is expected in a world of contestation of ideas, especially in South Africa, there are concerns that the numbers of South Africans on social grants are too high and have been increasing exponentially. The issue of grants causing dependency on the state has gained currency...Our conviction is that far from creating fiscal wastage and creating dependency, we are actually making an investment on children in South Africa, an investment on the future of our country. That is a responsibility we cannot turn our backs on. (Zola Skweyiya, Oxford, 17 May 2011). Also see Quote 2.1 in Appendix C.

However, in the case of the CIG, the DSD could not present a strong enough case to confidently push forward with the proposal and therefore decided not to pursue it further. The weakness in the policy proposal lay in the lack of accurate estimates of the number of people with chronic illnesses potentially eligible for the CIG. The large number and high prevalence of illnesses categorised as chronic, the complication of comorbidities (and related problem of double-counting) and the absence of health data that could be cross-tabulated with income created the appearance that very high numbers of people would qualify (Jehoma, interview, 2014 August 11). This raised concerns about the likelihood that the Treasury would take such a proposal seriously, especially in the context of existing concerns about the large numbers of DG beneficiaries. The government had also only recently (2009) agreed to extend eligibility for the Child Support Grant to age 18 (this came after a long campaign by civil society organisations). Dimakatso Pooe, the Director for Disability and Old Age at DSD argued that the expected increase in the number of CSGs concerned fanned fears that grants were promoting dependency and laziness, which made acceptance of a CIG proposal unlikely (Pooe, interview, 2014 September 10).

2.6.2 The Social Assistance Act Amendment Bill of 2010

In order to make the implementation of a Harmonised Assessment Tool legally possible, it was necessary to insert a definition of disability into the Social Assistance Act 13 of 2004. In 2010, the Social Assistance Amendment Bill (B5-2010) was introduced to parliament to “*disability*”, insert the following definition of disability into the Act to support the implementation of the HAT.

*in respect of an applicant, means a moderate to severe limitation to his or her ability to function as a result of a **physical, sensory, communication, intellectual or mental disability** rendering him or her unable to—*

(a) obtain the means needed to enable him or her to provide for his or her own maintenance; or

(b) be gainfully employed; [emphasis added]

This definition emphasised functional limitation and clarified that these must be moderate to severe, excluding minor impairments. It also included sensory, communication and intellectual disabilities which had been previously excluded. According to the Minister of Social Development, Bathabile Dlamini, the amendments were intended to create “a more rational and less arbitrary means of assessing disability through limiting the discretion of individual doctors and our officials.” (Parliament. National Assembly, 2010).

Although chronically ill people who were not functionally disabled had never technically met the criteria for eligibility, it was never clear how disability should be measured and doctors were left with significant discretion. It was hoped that introducing a new definition and assessment tool would reduce this discretion and thus the number of with manageable chronic illnesses who doctors were classifying as disabled. Again, the discussions in parliament centred on the role of doctors in driving the increase in DG numbers.

We are further well aware that many of these people are poor and unemployed, and as a result are manipulating the system by collaborating with the doctors in their area, because of lack of income support to these unemployed people....Let us take a Dr Van Wyk who knows a Mr Khumalo very well, and this Mr Khumalo has a condition called asthma. His asthma can be managed through appropriate medication and he can still enter the labour market. Now, in medical terms asthma is regarded as a chronic illness and not a disability. A chronic illness can be defined as an illness that is prolonged, and would not be resolved spontaneously, but can be cured completely. A person with a purely chronic illness alone cannot be deemed to have a disability. Yet Dr Van Wyk would classify Mr Khumalo as disabled for the purpose of the opportunity to receive the disability grant, because he is sympathetic to him, as Mr Khumalo is unemployed and lives in poverty. (Parliament. National Assembly, 2010)

See Quote 2.2 in Appendix C

The DSD hoped that this would reduce inclusion errors and that fewer inconsistencies in DG assessment would reduce the backlog of appeal cases against the rejection of grant applications or lapsing of DGs, which had remained an ongoing problem for the department in the absence of harmonised regulations. The Bill also sought to add physical and mental disability to the definition of disability for the CDG and GIA, enable applicants and beneficiaries to apply to the SASSA to reconsider its decision and amend the process of appeals against SASSA’s decisions (Portfolio Committee on Social Development, 2010).

Civil society organisations were invited to consult on the 2010 Bill through oral and written submissions in April 2010. Their submissions suggest that these organisations were as concerned as the DSD about the administration of DGs and, specifically, how doctors’

discretion lead to unequal applications of the law (AIDS Law Project, 2010; Black Sash, 2010; SPII, 2010; Treatment Action Campaign, 2010; SACC, 2010). These submissions agreed that chronic diseases were presenting a challenge to social security programmes. However, those that submitted argued that the wording of the amendments not only did little to address the lack of clarity around the definition of disability, but that the definition and the application of HAT would be regressive in its exclusion of persons with chronic illnesses if no separate grant was provided for this group. Organisations that presented at the hearings argued that intentionally excluding groups of people already receiving DGs from accessing social security was counter to the state's obligation to take reasonable legislative measures to achieve the progressive realisation of social security rights as outlined in Article 27(2) of the Bill of Rights in the Constitution of the Republic of South Africa 1996 (Act 108 of 1996).

Disability organisations, the Disability Action Research Team and Disabled People South Africa, made no comment on the issue of chronic illness and only recommended that 'impairment' be used to replace disability in the definition of disability. The argument against the proposed amendments was led by a coalition of NGOs⁴³ who reintroduced the idea of the CIG, arguing that the Act should make provision for a CIG in recognition of the daily struggle against illness and poverty that chronically ill people face.

Civil society organisations argued that although incorporating the chronically ill into the labour market was an important goal, given high levels of unemployment and the inability of the chronically ill to compete in it, the majority of the people concerned were not employed anyway and that excluding them from social assistance would only increase poverty and hunger rather than push them into the labour market. The discourse employed by civil society in the debates around the bill recognised that chronically ill people face dual disadvantages of illness and poverty and are therefore deserving of grants. Underpinning this discourse is the belief that social grants have 'transformative' potential and as well as the ability to promote inclusion and social justice (Devereux, 2010). The Chronic Illness Grant was seen as a way to create independence by supporting people with chronic conditions to lead healthy lifestyles, which would allow them to participate in society as active citizens and potentially find work.

⁴³ This group included the Treatment Action Campaign, the AIDS Law Project, Black Sash, DART, DPSA, NAPWA, SPII and the South African Council of Churches.

Members of Parliament (MPs) on the Social Development Portfolio Committee employed a conflicting, conservative discourse that saw grants as creating dependency and work disincentives rather than development. Whilst civil society saw the rumours around non-compliance with medication and the over-generous awarding of grants by doctors as indicative of limitations of the current social security system and the general lack of jobs, DSD and parliamentarians instead problematised this behaviour as fraudulent. Despite the fact that adherence is considered to be a complex health issue, especially for infectious diseases such as TB and HIV/AIDS that are most prevalent amongst disadvantage populations (Munro et al., 2007) those who defaulted or neglected their health and became disabled were blamed for being irresponsible with their health. This “victim-blaming ideology” (Bauer et al., 1998) neglected the socio-economic origins of ill health such as income, access to healthcare, levels of education, food security and housing.

These MPs argued that failures of the labour market and the burden of chronic illness should not be addressed through social grants and therefore a Chronic Illness Grant would not be appropriate. In their view, unemployment and poverty were not the exclusive problems of the DSD; thus an intersectoral approach was necessary and in keeping with this, discussions about these issues were not relevant to the amendments at hand. Issues around exclusion of the chronically ill, especially those with HIV/AIDS, were seen as part of a bigger labour market issue which should be addressed by employer education programmes and job creation strategies rather than social grants. Given efforts to ‘normalise’ HIV as a chronic disease and reduce the stigma around HIV, some parliamentarians also felt that a chronic disease grant would be counter-productive to these efforts (PMG, 2010a).

There was also concern amongst parliamentarians that people gambled and bought liquor with their grants and came to the same conclusion that ANC members at the 2007 policy conference had reached – that providing food vouchers rather than a new category of social grants was the best solution for dealing with the chronically ill. It was therefore generally agreed by parliamentarians from all parties that the best solution to the difficulties that chronic illness posed to targeting DGs was tightening definitions of disability to exclude chronic illness, except in cases where people were measurably impaired by their illness.

Whilst the Portfolio Committee on Social Development accepted the recommendation that impairment rather than disability be used within the definition of disability, it ultimately rejected the civil society’s chronic illness grant proposal and aimed to proceed with the Bill as planned (PMG, 2010b). However, all six sections of the bill relating to disability were

ultimately scrapped. This was because in May Dr Yogan Pillay, then Acting Director General of the Department of Health, made a presentation to the committee stating that the DoH was not ready to implement the assessment tool. The DoH had insufficient healthcare professionals such as medical doctors, occupational therapists and physiotherapists to conduct these assessments and had not trained professionals outside of the sites where the HAT was initially piloted. This came as a complete surprise and disappointment to the DSD, who had collaborated with the DoH throughout the process of developing the tool. Although this was not articulated in the parliamentary debate, because 250,000 people with chronic illnesses would be excluded from the DG (Jehoma, 2010), technocrats from the DoH and DSD argued that ANC politicians were concerned about implementing the tool ahead of upcoming municipal elections (Pooe, interview August 2014; Pillay, interview, 2014 September 9). It was therefore concluded HAT should be deferred until the DoH had better capacity to deal with chronic illnesses.

The DSD was tasked with re-developing the HAT to address the issue of chronic illness in DG assessment more adequately. However, although Dimakatso Pooe, from the Directorate for Disability and Old Age Grants in the DSD remains a strong proponent for the HAT, the department has not made any further moves to implement HAT. An important reason for this lack of action has been disagreement between the DSD and SASSA, about how disability assessment should be conducted. Until August 2014, SASSA's disability programs were managed nationally by Dr John Marite, a medical doctor, who had opposed the introduction of HAT and resisted a move from a medical model that relies primarily on the input of medical doctors (Jehoma, interview, 2014 August 11; Marite, interview, 2014 June 27). The capacity and willingness of the DoH to implement HAT also remains in question. A doctor contracted to SASSA indicated that the problem with the HAT tool "starts and ends with the Department of Health" and that "while the theory is nice, the practicality is not so straightforward" (Dr Jacobs⁴⁴, interview, 2013 October 24) because the healthcare system is unlikely to have the capacity to carry out Activity Limitations assessments for some time. As a result, the DG assessment process remains purely based on medical assessment by medical doctors.

Marston (2013) argued that governments can use the incentive structures, rules and guidelines of bureaucracies to pursue policy objectives that they may otherwise struggle to through legislative processes. Although legislative efforts in 2010 to implement a new multi-disciplinary assessment tool and introduce a new definition of disability into the Social

⁴⁴ Pseudonym

Assistance Act were ultimately unsuccessful because of implementation capacity and political concerns, through bureaucratic incentive structures, rules and guidelines, the government has successfully pursued its policy objectives of reducing DG numbers that were not possible legislative processes. Through the implementation of a Disability Management Model (DMM), SASSA was able to significantly reduce beneficiary numbers outside of legislative channels by 22% from 1.44 million in 2007 to 1.1 million in 2015. The decline in the number of AIDS-sick people as ARVs became widely available is also likely to have contributed significantly to this decrease

2.7 Conclusion

This chapter has shown that the post-apartheid state initially sought to extend access to disability grants through dismantling administrative barriers, supported by a socio-economic and disability rights discourse set against the perceived discrimination and exclusion under apartheid. This led to a drive to de-medicalise the disability assessment process and increase the number of people able to conduct assessments. These changes were not intended to make the DG system more lenient. Rather, the goal was to improve access to rightful beneficiaries through improved assessment mechanisms and reduced inefficiencies in the system.

However, through this process the amount of discretion available to disability assessors was inadvertently increased and the system effectively became more lenient. Given large amount of poverty in many communities, combined with the HIV epidemic for which there was no widely available treatment at the time, assessors used their discretion to recommend grants on humanitarian grounds for many more people than had ever been planned for. Through their decision-making, assessors shifted the DG, aimed at a very specific population, towards a bigger intervention that recognised labour market problems and the social and economic impacts of the HIV epidemic. What emerged was a “moral underground” (Dodson, 2009) of well-intended, rebellious bureaucratic action and the DG became, in effect, an HIV grant and a general poverty alleviation grant, serving a purpose beyond the one for which it was designed. As the number of grants paid escalated in the early 2000s, the state became concerned with what came to be seen as over-generosity and fiscal unsustainability. Efforts to incorporate social understandings of disability into DG assessment were quickly halted as beneficiary numbers increased.

Hacker (2004: 246) argues that when policy drift occurs, policymakers face a decision about whether and how to respond to the growing gap between the original aims of a policy and the

new realities that have emerged with shifting social conditions. In the South African case, the government did not respond to this emerging need. Although the viability of a Chronic Illness Grant and a Basic Income Grant to close the gap in what was clearly an incomplete social safety net, were investigated, they were ultimately abandoned on budgetary and ideological grounds. Instead, policy makers focused on fixing the principal-agent and targeting problem in DG administration. In an effort to re-take control, the government embarked on a process of retrenchment and rationalisation, largely focused on reducing assessors' discretion and subjectivity. This narrow problem definition ignored the underlying and much less tractable issues driving demand for the grant and reasons for why the actions of street-level bureaucrats like doctors diverged from official policy directives.

Through a feedback-loop, policy implementation created the politics that then very directly informed policy decision-making. In this case, doctors' actions (and for a brief period, APs) shaped policy in a way that extended access to the grant, but ultimately reduced their parameters for action. The story of overgenerous assessors and abuse of the grant by non-disabled people was used to frame the policy debate around the growth in DG numbers and drove reform of the social grant system towards strictness. Since then, regulation of the DG has been focused on defining and guarding the boundaries of the disabled category. SASSA, have also embarked on a series of efforts to better regulate the DG application and assessment process and constrain opportunities for differentiated interpretations of disability and the level of discretion in the system overall. However, underlying drivers of DG demand, such as structural unemployment and the lack of adequate social security for the chronically ill and general unemployed, have not been addressed. Efforts to tighten DG access within this context have distracted policy makers from developing a DG system that promotes the inclusion and development of disabled people in society.

Two additional points can be made about the history of the DG, and of disability assessment in particular. Firstly, although many of the efforts to reform the DG system have been driven by an administrative and fiscal management agenda and legal action by disgruntled applicants and beneficiaries, broader welfare discourses have also influenced the government's approach to providing social security to the disabled. Changes to DG policy over time reflects tensions between the ANC government's early social justice rhetoric and constitutional commitments to socio-economic rights and anxieties about financial sustainability and the development of a 'culture of hand-outs' and 'dependency' The government has struggled to present a coherent strategy for how to incorporate social grants into the post-apartheid and despite significant

growth in the number of social grants since 1997, government discourse has increasingly emphasised the dangers of growing welfare dependency (Surender et al., 2010; Meth, 2004; Barchiesi, 2011; Seekings & Matisonn, 2010).

“We have a governing party that boasts about the generosity of the social assistance system, but in reality despises it. That filters into how we construct the social security system, including the disability one. We had our glory years up to the end of Dr Zola Skweyiya’s political leadership. I think post him we have had leadership that just think social grants create dependency. The current political leadership doesn’t believe in social security, neither at the cabinet level nor within the department, but at the technical there is still a real understanding of the importance of it.” (Jehoma, interview, 2014 August 11).

Seekings (2015: 135-136) argues that concerns about decommodification come from two fronts – a progressive developmental position that prefers social development to welfare provisioning and conservative fears about the affects of decommodification on social order and values.

However, despite its reticence about grants, the ANC recognises how important they are to the electorate. The inter-governmental tensions about the value and purpose of social security interventions are visible in debates around the definition of disability, how to measure it and what resources should be dedicated to this process. While the likes of Zola Skweyiya in the DSD have for the most part seen social grants as developmental interventions, this view has not been shared in other parts of government. These disagreements have meant that despite achieving increased administrative efficiencies, the state has remained stuck with largely the same system that that was in place in the Apartheid era.

Secondly, the difficulties in accurately targeting the grant at disabled people reflect a set of deeper systemic issues such as structural unemployment that cannot be addressed by management techniques. Instead of focusing on systemic issues, regulation of the DG has been focused on defining and guarding the boundaries of disability to ensure that the grant is properly targeted at those who are functionally disabled. Although the DSD has made several attempts to move away from pure medical assessment of grants, the complexities and costs of assessing activity limitations and their relation to social, economic context and the physical environment, are too high for the current healthcare or social security system to manage effectively. This has meant that the state has remained stuck with largely the same system that has been in place since apartheid. Although the DSD and SASSA now have greater oversight and control of the assessment process, uneven application of assessment criteria continues due to ‘grey areas’ within the assessment process.

While accurately targeting the grant is important, in the process of trying to define disability

more narrowly, the political and public debate has lost sight of the objectives of the DG, which is to “provide individuals with the means to disrupt forces which maintain their predicament of chronic impoverishment” (Andrews *et al.*, 2006). The focus on cutting out people who do not deserve the grant has distracted policymakers and legislators from developing a DG system that promotes the inclusion and development of disabled people in society.

CHAPTER 3: The Disability Management Model in the Western Cape

3.1 Introduction

As Chapter 2 demonstrated, the administrative criteria for administering social grants have been contested in post-apartheid South Africa and remain poorly defined. SASSA, the street-level organisation charged with implementing DG policy, has inherited the unresolved political conflicts and ambiguities around DG policy and has had to develop its own criteria and organisational structures to control DG policy implementation and outcomes. The DG has also been highly problematic in terms of delays, backlogs and litigation brought forward by claimants and there have been significant differences in how the grant has been administered across provinces and between service delivery points. The Disability Management Model (DMM) was designed to attend to all of these problems and is a set of rules and bureaucratic processes which aims to ensure that DG assessments are conducted in an objective, rational, systematic and procedurally fair way. The DMM and its associated National Standardised Assessment Tool (NSAT) were designed in the 2007/2008 financial year by SASSA's Disability Management Department. Piloted in the 2008/2009 year and gradually implemented from 2009, it was intended as a broad management framework, which would lay the groundwork for the eventual rollout of the Harmonised Assessment Tool, which had been designed and piloted in 2006. As the HAT has not yet been implemented, the NSAT tool has remained in place.

As shown in the last chapter, the South African government's response to the increase in DG recipients in the last decade has focused on disability assessors and their 'overgenerous' awarding of grants based on social and material conditions. The DMM aims to control policy implementation by constraining doctors' discretion and increasing both their and SASSA officials' accountability through increased oversight. This reaction is similar to those of policy-makers in OECD countries that have responded to problems in disability benefit administration (including increases in beneficiary numbers and expenditure) by developing bureaucratic systems, protocols and refining assessment processes and administration procedures to limit the discretion of gatekeepers (Schram et al., 2010; Marston, 2013).

The DMM also forms part of other efforts made by the South African government to hold employees more accountable both to citizens and clients and the departments that they work for. This work has mainly been carried out by the Public Services Commission (PSC) and more recently the Department of Performance Management and Evaluation (DPME). The PSC has

developed procedure manuals, codes of conduct and monitoring frameworks whilst the DPME has a more explicit focus on improving monitoring and evaluation and planning capacity within government, including a specific focus on frontline service monitoring and client satisfaction surveys. The most prominent effort to improve frontline service delivery has been the introduction of the Batho Pele (“people first”) principles of public service delivery as a requirement for planning and service delivery in all government departments (Batho Pele White Paper, 1997)⁴⁵.

This chapter is largely contextual and intended to describe doctors’ situational context for the remainder of this thesis. It is vital to consider policy design, organisational capacity and implementation context when assessing street-level bureaucrats’ exercise of discretion and their contribution to policy outcomes (Meyers & Vorsanger, 2007). This is shaped by external and internal policy frameworks, institutional and organisational cultures and hierarchies, organisational or bureaucratic procedures, hiring policies, formal and informal incentive structures, performance standards, classification guidelines and service strategies (Barnes & Prior, 2011; Rice, 2012; Meyers & Vorsanger, 2007).

This chapter begins by describing the legal structures that govern SASSA and DG administration and the operations of the DMM, focusing specifically on its implementation in the Western Cape. It then provides a description of the DG application process from start to finish and the organisational structures and administrative procedures that structure this process. It outlines the service agreements with the Department of Health and medical doctors that govern how doctors are included and participate in the DG system. Finally, I describe the oversight systems, training and protocols designed to standardise doctors’ work. Although sometimes mundane, these details of the disability grant bureaucracy set the rules and goals for practice and are foundational in understanding how organisational factors shape the interaction between doctors and patients and therefore who is ultimately given access to the grant.

3.2 The SASSA Bureaucracy

SASSA is a Schedule 3A public entity, reporting to the Department of Social Development and mandated by the South African Social Security Agency Act of 2004 to manage, administer and pay social grants in accordance with the Social Assistance Act of 2004 (as subsequently

⁴⁵ These principals emphasise developing mechanisms for customer consultation and choice, developing precise measurable service standards, increasing access to clients, courtesy to clients, providing information to clients, openness and transparency, value for money and opportunities for redress (Batho Pele White Paper, 1997).

amended) and Regulations gazetted in terms of the Act, as well as the Constitution of the Republic of South Africa, 1996 (Act 108 of 1996). SASSA's slogan points to its main goals: "Paying the right social grant, to the right person, at the right time and place. Njalo⁴⁶" As a frontline service provider, the way that SASSA manages its staff, systems and processes shapes the way in which the millions of people who receive social grants in South Africa interact with the state. As Marston (2013) points out, this distributive role makes the work of agencies such as SASSA fundamentally political.

The SASSA Act (2004) requires SASSA to provide "honest, impartial, fair and equitable service delivery" and promote and protect the human dignity of applicants for and beneficiaries of social security. SASSA's organisational values are transparency, equity, integrity, confidentiality and a customer-care centred approach (SASSA, 2014). Its priorities, as outlined in its original Strategic Vision document are: reducing delays throughout the grant process, improving conditions at pay points, improving customer service and communication, reducing litigation against the government and standardising service delivery nation-wide. The DMM provides an example of SASSA's efforts to address these issues and improve service delivery.

SASSA is subject to Chapter 2 of the Bill of Rights in section 27(1c), which states that everyone has the right to have access to social security, including social assistance if they are unable to support themselves. Section 27(2) also commits the state to take reasonable legislative and other measures, within its available resources, to achieve the "progressive realisation" of each of these rights. This means that SASSA cannot unreasonably limit the rights of any individual or group of individuals to access social grants. It is therefore important for SASSA to balance providing social protection for the needy (providing opportunities for access) with protecting the boundaries of the disability category (reducing inclusion errors). As 2008 Regulations to the Social Assistance Act of 2004 stipulate that an applicant's disability must be confirmed by a medical officer, SASSA relies on the cooperation of these medical officers in achieving this balance. A *medical officer* is "any medical practitioner in the service of the State, or a person appointed under a contract to perform the functions or render services of a medical officer in terms of the Act." Medical officers are medical doctors registered as healthcare professionals under the Health Professions Act of 1974 and are subject to the codes of ethical and professional practice laid down in this act.

SASSA was careful to communicate with both doctors and the public that doctors did not have

⁴⁶ "Njalo" means always in isiZulu

the legal authority to award or reject applications for DGs (Observations of SASSA Training, February 2014; SASSA, 2011). Doctors make a recommendation on a client's eligibility based on their clinical assessment, but the final decision is made by SASSA who also administer the means test and perform other administrative checks (e.g. age, citizenship or permanence residence). This is typical practice internationally, where a caseworker or administrator generally makes the final decision regarding eligibility (De Boer, 2007). However, as a claimant could not receive the grant without a recommendation from a doctor⁴⁷ and SASSA administrators were not trained to interrogate the medical information or assess it in relation to other information from clients (e.g. age, education), applicants would typically receive the grant if they passed the means test. This meant that in most cases a doctor's decision on whether to recommend a DG determined whether a patient received a grant, making them very important gatekeepers to the system. Therefore, in order for SASSA to achieve its objectives, fulfil its legislative mandate and avoid litigation from claimants, it was important to ensure that the medical officers responsible for conducting assessments did so in-line with the Social Assistance Act and in ways that promoted its values.

An important part of SASSA's role in managing doctors' work was ensuring that doctors adhered to legal eligibility criteria. According to the Social Assistance Act of 2004 this meant that the person has a mental or physical disability that makes them unable to support themselves through work. Section 3(c) of the 2008 Regulations to the Social Assistance Act further defines eligibility in relation to employability and an applicant is eligible if "he or she is unable to enter the open labour market or support himself or herself in light of his or her skills and ability to work" and does not unreasonably refuse to any income generating employment within his or her capabilities. The DMM is designed to clarify how disability should be determined and make doctors more accountable for upholding these definitions in carrying out their assessments.

3.3 Structure of the DMM and organisational arrangements

The DMM focuses on rationalising and standardising the application and medical assessment process for disability-related grants (DG, Care Dependency Grant and Grant-in-Aid) in all regions in South Africa (SASSA, 2011). The DMM also aims to curb fraud and improve administrative efficiency throughout the system. This is achieved through standardised

⁴⁷ Although doctors can consult with other professionals, they make the final recommendation on the assessment. In Europe and North America, there is significantly more input from other professionals such as social caseworkers, labour market experts or rehabilitation experts as well as the client who provides reports their work history, activities and limitations (De Boer, 2007; Anner et al., 2013).

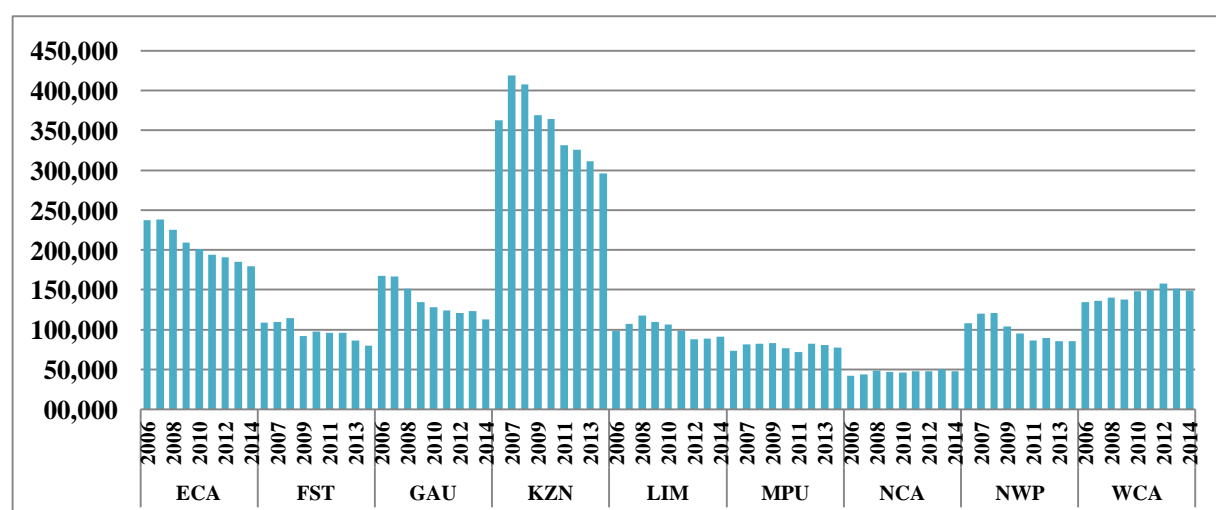
management procedures, a standardised assessment tool, a set of medical guidelines, training for doctors and quality assurance and auditing and oversight practices.

De Boer argues that it is difficult for society and claimants to accept that the final outcome of an assessment does not only depend on the claimant's physical or mental condition, but the discretion of the person who performs the assessment (De Boer, 2009: 168). The DMM therefore intends to shape bureaucratic action by reducing the discretion available to doctors and controlling doctors as bureaucratic "thinkers" (Heyman, 1995: 263) to ensure that they adhere to its norms and standards. Decision-making procedures and tools like the DMM create 'mechanical objectivity' (Daston & Galison, 1992), which Sherz (2011: 46) argues are an attempt to turn "the political problem of balancing citizens' rights and state responsibility into a technical problem". Standardised procedures and protocols also create a barrier to unwanted criticism (Busch, 2011), which in the case of the DG, was necessary to reduce the large number of court cases brought against the state on the basis of contested DG assessment processes (Marite, interview, 2014 June 27; Pooe, interview, 2014 September 10; Jehoma, interview, 2014 August 11)

Until August 2014, there was a Disability Management Department dedicated to the administration and management of disability-related grants, headed by Dr John Marite, a medical doctor. This has since been subsumed under the Benefits Administration and Support programme, managed by the Grants Administration Branch at the National Office as part of a general restructuring process. At the time of writing, each of the nine regional (provincial) SASSA offices had their own Disability Management Unit (DMU), tasked with overseeing the DG process from initial screening through to quality assessment and final award of the grant. The DMU in the Western Cape was responsible for managing the agency's relationship with the Western Cape Department of Health around the provision of assessment services and facilities, providing medical form management, overseeing the quality assurance process, training assessors and the implementing claims procedures for service providers (SASSA, 2011). Five district-level offices were meant to oversee the activities of the sixteen local offices and the satellite sites/service centres connected to them. At the time of writing, these district 'offices' were not yet operational, meaning the regional office was effectively managing all district-level functions, putting significant pressure on the very small regional DMU team in the Western Cape (manager, assistant manager and two clerks). This lack of capacity limited monitoring and evaluation activities and therefore the amount of oversight that the DMU could have over local offices and medical assessors (DMU Official, 2014 June 23).

The actual medical assessment booking, application and approval process was carried out at local SASSA offices within each province. Within each local office there were one or two Dedicated Disability Officers (DDOs) responsible for coordinating all medical management processes and activities at clinics, including coordinating with local health facilities and doctors, picking up and dropping off assessment registers and books and performing administrative quality assurance checks. Local offices kept a file of all assessments conducted at a particular site in order to keep track of the number of assessments booked, the appointments honoured by patients and the claims made by assessors.

At the end of June 2014, 150,630 people in the Western Cape received DGs, of which 24% (36,277) were temporary grants⁴⁸. Along with the rest of the country, the Western Cape experienced an increase in DG beneficiaries between 2000 and 2007. However, beneficiary numbers grew less than the national average. Between 2001 and 2004, when DG growth was at its peak, the number of permanent DGs increased by only 85%, which was significantly less than the 143% average national increase (Delany et al., 2005). This relative stability can be attributed to the fact that the Western Cape did not change its disability grant policy or procedures between 2001 and 2004 as other provinces did and was not as severely affected by the HIV epidemic (see Delany et al., 2005). Likewise, the downward trend in national disability beneficiary numbers has not been reflected in the Western Cape to the same extent as in other provinces. As can be seen in Figure 2, DG numbers have remained relatively stable since the DMM was introduced.



⁴⁸ I conducted fieldwork during the fourth quarter of the 2013/2014 financial year (1 December – 31 March) and slightly beyond the first quarter of 2014/2015 (1 April – 30 June). As far as possible, the administrative data presented reflects this time period.

Figure 1 Total number of DGs per province 2006-2014 (SOCPEN data compiled by SASSA)

Data provided to me by SASSA, which was compiled from the Social Pension (SOCPEN) database, shows there were 22,237 DG applicants in Western Cape in the 2013/2014 financial year, a 17% reduction from the previous year.

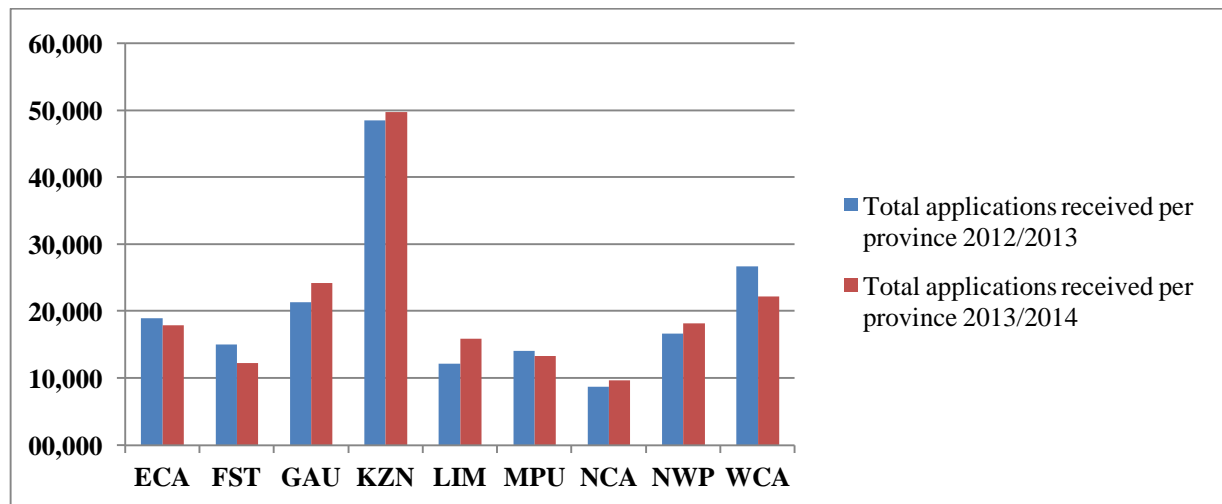


Figure 2 Total applications received per province

However, this data significantly underestimates the actual number of applications submitted in each province and the number of assessments conducted by doctors. This is because the SOCPEN system only counts first time applications and therefore would not register people applying for a temporary DG for a second, third or fourth time, which is very common. Provincial-level data provides a more accurate picture of the number of people applying for DGs because monthly statistical reports are produced from local office data rather than mined from the SOCPEN system. Table 3 below provides data on the number of assessments conducted in the Western Cape across all districts for the 2012/13 and 2013/24 financial year and demonstrates the discrepancy between the number of applicants as recorded in the SOCPEN database and the number of assessments conducted in the province. This shows that although first time DG applications decreased between 2012/2013 and 2013/24, the number of people actually receiving medical assessments increased.

Table 3 Comparison of medical assessments and applications received in the Western Cape

Financial year	Total medical assessments (provincial data)	Total applications (SOCPEN)
2012/13	106,674	26,734
2013/14	113,495	22,237

3.3.1 Interorganisational relationships around DG assessments in the Western Cape

The relationship between the Department of Health (DoH) and SASSA around the provision of assessment services varied across provinces. In the Western Cape regional SASSA office, the facilities and medical personnel used to conduct assessments were provided by the Western Cape DoH. This arrangement has been in place since March 2004, when the provincial Department of Social Services and Policy Alleviation (now Department of Social Development) began to provide funding to the DoH to supply medical assessors to tackle medical assessment backlogs in specific areas (SASSA/DoH, 2014). After SASSA was established in 2006 and took over DSD functions, the new regional SASSA office made similar arrangements with the DoH. From 2008 onwards, annual service level agreements (SLAs) have been signed between SASSA and the six health districts in the Western Cape, that covers service expectations, targets, quality assurance and monitoring and evaluation.

Disability assessments were conducted by doctors in all three levels of the healthcare system: at PHC facilities, at the secondary level in district and regional hospitals, and at tertiary hospitals. The majority of DG assessments in the province take place at the PHC level and are conducted by physicians contracted specifically by the DoH to conduct the disability assessments (in some cases SASSA contracted doctors directly, but this was rare). These supposedly impartial third-party agents, whom I will call 'SASSA assessors' do not treat patients they assess. SASSA has made a shift towards using third-party assessors for DG assessments, which is common practice internationally, because it is presumed that doctors with established relationships with patients may struggle to be objective or have incentives to privilege patients' interests over those of state or corporate bodies, both for financial reasons and because of feelings of obligation towards patients.

Treating doctors were, however, able to assess their own patients in hospital inpatient and outpatient settings. Their assessments were considered sufficient and patients did not need to be assessed further by SASSA assessors. In the past, all medical officers were able to fill out DG assessments for patients, but since the introduction of the DMM, SASSA has reduced its reliance on the assessments of treating doctors. This is because of potential bias in decision-making, the pressure it placed on the doctor-patient relationship and because of the additional work it created for overburdened doctors in the public sector (see Chapter 2). At the time of conducting fieldwork, the Western Cape and the Eastern Cape were the only provinces that had not completely eliminated the role of treating physicians in the assessment process.

In other provinces, SASSA contracted medical assessment services to medical consortia (e.g. Gauteng region), independent doctors (e.g. Limpopo and Kwa-Zulu natal regions), delegated all services to the DoH (Eastern Cape) or used a hybrid model (e.g. Northwest Province).

According to Dr John Marite, former General Manager of the national Disability Management Department, this variation in the models used across the provinces was a result of the variation in the DoH's capacity and willingness to provide doctors or facilities across the provinces (Marite, interview, 2014 June 27). The Western Cape's model was possible because of the high numbers of doctors in the province relative to other provinces (DMU Official, interview, 2014 June 23; Health Systems Trust, 2014). In provinces where DoH facilities are not used for the assessments, claimants could only be assessed by SASSA assessors in dedicated rooms in SASSA offices.

SLAs with the Western Cape DoH health districts were focused on regulating service standards for assessments conducted in PHC facilities by SASSA assessors and were less prescriptive about assessments conducted by treating doctors. According to the 2014/2015 SLA signed with Metro Health Services in Cape Town, the DoH was responsible for providing medical assessors, an appropriate assessment room and a designated health official to coordinate assessments at the clinic level. Doctors contracted to carry out assessments had to be registered with the Health Professionals Council of South Africa, be trained in the use of the NSAT tool and SASSA guidelines and could not conduct more than forty assessments per day. In turn, the DoH provided a schedule for each medical facility, prescribing the maximum number of assessments that SASSA officials could schedule at a PHC facility on a given day.

In accordance with the SLA, SASSA paid the Department of Health for each assessment conducted at the PHC level and at specific district hospitals that claimed for assessments conducted by treating doctors (not all district hospitals made claims). Tertiary hospitals did not make claims. In the 2014/2015 year, SASSA paid R123 for each assessment conducted for application or review purposes and reimbursed doctors for trips made to assessment sites further than 80km away (SASSA/DoH, 2014).

There is higher demand for DGs in high poverty areas and doctors ran assessment clinics in these clinics several times a week as opposed to once a week in other areas. The data in Table 4 is compiled from data presented in the 2014/2015 Service Level Agreement between Metro District Health Services and SASSA Western Cape in the 2013/2014 financial year. Table 2 shows the number of assessments that were conducted in clinics and hospitals served by local SASSA offices in the Cape Town Metropole (one of the six health districts) for all three

disability-related grants.

Table 4 Number of assessments conducted in 2014/2015 in the Cape Town Metropole

Local SASSA Office	DG	CDG	GIA	Total
Wynberg	6,107	148	99	6,354
Athlone	4,106	230	83	4,419
Bellville	9,562	264	179	10,005
Khayelitsha	11,180	55	141	11,376
Cape Town	4,243	66	61	4,370
Eerste River	11,261	106	238	11,605
Gugulethu	12,000	34	133	12,167
Mitchell's Plain	9,232	80	109	9,421
Total	67,691	983	1 043	69,717

According to a DMU representative, there were, on average, 132 doctors contracted to conduct assessment services at community health centres and clinics in the Western Cape (DMU official, email correspondence, 2015 February 12). SASSA kept a record of their signature and details and the quality assurance officer, who conducted audits on assessment forms was able to track their work and approval rates (although in practice, the capacity to do this was limited - see Section 3.3.3). SASSA did not keep track of the number of doctors who conduct assessments in hospitals because all doctors working in a hospital could, in theory, recommend DGs. This made it more difficult to train or oversee the work of doctors in hospitals.

In the case of SASSA assessors, the Department of Health typically sub-contracted the provision of medical personnel to locum agencies that recruited doctors to work as disability assessors in PHC clinics. In more rural areas, the DoH would directly contract general practitioners in private practice or, where there was a scarcity of doctors, SASSA would employ assessors to travel to these areas. Agencies were responsible for assigning doctors to certain clinics on particular days. SASSA was not involved in the relationship between locum agencies and the DoH or between doctors and the locum agencies they were contracted to.

Although doctors contracted via locum agencies did have some contact with SASSA through an annual training session, their work was not directly managed by either the Department of Health or SASSA. This meant that their daily work was especially difficult for the DoH or SASSA to oversee and it was therefore difficult for the DoH to ensure the quality of assessments promised in the SLA. To whom doctors in treating settings were accountable in conducting assessments was also unclear. I heard several reports from doctors that some of their colleagues rushed through assessments very quickly, but still claimed the hours for a full

day's work, in one case resulting in disciplinary action by the DoH. In order to have greater quality control, some DoH sub-district offices in the Cape Town Metropole, such as the Mitchell's Plain sub-district, had started to contract assessors directly. These doctors were also paid a sessional, hourly rate.

Relative to other 'sessional' or locum work or full salaried work, assessors are relatively poorly paid. Although the Department of Health was paid per assessment, they paid agencies an hourly sessional rate rather than for each assessment conducted. Agencies took a cut of this hourly rate and doctors working for agencies were eventually paid around R200 per hour (according to doctors). This amount was significantly lower than rates set by the Department of Public Service and Administration for medical officers working in treating settings (as of April 2014 the rate was R287 to R381 per hour, depending on experience). In cases where doctors were contracted directly to SASSA in rural areas, doctors had direct relationships with local SASSA offices and coordinated directly with the offices and clinics regarding logistics and were paid the full assessment rate as well as transport costs (R123 per assessment).

