Social Science & Medicine 175 (2017) 109–116

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Patient agency and contested notions of disability in social assistance applications in South Africa

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ARTICLE INFO

Article history:
Received 3 August 2016
Received in revised form
6 January 2017
Accepted 8 January 2017
Available online 9 January 2017

Keywords:
South Africa
Disability
Agency
Patient resistance
Doctor-patient interaction
Communication barriers
Social welfare

ABSTRACT

Problems in fairly allocating welfare and health resources are very often located in the spaces where citizens interact directly with state workers. This study draws on observations of doctor-patient encounters in disability assessments for the South African disability grant (DG) to examine how doctor-patient interactions and patient agency shape social welfare allocation in a context of high poverty and inequality. Data were gathered via interviews with healthcare workers and observations of doctor-patient interactions in twelve clinics and three hospitals in the Western Cape province between October 2013 and August 2014. Twenty-four doctors were interviewed, of whom seventeen were observed conducting a total of 216 consultations with patients. Two training sessions of DG assessors were also observed. Findings show that interactions between doctors and patients are sites of negotiation and contestation over rights to social assistance. Claimants' understanding of disability differed from biomedical and bureaucratic definitions. Patients attempted to influence doctors' decisions through narratives of suffering and performances of disability. Others used verbal or physical abuse as a form of protest against perceived unfair treatment. To defend themselves from these pressures and maintain authority in these interactions, doctors employed coping strategies that distanced and objectified claimants. This resulted in strained doctor-patient relationships and made the DG system confusing to the public. This demonstrates the importance of considering trust, power dynamics and the exercise of agency by both patients and providers in understanding policy implementation.

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1. Introduction

South Africa has a well-developed and wide reaching social assistance system providing a set of means-tested cash transfers known as 'social grants' to over 17 million people. These grants target children (via their caregivers), the elderly (over 60) and disabled people, but provide no support to the able-bodied unemployed. The disability grant (DG) - the focus of this paper - is available on a permanent or temporary basis (6–12 months) to people deemed unfit to work as a result of functional impairment and who do not have other sufficient means of support.

By providing disabled people with an income, the DG has the potential to enhance the capabilities of disabled people to function in society, but this is limited by the role it plays in general poverty alleviation (Graham et al., 2013). In a context of high levels of structural unemployment and limited social protection for the unemployed, many households are left dependent on the income of grant beneficiaries.

In the case of the DG, this has also created high demand for the grant from people whom it is not intended to target (Kelly, 2013). This poverty-driven demand, unclear policy and guidelines surrounding eligibility and the high burden of chronic disease (most notably HIV), have made the DG extremely difficult to target and administer effectively.

Access to the DG is defined in terms of the medical model of disability and confirmation of disability by a medical doctor is required for all DG applications. This makes doctors who conduct DG assessments (either as contracted assessors at community clinics or treating doctors in hospitals) very important gatekeepers to this highly sought-after form of social assistance. In their gatekeeping role, doctors can be considered *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.

This paper uses Lipsky's (2010) concept of street-level bureaucracy to examine the difficulties and micro-politics of allocating access to DGs in South Africa. Street-level bureaucracy is a bottom-up theory of policy implementation that considers frontline

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http://dx.doi.org/10.1016/j.socscimed.2017.01.013
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workers and the point of service delivery as key to understanding how policy works. It explains the 'gaps' that emerge between policy and practice as the result of patterns in workers' use of their agency and discretion to cope with the realities of work with clients and citizens in resource constrained settings where they must make complex decisions, often with limited information and time (Brodkin, 2012).

While the street-level bureaucracy framework has been widely applied in European and North American healthcare contexts, including disability assessment (Meershoek et al., 2007; Møller and Stone, 2013), its application in developing country settings is limited. There is, however, a small and growing literature in Africa on how healthcare workers shape service delivery, and thus how policy is 'realised' on the ground (Gibson, 2004; Le Marcis and Grard, 2015; Müller et al., 2016; Walker and Gilson, 2004). This research has shown that healthcare workers employ coping strategies to deal with high patient loads and under-resourced healthcare systems, employing stereotypes or making moralistic judgements about patients to rationalise their lack of care. My own research has demonstrated that, as well as responding to work stressors, doctors' behaviour is influenced by their personal and professional norms and values and broader discourses about welfare and social justice (Kelly, 2016).

