



# “The land of the sick and the land of the healthy”: Disability, bureaucracy, and stigma among people living with poverty and chronic illness in the United States



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## ABSTRACT

Disability benefits have become an increasingly prominent source of cash assistance for impoverished American citizens over the past two decades. This development coincided with cuts and market-oriented reforms to state and federal welfare programs, characteristic of the wider political-economic trends collectively referred to as neoliberalism. Recent research has argued that contemporary discourses on ‘disability fraudsters’ and ‘malingerers’ associated with this shift represent the latest manifestation of age-old stigmatization of the ‘undeserving poor’. Few studies, however, have investigated how the system of disability benefits, as well as these stigmatizing discourses, shapes the lived experience of disabling physical illness in today’s United States. Here we present qualitative data from 64 semi-structured interviews with low-income individuals living with HIV and/or type 2 diabetes mellitus to explore the experience of long-term, work-limiting disability in the San Francisco Bay Area. Interviews were conducted between April and December 2014. Participants explained how they had encountered what they perceived to be excessive, obstructive, and penalizing bureaucracy from social institutions, leading to destitution and poor mental health. They also described being stigmatized as disabled for living with chronic ill health, and simultaneously stigmatized as shirking and malingering for claiming disability benefits as a result. Notably, this latter form of stigma appeared to be exacerbated by the bureaucracy of the administering institutions. Participants also described intersections of health-related stigma with stigmas of poverty, gender, sexual orientation, and race. The data reveal a complex picture of poverty and intersectional stigma in this population, potentiated by a convoluted and inflexible bureaucracy governing the system of disability benefits. We discuss how these findings reflect the historical context of neoliberal cuts and reforms to social institutions, and add to ongoing debate around the future of public social provision for impoverished and chronically ill citizens under neoliberalism.

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## 1. Introduction

Over the past three decades, shifts in public discourse and policy

have transformed the way government assistance to individuals in need is perceived, configured, and experienced in the United States. During the 1980’s, widespread political attacks began to mount against federal welfare policy (M.B. Katz, 2013). Emerging public discourses formed around accusations of overdependence and abuse aimed at welfare recipients. Racialized rhetoric concerning ‘welfare dependence’ among the ‘underclass’ found its epitome in the castigatory, stigmatizing, gendered image of the ‘welfare queen’ (Gustafson, 2011; M.B. Katz, 2013). These developments culminated in President Clinton’s pledge to “end welfare as we know it” in

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1992, and, ultimately, in the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (M.B. Katz, 2013).

This legislation replaced the primary federal welfare program, Aid to Families with Dependent Children (AFDC), with Temporary Assistance to Needy Families (TANF). Unlike AFDC, TANF is constrained by a lifetime benefit cap of five years, stricter eligibility criteria, and requirements for workforce participation ('workfare'). Moreover, TANF case managers were compelled—using market-based work incentives often deployed by contracted private companies—to shift their approach towards disciplining clients into changing their own work-related behavior (Schram, 2015). This cost-saving divestment of responsibility from state to citizen—or 'responsibilization' (Brown, 2015)—was achieved primarily via penalizing and paternalistic techniques of governance, such as tracking and documentation of clients' work-related activities and financial sanctions for insufficient engagement (Schram, 2015). In parallel, General Assistance (GA) programs (state/local welfare for adults without families who are therefore ineligible for AFDC/TANF) underwent substantial cutbacks. The number of states either providing statewide GA or mandating counties to provide GA fell from 38 to 26 between 1989 and 2015 (Schott and Hill, 2015). Moreover, while 25 out of 38 GA programs (66%) offered assistance to non-disabled unemployed adults in 1989, only 11 out of 26 (42%) did so in 2015 (Schott and Hill, 2015). The real value of GA benefits also decreased over this period in almost every state that continued to offer them (Schott and Hill, 2015).

These changes were part of broader, long-term political-economic shifts away from government regulation and social provision towards a more market-oriented economy and state, characterized by financial deregulation, privatization, and the retraction of government responsibility for social welfare (Brown, 2015; Harvey, 2005; M.B. Katz, 2013; Ong, 2006; Schram, 2015; Wacquant, 2009). The resultant political-economic configuration is referred to as neoliberalism. This constriction of welfare for non-disabled individuals, however, has left federal disability benefits as the last form of substantial government cash assistance available to many indigent US adults—obtained through either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) (Hansen et al., 2014; Knight, 2015; Wen, 2010). SSI is a welfare program administered by the Social Security Administration (SSA) that requires no work history of recipients, who must be either aged over 65 years, blind, or disabled to access cash assistance. The SSA defines disability as having a medical condition that (1) prevents the individual from doing their work, (2) prevents them from adjusting to other work, and (3) is expected to last for at least one year or result in death (SSA, 2016b). SSDI is a social insurance program for disability supported by Social Security tax deposit withdrawals from monthly paychecks, also administered by the SSA. Eligibility is dependent on having a work history of certain length, determined by the applicant's age.