3.3.2 An overview of the booking to application process

This section presents an overview of the disability grant process as it existed in 2014 and is based on the *Social Grants Disability Management Model Process Guidelines* (SASSA, 2011), interviews with SASSA DMU staff and my own fieldwork.

With the exception of people treated in hospital settings, people wanting to apply for DGs were required to visit their local SASSA office to book a medical assessment at a PHC facility in their area. Before being given an appointment with a SASSA medical assessor, clients were pre-screened by SASSA officials. Using a client's identity document, SASSA officials checked the individual's status on the local office booking system and the national SOCPEN database. A medical assessment was considered valid for three months and booking would only be made on the local office booking system if the applicant had not been assessed in the previous three months or had documented proof that their medical status has changed since their last application. This gatekeeping procedure was introduced to deter people whose applications were refused from immediately re-applying, which Dr Marite described as an "abuse of access" and had happened regularly in the past. The implementation of this system has significantly reduced application numbers and presented a significant cost saving for SASSA (Marite, interview, 2014 June 27; SASSA, 2013).

Although the initial design of Disability Management Model included a National Medical

Assessment Booking system, this was never implemented. This meant that although a claimant could not apply more than every three months, a claimant could technically book multiple assessments at different SASSA offices. The claimant would however need to have a medical file at a clinic served by that office. Although a DMU official (interview, 2014, June 23) indicated that there is potential for people to “clinic around” (i.e. shop around for different doctors), it would require significant effort to cultivate comprehensive and up-to-date medical files at multiple healthcare facilities that served different SASSA offices. This potential abuse was therefore of only minor concern. During fieldwork, I noticed that people often received treatment at various different facilities. However, rather than creating opportunities to abuse the system, the lack of a centralised medical records system more often created a barrier to access. This was because people’s medical records were often dispersed over multiple facilities, making it difficult for doctors to piece together patients’ medical records and reduced the availability of medical information doctors needed to make a decision. This meant that patients sometimes had to return to previous places of treatment to request these records, which presented a problem to people with little money for transport and low levels of education.

In other provinces, where patients were not assessed at DoH facilities, claimants had to have a referral form filled out by their treating doctor before they could be booked for an assessment with a SASSA doctor. This referral system acted as both a gatekeeping mechanism and a way to ensure that adequate medical information was available to the SASSA assessor. At the time of writing, this referral system was not in place in the Western Cape as all assessments took place at DoH facilities⁴⁹. The lack of medical gatekeeping at the pre-screening phase meant that a large number of ineligible people were given appointments with DG assessors. During one of the SASSA training sessions I observed, doctors requested that SASSA implement a referral process at all facilities. This request was based on their experiences of assessing large numbers of people who they felt clearly did not qualify for the grant. They also blamed the large amount of abuse and physical threats they received from clients on the lack of adequate screening (see chapters 5 and 7). The Western Cape regional office, however, expressed serious reservations about implementing a referral system. This was because it would add an additional step to the application process and could be perceived as limiting access to social assistance and might therefore invite litigation from claimants (Observations of SASSA training, February 2014).

⁴⁹ An exception has however been made at three clinics where there is particularly high demand for the grant in the area and a referral system has been introduced to control applicant numbers.

After pre-screening the patient, a SASSA official would book an appointment for a claimant at a clinic serving that SASSA office, preferably the patient's regular clinic. Some clinics, where demand for the grant was lower, only received visits from an assessor on a fortnightly or monthly basis, whereas in areas of higher demand (generally high-poverty urban areas) a doctor was present in the clinic a few days a week, or even daily.

After an assessment booking was made, clients were issued an appointment slip with a date to see a medical assessor at a particular clinic. DDOs at local offices compiled pre-numbered Medical Assessment Booking Lists, which were forwarded to the relevant clinic so that patient files could be drawn and readied for the medical assessor. As there were not disability assessors in all clinics, people in many rural areas and some urban areas could not be assessed at their regular clinic. Where the assessment site was different to the patient's treating clinic, files should have been sent to the assessment site, but this did not always happen, especially at clinics outside of the Cape Town Metro. During almost all of my clinic visits, there was at least one person whose file had not reached the assessment site. A doctor working in a farmland area indicated that this happened in up to half of all cases. As assessments could not be completed without a medical file, patients would have to return at a later date.

As there are variations in how the assessment process works in healthcare clinics and hospitals, I will outline these processes separately, beginning with PHC clinics. Applicants typically arrived at the clinic early in the morning and presented their appointment slips at the clinic reception so their file and then waited for the doctor to arrive. On arrival, doctors were handed the patient files and a set of large books containing a two-page serialised form called the National Standardised Assessment Tool (NSAT), which were either dropped off daily by DDO from a SASSA local office or kept locked up at the clinic. All forms (used, unused, spoilt, expired and incomplete) had to be accounted for weekly, or at least monthly. This tight control was aimed at preventing forms from being tampered with or stolen, reducing the potential that fraudulent assessments might enter the system.

Doctors called patients into the room based on the order of their files. During the assessment doctors were responsible for verifying the identity of the person being assessed, stamping their appointment slip to confirm that the patient was assessed, performing the assessment and making a recommendation about the patient's eligibility for a grant. Once the assessment was complete, the doctor would then instruct the client to take their appointment slip back to SASSA to apply for the grant on the given date, which was typically two weeks after the assessment. After the client left, the doctor would make their recommendation by selecting

from one of the following options on the form: “Does not qualify”; “Temporary”, along with a period of time from six to twelve months; and “Permanent”, either with or without review⁵⁰.

Doctors could recommend “Social Relief of Distress” (SRD) instead of a DG if the patient was likely to be disabled for a period of less than six months⁵¹. Social workers could also recommend the SRD based on financial hardship or social circumstance, but doctors were technically only allowed to recommend an SRD on medical grounds for people. If a disabled applicant was in need of permanent care, doctors could also recommend the “Grant-in-Aid”, an additional grant paid to DG recipients to assist them with the costs of this care.

Once the doctor had completed all the assessments booked for the day, the books were returned to the designated health official. Completed forms were collected by a SASSA official who performed an administrative quality check on each form and returned them to the relevant local office. To prevent fraud, local offices kept samples of the signatures of assessing doctors working in their area, which were used to confirm the authenticity of completed assessment forms. Back at the SASSA office, the status of the client was assessed against the SOCPEN system and a second check was performed to ensure that the client had not applied within the previous three months.

Two weeks after their assessment, the claimant would visit their local SASSA office to apply for their grant. By this time, the assessment forms should have undergone administrative and possibly technical (medical) quality assurance and should have been processed by the local SASSA office. During this time, an application was completed, the means test conducted and the doctor’s recommendation considered. Based on the information entered by the various officials during this process, a letter was automatically generated for and handed to the client, which indicated whether a grant had been approved or refused. In the case of rejected applications, the official handing the letter to the client was meant to explain to claimants that they had ninety days to request that SASSA reconsider its decision and another ninety days to lodge an appeal with the Minister of Social Development. Unfortunately, the reconsideration and appeals process was poorly explained by SASSA officials and on a number of occasions I witnessed patients arriving at clinics, often without an appointment, to see the doctor because

⁵⁰ Patients whose grants are reviewed are called in after a year for an assessment, but do not need to re-apply for a grant in the same way as temporary recipient receiving it for one year. All other permanent beneficiaries are reviewed every five years.

⁵¹ Social Relief of Distress grants are issued monthly for a maximum period of three months and can be given in the form of food parcels, vouchers or cash to people considered in dire need. The value of this award is discretionary and subject to budget availability.

they did not understand the rejection letter or know what appeal processes to follow. Given that clients could re-apply for the grant after ninety days, the reconsideration and appeals process was seldom used and patients simply re-applied after ninety days instead. *See Quote 3.1.*

Appendix C.

The assessment process is markedly different at the hospital level and varied based on administrative arrangements made within each hospital. Assessments are either conducted in the wards shortly before discharge or, more commonly, at outpatient clinics attached to hospitals where previous inpatients are followed-up on and where patients referred from lower-level clinics or hospitals are seen for specialised diagnosis and care. Hospitals were typically issued with a number of disability assessment books containing the NSAT forms, which were shared between departments in the hospital. When a patient requested a grant or the doctor felt one should be recommended, doctors would obtain the book from whoever was responsible for it at the clinic or ward. The exception was Whitney hospital, which was considered too large for such a system to be feasible (it would be difficult to share books) and the old provincial form rather than the book system was used instead. At Whitney hospital, they would refer patients to the social work department who would issue the patient with a form (the provincial form used prior to the NSAT) and were responsible for receiving it after completion.

Forms were collected from all hospitals by a SASSA official and each claimant's form sent to the SASSA local office closest to where the claimant lived, where would undergo the same application process as those assessed at the PHC level (i.e. complete application form and means test). The social work departments at both De Waal and Whitney were responsible for coordinating with SASSA around the collection of assessment forms and following up on cases. Social workers at Welgemoed hospital had, however, relinquished their role in the DG system because they felt that their position as administrative gatekeepers had become overwhelming. This was largely due to the number of inquiries they received from patients and their families regarding DGs and frustrations they had experienced in dealing with the SASSA administration, which they saw as unreliable and unresponsive and a nurse was made responsible for the book instead. Social workers at De Waal and Whitney hospitals expressed similar frustrations about SASSA administrators and the frequency with which forms were lost and applications delayed in the system.

3.3.3 Managing doctors' work

When doctors carry out disability assessments, the decisions they make form part of a bigger

bureaucratic process and it is therefore important that their decisions are coordinated with SASSA's goals. Doctors are required to make recommendations on DG eligibility within the parameters of Section 9 of the Social Assistance Act of 2004 and the 2008 Regulations to this Act. As discussed in Chapter 2, there is no clear definition of the term *disability* in either the 2004 Act or its regulations, which leaves room for a wide variety of interpretations by doctors. As disability is a broad and complex concept and doctors rarely have specific training in disability assessment, SASSA provides a set of medical assessment guidelines and training to doctors in an attempt to shape their understanding of what disability 'is' and to communicate SASSA's norms and standards for assessment practice. Rules and guidelines create a type of technocratic knowledge that is rational, impersonal, quantitative and universal (Scott, 1998) and, in the case of medicine, are intended limit doctors' subjectivity and standardise their practice. Guidelines can be read as "a set of instructions telling medical personnel to do a certain thing in a certain situation" (Berg, 1997: 2) and like all standards and classification systems, are aimed at making decision-making more "visible" (Bowker & Starr, 1999; Scott, 1998), in this case, to SASSA.

The set of guidelines in use at the time of this study, *Guidelines for the Medical Assessment of Disability for Social Assistance Purposes* (SASSA, n.d), provides a summary of the legal framework underpinning the DG system, explains the function of medical assessors and provides conceptual definitions of impairment, disability and employability. It also provides some vague direction to doctors on establishing claimant's employability. Both these guidelines and the material presented during training strongly emphasised the difference between *employability* and the *availability* of employment. Given high levels of unemployment and poverty amongst applicants and a history of the grant being offered on a humanitarian rather than medical basis, the guidelines explicitly stated that the high unemployment rate should not be considered by doctors during assessments.

Disability grant is not [the] Basic Income Grant (Employability not Availability of Employment.) (SASSA, 2011).

The guidelines expressly discouraged doctors from awarding DGs on a temporary basis and were advised to only recommend temporary grants when the disability was severe and under highly specific conditions:

Unfortunately, there is a tendency for temporary grants to create dependency and poor motivation for recovery. Due to this component of secondary gains these grants must be given

out cautiously (SASSA, n.d.: 25).

In establishing employability, guidelines advised doctors to consider the nature and severity of the medical impairment; the age, intellectual capacity, educational attainment, skills and labour market knowledge of the particular person; the nature of the work the applicant could perform; and ergonomics and how reasonably an individual could be accommodated by an employer (SASSA, n.d). However, these factors could only be considered in cases of moderate impairment the application of the definition of disability should remain central within the clinical reasoning of the medical assessor (DMU official, personal correspondence, 2014 May 6). As the guidelines explicitly note: “certainly most of our population live in very poor social circumstances that cause a lot of suffering, but this alone does not constitute grounds for a disability grant.” (SASSA, n.d.: 5)

The guidelines also provided list of medical criteria and impairment tables for use in assessments. These guidelines were distributed to SASSA assessors during individual training sessions, which were conducted when doctors first began conducting assessments and at annual regional and national group training sessions. They were not distributed to doctors working in treating settings. In the Western Cape, group trainings were run by the DMU office in Cape Town or organised by Department of Health in other districts. There was also one national annual training facilitated by the SASSA head office, but it was unclear whether the annual national trainings would continue after national disability management was dissolved into general SASSA operations. The DMU staff also provided individual training sessions to doctors who were starting in a period between group trainings. DDOs from local branches might also explain the general operational procedures to new doctors.

The training that SASSA provided to doctors focused on the legal and administrative framework of DG assessments rather than on the medical aspects of assessments and it was presumed that doctors would be able to make reasonable recommendations based on their medical expertise and the set of medical guidelines provided to them. The focus of the training was on how complete the form correctly rather than on tackling the complexities of the decision and ignored the larger macro-level factors that shaped the interactions they had with patients.

SASSA has also put in place a number of quality control and oversight measures. These roughly align with the three types of quality control measures that De Boer (2009: 25) identified as common in most disability benefit application processes internationally: *administrative* quality control, *professional* quality control and *legal* quality control. In the

SASSA system administrative quality checks were conducted by DDOs to ensure that assessment forms were properly completed and legitimate. Technical quality assurance was performed by a medical doctor who worked assessed forms to establish whether recommendations were based on sound medical reasoning and evidence. An Independent Tribunal for Social Assistance Appeals (ITSAA) convened in cases where claimants appealed decisions made to establish both the technical quality and legality of eligibility decisions. As ITSAA fell outside of SASSA's realm of activity, I have only focused on administrative and technical but not legal quality control.

Although DDOs were not trained to technically interrogate a form, these officials were generally able to identify inconsistencies on the form. If, for example, a doctor indicated that a patient had scored low on the impairment scale, but had still recommended a grant, officials could request technical quality assurance or follow up on the inconsistency with the doctor directly when next visiting the clinic. On a number of occasions, I observed DDOs arriving at the clinic to ask doctors for clarification on the forms they had filled out on previous days. DDOs could also pick up on general trends or patterns in doctors' assessments, such as very high recommendation rates, which would be referred for further investigation by the medical quality assurer (DMU Official, interview, 2014 June 23). The work of DDOs therefore presented a fairly direct form of quality assurance. As doctors often began work as assessors before receiving formal training, DDOs also performed the important function of informally coaching doctors on how the assessment process worked and how to complete the assessment form.

In order to improve the quality of medical assessments, minimise assessors' discretion and curb potential fraud, SASSA employed a medical quality assurance officer to conduct both pre- and post-application quality assurance of medical assessments. During pre-application checking, the quality assurer was able to make changes to doctors' recommendations. Post-application quality assurance was an auditing process conducted on a sample of assessments drawn from the sixteen local SASSA offices across the Western Cape.

Pre-application quality assurance (QA) took place in the time between the date of assessment and the date the client returned to the SASSA office. This type of QA only took place at specific fraud 'hot spots.' At the Gugulethu office, which experienced high levels of fraud, 100% of all assessments were quality assured. In other offices, pre-application QA was only conducted on forms filled out by doctors who the medical quality assurer or a DDO had identified as having very high allocation rates, awarding high numbers of permanent DGs or

filling out assessment forms poorly. Doctors' work was monitored until by the QA until his or her assessment rate and quality improved sufficiently. Post-application QA was conducted after a grant was already in payment and was intended to track assessment trends and monitor the work of doctors on an on-going basis.

The Disability Management Model was initially designed with the assumption that a district-level DMU would be in place and that considerably more resources would be allocated to the model than have been in practice (Marite, interview, 2014 June 27; DMU official, interview, 2014 June 23). SASSA had also originally planned to develop an electronic Medical Assessment Profile of each assessor, based on a 20% sample of assessments conducted by each doctor. This profile would allow the DMU to monitor the number of assessments conducted, the approval rate and errors made by the assessor. In order to implement this model effectively there would need to be an assessor allocated to each of the five SASSA districts in the Western Cape. At the time of writing there were only six quality assurers had been appointed nationally, one of whom was based in the Western Cape region. This made it impossible to assess the quality of 20% of the forms completed by each assessor. The target was therefore revised and the DMU instead worked towards ensuring that 20% of all assessments in the Western Cape were reviewed. This target included assessments conducted at both tertiary and secondary levels, both pre- and post-application. As pre-application quality assurance took precedence over post-allocation assurance work, a large proportion of the forms reviewed each year were assessed at the pre-application stage. This meant and that quality assurance activities were not evenly spread across the sixteen local offices.

These factors all acted to limit the scope of SASSA's quality assurance work. Therefore, unless a doctor had a very high allocation rate or was filling out forms extremely poorly, they were unlikely to be held accountable for their decision-making. I was unable to establish the overall approval rate during the time of my fieldwork, however data I could obtain for Quarter 2 of 2013-2014 (July-September 2013) that showed that 75.3% of claimants were certified disabled by doctors and that 74.67% of applications received by SASSA operations were approved. These approval rates are considerably more generous than in many other countries. For instance, in the United States the initial approval rate (before reconsideration and appeals) was 33.6% in 2013 (Social Security Agency, 2013).

During pre-application quality assurance, the QA was responsible for reviewing the decision of the medical assessor. In the absence of an electronic system, the quality assurer sampled assessments by physically drawing files from the sixteen local offices at the provincial records

management centre, which were stored separately from the files for other grant-types. The quality assurance review was a desktop review of the NSAT form and the claimant's file was not available to the QA officer. He therefore relied heavily on the information provided by the doctor in the form. The QA officer noted that doctors tended to fill out forms extremely badly, providing little clinical justification for their decision-making. This often made quality assurance work difficult. As a medical diagnosis was considered insufficient for declaring someone disabled, the assessor needed to present evidence that an applicant was functionally impaired despite receiving optimal treatment. It was therefore important that doctors reported on the type and dosage of medications or other treatments or rehabilitative interventions. Although doctors complained to me that there was insufficient space to provide detailed notes on their decisions, an interview with the QA officer and my own observations indicated that doctors seldom used the space that was available. While some doctors filled out forms carefully and took pride in this, many were very poorly filled out, indicating that doctors rushed through completing them. Unfortunately, if insufficient evidence or medical reasoning was provided for a grant recommendation, the QA officer would be forced to reject the doctor's recommendation or reduce the length of time that the claimant could receive the grant for.

The QA officer used an electronic quality assurance database, which was used to pick up patterns and trends in assessments. The DMU did not target a particular recommendation rate, acknowledging that this rate was often context-dependent. For instance, cancer clinics and hospices were likely to have higher recommendation rates than PHC facilities. However, if a doctor had an obviously and unacceptably high recommendation rate, was providing insufficient evidence or regularly making recommendations inconsistent with their clinical findings, the quality assurer would write reports on these findings. The DMU would then approach the doctor concerned to discuss these issues. SASSA could also refuse to accept or pay for poorly conducted assessments (outlined in SLA) and the doctor would be required to re-do the assessment. The QA officer was also responsible for producing quarterly reports on medical assessment trends for SASSA.

Both the DMU and the Department of Health took what a SASSA official called a 'developmental' rather than punitive approach to addressing quality issues with doctors. Assessors were seen as a scarce resource and the DMU and DoH preferred to provide feedback on performance and additional training than terminating the employment of the doctor. However, fraudulent behaviour such as over-claiming hours was not tolerated. Three of the assessors I worked with during the study were called in to discuss the quality of the

assessments they provided. After intervening, SASSA closely monitored the work of these doctors by examining all of their forms until their work improved sufficiently. A DMU representative reported that after ‘engaging’ with doctors there was generally a rapid improvement in the quality of their work. There have, however, been a small number of cases where the DMU informed the DoH that they would like certain doctors to cease assessment work at particular sites.

The initial design of the DMM imagined a greater role for quality assurers, which included training and information sessions, liaising with medical officers, trouble-shooting and advising regional DMUs and participating in the reconsideration process. However, 2014/2015, the contract of the quality assurer in the Western Cape did not include any of these activities and his interaction with doctors was limited.

3.4 Conclusion

This chapter discussed the bureaucratic structure of SASSA’s disability grant system. It has shown that although the DMM has significantly reduced fraud, reduced backlogs, has stabilised DG numbers and has done much in the way of creating a standardised approach to disability assessment nationally, budget constraints have limited its full implementation. This means that the system has limited capacity to reduce doctors’ discretion in practice and doctors retain significant gatekeeping power. In the Western Cape, the outsourcing of doctors through locum agencies and the lack of genuine accountability of treating doctors within the system can make it difficult for the understaffed DMU to manage doctors’ work. The lack of a gatekeeping system in the Western Cape around who is able to apply for disability grant means that large numbers of people with little to no impairment are assessed by doctors. This creates pressure on doctors who must deal with large patient loads. Doctors who conduct assessments are either not paid for their work or are paid little for this work and often work in difficult conditions. In the next chapter, I will discuss how doctors use their discretion to make their work easier in these conditions.

CHAPTER 4: Medical doctors as disability ‘experts’

4.1 Introduction

I was sitting with Dr Bury in one of the consulting rooms in the outpatient section of a small regional hospital in the farmland areas in West Coast region of the Western Cape, which was used weekly for disability grant assessments; when Mr Jones, a man in his forties with a heavily-scarred face walked into the room.

Mr Jones’s main complaint was that he had a problem with his wrist. He explained that he had been assaulted and that his wrist and collarbone, which had been broken as a result, were still bothering him. Doctor Bury examined his wrist and hands, testing and comparing the mobility of his injured and uninjured wrist by asking him to clench both of them and move them up and down. Mr Jones struggled with this and the doctor had to show him what to do a number of times. The mobility of his wrist was normal and it appeared to Dr Bury that he was either pretending he could not do this or was unable to concentrate on performing the activity (he seemed unfocused and had a history of drug abuse). Dr Bury then examined his shoulder and Mr Jones complained that there was a ‘knob’ there and that it made a cracking noise when the doctor moved it. Dr Bury told him that it is possible to live without a collar bone, saying that “some people are even born without them; it’s got nothing to do with sickness.”

Mr Jones, however, was insistent that his collarbone was a problem and said again that it cracked and has a knob on it. Dr Bury dismissed this, simply saying “it’s alright”. Trying another angle, Mr Jones complained, “my wrist is really what is worrying me, in the joint”. Dr Bury patiently went back to the notes and asked, “when did you injure it?” and saw in the file that he had an operation on his wrist in 2008 (six years prior). Mr Jones proceeded to sit there and play with his wrist, making various complaints like “I can only use this one hand” and saying something about not being able to go back to work. He then added, “Can’t they do something to get rid of this knob?” “No, it’s fine” said Dr Bury, and Mr Jones responded “It cracks. I also can’t hold it up too long.” At this point Dr Bury began to ignore him, focusing on filling out forms related to the consultation.

Dr Bury described Mr Jones’s case as a text-book case of malingering and something he encountered quite regularly. “Really”, he told me “there is nothing, nothing [wrong with him]...just ask him to get onto the bed and watch him from behind how he gets onto the

bed...easy - there is no problem getting onto the bed and off because he doesn't know [that he is being watched.]”⁵² Mr Jones’s appearance and drug use history also added to Dr Bury’s mistrust and suspicion about his motives for the consultation.

Mr Jones’s case was not an unusual one. During my time in the field I frequently observed cases where doctors felt that a claimant was malingering. Although it is extremely difficult to determine whether in fact someone is malingering, healthcare workers believed that they encountered large numbers of people who were evidently not disabled on the basis of objective medical criteria. Experience with claimants like Mr Jones, who were assessed as exaggerating or feigning symptoms, made doctors alert to and suspicious of patients’ motivations in reporting their symptoms and lived experiences of disability during DG assessments.

Doctors assess injury impairments frequently in their work. However, the need to detect ‘fraud’ changes the premise and nature of doctors’ work in DG assessments; in contrast to their usual diagnostic and therapeutic work, where the patient can be assumed to be honest, because they want the correct diagnosis and treatment. Whilst in other parts of medical practice patients are sick until proven healthy, in disability assessments the patient is healthy until proven sick (Stone, 1979). Rather than diagnosing and treating patients, doctors engage in a process of gathering evidence and putting it together to show why a patient is or is not eligible for a DG.

The political and economic privileges and exemptions that come with being categorised as disabled mean that disability is commonly understood to exist in both genuine and artificial forms and the suspicion that people will *malingering* - feign or exaggerate impairment for secondary gain (American Psychiatric Association, 2000) - is integral to how disability is both defined and understood (Stone, 1984: 28). Given the assumption that people are likely to misrepresent themselves in order to meet the categorical tests of welfare programmes or for other secondary gains, the concept of disability has long tied to the need to detect deception (Stone, 1984: 51). Welfare bureaucracies like SASSA therefore guard the boundaries of the disability category to prevent ‘shirkers’ and disability benefit ‘scroungers’ from using fraud, fakery and malingering for exploiting the system.

Historically, biomedical criteria have been the most commonly used mechanism for restricting access to disability benefits and a medical report of a doctor is a requirement of most social protection programmes for people with disabilities around the world (Bolderson et al., 2002).

⁵² This was only his assumption and he did not ask the patient to do this.

Disability has historically been considered a pathological deviation from a biomedically accepted 'normal' condition, therefore falling under the purview of doctors. Given their medical expertise and professional status, doctors have been trusted to judge the authenticity of illness and impairment and the legitimacy of related social benefit claims. This has been the case since the mid-19th century when doctors were first legally positioned as gatekeepers to social protection programmes when Germany introduced sickness and disability insurance legislation and workmen's compensation schemes in the 1880s (Robinson, 2004; Stone, 1984; Priestley, 2010).

In South Africa, medical doctors have been involved in validating occupational injury claims since the introduction of the Miners Phthisis Allowances Act 34 of 1911 and the Workmen's Compensation Act of 1914. The report of a medical doctor has been required for disability grant claims since they were introduced by the Blind Persons Act of 1936 and the Invalidity Pension Scheme of 1937. Doctors have also played an important historical role in conscription efforts and war injury claims. For example, doctors played a prominent role in the 1914-1918 war effort in Europe, developing special tests to detect malingerers and thwart conscripts' effort to avoid the draft or to leave active duty through claims of medical injury (Wessely, 2003).

Although medical understandings of disability have since evolved and disability is considered a function of social and contextual as well as biomedical factors, doctors still play a key role in assessing physical impairments that can cause disability. Doctors are regularly requested to provide impartial medical opinions to third-parties for legal proceedings in: occupational health matters; private health, life, accident and disability insurance; public social insurance claims; and for establishing eligibility for disability-related social assistance programmes such as the DG⁵³. Although not necessarily the main decision-makers on eligibility, doctors play a key legitimising role in these processes.

This chapter discusses the application of – and limits to – biomedical knowledge and expertise in the assessment of disability. As I have already argued, disability is neither a purely medical phenomenon nor a social construct, which makes disability difficult for doctors to assess. In Chapter 6 and 7, I will discuss how social norms, values and doctor-claimant interactions influence medical decision-making, but this chapter will focus on the more technical aspects of

⁵³ South African doctors also conduct medical assessments for the Road Accident Fund and Unemployment Insurance Fund and for claims made under the Compensation for Occupational Injuries and Diseases Act. They also frequently consult privately to insurance companies as claims assessors.

assessment and what the limits of these are in determining disability. I also reflect on the differences between the work doctors do in distinguishing between ‘normality’ and ‘disability’ and other types of decision-making in medicine, and what this means for doctor-patient relationships in both treating and non-treating settings. Lastly, I will discuss why, despite its limitations, medical expertise remains key in legitimising disability claims in South Africa.

4.2 How doctors make decisions on medical eligibility

Medical doctors are experts in the anatomy (structure), physiology (function) and pathologies (abnormalities) of the human body and undergo extensive and rigorous training to use medico-scientific principals and methods to diagnose and treat medical conditions and physical injuries. This expertise on the body allows them to identify the presence of impairments that may be disabling, making their input valuable in disability assessments. Although doctors identify impairment in the course of their regular work, there are a number of key differences between the work doctors do in DG assessments and the work that doctors do in diagnosing and caring for patients.

Patients generally visit doctors because they are in pain, and have experienced or otherwise believe that medicine may be able to provide a solution. They expect doctors to diagnose the malady and prescribe treatment, which will result in a cure (in the case of acute illness or injury) or at least assist in managing their condition (in the case of chronic disease). Doctors’ ability to cure patients makes their expertise highly valued and in this way medicine is ‘succour as well as science’ (Collins & Pinch, 2005). When a patient is diagnosed, they are ascribed a label (a diagnosis) which defines and accounts for what is ‘wrong’ with the body, effectively ‘organising’ the illness and treatment possibilities (Brown, 1995; Freidson, 1970). The process of diagnosis validates what does and does not count as disease (Bowker & Starr, 1999) and through their diagnostic authority doctors have undeniable control over deciding what it is to be sick and who should be classified as such.

Freidson (1970) argued that “by virtue of being the authority of what illness ‘really’ is, medicine creates the social possibilities for acting sick” (206), thereby defining illness as an official social role. This diagnostic, labelling power gives doctors significant social and professional status and authority, both within the healthcare system and in society more broadly. In order to diagnose patients, doctors gather information on patients’ presenting complaints; take medical, family and social histories (summary of lifestyle practices and habits such as smoking or drug use history); conduct physical examinations; and review laboratory

reports and the results of other technical tests. This can be a rapid and straightforward process driven by 'gut feel' or managed through the process of differential diagnosis - the process of testing and eliminating a series of different diagnoses. Family and social background and history are key to narrowing diagnostic possibilities by identifying potential genetic or behavioural risk that may predispose patients to a certain illness and are part of doctors' sense-making process (Davenport, 2011). Understanding the multi-causality of disease is part of doctors' expertise and a patient's account of their history and symptoms can help to direct their diagnostic process and frame their technical decision to apply a certain biomedical category to an individual (Davenport, 2011). Gathering this information from the patient or others typically involves a dialogue with the patient (or their relatives or friends in cases where the patient is unable to communicate) to obtain information on their medical history, symptoms and complaints, making diagnosis a relational process (Brown et al., 2011).

Once a diagnosis and the cause of the condition has been established, the doctor can then develop a prognosis, which is a prediction on the duration and outcome of the disease based on clinical and systemic factors and the pathogenesis of the disease. Based on the diagnosis and prognosis the physician then typically recommends a course of treatment for the patient and may make recommendations that restrict patients from carrying out physical or work activities, releasing patients from certain social duties until they recover and allowing them to assume what Parsons (1951) called the 'sick role.'

Parsons understood illness as an acceptable form of social deviance, which is legitimated by medical proof that an individual is sick and the agreement that individuals will submit themselves to the medical expertise of doctors, based on the expectation that doctors have their best interests at heart. Doctors on the other hand expect that patients will participate willingly in the treatment process and do their best to recover their health. Assuming the 'sick role' or 'handicapped role' (Gordon, 1966) also allows individuals to claim certain exemptions from society such as paid sick leave, be excused from compulsory military service, gain access to particular services and earn the right to make claims on private and public disability insurance or social assistance programmes (Jutel & Conrad, 2011; Nettleton, 2006). Although Parson's structural functionalism has been largely discredited and is complicated by chronic illness (where there is no assumption of recovery), the sick role and the work of doctors as gatekeepers to this role has remained a major grounding theme in the field of medical sociology, and remains important in thinking about doctors' work in legitimising disability claims. Although in practice people certified disabled gain access to the 'sick role,' it is also important to note that

illness and disability are not the same. Someone who is ill may not feel disabled (e.g. someone with hypertension) because despite their pathology or impairment they may be able to participate fully in economic and social life. Likewise, someone who is disabled may not feel ill (e.g. a hearing-impaired person) (Cassell, 2002: 39).

Disability assessments have a different purpose and are structured quite differently from other doctor-patient interactions. Instead of seeking diagnosis and treatment, patients are looking for affirmation that they are unable to work because of an impairment and that they therefore deserve to be compensated either by their insurer or the state. It is the doctor's role to establish whether this claim is legitimate and there is a valid connection between the symptoms or complaints, functional limitations and restrictions reported by the individual, and the presence of an actual disease or dysfunction (Alyward, 2003). Whereas a patient's description of their symptoms and history are an important part of the diagnosis, disability assessors cannot not entirely trust claimants' accounts of their experiences, making objective evidence more important. In the DG system, disability recommendations must be based on pre-existing diagnoses and claimants making DG claims have generally already been prescribed treatment or have undergone rehabilitation. Therefore, rather than determining the cause of dysfunction (as is the case with diagnosis) doctors look for medical evidence to confirm a patient's claim that they cannot work. Doctors must also establish the extent to which a claimant is physically impaired and how this affects individual functioning and employability. They either establish impairment using the set of impairment tables provided by SASSA (or whichever bureaucracy they are working for), or make their own estimation based on their examination of the patient or their own experience. Perhaps most importantly, doctors work (or at least are expected to work) within the parameters of social assistance legislation and administrative guidelines to make recommendations on eligibility.

In DG assessments doctors determined the extent and expected duration of impairment based on the patient's symptoms, diagnosis, severity of the condition, complications, response to treatment or rehabilitation, and prognosis and use of assistive devices (see the NSAT tool in Appendix E for more information on what doctors were expected to report). There were a number of sources doctors they could use to obtain evidence for assessments: observation; the patient's medical file – which (hopefully) provided information on their diagnostic and treatment history; physical examination; and the claimants' subjective account of their condition and related impairments.

Doctors used observation to detect whether patient claims of disability were genuine, and were

constantly alert to how patients behaved, moved, communicated and narrated their medical histories. They would watch patients walk into the room, observing their gait, general body language, facial expressions and behaviour, whether they could pick things up off the floor, or if they looked or sounded breathless. This allowed doctors to check patients' reported symptoms against their actual behaviour and this is a technique also employed by occupational therapists (OTs) who conduct work assessments (*See quotes 4.1 and 4.2 Appendix C*).

I saw recently a patient also, she couldn't walk and she was walking like this [demonstrates someone walking hunched over] inside the room but I know her because I was working at Matiesfontein and when she's out [the room] I gave her a chance, say 5 seconds, so I looked at her down the passage - she was walking normally. (Dr Bury, interview, 2014 July 22)

Doctors used the collection of medical notes, referral letters and test reports and the prescription chart to piece together claimants' medical histories and validate or refute their claims. Especially important in the patients' files were *biomarkers* – objective, quantifiable and comparable indicators of a patient's medical condition – (e.g. CD4 count, viral load, cholesterol level, blood pressure, or insulin level) which indicate the presence and severity of a disease, as well as treatment response. These biomarkers could not, however, measure the level of impairment experienced by the claimant. For someone to qualify for a DG there needs to be both evidence of a medical condition and impairment caused by the condition. Mrs Jansen provides an example of one such case. She was a woman in her fifties with rheumatoid arthritis, an immunological disorder, the presence of which is established through a positive rheumatoid factor blood test. Although she had tested positive for this factor, this alone was not sufficient for her to qualify. Although a degenerative condition, rheumatoid arthritis is not immediately disabling and some people on treatment have no symptoms. Dr Bury, who assessed her, therefore examined all of her joints, looking for swelling and tested her mobility. Based on his examination, he determined impaired functioning measurable in terms of significantly reduced wrist and knee flexion (50%) and visible signs that her joints were affected by the disease and therefore recommended a grant.

The list of medications prescribed to patients could also provide a good indication of the severity of the claimant's presenting complaint and whether a person was on optimal treatment. Patients may not refuse treatment and those who were non-compliant were not eligible for the grant. Assessors were expected to report any history of non-compliance to SASSA. Doctors would typically ask patients questions about the type and dosage of medications they were taking to establish whether they were in fact taking it correctly (or at all). Non-compliance to

medication could also be easily picked up by checking the dates that claimants had visited the clinic to fetch their prescribed medication, which was typically recorded on the prescription chart in the file. When patients reported having frequent epileptic seizures, doctors would conduct serum tests to establish compliance. *See quotes 4.3 to 4.5 in Appendix C.*

As claimants must have an established diagnosis to be eligible for a grant, SASSA assessors are not obliged to conduct physical examinations and a review of the patient's medical history based on their existing file is considered sufficient for a DG assessment. My observations of SASSA assessors showed that few conducted more than a quick and focused examination of a patient's primary complaint (e.g. examining the mobility of a joint) and their decision-making was based primarily on the medical history recorded in the patient's file and usually – but not always – a conversation with the patient. Inappropriate or inconsistent symptoms, complaints or pain inconsistent with clinical findings and verbal or physical over-reactions on examination (e.g. wincing or crying out) were all red flags that alerted doctors to the possibility of malingering.

Doctors also had to think about the likelihood of the condition improving (prognosis). In the case of manageable chronic disease doctors would not recommend permanent grants. However, there were clear cases where based on medical knowledge doctors knew improvement was unlikely; for example, in cases of intellectual impairment, cerebral palsy and paraplegia. In these cases, doctors would quickly and willingly recommend permanent grants, as is shown in the case of the 50-year old man with glaucoma below, whom Dr De Villiers would deteriorate and likely never work again:

The patient complains that he has a problem with his eye and brought a referral letter from another doctor with him. The letter says that he has end-stage glaucoma in both eyes and that in this case a permanent disability grant would be recommended. The doctor asked him when he last worked and it was this year. The doctor says that he has 3 metre vision in his right eye and 2 metre vision in his left and that he has been treated since 2014, so there is little chance of improvement. (Field notes, 2014 July 18)

The extent to which doctors used these different sets of information depended on its availability, the doctor's individual approach and individual patients. Although both SASSA assessors and treating doctors needed to fill out an assessment form and take the same factors into consideration, the information available to them varied. SASSA assessors act as third-party assessors and typically had no prior knowledge of a claimant's particular case or prior relationship with the claimant (except in the case of repeated applications). These assessors very rarely diagnose or treat patients and where claimants are in need of further medical

services they typically referred them back to their treating doctors. On the other hand, ‘treating doctors’ received DG requests from patients or initiated the application process during the course of their daily work as physicians at hospital-level institutions in the public healthcare system. Most treating doctors were assessing current or previous patients and therefore had at least some idea of the claimants’ history⁵⁴.

In hospital settings there was also more opportunity for interdisciplinary input, especially in inpatient settings where physiotherapists, OTs and social workers were typically attached to wards. At De Waal hospital, psychiatrists made the final decision regarding DG recommendations, but DG assessments were first discussed in multi-disciplinary treatment teams composed of psychiatrists, social workers and nurses⁵⁵. It was also often easier in outpatient settings to make referrals to social workers and occupational therapists when they were uncertain about whether a patient was eligible. *See Quote 4.1*

Another major difference between assessments carried out by SASSA assessors and treating doctors was their relationship with patients. Although in the public healthcare system in South Africa, the relationships that form between doctors and the patients they care for are often limited and far from ideal (see Chapter 7), treating doctors were more likely to feel a sense of responsibility towards their own patients. In the case of SASSA assessments, there was a lack of collaboration between the doctor and claimant around ‘getting well’, which on the one hand allowed doctors to be more objective, but on the other hand made it difficult for assessors to trust claimants.

To help doctors estimate impairment based on diagnosis, SASSA provides a table of condition-specific directives in its guidelines for determining the percentage of impairment present based on diagnosis. For example, poor vision in both eyes (worse than 6/36 in both eyes) that is not correctable, should receive an impairment rating of 50%. Based on the tables, doctors then categorised the overall severity of impairment as ‘none’ (0%), ‘mild’ (<25%), ‘moderate’ (25 – 40%) or ‘severe’ (>40%). The SASSA tables are basic and provide broad impairment ranges and no instruction on how to combine information from the impairment tables or information on what tests should be used to establish impairment. As few treating doctors had access to the guidelines, few were familiar with these tables.

⁵⁴ Many doctors work at multiple facilities or rotate between facilities, meaning there is not always continuity of care.

⁵⁵ Although OTs did not form part of this team, they could be consulted as part of the decision-making process

Even if doctors did use the tables (few did), they still needed to determine how an individual's impairment impacted on his/her ability to work because impairment is not necessarily equivalent to work disability. In cases where claimants were severely impaired or had zero to very little impairment, the connection between impairment and disability could be fairly obvious and it was relatively easy for doctors to make a decision about an individual's functional capacity on a purely medical basis. Mrs Jansen with rheumatoid arthritis and the man with glaucoma clearly fell into this category – the severity of their impairment, in their cases, could act as a fairly effective proxy for disability. According to SASSA guidelines, a patient who was classified as having a minor impairment would not qualify for a grant regardless of his or her social or environmental conditions and these cases could be quickly dismissed. These were typically patients with well-controlled and manageable chronic illnesses. The guidelines note that conditions such as early stage HIV, acute pulmonary tuberculosis, asthma, well-controlled epilepsy, minor depression, diabetes, hypertension and healed fractures did not qualify applicants for DGs.

Not all cases were as easy to categorise because the connection between impairment and disability was less clear. Cases where claimants' impairments were moderate (25% - 40%) were more complicated because, in cases of moderate impairment, some claimants may be more capable of work or employable than others depending on their age, education, occupation, geography and socio-economic factors and opportunities for referral in addition to the impairment present. Psychiatric conditions, epilepsy and other chronic health conditions, which are often called "invisible disabilities", were particularly difficult for doctors to assess because the functional and participation limitations they cause are not easily observed. Although in most cases these conditions can be controlled, people's capacity to function effectively in the workplace and the stigma attached to epilepsy and psychiatric disorders in particular, made establishing claimant's capacity to find and carry out work fairly challenging.