While useful in unpacking the contextual, subjective factors and logics that structure the application of policy in practice, this literature has largely neglected the perspectives and agency of patients, as well as the relational and performative aspects of street-level interactions (Bartels, 2013; Eskelinen et al., 2010; Prior and Barnes, 2011). Although bureaucratic systems can leave citizens feeling trapped and powerless, they are not necessarily passive or docile in their dealings with bureaucracy and bureaucrats do not necessarily hold all the power in social relations at the frontline. Scott (1985, 1990) and de Certeau (1984) have both argued that people use small, tactical acts of defiance in everyday life to resist forces of power, even if they are often short-lived in their effects. Scholars employing a Foucauldian perspective on power and resistance also argue that the 'targets' of policy are capable of resisting and subverting bureaucratic systems and processes (Prior and Barnes, 2011). Empirical studies in North America and Europe have demonstrated that patients (Bloor and McIntosh, 1990; Salmon & May, 1995) and welfare clients (Dubois, 2010; Morgen et al., 2010) may resist administrative categories and attempt to assert their position by engaging in relational or oppositional struggles with street-level bureaucrats.

The literature on how patients navigate and exercise agency within the South Africa public healthcare system is limited, but Schneider et al. (2010) and Eyles et al. (2015) showed that patients negotiated access to care and found ways of coping in resource-constrained settings by making tactical use of social networks, complaint mechanisms, narratives of resistance and becoming expert, compliant patients. How this behaviour influences frontline workers and policy implementation in this context has not been studied.

This paper examines the social relations around DG assessments. In particular, it focuses on how claimants use their agency to negotiate access to DGs by creatively engaging with and, sometimes, disrupting the assessment process. Understanding these acts of resistance to the state's eligibility criteria and doctors' authority provides important insight into the gaps and inequities in both the healthcare and welfare systems in South Africa. Few developing countries explicitly target disability as a category for inclusion in social assistance programs (Gooding and Marriot, 2009) and with the largest and most generous cash transfer program for people with disabilities, South Africa provides a good case for exploring effects of categorically targeting the disabled in contexts of high poverty. There are also many lessons to be learnt from DG policy implementation that can be useful in developing social protection policy that addresses the needs of disabled people in lower and middle income countries.

2. The challenge of DG assessment in South Africa

Disability is a multi-dimensional and universally difficult concept to define and assess for social assistance and social insurance purposes and these benefits have proven difficult to administer internationally because of ambiguities present in the process of determining the employability of people with physical impairments (Priestley, 2010). The South African context creates a number of additional difficulties in accurately targeting intended beneficiaries. These contextual problems include: high 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.

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. This is because the main eligibility criteria (work disability) is considerably 'fuzzier' than the age criteria used to identify 'deserving' categories of people as eligible for other types of grant. 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." However, *disability* itself is not defined in the Act or its regulations and the government has struggled to legislate a proper definition or assessment tool that minimises inclusion and exclusion errors and is affordable and practical to implement in a stressed health system (Swartz and Schneider, 2006). As a result, eligibility criteria remain open to interpretation. Disability is closely tied to notions of employability, but it is difficult to draw clear lines between being unemployed, unemployable and disabled (Mashaw, 1983), especially in the South African context. Most medical doctors are poorly equipped to make these distinctions because without specialised training (which is not required to conduct DG assessments), they lack formal expertise on measuring functional capacity and on labour market and vocational issues (Kelly, 2013).

The high demand for the DG also complicates its administration. Disability is a desirable category and form of 'opportunity' (Hansen and Sait, 2012) because it has the potential to offer some kind of social and economic inclusion. DGs have a history of being been used as a 'ticket' to an income in poor communities, often in collaboration with sympathetic health and social workers (Segar, 1994). Others have provided examples of people reacting positively to an HIV or TB diagnosis, or refusing to take medication to remain ill because they are stuck in a sickness-poverty trap where recovery means the loss of an income on which households are dependent (de Paoli et al., 2012; Leclerc-Madlada, 2006; Nattrass, 2006).

Concerns about targeting the DG escalated in the early 2000s after attempts by the post-apartheid government to deracialise and reduce barriers to access inadvertently increased the amount of discretion available to disability assessors. This effectively made in the system more lenient and the grant became a *de facto* poverty and AIDS grant as assessors used their discretion to recommend grants on humanitarian grounds. This resulted in a rapid growth in beneficiaries (120% between 2001 and 2007) and growing concern about over-generosity and fiscal sustainability of the system (Kelly, 2013; Mitra, 2010). Desperate attempts to access the DG in situations of high poverty have been seen by civil society and academics as indicative of limitations of the current social security system and

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