

“Being on SSI is a Full-Time Job:”
How SSI and SSDI Beneficiaries Work Around and Within Labor Incentive Programs

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The research reported herein was performed pursuant to a grant from Policy Research, Inc. as part of the U.S. Social Security Administration’s (SSA’s) Analyzing Relationships Between Disability, Rehabilitation and Work. The opinions and conclusions expressed are solely those of the author(s) and do not represent the opinions or policy of Policy Research, Inc., SSA or any other agency of the Federal Government.

Abstract

Background and Purpose:

Disabled individuals, their families, and communities are more likely to live in poverty than their non-disabled counterparts. The Social Security Administration (SSA) is social safety net that provides cash assistance programs through social insurance (Social Security Disability Insurance, or SSDI) and public assistance (Supplemental Security Income, or SSI) programs to people who meet eligibility criteria. The SSA offers work incentive programs that encourage enrolled disabled people to return to the workforce yet has found that these programs are infrequently utilized. This research aims to fill both knowledge and methodological gaps in the literature on why those support mechanisms are under-utilized. Previous research has not yet investigated how disabled people make occupational and economic decisions and what barriers and strategies exist to survive within SSI/SSDI programmatic restrictions. Qualitative methods that uncover this decision-making by involving those impacted by the program can help to fill this gap in understanding.

Methods:

This study relies on data collected during semi-structured, in-depth interviews with a purposive sample of 13 self-identified disabled adults living in the Bay Area of California. Respondents were interviewed for approximately one hour each about their sources of income, budgeting strategies, and economic and occupational behavior. Subsequently, respondents met together in a focus group setting and were asked to speak to veracity of the researcher's interpretations of the interview data. Interviews were transcribed and analyzed using the data analytical software Dedoose. Both deductive and inductive strategies were employed in this qualitative analysis. The themes that emerged from the transcribed interview data spanned multiple domains such as experiences of ableism, concrete strategies to make ends meet, and critiques of the SSI/SSDI program structures. This report focuses on the concrete strategies for survival and other work-related domains offered in response to the research questions aimed at filling gaps in the literature.

Results:

While only two respondents had participated in an SSA work incentive program, all study participants described a tremendous amount of routine labor ranging from 5-40 hours per week. Discussions of work revealed both nostalgia and reverence for the value of working. Types of work included side jobs that were unreported to the SSA such as house-cleaning for cash; work in underground economies such as sex work; taking buses and waiting in lines for hours to take advantage of a wide array of social services; and volunteer service and activist work. All but one participant discussed chronic and severe worries about having enough money to meet their basic needs and were often looking for extra sources of income or ways to make do with less. All participants described detailed rationales for their budgetary and work-related behavior as they interacted with perceived SSA policies.

Conclusions and Implications:

Collecting data that illuminates the behaviors of people on SSI/SSDI provided an empowering experience for interview participants, many of whom alluded to feeling "heard" and were eager to communicate with policy makers whose decisions impact their daily lives. Moreover, participants' work lives showed that while they were not using the SSA work incentive programs, they were in fact working. These findings warrant further investigation in a wider sample and alternate geographic areas to assess for their generalizability to a wider cohort of beneficiaries. Further, they suggest that for this sample, incentives to work are far from

lacking. Instead, recipients have communicated a call to expand the scope of recognized and acceptable work effort under SSA policies.

Problem Statement

Poverty and disability are inextricably and bi-directionally linked. A health and wealth gradient demonstrates that poorer communities and families are more likely to be (come) disabled¹ and disabled individuals and their families and communities are more likely to live in poverty (Buetting et al., 2012; Deaton, 2002; Yeo & Moore, 2003). Unsurprisingly, the disproportionate representation of poverty in disabled populations accompany myriad other social inequities. Disabled people are far more likely to be unemployed than their non-disabled peers and if they are employed, they can expect to earn at least \$10,000 less in annual wages than able-bodied workers (Kraus, 2017). The disabled are less likely to graduate from high school, access higher education, and graduate from higher education (Kraus, 2017). They are overrepresented in the carceral state and amongst the homeless population (Barnes & Mercer, 2005; Erevelles, 2014; Janechek, 2015; Peters, 2007).

The Social Security Administration (SSA, hereafter) is social safety net that provides cash assistance through social insurance (Social Security Disability Insurance, or SSDI) and public assistance (Supplemental Security Income, or SSI) programs to people who meet eligibility criteria through a combination of current medical and functional status, past education, employment, and job skills, and factors such as age and current level of activity (SSA, 2017). Once receiving SSI or SSDI, beneficiaries are eligible to participate in programs that allow them to work under certain conditions alongside receiving disability. The Ticket to Work (TTW) program allows beneficiaries to continue receiving cash benefits for nine months in addition a full-time equivalent salary and allows them to remain eligible for public health insurance for 60 months, with the option to reinstate disability during that period if work is not feasible due to disability. Despite programs aimed at incentivizing program beneficiaries' return to work, such as the TTW, disabled people remain a small fraction of the workforce and therefore are excluded from the primary mechanism for social inclusion for American adults (Barnes & Mercer, 2005). This research examines this significant social problem using a social model of disability that views the locus of disability in the attitudinal, environmental, and architectural built environment (Dirth & Branscombe, 2017; Oliver, 2013).