Dr Soet described people who fell into the grey area between disabled and able-bodied as "in-betweeners". Sometimes these grey areas were created by a lack of medical evidence in the file, uncertainty about a patient's longer-term prognosis, but mostly what made these cases difficult came down to the crucial and more difficult question to answer on the NSAT form, "Does the impairment affect the client's ability to enter the open labour market?"

It is fairly standard practice in disability assessment internationally and within other disability compensation programmes in South Africa to consider the education and previous work experience of claimants as a baseline for determining whether claimants would be able to find

work or resume their previous activities. SASSA acknowledged the importance of considering non-medical factors in its guidelines, but how this information should be incorporated and weighted in decision-making was unclear and not explained in either the guidelines or training provided to doctors (SASSA, n.d.). One doctor reported being told by the National Disability Manager during a training session that there was no legal requirement for doctors to consider education during assessments, indicating that this could be ignored. “In fact we are not even supposed to take education into account, which is wrong. But on the other hand others are not trained on how to do that.” (Dr Jacobs, interview, 2013 October 24) There was also no section on the NSAT form to capture social, environmental or economic factors that influence disablement.⁵⁶ As I will discuss in the next section, although doctors regularly deal with social issues in their work, they typically have limited expertise in how to deal with them or incorporate them into their decision-making. The lack of detail on non-medical elements of the assessment process in the assessment guidelines and conflicting information about whether they should even consider it left doctors feeling considerable uncertainty in their decision-making.

4.2.1 Uncertainty in disability assessment and the limitations of the medical model

Although disability assessments are a structured process and guidelines for assessment do exist, these are vague and not always available to doctors. It is fairly difficult to determine a person’s ability to work based on their physical capacity as barriers to employment are often external and contextual. Moreover, illness, impairment and disability present themselves in the lives of individuals in highly specific, contextual and often ambiguous ways (Swartz & Schneider, 2006; Gooding & Marriot, 2009). Disability is rarely absolute and is more of a spectrum or range where people have differing degrees of functional capacity and independence (Jette, 2002). Furthermore, DGs are premised on the idea of “economic disability” (de Villiers, 2002: 324), meaning that disability is a function of both medical disability and the relative availability of economic opportunities for persons with disabilities at any given time. This is a decision which medical doctors, who have limited formal expertise on labour market and vocational issues, are not necessarily properly equipped to make. Studies in Europe and North America have demonstrated that doctors can interpret the same patient information in very different ways, making different decisions about the same patients’ work ability, employability and eligibility for benefits (Zinn & Furutani, 1996; O’Fallon & Hillson, 2006; Dell-Kuster, 2014;

⁵⁶ Age and the highest level of education are the exceptions. However, the job of capturing this information was generally left to SASSA DDOs.

Schellart et al., 2011; Slebus; 2009).

Patients may also have different subjective experiences of disability. People are unreliable observers of their own bodies and self-perceptions of disability may not always align with objective observations of health or disability status (Monks, 2000: 19). Different people with the same impairment may experience different levels of disability based on psychological factors and sensitivity to pain.

“The problem is there is also this element of fatigue, which is very subjective. So I have patients who have an ejection fraction of 45⁵⁷ who feel great, who do fine because that's the kind of person they are. But then you have patients who have an ejection fraction of 45 and feel completely incapacitated. It's very difficult to know if they are. So the fatigue factor is very difficult. So even though with ejection fraction of even 25% you can function fairly okay - up and down the stairs you'd get tired, but would you be able to do an 8-5 every single day, would you be able to catch the bus to the job like that? It becomes very difficult you know.” (Dr Harvey, Interview, 2014 April 29)

Robinson (2004) argues that fatigue, weakness and pain are really what prevent people from working. However, because these subjective factors cannot be easily seen or measured, they are given little weight in disability assessments and doctors typically prioritise ‘objective’ biomedical evidence over patient narratives (Dodier, 1998). Patients who lack visible explanations of their pain are often trivialised or dismissed by doctors (Conrad & Barker, 2010: S72; Fassin, 2008). The possibility of malingering in DG assessments also means that doctors are cautious of relying too heavily on self-reported information from patients. Furthermore, taking subjective factors into account requires engaging with a patient’s individual experience and doctors do not necessarily have the time, training or inclination to do this – especially when SASSA assessors have very little time to see a patient and complete all their paperwork.

As a profession, medicine has moved away from a purely biomedical model toward a bio-psycho-social model of health (Engel, 1977), which involves bringing together biomedical, psychological and social aspects of health in a holistic and integrated approach to patient care. In the early 2000s, the curricula of most Bachelor of Medicine Bachelor of Surgery (MBChB) degrees in South Africa were reoriented towards primary and person-centred healthcare and teaching students within the frame of the bio-psycho-social model. However, many of the doctors conducting disability assessments in this study had qualified prior to this change in teaching approach and even young doctors taught with new curricula, had limited exposure to

⁵⁷ Ejection fraction is a measure of the heart’s ability to pump blood with each contraction. An ejection fraction of below 50% is generally considered an indication of chronic or congestive heart failure.

disability and rehabilitation issues. This is because coverage of these topics in the curriculum remains extremely limited and is presented in the pre-clinical years.⁵⁸

Professional experience and socialisation also shape how doctors think, interact with patients and make decisions on how medical knowledge is communicated and reproduced. Collins and Pinch (2005) argue that it is not ‘book learning’ that ‘makes a doctor’. ‘Becoming a doctor’ involves tacit knowledge and interactional expertise that develops as doctors gain experience, and learn the spoken discourse of the profession through socialisation. The way in which doctors are socialised into medical practice during their clinical training can also undermine more holistic, biopsychosocial and patient-centred approaches taught in the formal curriculum. This *hidden curriculum* is communicated through the informal lessons about medical culture and ethics that medical students are unintentionally taught outside the classroom in clinical and other medical settings⁵⁹ (Hafferty & Hafler, 2011: 7; Hafferty & O’Donnell, 2014; Hafferty & Franks, 1994; Martimianakis, 2015).

Vivian et al. (2011) studied the hidden curriculum in the training of Cape Town medical students, finding a disjuncture between what students were taught about human rights and professional ethics and what they observed in clinical practice. This ‘street knowledge’ about how medicine really works and what it means to be a medical professional is shaped by organisational context, mentors and role models, the relationships they observe between members of the healthcare team, as well as what is not taught (Hafferty & O’Donnell, 2014). This can lead to both good and bad outcomes, but in poorly resourced settings such as are common in South Africa this is most likely to lead doctors to medically objectify patients and erode empathy and ethical practice.

Medical expertise is essential in establishing the presence of disease or demonstrating the presence and extent of medical impairment (e.g. palpating a joint to establish deformities and tenderness in the case of osteoarthritis) and objectively measuring loss of physical function across the various body systems through established tests (e.g. range of motion of a joint or visual acuity.) However, medical expertise is not sufficient to establish disability and the biomedical model of disability has been criticised both in the South African system and more

⁵⁸ For example, at the University of Cape Town, medical students only engage with disability issues in one introductory course aimed at building professional skills that sensitises medical students to disability issues (UCT Handbook, 2015). This course was piloted in 2009 in response to a perceived lack of sensitivity to disability issues amongst medical students and professionals and is not related to disability assessment specifically (Amouson & Taukobong, 2010).

⁵⁹ This can include meetings, conferences, interactions with professors and peers.

generally, for its inability to account for individual experiences and social and structural factors that can be disabling. It has also proved inadequate in accounting for how chronic diseases, mental health issues and musculoskeletal complaints, which now generate the majority of work disability claims, affect individual work ability (Krone & Brage, 2008). Although the guidelines acknowledge that non-medical factors should be considered in borderline cases, it was clear that social and economic factors or sympathy for the patient should not define the assessment. Doctors were told during training sessions I attended that SASSA used a medical model of disability. Some overcame this uncertainty by not considering non-medical information at all, while others, as I will show in Section 5.4.2, developed their own approaches, weighing medical, personal and environmental factors differently in making their assessments of patient eligibility.

How an impairment (or set of impairments) affects an individual, needs to be considered in terms of his or her activity limitations (especially work-specific activities) and participation restrictions, which may be highly individualised and contextual (WHO, 2002). However, most doctors are not adequately trained to use the tests and measurements that can be used to assess activity or participation restrictions (Govender & Miji, 2009: 229; Rondinelli & Katz, 2000). Unlike occupational therapists, physiotherapists or speech and language therapists, doctors without specialised training in rehabilitation or occupational medicine rarely focus on how impairment affects the individual outside of the consulting room and have limited knowledge on what type of work can be carried out and is available to an individual with a certain set of impairments (Zinn & Furutani 1996; Schneider, interview, 2013 June 14; Occupational therapist, interview, 2014 July 15). They are therefore more likely to assess disability in terms of the presence of a medical condition than in terms of actual functional limitations.

Although doctors receive minimal training on impairment and disability assessment in their general training, there are specialised branches of medicine that focus on physical rehabilitation (e.g. *physiatry*) and occupational health, where doctors are trained to assess impairment, functional capacity and disability and in Europe doctors can specialise in social insurance medicine and become certified Social Insurance Physicians (De Boer, 2007; Berg, 2000). There is no training for physiatry or social insurance medicine in South Africa, but doctors can specialise in occupational medicine⁶⁰ and acquire these skills through short trainings on specific

⁶⁰ Occupational health specialists receive comprehensive grounding in fitness, impairment and functional assessment tests and standards as well as the requirement for particular types of jobs in terms of their physical work demands, work environment, organisational or social aspects, temporal aspects, ergonomic aspects and travel

disability assessment tools such as the International Classification of Functioning (ICF) and American Medical Association guidelines⁶¹, which are used by the Road Accident Fund and some private companies. However, outside of the requirement that SASSA assessors attend a short SASSA training session, no specialised training was necessary to conduct DG assessments and only two of the twenty-four doctors involved in this study had received any of this training. Treating doctors are not required to participate in SASSA training. This means that the doctors who conducted assessments very often did not have the adequate knowledge, skills or tools to assess disability in a consistent way. As one doctor pointed out during a SASSA training session I observed, “None of us have specific training related to disability and there is a lot of subjectivity in our choices.” (Dr Brown, SASSA training, February 2014)

As rehabilitation professionals are arguably better equipped to address the functional and psychosocial aspects of assessments than most of the doctors conducting DG assessments, occupational therapists (OTs) were frustrated by the privileging of medical expertise in the assessment process. OTs also felt doctors did not have the time to conduct tests to establish functional capacity and argued that doctors typically did know enough about a patient’s personal history or background to conduct accurate assessments.

“If a doctor has a patient and he decides ‘based on your medical condition I am not going to give you a grant’, but then he doesn't know how that impacts on function, on a person's bigger life roles or if he decides to give a person the grant, it's going to be an unfair distribution of SASSA funds. No one person is the same... So if they would have a little bit of insight on a person's life and the context and the holistic person... but I think they don't have the time.” (Occupational therapist, 2014 April 25).

4.2.2 Dealing with uncertainty

The fact that doctors may not be experts on non-medical issues or trained in social security medicine, does not mean that they are not capable of using their past experiences to make reasonable decisions. The human experience of sickness is not exclusively biological and although they may not have formal training in this area, doctors often have to include these factors in other types of decision-making. Whilst medicine prides itself on being a scientific, evidence-based practice, doctors must also learn the pragmatism that is required to make diagnostic and treatment decisions in the face of uncertainty or ambiguity. Illness rarely presents itself as a textbook case and although making decisions with imperfect information

(CMSA, 2012).

⁶¹ American Board of Independent Medical Examiners (ABIME) certifies physicians as internationally recognised medical examiners.

involves risks, doctors could not operate if they required epistemological certainty to act. (Beresford, 1991: 8).

In the absence of formal training on disability assessment and unclear and sometimes unavailable guidelines, doctors used their own common sense approaches, filling the gaps with their own understanding of disability based on their professional experience and their discussions with colleagues, employing a pragmatic rationality in their clinical judgement on disability. In cases where claimants fell into grey areas and the patient's ability to work depended on contextual determinants which they did not know of have the ability to assess, doctors developed their own rules of thumb to determine claimants' employability.

They could make referrals to occupational therapists, physiotherapists or other medical specialists where they needed further input on assessments before making a recommendation.⁶²

Doctors could delay making a decision, and recommend a six-month temporary grant for patients who appeared to be impaired, but whose medical condition had not been properly documented, investigated or treated; provided they were referred for further testing and treatment. Many doctors who were uncertain about decisions therefore recommended temporary grants in the hope that patients would in fact seek out further care. Particularly complicated cases could be referred for comprehensive work assessments with an OT at a specialised work assessment centre, where claimants would perform tasks and tests over a period of a full working day to establish their ability to function in the workplace. However, this was a time-consuming process for patients and some doctors considered it a burden to the system and therefore simply made a judgement call.

When I asked doctors how they made decisions, they generally told me about their own informal set of assessment rules, based on their clinical experience, understanding of disability and conversations with colleagues. For instance, Dr Malik, who specialised in infectious diseases and who had never seen any guidelines, had developed his own set of criteria, infused with his own particular understanding of disablement and 'deservingness', which he explained as follows:

Physically disabled, meaning a patient that is wheelchair-bound or otherwise disabled due to their medical condition;

⁶² OTs at work assessment units at two different tertiary hospitals complained that many doctors, who wanted to avoid making decisions about eligibility or pressure from patients, abused the referral system by referring even straightforward cases to them.

Chronic and other incurable illness, including malignancies and chronic kidney disease;

'Demographic' considerations. (As many of his patients were poor, he tried to differentiate between someone looking for easy money and someone who genuinely needed it because they were sick). (Field notes, 2014 May 6)

One doctor even admitted that he didn't give his decision-making very much thought and took a 'thumb-suck approach', which in South Africa has a meaning akin to pulling something out of thin air. The clinical mind is action driven and pragmatic in the face of needs to make decisions, and doctors come to rely on the authority of their own senses and trust in first hand experiences, more than abstract knowledge (Freidson, 1970). For this reason, doctors may evaluate the world more in terms of own experience than in terms of what authorities like SASSA tell them (Freidson, 1970).

"You know a lot of medicine is about experience and feel, like so I think that experience helps. Like for example Prof S walking in the other day and saying 'this patient needs a permanent grant, she's not going to recover.' Now it's easy to say that when you've [patient] had a condition for over a year and you've [the doctor] been doing this for over three decades. It's very different when you are brand new on the block and we see patients at one point in time so that one point in time doesn't necessarily reflect how they are - especially in this hospital... I mean so much of medicine is about feel and about gut feeling. I just know and you're sometimes wrong and you're sometimes right and when you look back in retrospect it's easy to come to that conclusion, but when you were standing looking at them, how did you know that?" (Dr Harvey, interview, April 2014)

Dr Harvey's feeling of 'knowing' is grounded in a deep experience-based practical wisdom that allows her to combine medical knowledge and practical skill to address the context-bound particularities of individual cases (cf. Montgomery, 2006). Like Dr Harvey, several other doctors spoke of the role of "gut feel" or making "judgment calls" based on precedent and the tacit knowledge that comes from experience, which Cassell (2002) called 'experienced knowing'.

Contrary to what Parsons (1951) argued, medical knowledge is particularistic rather than universal (Freidson, 1970). Studies of medical practice have consistently demonstrated that doctors very often rely on their clinical experience and tacit knowledge than on learned scientific knowledge (Greenhalgh, 1999; Boshuizen & Schmidt, 1992). Medical students are taught to diagnose patients using a hypothetico-deductive model of medical reasoning, using the process of differential diagnosis and existing research evidence to systematically work through and refine possible explanations for a given set of symptoms. However, as they develop expertise they refine their skills and knowledge through reflecting and learning from

their experiences rather than from technical guidelines. They learn rules of thumb, maxims and dictums that guide and simplify their diagnostic thinking, for example: “among competing hypotheses, favour the simplest one” (Occam’s razor), “when you hear hoof beats think of horses not zebras” and “uncommon presentations of common diseases are more common than common presentations of uncommon diseases” (Montgomery, 2006).

Medical practice is commonly described as an ‘art’ as well as a science because of its applied nature and the need for doctors to make complex decisions in uncertain contexts. The processes through which doctors translate scientific knowledge into action and apply it to individual patients has fascinated scholars in both the sciences and social sciences for decades. Various theoretical explanations of clinical reasoning have emerged, mainly in cognitive and behavioural science, but no single theory yet fully accounts for how doctors think and make clinical judgements (Higgs & Loftus, 2008)⁶³. Scholars in the humanities and social sciences have recently taken up the question of clinical reasoning, arguing that it is a multi-dimensional, context-dependent, constructed and interpretive rather than scientific practice (Greenhlagh, 1999; Mattingly, 1994; Montgomery, 1991, 2006; Higgs, 2008).⁶⁴ The accumulation and application of specialised knowledge in other professions is also increasingly understood to be a hermeneutic process, developed through reflective practice rather than the mastery of technical knowledge (Eraut, 2004; Schön, 1983, 1987; Higgs, 2008). Donald Schön describes the ‘topography’ of professional practice as made up both of a highland of problems that can easily be solved with research-based theory and technique and a ‘swampy lowland’ - a space of messy, confusing but usually important problems that cannot be solved with technical knowledge alone (1987: 3).

Beresford (1991), Siegler (2000), Human (2011) and Montgomery (2006) describe doctors’ clinical judgment as a type of *phronesis*, an interpretive capacity and intellectual virtue that enables doctors to combine medical knowledge and practical skill to address the context-bound particularities and ethical aspects of individual cases. Oakeshott’s (1962) concept of *practical knowledge* has parallels with the concept of *phronesis*, as does Polanyi’s (1962, 1966) idea of *tacit knowledge*. This type of knowledge reflects a kind of know-how that can only accumulate

⁶³ There are numerous theories that explain clinical reasoning: cognitive processes such as scripts and schemas (Barrows & Feltoich, 1987; Bozhuizen & Schmidt, 1995) to the hypothetico-deductive models and Bayesian methods, to more heuristic, gestalt, narratological and interpretive processes (Greenlagh, 1999, Montgomery, 2006).

⁶⁴ This interpretive turn can be understood as a reaction to the Evidence Based Model of medicine, but is not unique to the study of medicine.

with experience and which eventually becomes almost unconsciously applied – e.g. driving a car. This capacity is not easily captured by science, learnt in medical school or bound by rules; rather, it is learnt through experience and practice and represents what is often described as the ‘art’ of doctoring (Meershoek et al., 2007). Even ‘objective’ data from x-rays, stethoscopes and spirometers have to be interpreted and cannot be understood in isolation from the patient and their context and needs to be interpreted alongside the patient’s medical history and experience (Greenhlagh, 1999)⁶⁵.

This more intuitive and situational aspect of medical practice is not captured or easily governed by medical or administrative rules and guidelines. This does not mean that professional action is arbitrary, rather that its rationale is not fully explicable (Meershoek, 2007; 2012). Formal guidelines are based on “abstractions and generalizations of the practical situations in which they are intended to be applied” (Meershoek et al., 2007: 499), they assume that patients can be placed into homogenous categories that should be treated in the same way (Berg et al., 2000) and therefore do not necessarily capture the nuances of medical practices and individual patients. For this reason, medical doctors may resist what they perceive as the reductionist nature of these protocols (see Chapter 5 and 6). In order to provide the care that individual patients need, doctors sometimes have to side-step protocols and rely on their clinical judgement instead (Human, 2011; Harper, 2005). In the case of DG assessments, numerous doctors, especially those in treating sessions, resisted the idea of classifying patients and preferred to treat each client as an individual case, choosing to ignore the guidelines in favour of their own clinical experience and knowledge of the patient.

4.3 Why doctors lend legitimacy to disability assessments disability

Despite the limitations of medical knowledge and expertise in disability assessment, medical expertise remains highly valued in disability assessment and doctors continue to be important gatekeepers in most disability welfare systems, including South Africa’s - which is heavily reliant on doctors’ input. Policymakers and administrators want rules and standards that can be routinely and accurately applied. Medical knowledge presents what appears to be an

⁶⁵ Another useful and ancient concept of practical knowledge that is useful for understanding how doctors think and deal with uncertainty is *mētis*. Scott (1998) describes *mētis* as a set of practical skills and “acquired intelligence,” embedded in local experience that allows actors to respond rapidly to ambiguities and complexities in their environments. Although Scott refers to medical doctors as using *mētis*, it has not been widely used in the literature on medical judgement, perhaps because of its association of wile and cunning.

appealingly rational, scientific and objective way to establish whether medical complaints and impairments are genuine and to distinguish between people who should qualify or not qualify for benefits.

There are other forms of professional (occupational therapy) and 'lay' expertise (patient knowledge or employer expertise) relevant to disability assessment. Medical knowledge is, however, the most powerful form of knowledge about the body and doctors' input is valued over other forms of knowledge despite its failures struggles to measure disability because biomedicine has been ascribed scientific authority over matters of the body. Starr (1982) and Freidson (1970) have both attributed medicine's connection to science as setting them apart from other health professions and central to their authority and legitimacy. Doctors have the officially approved monopoly over defining disease, health and treating illness (Freidson, 1970) and the power to decide what is 'normal' and what is pathological (Canguihelm, 1978) or deviant (Lorber, 1972).

In addition to their biomedical knowledge, another reason why doctors play such a leading role in disability assessment world-wide is due to their perceived professionalism, which can be defined a set of values, behaviours, and relationships that underpin the trust the public has in doctors (Royal College of Physicians, 2005). Medical training is not only a process of knowledge acquisition but also a process of professional socialisation that initiates doctors into a 'moral community' (Durkheim, 1992) of professionals committed to explicitly normative goals and norms of acceptable behaviour. Doctors learn from other doctors how to interact with and treat patients and how to deal with ethical dilemmas; and through this process doctors come to see and interpret things in very particular ways. Being a doctor, therefore, becomes a "way of being in the world" (Higgs & Loftus, 2008: 214). Parsons (1951) imagined doctors in a normative or moral role, positioning them as altruistic, caring, trustworthy, community-oriented, but ultimately neutral agents. Although this trust in doctors has been eroded to some extent, the idea that medicine is a moral enterprise and doctors should behave in objective and ethical ways remains central to how the profession positions itself (Freidson, 1970; Kleinman, 1995). Society has high expectations of medical professionals; they are expected strive for excellence and display wisdom, strong character and integrity and a commitment to relieving human suffering, curing disease, true reliable knowledge and furthering the profession (Barlian, 2009; Freidson, 1972). Doctors are expected to hold humanistic values and adhere to a professional and ethical code of conduct. In South Africa this is expressed in the introduction to the Code of Conduct of the Health Professionals Council of South Africa

(HPCSA) which governs the medical profession in the country:

*“Medicine, dentistry and the medical sciences are professions based on a relationship of trust with patients...To be a good doctor, dentist or medical scientist requires a life-long commitment to good professional and ethical practices and an overriding dedication to the good of one’s fellow humans and society. In essence the practice of medicine, dentistry and the medical sciences is a **moral enterprise** [emphasis added].” (HPCSA 2008: 1)*

Some of the core principals of good medical conduct are integrity, truthfulness, confidentiality, tolerance, justice, a respect for persons and human rights, non-maleficence and beneficence (HPCSA, 2002). Doctors are therefore trusted to make objective, unbiased decisions and have traditionally been given significant autonomy and discretion in terms of how they make decisions and deal with ethical dilemmas. However, as I will argue in Chapter 6, doctors may in fact struggle to be neutral parties in DG decisions. This is because these decisions are inherently normative and there are other pressures and constraints on them that shape their practice and because medicine alone is inadequate for assessing disability.

4.4 Conclusion

Doctors are asked to conduct disability assessments because of their medical expertise and because it is supposed that they think and operate in rational, objective and scientific ways. However, as this chapter has shown, medical assessments of impairments and disability are not straightforward and medical knowledge alone is not sufficient to conduct disability assessments.

The social and medical aspects of disability cannot be easily disentangled and division between the clinical evaluation of the patient and social factors, including the interaction that the doctor has with the patient, is an artificial one. However, in conducting assessments doctors are told to consider these factors separately, but are also expected to bridge the gap between impairment and disability by incorporating psychosocial issues in cases of moderate impairment. Without the training and knowledge on how to do this, doctors in the current study generally created their own rules of thumb for making decisions. Using their clinical judgement, experience and conceptual understanding of disability, doctors developed a set of shortcuts or heuristics to simplify their decision-making.

There are aspects to illness and disability that a purely biomedical model of illness cannot reveal, but current disability grant system treats the non-medical aspects of disability assessment as extraneous detail or what in the guidelines were referred to as “discriminating

factors” (SASSA, n.d.: 23). As a result, these issues, which are actually the most challenging part of disability assessment are ignored, and the focus has been on top-down compliance. Efforts to rationalise the assessment process that do not take the normative aspects and complexities of doctors’ reasoning into account only obscure the actual logic that doctors employ when making decisions (Meershoek et al., 2007). The disconnect between the guidelines and the actual reasoning required to make decisions result in SASSA guidelines being dismissed by some doctors as arbitrary and unhelpful. It also results in rigid application of a purely medical model of disability, which is not helpful or useful in cases of severe or minimal impairment.

As I have discussed to some extent and will discuss in later chapters, these informal rules are influenced by a myriad of other factors, including the circumstances of their work in the SASSA and healthcare bureaucracies, their own personal norms and standards and related ideas of ‘deservingness,’ and the nature of their interactions with individual claimants. The decision on whether to recommend a grant is not only an administrative and medical decision but one that relates to human experiences and which at same time is implicitly normative. The inescapably qualitative nature of the disability experience means that doctors may not be able to act as the objective and rational arbiters of questions around disability and illness that welfare administrations hope them to be (Stone, 1984; Montgomery, 2006; Meershoek et al., 2007; Mashaw, 1983). However, the fact that the disability category is ‘fuzzy,’ can be defined in multiple ways does not mean it should be treated as if it is not real or totally relative.

Much as it is important to consider the ‘person,’ their context and their experience of illness and disability in assessments, disease and impairment are also rooted in real biological processes, of which doctors do have expert knowledge. The fact that disability has dimensions that exceed the bounds medical expertise or knowledge, does not mean that medical expertise and the biomedical components of illness (disease) and disability (impairment) are not important in decision-making (Cassells, 2002: 24). On the contrary, as Brown, (1995) noted in his critique of social constructionism in medical sociology, “we are, after all, talking about phenomena which occur in people's bodies. If we do not take seriously this reality, our search for socially constructed definitions will be very short-sighted.” (Brown, 1995) This opens up questions about what is required

CHAPTER 5: Doctors as street-level bureaucrats: the role and position of medical doctors within the social assistance system in South Africa

5.1 Introduction

This chapter focuses on the tension between professional expertise and bureaucratic accountability that is specific to medical doctors serving as DG gatekeepers. I show how doctors navigate between their role as medical professionals and their bureaucratic role as DG assessors for the state and respond to the pressures, constraints, incentives and disincentives within their environment.

Although medical doctors are typically considered a professional group, in their gatekeeping role as disability assessors, doctors operate as street-level bureaucrats in SASSA's DMM model. In order to make decisions about patients' eligibility for grants, doctors must apply the protocols and rules that govern DG allocation to individual patients. Baron (1992) suggests that in doing so, South African doctors take on the role of medical professional on the one hand and detective and judge for the state on the other. They are simultaneously expected to follow the rules and bureaucratic processes of SASSA's DMM and use their professional judgement to evaluate the case at hand by engaging in 'thought-work' (Heyman, 1995).

Having outlined the DG systems' broad design in Chapter 3, here I examine the material organisation and everyday realities of the DG assessment process and what doctors do in practice. The authority, discretion, role expectations, workload of and level of support received by frontline workers, as well as their beliefs about their environments have distinguishable effects on the dynamics of worker-client interactions (Jewell & Glaser, 2006; Meyers & Vorsanger, 2007). Drawing on Lipsky's (2010) work on street-level bureaucrats, I look at how the organisation and management of the DMM motivated and constrained the actions of medical professionals in the DG system as they attempted to cope with uncertainties and work pressures in this environment and straddle the often conflicting demands of SASSA and claimants and their own personal and professional interests. I show how doctors developed their own systems of meaning and coping strategies that simplified their decision-making and lightened their workload in the context of an overburdened health system, poor record-keeping and pressure from patients.

As the majority of assessments were conducted by SASSA assessors at the primary healthcare level, this chapter focuses predominantly on this context and their work. The specific case of treating doctors and the particularities of carrying out assessments in hospital settings will,

however, be briefly considered.

5.2 Accountability vs. discretion in disability assessments

There is an inherent conflict between the logics of SASSA's bureaucracy and medical professionalism. Whilst SASSA wants doctors to make standardised decisions, doctors are trained to respond to individual needs. In bureaucracies, worker compliance is achieved via supervision, whereas professionals are generally socialised to comply with the norms and standards of the profession they belong to (Scott, 1966).

Medicine is the archetypal learned profession and is not well understood by lay people. This makes it difficult for the non-medical public to evaluate the work of doctors (Horobin, 1983).

While doctors' legitimacy and right to practice medicine depends ultimately on sanction and registration by the state (Doyal, 1979 in Wainwright et al. 2015), over time medicine developed the distinct legitimate authority to regulate its own work (Freidson, 1970).

Historically doctors have had significant *de facto* discretion and independence in how they diagnose, treat and assess patients. However, as discussed in the introduction to this thesis, the practice of medicine is becoming increasingly bureaucratised and standardised. Protocols, guidelines and assessment criteria based on randomised control trials and observational studies are now commonly used throughout medicine in an effort to rationalise expert judgements and professional action, make medical-decision making more transparent, increase professional accountability and reduce variation in and improve quality of care (Meershoek et al., 2007; Timmermans & Berg, 2010; Bowker & Star, 1999; Berg et al., 2000).

Lipsky (2010) argued that using their discretion, street-level bureaucrats develop coping mechanisms to simplify their work in response to environmental conditions and conflicting demands. As this behaviour can undermine policy intentions, organisations like SASSA seek to curb bureaucratic discretion in a pursuit of a Weberian neutral, rational bureaucracy and "bureaucratic justice" - accurate and consistent decision-making by bureaucrats (Mashaw, 1983). This is what SASSA has attempted to do with its DMM. However, it is difficult to and undesirable to completely eliminate medical discretion. SASSA guidelines, rules and general medical standards largely eliminate the possibility for doctors to exercise "strong discretion" - the potential to make decisions unbound from any authority in making decisions - but do not eliminate the "weak discretion" that exists in the space between rules, where it might be necessary to make judgment calls (Dworkin, 1978).

SASSA has struggled to constrain doctors' discretion and monitor doctors' work because of

their professional status, specialised knowledge and resistance to bureaucratic oversight. While curbing the discretion and increasing control of lower level interface workers can help to decrease bureaucratic drift and curb corruption, in the case of professionals it may constrain their ability to be responsive to individuals and they may value their professional obligations to patients over efforts by outside bodies to regulate their work. Others have shown that although doctors appreciate guidelines and protocol, they tend to use them pragmatically, applying them when they are practically useful and ignoring them when they overlook individual patients' needs or their own private and professional goals (Human, 2011; Timmermans & Berg, 2003). While doctors in this study appreciated efforts to standardise the system and make their decision-making around DGs easier and more objective, guidelines are not sufficient to guide doctors' practice and limited oversight made it easy for doctors to ignore them.

5.3 The daily work of DG assessment

The organisational environment that doctors worked in was an important factor in structuring their decision-making behaviour and how they treated claimants. Hoff argues that doctors think and act subjectively in response to their work environments, in ways that do not always accord with the norms and ideals of the medical profession but which helps them to 'normalise' their work lives and cope with uncertainty in their surroundings." (Hoff, 2010: 54).

The DG assessment process varied in hospitals, where treating physicians filled out DG assessment forms for patients during outpatient consultations. Therefore, for the purpose of clarity, this section focuses on the nature of assessments conducted at the clinic level and the specificities of hospital assessments are discussed separately in Section 5.3.1. Contrasting the nature and context of assessments conducted at the PHC level by SASSA assessors with those conducted at hospital-level by treating physicians demonstrates also demonstrates how organisational context framed the doctor-patient interaction and shaped assessment outcomes. This is because the pressures, constraints and rewards in these environments differed.

Within the healthcare system, SASSA assessors were considered 'outside doctors' because they operated independently of the clinic structure. They were technically 'managed' by the DoH via staffing agencies but these agencies seemed to do little to regulate doctors' work. SASSA assessors typically worked at a number of different clinics during the week. This 'freelance' arrangement allowed doctors to work shorter, more flexible hours than in other more demanding areas of medicine. Many of the doctors considered doing assessments to be 'easy'

or 'laid-back' work because it is almost exclusively paperwork based. Disability assessments work therefore appealed to retired doctors, those caring for children who needed flexible part-time work and doctors with private practices who were looking for some additional income. Conducting assessments was also a form of transitional or temporary work for doctors waiting for a permanent post to become available. As it was also low paid, doctors therefore had little motivation or incentive to carry out this work particularly well.

I observed that as a result of poor communication between SASSA, agencies and the clinic, clinic staff were not always sure who the SASSA doctor was or when they were scheduled to visit the clinic. It was also more difficult to keep the doctor accountable and I noticed that several of the doctors arrived extremely late, keeping patients waiting for hours. This frustrated both claimants and clinic staff. On the other hand, assessors at some clinics complained that because they were not treating patients their needs in terms of space and examination facilities were given low priority. Doctors were often placed in public use areas and beds were not always available as required in the Service Level Agreement with the DoH. In one particularly memorable case, the doctor was sharing a room with nurses who regularly came into the room to make tea and fetch things from their handbags during assessments, sometimes even making casual conversation with the patient or doctor. This was disruptive, undermined the privacy of the consultation and demotivated doctors. As locum doctors were not contracted directly to the Department of Health, they were in a weak position to complain to facility managers about the resources made available to them. As SASSA had no involvement with the employment of these doctors or the facilities they work in, doctors had to rely on their locum managers to represent their interests, which some complained was ineffective (Observations SASSA Training, 2014 February 19-20). This meant left assessors feeling frustrated and isolated from official structures – possibly inclining them to take official rules less seriously.

The healthcare system in South Africa is generally highly bureaucratized by paperwork and standardised practises, but the bureaucratization of the physician's role was particularly salient in the case of SASSA assessor, whose interactions were very much structured by SASSA's managerial processes and the standardised assessment tool. Patients became SASSA's 'clients' and doctors were expected to offer good customer service rather than form the type of relationship with patients more typical in a treating setting. Working as a SASSA assessor is repetitive, sometimes mundane work. Doctors worked through the list of patients, filling out the same form over and over again, day after day. In doing so, they developed routines of practice and standardised ways of communicating with patients and their actions become a form of

“people processing” (Prottass, 1979). This routinisation did not, however, result in standardisation in decision-making and despite the guidelines and the standardised forms that doctors used to report their findings and conclusions, there was significant variation in how doctors engaged with the patients they assessed and the processes they developed to deal with patients.

The SLAs between SASSA and DoH districts stipulated that no more than forty claimants should be booked per clinic per day. This left twelve minutes per patient, including paper work and presuming no time between patients. Although not all doctors saw this many patients a day, doctors in high-demand areas reported cases where, because of poor process management, up to sixty patients had arrived to be assessed. This put significant pressure on these doctors in terms of the time they had available per assessment. Both for themselves and the patients waiting in line – many of them from the early hours of the morning – doctors needed to work quickly and would watch the time, consciously speeding up when they started to fall behind. Many doctors rushed through the assessment forms, crossing out any sections that they felt were not directly relevant to the patient, filling in the bare amount of information in each section. This tendency made quality assurance difficult as this was conducted purely on the basis of the form. This could negatively affect patients because the quality assurance officer could alter a doctors’ recommendation if insufficient information was provided on the form to support their recommendation.

As the inspection of a medical file was considered a legally acceptable form of assessment, physical examination was not compulsory and due to time pressures, infrequently used as a method of assessment. Sometimes beds were not even available in the assessment room for this purpose. Only four out of the eleven SASSA assessors I observed conducted physical examinations. Although doctors were meant to report on the weight, height and blood pressure of the patient, very few took these measurements and either did not fill in this information on the form or used measurements already in the file.

Although guided by the assessment forms, doctors were able to structure their interaction with the patient as they wished and generally developed their own standard ‘scripts’ and assessment approaches, based on what they thought was important to consider in decision-making. These often diverged from SASSA’s guidelines (see Chapter 6 for further discussion on doctors’ framings of DG eligibility). Some never questioned patients about their educational or employment histories and focused exclusively on functionality or medical diagnosis. Others focused more on employability and asked patients about their level of educational attainment,

when they had last worked, what type of work they had done and why patients felt they could not work and combined these responses with their medical findings to establish an applicant's employability.

Doctors also found various ways to categorise patients and simplify their decision-making. With limited times to think through decisions, doctors developed practical and routine ways of classifying and treating patients, based on their own rules and stereotypes, the development and application of which is discussed in detail in the next chapter. One quick way of establishing claimants' eligibility was determining their past DG application history and the success of these applications. This history provided an indication of whether the patient was likely to be a serious case or not and helped different doctors keep their decision-making consistent. In addition to asking claimants directly, most also kept track of the date and outcome of each assessment and the reason for recommending or refusing to recommend a grant, by making a note in the claimant's folder. Assessors could therefore scan the folder to see whether they or another doctor had made notes about any previous assessments. This was particularly useful for identifying cases where a person's condition was not improving and perhaps a permanent grant should be considered. It is also helped in identifying cases where patients were repeatedly applying for the grant, often despite not qualifying, as was the case in the assessment below. The doctor saw from previous notes that the patient had visited the clinic for DG applications more often than for any treatment and called her a "chancer" because (as he saw it) she had admitted that she could work but did not seem interested in working.

He asks the patient, "Why can't you work anymore?" She is quite agitated and speaks very rapidly saying that she was only getting paid R80 as day as domestic worker. He asks her, "If you could get work would you?" She says "yes" and then she proceeds to complain about how the government stopped her CSG because her child was now over 18. The doctor asks her what is wrong with her – she says she has a headache, is tired and that she has asthma. The doctor examines her chest and says that the asthma doesn't look too bad. As he looks through her file he asks, "When last did you see the doctor?" and then answers the question himself, "The last time you saw the doctor was August last year – you can't be that sick." I see in the folder that she has applied twice before and that both time she was DNQ [does not qualify]. The doctor is very sceptical about her and quickly gets rid of her. (Field notes, 2014 22 July).

This reliance on past notes could bias doctors' decision-making and disadvantage patients who had been refused the grant in the past. Dr Du Toit mentioned that he had seen long negative notes written in claimants' files, which were likely to influence any doctor conducting assessments in future.

During training doctors were strongly discouraged from telling patients whether they would

recommend the grant and the NSAT form was designed to prevent patients from seeing the doctor's recommendation on the assessment form. This was intended to reduce the likelihood of negative reactions from patients and because doctors' recommendations could be altered by the quality assessor if selected for pre-application quality assurance. Doctors typically followed this protocol and doctors ended the assessment by telling patients to return to SASSA in two weeks to apply. This neutral way of ending the conversation usefully closed off opportunities for the patient to probe the doctor about the outcome of their assessment. However, some doctors did seem to derive satisfaction from being able to tell patients they felt were 'deserving' that they had recommended a grant and shared this news with claimants. Sometimes doctors also chose to risk having a heated interaction with a claimant in order to explain to them why they did not qualify, but this was less common.

Not telling claimants about the outcome of their grant was not necessarily effective in reducing the pressure on doctors. According to doctors, SASSA officials at local offices often diverted negative reactions by rejected applicants from themselves to doctors, who they explained had refused to recommend a grant. Although SASSA discouraged this practice, regional and national office representatives acknowledged that officials sometimes failed to communicate that the decision was in fact made by SASSA, not by the doctor. This led rejected angry applicants to return to the clinics to confront doctors, often aggressively. Blaming doctors in this way reinforced patient misunderstandings about the role of the doctor in the system and undermined other efforts to reduce patient pressure on doctors. This was discussed by doctors at the training session:

Dr Y: Or they say "doctor didn't write clearly" and that is why it was rejected.

SASSA official: It should not be like that.

Dr Y: It puts you on the frontline. They are aggressive.

Dr X: In Gugulethu they hit a doctor once.

SASSA official: This also happened at the Overberg office. It should not be the doctor explaining. It should be the SASSA official because otherwise you open yourself up.

Aside from time constraints and pressure from patients to recommend the grant, doctors faced numerous other challenges during the assessment process. Given the importance of the file in the assessment, assessors were heavily dependent on the quality of the notes written by treating doctors. Unfortunately, these were often illegible and inadequate and patient files often did not contain the necessary test results, reports or scans to allow the assessor to make a fully-informed decision. This was especially likely if the patient had been seen at the hospital level in

past or if the patient had moved between clinics. Although a small minority of patients brought referral letters or personal copies of reports or x-rays with them to add to the information in their file, the majority of patients lacked evidence of treatment outside their main clinic. In cases where a claimant's file had not arrived from another clinic, doctors would have to turn patients away, telling him or her to return either with their file or a letter from a treating source that provided an overview of their medical history (or at least their main presenting complaint).