The number of working-age adults (aged 18–64 years) enrolled in these two programs has grown significantly in the last two decades (SSA, 2015). While this is likely driven in part by the increasing prevalence of chronic illness in the US (Bodenheimer et al., 2009), it also gives weight to recent claims that a 'medicalization of poverty' is occurring here, as diagnoses of disabling chronic illness represent increasingly prominent and important gateways to cash assistance for individuals in need (Hansen et al., 2014; Knight, 2015; Wen, 2010). The associated shift in visibility from welfare to disability benefits, however, has been accompanied by a rise in stigmatizing public discourses on 'disability fraudsters' and 'malingerers' (Fox News, 2014; Karlinsky et al., 2014; Kessler, 2015; *The Wall Street Journal*, 2014), who have replaced welfare dependents as the latest manifestation of the recurring specter of the 'undeserving poor' (Hansen et al., 2014). This most recent

rhetoric, relatively under-researched in the US context, mirrors well-documented depictions of 'benefit cheats' and 'scroungers' in the United Kingdom (Baumberg, 2016; Garthwaite, 2011; Patrick, 2016), thereby perpetuating a stigmatizing, transatlantic preoccupation with deservingness originally imported from England that traces back to the Elizabethan Poor Law (Schram, 2015). Moreover, as with welfare in the 1990's, these discourses are reflected in how disability policy is implemented. The SSA's current anti-fraud strategy comprises eighteen separate components—including regulations and sanctions, national review committees, specialized investigation and prosecution units, and research efforts into psychological testing and symptom evaluation—to identify and discourage fraud, many of which have been enacted over the past few years (SSA, 2016a).

Few studies, however, have investigated the lived experience of receiving disability benefits in today's US, particularly among individuals living with a chronic physical health condition. Specifically, it has not been asked how the post-reform disability benefits system, as well as its associated stigmatizing discourses, shapes the lived experience of chronic, physical illness. Here we use qualitative data from individuals living with HIV and/or type 2 diabetes mellitus (T2DM) in the San Francisco Bay Area to examine these relationships within populations living with two important chronic illnesses in the US, both of which can lead to disability. Chronic HIV infection can have various systemic effects including chronic diarrhea, wasting, fatigue, and neuropathy, and also increases the risk of cardiovascular disease and other chronic diseases in the long-term. Poorly controlled T2DM can lead to neuropathy, kidney failure, retinal damage, and cardiovascular disease, and is a leading cause of amputations in the US. Any of these sequelae may cause bodily impairment, activity limitation, or participation restriction. Work-limiting disability results when any such consequences occur *and* negatively interact with contextual factors (environmental and personal factors) to prevent the individual from carrying out their work or adjusting to other work (World Health Organization, 2002). In the US, class, race, and other social factors strongly affect the development and progression of chronic illness and disability. Both HIV and T2DM disproportionately burden poor and ethnic minority individuals—particularly African Americans—who also have worse access to healthcare, accelerating the onset of chronic disease-related disability among these populations (Pellowski et al., 2013).

### 1.1. Theorizing stigma

Our research draws on theoretical frameworks from the literature on stigma. Stigma is the convergent process of labeling, stereotyping, separating, and discriminating against individuals possessing a particular attribute by stigmatizers with access to social, political, and/or economic power (Mahajan et al., 2008). It takes enacted, felt/anticipated, and internalized forms (Turan et al., 2017). Enacted stigma describes acts of hostility or discrimination towards individuals possessing a stigmatized attribute. Felt/anticipated stigma is the anticipatory fear among such individuals of being subjected to enacted stigma. Internalized stigma occurs when individuals with a stigmatized attribute come to accept these attitudes as natural and valid, thereby developing negative self-perceptions and feelings of shame (Turan et al., 2017). Here we also employ the concept of structural stigma, which is defined as "societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized" (Hatzenbuehler and Link, 2014, p. 2). This concept extends understanding of stigma beyond an interpersonal phenomenon, demonstrating how it is not only created and propagated within networks of individuals but also embedded in broader

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