One doctor complained that requests for supporting evidence such as x-rays or blood-tests for DG assessments were given low priority, but this did not seem to be the case everywhere. A few doctors, who regularly conducted assessments at the same sites, appeared to have built good relationships with staff at the facility and were easily able to refer patients for tests within the clinic. In order to obtain reports from specialists or undergo more specialised tests, patients very often had to be seen at the hospital level. Some tests, such as a lung-function tests and work assessments could only be conducted at the two tertiary hospitals in Cape Town. This resulted in backlogs and created a barrier to access for those who could not afford the costs of travel or paying medico-legal fees at hospitals to get their documents. Brodtkin and Majmundar (2010: 827) call non-participation on the basis of "bureaucratic run around" and its associated costs, "administrative exclusion".

Although doctors could recommend a temporary grant of six months whilst supporting medical evidence was obtained or while the claimant received further treatment, this was only meant to apply in cases where the claimant was clearly impaired. In practice, this incentivised assessors to avoid making concrete decisions on a patient's eligibility and many would repeatedly recommend the grant for six-month periods, using them as what de Villiers (2006: 3) described as "convenient half-grants." During training, one doctor raised her concern that this supported what she called the "culture of the six-month grant." Applicants could only receive the permanent grant if substantial evidence of permanent disablement can be obtained, which was often difficult and, given the perception that SASSA was very strict in reviewing permanent grants, doctors were hesitant to recommend them, recommending one year temporary grants instead. Whilst recommending temporary grants helped doctors to alleviate the pressure on them as decision-makers, this resulted in some patients being on temporary grants for several years, which was stressful and inconvenient for applicants.

Many of the applicants could not read or write and had very poor medical knowledge. This made it difficult for patients and doctors to communicate and language barriers very often exacerbated this. Many patients had poor knowledge of their medical histories and treatment

and did not know the name or dosage of the medication they had been prescribed. In some cases, this made it difficult for doctors to fill in gaps in a patient's file. The language barrier between Xhosa-speaking patients and English or Afrikaans speaking doctors is a general issue, which interferes with the clinical process at all levels of the healthcare system in South Africa (Swartz, 1998; Swartz & Drennan, 2000). This can lead doctors to dehumanise patients and practice what some South African scholars have called "veterinary medicine" (Crawford, 1999; Oppenheimer & Bayer, 2007). In many cases I observed, both related and unrelated to the DG, it was obviously difficult for patients to clearly articulate their medical histories and functional limitations and communicate their experiences in the way they wanted to. It also made it harder for doctors to ask patients questions about their conditions or explain SASSA processes and requirements to them. This was particularly problematic at clinics and hospitals where there was a mix of patients from different racial and linguistic backgrounds and at the PHC level where patient loads were higher and doctors were time extremely time-constrained.

I will discuss how this affected the doctor-patient dynamic further in Chapter 7, but as it is important in understanding doctors' work context, I will briefly highlight some of the difficulties it created for doctors and strategies they devised for overcoming this this issue. Although Xhosa-speaking doctors were placed in some of the busier township clinics, this was definitely not always the case and on three occasions, I encountered English or Afrikaans speaking doctors working in predominantly Xhosa-speaking areas. Although formal translation services are available in hospitals, this service appears almost non-existent in clinics and I did not observe these services in use at either hospitals or clinics. In most cases where translation was necessary, nurses, administrative staff, and even other patients, were drawn into the room to translate. At one facility, a Xhosa-speaking woman, who spoke reasonably good English had capitalised on claimants' frustrations at being unable to communicate with assessors by providing informal translation services, accompanying patients into the room with the assessor to act as a translator, presumably for some sort of fee.

Both finding and using a translator can be time consuming and frequently SASSA assessors (and occasionally treating doctors) chose to stumble through consultations without translators, focusing on the contents of file rather than interacting with the patient. Two of the PHC clinics in Xhosa-speaking areas attended by doctors who did not speak Xhosa, had made a nurse available to assist with translation and clerical work, but this was not always the case. Dr Vrede, for instance, worked in a Xhosa area, spoke no Xhosa and had no translator available to her. Although she sometimes called in other patients to assist, this was too time consuming to

do in every case and she admitted to sometimes fabricating patients' 'self-reported' complaints, basing them on what she read on the file rather than making the effort to try and communicate with them or find someone to translate.

In summary, the freelance, sub-contracted nature of DG assessment work meant that there was little management of SASSA assessors work and lines of communication were often unclear. Their isolation from any real management structure meant that it was difficult to hold doctors accountable or for them to communicate about their frustrations. Doctors worked in difficult conditions, seeing large numbers of patients, which incentivised them to rush through their work. This led them to take numerous short-cuts, which had implications for both the quality of both their interaction with claimants and the assessments they produced.

5.3.1 The assessment at hospital-level

Doctors conducting DG assessments in state hospitals completed assessments forms in addition to their regular and already significant workloads and unlike SASSA assessors they were not paid for this work. Doctors working in the public sector in South Africa do so in an environment of significant emotional stress, punishingly long hours, staff shortages and poor working conditions, getting paid significantly less than doctors working in the private sector (George et al., 2013). The hospitals where I worked were considerably better resourced than public hospitals in many other provinces. Nevertheless, the specialists I engaged with worked long, difficult hours. As a result, DG applications were therefore often considered burdensome and annoying in a healthcare system that already required doctors to spend a large amount of time completing forms.

He says that in a busy clinic when a DG form appears 'faces often drop'. This is because people are usually coming forward with 'soft indications' and the forms are long and time consuming and a lot of doctors feel extremely frustrated by this when they have a lot of patients to see (Field notes, 2014 March 14).

Orthopaedists were perhaps the most frustrated by DG requests because, based on interviews with management staff, social workers, OTs and doctors across a number of specialties, it seemed that orthopaedic and infectious diseases (which dealt with TB and HIV) departments, received the highest number of DG requests. To save time, doctors would therefore typically only agree to fill out an assessment form if they have already decided to recommend a grant. Very often the task of filling them out would then be allocated to the most junior doctor or an

intern working in the clinic⁶⁶. Although they would often tell a patient upfront that they were not eligible for a grant (and refuse to fill out a form), if pressurised, doctors would fill out the form, indicating that the patient did not qualify. Some others would recommend a six-month grant just to get rid of a patient.

In her study of the professional socialisation of trainee doctors, Mizrahi (1985) argued that to cope with long hours and stress in environments where they felt unappreciated and overworked, doctors learnt to adopt a negative, “getting rid of patients” (GROP) mentality that objectified patients and encouraged them to avoid interacting with patients. In short, doctors felt abused and neglected and passed this onto how they treated patients.

In Cape Town public hospitals where doctors, especially registrars who are in the process of specialising, have large patient loads and work incredibly long hours, people ‘looking’ for grants are quickly placed into the category of patient undeserving of their time. In treating settings, doctors were quick to pass people wanting DG assessments onto more junior doctors and work assessment units, where occupational therapists complained that they received large numbers of ‘inappropriate’ referrals from doctors trying to avoid spending time making decisions. However, although I observed far fewer cases in hospital outpatient settings where patients were not eligible for grants than I did in PHC settings, I observed that doctors were generally sensitive and kind to patients despite their feelings of frustration and irritation. This could, of course, also be the result of my presence in the room (See Appendix A on reflections on the research process).

Some doctors were hesitant to recommend temporary grants because of the commonly held view that those who enter the system become stuck there and return repeatedly to the hospital for renewals after they have recovered and are no longer receiving care. One head of department at one of the hospitals indicated that he had a personal policy of refusing to recommend social grants for this reason. He instead referred these patients down to the PHC level for assessment. A social worker De Waal indicated that some doctors she worked with also refused to recommend grants on a similar basis:

“I’ll get somebody who will say “don’t give this person a DG because I’m the one that follows them up at clinic level [outpatient] and then I’ve got to tell them that they can’t get for another year or another 6 months. Then I sit with the problem of having to tell them and we’re the bad object in everything.” (Focus group, social workers, 2014

⁶⁶ Interns are not technically allowed to complete DG assessments, but sometimes the intern would fill them out and they would be signed by the treating doctor.

February)

Despite opportunities for more multidisciplinary input from other health professionals, like at the PHC level, doctors in hospitals were also faced the challenge of missing notes and files and generally poor recordkeeping, which made assessments difficult. As patients receiving specialist care in hospitals were presumed to be more severe and given the logistical difficulty of training and overseeing all doctors working in hospitals, treating doctors were given significantly more discretion in making recommendations and they were not involved in SASSA's training efforts. This meant that doctors in treating settings were often unfamiliar with SASSA's requirements and processes. One doctor at De Waal hospital had worked with SASSA DMU to offer training sessions at the hospital on a number of occasions but this had largely fizzled out. Other doctors complained about the lack of guidelines, training and feedback they obtained from SASSA on their recommendations and expressed their frustration when they learnt that patients they were actively treating faced long delays in receiving grants. This lack of engagement with and trust in SASSA left them feeling little responsibility towards the SASSA system and were therefore more likely to favour their own judgements and patient's needs over SASSA's requirements.

5.4 Doctors' responses to SASSA's regulation of their work.

Treating doctors and SASSA assessors engaged with SASSA differently and had different perceptions of the organisation's effort to regulate their work. Treating doctors, who did not attend SASSA trainings, were generally totally unaware of SASSA's guidelines and quality assurance processes - only two of the doctors working in hospitals had ever been exposed to these guidelines or had engaged directly with SASSA staff. All SASSA assessors were, however, aware of the presence of a quality assurance officer and the fact that their recommendations could be overruled in the pre-application phase and were therefore more cautious in their recommendations. However, none of these doctors had any contact with the quality assurer or knew who he was⁶⁷. This lack of transparency and professional engagement made some doctors suspicious of the quality assurance process and the right of another doctor to make changes to their recommendations without seeing the patient or their file.

⁶⁷ Ideally the quality assurer would interact directly with doctors and during interviews both the QA and the DMU representative expressed the hope that this would be possible in the future.

“Another doctor will review your work. What other doctor? Who is he? What right has he got to review my work? What is he doing when he reviews my work? Is he looking at the writing or is he trying to understand the patient? He’s not there with the patient so how the hell is he going to know anything about what you really think about that patient and that choice - your choice to give him this or give him that?” (Interview, Dr Brown, 2014 April 4)

“Feedback is just appalling. Doesn't exist. So, you know occasionally one of my patients comes and says, ‘they refused me the grant.’ Do you think anyone ever tells me? Do you think I can phone anyone to find out why? It’s just completely impossible. You know, how can you expect to run any sort of standard, rigorous process without giving feedback to the people you are trusting to make the decisions you know? It’s a joke.” (Dr Wright, Interview, 2014 April 8)

Studies of welfare bureaucrats in Sweden (Eggebo, 2013) and occupational doctors in Holland (Berg et al., 2000) indicate that decision-makers sometimes prefer less rather than more discretion and autonomy, especially when the legitimacy of individual decision-making is questioned. In the case of the DG, doctors were divided in their opinions on the usefulness and appropriateness of the guidelines. Treating doctors criticised SASSA for not making guidelines and training available to them, whilst SASSA assessors often criticised the guidelines for being vague and unclear or not comprehensive enough. Some assessors carried a copy of the guidelines with them and referred to them regularly in their decision-making, whilst others felt they were incomplete or impractical and did not help assist them in the most difficult aspect of assessment – deciding how a medical diagnosis actually impacts an individual’s ability to work. These complaints indicate that doctors desired decision-making support and guidance that would limit their subjectivity and responsibility for the decisions they made.

Dr Soet says that when they started they gave her the guidelines and you have the opportunity to discuss it with them. The guidelines are vague but you get the gist. The difficult things is that you don’t know how a condition takes its toll on a person. It is very subjective and it probably means a lot of people are cut out. The guidelines need to be more clear-cut on the over 50s. For example someone who has epilepsy and is over 50 – it is so hard for him/her to get a job. If the epilepsy is controlled technically they should not get a grant and should get a job, but you know how unlikely that is. (Field notes, 2014 January 29)

On the other hand, some doctors were very sceptical about the guidelines and the right of SASSA to regulate their work. As they had not been consulted on the guidelines doctors felt little ownership in the process and therefore found them easy to dismiss, as was the case with Dr Wright.

“You need to have them and look at them as a quick easy reference because number one, we're working flat out [laughs]. I'm not joking when I say that part of my

consideration is “well do I have time to fill this out today?” So you're working flat out, you want to make decisions as quickly as possible and if you don't have a reference in front of you, you...it becomes more of a judgement call. That's what doctors do all the time - they take shortcuts by making a judgement call based on past experience. If you want people to stick to guidelines you've got to have the guidelines in their faces all the time and you've got to have guidelines that make sense. That's only going to happen if there's adequate consultation in drawing the guidelines up...So there needs to be a transparent process to how guidelines are drawn up, which there hasn't been - none of us really understand how the guidelines came to be. So we don't own them, so we don't really care about them. In South Africa [laughs], laws are meant to be broken. So it's just another law.” (Dr Wright, Interview, 2 April 2014)

Dr Wright's statement: “laws are meant to be broken,” also speaks to the more general tendency of doctors to bend and break the rules to help patients and themselves within an underresourced and inflexible healthcare system. For example, orthopaedists chose to ignore the state's regulations against offering total joint replacements to patients under sixty because they felt it unfairly disabled people who, with surgery, could lead fully-functional lives.

Dr Brown was particularly sceptical of SASSA's processes and although he took his work as an assessor seriously and thought a lot about how he should make decisions, he conducted assessments very much on his own terms. He had strong confidence in his own medical judgement and did not feel the need to justify his decisions to SASSA or follow their guidelines despite the fact that he was employed by them to specifically conduct these assessments. He argued that “SASSA lives in a safe world with little blocks”, without any real connection to the actual DG assessment process. He felt that his interaction with the patient and expert opinion was what really counted and that this should be taken at face value by SASSA. *See Quote 5.1 Appendix C.*

He provided very little evidence of his clinical decision-making on the form, writing a set of notes for patient's files instead to help him keep track of patients and to provide other doctors with insights on his work. Before each patient arrived he would cross-out over half of the form with his pen, never intending to fill in any of this information because he thought it is irrelevant. For example, he would not list patients' medications on the form (a requirement) because he did not believe it was relevant to the assessment and that this information in patient's files was often unreliable and illegible. He also felt this made it impossible to establish whether someone was on optimum treatment. Although perhaps grounded in some genuine concerns about the assessment process, this behaviour was not only a dereliction of duty but jeopardised patients' chances of receiving a grant because the lack of medical evidence on the form would likely result in the decision being overturned if subject to auditing by the medical

quality assurer. This did in fact happen and (quite coincidentally) the quality assurance officer showed me a form where Dr Brown had recommended a permanent grant on the basis of an HIV diagnosis with no supporting information.

“Isn’t that terrible? The patient is being treated with total disrespect. The system is being treated with total disrespect. The doctor says “I’ve got the power to make decisions” and if I weren’t quality assuring this, this doctor’s recommendation would go through. Do you understand what I am saying? Here, scratches, here [referring to crossed-out sections]. There is no evidence to confirm the diagnosis because the medication is not stated - just that” [pointing to the word “HIV” written on the form]. (QA officer, interview, 2014 March 31).

In general, doctors expressed a strong desire for more engagement with SASSA around the decisions which many of them found difficult to make and a system that they identified as problematic. They wanted to collaborate more in drawing up guidelines, meet with the medical quality assurer and have discussions with their peers. The Western Cape SASSA disability management unit appeared to understand this need, but lacked the capacity to create these opportunities outside of fairly cursory annual training sessions (DMU official, 2014 June 27; QA Officer, 2014 March 31).

5.5 Conclusion

In their work assessing patients for DGs, doctors become gatekeepers to state welfare benefits. They are subject to the pressures, constraints and rewards of both the overburdened public health system and SASSA’s DMM, but also used their professional discretion to challenge or subvert attempts to regulate and standardise their behaviour. They faced significant social pressure and coercion from patients to recommend the grant and introduced conflict into doctor-patient interactions and undermining relationships between treating doctors and their patients.

SASSA’s guidelines do not sufficiently cover the challenges that they face. SASSA was also unable to provide them with the support they needed in making decisions. Despite better regulation and general improvements in the functioning of the system, pockets of discretion remain and doctors used this space to develop their own systems and routines for managing patients, simplify their decision-making and cope with the general stresses of their work. Part of this was selectively applying and ignoring guidelines as it made practical sense. Doctors were also generally suspicious of SASSA’s efforts to standardise or regulate their work, privileging their own professional experiences and ideas about what constitutes disability (which I will discuss in the next chapter) above SASSA’s bureaucratic norms and standards.

Although SASSA doctors have a greater awareness of SASSA's processes and sense of obligation towards SASSA, doctors in treating settings who had little to no engagement with SASSA or its guidelines had little respect for the organisation and little incentive to uphold SASSA norms and standards. This demonstrates the need to engage with doctors as professionals rather than through top-down control, an argument I will pursue further in the next chapter.

CHAPTER 6 ‘Hard’ and ‘soft’ medicine: Framings of eligibility in DG assessment

Doctors are not mere observers of clinical encounters, but participants, directly affected by what they see and called to act. (Beresford, 1991: 8)

6.1 Introduction

Mr Mashaba sat down in front of the doctor and Dr Rahman asked him why he was here. He told the doctor that he has tuberculosis and had lost his job on the farm as a result. “Normal TB or Multi-drug resistant TB?” asked Dr Rahman. Tuberculosis (TB) is rife in the Western Cape, with 800 reported cases of TB per 100 000 people in 2012 (Health Systems Trust, 2014). A TB diagnosis is therefore considered fairly run-of-the mill in poorer communities in the province. As a result, the guidelines of the South African Social Security Agency explicitly advise doctors against awarding temporary DGs to people with “ordinary” pulmonary tuberculosis (SASSA, n.d.). Mashaba got out his green card – the marker of the TB patient in South Africa – and showed it to the doctor. The green card is used as part of Directly Observed Treatment Short Course to keep a record of medications and patient-compliance for the six-months or longer that a patient receives treatment.

Mr Mashaba was not quite sure what type of tuberculosis he had, but Dr Rahman was able to work out from the card and his file that he had a straight-forward pulmonary TB diagnosis and that he had started his medication the month before. After looking through Mashaba’s file for a while, Dr Rahman commented that his CD4 count of 175 was very low and that his HIV viral load was very high. Tuberculosis is one of the most common opportunistic infections associated with HIV. Generally, HIV/AIDS patients who have opportunistic infections are considered to be in Stage 3 of the disease and, according to SASSA guidelines are therefore eligible for a grant. However, because TB is endemic in the country, the guidelines state that HIV-TB comorbidity does not necessarily mean that patients have advanced to this stage of the disease (although in this case, with such a low CD4 count this was possible). The doctor listened to Mashaba’s chest and then filled out of the assessment form. After Mr Mashaba left, Dr Rahman explained to me that he would recommend a temporary grant for six months because, although Mr Mashaba’s chest was clear and he was not displaying any of the symptoms of TB (meaning he was not being impaired by the illness) and did not appear to have any other HIV-related conditions, he needed to eat. He also told me that Mr Mashaba wouldn’t be “here” if he was not well.

Dr Rahman demonstrated the same trust in the intentions of all the patients he saw that day.

This approach was quite different to those of other doctors I observed, most of whom were constantly on the lookout for “fakers” and “malingerers”. I was surprised that he made all these assumptions about patients without talking to them very much, but he explained that patients are not very good at expressing themselves or explaining the nature of their disablement. Patients often come in simply saying that they couldn’t find work, but in his view, this did not mean that they were not sick or disabled. “When he said he lost his job, I already knew the whole story.”

Dr Rahman believed that people in the area who cannot do manual labour are not employable because farmers don’t want to hire unproductive people, especially when there are so many able-bodied unemployed competing for the same job. After a few months of being on treatment, a person with TB should be able to work and should technically only qualify for Social Relief of Distress (SRD)⁶⁸, but Dr Rahman told me that this system is broken because the budget available for SRD is insufficient for all those who qualify.⁶⁹ He usually recommended a six-month temporary grant instead, as he had done in Mashaba’s case. Although providing a six-month grant may not seem particularly generous, SASSA is very strict on HIV cases and doctors were generally wary of recommending grants for chronic disease cases for more than six to twelve months.

Dr Bury, who also worked in a rural area, had an almost opposite approach to Dr Rahman’s. Where Dr Rahman framed his decision in social terms, thinking about both individual experience and structural reasons for this situation, Dr Bury framed his decision in completely bureaucratic terms. When I met him, he been conducting assessments for SASSA for eight years and took his job as an assessor very seriously. He expressed disinterest in the subjective experiences of claimants, arguing that there was “no grant for pain” and justified this by reiterating that his role was to conduct a medical assessment, not consider other factors related to disability. When he had doubts about a patient’s eligibility, he erred on the side of caution, refusing to recommend the grant because “I am a taxpayer”.

⁶⁸ Doctors are only meant to recommend the SRD on a medical basis to people who are unfit to work for a period of less than six months. However, doctors tended to recommend it for people who did not meet the eligibility criteria for the DG but were in clear need of assistance.

⁶⁹ The budget for SRD also caters for those affected by disasters such as the regular winter floods in the Cape Flats area.

Where Dr Rahman considered the specific reason for defaulting, Dr Bury was less pragmatic. He told me “SASSA is very, very strict on defaulters. They must use their medication. I had a few that I declined because of that - even AIDS patients in a very bad condition”. In his experience, people who presented with pneumocystis, pneumonia or carposi sarcoma were always defaulters and in these situations he agreed with SASSA saying, “No way. No pay check.”

Dr Bury’s and Dr Rahman’s approaches illustrate the two extremes in the ways that doctors frame and deal with DG assessment. As I showed in Chapter 2, in the past many doctors were extremely generous with the grant and several doctors in the study admitted to approving DGs to anyone who requested them. Since the introduction of the Disability Management Model, this is now less common.

Another doctor in the study described the distinction between a flexible, sympathetic doctor like Dr Rahman, who bent the rules in favour of the patient, and a doctor like Dr Bury, who strictly applied SASSA guidelines and focused exclusively on clinical factors, as the difference between being a ‘hard’ or a ‘soft’ doctor. This distinction is useful, not because I want to provide a structuralist analysis of doctors’ decision-making, but because ‘hardness’ and ‘softness’ provide a useful description of the two different sets of behavioural options or strategies available to doctors when they interact with patients and make decisions. When in doubt about patients’ eligibility, taking a ‘hard’ approach meant erring on the side of refusal, whereas taking a ‘soft’ approach meant erring on the side of leniency. The majority of doctors sat on a continuum between soft and hard and varied between strictness and generosity, responding to patients based on how they framed a particular patient and their situation. In short, doctors pursued strategies for action based on how they understood a particular case as deserving, and such exceeded the bounds of medical evaluation criteria.

This chapter focuses on how doctors make decisions on how to categorise patients in DG assessments, especially in spaces between the rules, where specialist medical knowledge and SASSA guidelines do not offer clear answers on DG eligibility, and how this shapes DG policy implementation. As claimants often do not fit neatly into the disabled category, doctors rely on their own categorisation systems or schemas to make decisions about who should get disability grants and to draw boundaries between who is and is not disabled. These are influenced both by their medical expertise and by social constructions which they as individuals tacitly subscribe to.

In the previous two chapters I showed that doctors have varying approaches to DG assessments and may make decisions that diverge from SASSA's rules and guidelines. This chapter sets out to explore the extent to which these decisions are the result of doctor's personal and professional norms and values and notions of social, economic and health justice. As Kaufman argued, bureaucrats enter organisations with "opinions, values, preferences and their own interpretations of the world" (1960: 80-81) that influence their behaviour within them. I argue that these decisional outcomes reflect different ways of framing the disability 'problem' and therefore interpreting both guidelines and the cases in front of them. Framing is the active process of arranging medical knowledge, SASSA's rules and standards, and professional and personal norms and values to answer the question of eligibility in individual cases. Whilst these framings of disability are, as Lipsky (2010) argued, shaped by the structure of their work and coping strategies they develop to deal with time constraints and other work pressures, they are also related to normative ideas about their role as moral and professional agents.

While some street-level bureaucracy scholars (Maynard-Moody & Musheno, 2003; Dubois, 2010; Hasenfeld, 2000) have paid attention to influence of norms and values on street-level decisions, the literature on street-level bureaucrats has paid insufficient attention to how these are used to categorise people (Harrits & Møller, 2011). This literature also neglects the particular role of professional norms in street-level decision-making. Although Lipsky (2010) has argued that street-level bureaucrats are governed by professional and occupational ideology, his work and the street-level literature in general has paid little attention to groups like doctors who most strongly associate with a defined set of professional norms and values (Hupe, 2007; Evans, 2010). The concept of framing captures the pluralism of norms and ideas that ground street-level actions, whilst allowing us to observe and explain patterns emerging in street-level decisions. It is also useful in examining the relationship and potential conflicts between professional expertise, social norms and values, and bureaucratic rules.

I propose that four frames pattern doctor's decision-making behaviour: 1) the *bureaucratic frame*; 2) the *clinical frame*; 3) the *moral frame*; and 4) the *social frame*. I then discuss the effects that these frames have on how doctors make decisions and treat claimants, and how they intersect with or contradict the specific eligibility conditions laid down by SASSA and their obligations to the state. In doing so, I will also reflect on the misalignments between the daily realities of doctor-patient interactions and SASSA's bureaucratic 'script'; and what this means for DG policy implementation.

6.2 An analysis of doctors' decision making

During disability assessments, doctors have to make sense of and categorise a claimant's individual case and make a recommendation that can be supported by clinical evidence. They do this by engaging with information from multiple sources and determining what information is relevant to developing a coherent theory of the situation at hand. This process is both cognitive and conceptual and one that I argue relies on the interactive and intersubjective process of framing.

When a patient enters the room, a doctor has to think through two different things. Firstly, "what type of applicant is this?" and secondly, "should I recommend a disability grant for this person?" The first question is essentially the framing question that Goffman (1974: 8) argued individuals unconsciously ask when faced with any situation: "what is it that is going on here?" The second question, although directly connected to the first, is a more strategic one: "how do I deal with or treat this person?" The way in which doctors understand the context in which the DG application is being made is crucial to informing what information they look out for when conducting an assessment, how they interpret this information and ultimately what decision they make. In other words, doctors reach different conclusions about patient eligibility based on how they decide to frame a situation (Berg et al., 2000, Dodier, 1998).

The terms 'frame' and 'framing' are widely used by diverse disciplines that include social theory and sociology, cognitive science, communication theory, policy studies and political and finance (amongst others). It is therefore necessary to clarify how I am employing this term and what specific literature I have drawn on in applying this idea to DG assessments.

Goffman (1974) argued that within a given context, people need to define a situation in order to know how to act and interact with others. Drawing on Bateson's (1955) work on animal play, he called this process *framing*. Frames allow people to "locate, perceive, identify and label" social experiences and help to guide further action (Goffman, 1974: 21). Separately, but also drawing on Bateson's work in his work on reflective professional practice, Schön (1983, 1987) argued that when professionals make decisions they engage in a process of "naming and framing", latching onto particular pieces of information to make decisions.

*Through the complementary acts of naming and framing, the practitioner selects things for attention, guided by an **appreciation of the situation that gives it***

coherence and sets a direction for action. So problem setting is an ontological process – in Nelson Goodman’s (1978) memorable word – a form of worldmaking. Depending on our disciplinary backgrounds, organizational roles, past histories, interests, and political/economic perspectives, we frame problems in different ways (Schön, 1987: 4).

Giddens (1984) took up Goffman’s notion of framing and used it in developing his theory of *structuration*. Whilst Goffman’s work has mainly been applied to understanding social interactions in face-to-face encounters, Giddens’ work has mainly influenced theories of institutions. He understood frames to be “clusters of rules which help to constitute and regulate activities, defining them as activities of a certain sort and as subject to a given range of sanctions.” (Giddens, 1984: 87) Like Goffman, he saw frames as interpretive schemas used in interactions, that both structured interactions and could also be transformed by reflective and knowledgeable social actors: “Framing as constitutive of, and constricted by, encounters ‘makes sense’ of the activities in which participants engage, both for themselves and others.” (Giddens, 1984: 87)

Drawing on and extending Schön and Rein’s (1994) work on how framing affects public policy specifically, Van Hulst and Yanow (2014) emphasise that framing is a dynamic and action-oriented process of making sense and organising prior knowledge and values. Frames guide emerging action in intersubjective situations and actors bring their own prior knowledge (from experiences, education, and other sources) to situational sense-making” (Van Holst and Yanow, 2014: 8). In the case of doctors, they bring to their interactions with patients or claimants their medical knowledge, clinical experience and social and cultural knowledge.

These framing effects correspond to the Bourdieusian notion of *habitus*. Drawing more directly on Bourdieu, Harrits and Møller (2011: 241) argue that street-level bureaucrats present an “embodied habitus”, bringing with them, “ingrained in their own bodies, categorical systems and a position in systems of symbolic and social relations.” For example, a middle-class white cardiologist brings to DG assessments her own perspectives and experiences of both the medical and social world, which are informed by her race, class-position, culture, gender, specialist training and collection of past experiences with patients, which she uses to navigate the assessment process and which will inform her practice and decision-making.

Dubois (2010, 2013) also extends Lipsky's work by connecting it with Bourdieu's sociology and Goffman's micro-interactionist sociology, considering the nature and meaning of bureaucratic interactions but attending also to *habitus* - the dispositions that structure these interactions. Like Maynard-Moody and Musheno, he argues that norms and the individual identities, histories and dispositions of bureaucrats are important in understanding street-level work. He argues that there are no standardised clients nor impersonal bureaucrats; "only social agents with individual personalities who, within certain conditions and limits, are required to play the role of the impersonal or standardised bureaucrat or client" (Dubois, 2010: 3).

I take a frame to mean an interpretive schema that social agents use to make sense of their situation and guide their actions (in this case, decision-making), which is shaped by their background and dispositions as well their professional knowledge and norms. In the case of disability grant assessment, *framing* is primarily a tacit process that facilitates decision-making. The decision frames that doctors develop represent a hybrid arrangement of SASSA's rules and regulations and doctors' responsibilities as medical professionals, moral and social agents that establish the boundaries and constraints for decision-making. However, following Van Hulst and Yanow's (2014) proposition, *framing* the disability problem is an active, agency-driven process. My research suggests that, whilst they were neither fixed nor exclusive, four main frames informed doctors' decision-making and behaviour towards DG claimants in Cape Town: the *bureaucratic frame*, the *clinical frame*, the *moral frame* and the *social frame*, all of which represent different arrangements of rules and definitions of disability, employability, need, entitlement and deservingness.

This typology of frames is influenced by Nicholas Dodier's (1994, 1998) work on frames. Applying the notion of framing to decision-making in the practice of occupational medicine, Dodier (1998: 53) argued that, "a person adjusts to a situation not by using discrete resources, but through arrangements of resources (words, rules, objects) in which past experiences are inscribed, that is, through frames." Dodier put forward a number of different frames, including the *administrative*, *clinical*, *psychological* and *solicitude frames*, as alternative ways of understanding and assessing patient's complaints and attributing health-based 'rights' to patients in occupational medicine. His concept of frames has been employed in Human's (2010, 2011) study of doctors' practical use of treatment protocols in HIV clinics in South Africa. Eikenaar *et al.* (2015) has also applied this concept to explore the normative aspects of professional judgements made by street-level bureaucrats involved

in work reintegration programmes in the Netherlands.

Other scholars of bureaucracy have studied the patterning of discretion, describing the different rationalities (Willems, 2001), models of justice (Mashaw, 1983), strategies (Jonsson, 1998) or operational styles shaped by beliefs (Brown, 1988). However, I argue that the concept of framing is more useful as it suggests a more active and situational process of sense making. The likelihood of a doctor adopting a certain frame was influenced by their *habitus* and the nature of their social interaction with an individual patient. Influences on doctors' adoption of certain frames were their medical speciality and training, institutional environment, personal norms and values and notions of justice, social background, approach to patient care, previous experiences with patients requesting the grant (especially negative ones), and views about the healthcare and welfare system. The table below presents the broad distinctions between the four different frames used by doctors.

	Bureaucratic	Clinical	Moral	Social
Knowledge system	Rules & guidelines	Professional experience and specialized knowledge	Personal experience	Social model of health and disability
Ethical framework	Administrative fairness / legalism	Professional ethics	Social /cultural norms and values	Socio-economic justice / human rights
Political	Neutral	Neutral	Ideology is influential (conservative)	Ideology is influential (social democratic)
Focus	Collective / state	Individual health	Individual desert	Societal / structural issues
Professional role definition	Bureaucrat	Independent medical professional / clinician	Citizen-agent	Community / public health professionals
Outcome	Rigid / strict	Flexible	Varied based on deservingness	Generous

Although I present four framing options, these were neither discrete nor mutually exclusive ways of making sense of cases. Capable of reflection, doctors are social actors able to apply “a wide range of different and even incompatible schemas and have access to heterogeneous arrays of resources” (Sewell, 1992: 17). When practically applied in medicine, social norms and values may clash or contradict each other, shift or coexist (Timmermans & Haas, 2008: 671). Doctors moved between or combined different frames and thinking was very often shaped by their specific interactions with individuals, the particularities of certain cases and

material circumstances. Doctors might also frame their decisions in ways that help them to cope with the stressors and constraints of the system, for instance framing eligibility as a purely administrative issue to avoid feeling sorry for people, as was sometimes the case with the *bureaucratic frame*.

The way in which doctors framed disability claims inclined them towards handling cases in ways which may coincide or conflict with the way in which SASSA has framed the disability issue and the type of decisions it expects doctors to make. The frames doctors used affected their attitude - and adherence to - SASSA's rules. For instance, doctors who framed disability as a multi-dimensional or social phenomenon might prioritise the consideration of economic, social and environmental factors over strict adherence to SASSA's guidelines and might stretch or bend the rules to accommodate them. On the other hand, a doctor who valued administrative justice, equity and impartiality would focus on strictly applying rules and guidelines, refusing to make individual exceptions. This is not to say that doctors simply do what they wish - they are of course constrained by their legal and professional obligations. However, where they have discretion, their framing of certain situations might make them more or less likely to rigidly apply the rules, or bend or stretch them to accommodate people that meet their own private understanding of disability but perhaps not SASSA's formal definition.

It is however important to note that doctors, especially those working as SASSA assessors who had to conduct assessments day after day as consistently as possible, did not necessarily have the time or inclination to think through the complexities of each case. Doctors were therefore likely to develop quick and standardised ways of identifying and treating certain clients. In this way frames can harden into routine ways of classifying clients, treating clients based on existing categories or stereotypes (e.g. the malingerer).

6.2.1 Bureaucratic framing

To structure doctors' thinking and decision-making, SASSA provides a set of medical guidelines and training to doctors (see Chapter 4). This *bureaucratic frame* promotes the objective categorisation of patients according to set criteria and simplifies decision-making by effectively limiting the options or possible solutions available to decision-makers.

The bureaucratic frame is the equivalent of strategies discussed in the literature on street-level bureaucrats, for instance what Dubois (2010) would call *bureaucratic formalism*, what Jonsson (1998) called a *bureaucratic administrator strategy*. It also bears strong similarities

to what Eikenaar et al. (2015) called a *procedural frame of reference*. Using this frame, medical knowledge is applied in a reductive and objectifying way, placing patients into categories and applying a strictly biomedical approach to disability. Disability grants were understood as a specific intervention for a certain group, not a general poverty intervention and doctors saw it as their responsibility to protect the boundaries of the disability category by using their medical knowledge to detect malingerers, fakers and defaulters.

As training and guidelines were only provided to doctors contracted specifically to do assessments, this frame was not employed by treating doctors. Doctors could easily apply SASSA's bureaucratic framework in cases where patients clearly did or did not qualify on medical factors. Most SASSA assessors did so. However, what distinguished doctors with a bureaucratic ethos from others was that even when a patient's eligibility was less clear, these doctors would lean towards conservative decision-making, seeking out further clinical evidence through objective tests or referrals rather than considering more contextual and subjective factors. Applying a kind of deontological ethics, they justified their decision-making in relation to the rules, regardless of a claimant's individual circumstance. In short, they would err on the side of SASSA rather than the patient.

While in fact the guidelines do provide some leeway for the use of professional discretion, doctors approaching the assessment of a patient through this frame positioned themselves as SASSA workers, denying that they had any discretion and claiming that they were strictly following procedures and interpreting guidelines in a very conservative and restrictive way. Doctors using a bureaucratic frame construed employability as the *physical* ability to work and did not take contextual factors such as availability of employment or an individual's competitiveness in the labour market with a given health condition into account. Doctors working as SASSA assessors, who were specifically employed to conduct assessments, had received SASSA training and were most likely to employ a bureaucratic frame.

For example, Dr Bury took his job as an assessor seriously and understood his role as a gatekeeper for the state and took a quite literal interpretation of the guidelines. According to SASSA guidelines, doctors should consider disability in terms of a person's ability to do any sort of work in the open labour market, regardless of the *availability* of employment⁷⁰.

⁷⁰ Although guidelines indicate that a claimant's education or age could be considered in certain cases this was not a requirement and how this should be considered was very unclear.

Applying this principle, he understood “open labour market” to mean an individual’s ability to do any kind of work, regardless of whether they actually had the skills or education to do this. This because he felt he was only there to make a medical assessment and it was not his role to consider other factors related to disability. *See Quote 6.1 Appendix C*

Unlike some doctors, he conscientiously filled out the assessment form in detail and thoroughly assessed patients. He strictly applied the guidelines and SASSA’s impairment tables to make decisions and avoided considering any non-medical issues or subjective experiences, even in cases of moderate impairment when the SASSA guidelines gave him discretion to consider factors such as the age, education level or employment history. As noted earlier, he refused to recommend grants to defaulters even if they were gravely ill and incapacitated because these were the ‘rules’. This hard-line approach was not necessarily endorsed by SASSA and Dr Marite, the national manager of the DG program said that the medical ethics of beneficence and non-maleficence should be brought to bear in such cases, provided that it could be clinically justified (Dr Marite, interview, 2014 June 27).

However, their strict application of the rules did not mean that doctors applying this frame were necessarily insensitive to claimants’ suffering. For some it was a professional ethical stance (Zacka, 2015) in that they were doing what they were both paid to and legally required to do. The bureaucratic frame is grounded in the idea of equal treatment or what Mashaw has called ‘bureaucratic justice’ – the notion that applying the rules in the same way in every case is the most procedurally fair and just way to handle DG assessments. In this way, the guidelines become a normative framework for action.

For doctors, applying the rules in a very literal way could also be a way to cope with what was otherwise a very stressful and morally taxing job. For example, one of the reasons Dr Bury so rigidly applied a medical was approach was because:

‘...as soon as you consider anything else then it’s not about disease or dysfunction and that’s the only thing. Look at the records and examine the patient if necessary – that’s that. I don’t look at anything else because then you might feel sorry for the patient and you say “yes” to a grant when it’s not necessary’.

Invoking rules and denying discretion or professional autonomy can be used by frontline workers as a defence “against the possibility that they might be able to act more as clients would wish” (Lipsky, 2010: 149). “Bureaucracy offers a formal structure to withdraw from social relationships and concomitant feelings of reciprocity and social duty” (Bartels, 2013: 470). Thus, even choosing to “go by the book is a discretionary judgment” (Maynard-

Moody & Portillo, 2010: 19). This approach is not unique to disability assessment, for instance in a US study Cassell (2004) found that medical doctors may ignore patient's stories out of concern that they may interfere with patient care. Hupe (2007) argues that professions may impose rules upon themselves to manage their work and, as I will discuss in Chapter 7, doctors would use the guidelines as a way to legitimise their decisions to patients who questioned their decisions. However, applying a hard-line approach also had consequences and SASSA assessors could be very unpopular with claimants who found assessments depersonalising and perceived them to be inflexible and insensitive. This drove some of the abusive treatment of doctors by patients that I will discuss further in Chapter 7.

6.2.2 Clinical Framing

I will use treatment to help the sick according to my ability and judgment; I will keep them from harm and injustice (Hippocratic Oath in Siegler, 2000).

In contrast to bureaucratic framing, doctors employing a clinical frame were less concerned with SASSA's rules, guidelines and set procedures and instead made decisions based on what Bourdieu described as their 'feel for the game' (Bourdieu, 1990). Doctors employing a clinical frame generally justified the need for DG on a clinical basis, based on a claimant's medical history and individual circumstances. Clinical framing resists administrative patterns of determinism and depersonalisation and allows more space for thinking about patients as unique individuals.

Using the US disability program as an example, Mashaw (1983) argues that these differences between a bureaucratic rationality and professional judgment result in different conceptions of justice and can result in professionals being cast as subversive to bureaucratic ends. Whilst doctors certainly have subverted DG policy in South Africa in the past, not all doctors have the same training and clinical experience or professional and intellectual approach to the practice of medicine, particularly in relation to the psychosocial aspects of care. Professional judgement therefore cannot be understood as a singular rationality. Ethnographic research has shown that professional beliefs and perspectives on medical decisions may vary depending on position in hospital structure (Nurock, 2009) and specialty area (Mol, 2002).

Such beliefs were also developed through the doctors' interactions with others within their organizational environment, whether it be interactions with SASSA officials and other SASSA doctors during training or with other colleagues (especially senior doctors) in

hospitals. Hasenfeld (2000) calls these ‘practice ideologies’; collections of beliefs shared within organisations about clients’ needs and appropriate responses to them.

Doctors using a clinical frame differed responded to claims based on how they conceptualised their role and responsibilities as medical professionals in relation to disability assessments. There were doctors who took a hard-line approach, fairly similar to those adopting the bureaucratic frame, whilst others with a more humanistic approach engaged with patient’s individual lives more and considered this in their decision-making. This section will show how doctors’ differing ideas of what falls into the medical domain and their self-perceived roles as doctors, shaped their decision-making.

As I discussed in Chapter 4, doctors are asked to assess disability because of their expertise on the human body, the supposed objectivism of medical science and the idea that doctors should behave in objective and ethical ways. Although SASSA wants doctors to employ a technical, bureaucratic rationality in their decision-making and follow their rules and guidelines to classify patients, medical professionals also have a set of norms of acceptable behaviour, and standards and ethics that guide their practice; one of which is putting the patient first. Their strongly engrained professional values and commitment to patients’ wellbeing could also result in doctors feeling torn between their goals as bureaucrats and responsibilities to assist patients (Wainwright et al., 2015). In this study, this was particularly likely when a doctor was assessing his or her own patient and doctors in hospital settings were more likely to employ a clinical than a bureaucratic frame, reflecting a stronger association to medical rather than bureaucratic values. This was less likely in cases where doctors worked as third-party assessors.

It is for this reason that SASSA is moving towards a model that separates the assessing doctor and the treating doctor. However, this dilemma remained significant for doctors participating in the study.

As I argued in Chapter 4, medical decisions require more than just scientific knowledge. Decision making in this context is an interpretive process that relies on doctors’ clinical experiences and the individual patient and clinical judgment is often described as tacit, interpretive and action-oriented rather than a product of technical rationality (Montgomery, 2006; Freidson, 1970). This *phronetic* way of thinking can conflict with administrative, “box ticking” rationality that SASSA promotes as doctors focus on making sound judgments rather than following set procedures. As a professional group, doctors typically have discretion in

how they carry out their work, and their expectations of autonomy can contradict notions of bureaucratic control (Freidson, 2001). Therefore, some doctors, especially those conducting assessments in treating settings and who were not paid to conduct assessments, resisted the idea of classifying patients according to bureaucratic criteria. They preferred to treat each client as an individual case, privileging their own clinical experience and knowledge of the patient over SASSA's externally imposed rules and guidelines, and they disregarded these where they felt they did not apply. This dislike of bureaucratic rules does not mean that doctors do not develop routine ways of dealing with patients. In their general work managing medical cases, doctors develop personal working models for managing problems that they encounter on a regular basis, as Lock (1985) showed in her study of how doctors approached menopause.

Another aspect of doctors' clinical socialisation that impacted on their decision-making was their interactions with their colleagues. As Atkinson (1995) argues, we cannot look at doctors' decision-making exclusively in terms of what happens in their consultation rooms during their interactions with patients. Rather, their decisions are also shaped by what he calls 'medical talk' – the collegial interactions that take place in medical settings such as conversations with other doctors, medical meetings and ward rounds. In hospitals where I conducted fieldwork there was considerable dialogue and consultation between doctors, especially between more junior and more senior doctors. Doctors passed in and out of one another's consulting rooms or congregated in the halls, consulting with one another and this influenced their decision-making. Although SASSA assessors had fewer opportunities to interact with colleagues, at training sessions they shared their approaches, ideas and stories and in fact seemed to learn more from one another than the SASSA official training them.

Doctors' response to claimants differed based on whether they understood disability as a biomedical or psychosocial issue. As I argued in Chapter 4, as medical thinking has evolved, doctors have been encouraged to think more holistically about patient care and in terms of a biopsychosocial model of medicine, especially in the context of chronic illness. Doctors, particular younger doctors, who understood clinical decisions to mean more than just making a medical diagnosis and who had a more holistic approach to patient care, were generally more conflicted about their role in the assessment process and most likely to disagree with SASSA's guidelines.

“I enjoyed looking at the SASSA document, it's quite well written, it's quite detailed but it's a lot of bullshit because with a lot of these conditions you're making your

decisions on clinical grounds. In other words, what is that person really suffering and what is their ability to really cope with work really? Because it's got nothing to do with whether they've got HIV or HIV and TB or osteoarthritis. What is their state of mind and body and can they work?" (Dr Brown, interview, 2014 April 4)

Doctors employing a *clinical frame* generally justified the need for DG on a clinical basis, based on a claimant's individual circumstances and medical history. They might engage with social factors, but only as they related to clinical issues and the health of the patient. In these cases, a DG was considered a way to address social determinants of health or address health system failures. Doctors whose primary role was to treat patients were particularly likely to make exceptions for individual patients where they thought the grant could improve health outcomes. In this way, DGs were included as part of their treatment intervention – a way to fund transport to the hospital to attend follow-up appointments and fetch medication, and to ensure adequate nutrition to recover their health and alleviate psychological stress.

Dr Harvey, for instance, felt that “it’s never purely medical” and was frustrated that the form did not provide space for her to make note of social circumstances. She argued, “You can make the argument that not having money is going to affect their health, although they are not disabled as such.”

“I think in terms of the way in which you fill in a form you can actually make it sound worse than it is. I've had a couple of patients where they're borderline so you've sort of given them the benefit of the doubt because of their social circumstances and their social circumstances do unfortunately affect their healthcare and so for example, if you're hypertensive you really should be able to do your job you know, but you know if you have to go to the clinic every month it becomes really difficult when you have difficult social circumstances. I've never lied on a form because I think a patient warrants a grant but they don't qualify. I've never made up a fictitious thing so that they can get a medical grant, but in terms of borderline cases there are a few that you just weight it a little bit more heavily, but you can't lie about actual facts so it's very difficult. So you can't say for example on the form there is shortness of breath when there isn't but you can say that they are more short of breath than they are.” (Dr Harvey, interview, 2014 April 15).

A senior doctor who helped me arrange access to an infectious diseases clinic explained the approach of some of his colleagues as follows:

“They do understand that the patients are often unemployed and that it is a process for them to get to us. Although the patients are not necessarily physically disabled, they are disabled by their disease. They will give the patient a 6 or 12 month grant and there is difficulty about loopholes – the reality is that they are sick and unemployed and need to get to the hospital and the grant plugs that hole. Some of

them don't necessarily deserve the grant but you put them on a temporary grant. You put them on a temporary grant while they recover – although sometimes by the time they get the grant they are already better.” (Xhobani, email correspondence, 2014 March 23)

In the case of HIV and tuberculosis, some treating doctors saw the grant as a valuable tool for encouraging compliance. For instance, Dr Naidoo, a doctor working in infectious diseases, took a highly individualised and holistic approach to DG assessments she was requested to do in the course of her clinical practice. She felt that her goal as a doctor was to ensure that a healthcare problem was optimally managed. For her optimal management extended beyond just medicine to include food and the psychological security of not having to constantly worry about money. She was strongly in favour of the DG: “I am completely for them – there is very little that has been done to address social determinants of health before patients get to me. Health is a manifestation of everything wrong in society” and felt that recommending a grant is one small thing she could do to assist people. She therefore tried not to stand in judgment of people who ask her to fill out a DG assessment for them and told me, “There are so many things you can't understand as someone who is not poor – you don't know what it means to have no money and don't understand how desperate people are.” She criticized some of her colleagues who she felt were “punitive and short-sighted” in their hardline approach to assessments. Working at a secondary hospital meant that the patients she saw were too ill to be seen at the primary level, but had the potential to recover and she therefore never gave a grant for more than a year, but saw the grant as an integral part of the recovery process during this time.

Dr Wright also framed his thinking about disablement in clinical terms and expressed the dilemmas he faced as both a clinician and disability assessor. He felt that SASSA's categorisations of disease and disability were over-simplified and he focused his thinking on the individual symptom profile of his patients and used his clinical judgment rather than SASSA guidelines to make decisions. He believed that working is an essential part of being a healthy person. Many doctors took this same approach, valorizing work on the basis that it was essential for psychological well-being and thinking that receiving a DG could be psychologically ‘disabling’. This made them hesitant to recommend permanent grants when there was any (even small) potential for them to recover.⁷¹ Although not necessarily blaming

⁷¹ OTs interviewed, were equally concerned that DGs could potentially reinforce patient notions of their disability and inability to participate in some sort of productive work. They were particularly concerned that people who received temporary grants over long periods of time had little chance of ever re-entering the labour

individuals for their 'dependence' on the state, they saw the DG as perpetuating a type of dependent mindset that disadvantaged or 'disabled people'. This is a view also held by some disability rights activists that have criticized the government for focusing on social grants rather than empowering people to work (Gatharim, 2008). Doctors felt that young people in particular should be strongly encouraged to enter or re-enter the workforce or participate sheltered employment programs,⁷² even if they were severely disabled, as they felt it was unhealthy for young people not to work.

"It's hard to generalise but there seems to be a certain attitude out there of 'I've got a grant, I don't have to work again' so you have got to guard against that because it's very toxic I think because to not work...actually you see people going downhill and I don't think it's healthy to not work." (Taylor, interview, 2014 March 17)

Although very reluctant to recommend permanent DGs, Dr Wright felt that grants were important in encouraging and supporting people with mental illness who were actively working towards their recovery. He saw financial despair as one of the 'vicious cycles' that people with mental illness can get stuck in, and felt that a grant was useful in helping them to get their lives together enough to find work. However, this became complicated when patients with whom he had long-standing relationships had been working very hard to recover, but were still unable to find work and asked to renew their grants. In these circumstances it was hard for him as a clinician to justify following SASSA's regulations without undermining the health and wellbeing of his patient.

"When patients are working really hard at recovery and their conditions has improved, you are meant to take it away even though many of them still haven't got a job because unemployment is so high. So I'm not the strictest at just cutting it at that point. I cut them when someone is not using the grant to do anything. So I'm very biased that way - if someone's really doing everything they can to get a job and they are not getting a job I find it very difficult to say too bad, back to zero [i.e. refuse to recommend a grant and undo all the progress they have made]." (Wright, interview, 2014 April 2).

Generally, doctors saw taking one's health and recovery seriously as an important individual and moral responsibility and were frustrated by patients who were non-compliant or not motivated to recover and were thus failing to fulfill the responsibilities of the 'sick role' (Parsons, 1951). However, several doctors, who took a more individualised approach to

market if a doctor decided that they were no longer eligible.

⁷² People who work in sheltered employment programs still qualify for a grant because they are unable to compete in the open labour market and receive less than the means test threshold.

assessments, disagreed with SASSA's objectifying simplification of the complex nature of patient adherence issues and felt uncomfortable 'punishing' claimants for non-compliance. They therefore did not refuse to recommend grants for non-compliant patients whom they felt otherwise qualified and needed the grant to recover their health and would use the grant to motivate compliance.

He says that looking at the file you can see when a patient has defaulted and he says that in many cases doctors will not give the grant – “defaulting equals no grant.” He feels that this is a pity because the defaulting and the grant are really two different things and that usually there is some reason that the patient is defaulting that needs to be explored. (Field notes, 2014 March 14)

Not all doctors took such a holistic approach to medicine. Some understood their role as medical professionals as strictly limited to biomedicine and the treatment of injury and disease. Even if they recognised that poverty and demand for the grant was a systemic rather than an individual failing, many felt the social, economic and environmental position of patients did not concern them as medical professionals.

Fassin (2008) suggests (although perhaps too sweepingly) that because doctors see themselves as technicians and scientists rather than humanists, they are more interested in curative activities and interesting cases than in the social dimensions of care. Good et al. (2005), has suggested that the culture of medicine privileges time and efficiency and that doctors will therefore avoid 'problem' patients, including those with complex social issues. Dr Brown argued that some doctors saw dealing with disability cases as “being on a losing wicket”, saying that “they're not interested because they are essentially people that are falling apart; there's not much that you can do for them medically.” In Whitney, which is a large academic hospital, known for its highly competitive working environment, social workers reported that some doctors saw DG assessments as 'beneath' them. Jeffrey (1979) argues that the prestige of doctors relative to other healthcare professionals is related to their distance from patients (which is one of the reasons the chore of disability assessments was often passed to interns and junior doctors).

With less interest in the psycho-social aspects of care and complicated personal or social issues, more clinically-focused doctors were more likely to focus on purely objectively assessing a patient's physical state and function and refuse to engage with other issues. Other aspects of care were seen as the responsibility of social workers and doctors would frequently interrupt patients who were sharing their subjective experiences, telling them that they were only concerned with their medical issues. Some medical specialists in hospitals totally

refused to conduct assessments for their own patients, seeing it as a waste of their time and scarce medical resources and instructed patients to visit their local clinic where they would be seen by a SASSA assessor instead. Disinterest in DGs was particularly noticeable amongst orthopaedic surgeons and according to a number of hospital staff interviewed (including orthopaedists themselves), the field has a reputation (not necessarily fairly) for being ‘macho’ and ‘jockish’, oriented around ‘fixing’ the patient rather than becoming involved in the psycho-social aspects of care. In one instance, an orthopaedic surgeon at Welgemoed hospital boasted, “I didn’t realise that they had changed to a book system for six months – shows how many disability grants I give out!”

This is not to say that by attempting to be objective doctors are necessarily insensitive to the social and economic context of patients, as Dr Taylor reminded me: “Doctors make enormous personal, social and financial sacrifices by being doctors, so it is inherent (for most) to want to help the patient.” Rather, these doctors acknowledged their limited capacity to fix claimants’ social and economic issues, and as one of his colleagues commented, “It is not our responsibility to fix the unemployment problem.”

6.3.3 Moral framing

In assessing patients for DGs, doctors are effectively making decisions on how to allocate the state’s resources. In many ways these are ethical decisions because they affect how resources are distributed in society. Implicit in these allocative decisions is the idea that some people ‘deserve’ DGs whilst others do not. According to Hasenfeld (2000) this work of categorisation makes the work of street-level bureaucrats such as doctors ‘moral work’. These moral categorisations of who deserves social grants have been defined to a certain extent by the state through legislation and regulations and institutionalised within SASSA. However, given their high level of discretion, frontline workers may make moral judgments of their own that either undermine or reinforce these state categories. Although street-level bureaucrats are supposed to follow rules and procedures in dealing with clients, in reality they “like everybody else, have personal standards of whether or not someone is deserving” (Lipsky, 1980: 23). Social positions are negotiated and renegotiated within the bureaucratic setting and “desk interactions are frequently an occasion to assign - sometimes in a harsh way - identities and to impose behavioural rules” (Dubois, 2010: 5).

According to Bourdieu, “agents are both classified and classifiers” (Bourdieu, 1987 in Harrits & Møller, 2011) and therefore doctors are themselves part of the categorical system. Street-

level bureaucrats therefore cannot be seen as outside-observing agents and social categorization is reproduced in street-level work. More simply stated: street-level bureaucrats always act “as human beings confronting other human beings.” (Harrits & Møller, 2011: 242) Beliefs about fairness strongly influenced doctors’ decision-making and doctors using a moral frame thought about their decisions in moral terms. Although not necessarily exclusively, doctors often used *moral framing* to make decisions at times where medical eligibility was not completely clear, thinking about eligibility using socially and politically constructed notions of ‘just desert.’ As Maynard-Moody and Musheno have argued, the decision-making of street-level bureaucrats is “complexly moral and contingent rather than narrowly rule bound and fixed” (2003: 93).

Doctors are rarely (if ever) neutral agents. They enter the assessment process with a set of existing subjectivities and biases that influences their decision-making. Numerous sociological studies have shown that medical values of ‘non-judgmental regard’ and beneficence are not always adhered to and that moral evaluation and the designation of patients into ‘good’, ‘interesting’, ‘bad’ and ‘rubbish’ patients is a regular part of medical settings which influences how patients are treated (Roth, 1963; Strong, 1979; Jeffrey, 1979; Stein, 1990). Doctors rely strongly on pattern recognition, making them highly likely to stereotype patients (e.g. hypochondriac, malingerer, drug addict) and use these in their evaluations (Groopman, 2007). Alcoholics, drug addicts and ‘dirty and smelly’ patients may be seen judged by hospital staff as deviant and therefore categorised by medical staff as deserving of less care and attention than other patients (Jeffrey, 1979). Moral assumptions made about patients tend to derive from judgements about their social worth as individuals, their responsibility for creating their own conditions of ill-health and poverty, their degree of amenability to change and their own desired end results, and the degree to which view they view themselves as object or subject in terms of agency (Hasenfeld, 2000: 332). In his book on the culture of medicine in the United States, Stein (1990: 98) called this an “unofficial, moralistic taxonomy of types of patients.” The literature on medical rationing discussed in Chapter 1 shows that this is particularly likely in resource constrained or emergency settings, as has shown to be the case in a number of South African hospitals (Le Marcis and Grard, 2015; Gilson, 2004). Moral and social evaluations of claimants’ worth are particularly likely in disability compensation claims, where doctors are less likely to trust patients’ intentions (Hickel, 2001).

Doctors considering DG eligibility in moral terms may be less inclined to recommend the

grant for those who they feel are responsible for their own poverty and illness and deemed to be taking advantage of the system, and more inclined towards generosity in cases where they see patients as worthy of support for reasons of being victims to external misfortune or bad luck, for example. Hasenfeld (2000: 337) calls the process of making service decisions and rationalizing them through moral constructions ‘moral entrepreneurship’. Maynard-Moody and Musheno argue that street-level bureaucrats “apply, bend, or ignore rules and procedures to support their moral reasoning. Identity based normative judgments determine which and how rules, procedures and policy are applied” (2003: 155). Ideas about deservingness in human service organisations are rooted in moral rules that are shaped by political interests, community environments, organisations and the work of street-level bureaucrats (Hasenfeld, 2000).

Research on South African’s attitudes towards redistribution shows that South Africans clearly distinguish between people who are deserving and undeserving of social assistance, which are based on the capacity and willingness of people to work (Seekings 2007, 2008a 2010). The disabled and sick are typically considered a category of the deserving poor and in a study of attitudes towards distributive justice, Seekings (2010) showed that Capetonians felt that sick and disabled people, including people with AIDS deserved assistance from the state. The attitudes that doctors had towards certain categories of ‘undeserving’ DG claimants can therefore be seen as doubts about the genuineness of their disability and inability to work, rather than a belief that disabled people are undeserving. Doctors’ trust in patients’ reports of disability is based on the claimants’ perceived moral worthiness.

Doctors political beliefs about the value and effectiveness of the South African social grant system and poverty alleviation policy also shaped how doctor framed eligibility. Whilst no doctor in the study was totally opposed to a social grant system (all doctors appeared to agree that some sort of grant was important to support disabled people), many were concerned that it was being abused by lazy work-shy people, and that the government was spending too much money on social grants which created a culture of entitlement and dependency, especially amongst the youth.

Dr Soet said that she has heard from another doctor that many Eastern countries there is no social security for pensioners or the disabled and expressed the view that “people here are so ungrateful” saying: “South Africa is a lazy country. Those in Eastern countries are so productive – they work full days and are so productive and they don’t seem so unhappy – they are not living in squalor and have food on the table”. She added that people are used to being at home (referring mainly to young people) and that they “sit on their parents’ necks” – not that parents don’t motivate

them, it's the kids they are spoilt (even though parents may be poor) – the tough love doesn't happen". She went on to say that "Children should not get fancy tekkies [trainers] - if you want that then you must go out and work to get it yourself." (Field notes, 2014 February 12)

Also see quote 6.2

Dr Soet's statement partly signals her belief in a 'culture' of poverty, in which 'living in squalor' is based on values and life choices. This was echoed in the words of a doctor from a West African who reported "In my country there is no grant, you must go work", imputing that the grant system in South Africa had contributed to a culture of dependency or diminished self-agency and resilience.

At a training session SASSA held for its assessors, a number of doctor contrasted the attitudes of South Africans towards work against those of hardworking foreigners.

Dr Y: "Young people (South Africans) are in the hospital just queuing for grants but Somalis and Zimbabweans are working."

Dr X: "It's up to us."

Dr Y: "That dependency."

Dr B: "It's about social deprivation and 'now I am entitled because society has deprived me' – the grant reinforces this - you are deprived so we will give you the grant poor thing."

Dr X: "But in the context of poverty you give a grant for six months and they buy a TV or burial society membership and so become dependent."

One day in the field I had an animated conversation about the DG with a group of four young doctors during their lunch break. They argued that grants create disincentives to work and were frustrated by what they called 'chancers' and 'bullshitters' who had never worked before and yet felt entitled to a grant. One of the doctors expressed his irritation at people who thought "because they did a few days of manual labour they are now manual labourers and they don't want to try and look for anything where they can sit on their bums all day". When Dr. Taylor argued that someone might not have the education to obtain work, a colleague countered this by arguing that there was "always something someone can do". The doctors all told stories of patients who refused medical interventions because they did not want to lose their grants. They also argued that more people received grants than were working⁷³. These discussions between doctors demonstrate a set of concerns that were held

⁷³ Whilst according to Statistics South Africa 8.9 million people are formally employed in South Africa in 2014, and at the time SASSA paid grants to just over 16 million people, this is true. However, this is not a legitimate comparison to make as 11 million of these grants are targeted at children and 3 million are paid to the elderly,

by many doctors about the social grant system in general: its costs, its abuse, the disjuncture between the rights people claimed and their willingness to accept their responsibilities as citizens and so-called perverse incentives.

While this kind of talk between doctors does not necessarily reflect how they actually interacted with patients or actually made decisions about DGs, it does point towards a frustration with and lack of support for a system in which they played an integral part. These stories, which are framed by bigger policy debates and stories of welfare ‘scroungers’ in both the South African and international media, also have a strong influence at the implementation level in terms of how many doctors think and talk about who ‘deserves’ DGs. The idea of an ‘undeserving’ poor “lacking the moral fibre to enjoy the benefits of economic growth” (Everatt, 2008: 293) has played a central role in the public discourse about poverty in South Africa. I frequently heard arguments from doctors that DGs create dependency, create incentives for patients to remaining ill, reward laziness, represent an unsustainable cost to the taxpayer (including doctors themselves) or clog up the healthcare system. It also reflects middle class values surrounding work and individual responsibility and an insensitivity to structural factors such as high levels of unemployment, which for the most part is involuntary.

Even doctors with more positive views on DGs felt that some claimants abused the system and felt that the large number of non-eligible people that applied for DGs undermined the system by creating backlogs in the processing of applications, burdening the healthcare system and absorbing resources that could be better spent on creating a better DG system for the ‘truly’ disabled. It was therefore important to root out those who were ‘spoiling’ it for others. *See quotes 6.3 and 6.4.*

The concern about disability ‘fakers’ and malingerers has existed for as long as states have offered programs that compensate work-place injuries, military veterans or provided social insurance or assistance to ill or disabled people (Stone, 1984). It is part of doctor’s role to be alert to and guard against this, but there is also an implicitly moral judgment made about the archetypal malingerer or faker – people who one doctor called “chancers and rubbish who “spin stories” to get the grant. Although doctors generally thought the sick and disabled were deserving of state support, based on their frequent encounters with malingering patients they actively guarded against illegitimate claims and ‘abuse’ of the grant system. This has also

who are not part of the working population (SASSA, 2014).

been shown to be the case in other South African studies (Macgregor, 2006; Segar, 1994).

Sometimes this led doctors to be unfairly strict with patients and social workers on the wards at both Whitney and De Waal facilities, reported acting as patient advocates in cases where they felt that a doctor was unfairly refusing to recommend the grant. Although doctors seem to have been influenced by broader anti-welfare discourses, it is difficult to establish the extent to which it was these discourses shaped their decision-making, rather than their legitimate efforts to perform the gatekeeping work that SASSA expects of them to that. It is important to note that there were also distinctions between how doctors acted in individual cases and explained these actions to me. In other words, it was possible for a doctor to feel immensely frustrated with the system but simultaneously feel tremendous empathy towards individual patients. Research has shown that people may have held complex and internally conflicting views regarding distributive justice and the type of welfare state they believe is helpful for both the country and individuals, which has been shown in the case of the United States (Keiser, 2010; Gilens, 1999) and South Africa (Seekings, 2007; 2008).

As well as broader discourses, doctors' framing choices are influenced by past experiences with patients. Doctors were often cynical about DGs based on what they had seen and experienced as doctors working in the public health sector. One doctor mentioned that although it was perhaps only the minority who abused social grants, they tended to see the minority in their everyday practice more regularly than other people and this influenced their perceptions of patients. They had seen people coming in drunk after grant payment day and had dealt with people who stopped taking their medication or refused treatment. They had seen people who reapplied repeatedly for grants and had experienced bullying from patients who wanted them to recommend the grant. They had also seen patients who had overcome difficult circumstances, illnesses and disabilities that were not 'dependent' on grants and tended to compare them. For example, Dr Taylor contrasted the attitude of an older woman with end-stage rheumatoid arthritis, motivated to do absolutely anything to improve, with that of a young, overweight 31-year-old woman with back pain "who someone had stupidly given the DG" in the past and who refused to leave until he recommended its renewal. He described her entering the clinic "with her jewellery and her smart handbag" and said, "she managed to drive herself here, walk up the stairs and find the Kentucky Fried Chicken okay, but felt she could not work because someone had told her she couldn't". He had spent thirty minutes of his time trying to encourage her to work and had found the experience very frustrating. "The only thing that was broken was her attitude. Someone had given her the temporary grant for

six months and now she felt she needed it for life.” He added, “sometimes the compassion of the doctor shoots the person in the foot.”

Whilst general ideas and biases structured doctors’ thinking, it was often the individual characteristics of claimants that influenced decision-making. Based on how patients looked, spoke and behaved, doctors placed patients into socially constructed categories or made moralistic judgments about an individual patient’s character and their relative deservingness. This is not to say that patients fit neatly into categories and I agree with Maynard-Moody and Musheno’s argument that citizen-client worthiness is a continuum and that many clients present a mixture of worthy and unworthy characteristics (2003: 111). The comparative and theoretical literature on street-level bureaucrats identifies street-level bureaucrats as responding positively or negatively to the physical attributes, nationality, educational level, perceived morality, attitudes, and character types of applicants (Rice, 2012; Maynard-Moody & Musheno, 2003; Horton, 2004; Dubois, 2010). In his summary of the literature on deservingness, Larson (2005) highlights the five main criteria that are found to influence perceptions of desert: 1) the perceived control the individual has over his/her social and economic situation; 2) degree of need; 3) feelings of shared identity; 4) attitude towards the helper (docility, gratefulness); and 5) the likelihood of reciprocity.

Looking at eligibility through a moral frame, claimant characteristics such as age, appearance, previous work history, self-motivation, compliance to treatment and responsibility for their health and economic position and family support structure became important factors in establishing desert. Whilst I did not observe doctors discriminating against patients in any direct way, these patient characteristics did influence how rigidly or flexibly they applied the rules to individual patients. Although doctors attempted to overcome negative biases they had towards particular kinds of patients, they were more likely to rigidly apply rules if they felt a patient was undeserving. They were also more likely to be flexible and generous if they felt sympathetic towards a patient that they ‘felt’ was deserving.

As young people are better able to compete for unskilled jobs, gain further education and training or recover their functions, doctors were least likely to recommend grants for this group, regardless of how doctors framed the disability problem. Unless young people had significant impairments, doctors were likely to classify them as lazy and see their application as an attempt to avoid work. This applied particularly to the large number of young patients living with HIV who, with anti-retroviral therapy, doctors felt should be physically able to participate in the labour force. Some doctors openly chastised young

people for applying, saying things along the lines of “you are young, you should go to work”.

“The old people, they can’t find jobs, but the young ones...they want only money – especially the HIV - I don’t like to give them any because they can work. The HIV is not...you have HIV and high blood sugar I can understand, but HIV on its own...you must go work. They don’t want to go work, they are lazy. I tell them also ‘sisi, you are lazy, you must go work.’” (Dr Mulumba, interview, 2014 February 4)

Doctors sometimes tried to convince claimants that they were capable of work, using examples of resilient patients, colleagues, family members or invoking tropes of the ‘heroic’ disabled person to demonstrate that it was possible to work despite illnesses or physical impairments. The implication was that claimants who were claiming work disability with relatively minor impairments were just not ‘trying’ hard enough. *See quote 6.5.*

A claimant’s contribution to the economy and society was also an important factor for many doctors, which accounts for why young people were seen as undeserving. People who had never worked were seen as undeserving for one of two reasons: 1) they had never contributed to society through work; and 2) if they had been already been unemployed prior to becoming sick or disabled - often for many years - why should did they now deserve a grant? *See quotes 6.6 to 6.8*

Such constructions were well illustrated by an event that occurred during my fieldwork in Whitney Hospital. I was observing one of Dr Taylor’s consultations with a disability grant applicant when another doctor, who I will call Dr Cronje, stormed in and came over to Dr Taylor’s desk. He was angry about a patient he had just seen, who had rheumatoid arthritis. He told us that the patient was receiving a permanent grant although she had not worked for the past ten years. He said that this meant “from 55 to 65 or 63, whenever women get it [referring incorrectly to the age of eligibility for the age grant]⁷⁴, you will get the state funded DG for doing fuck all”. My immediate thought was how inappropriate this conversation was with another patient applying for the DG sitting in the room, but Dr Taylor appeared unfazed and simply said to me, “this is a case in point.” Although I had never met Dr Cronje before, he had obviously heard about my study from other doctors and he clearly wanted to voice his frustration. Just as he was about to exit the room he stopped and addressing me directly, said: “is it true that more people in South Africa receive social grants than work?” This was apparently a conversation that the doctors have had amongst themselves because I had heard another one of the doctors say almost exactly the same thing in the clinic earlier that day and

⁷⁴ In the past women were eligible for the old age grant (pension) at 60 and men at 65, but this was reduced in phases after 2008 and equalised at 60 in 2010.

later in my research from another doctor in another hospital, but also affiliated with this department in Whitney. He added, “We must have one of the highest percentages of people receiving grants in the world.” Feeling forced to respond, I explained that the majority of these are child support grants and added that other welfare states offer much greater benefits. He interrupted me saying, “But we are not a welfare state.” He dismissed this and joked that he was clearly making a mistake by only having one child.

People whose unhealthy lifestyles had contributed to their poor health were also considered less deserving. Patients who were overweight, heavy smokers or drinkers were particularly likely to be seen as lazy or irresponsible and received little sympathy from doctors for self-inflicted illnesses. Doctors expect patients to comply with treatment and take responsibility for their health and doctors may feel little moral obligation to treat patients who aspire to the sick role, do not look after their health or do not cooperate in getting well, though the legal and professional obligation does remain (Nurock, 2009). Doctors were very frustrated by people with chronic obstructive pulmonary disease, diabetes, hypertension and arthritis who did not make the effort to lose weight, stop smoking or manage their illnesses but returned annually or bi-annually to apply for temporary grants. In some cases, doctors openly voiced these judgements to patients. For example, Dr Michaels told a patient who had been a victim of domestic abuse: “you make poor life choices”.

Doctors often faced patients who became ill or were injured through drug or alcohol abuse or involvement in criminal activity such as gangs. Doctors could not ethically or legally refuse to recommend a grant to someone with a legitimate disability regardless of the source of impairment unless someone was known to be an active substance abuser which automatically disqualified them. However, in grey areas, doctors were cautious about recommending the grant for people who they felt might use their grant money for ‘questionable’ purposes such as buying alcohol, drugs or cigarettes, or who generally were not ‘good’ people.

Whereas those patients who are not interested in treatment for a medical condition if it doesn't lead to a DG, that believe they deserve a DG because they are not employed even though they don't have a disability, that make use of tik [methamphetamine] or any other drugs and enter the clinic as though they own the place - they can cause a change in the [doctor-patient] relationship from their behavior. I have been confronted with a gangster patient who refused appropriate treatment, whilst stating, “I'll just get the grant” and laughing as he said it, despite understanding that refusing treatment may result in the loss of his limb due to complications. If he later asked me for a DG I'm certain that I would be reluctant to submit the form. (Taylor, email correspondence, 2014 February 13)

See quotes 6.9 to 6.12

As much as doctors guarded against the undeserving poor, doctors using a moral frame were willing to make exceptions for people that had minor impairments who they felt were somehow ‘deserving’ of assistance:

“I have certainly heard harrowing stories here, which seemed appropriate to listen to, but on the whole people are just saying things like “I’ve got no money” or “I’m struggling” but they don’t say it as if they are struggling, they say it like they are beggars who are asking for something and I’m trying to say to them, “look, disability is disability, the disability grant is a grant, it’s not a right and you can’t come and bully me into it,” which is what they really are doing. I mean the same thing happens when this person comes with this little cup on the side of the road and I don’t even look at them anymore, for years I haven’t looked at them - I just wave my hand and that’s it, end of discussion. That applies to everybody...and yet there are times when I’ve picked up the odd person on the side of the road just because instinctively they are different and there’s something that they need which, okay a lift, but it’s something else as well and I’m willing to make exceptions but generally if anyone’s begging they’re not going to get much um sympathy from me.” (Brown, interview, 2014 April 4)

During the face-to-face encounter of the disability assessment process, doctors ‘bear witness’ not only to the disablement of a patient but to the vulnerability and suffering of another human being. This may create feelings of responsibility and moral obligation towards patients (Olthuis, 1996; Raef, 2006), which could affect how they treated them. According to Swartz and Schneider (2006: 243), “It is difficult to apply principles of distributive justice when one is faced with the reality of poverty”. South African doctors are aware of the impact that decisions to award or renew grants can have on the quality of life of patients living in poverty. A study of anti-retroviral adherence and the DG (De Paoli et al., 2010) found that doctors reported high levels of discomfort at what they described as “feeling like God” when making decisions on whether or not to award or re-new grants. In the past doctors regularly recommended grants on humanitarian grounds rather than on actual impairment (De Koker et al., 2006; Steele et al., 2006; De Paoli et al., 2010). As a result, the DG has been referred to by some as the “ag shame” grant (Interview Margaret Schneider, June 2013). “Ag shame” is a commonly used South African expression of sympathy, which means something akin to “you poor thing” or “I feel sorry for you”.

What a number of doctors referred to as the ‘sympathy factor’ was intensified in interactions between doctor and patients who were visibly poor or in social distress. Although some doctors were able to emotionally distance themselves in their assessments or

were so clinically minded that they were not interested in these issues, some felt real guilt about rejecting patients knowing that they could offer no other real solutions other than a referral to an overburdened social worker. The doctor working as quality assurance officer for SASSA explained how his work is easier than those of other doctors because it does not involve seeing the suffering of applicants:

“But it also makes it easier unfortunately, from the non-medical point of view, to be removed from the patients because I can understand very much that the doctors are very much inclined towards patients and there will always be a sympathy factor involved. With me too - I know that if I was involved and I was looking at somebody...you know you will always look at people's social backgrounds and you would probably tend to err on the side of the patients. As opposed to when I do it now on a desktop I don't have that influence - where I don't see the people, I don't see the social circumstances, I don't see the poverty. I'm not influenced by that.”(QA officer, interview, 2014 March 31)

Doctors were more likely to feel sympathy for older people, mothers with children and “ordentlike mense” (decent people) who fell into the category of the ‘deserving’ poor. This reflects more the more general conceptions of desert held by South Africans as well as the overall design of the welfare state. Attitudinal surveys conducted in Cape Town showed that respondents considered older people more deserving than younger ones and favoured women and people with dependents more than men (Seekings, 2008a, 2010). The South African state treats elderly people as a deserving group and provides non-contributory, means-tested old age pension for people over sixty, which enjoys general legitimacy in South Africa (Seekings, 2010). Underlying this support is the belief that older people are less responsible for their poverty because they are disadvantaged by worsening health and opportunities for employment as well as the disadvantages they experienced in the past under apartheid that prevented them from obtaining a decent education or work, which made it harder to save for retirement. (Seekings, 2008b)

SASSA is very aware of doctors’ tendency to be particularly sympathetic towards older applicants and during a training session held for doctors as SASSA staff member said, “You are a human being first – that is the 55 year-old, I am asking you to be inhumane.” The case of Dr Brown and Mrs Musimane below is an example of a doctor framing his decision in terms of deservingness rather than medical impairment or function. Dr Brown understood Mrs Musimane to be as a decent lady who deserved the state’s support, recommending a grant when technically she was not eligible.

The doctor turns to me and explains that, based on her file, she has minor complaints and that she is getting treatment for painful limbs. After thinking for a bit he says, “I could throw her out and make her sell chicken feet [which she had been doing to try to earn an income]. Is it about compassion?” and then adds, “She is a **decent** lady who has been trying.” The clerk chips in that she is 54 years old and Dr Brown says, “Good point, there is not much of a market for it.” He decides to recommend a 6-month temporary grant, saying that arthritis is about strain and you end up with a condition of ineffective hands and feet and “You can’t really do much with that. You can’t sell anything with hands that don’t work.” Dr Brown then tells her that she will be getting the grant. Mrs Musimane becomes emotional and says, in English, “I didn’t have a hope!” Dr Brown tells me, “Giving hope to people is important.”

Cases like Mrs Musimane’s were common and many doctors responded in similar ways to Dr Brown, who by fitting her into his framework for understanding disability stretched the rules to accommodate her within the system. Doctors were sympathetic to patients who were trying to earn their own income or were trying to ‘overcome’ their circumstances in some way, seeing them as more deserving than those who were ‘lazy’ and ‘dependent’.

Some doctors looked to family and household structures to determine desert. Dr Haddid, along with Dr Miller, considered the responsibility of kin as important in deciding whether a person or a household actually “needed” a grant. Dr Miller asked every patient who they lived with to determine whether there was someone who was another able-bodied person who could support them instead. Dr. Haddid felt that in old-age, sickness and disability it was the responsibility of the spouse to care for his or her partner and that they did not deserve to be compensated for this by the state and also applied this logic to applications for the Grant-in-Aid. However, when this support did not exist they were more likely to recommend the grant⁷⁵. (*See quotes 6.13 and 6.14*)

It is important to note that although doctors may be inclined to feel great sympathy for patients applying on the basis of poverty, this did not necessarily define their decision-making and doctors would not necessarily deviate from SASSA guidelines. They might however try to help patients by referring them to social work services; educating, encouraging and motivating patients; providing employment suggestions; and in Dr Bhele’s specific case, collecting and handing out clothes to claimants. Several doctors also bent the

⁷⁵ He was particularly sympathetic towards older Muslim women who were divorced by their husbands but had never been employed and were unlikely to find work..

rules of the Social Relief of Distress award to accommodate patients who did not qualify for a grant but were in clear financial need.

6.3.4 Social framing

Doctors employing a *social frame* typically understood disability in terms of the social or bio-psycho-social model of disability rather than in terms of SASSA's highly medicalised model. Using this frame of disability, doctors considered both an individual's medical profile and the structural economic, social and environmental factors that shape individual circumstance and ability to work. They considered claimants' ability to participate in the labour market in terms of a claimants' age, education and training, ability to speak English, previous work experience and skills. They also considered more structural factors such as the tightness of the labour market and opportunities for re-training and employment in relation to these individual factors. They might also consider the implications of ongoing medical treatment might have on their ability to retain a job (e.g. frequent clinic visits, dialysis, transport or care). (See quote 6.15 to 6.18)

What distinguished the moral and the social frames was whether doctors understood deservingness in terms of individual agency (and failures of agency) or structural factors. While the process of moral framing involves looking at how deserving an individual claimant is of state support, a social frame takes a bigger picture view of deservingness, informed by the social structures that drive DG applications. Through this lens, doctors saw a case of a patient who was clearly not eligible for a grant more as a symptom of bigger social and economic problems than an individual case of malingering. The social frame recognises the contribution of South Africa's apartheid past to current patterns of inequality in the Western Cape. Doctors using this frame expressed a rights-based approach to social welfare generally, grounded in ideals of social justice and equality. Despite belief that some undeserving and lazy people try to 'fleece' the system, many doctors recognised that attempts to feign disablement were very often based on financial desperation rather than a desire to avoid work. This reflects the kind of redistributive justice rhetoric promoted by the South African constitution, which promises socio-economic rights, including social security to South Africans (see Chapter 2).

Dr Du Toit presents a good example of how a social framing of disability differs from a bureaucratic or moral framing. His experience working in a European country with a generous welfare system had markedly influenced both his approach to assessing DGs and

his view of the DG system in general. Unlike most other doctors involved in the study, he expressed a strong rights-based approach to social grants and social welfare generally that was grounded in an ideal of social justice and equality. While he recognised that there were difficulties in managing the DG system, his view was that “individual rights should not be subsumed by the greater problems in the system.” (Field notes, 2014 March 14) Du Toit and others like him were less likely to think in terms of the ‘deserving’ and ‘undeserving’ and framed their decisions in more social, structural terms. He was highly critical of the DG system in terms of the nature of the assessment process and the approach of his colleagues to health and social issues. He felt that the system failed to take social factors into account and that rather than objectifying patients, he believed that it was important to listen to people’s stories.

He argued that other doctors were too strict in their approach and that South African doctors had become hardened to poverty and the severity of diseases such as HIV/AIDS and tuberculosis, which while manageable, still have significantly impact people’s well-being. He felt that in South Africa these diseases had been normalised and had become uninteresting to doctors. He was particularly perturbed by doctors who, rigidly applying SASSA directives would not take age into account in their decision-making, using the example of a doctor not giving a grant to a 59-year old woman with arthritis because she could technically still participate in the labour market. He and two other doctors in the study identified the migration of people from the Eastern Cape to the Western Cape in search of employment who could not find work, as a major social issue driving the demand for disability grants in the province. “You often have people coming from the Western Cape with no education and no English ability with HIV and lots of children and that these people would just keep on coming – it’s a major social problem” (Field notes, 2014 March 14).

This more inclusive approach often resulted in decisions that diverged from SASSA’s guidelines and rules, as was demonstrated earlier in Dr Rahman’s case. However, these decisions were not necessarily driven by sympathy. Doctors using a social frame generally felt that their assessment criteria were appropriately grounded in the social model of disability and were made on the basis of people’s actual ability to participate in the labour market. Considering social factors does not make medical factors unimportant and doctors using a social frame did not simply recommend the grant to anyone who was unemployed. Dr Du Toit would, for instance, spend more time than most doctors asking a patient about their medical problems and how this affected their ability to carry out functional activities.

Although his threshold for impairment was fairly low, he would not recommend the grant to applicants unless they had some sort of medical diagnosis that he could use to justify his decision. Social factors were very strongly weighted in his assessments. These factors included that patient's ability to speak English, age, education, previous work experience and degree of poverty. Although he spoke of his guilt and discomfort driving through shack settlement areas on his way from work, his decisions were not necessarily made on a humanitarian basis. Also, although he acknowledged that his decision-making broke with SASSA's medical model, he argued that he had never received a work assessment back from an OT that had not recommended a grant and seemed to feel that his assessments were rooted in a similar approach.

Dr Wright, whose decisions appeared to be informed by both a medical and a social frame, had not only medical views, but also personal and political views that conflicted with his commitments to SASSA. Aware of the high levels of poverty in the communities he served, he struggled not to base his individual decision-making on these economic factors.

“The only way I can understand it is that it is informed by your own political views. So you've got doctors who make it their business to make sure that anyone who in an economy with 100% employment might get a job doesn't get a grant and then you've got the other extreme (I'm probably towards the other extreme). So probably I'm quite lenient...I don't like hearing about people starving. If you can't get a job it's very easy to argue that the mental illness has something to do with it, but I'm probably...I'm aware that there is a bias in there because there are lots of other people who don't have jobs.” (Dr Wright, interview, 2014 April 8)

He did however draw the line when patients had “everything in place to get a job” and wanted to renew their grants, explaining to patients that he was not prepared to lie for them.

Dr Haddid commented that in his experience, very few DG applicants have matric certificates. Based on my observations of assessments and the general level of literacy amongst claimants I interacted with whilst obtaining informed consent, it appeared that many claimants had not progressed beyond primary school. This is supported by other studies of DG beneficiaries. A study by Govender and Miji (2009) showed that 62% of DG applicants surveyed had only a primary school education, with only 4% having completed matric. De Koker (2006) found that across twelve managerial districts in the Western Cape, an average of 3.8% of respondents applying for grants had a matric certificate. A shortage of unskilled work means that people without a matric certificate, who do not obtain any artisanal or other skills training after leaving school, struggle to find employment in South Africa (Dias and

Posel, 2007). Without the credentials or skills and lacking the social and cultural capital to secure regular and well-paid employment in an economy that is becoming increasingly skills-intensive, and where most labour-intensive work has been pushed into the precarious informal economy; these people are only able to obtain precarious informal work (Seekings and Natrass, 2005; 2015).

Being sick or disabled makes competing for unskilled work extremely difficult and escaping from poverty even less unlikely. Given the large numbers of people available to perform unskilled work and 'slack labour' demand, employers are able to choose among large numbers of high productivity recruits. This means that people perceived to be less productive - older, sick or disabled people - are placed at the back of the job queue and are therefore unlikely to find work (Reskin and Roos, 2009). Even people with very mild impairments or manageable illnesses, or in their fifties, are placed in a non-competitive position in this section of the job market. Although disabled claimants with higher levels of education could technically work in more skilled jobs, they often struggled to find or retain work because of employer discrimination, inaccessible transportation and facilities and work environments that did not take their needs into account (Marumoogae, 2012; The South African Presidency, 2014). (*Also see quote 6.19*)

I was also struck by the large number of people in their fifties applying for disability grants. Many of these claimants were applying on the basis of chronic diseases such as hypertension, diabetes and asthma or age-related ailments such as osteoarthritis or vision problems, which were often mild and non-disabling. The medical quality assessor, nurses, occupational therapists and doctors that participated in the study supported these observations. Mitra (2010) found DG beneficiaries tend to be mostly older individuals with low levels of education, who have detached from the labour market for a long time compared to the rest of the working population (Mitra, 2010). Older people from, rural areas in particular, have often not progressed beyond primary school or far in secondary school. As of June 2014, over half of DG beneficiaries (51%) were between 46 and 59 (SASSA, 2014), which is unsurprising given that the incidence of disability increases with age and the lack of jobs available for this section of the population. Skills development and training programs largely exclude people over forty and older people therefore have little chance of improving their employability or moving to another employment sector (Interview with occupational therapist, Whitney Hospital). In a Western Cape study, some doctors reported that they felt pressurised to recommend the grant in cases where claimants were too old to work as

unskilled labourers, but were too young to qualify for state old age pensions (De Waal & Vorster, 2006).⁷⁶ (*See quotes 6.20 to 6.21*)

Recognising the difficulties that older people faced in finding employment, doctors often recommended grants for applicants in their fifties with mild health conditions that were not necessarily disabling and age was perhaps the strongest non-medical factor considered by doctors during assessments. Even doctors who strictly adhered to SASSA's bureaucratic frame would recommend temporary grants for longer than they might have for a younger person or recommend a permanent grant rather than a temporary grant. This differed from the moral framing of older patients in that these decisions were rationalized more in terms of 'employability' than older patients being more 'deserving' (although these two conceptions of eligibility may of course overlap).

Many doctors considered claimants' eligibility for the DG in relation to pension age and are particularly generous towards people who would soon qualify for this pension. A number of doctors admitted to seeking out additional conditions such as osteoarthritis in older patients who might not otherwise qualify. *See quotes 6.22 to 6.23*

6.4 The influence of race and class on framing

Given South Africa's apartheid past, including the racially segregated medical system and persistent social and economic segregation between races in South Africa, it would be reasonable to assume that racial stereotypes held by doctors in this study would influence who they understood to be the 'deserving' poor. Research on physicians in the US has shown that some associate negative attributes such as non-compliance, low intelligence and drug and alcohol abuse with black and immigrant populations, which affects physicians' engagement with patients and their decision-making and medical decision-making (Van Ryn & Burke, 2000; Krupat et al., 1999; Schulman et al., 1999). This, however, did not appear to be the case with doctors I observed. In studies of attitudes towards redistribution policy in Cape Town, Seekings (2007, 2008a, 2010) found that despite South Africa's history as a racist state, attitudes towards distributive justice in Cape Town do not appear to be shaped by racial considerations. Seekings (2008a, 2010) did however find that white respondents were more

⁷⁶ The use of grants for disabled people being used as proxy old age pensions is not a new phenomenon. Gevers's (2014) historical account of the emergence of old age pensions shows that the ex-gratia Blind Grant for Africans, introduced in 1937 as the first monetary social grant for Africans, was sometimes awarded to elderly people who were not blind.

generous in the amounts of money they suggested should be paid towards the unemployed, which he attributed to guilt about enduring racial economic inequality, which may have contributed to how some white doctors framed disability.

Of course, given that racism is now considered socially unacceptable in South Africa and medical professionals are expected to be objective in their decision-making, it was highly unlikely that doctors would have admitted any racial bias to me in conversation (or to fieldworkers in Seekings' attitudinal survey). However, based on my observations, 'white', 'African' and 'coloured' doctors involved in the study made similarly negative value judgements about patients of all races and did not appear to be any more or less lenient with people from their own racial group. This did not mean that doctors' ideas about the deserving and undeserving poor were not tinged with racial bias or that overtly racist doctors do not exist. The quality assurance officer told me of a doctor in a rural community outside Oudtshoorn (a farming area about 400km from Cape Town) who recommended social relief of distress grants (food parcels) for people with paraplegia and strokes. In George, a small city in the same area, the quality assurance officer had received report of a doctor who had recommended a six-month temporary grant for a person with visual and hearing impairments, who had also suffered from a stroke. He felt this could probably be attributed to racism on the part of these doctors, who assumed black people were lazy and undeserving, but emphasised that this kind of behaviour was uncommon.

It is more likely that doctors' understandings of disability and poverty and their interpretations of particular claimant characteristics were informed more by their middle-class backgrounds than racial stereotypes. Doctors were noticeably more friendly and trusting towards patients that displayed middle-class attributes or behaved in ways that aligned with middle-class values. As Harrits and Moller (2011: 239) argues: "the category of middle class is related not only to possessing a certain amount of cultural and economic capital, or to a specific lifestyle and consumption pattern, but also to a specific taste and morality, associated with, for example, the 'right' way to carry oneself, to raise children and to engage in work" and these are reinforced when confronted with other categories that are different. The *habitus* of middle-class doctors may make it difficult for them to identify with poorer patients and understand their decisions. Chirayath (2007) has argued that doctors are more likely to attribute negative actions to personal characteristics (laziness) and choices of members of different racial or class groups than to their own group, over-attributing poverty and unemployment to patient choice or fault, leading people to thinking of individuals as

undeserving. This can lead to stereotyping and reinforce notions of the ‘culture’ of poverty (Chirayath 2007). This makes them less likely to acknowledge structural factors and more likely to frame assessments in moral terms. As shown in Section 6.3.3 numerous doctors commented on the cost of grants to the taxpayer and the growing numbers of social grants, which reflect middle class concerns and a real limitation on the willingness to support redistributive policies like social grants.

6.5 Conclusion

This chapter has shown that DG decisions are strongly shaped by how individual doctors interpret cases, and that the subjectivity that comes with being a human actor has not been eliminated by greater regulation of the system. I have argued that doctors’ decision-making depends on how doctors frame their decisions. SASSA guidelines and processes create an administrative frame of action for doctors that is meant to guide their thinking about disability. However, there are tensions between this *bureaucratic frame* and alternative frames that doctors use for thinking about disability and employability in the South African context. As I have shown throughout this chapter, the frames doctors used were derived from broader discursive framings of health and socio-economic rights and entitlements, needs and social justice within the healthcare system and in South African society more broadly. The *moral frame* strongly aligns with popular conceptions of the ‘deserving’ poor; the *clinical frame* is shaped by professional values and culture, beliefs about the psychosocial aspects of care and the structure of healthcare system; and *the social frame* is rooted in the social model of disability and discourses of socio-economic rights. This does not mean that eligibility was merely a social construct or a function of culture. Even if doctors interpreted cases differently, their decisions were, for the most part, rationalised by the physical realities of patients’ bodies and their medical expertise.

While frames help doctors cope with and manage the difficulties of making complex decisions in uncertain and demanding environments, this chapter has also shown that doctors do not only use their discretion or bend the rules to make their work easier (as Lipsky (2010) argued), there are times that they will bend the rules for people they think are deserving and there are people who they will rigidly apply the rules to because they feel compelled to. This is because they are citizen-agents (Maynard-Moody and Musheno, 2003), who are affected by the interactions that they have with claimants. “The street-level worker’s frame of reference is not the agency of the state but the citizen-client encounter.” (Maynard-

Moody & Musheno, 2000: 349) This means that individuals applying for disability benefits must perform the role of the ‘deserving’ poor to the person playing the role of the impartial bureaucrat (Dubois, 2010), which I will discuss further in the next chapter.

Building on Maynard-Moody and Musheno’s definition, I argue that doctors are also *professional-agents*, whose ideas about their role as doctors and the medical ethics, norms and values they hold also influence their decisions. The literature on the sociology of professions and studies of medical professionals in particular (Freidson, 1980) have demonstrated the influence of professional values and notions of autonomy on how professionals operate. Despite the fact that many professionals are street-level bureaucrats, this literature has not been connected to studies of policy implementation. Distinguishing between different frames for decision-making helps to bring some of the professional and bureaucratic values and demands into comparative perspective, showing why, in this case, doctors have been so difficult to manage within the SASSA system.

Whether because they felt solidarity with an individual whom they felt deserved a grant, saw it as medically important that someone receive food to eat, or because they knew how unlikely it was that many claimants with even minor disabilities were to find a job, I found that doctors regularly made decisions that diverged from SASSA’s guidelines. This did not happen in every case and given the increased strictness and routinisation of SASSA’s new system, it appears to happen less frequently than in the past. However, this variation creates confusion amongst beneficiaries and potential beneficiaries about eligibility criteria. Doctors’ subjectivities, particularly their likelihood to feel sympathy towards deserving claimants creates opportunities for claimants to influence doctors’ decision-making, which I will discuss in the next chapter.

CHAPTER 7: Performance, pressure and coping: Encounters between doctors and claimants in disability grant assessments

7.1 Introduction

A woman in her late fifties entered Dr Mulumba's assessment room at Zenzele community clinic, a very busy primary healthcare facility in one of Cape Town's larger townships. Mrs Nkosana pulled out a chair in front of the doctor's desk and with one hand on her back and the other hand on the table, lowered herself carefully into the chair, complaining loudly and dramatically about her backache. Dr Mulumba greeted her and asked her why she was applying for the grant. Mrs Nkosana told her that for seven years she had had "no food and no job" and had "been waiting for a grant" since 2008. Mrs Nkosana went on to tell Dr Mulumba that she had "terrible diabetes." After discussing Nkosana's medical history and treatment for a while, Mulumba began to fill out the assessment form. While she did this, Nkosana started to tell her about what a terrible disease the "sugar" was. She also described her incontinence, saying that when she went back to the Eastern Cape she had to use babies' nappies because she was "leaking." Dr Mulumba was only half listening and did not respond to this storytelling, focusing her attention on the form in front of her instead.

Recognising this, Mrs Nkosana turned and, hoping for some more sympathy from me, complained that her back was sore. Trying to avoid becoming involved, I simply nodded. She was not deterred and added that she also couldn't see properly. Dr Mulumba intervened by looking up from her paperwork and telling her that she needed to glasses and that she should see someone about this. Mrs Nkosana was not so easily dismissed and started complaining that her nose was running and that it gave her a headache and made a knocking noise in her head, rapping on the table to demonstrate. Dr Mulumba asked her if she had always had sinus problems and Nkosana responded with a complex story about leaving work because of her back pain. Mulumba asked her, "is it your back only or also your knees?" and Nkosana answered that her knees were also a problem: "Yoh⁷⁷, my knees are stiff! Sometimes I leave the table and I have no food inside and I say 'Hey Jesus, you must look after me.'" The doctor asked Nkosana where her husband was. "Yoh, yoh, yoh!" exclaimed Nkosana. She then continued to tell the doctor about how her husband had retired and returned to the Eastern Cape without her: "He sweet talks you nicely – I hate him. That is why I am getting the diabetes." She added that her daughter has been smoking and drinking since 2003 - "that

⁷⁷ "Yoh" is an exclamation denoting emphasis or surprise.

is why life is so terrible.”

Until now, this thesis has focused on the perspectives and decision-making of doctors and how they interact with the SASSA bureaucracy, without paying much attention to the possibility that claimants can be active participants in DG assessments who can act to influence these decisions and the assessment process itself. Although their social position, medical expertise and the bureaucratic decision-making authority places doctors in a dominant position in DG assessments, Mrs Nkosana’s case shows that DG claimants, who often had their own ideas about their rights in the system, were not necessarily subordinate or passive victims in their interactions with doctors.

In this chapter, I examine the interaction between doctors and claimants, showing how claimants put forward their individual disability claims by performing the role of ‘deserving’ disabled person and how doctors respond to patients as they perform their role as doctors. There is a general gap in the street-level bureaucracy around the agency of clients, who have mainly been considered in terms of how they are acted upon rather than as contributors to bureaucratic processes who co-construct institutional categories (Eskelinen et al., 2009)⁷⁸. Relatively little attention has been paid to the relational, situational and performative aspects of bureaucrat-citizen interactions – what happens “between” doctors and claimants (Bartels, 2013).

In the previous chapter, I showed how doctors’ own framings of disability can shape policy implementation. Here I extend this argument and contribute to attempts to build on Lipsky’s work by showing that it is not only workers, but also clients, who bring their agency to bear on street-level encounters and shape policy implementation through their creative engagements with bureaucratic systems (Barnes & Prior, 2009).

When people are co-opted into the policy process as clients, patients, beneficiaries or claimants, their position and agency within bureaucratic encounters is not only defined by administrative structures, but also by their individual experiences, own sources of knowledge and interpretations of the situations in which they are required to act (Barnes & Prior, 2011). It is not only doctors who must make sense of DG policy – claimants also interpret policy (for instance eligibility criteria) based on information they receive from SASSA, from healthcare professionals, from what they see in communities (who is receiving grants) and

⁷⁸ Lipsky does acknowledge that clients can impose low-level costs to bureaucrats in their interactions, but sees their ability to shape the interaction as fairly limited.

information that is shared by other claimants. Based on these interpretations of their rights and how the system works, claimants may try and negotiate with doctors or take advantage of ways they see to get 'into' the system (Kelly, 2012). When they come face-to-face with doctors, claimants are able to intentionally de-stabilise power relations and influence the assessment context by presenting themselves to doctors in particular ways, exploiting gaps in existing information and capitalising on the uncertainty and fuzziness of the disability category, as well as the moral dilemmas that doctors face when making assessments.

Drawing on Foucauldian (1979) notions of power as decentralised, productive and dynamic, I demonstrate that disability grant assessments are a dialogical and contingent process - a space of resistance and contestation as well as disciplining and control by the state.

Power, if we do not take a too distant a view of it, is not that which makes the difference between those who exclusively possess and retain it, and those who do not have it and submit to it. Power must be analysed as something which circulates; or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised in a net-like organization, and not only do individuals circulate between its threats; they are always in the position of simultaneously undergoing and exercising this power. (Foucault, 1980: 98).

Foucault was interested in the microphysics of power: "power that operates at the level of minute and previously unobserved discourses and practices" (Newman, 2005: 54). Foucault's pervasive notion of power is typically criticised for leaving no space for agency or resistance because there is nowhere from which resistance can emerge (Newman, 2005). However, McKee (2009) argues that Foucault's notions of power actually presupposes that subjects have agency, just that he understood resistance as part of power rather than external to it. As Foucault argued: "where there is power there is resistance" (Foucault, 1979: 96). "There are no relations of power without resistances; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised" (Foucault, 1980: 142). Furthermore, the Foucauldian notion of governmentality – "the conduct of conduct" – implies that the 'governed' are capable of acting and thinking and exercising agency (Dean, 1999 in Hansson and Hellberg, 2015).

In this chapter, I show how claimants use medical performance, narratives of personal suffering, violence and social pressure in an attempt to influence doctors' decision-making processes and re-assert their personhood and the relevance of their lived experience in the DG assessment. These acts of resistance to the state's narrow definition of disability represent an attempt to be 'seen' by the state, but they are not necessarily political, conscious,

noticed or acknowledged by doctors. As I will demonstrate, claimants' attempts to assert themselves during DG assessments in fact typically had little effect on doctors' decision-making. Instead, these acts often undermined patients' position in the assessment as doctors, hardened by large numbers of patients that they perceived as attempting to manipulate and bully them into recommending the grant, employed coping strategies to defend against these pressures and reassert their authority in interactions. Although largely ineffective, these attempts at resistance do point to differential understandings of rights to inclusion and support from the state as well as a sense of frustration at the marginalising effects of the current DG system.

7.2 Power-inequalities and claimants' understandings of disability

Although doctors' work is subject to administrative and legal restraints, physicians have considerable power relative to claimants in the DG assessment. They have obvious gatekeeping and expert authority. This is reinforced by the ceremonial order and bureaucratic format of clinical encounters, which enables and supports the expression of medical authority (Strong, 1979). The notion that clinical encounters produce and reproduce asymmetries of power and knowledge is a well-worn idea in medical sociology. Sociological critiques of medicalization in particular strongly emphasise the asymmetry between patient and doctor and often paint patients as victims (Lupton, 1997). While medical imperialism and the caricature of *biomedicine* put forward in the medicalization thesis⁷⁹ are exaggerated and not necessarily accurate in an age where lay people have more access to information and doctors' work is increasingly regulated by corporations and the state (Williams, 2001; Kelly and Field, 1994 in Williams, 2001), significant power differentials continue to exist between doctor and patient in circumstances where patients are illiterate and poor.

This is often the case in DG assessments, where the fissures created by the history of apartheid continue to structure the South African public health system, entrenching the dominance and paternalistic role of doctors in their relationship with patients and relegating patients to a "submissive, compliant and reactive role" (Grant, 2006: 55; Saohatse 1998; Crawford 1999; Kane-Berman & Hickman, 2003). Doctor-patient interactions are

⁷⁹ Critics of medicalization argue that this power allows medicine to expand its authority to address social problems or forms of deviance from the norm. They argue that this makes medicine a form of social control (Waitzkin, 1999; Zola, 1972; Conrad & Schneider, 2010).

interpersonal and the micro-politics of these also reflect and perhaps (to some extent) support broader social relations (Waitzkin, 1991: 9). The interactions I observed between doctors and claimants were representative of the socio-cultural cleavages that exist in and define relations in broader South African society. These cleavages were created by class, race, educational and cultural differences which accentuate social distance between doctors and patients and encourage “performances of distance and domination” (Heyman, 1995; 2004: 492). The obvious social and economic inequality between doctors contributed to power inequalities in the assessment. On two occasions, I observed patients asking doctors to borrow money from them and another doctor told me that sometimes patients asked her for money to buy bread. According to Dr Brown, this resulted in doctors treating patients as “poor unfortunates” (Dr Brown, interview, 2014 April 4).

Language and knowledge barriers amplify these inequalities. Watson *et al.* (2006) argue that applicants should take the central position in DG assessments and that they should have the opportunity to express their experiences, opinions and subjectively relevant information. In turn, assessors should strive to understand why claimants are applying and what their perceptions of function are. This was not often not the case in DG assessments I observed and SASSA doctors sometimes asked claimants very little about their experiences, leaving them to sit quietly in the room while the doctor filled out the forms – their presence almost a secondary part of the doctors’ work. As well as being a function of a doctors’ particular approach and time constraints, this was the result of the language barriers, illiteracy and claimants’ poor medical knowledge, which limited their ability to give accurate medical histories or give accounts of their functional limitations.

Patients who understood or spoke no or very poor English or Afrikaans struggled to communicate their personal or social experiences of disability effectively to doctors. As few doctors conducted physical examinations during assessments, these patients often simply sat quietly in the chair whilst the doctor looked through their files before dismissing them. As most doctors could speak both English and Afrikaans, this put Xhosa-speaking claimants who did not speak the socially dominant languages of medicine at a distinct disadvantage, even when ad hoc translators were used. This reinforced racial differences between black patients and white, ‘coloured’ or Indian doctors. This, as Crawford’s (1999) study of language in South African healthcare facilities also showed, disempowered patients and reinforced

doctors' dominant position. In contrast, patients who could communicate with the doctor in their own language or at least had a good command of English or Afrikaans were significantly more communicative and confident with the doctor and were better able to actively participate in and shape the nature of the assessment. Doctors, in turn, were able to develop better rapport with these patients and were more receptive to their claims. Likewise, patients who were better educated, who shared a cultural background and had more of an understanding of what the doctor needed to know from them were able to develop significantly better rapport with doctors. In a study of face-to-face encounters between rehabilitation workers and long-term sick immigrants in Sweden, Jonsson (1998) found that clients' language abilities and cross-cultural skills strongly affected how they were able to express themselves and how they are perceived and treated by street-level bureaucrats. Similar findings have been made in numerous other healthcare (Horton, 2004; Porter, 1990; Beach et al., 2006) and welfare programme settings (Kriz & Skivenes, 2010).

A lack of medical knowledge and information about SASSA's eligibility criteria also hampered claimants' ability to present their case to doctors. For instance, when doctors asked patients why they were applying for the grant or why they could not work many claimants (particularly first-time applicants) did not understand that doctors were interested in hearing about their medical complaints, how these impaired them and prevented them from working. Social workers at Whitney Hospital explained that some psychiatric patients would apply on the basis of old scars or injuries, rather than their psychiatric conditions because these more visible signs of injury were easier for them to describe than their experiences of mental illness.

It is the patient's first application and the doctor asked her why she was applying. She replies that she is applying because she was still looking for a job. The doctor said, "So it's not that you cannot work, you just cannot find a job?" Without any attempt to convince the doctor of why she might qualify on the basis of her HIV diagnosis, the patient replies, "yes." (Vrede, Field notes, 2014 January 1)

The doctor asks, "What is wrong with you?" She says that she doesn't feel well every day and she doesn't have an income. She uses medication for high blood pressure and asthma. He lists a number of medications but she is not sure of what the names of the ones she uses and can only describe them in terms of being white pills and red pills. He takes her BP and examines her legs and then does an eye exam to check for hypertensive retinopathy. He tells her that her blood pressure is very high (220/120). He looks through her file and sees that her blood pressure has been 220/140, 220/130 for several months. He checks with her that she is really taking her medication. After the assessment is complete and the patient has left, he says that this lady is quite unwell - although she doesn't necessarily look like she is. He says that people don't know how to express themselves – when he asked her what was wrong she simply says

she doesn't have an income (Rahman, field notes, 2014 July 10).

Also see quote 7.1 Appendix C

As well as communication barriers, the first case above also points to a more general misunderstanding of eligibility criteria. Other studies have found that patients think that because they are receiving medication or have a file at the clinic that they are eligible for a grant (Macgregor, 2006). This was echoed by doctors in this study (see quote 7.2). Misperceptions about eligibility criteria were also fuelled by the previous lack of regulation and standardisation around eligibility (see Chapter 2) and ongoing differential application of eligibility criteria by doctors. These misunderstandings have been difficult for SASSA to correct. During one of the SASSA trainings I attended, one doctor commented: “It’s quite pathetic and it’s quite sad that people come and they say ‘I was told I could get the grant’. It is naïve and you feel horrible saying, ‘well actually you don’t qualify.’”

Based on the questions claimants asked doctors and myself, it seemed many did not understand why some people would receive grants and others would not, why they would receive a temporary grant from one doctor and not another, or why their eligibility would change from one application to another. SASSA discouraged doctors from telling patients whether or not they have recommended the grant and although this practice protected doctors from patient retaliation, it prevented doctors from explaining to patients why they were not eligible and did little to reduce confusion around eligibility or reduce the perception that the grant system is arbitrary and unfair. Dr Haddid, told me that patients would often ask him “have I been lucky doctor?” at the end of their assessment. The idea that DG applications are a game of chance, speaks to the subjective nature of the assessment process and the confusion this has created amongst the public.

These misconceptions about eligibility criteria were driven not only by naivety and poor communications, but what appeared to be fundamentally different understanding of what it means to be disabled. Various studies in South Africa have demonstrated that lay constructions of disability and illness and DG eligibility differ from the narrow bureaucratic and medicalised definitions of eligibility (Reynolds and Swartz, 1993; Delany et al., 2005; Segar, 1994; Macgregor, 2006; Kelly, 2012). In their ethnographic work in the Eastern Cape, Hansen and Sait (2012: 100) encountered people who had “talk[ed] themselves into disability” and who understood their poverty and inability to find work as a form of disablement. DG claimants in these studies understood illness, impairment, poverty and

distress as disability, even if their embodied experience of suffering did not fit the biomedical definition of disability – a definition which does not take personal experiences and related suffering into account (Kleinman & Kleinman, 1991; Kleinman, 1995).

Claimants tend to express their experiences as individual problems and want their personal experiences to be taken seriously (Lipsky, 1980: 60; Prottass, 1979; Soss, 1999). This need stands in sharp contrast to the reductive and objectifying nature of the disability assessment.

Mechanic (1995) argues that patients conceive of illness differently, displaying difference “illness behaviour”, responding to bodily indications, interpreting symptoms and taking action in often very different ways. Patients tend to experience disease in terms of function and their daily activities, whereas doctors tend to think more about patterns of disease (Mechanic, 1995: 1208). Although not all doctors prescribed to a purely medical-bureaucratic definition of disability, this was official policy, and I have understood claimants’ attempts to convince doctors to stretch or abandon this definition as contestations of the definitions that structure their exclusion. While many claimants were simply brushed aside by doctors, there were claimants who attempted to assert their demands for inclusion based on how they understood disability.

7.3 Forms of contestation, resistance and insubordination: re-asserting personhood and strategies for making claims on the state

One of the more bizarre doctor-patient interactions I observed in the field took place between 33-year old Mr Khaya and Dr Marais, an orthopaedist in an outpatient clinic at Welgemoed hospital. Mr Khaya, a new patient at the clinic, entered the room limping and wearing a knee brace incorrectly – it was only half tied up and upside down and he clearly had no need for it. He was there on the premise that he was seeking treatment for his knee, but Dr Marais very quickly said to me, “Can’t you tell he’s only here for a grant?” Khaya could not understand any English and a nurse was brought in to translate. She explained to Marais that Khaya had been injured during strike action in Rustenberg where he had been a miner and had ataxia (poor balance) as a result of a head injury. He had been medically boarded in 2011 because he had Stage 4 AIDS and had been paid out R104 000, but this money was now finished. He told the doctor that he was looking for money from SASSA because he was not working. He claimed that he had tuberculosis, but he was not receiving treatment for it or his HIV because he had moved from Philippi to Khayelitsha and did not know where the clinic was.

On examination, it appeared that there was nothing wrong with Mr Khaya's knee, he did however have a sore on his hip and he appeared underweight and unwell. The doctor asked Khaya what he *wanted* and he responded that if his leg could be healed then he would work, but if it could not be healed then he would like a grant. He added that one of his legs was shorter than the other. Dr Marais told me that he was frustrated because he was not sure what the patient wanted and whether he could help him as his problems were clearly not orthopaedic, despite him claiming that they were. He said to the nurse [a different one by this point], "Tell him that no doctor can fix his legs and that he needs to see a doctor for the HIV because this is his main problem at the moment." He told Mr Khaya that he could "get a grant" because of the HIV and the problems related to it. He did not, however, conduct any real assessment of his HIV status. He was also likely unlikely to qualify because he was non-compliant. Khaya grinned widely, perking up significantly. He and the nurse spoke in Xhosa for some time. The nurse then shared this conversation with the doctor, saying that Khaya had told her about the conversation they had had about the possibility of Marais lending Khaya money. Dr Marais was very amused because no such discussion had taken place. The nurse spoke to Khaya again and he reiterated that Marais had agreed to lend him money. Dr Marais told the nurse that he never lent or gave patients money and, clearly annoyed, got some pills from his bag, explaining he that he was getting a migraine. I didn't understand much of the conversation that continued between the nurse and Khaya, but heard her saying "uMlungu" (white man). Clearly not directly translating this conversation she told Dr Marais that because he was white, people thought he had money. Whilst we waited for the DG book to arrive, the nurse carried on chatting with Khaya. She didn't seem to think that the Mr Khaya was unjustified in his expectation and joked with him: "instant loan". When Dr Marais finally filled out the form he wrote that Mr Khaya had pulmonary TB, a previous head injury and HIV and recommended a permanent grant without review, clearly never wanting him to return. When Mr Khaya got up to leave the doctor told him to leave his knee brace behind because he didn't need it anymore.

In this case, almost in collaboration with the nurse, Mr Khaya was able to assert his demand for a grant quite directly, resisting the inherent power disparities between him, the poor black man who could not speak English and the wealthy, white, English speaking medical professional, despite the fact that he was both non-compliant and feigning illness. Although claimants were seldom so successful in doing this, he succeeded in wearying the doctor to the point that he recommended the grant simply to get rid of him. Dr Marais admitted that he

appealed patients in this way fairly often and I also observed him advising a junior doctor who was being pressurised by one of her own patients to recommend a temporary grant if the patient continued to insist on it.

This case shows that DG applicants and beneficiaries are not always passive victims without options or strategies. De Certeau (1984) and Scott (1985, 1990, 2009) have both argued that the powerless are not necessarily passive or docile and that small, tactical acts of defiance in everyday life can be used to resist forces of power. In *Asylums*, Goffman (1961) argued that people used “secondary adjustments” to re-assert their personhood resist the categorization and stripping of the ‘self’ in the institution. A number of other ethnographic studies have shown that people employ what James Scott has described as “weapons of the weak” (1985) or “arts of resistance” (1990) and what De Certeau (1984) calls “tactics” or “arts of the weak” – small, everyday and often unnoticeable forms of resistance to systems of domination that show the limits of power, but which are often short-lived in their effects. Barnes & Prior (2011) argue that the subversion of policy directives and disruption of bureaucratic processes in public service settings is driven by “agencies of resistance” of both street-level bureaucrats and service users. While scholars of street-level bureaucracy have paid significant attention to the subversive actions of frontline workers, acts of resistance by citizens and clients in bureaucratic encounters and its effect on policy outcomes has been less studied. Resistance by service users includes the development of alternative strategies and practices that result in distinctively different outcomes than those intended or the outright refusal to participate in programmes to address their needs (Barnes & Prior, 2011: 7). Clients do not always accept being placed in administrative categories and may work to assert their agency in street-level interactions and they can subvert and disrupt existing systems and refuse to participate in the system in the way institutions and bureaucrats want them to (Dubois, 2010: 6).

For example, in his work in French welfare offices, Dubois (2010) observed cases where clients would defy the bureaucratic attempts to place them into administrative categories through personalisation - attempting to gain control of the interaction by creating cracks in the bureaucratic or professional façade of bureaucrats or introducing an emotional dimension into interactions through narratives of misery. There are a number of other examples of this in European studies. Bloor and Macintosh (1990) showed how female patients living in therapeutic communities resisted the medical “surveillance” of healthcare workers through concealment and non-cooperation. Salmon and May (1995) also found that through somatization, patients used the biomedical model to manipulate doctors. McDonald and

Marston (2005) showed how unemployed people in welfare to work programmes resisted efforts to imbue them with the ethics of self-responsibilisation by exiting or refusing to participate in programme activities. Ewick and Silbey (2003) provide examples of citizens' resistance to legal authority through masquerade, rule literalness, disrupting hierarchy, foot-dragging and colonizing space. In South Africa, using de Certeau's concept of 'tactics', Schneider et al. (2010) showed that patients negotiated access to care and preserved their dignity in a resource-constrained public hospital by making tactical use of social networks, complaint mechanisms, narratives of resistance and becoming expert, compliant patients.

I argue that in DG assessments, claimants interrupt disability assessments in an effort to assert themselves and their rights by engaging in relational or oppositional struggles with doctors around access to the grant. Patients attempted to achieve this inclusion through performances of disability, presenting their genuine, somatic or feigned impairments to doctors and communicating stories of psychic, social and economic suffering to convince doctors that they 'deserved' a grant, or through coercion. It is, however, important to note that not all claimants resisted the assessment process and I am not attempting to distinguish between acts of compliance and resistance in terms of agency, because accepting the rule can also be a form of agency (Hansson and Hellberg, 2015: 31). In fact, perhaps one of the most effective way of negotiating access to the grant was by being compliant, well-mannered and demonstrating that one was a 'decent' and therefore 'deserving' person. There is of course also a risk of overstating the agency of claimants and over-interpreting DG claimants' behaviour and self-expressions and labelling them as resistance, or assuming that there is a unity in how the 'weak' think, which is assumed to be antagonistic to power, criticism that has been levelled at Scott and de Certeau (Gupta, 2001; Vinthagen & Johansson, 2014; Howe, 1998).

As in the case of Mr Khaya, who used an old knee brace as a prop in his performance of disability, malingering or exaggerating impairments was a commonly used tactic by claimants. Dr Bhele summed up this scenario quite well: "If you cannot find work then you remember that you have an old injury." Back pain, osteoarthritis and pain from old injuries were most commonly exaggerated or feigned by claimants. The quality assurer who reviews large numbers of completed assessment forms joked during an interview that based on the number of patients who complained of arthritic pain it appeared that there was a "pandemic of osteoarthritis." However, according to provincial health data and given the young age of many people making these claims, this was clearly untrue. Claimants with epilepsy were

generally aware that only uncontrolled cases of epilepsy are eligible for the DG and because the frequency of their fits was difficult to authenticate, some exaggerated the number of seizures they had per month. Failure to comply with treatment in order to remain ill can also be understood as a strategic attempt to manipulate the system gain access to the grant.

Psychiatric social workers at De Waal hospital, reported that claimants frequently ‘relapsed’ shortly before their grants expired. Occupational therapists from work assessment units at Marais and Welgemoed hospitals also highlighted the frequency with which DG applicants that had been referred to them by doctors for formal work assessment exaggerated their disablement or intentionally underperformed on mobility, motor or functional tests. (*See quote 7.3*)

Many of the people applying for grants on ‘false’ premises had received temporary grants in the past (often for tuberculosis), but had not found work after these grants had lapsed and were looking to either draw out the benefits that this impairment had given them or find new opportunities (e.g. old fractures) to re-new these grants and avoid the devastating effects of losing their monthly income. These repeat applicants, who very often had a better idea of how the SASSA system worked and what doctors wanted to hear, would arrive at the assessment with a list of symptoms and complaints (Dr Jacobs, interview, 2013 October 24). Although defaulting on treatment may have presented a strategy for retaining a temporary disability grant in the past, few doctors now recommend grants for people who do not adhere to treatment (*See quote 7.4*). As discussed in Chapter 4, because deception by claimants is a central concern in disability benefit administration, doctors were alert to the possibility that patients were exaggerating their impairments. This meant that these performances were seldom convincing to doctors.

As well as people who intentionally performed their disablement, there were people with relatively minor impairments appeared to genuinely believe they were disabled. According to OTs I interviewed, who often spent days with patients during work assessments, some patients felt more disabled by their medical impairments than functional assessments would suggest. “Suffering is an affliction of the *person*, not the body” (Cassell, 2004: xii) and different people with the same disease may not have the same illness. Individuals with low self-esteem and motivation as a result of their life circumstances and subjective experiences of illness or impairment may become convinced that they are not able to work (Mechanic, 1995) and both doctors and occupational therapists recognised that low motivation drove perceptions of disablement.

I get a lot of women that have come in here because of abuse - like they are broken because of abuse and you can actually see it in their entire demeanour already, the way they dress, the way their hair is, the way they smell. We do get patients that look horrible, they look really worn out, so life has kind taken from them, just in general - whether it be other people that have broken them down or circumstances that have broken them down or maybe they are just negative people - you get pessimistic people. So there's a lot of reasons why their motivation is not where it should be to return to work - to go out and seek work. We see a lot of people whose children are on drugs and that also takes a lot out of them - that takes a lot of their motivation away and they've lost their faith whether it be in God or in a different deity, they've just lost the spirit basically. They feel like they are victimised, they feel like they just are...they can't do anything (OTI, interview, 2014 April 23) .

Also see quote 7.5

Physical pain and suffering that is not connected with or disproportionate to physiological problems can be driven by somatisation, which is a bodily mode of experiencing personal and political distress (Kleinman & Kleinman, 1991: 280). Both physical and emotional pain can be increased by fear, powerlessness, anxiety, depression, and lack of control (Francis, 2006). In another study of DG applications in South Africa, Macgregor (2006) found that claimants in the Cape Town township of Khayelitsha somatised the stresses of their economic and social circumstances, expressing their suffering as a psychiatric condition they called “nerves”. Although not connected to attempts to obtain social benefits, Fullwiley (2006; 2014) describes how Senegalese women carrying the sickle-cell trait (a benign condition with no symptoms) articulated their emotional, social and physical suffering as “sickle cell crisis”. Fullwiley theorises that this enunciation of suffering in biological form is an expression of *biosocial suffering*, an idea drawn from Rabinow’s concept of *biosociality* (1992) and Kleinman et al. ’s (1997) concept of *social suffering*. Scheper-Hughes (2002) argues that illness can be used as a “passive aggressive weapon of the weak” and that malingering and somatisation are “inchoate acts of protest and defiance against oppressive roles and/or feelings of inadequacy, frustration, or failure.” (2002: 153-169)

As the disabled body is entitled to support from the state, disability becomes a positive collective category that people can draw on (consciously or unconsciously) to be ‘seen’ by the state (Hansen & Sait, 2012; Kelly, 2012) to assert demands on the state as suffering bodies and seek inclusion in the welfare system. Becoming sick presents an ‘opportunity’ to seek an income from the state, resulting in people reacting positively to an HIV or TB diagnosis, or, although not necessarily something carried out in practice, wanting to remain ill. (Leclerc-Madlada, 2006; Natrass, 2006; Hardy & Richter, 2006). Dr Bhele noted that in cases of longterm unemployment, claimants people thought of hypertension and diabetes as a

“bonus”, because they believed their diagnosis would allow them to receive a grant (Dr Bhele, interview, 2014 April 30).

Petryna (2002) defines the embodiment of a demand for support from the state as *biological citizenship* – a link to “a form of social welfare based on medical, scientific and legal criteria that both acknowledge biological injury and compensate for it” (2002: 6). This concept was drawn from her work in Ukraine, where, after the Chernobyl accident, people claimed pensions and free health care from the state on the basis of radiation exposure and related indexed levels of suffering. In considering the awarding of asylum to undocumented migrants in need of health care in France on a humanitarian basis, Fassin (2001, 2009) and Ticktin (2006) also draw connections between the suffering of the human body, humanitarianism and a new kind of biological citizenship that is stripped of its social or political elements but presents a set of benefits to sufferers such as medical treatment or the freedom to stay in the country. Nguyen (2010, 2013) describes how in West Africa people seeking access to limited anti-retroviral technologies would tell compelling stories of their experiences with HIV narrative to broker access to life-saving medications. Those who could draw on and commodify their suffering using narrative techniques were more successful obtaining treatment than those who could not. Hoffman (2006) describes how victims of machete attacks, living in the amputee camps after the civil war in Sierra Leone, consciously used the symbolism of their disabled bodies to access aid and relief funds from the international community.

Embodiment was not, however, the only way that claimants expressed their suffering. DG claimants’ accounts of their disablement were very often expressed as narratives of their everyday struggles of trying to find work and living in poverty rather than as descriptions of medical symptoms or physical limitations. Although many patients employed pathos to strengthen their cases, this story-telling was not necessarily intended to manipulate or deceive doctors and may, as in Hansen and Sait’s (2012) study, simply represent different understandings of disablement. It does, nevertheless, represent a demand for social assistance.

Physicians also faced social pressure from claimants. For example, Dr Bhele, an assessor in township clinics around Cape Town, where there was high demand for DGs, faced significant social pressure from patients to recommend the grant. Dr Bhele described how on *Mandela Day*, a day when South Africans are encouraged to volunteer their time to help others, applicants waiting outside tried to convince her to recommend grants for all of them as her

act of kindness for the day. They were very angry when she did not fulfil their expectations. She described how people in the corridors of the clinics she visited would regularly swear at her, complaining: “It’s not even her money!” Unlike the rest of doctors included in the study, Dr Bhele was able to communicate with Xhosa patients in their own language. This allowed patients to confidently convey their stories in great detail to Dr Bhele, which was not possible with other doctors I observed working in Xhosa areas who had to use translators. These patient narratives made Dr Bhele profoundly uncomfortable in her role and she found it very painful to reject people knowing their social circumstances: “But then you still put ‘no’ at the end – it’s not nice. We are human beings also.” She described driving through the squatter camps to the clinic and told me, “you *feel* it, you *know* it, but you don’t have grounds to give the grant. As a doctor you choose this profession to help people, not to be unkind.” She told me about another Xhosa doctor who had given up doing DG assessments because she couldn’t handle this dilemma. At one point, Dr Bhele had also felt so despondent about the DG system that she had temporarily stopped doing assessments. However, after some thought she had decided to resume this work because many people genuinely “deserved” and benefitted from the grant.

Another doctor working in small towns felt that rural doctors experienced more social pressure to recommend the grant than those working in the city because of their familiarity with patients or the chance that they might encounter patients in public spaces. Rural doctors are very often the only or one of a handful of doctors in their area and must assume multiple roles, from district surgeon to disability assessor and private practitioner. As one doctor working in a rural area told me:

“In Cape Town it doesn't matter. In a small town, you know everybody and that patient goes around and says “eeh, that doctor says there's nothing wrong with me and he knows how bad I am” and so on. When I see him the shop I will hear him say “aah daai doktor se mos ek mekeer niks”⁸⁰. It's totally different. Small town, everybody knows everybody's business and that is true. You know it has an impact on this sort of thing - definitely has an impact.” (Interview, Dr Bury, July 2014).

Claimants also asserted their demands and frustrations in more aggressive ways. Although this was less common, some patients used verbal and physical aggression to disrupt power relations and make doctors feel vulnerable. In interviews, as well as training sessions I attended, doctors frequently raised safety concerns or shared stories of patients that had threatened or verbally abused them either in an attempt to coerce them into

⁸⁰ Aaah that doctor says there is nothing wrong with me

recommending the grant or to express their anger at what they saw as unfair treatment. This was experienced most commonly at the PHC level by doctors who spent hours presenting the 'face' of SASSA to disability grant claimants. These SASSA assessors were often intensely unpopular with patients because they were perceived as strict and inflexible. They were not only coerced by claimants during consultations, but were sometimes heckled by people waiting in the corridors.

Dr Bhele had been threatened with a knife at two of the clinics she worked at and had also had a patient return to the clinic to confront her aggressively after learning from SASSA that his application had been rejected. Dr Bhele felt that she and other doctors were often blamed for not "giving" the grant and that patients "made it personal", not understanding that their decisions were based on SASSA's guidelines. In another case, Dr Kruger, a SASSA assessor, was physically assaulted by an angry patient who had hit him with a chair during a consultation. He told me via email, "I have been verbally abused a few times and had patients scream at me and get quite aggressive, but I was never physically abused until now." When he pressed charges and reported it to a senior SASSA doctor in the region where he worked, he was told that he was the third doctor in the region to be assaulted by a patient. This treatment was not limited to doctors and nurses and occupational therapists also experienced verbal threats and physical abuse from patients. Dr Marais shared the story of the nurse who managed his clinic who had encountered a patient at a local shopping mall who believed that she had discouraged Dr Marais from recommending a grant. The patient had chased the nurse through the mall, insulting and threatening her. Occupational therapists, who are effectively included in the gatekeeping process by doctors who refer patients for functional assessments, reportedly also encountered considerable coercive pressure from patients who swore, shouted and threw objects at them.⁸¹

Dubois (2010) puts forward three possible reasons why welfare claimants may use or threaten violence in administrative settings. It can be a resort of victims of structural violence who don't understand the system, are frustrated by it and aren't able to express themselves in other ways. Violence can also be strategically employed to get attention or expedite bureaucratic processes. It can also be used by people as a way to demonstrate their personhood and demonstrate that they exist beyond administrative categories. In the case of

⁸¹ An OT at a work assessment unit at a tertiary hospital indicated that they often get inappropriate referrals from OTs working at PHC level in what she described as "dangerous areas" because OTs were too frightened to report that a patient had no functional limitations.

the DG, it seemed to be mainly driven by frustration and anger at a system that was confusing and unfair or how they were treated by doctors.

All the SASSA assessors I encountered in the field attributed these attacks poor screening practices and poor communication by SASSA about eligibility criteria and doctors' role in the assessment process. Dr Bhele told me that people understood the DG as a form of social relief for any unemployed person who received regular medical treatment: "If you are unemployed and have a folder at the clinic then people think that they can apply and people think that being on medication means you are eligible for the grant." Another doctor at the SASSA training I attended told the group of other doctors in attendance: "I wish the community was educated – we become the bad doctor and they are always on our necks." Participants in my earlier study of disability grants in an impoverished urban settlement in Cape Town (Kelly, 2012) indicated that people who had applied for grants felt unheard and unfairly treated by doctors and the system more generally. They expressed frustration with the government and the increasing difficulty of accessing benefits and could not understand why they were not physically examined or why doctors told them they were capable of working when their daily experiences with illness and inability to find work indicated otherwise. One participant in that study joked, "if you die in the hospital today and they give you a death certificate then they will say "okay *now* you are fit for the disability"" (Kelly, 2012: 101).

Aggression by claimants was also a reaction to doctors who were rude or moralising in their interactions with patients. One claimant in Dr Mulumba's clinic, for example, shared her experience of being told by another doctor: "you are robbing the government, you must go work." She had responded by swearing at him, which she felt was a legitimate response to being treated so rudely. This also represents a bigger breakdown in the doctor-patient relationship and trust in doctors, where doctors are seen as functionaries of the state – their work as arbitrary and corruptible as those of other administrators. China has seen a similar but much more widespread phenomenon, where the doctor-patient relationship and respect for and trust in doctors has deteriorated to such an extent that doctors are frequently violently attacked by patients and their families (Beam, 2014).

The tools of guilt and fear only temporarily disrupt power dynamics within the disability assessment. Although heckling or attacking doctors may allow patients to express their anger and frustration and performances of disability and suffering may dupe doctors or make them feel sympathetic to patients, doctors ultimately retain authority in assessments. Aggression or

what doctors perceived as attempts at manipulation also made doctors more likely to make negative moral judgments about claimants, whereas being knowledgeable, friendly and compliant made doctors more likely to see claimants as deserving. As I will show in the next section, doctors deal with the difficulties of conducting assessments and limit their vulnerability in these circumstances (and in the practice of medicine in general) by re-asserting their bureaucratic, symbolic and medical authority.

7.4 Strategies used by doctors to cope with patient pressure

Few occupations encounter as much suffering as healthcare professionals do in their daily work. Doctors' work is often emotionally draining and, in the case of DG assessments, this is largely because doctors make decisions that can significantly affect the welfare of claimants. Doctors often described their work as stressful and difficult, especially when they were uncertain about a patient's eligibility, they felt compassion for patients who did not qualify or experienced pressure from patients to recommend a grant.

Although the Weberian bureaucratic ideal presumes that bureaucratic encounters are emotionally neutral and rational spaces, there is clearly an unavoidable emotional component to the type of face-to-face encounters that occur during DG assessments (Graham, 2002; Eggebø, 2013). The literature on emotion in bureaucracy and medicine indicates that bureaucrats and doctors are "emotional actors" (Hunter, 2015), who may feel interest and boredom, fear and detachment, sadness and fulfilment, anger at being manipulated or at people abusing the system and guilt during their interactions with clients (Tumbo, 2008; Eggebø, 2013; Graham, 2002; Rousseau & Foxen, 2010; Fassin, 2005; Butt, 2002; Ticktin, 2006).

During one of Dr Rahman's consultations, the patient he was examining began to cry and reflecting on this afterwards, said: "In this job you have to deal with people's emotions." However, professional norms of self-control and being in control (Gastelaars, 2009) meant that Dr Rahaman, both as a SASSA bureaucrat and a medical professional, is expected to manage and contain his emotions and remain rational and objective in his assessments, while at the same time being reassuring and empathetic towards claimants⁸².

Doctors are trained to manage "unprofessional" emotions by using distancing, distraction,

⁸² The "emotional labour" (Hochschild, 1979) of managing displays of public emotion is associated with exhaustion and burnout.

humour, and avoidance (Smith & Kleinman, 1989). In the epilogue to his 2006 book, medical anthropologist and psychiatrist Arthur Kleinman discusses Picasso's painting, *Head of a Medical Student* (1907), which depicts a medical student sitting with one eye closed and the other eye open. For him the opening of one eye represents the need for medical students to learn to open their eyes to the pain and suffering of patients. He interprets the closing of the other eye as the learning of clinical distance that will enable them to protect themselves from pain and suffering and their own professional interests (Kleinman, 2006: 264).

As I have discussed in previous chapters, doctors develop their own approaches or routines for handling the stresses that accompany their work. One of the most significant sources of stress is their interaction with patients and they therefore develop coping strategies to deal with these encounters.

Doctors developed defensive coping strategies to protect themselves psychologically and manage the demands of their emotional and decision-making work, to guard against "system-abusers" (Hoag, 2010: 19) looking to manipulate or trick them and to deal with people who the DG system could not accommodate. One way of coping with these pressures was through psychological withdrawal, cultivating what Herzfeld (1992) calls "bureaucratic indifference" to detach and distance themselves from the needs of clients.

Through her study of nursing practices in a hospital in the UK, Isabel Menzies Lyth (1960) developed a framework for understanding how healthcare workers manage the anxiety and stresses of patient care. She argues that nurses have developed practical strategies that act as social defence mechanisms against anxiety created by their work. These mechanisms include focusing on specific tasks rather than on patients, avoiding eye contact and the depersonalisation of patients through the standardisation of care.

Walker and Gilson's (2004) study of the impact of the introduction of free healthcare on nurses in South Africa, found that nurses responded to feelings of being overworked and disempowered by developing coping strategies to rationalise their inability to provide adequate care to patients. These strategies included using simple information to make judgements, categorising patients, exercising favouritism, being suspicious of clients, distancing themselves from clients and developing lower expectations of themselves and their work (Walker & Gilson, 2004: 1259-1260). Fassin (2008) found that healthcare workers in a South African hospital 'learned' emotional indifference and employed tactics to distance themselves from patients.

In many cases, patient's real problems extended well beyond doctors' ability to assist them. Unable to deal with people's poverty they may become frustrated, despondent, disinterested, suffering from burn-out or compassion fatigue. Lipsky argues that street-level bureaucrats stereotype and mentally discount clients to rationalise their inability to assist them. Numerous studies and historical accounts of the South African health system at the peak of the HIV epidemic, before anti-retrovirals were widely available, healthcare professionals, unable to heal patients or cope with the huge burden that the epidemic placed on the healthcare system, became nihilistic about the epidemic and their inability to cure patients and the repetitive of their work grew bored of their work and were neglectful of patients and indifferent to their suffering (Oppenheimer & Bayer, 2007; Le Marcis, 2004, Le Marcis & Grard, 2015). As Le Marcis and Grard (2015) argued, "withdrawing from a caring relationship is for health professionals a way to carry on working" and a driver for the standardization and de-personalisation of care.

Tummers et al. (2015) classify the behavioural ways that bureaucrats cope with the stresses of their work and the demands from and conflicts between bureaucratic rules, client's needs, professional codes and their own values during client interactions in three ways: *moving towards, moving away or moving against clients*. Outside of their interactions with claimants, bureaucrats might use more cognitive coping mechanisms such as emotionally detaching themselves from clients, becoming cynical about their work or seeking support from colleagues and may also become alienated from work more generally (Tummers et al., 2015). Coping by moving towards clients may involve bending the rules in favour of the client or bureaucrats, spending extra time on cases or using their own personal resources to assist clients. Coping strategies that move away from clients include distancing moves that use bureaucratic categories and processes to limit engagement and services to clients.

In this study, I found that doctors employed numerous strategies to protect their professional objectivity, cope with the pressure of making DG decisions, manage the large number of patients that they saw on any given day and to re-assert control over assessments where patients' sought to take over. Strategies for *moving away* from claimants included confrontation, getting rid of patients, avoidance and distancing. Some doctors also moved *towards* clients by bending the rules, a strategy that alleviated their own guilt.

One quick way for doctors to put a quick end to what they perceived as patient manipulation, was to confront it directly by asserting their professional and bureaucratic authority to regain control over the interaction. Dr Brown enjoyed interacting with patients and was generally

genial and friendly to them, but sternly kept the assessment on his own terms, refusing to allow patients to emotionally manipulate him with their stories and dealing with pushy and argumentative patients very bluntly. He told me, “A lot of disability grant people are very aggressive and have an axe to grind. They are like Jehovah’s witnesses! You can’t be friendly and accommodating when people want to take over.”

Dr Brown tells the patient that her listed conditions have effective medications and are not eligible for the DG. He asks her if there is anything else and she does not come forward with any additional complaints. He says, “Disability means unfit for work.” She then tells him about how she is caring for her son with cerebral palsy who is blind and can’t walk, adding that she gets tired easily. He says, “So you can’t work because you are looking after him?” He says, “Your problem is not the diabetes, it is looking after the child. You look grey.” She however seems convinced that she is indeed disabled and says “my sicknesses are also make me feel unwell.” He recommends exploring other options for support such as the Grant-in-Aid (GIA). She does not seem interested and insists that she be given the grant saying, “Why did they give it to me last time for 6 months?” He says, “Well the other doctor could have given it, but I can’t because there are no grounds. You need the GIA.” The patient then asks, “How many sicknesses must you have to be disabled?” The doctor responds “it’s nothing like that”. She says, “Because the sugar is not going away”. Dr Brown becomes very annoyed at this and says, “I don’t want to argue with you.” “I am not arguing”, she protests. “You are. I have told you about the DG”. The clerk wants to chip in at this point, but Dr Brown warns him, “say any more and I will ‘klap’ (hit) you – the subject is closed”. Dr Brown then feels bad about how harsh he has been to the patient and says gently, “I know you are upset and I understand, but we have procedures and rules.” The patient then leaves.

In treating settings, doctors might, like Dr Marais, may simply avoid conflict with patients by recommending a grant to a patient to get rid of them. Bending the rules for people they felt were deserving of support can also be understood as a form of coping because it alleviated the guilt that doctors felt about individual cases and reduced the immediate pressure from patients. SASSA doctors, who saw dozens of DG applicants a day were not able to pursue this strategy and instead used numerous strategies to avoid engagement with patients. Doctors found claimant narratives either trying (redolent of the “heard it all” mentality of street-level bureaucrats described by Lipsky) or difficult to cope with and attempted to avoid them by either refusing to discuss social issues or ignoring patients when they started to tell these stories, focusing on their paperwork rather than the patient. Dr Vrede, for example most of her time focused on the file and paperwork in front of her, rather than looking at and having to engage with patients. If Dr Vrede felt that an applicant was clearly ineligible, she simply

wrote “unemployed” or “RVD”⁸³ under the complaints section of the form, had the patient sign the form, telling them to return to SASSA after two weeks and moved quickly onto the next patient. As already discussed, I observed her working in a Xhosa-speaking area where many patients had a very poor command of English. The language barrier also seemed a useful tool in avoiding engagement with patients and getting them out of the room as quickly as possible and most of the time she did not use translators. Swartz and Drennan (2000: 193) also argue that in South African psychiatric settings, clinicians may in fact choose not to understand patients:

The prospect for the monolingual, white clinician to understand fully the situation of patients for whom there is in reality very little available in terms of mental health care may simply be too overwhelming. Better, in this context, not to understand patients than to risk being overwhelmed by their needs and by the gap between their needs and what help can be offered.

At least part of her approach appeared to be some sort of a coping strategy. This became clear when she deviated from her usual pattern of behaviour and attempted to explain to a patient why she did not qualify.

A healthy-looking young woman enters, applying for grant for the first time. Dr Vrede asked her why she was applying and she said that it was because she was still looking for a job. The doctor said, “So it’s not that you cannot work, you just cannot find a job” and woman says “yes”. The doctor explains that because “it’s still early in the HIV” and that if SASSA does not give her the grant then they will give her food packages. She explained that you can only receive it if you are disabled. The woman is clearly upset (close to tears) and feeling guilty, the doctor asks her if she wants to say something and then proceeds to explain the system more. After the woman leaves the doctor turns to me and says “that is why one should just say nothing”. She does not talk about the possibility of rejection to anyone else that day. (Field notes, 2014 17 January)

Dubois (2010) describes frontline workers have having two bodies: that of the impersonal, standardised bureaucrat and the complicated individual with her own individual identity and personality who moves between two extremes - the “institution-made man vs. the humanised institution” (Dubois, 2010: 74). During interactions with patients, doctors can employ either

⁸³ RVD (retro-viral disease) is a commonly used code-word for HIV in the public healthcare system.

of these identities and respond to claimants in different ways, alternating bureaucratic formalism and strict application of the rules with friendly casualness, compassion and flexibility, depending on the claimant and situation at hand. Doctors were generally far more open and friendly to patients who were clearly eligible for the grant than those who were not. Dr Soet, for instance, managed her position within the assessment process by making a preliminary decision about the patient based on their file before they entered the room. Based on this decision, she treated people likely to be eligible for the grant differently from those who were unlikely to qualify; she was friendly to people who she thought she would qualify and treated others with suspicion.

Although she told me that this made her feel uncomfortable and like a “bad doctor”, she felt she could not put forward a friendly front to patients who may not qualify as this could be misinterpreted by patients as a positive sign that they would receive the grant. “If you treat people normally it creates the expectation – if then you don’t get the grant two weeks later then they will see you as two-faced”. She felt that being too open and friendly would give people ineligible claimants the opportunity to tell her about their financial issues. These narratives left her feeling guilty at not being able to assist patients and in her view they were therefore best avoided: “You end up feeling worse because they tell you their story and you still say no. You can’t make the person that does not qualify for the grant feel good.” (*See quote 7.6*)

SASSA assessors also used guidelines during assessments to create distance between them and patients (“I only focus on what is in the guidelines, not individual situations”) and between them and SASSA (“It is not my decision, I am only following the guidelines”). As discussed in Chapter 5, framing interactions in bureaucratic terms and rigidly following the rules was one possible defence against the stresses of decision-making and client interactions (bureaucratic framing), but Dr Bhele also used them in a more material way by physically showing them to patients to publicly separate herself from decisions she knew would make patients unhappy and she had enlarged and stuck the SASSA guidelines to the walls of the clinics she worked at regularly. She also hoped that educating patients about SASSA’s eligibility criteria would reduce pressure on her in the consulting room and would go outside to speak to waiting patients about the grant before the start of the clinic to inform them about SASSA’s criteria. In these presentations she highlighted that the DG is not a form of social relief, but a grant specifically for people with disabilities. Unfortunately, this did not deter ineligible claimants from waiting to see her because

they had nothing to lose by doing so. Dr Bhele told me, “Everyone wants to try their luck.”

7.5 Conclusion

This chapter has shown that relationships between doctors and claimants were often fraught with tensions that were the result of divergent understandings of disability and rights to social assistance. Many patients actively attempted to express their own understandings of disability and influence doctors, but were limited in their capacity to do this by doctors’ ability to dictate the terms of the assessment. Claimants who were most successful were those who exhibited appropriate behaviour that made doctors more likely to believe they ‘deserved’ a grant, while more overt efforts to manipulate doctors lead to a break-down in the doctor-patient relationship. Doctors’ belief that claimants were trying to manipulate or deceive them, together with the pressures inherent in the medical work environment often led doctors to employ defensive strategies that distanced them from claimants. Doctors’ defensiveness limited patients’ ability to participate in the assessment process, already limited by language and education barriers. Being unable to tell their “side of the story” and the perceived unfairness of the system was extremely frustrating to claimants. This frustration led some patients to be highly aggressive with doctors, which created a vicious cycle that further entrenched barriers between patients as doctors acted to protect themselves against patients’ demands.

CHAPTER 8: Conclusion

This thesis has focused on the challenges of disability determination in South Africa's DG system, looking specifically at the gatekeeping work of medical doctors who conduct disability assessments for SASSA. I have shown that as doctors interact with claimants and interpret and apply formal eligibility criteria to individual cases, they mediate access to the grant and shape policy outcomes.

In discussing both the historical and more recent decision-making of doctors, I have highlighted some of the key definitional conflicts and operational tensions that exist within DG administration. Assessing disability for social protection programmes is generally difficult and, in a context like South Africa, these issues are magnified and tensions between the social and medical model of disability are made even clearer. The overlapping problems of poverty, chronic illness and disability have been hard to separate. The multiple ways that disability can be understood and operationalised has created confusion and tensions both at the higher levels of the policy making process and at the frontlines of service delivery.

The lack of political consensus around how to define disability has left doctors to resolve conflicts about how to measure and define disability at the implementation level, using unclear guidelines and an outdated medical model that is difficult to apply in practice. My observations of doctors' work as DG assessors have shown that physicians play multiple and sometimes conflicting roles in DG assessments. They play the role of medical professional - with its attendant norms, responsibilities and knowledge-forms - and the role of bureaucrat within the structure of SASSA's disability management system. They are also human actors with their own agency and set of personal experiences, norms, moral dispositions and notions of social justice, who are likely to have subjective reactions to claimants (Barnes & Prior, 2009). The socio-economic, political and policy context doctors operate within also influences their understandings of concepts like disability, employability, health and desert. Claimants also bring their own agency to bear on the assessment as they present their stories and bodies to doctors, along with their own understandings and interpretations of SASSA's eligibility criteria. The broader policy environment and poor DG policy design also shaped the implementation context. The decisions that doctors make about claimants are contingent on all these factors and dynamics, which shape how the doctor makes 'sense' of or *frame* a particular case and implements DG policy. The extent of the poverty and unemployment in South Africa shows how systemic structural issues can affect both policymaking and decision-making in a way that is perhaps less obvious in the North American and European

contexts. Though not in the direct way that rules and regulations or organisational context might, these systemic factors contribute to the implementation context and inform doctors' understanding of claimants' eligibility.

By examining how doctors and claimants interact, both with each other and the policies and bureaucratic machinery of the state, I have shown that the DG assessment is a space where different welfare, medical and disability discourses are instantiated. The process of DG assessment turned the clinic and the hospitals where I carried out my research into sites of policy administration and social politics, where rights to social assistance were negotiated. Disability as a social, medical and administrative category was socially and discursively constructed, (re-)defined and applied in ways that sometimes contradicted official policy.

My ethnographic account of these dynamics provides useful insight into what policy implementation scholars call the 'gap' between policy and practice (Pressman & Wildavsky, 1984). It makes an original empirical contribution to the study of conceptions of the 'deserving' poor in a context of high poverty. This research shows the value of studying professionals as a 'special case' of discretionary behaviour at the street-level. It also shows the usefulness of ethnography in unpacking problems of policy implementation.

Before highlighting some more general contributions of this thesis to the literature on street-level bureaucracy, I will highlight the main findings and contributions of each chapter.

Chapter 2 presented the history of the ANC governments' efforts to manage the DG system inherited from the apartheid government. As the case of the DG shows, in the face of a major shock to policy like the HIV epidemic, frontline responses to a changing implementation context can radically change what a policy does. In this case, the DG became, in effect, an HIV and a general poverty alleviation grant, serving a purpose beyond the one for which it was designed. The history of DG policy shows that the process of policy implementation created the politics that then very directly informed policy decision-making and drove reform of the social grant system towards strictness. This demonstrates how important the actions of policy implementers can be in shaping both policy outcomes and policy development. The circular relationship between the design of DG policy and its implementation therefore provides an excellent case for thinking about the policy-making process as less of a unidirectional, top-down process and more of a feedback loop (Skocpol, 1992; Pierson, 1993; Hacker, 2002).

In Chapter 3, I explained SASSA's efforts to 'rationalise' the DG system and constrain

doctors' discretion through the implementation of the DMM. I detailed workings of this system in the Western Cape, showing that in practice, SASSA had limited capacity to oversee doctor's work. Doctors retained significant gatekeeping power in assessments and it was difficult to hold them accountable for their decision-making, especially in treating settings. The system has not been able to reduce the large number of claimants applying for grants, which creates pressure on doctors who must deal with large patient loads.

Chapter 4 discussed the role of South African doctors as medical experts in the DG system. Findings showed that medical assessments of impairments and disability are not straightforward and because disability is determined in relation to employability, medical knowledge alone is insufficient to conduct disability assessments. Doctors therefore faced a high degree of uncertainty in making decisions. The disconnect between the guidelines and the actual reasoning required to make decisions resulted in SASSA guidelines being dismissed by some doctors as arbitrary and unhelpful. In the absence of formal training on non-medical aspects of disability assessment, doctors used their own common sense, pragmatic approaches in their clinical judgements.

In Chapter 5, I showed how SASSA's DMM system, in combination with the organisation of the Western Cape healthcare system, structured doctors' work. I demonstrated how the demands, constraints, incentives and frustrations created by these two systems shaped the way that doctors conducted assessments. Doctors used their discretion and autonomy to develop strategies to simplify their decision-making and cope with large patient loads, difficult working conditions, poor medical record keeping, significant communication barriers with patients and a lack of medical evidence on which to base their decisions. Unwillingly drawn into the system, treating doctors felt alienated from SASSA and felt little obligations to uphold its norms and standards. In general, doctors wanted to standardise their assessments, but wanted to achieve this through professional, peer-to-peer engagement and more specialist input into assessment guidelines rather than through SASSA's monitoring approach.

Chapter 6 showed that within the bounds of social security legislation and regulation, doctors exercise considerable discretion in making recommendations on grant eligibility. In this discretionary space, doctors were able to insert their own understandings of deservingness into the assessment process. I used the idea of *framing* to show how doctors make sense of patient cases and their particular contexts. These decision frames represent different arrangements of SASSA's rules and regulations and doctors' responsibilities as medical

professionals and moral agents that establish the boundaries and constraints for decision-making, acting like a set of rules to guide emerging action. How a doctor framed a particular case inclined them to be stricter or more flexible in applying eligibility criteria to patients. Whilst frames show that bureaucratic action is structured by institutions, *habitus*, social relations, knowledge and prior experience, frames do not preclude agency and doctors have the capacity to pragmatically and actively move between and combine frames in different situations. Looking at their work as a process of framing shows that doctors were not necessarily ‘hard’ or ‘soft’ on patients because they felt unsympathetic towards or felt sorry for patients (although this was the case in some instances) and they did not make conscious decisions to break the rules or stick to them because they opposed or supported DG policy. The concept of framing allows us to see beyond these dichotomies to understand how multiple factors influence how doctors think about the disability problem and the person in front of them. It also shows how both personal and professional norms and subjectivities matter in street-level decision-making.

Chapter 7 examined the interaction between doctors and patients during DG assessments. It showed that the DG assessment is not only a bureaucratic and medical process, but a social interaction shaped by the emotions and relative power and agency of the doctors and claimants who participate in the assessment. The ways in which claimants interpreted eligibility criteria, interacted with doctors and strategically positioned themselves in relation to the disability category influenced doctors’ decision-making. I showed that claimants could be active participants who creatively engaged in the assessment process, using narratives and physical performances of disablement and suffering to influence doctors’ decision-making. Claimants’ understanding and subjective experiences of disability differed from biomedical conceptions of disability and claiming disablement represents an attempt to have their financial hardship and social suffering “seen” and legitimised by the state. Others, frustrated by the perceived unfairness and arbitrary nature of assessments verbally harassed or used violence against healthcare workers as a form of protest against the system. Some claimants were also legitimately confused about eligibility criteria, which also shows how important the historical application of an administrative category by street-level bureaucrats is in creating expectations about who should rightfully be included in that category⁸⁴. The high demand for the grant from people with minor health conditions is driven by the expectations created by

⁸⁴ Hacking (2006) refers to this as the process of “making up people”

previous applications of the DG category, which communicated an idea of what disability “is” that has been hard to change and which creates ongoing confusion about eligibility criteria. This provides an example of how street-level bureaucrats’ categorising work can influence and reconfigure power relations, social identities and ideas about deservingness as they interact with citizens (Yanow, 2003).

In highlighting these forms of contestation, I demonstrated that DG assessments are a dialogical and contingent process - a space of resistance as well as disciplining and control by the state. The agency of claimants who resist and disrupt the DG assessment process and the ways in which doctors respond to this highlights power dynamics that are often overlooked by the street-level bureaucracy literature, which tends to presume that, as decision-makers, bureaucrats hold all the power in social relations at the frontline. This chapter showed that the ways in which citizens understood eligibility criteria and utilised the DG system as a poverty alleviation mechanism shaped the system from below, putting pressure on doctors and the system more generally. Therefore, contributing to the work of policy feedback theorists like Moynihan and Soss (2014), this chapter concludes that it is not only the agency of street-level bureaucrats, but also the agency of the people who are the supposed targets of policy that can shape its implementation. This means that they are also active in the process of ‘making’ policy and that their actions are an important part of the feedback loop that informs further policy development (as shown in Chapter 2). This is also an important contribution to recent efforts to include the perspective of clients in street-level scholarship.

The case of the DG demonstrates the importance of considering how the macro-level environment shapes street-level work, something only recently recognised as important by those applying the concept of street-level bureaucracy to their work (Rice, 2012). In this thesis, I have shown how claimants and doctors are embedded in a wider net of political, social, cultural and economic factors. This includes their individual social positions, race and class, but also the actual economic, political and social realities of South Africa. By paying attention to historical and structural issues, this thesis also makes a contribution to the policy implementation literature by showing how street-level action is shaped by the broader socio-economic and policy environment and how the outcomes of street-level action feed back into the policy development process.

In highlighting some of the deep ethical conflicts and moral stresses that doctors face in their work, this thesis contributes to work that focuses on the moral agency of street-level bureaucrats (Maynard-moody & Musheno, 2003). When facing individual claimants, doctors

often felt the urge to help them with their often severe financial and social problems and the grant was one way of doing that. This puts them in the position of breaking the rules or distancing themselves from patients in a way that makes it easier to avoid making difficult decisions.

*The truth is doctors, yes we're supposed to be so Hippocratic and **the truth is important, but it comes second to helping people and so you get in these fixes.** This is the problem: when you've got that many people going hungry - to expect people who are paid to look after people to then make decisions around whether they get food or not...it's not a good position...it's not going to work. (Wright, interview, 2014 April 8)*

This supports Maynard-Moody's citizen-agent narrative, which presents street-level bureaucrats as moral agents that respond to individual need and worth, making "micro-justice decisions" (Maynard-moody & Musheno, 2000, 2012). Adding to Maynard-Moody and Musheno's work I would add that through their clinical framing of disability we can see how doctors are also *professional agents*. They are not just caught between the state and their humanity, but between what they feel they need to do to be a 'good' doctor and what they are asked to do as bureaucrats of the state. In trying to carry out their role as physicians, bureaucrats of the state and moral agents, doctors face a dilemma because the gatekeeping work they are asked to do is "antithetical to the requirements of the social role that he or she occupies" (Zacka, 2015: 8). As a result, they become caught in what Zacka (2015: 26) defines as an "impossible situation":

As in the double bind, agents who are caught in an impossible situation face two injunctions that operate at distinct levels: one that requires them to act in a particular way ("implement this new law, or else you will be punished"), and another, more personal, that enjoins them to act in line with long-term moral commitments they have developed ("act as a good police officer would").

Street-level bureaucracy theory largely neglects the narrative of the professional in frontline work. Most of the existing research on street-level bureaucrats has focused on lower-level frontline workers who have some discretion in their work. Although the importance of professional values is mentioned in passing in much of the street-level bureaucracy literature, there has been little effort to theorise how professional ideas about the 'right' way of implementing policy colours the way that frontline workers carry out their work. By focusing on medical professionals - the archetypal profession - my work contributes to efforts to extend street-level bureaucracy theory by demonstrating how more professionalised groups of workers navigate the interstices between professional knowledge and values and bureaucratic systems.

Although much of the work they do is bureaucratic, few, if any of the doctors in this study thought of themselves as bureaucrats or policy implementers. Treating doctors in particular would dislike being considered part of the SASSA system, very often positioning themselves against it or going out of their way to avoid participating in it. The work of doctors in DG assessment shows how important professional identity, status and a strong association with a set of professional values, knowledge and codes of conduct is in shaping street-level action. One of my main findings was that although some doctors found it easier to just directly apply SASSA's guidelines, many doctors strongly valued their own professional opinions over SASSA's recommendations and gave them priority in their decision-making. As I showed in Chapter 6, when doctors framed the disability problem in clinical rather than bureaucratic terms, their ideas of eligibility conflicted sometimes conflicted with formal policy, which drove policy divergence (Hupe and Hill, 2003, Bergen and While, 2005). In addition, the discomfort that doctors felt in their role as DG assessors showed that street-level workers' sense of professional purpose and feelings of obligation towards patients might not easily be ceded in the face of new rules and public management initiatives.

The case of the DG also shows how efforts to rationalise expert judgement and professional judgement to increase accountability may not be effective. This study calls into question the ability of guidelines and rules to achieve goals of distributive justice when the daily practice of professionals like doctors requires a more pragmatic and tacit kind of thinking (Schön, 1983). Efforts to rationalise the assessment process and police it from the top-down do not take the normative aspects and complexities of doctors' reasoning into account and only obscure the actual logic that doctors employ when making decisions (Meershoek et al., 2007; Eikenaar et al., 2015). Rather than enforcing rules and processes that doctors are likely to find unhelpful and ignore, this study highlights the need to create opportunities for multidisciplinary engagement with and contribution to assessment guidelines⁸⁵, greater opportunities for peer interaction and discussions on the challenges of disability assessment and greater transparency about oversight processes. In short, in order to encourage doctors to cooperate better with SASSA, they need to be engaged with as professionals and not just as bureaucrats.

However, as the case of the DG shows, despite their professional values, doctors may still

⁸⁵ To the credit of the Western Cape SASSA office, they have made several attempts at this but they have limited capacity to actually develop or implement any new guidelines or policy as these are national-level functions.

make biased or moralising decisions that may not be addressed through greater engagement with SASSA. Perhaps this is because disability assessment work itself is not sufficiently professionalised and doctors' lack of training and expertise in this area leads to unprofessional behaviour. However, as the literature on the work that doctors do in other settings, especially resource constrained settings like the SA public health system, has shown, unequal treatment of patients or breaking rules to benefit patients is common and unlikely to change until there is radical improvement in the health system.

The disjuncture between the design of DG policy and its actual application on the ground not only reveals the limitations of the DG system and the medical model of disability, but also fault lines in social policy to address poverty and inequality and integrate disabled people into society. If the meaning of disability exists in relation to the "normal," the administration of the DG not only raises questions about how to define disability but also of what the definition of "normal" is. As this study has shown, the state's distinction between the deserving disabled and undeserving non-disabled does not necessarily reflect either community or individual understandings of suffering and rights to social security or doctors' understandings of disability. This not only creates potential for doctors to stray from official policy and guidelines, but also brings into question the boundaries between physical and other types of disadvantage and marginalisation. The categorical targeting of people with physical impairment for social assistance may not necessarily be viable or appropriate in a context where large numbers of people are unemployable (and therefore impaired by) social and economic factors and also in need.

The fact that the sickness and disability become desirable in this context creates a perverse reversal of values and norms around health. Using the disability category to gain access to an income and soliciting compassion from gatekeepers in the hope of being the beneficiary of a humanitarian act or compromising one's health in order to qualify for a grant is an undesirable and uncertain way of achieving economic inclusion, especially when one's performance of disability has to be re-enacted every six to twelve months. Although it has become more difficult to acquire a grant in this way, in the Western Cape, where no referral from a treating doctor is needed to book an appointment to see a SASSA assessor, many people still apply for the DG out of desperation. Doctors and OTs involved in this study repeatedly highlighted the need to educate people about eligibility criteria. However, whilst this is certainly necessary, it does not remove the underlying reason for people applying, nor does it deter people who have nothing to lose from 'trying their luck'.

The state has focused on reducing medical discretion and tightening eligibility criteria, but this cannot solve the bigger social and economic problems reflected by the demand for DGs and the inability of people receiving grants for temporary illnesses to graduate from grants into employment. This shows that regardless of how disability and chronic illness are defined or measured, the conversation on how to incorporate people whose participation in society is limited by their physical capabilities cannot be separated from a wider conversation about poverty in South Africa. With the labour market unable to absorb large numbers of unemployed people who are poorly educated and without adequate protection to support everyone living in or at risk of falling into poverty, the DG system will continue to serve a purpose for which it was not originally intended.

This thesis has engaged with a practical problem that requires real policy solutions. Although the best solution to these problems would be to create more stable jobs, this has proved difficult. Bearing this in mind, I highlight a number of policy solutions that have been suggested (beyond just top-down control), that may be useful in thinking about how the social grant system could be reformed to promote social and economic inclusion.

One set of possible policy options focuses on the systemic pressures underlying the administrative problem of targeting and proposes extending benefits to other groups. The best-known of these proposals is the Basic Income Grant, which would be a small monthly cash transfer offered to all South Africans, which would relieve the poverty-driven pressure on the DG system. This policy was proposed in 2002, but after much public debate and strong resistance from the government, it was eventually abandoned. As I showed in Chapter 2, similar attempts to introduce a Chronic Illness Grant also failed, although many (including doctors in this study) still feel that these would be useful in supporting people to manage their health conditions.

In general, the state has been very resistant to extending the social grant system outside of existing categories. This may, however, be changing and the Department of Social Development's most recent Strategic Plan (2015-2019), includes the development of a policy to expand social security to people with chronic conditions, who are excluded from existing DG policy as a high-level strategic objective. This would form part of a series of other planned policy initiatives that include: providing income support for the working-age population; a guaranteed employment scheme; mandatory cover for retirement, disability and survivor benefits; inclusion of informal sector workers in social security provisioning; universalization of the CSG and OAG; and increased social assistance for orphans and

vulnerable children (DSD, 2015). How the Treasury will respond to these plans given current slow rates of economic growth and other pressing demands on the budget remains in question.

Another set of options involves finding ways for people with disabilities as well as the people with manageable illnesses or injuries who could technically work, but struggle to compete in a very tight labour market, to become part of the economy in some way. There are very few opportunities for re-skilling people, especially older people, to participate in the workforce in different ways. Although the Employment Equity Act of 1998 requires that employers use affirmative action methods to create equal opportunities for disabled persons within the workplace and sets quotas for disabled people within certain sectors, these are seldom filled⁸⁶. The *Code of Good Practice: Key Aspects on the Employment of People with Disabilities* (DoL, 2015) further states that employers should attempt to accommodate employees who are or become disabled by adapting their work role. However, in reality, it is very difficult for people with disabilities with low levels of education to find or keep employment in the open labour market and workers are often dismissed or, if they are lucky, ‘medically boarded’⁸⁷, when they are no longer deemed able to perform their regular work duties.

Despite public declarations about the need to include people with disabilities in the economy from the Department of Social Development, there is a large amount of policy evaporation in this area. Disability rights activists have argued that the government’s spending on DGs comes at the expense of making more meaningful efforts to include disabled people in the labour force and society in general (Gooding & Marriot, 2009). More supply-side efforts are needed to create work for people with physical limitations. The DG has historically been compensatory, targeted at people who cannot work, rather than having any developmental aspects. Whilst providing this type of support is important, it does not align with societal shifts in understanding disability and disabled people’s place and role in society. Linking re-training and employment programmes to the DG would provide opportunities for people, especially those caught in a cycle of re-applying for temporary DGs, to find work. Involving other professionals who understand vocational and rehabilitation issues (e.g. occupational

⁸⁶ Neither the private sector nor government agencies have been able to meet the 2% employment quota laid down in employment equity policy. In 2013, only 0.9% of formally employed people were disabled (Commission for Employment Equity, 2014).

⁸⁷ Employees part of provident or pension funds dismissed because of incapacity may be effectively placed in early retirement and receive disability benefits from the fund.

therapists) more substantively in the DG process, would not only make it easier to make decisions on claimant's actual employability, but provide greater opportunities for linking people to opportunities outside of the DG system. This will require collaboration between government departments to coordinate other existing programmes such as the Expanded Public Works Programme and the work Sector Education Training Authorities and Job Centres.

Ideally, efforts to link people to the labour market and more accurately assess discretion would be combined with efforts to create a more comprehensive social protection system. Applications from large numbers of ineligible people cost the government significant money and a more comprehensive safety net would take the pressure off the DG category. This would free up resources to develop a better-targeted DG programme that provided more comprehensive support to people with long-term disabilities, linking them to other programmes, services and job opportunities.

While this study has shown that tools and definitions alone cannot fix the underlying problem of disability, it has also demonstrated that the current model of assessment is seriously inadequate. A multidimensional assessment tool like the Harmonised Assessment Tool, which provides a comprehensive model for assessment and can take functionality or employability into account would reduce the discretion and uncertainty that doctors face in their assessment. Combined with other bigger policy interventions it would reduce both exclusion and inclusion errors.

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APPENDIX A: Reflections on the research process

Gaining access to the field is an incredibly important part of the research process, not only because it is necessary to obtain information, but also because the form and quality of access establishes what information is available to researchers. Gaining access to do ethnographic work and recruiting research participants is also one of the most time consuming and difficult aspects of conducting research (Smith, 2001). According to Feldman, Bell and Berger (2003) gaining access requires persistence, flexibility and luck as well as interpersonal skills.

A SASSA Disability Management Unit (DMU) official was helpful in identifying a number of doctors that were directly contracted to the Western Cape regional office, who I was able to interview and gain an initial idea of how the system worked and obtain permission to observe them at work. After this, doctors were largely selected to participate in the study based on where they worked.

Although I was fairly familiar with the basic healthcare system in the Western Cape, making choices about what sites to select was challenging and was complicated by administrative factors. Acquiring access to clinics, hospitals, specific hospital departments and the healthcare personnel that worked in these facilities, required navigating the bureaucratic structures of and engaging with personnel from SASSA, the Western Cape Department of Health and the City of Cape Town, which managed some clinics in the metro (or in some cases, part of a clinic). Tertiary hospitals are managed by Speciality Services in the Western Cape and have their own procedures for managing research requests. This meant that after obtaining ethical approval for the study, I had to submit separate research proposals to four different administrative bodies. In the case of primary and secondary level facilities, my requests to work at specific clinics were relayed to the relevant district or metro substructure managers who then decided whether or not the research could be feasibly carried out in these facilities and in some cases my requests were rejected. I then needed to secure access through the relevant sub-structural manager and then manager of the specific facility concerned. My ability to work in a clinic therefore depended on managers' perception of the usefulness of the project, the willingness of the district or substructure manager to host a researcher, the capacity of the clinic to host a researcher, the presence of a disability grant doctor in the clinic (which was often unclear before beginning the process), doctors' willingness to participate and the signed consent of individual patients.

The process of gaining access to doctors working in hospitals was similarly convoluted. As

well as obtaining permission from the hospital manager, I had to approach department heads to gain access to clinics and doctors. Often the head of department or a specific clinic would decide or suggest which doctor I should work with. Whereas in the primary care settings DG doctors only saw patients applying for disability-related grants – DG, Care Dependency Grant and Grant-in-Aid - in hospital settings many patients were already receiving DGs or were not applying for DGs. This meant that not all interactions I observed involved an actual grant assessment. It was nevertheless helpful to get a sense of how doctors and patients interacted when the DG was not involved.

The initial research design of this study was focused on developing case studies of the work of ten to twelve doctors, selected based on factors such as gender, race, contractual relationship to SASSA and their approach to disability grant assessment, but this proved impossible from a practical perspective. Permission to access the various clinics and hospitals in the Western Cape is not centralised and I could only obtain access to doctors' information once I had proof of my right to work within the clinic or hospital department concerned, which typically took several weeks. While I had hoped to spend time with fewer doctors of longer periods of time so that they would grow more accustomed to my presence, this proved logistically difficult in many cases. Doctors working for SASSA generally worked at multiple clinics and in most cases there was only a doctor at a specific clinic once or twice a week, sometimes only every two weeks. However due to the permission process, I was unable to move between clinics with doctors who had agreed to work with me, except in one case where the same doctor worked at two clinics that I had already coincidentally obtained permission to work at. Gaining permission from individual patients and having them sign formal consent forms could also be disruptive and, given how busy doctors were in both clinics and hospitals, two days of observation seemed to be the maximum period of time doctors could reasonably tolerate.

Data collection at De Waal hospital varied from the other two hospitals. I met with the head of the social work department and we decided on the most appropriate form of data collection in this specific hospital, which served patients with intellectual disability and psychiatric disorders. A multi-disciplinary team that involved psychiatrists, nurses and social workers made the majority of decisions about disability grants in this hospital, except in the outpatient unit, where psychiatrists made the decision independently. Given the nature of psychiatric consultations, observing doctor-patient interactions in this setting would not be appropriate. I therefore interviewed a psychiatrist who worked in the outpatient unit and conducted a focus

group with social workers from across different units at the hospital and another one with nurses. In August 2014 I presented my provisional research findings to a larger group of social workers at De Waal, who provided further useful input on the study.

I also interviewed social workers at the other two hospitals and an occupational therapist at the work assessment unit at Whitney Hospital and two occupational therapists from the work assessment unit at another hospital (Marais), where I did not conduct any other form of data collection.

Ethical considerations

The aim of the study and goal of this study was **not** to focus on experiences of, or the physical nature of disability or illness, or the medical histories of patients. Rather, it was to explore how the opportunity for income through the disability grant was seen and negotiated in an environment where opportunities for formal employment are limited and unemployment insurance and support is minimal or non-existent. However, as the study was carried out in medical facilities, I was required to obtain ethical consent from the University of Cape Town's Health Research Ethics Committee.

Healthcare personnel and government officials participating in the study all provided their consent to participate. Some SASSA staff preferred to remain anonymous, but the remainder of interviews with government officials were conducted on the record. All interviews and focus groups with healthcare workers and all patient interactions were conducted on the condition of anonymity. To this end, I have used pseudonyms when referring to any patient, doctor or facility and have avoided using any personal identifiers or other information that might reveal the identity of any participant. Power-relationships in healthcare settings are often unequal and it was important to obtain patient's consent to observe what is typically a private interaction between them and a doctor in a way that minimised any perceived pressure to participate. In order to avoid this, I introduced the study to the patients as they sat lined-up in the corridors waiting to be seen by the doctor, when they were in a large group rather than in the room with the doctor and myself. I would explain the study to patients and answer any questions they had, either about the study or other social-grant related questions. During this time I reinforced the fact that their disability grant applications would not be influenced at all by either their participation or decision not to participate in the study. I also provided a consent form and written description of the study and then left them with pens, allowing them to make the decision to sign the forms in my absence. This allowed them to

make the decision about whether to participate prior to entering the room. The consent form and study description had to be modified when I began working in hospitals because not all patients were applying for disability grants. In order to avoid influencing the nature of the doctor-patient interaction by introducing the idea of disability grants, I explained the research as a study of doctor's decision-making rather than a study focused specifically on the disability grant.

Data Analysis

Atlas.ti, a qualitative data analysis software package was used to manage the data collected and to identify themes in data by first breaking it down into codes which were categorised and then linked together during the process of analysis. I used this approach to analyse interviews, field notes and hundreds of pages of parliamentary minutes and Hansards. Using this software was particularly useful in that it allowed easy access to small pieces of data but preserves them within the larger context of documents or interview notes being analysed.

Reflections on the research process

Mechanic (1989) writes that qualitative researchers, who use themselves as a research instrument, must calibrate themselves. He argues that the way we make sense of and organise observations is a construction of the researcher's social biography. The subjectivity that is inherent in qualitative research, makes it important to engage in reflexive practice. It is also only through reflexive practice that more junior researchers like myself can learn to navigate the ethical and practical realities of fieldwork.

As part of this reflection I have taken detailed notes, not only of my time in clinics and hospitals, but of all my experiences conducting interviews, informal conversations and meetings and experiences of gaining access that have shaped my understanding of the disability grant system. Note taking also helped to guide and focus the research process in a way that allowed me to build concepts rather than a collection of colourful quotations. I have also provided detailed accounts of my research methods and findings and consulted the literature in my area of focus to learn from the methods others have used. Qualitative research is less a process of capturing data than an interaction between people, through which very specific and contextual information will emerge. This often means that entering the field requires the re-evaluation and adaptation of research strategies. In this section I acknowledge and consider the 'throwntogetherness' (Fraser, 2012) of research by reflecting on my fieldwork experience.

Although I adopted a non-judgemental approach in my observations, it is impossible for me, as a social actor, to claim that I was totally objective in my data collection or analysis. Like the doctors who interpret DG cases, my own social biography and position influenced how I framed or ‘made sense’ of the data I collected in the field. My own social democratic political beliefs and views on the social security system in South Africa perhaps made me more biased towards doctors who took a more sympathetic approach to claimants. My attempt to understand the perspectives of doctors whose views differed from my own is what initially led me to the idea of framing.

Although I have had many conversations with patients in the passageways and consulting rooms of clinics and hospitals, in this PhD research I largely positioned myself on the doctors’ side of the desk. This research therefore cannot provide a new account of patient motivations or understandings of desert, except as doctors and I have interpreted them. This research can, however, reflect on how doctors and patients enact their roles, how doctors interpret and react to patient’s actions, what this means for the doctor-patient relationship and how doctors ultimately reach decisions. I acknowledge that although I observed the doctor-patient interaction, I was positioned closer to doctors than patients in this study, which may have introduced a certain bias to my perspective, but I hope that this was countered somewhat by my previous experience working with disability grant claimants (Kelly, 2012).

As Simpson (2006) has observed, research can be a messy and there were a number of reasons why my research did not go to plan. Firstly, I had hoped that could be an invisible observer in the assessment and that doing this repeatedly over time would reduce the effect of my presence in the room and the effect of any observer bias. In fact, I ended up working with twice the number of doctors I had anticipated for only one or two days, because I soon realised that it was more difficult for me to disappear than I had hoped and I felt that this made my presence in the room burdensome to doctors. As a result, I only ended up doing repeated observations with four doctors.

There were a number of reasons why my presence in the observation was more noticeable than I had hoped, all of which were logistical. In order to observe their consultation with the doctor, I needed to obtain signed consent from individual patients. Although I explained the study to patients outside of the room and many of them signed them, very often I needed to re-explain the study to them. This meant that my presence added time to the doctor’s consultation and I was very conscious of this, especially in PHC settings where doctors had dozens of patients to see. The consultation rooms were small and I often needed to move

around to accommodate patients and the family members that often accompanied them – sitting on beds, stools or standing where necessary.

A large part of the assessment involves reviewing folders and tests and filling out forms and this meant that I would either have to sit directly next to the doctor to see what they were reading or writing or would have to explain their decision-making to me afterwards.

Although I told doctors that I was only there to observe, often doctors would often also talk to me during the consultation, sharing information with me about what they were doing and what they were considering. Doctors would also often start talking to me about claimants as soon as they left the room and I quickly learnt that probing doctors about their decision-making at this point was a very effective way of understanding how they made decisions in a concrete way and this often segued into deeper conversations about their experiences as assessors. This, however, made it made me difficult to disappear.

It was also not unusual for there to be other people in the room, especially in hospitals where medical students, interns, registrars and consultants all collaborate and new people came into the room either to seek or give advice and my presence was then explained. This often led to impromptu conversations about the social grant system, which were useful. Patients would also sometimes address me directly during the consultation, looking to me for reinforcement or support especially when doctors were consciously ignoring them.

Although medical doctors are generally supportive of and interested in research (and are often researchers themselves), they are also busy professionals and this limited the length of time I was able to sit and observe their work. Initially some doctors were sceptical about me observing them, but commented after the experience that they had found it less intrusive and more interesting (as a form of self-reflection) than they had expected. Where I could, I made myself useful by assisting doctors with small tasks or with their paperwork.

Language and knowledge barriers

All study information and consent forms for the study were made available to participants in English, isiXhosa and Afrikaans. I explained the study to potential participants in Afrikaans and English, but because my ability to speak and understand Xhosa is quite limited, other clinic staff had to assist me in explaining the study to Xhosa-speaking participants. These informal translation arrangements are very common in clinics but are far from ideal as I was unable to understand exactly what had been explained to patients, but the written study materials were useful in this regard and I was able to field any other questions. There was

however usually one person who spoke English and isiXhosa I spent one day observing a Xhosa speaking doctor assessing Xhosa-speaking patients in a clinic in a township area with the doctor providing a synopsis of the assessment in English after the patient which provided useful material for discussion, I was not able to understand what patients were saying in any real detail. Observing the differences in the structure, length and tone of the conversations held in Xhosa with those held in the patient's non-native language were also very useful from a comparative perspective.

Researchers with health expertise are perhaps able to assimilate into these settings more easily by taking on the role of a doctor or a nurse. Although not a major challenge, my lack of medical training limited my ability to interrogate the medical eligibility of patients. By familiarising myself with SASSA's medical guidelines, the medical literature on disability assessment and gradually developing a basic medical vocabulary helped to overcome these challenges somewhat. My layperson status also had advantages as it broke down any anxiety they may have had at being assessed or judged by me.

Research quality

Given the qualitative nature of this study, I was concerned more with context and meaning than inference and generalization. I have used Lincoln and Guba's (1985) four criteria for evaluating qualitative research (*credibility, transferability, dependability and confirmability*) reflect on the quality of this research.

The credibility of qualitative research generally refers to how congruent findings are with reality and is key to establishing the trustworthiness of findings (Merriam, 1998 in Shenton, 2004). Key to establishing credibility is the degree to which the sample group represents the overall population under consideration. As discussed previously, difficulties in recruiting people resulted in looser forms of recruitment than I initially envisaged.

Also important is how representative my research was of reality – whether I had captured the whole picture and the complexities of the disability grant system. I have tried to achieve this by keeping my analysis strongly grounded in the data collected, by triangulating findings with other sources of data, and by including people with multiple perspectives on the system. Using overlapping methods (Lincoln & Guba, 1985) in the form of both interviews and observations allowed me to reflect on the differences between what actors said they did and how they actually behaved. Through presentations and papers, I have shared my findings, with the Disability Management Unit at SASSA as well as the General Manager of SASSA

Western Cape who were comfortable with my presentation of the DG system and found the results useful to their work.

However, it should be noted that the small sample size and non-random sampling method present limitations to the study in terms of the transferability of research findings⁸⁸. In addition, limiting the study to the Western Cape, which has quite a different system to other provinces, reduces opportunities to generalise findings to the rest of South Africa or make comparisons between different environmental contexts or the implementation of policy across provincial departments. However, by providing a large amount of background context and grounding findings in existing literature, it is hoped that the findings of this thesis can be transferred to other contexts.

Dependability is closely linked to credibility but focuses more on what quantitative researchers would consider to be the *replicability* of the study. Whilst I have attempted to reflect extensively on my research methods, as discussed above, the research process was driven heavily by contextual factors (where doctors worked, their position within the hospital) rather than an easily repeatable process. Although through rigorous research practice we can approach a valid understanding of the world, ‘all knowledge is contextual and partial and perspectives are always possible’ (Altheide & Johnson, 2011: 581-582).

⁸⁸ This corresponds to the quantitative concept of external validity

APPENDIX B: List of research participants

1. Description of medical doctors involved in the study (pseudonyms)

	Pseudonym	Description	Contracted to	Type of facility	Specialisation	Data collection
1	Dr Jacobs	Coloured, 50s, male	SASSA	Community Health Centre	Occupational health	Interview
2	Dr Vrede	Coloured, mid-30s, female	SASSA (previously agency)	Community Health Centre	GP (interest mental health)	Interview, 2 observation sessions
3	Dr Soet	Coloured, mid-30s, female	Agency	Community Health Centre	GP	Interview, observation session
4	Dr Kewasi	Congolese, mid-30s, female	Agency	Community Health Centre	GP	Interview, 2 observation sessions, DG training
5	Dr Du Toit	White Afrikaans, 40s, male	Agency	Community Health Centre	GP	Interview, observation session
6	Dr Brown	White, 60s (retired), male	Agency	Community Health Centre	Forensic medicine and former district surgeon	Interview, observation session, interactions at SASSA training
7	Dr Taylor	White, early 30s, male	DOH	Tertiary	Orthopaedic surgery	Interview, observation session
8	Dr Donaldson	White, early 30s, male	DOH	Tertiary	Neurosurgery	Interview, observation session
9	Dr Elster	White, early 40s, female	DOH	Tertiary	Neurosurgery	Interview, two observation sessions
10	Dr Harvey	White, early 30s, female	DOH	Tertiary	Cardiology	Interview, two observations sessions
11	Dr Richards	White, 50s, male	DOH	Tertiary	Neurology	Interview
12	Dr Isaacs	White, 40s, female	DOH	Tertiary. Also runs paediatric community clinics	Infectious diseases - mainly HIV	Interview, observation session
13	Dr Wright	White, 40s, male	DOH	Psychiatric hospital	Psychiatry	Interview, no observation
14	Quality assurance officer	Indian, 60s, male	SASSA	N/A	Quality assurance officer	Interview
15	Dr Naidoo	Indian, early 30s, female	DOH (now left)	District hospital	Infectious diseases	Telephonic interview

16	Dr Marais	Male, 40s/50s, white	DOH	District Hospital / Tertiary	Orthopaedic surgery	Interview, observation
17	Dr Malik	Coloured, late 30s, male	DOH	District hospital	Infectious diseases	Interview
18	Dr Bhele	Black, 40s, female	Agency	Community Clinic	GP	Observation, interview
19	Dr Haddid	Muslim, 76, male	Agency	Community Clinic	GP	Observation, interview
20	Dr De Villiers	White, 50s, male	DOH	Community Clinic	GP	Observation, interview
21	Dr Rahman	Muslim, 40s, male	Agency / DoH	Community Clinic	GP	Observation, interview
22	Dr Bury	White, 70, male	SASSA	Community clinic	GP	Observation, interview
23	Dr English	White, 50s, male	DOH	Hospital	Infectious diseases	Interview
24	Dr Kruger	White, male	SASSA	Community clinic	GP	Email

2. Description of other health professionals included in interviews or focus groups

Hospital	Description	Type of hospital	Department	Data collection
Whitney Hospital	Coloured, female, 40s	Tertiary	Social work	Interview
Whitney Hospital	Coloured, male, 40s	Tertiary	Social work	Interview
Whitney Hospital	Coloured, female, 20s	Tertiary	OT - Work Assessment	Interview
De Waal Hospital	Coloured, male, 40s	Psychiatric hospital	Social work - Intellectual disability	Social worker FG
De Waal Hospital	African, female, 30s/40s	Psychiatric hospital	Social work - Forensic psychiatry	Social worker FG
De Waal Hospital	White, female, 30s/40s	Psychiatric hospital	Social work - General Psychiatry	Social worker FG
De Waal Hospital	Muslim, female, 50s	Psychiatric hospital	Nurse - Forensic Psychiatry	Nurse FG
De Waal Hospital	Coloured, female, late 30s	Psychiatric hospital	Nurse - General psychiatry	Nurse FG
De Waal Hospital	Coloured, female, 50s	Psychiatric hospital	Nurse - General psychiatry	Nurse FG
De Waal Hospital	African, female, 40s	Psychiatric hospital	Nurse - Intellectual disability	Nurse FG
Work assessment Centre	Coloured, female, 30s	Tertiary	OT - Work Assessment	Interview
Work assessment Centre	Coloured- female, late 30s	Tertiary	OT - Work Assessment	Interview

Welgemoed Hospital	Female	District hospital	Social Worker	Email
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3. Interviews and correspondence with government officials and disability experts

Participant	Position
Thomas Ongolo	Programmes Manager African Decade of Persons with Disabilities
Margie Schneider	University of Cape Town – disability expert
Irmgard Marais	Western Cape SASSA DMU
John Marite	Former General Manager of Disability SASSA
Selwyn Jehoma	Former Deputy Director General Social Security DSD
Nomfundo Sasa	Western Cape SASSA DMU
Yogan Pillay	Deputy Director General Department of Health
Dimakatso Poee	Director Disability and Old Age Grants DSD

APPENDIX C: Additional interview quotations and field notes

- 2.1** *Households that are in receipt of social grants are more active in job searches and go onto start survivalist and small enterprises. The income security and predictability that the social grants provide also allow households to take risks to augment their overall income. Teenage pregnancy has been on the decline in South Africa for more than a decade. The view that South Africans struggled to free their country and themselves from racial discrimination and are now not interested in building their country but want to lie down and laze in the African sun and wait for government to give them free handouts without them lifting a finger is indeed a disturbing, unfortunate and untrue one. (Skweyiya*
- 2.2** *What happened was that the health professional was confronted with the poverty of the patient. Even if the patient was not disabled from a medical point of view, some doctors would declare him/her disabled so that he/she could access a grant (Unnamed Social Development Portfolio Committee Member, 2010)*
- 3.1** *A middle-aged woman then came up to me asking about her grant – she was assisted by a man who helped to translate. She was waiting for the doctor because she had made an application in October/November but not heard anything from SASSA (it is now January) and wanted to find out from the doctor what had happened. I asked her if she had a slip for an appointment from the doctor but she did not. I tried to explain via the translator that the doctor could only help her if she had a slip and that she did not make the decisions or do the administration for the grant – it was SASSA’s job and she would need to take it up with them. Not sure how much was understood but she did end up going anyway. There seems to be a lot of confusion around the appointment system – obviously people know when the DG doctor is in but don’t understand that it works centrally through SASSA (Field notes, 17 January 2014).*
- 4.1** *The person will say that they are in pain but you can give them test like the ramp and the stairs to do...which are physical tests, but then they will have no indicators of pain. Their facial expression will be the same, there will be no facial expression of pain, their body language will tell you they are not in pain but they will SAY they are in pain about everything they are doing, they are still doing it underneath the normal times taken and they are not using the railings, there's no abnormal gait pattern - those type of things and then you can also see if they know that we are testing them they will excessively walk slower, much slower, on the stairs and then we'll record the time but they don't realise that we are still assessing them during tea and lunchtime. (Occupational therapist, interview, 2014 April 23)*
- 4.2** *In the ward you’ve got a whole team of people and it’s quite evident whether or not someone is disabled because your patients are seen by physiotherapists, occupational therapists and speech therapists attached to the ward. It’s not too hard to make that decision by the time they are due to be discharged. (Dr Richards, interview, May 2014)*

- 4.3 *“Sometimes the clever ones lie and say that they were given enough pills to last three months. In these cases he tells people, “You should perform the same miracle on bread and fish.” (Dr Haddid, field notes, 22 July 2014)*
- 4.4 *Dr Vrede usually starts by reading through the file before engaging with patients and she notices that there is something in the file that indicates non-compliance. She asks the patient whether she is attending her [treatment] club and the patient tells her that she is. She then asks her why she is applying and the patient replies, “I am not working and I am suffering.” (Dr Vrede, field notes, Feb 2014)*
- 4.5 *You start asking yourself, “why, what is this treatment for?” and sometimes from the stories that they tell you, you can see that they know nothing about this treatment - it is probably borrowed treatment - so we have had to be vigilant in terms of how we go about and sometimes asking questions. You would ask them, “this tablet that you say is yours. I am accepting that you say it is yours. How do you take it?” and if the person gives you a totally wrong dosage intervals for that so that you would know that they don't know this treatment - they cannot be taking that high, you know. (Marite, interview, 2014 June 27)*
- 5.1 *Is it good medical advice or is it bad medical advice – that's got to be shown by your behaviour as a doctor, but the form doesn't help you do any of that because none of that is allowed. You're not entitled to write what you think - you've got to write what **they** think...The person who sits here is the person who needs the disability and you the doctor have to decide. Now either you are able to do that or you are not and that is based on experience. I mean I had 20 years as an occupational health...workmen's compensation stuff - that's a lot of experience. (Dr Brown, interview, 2014 April 4)*
- 6.1 *It is about employability, but it's for the open labour market, not for sheltered labour, so many people can still...a person with a chronic back problem, he can sit down, he can do office work, but I do not know what is the education level of the patient and it's not necessary because there it is on the form [points to form] “open labour market.” That is important. That is the thing I discovered a long time ago. It says, “Does it affect the client's ability to enter the open labour market?” So in other words, I can say “this and this patient is okay for this type of work or that office work, clerical work, but not fit for physical labour...but it is OPEN labour market, so we do not distinguish.” (Bury, interview, 2014 July 22)*
- 6.2 *Are you encouraging people not to work? But you also see people that people in South Africa are somehow lazy and not interested in work – you see young people. r Bhele, Field notes)*
- 6.3 *Grants should be made available to those deserving and more of them should be getting them and those non-deserving ones should be taken out of the system. It's been open to abuse. (Quality assurer, interview)*
- 6.4 *She says it's the same with the child support grant and people that leave their child the grandmother and use the money from themselves. But she is very clear in saying that it's not everyone – in every system there is abuse but there are people that also*

really need it. (Dr Bhele, interview)

- 6.5** *Because you see that sister [referring to a nurse who is assisting her with her paperwork] she is also sick – she has high blood pressure. I tell the people “she is almost 56/57 but she is sick and she is still working, you see. So you must try to do something, you can’t be lazy.” [Laughs](Dr Kewasi, interview, 4 February 2014)*
- 6.6** *And quite often those people who have never worked...they say I've never worked"- how can you apply for a disability grant when you're 56 or whatever and if they have family to look after them then they don't really need the grant, especially if they've never worked [chuckles]. No, if someone has been looking after you for years - for many years - I don't think you deserve a disability grant because you're then not really disabled. (Dr De Villiers, Interview)*
- 6.7** *Well that's my impression, but it's very difficult if they've never worked before and you also have that feeling of like, “so you've never worked before, you've never earned any money, you've never contributed anything” and then it's difficult to know whether they just haven't contributed anything or they just can't find work... like do you know what I mean? Life is hard, you don't know. (Dr Harvey, Interview, April 30)*
- 6.8** *A lot of patients in black communities are uneducated and come from the Eastern Cape, but this does not mean you can't work”, she says. We then talk about education and to what degree it should be considered. She doesn't have much sympathy for those who are uneducated and seems to think that people can do other kinds of work. She thinks differently if someone has certain skills (uses the example of a machinist that uses their hands) and then lost that ability to do that specific job and became “stuck.” (Dr Soet, fieldwork, 12 Feb)*
- 6.9** *Drug addiction is a real difficult one...like I mean, once a drug user, always a drug user and once you give them money sometimes it's enough of an initiation to start using again and it's very difficult to predict. But you can't punish them because...And I mean we don't really test...do drug tests...I can but again should you give the grant to someone who has chronic obstructive airways disease or emphysema from smoking? They continue to smoke - should you still give a grant? I have another lady who is tik-induced cardiomyopathy but she's got 5 kids, but she's never worked a day in her life - she's 28 and she's got not a great heart and medically she qualifies but how do I know for sure that she's not going to use, but it would make a real difference to her life if she could have a grant for her kids and for her well-being, but she's never actually worked before that so it's difficult...I don't know, I don't know the answer. (Dr Harvey, interview, 2014 April 30)*
- 6.10** *She says there are a lot of drug problems in the Muslim areas – “people who have fried their brains with drugs” She is very strict about these applications and does not give the grant unless the psychiatrist recommended it. “It is taking from others”. She will consider it if they have stopped using drugs and they have ongoing symptoms and the psychiatrist has said that they are not functioning.*
She tells me of a patient in his early 20s with MDR living in Bonteheuwel (coloured). She says that with MDR you usually get 1 – 1.5 years on the grant mainly because

they want to isolate you from the work environment. She said that he defaulted and came back very sick and restarted medication. She personally felt that she should not get the grant but she could see he was very unwell.. He also looked like a "drughead". She did not want to give him the grant but felt she had to but only made it 6 months. She says that you can't "let your personal bias come in". She said that if she saw him getting well she would probably not continue it. (Soet, field notes, 2014 February 12)

- 6.11** *He is as mad as a hatter! He obviously needs something, but not a disability grant. All he will do with a grant is go and buy drugs. (Dr Brown, field notes, 4 April 2014)*
- 6.12** *G: The one question that you seem to ask most patients is 'Who do you live with?' 'What are you trying to establish there with that kind of question?*
D: The thing is...I once saw a patient in Groot River and the sister there, the head sister she knew...she's been working there for a long time and she basically knew everyone and this lady came in for disability grant and she was nearing 60 and sister Fredericks said, But this patient, her children can look after her. We all looked after our mothers and fathers and so on'and that's obviously true you know. If I have a sick mother, I would look after her. If I have work and my wife didn't work etc. etc. and then she doesn't really need it. (Interview, Dr De Villiers, 2014 July 18).
- 6.13** *He has a problem with the grant-in-aid because he sees women coming in looking for the grant to compensate them for looking after their husbands. He thinks that this is part of one's marriage vows and asks me whether I would apply for a grant to look after my husband. He says that the argument they make is that they could be working but instead are looking after the husband but he says that the grant can also be used to pay for a caregiver and the woman could go work. He says that he often tells women this (he has a tendency to lecture claimants). (Field notes, 2014 June 11)*
- 6.15** *I tell him that I had noticed that he asks everyone their age, education-level, and work experience and I ask him how he takes this information into account. He says that he takes these factors into account in terms of the person's likelihood of getting a job. (Field notes, June 2014 11)*
- 6.16** *It's very well and good to say 'well actually you can get a job that isn't manual labour' but they're not really qualified to do anything other than that. (Dr Harvey, interview, 2014 April 15)*
- 6.17** *She says the main reason for applications is high unemployment. She sometimes asks patients if they have worked before and many of them haven't, even those in their 40s. (Dr Bhele, Interview, 2014 April 30)*
- 6.18** *...sometimes I think social circumstances do play a role - education level, you know if you, if you've got skills you can have a much higher level of pathology and still work than if you don't have skills. I mean some people - labourers - don't require a lot of skills either but the job market is very tight so...so ja, I do think about those things, I can't say that they don't influence. (Dr Wright, interview, 2014 April 4)*

- 6.18** *Generally it is not a problem if it's a labourer and the guy has gone to school until Std. 2 or 3 (Grade 4 or 5) and he can't work – he will clearly qualify for a grant. But if you get a guy with matric or any other sort of skill then generally it's a problem to give someone a permanent disability. Normally he will qualify easily for a TDG and we will encourage the guy to find some work. What I will also do in those cases is refer to an occupational therapist if there is any uncertainty but you'll find with some of these guys they are just on the grant all the time and you will try R1000 a month if you've got matric if you can't find you've got no choice but to just repeat it, but I have a problem giving them permanent. The guidelines are not very clear when it comes to that. (Dr Jacobs, interview, 2013 October 24)*
- 6.19** *I ask the nurse about the type of people that come to apply for the grant. She said that often the people come because they are over 50 and say they can't get a job because they are not 100% well. A lot of people re-apply after 3 months because they have no other options. (Field notes, 28 January 2014)*
- 6.20** *He shows me someone else's file and we talk about age – he says that lots of people in their 50s come to apply. Work is difficult to find and that work [that is available] is always given to a younger person with no record of illness. (Field notes, 9 June 2014)*
- 6.21** *Patient 16: Older lady. She is applying 6 months after her TB treatment was completed. She says that she was trying to sell things on the streets but she is tired, coughing and “not right for working” - she is quite emphatic about this. Doctor Vrede says to her “why do you come to me now once the TB is finished?” She asked her where her TB was and she says that it was in her glands. She recommended the SRD but no grant. After the patient leaves she says that with the older people who are too young for the pension but are not eligible for the DG she looks for something such as osteoarthritis, but if there is nothing then she will just give SRD (Field notes, 2013 October 24).*
- 6.22** *When it comes to age then it also becomes quite subjective. I am aware of how difficult it is for older people to find employment (even older doctors!) and I have seen colleagues have a low threshold to submit DG forms for a patient close to pensionable age. (Dr Taylor, email correspondence, 12 February 2014)*
- 6.23** *After the patient leaves Dr Soet tells me that this woman fell into a grey area. She is in that age category where it is very difficult for her to find a job. She does not look like she is actively drinking, but clinically she is not “sick, sick”. She says that she was looking for things wrong with her and that is why she had examined her joints – “normally in her age group they will have arthritis”. She says that there is a need to make her understand that she might not get the grant but she would give her the grant for combined TB/HIV just because of her age – she has not lost much weight (only 2 kilograms) and looks relatively healthy so if she has TB it is still very early. She adds, “When you are young you have more of an opportunity to find work”. (Field notes, 12 February 2014)*

- 7.1** *When asked by Dr Vrede why she is applying the patient says that she doesn't have a qualification and admits that it is difficult to find a job. She adds that she is married with three children, but has no husband and lives with her sister. (Field notes, October 2013).*
- 7.2** *He said that he had a boy in matric coming in recently to apply for the grant. When he asked him why he said that he was wanting money for his gran because his gran was having to look after him. When he asked him what was wrong with him he said "my little toe is crooked". He said the boy's intentions were good but that there was this complete misunderstanding of what a disability is. He says that people who have had an operation or a broken leg (even many years ago) think they must get the grant even if they no longer have symptoms – he says there is no understanding that the operation "fixed" them. He tries to explain that the reason they had the operation was to make them better and having an operation does not mean by definition that there is something wrong with you. (Field notes, 2014 June 9)*
- 7.3** *A big thing are limps - you really need to be very vigilant, sometimes limps change (sometimes the limp was in that leg and now it's in this leg) or things like we have a test where they need to pick up bricks and they say, "no but I can't pick up this brick" and we've had a couple and then they can pick up their bag, which was heavier than a brick, or you watch them walk and they have a good pace and then you put them in a test where they have to walk for 6 minutes and all of a sudden it's a tortoise, so those things...you pick up between your standardised tasks and your simulated tasks - the two don't match somewhere either you're doing something wrong or the patient is trying to... (Occupational therapist, interview, 2014 April)*
- 7.4** *She mentions that some people even default on their medication to get sick again – but according to the SASSA guidelines defaulting means no grant. She says that you can listen to the history of defaulting and if there is no clear reason why they have defaulted you can give them SRD, but not the grant. She says that this is a problem with epilepsy because people sometimes abuse alcohol or drugs that interfere with the effectiveness of their medication. She says she can see this from their file where the doctor has noted on a number of occasions that they have advised the patient to change their behaviour and they have not. She says that she also often tries to encourage them to stop. (Dr Bhele, field notes, 2014 April 30).*
- 7.5** *You'll get the people - the aunties or the older ladies who would say "I won't be able to do that" - so they've already got this perception of "I can't" and then when they do do it, it's like "[sigh], it's like so difficult." I also don't know if it's because of who they are, their perceptions of themselves like "I'm not good enough" and I think that it feeds into their motivation to eventually go and look for work because "I can't do anything". I've had 21 year olds come in here and say they need a disability grant because they broke their arm! So it's like for me it's like wow, it's amazing how people view themselves (Occupational therapist interview, 2014 April 25).*
- 7.6** *In reponse to a woman who was complaining about having to pay for taxi fare to go to Woodstock of an xray she says "People only like you when you give them the*

grant” People hold community meetings to complain about the doctors. (Field notes, 2014 Feb 12)

APPENDIX D: Medical Assessment Form

**MEDICAL ASSESSMENT:
DISABILITY GRANT.**

*Instructions on completing this form: Please write legibly and in capital letters
This form must not be handed over to Client
Mark with X where appropriate*

Part A: Clients's Particulars (To be filled by SASSA Official)

Form of Identification	ID	Other methods of Identification used				Male	Gender	Female
Identity Number								
Surname								
Maiden Surname								
Full Names								
Client's Contact No.					Alt no			
Local Office					Service point (if applicable)			

Assessment date	<input type="checkbox"/> D <input type="checkbox"/> M <input type="checkbox"/> J <input type="checkbox"/> K <input type="checkbox"/> F <input type="checkbox"/> S <input type="checkbox"/> A <input type="checkbox"/> T <input type="checkbox"/> R <input type="checkbox"/> Y	Purpose of Assessment (tick a box)		
		<input type="checkbox"/> 1st Application	<input type="checkbox"/> Re-Application	<input type="checkbox"/> Review
Highest level of education attained		Previous Occupation		

Part B: Details of SASSA official

Official's Name		Socpen user ID	
Signature		Contact no	
District		Assessment Site	Town

Part C: History & Confirmation of Impairment (To be completed by Medical officer) Attach relevent report (s) if available

Has the doctor confirmed the Identity of the client? Yes No If answer is no, state reason: _____

Presenting complaints: _____

Is the client receiving treatment? Yes No Where? Hospital Clinic If other specify _____

Type of intervention & compliance Yes Medical No Yes Surgical No Yes Rehabilitation No

Elaborate (Especially if surgical or rehab): _____

Relevant treatment given	Compliance		If no, elaborate
(a)	Yes	No	
(b)	Yes	No	
(c)	Yes	No	
(d)	Yes	No	

Part D: Examination/ Verification (Assessment of disability). Attach relevent report(s) & previous assessment form, if applicable

General Physical Appearance: _____

Vital Signs, if Applicable

BP		Weight		Height		RBG	
----	--	--------	--	--------	--	-----	--

	Functional Curtailment					Elaborate
	Very Serious	Serious	Moderate	Slight	None	
Cardiovascular	1	2	3	4	5	
Respiratory	1	2	3	4	5	
Neurological	1	2	3	4	5	
GUMetabolic	1	2	3	4	5	
Musculoskeletal	1	2	3	4	5	
Sight	1	2	3	4	5	
Hearing	1	2	3	4	5	
Mental condition	1	2	3	4	5	
Other specify	1	2	3	4	5	

Results/ Reports of Relevant Confirmatory tests/ Investigations (for scores below 1-3)

Diagnosis (evidence based) detailing Complications and prognosis

Is there activity limitation? Yes No If yes, with assisted device(s) Yes No

Elaborate (relate to benefits of assistive device(s))

Comments on referral clinical findings Agree Disagree Elaborate

Medical Reports/Relevant Confirmatory test (s) provided? Yes No If yes, specify

According to Section 30 of Social Assistance Act 13 of 2004 any person is guilty of an offence if he/she intentionally furnishes the Agency with false or misleading information. Section 31 of the same act states that any person convicted of an offence in terms of this Act is liable to a fine or imprisonment for a period not exceeding 15 years.

I hereby acknowledge that I was assessed by the medical assessor

Signature of client
 Thumb print of client

Part E: Recommendations

Identity number

Clinical Summary

Diagnosis

Complications	Yes	No	Elaborate
Optimal Treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Refer for further treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Compliance with treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Has the client reached Maximal Medical Improvement?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Is the client in a state funded institution?	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, give name of institution <input type="text"/>

The client is expected to be in a state funded institution for a period of >6/12 <6/12 N/A

Severity of impairment None Mild Moderate Severe

Does the impairment affect client's ability to enter open labour market? Yes No

Certification

Having conducted the assessment and considering the findings I certify the applicant disabled Yes No

Social Assistance/ Grants Recommended

Disability Grant Yes No Temporary Permanent

Indicate period in months 6 7 8 9 10 11 12 Yes With Review No

SRD Yes No If the Disability will last for less than six months

GIA Yes No If the client's disability necessitates regular attendance by another person

Part F: Declaration

The assessor is also bound by Sections 30 and 31 of Social Assistance Act 13 of 2004 as highlighted above. I hereby declare that I have examined the identified client. All particulars furnished by me in this assessment report are true and correct to the best of my knowledge.

Please write legibly and in capital letters.

Doctors's full names	<input type="text"/>		
Contact details	Tel: <input type="text"/>	Cell: <input type="text"/>	
MP Number	<input type="text"/>		
Doctor's Signature	<input type="text"/>		Official stamp: <input type="text"/>
Date	<input type="text"/>	<input type="text"/>	<input type="text"/>

SASSA reserves the right to conduct quality assurance on all completed Medical Assessment reports.

APPENDIX E: Maps of the Western Cape Health District

MAP 1: Western Cape Provincial Health Districts



MAP 2: Cape Town Metro Health Districts



APPENDIX F: Interview/Focus Group Guides Other Healthcare Professionals

QUESTIONS SOCIAL WORKERS AND NURSES:

1. Maybe we could start off with you telling me how the DG process works at the hospital.
 - a. Does it work differently in the different departments of the hospital
 - b. Who is involved in the decision-making?
 - c. Who initiates the DG process?
 - d. Do staff involved always agree? What happens when they don't?
 - e. To patients normally get temporary or permanent grants?

2. Other than the medical considerations, what else do you take into account when thinking about who should get a grant or not?

3. What is the biggest challenge around the disability grant?

4. Can we discuss a few cases of patients where you have advocated (try to convince the rest of the team) for the patient to get or not get the grant?

5. Anyone worked in other settings outside of mental health around the DG? How is it different?

TOPICS FOR DISCUSSION OTs

- What is work assessment and how does it “work”?
-
- How do DG patients come to have a WA at x?
 - What areas of hospital refer the most?

- What is the role of occupational therapists in the assessment process in relation to the disability grant? *Why are OTs called on – what do they know that doctors don't?*

- Bio-psycho-social model / social model?

- What challenges does the DG present to your work?
 - Inappropriate referrals – why?

- What makes someone disabled rather than impaired? *What does disability mean in the South African context?*

- How accurately is the current DG tool and processes able to accurately identify disability?
- New vs. old system
- A discussion on patients – what complaints do they present with? Socio-economic factors; attitudes; “performances”
- General views on the social security system
- Recommendations on how the system could be improved / refined.