Given the social model of disability and the multitude of social inequities

¹ Throughout this report, the term "disabled people" will be used rather than "people with disabilities." There is lively debate regarding the proper nomenclature to refer to the disability community which is typically referred to as person-first (person with disabilities) language vs identify-first (disabled person) language. Person-first language is promoted by professional organizations such as the American Psychological Association in effort to reduce stigma and dehumanization (Dunn & Andrews, 2015). Alternatively, disability advocates and disability studies scholars note that identify-first language is typically preferred by disabled people and therefore promote its usage. They also note that the avoidance of using "disabled" as a descriptor similar to many other identity-based descriptors (e.g. race, gender, sexual orientation) imbues disability with negative connotation in need of evading, hence magnifying stigma (Gernsbacher, 2017). The social media movement, #SayTheWord, attempts to promote positive connotation with all forms of the word "disability" as part of a perception of disability as a sociocultural identity rather than a tragedy in need of euphemisms (Andrews, Forber-Pratt, Mona, Lund, Pilarski & Balter, 2019). As with many marginalized communities, preferred language changes over time and differing opinions are inevitable. This report is informed by the social model of disability which recognizes disability as a status marginalized by society. All writing therein is consistent with this theoretical framework, language used by research participants as well as researcher to use identity-first language throughout.

disproportionately impacting the disabled population, the question arises as to what are the structural barriers to inclusion of disabled people in mainstream American society, particularly through the labor market. This research aims to augment and expand upon our existing quantitatively-derived knowledge base, by addressing the following exploratory questions through qualitative data collection and analysis.

Research Questions

Q1) How do beneficiaries experience Social Security disability programs as safety net programs with an intended goal of poverty reduction?

Q2) Within the context of the particularly high cost of living in the Bay Area, compounded by the incurred costs of disability, and Social Security-based income and asset restrictions, how do SSI or SSDI beneficiaries make ends meet to afford their basic needs?

Q3) Are there any strategies this population uses within or outside of the formal economy to survive? And, if so, what are the drivers that shape the decision to engage any of those alternatives?

Q4.) How might beneficiaries' reported efforts to ensure economic viability inform SSI/SSDI work incentive programs, e.g.:

- (1) Substantial Gainful Activity amounts;
- (2) length of time in the Ticket to Work program when an individual may return to receiving benefits; and
- (3) length of time in the Ticket to Work program when access to Medicare/Medicaid is guaranteed?

Literature Review

Defining Disability

During the international disability rights movement of the 1970s, activists and scholars coined the “social model of disability” (Oliver, 2013). In contrast to the “medical model of disability,” which locates disability in an individual’s biomedical makeup and perceives it as a flaw that requires fixing or at least managing, the social model of disability uses an ecosystemic perspective that examines the interplay of people and their architectural and attitudinal environments. The social model views disability as a clash between a person and their environment when an environment is not structured to meet their access needs. The classic example used to explicate this model is the idea of someone in a wheelchair confronted with a set of stairs. The medical model locates the problem in the individual’s biology that prevents them from walking up the stairs while the social model locates the problem in the stairs and the lack of ramp that prevents the individual from rolling upwards. In the social model, then, the condition that results in the individual using a wheelchair is referred to as an impairment as opposed to a disability, which would take into account biological and environmental factors (Oliver, 2013).

The social model of disability is not commonly used in the setting of social welfare policy. Disability studies and legal scholar Mark C. Weber (2009) argues that there is an intrinsic

conflict between social insurance, which conceptualizes disability as a risk, and the disability studies civil rights perspective. Since the adoption of Elizabethan Poor Laws in early American colonies, disabled people were categorized as “worthy poor,” or, those who were not expected to participate in the wage-earning labor market. However, the original New Deal did not include benefits for disabled people as it does today, initially including only disabled workers ages 50-65 years in the first iteration of disability benefits in 1956. Broader disability insurance, as well as a national healthcare program that would become Medicare and then Medicaid, faced opposition by business lobbies, organized labor, and the American Medical Association, among others (Kearney, 2006; Weber, 2009). Dialogues similar to those surrounding welfare in the mid ‘90’s took place, with fears that Social Security disability could incentivize fraudulent performances of disability and disincentivize rehabilitation and participation in the labor market (Berkowitz & Wolff, 1986; Weber, 2009). The SSI/SSDI programs that exist today are a result of the heavy controversy passing the first Social Security Amendment to provide disability insurance of 1956 and continuing debates and amendments throughout the decades since (Kearney, 2006).

Initially, benefits were expanded to include dependents of disabled workers (in 1958), to remove the age restriction of 50 for disability beneficiaries (in 1960, and perhaps of most significance out of the amendments), and to establish the SSI program and extend Medicare coverage to disability insurance beneficiaries after the 2-year waiting period (in 1965). Reflecting the increased neoliberalism that characterized the Nixon presidency, subsequent amendments to Social Security disability tightened guidelines and benefit amounts with the new formulary for determining benefits (in 1977), caps on benefits to families of disabled beneficiaries (in 1980), and revising the criteria for determining disability with new criteria for psychiatric disabilities (in 1984) (Kearney, 2006; Weber, 2009). Amidst these legislative expansions, the definition of disability changed as well. For example, in the Social Security Amendments of 1967, the definition of disability was changed such that an individual must be unable to do their previous work, but also any work in the national economy for which they might be qualified (Kearney, 2006; Weber, 2009). By 1980, Social Security disability had double the number of beneficiaries than it had a decade prior, in 1970. The costs of the program ballooned as benefit amounts also increased during this time. Thus, the amendments of 1980 signed into law by the Regan administration had the primary goal of curbing costs which was done in part by mandating a medical review for all beneficiaries, regardless of their prognosis. Faced with a media backlash and stories of disabled people being stripped of their benefits, the 1984 amendments eased the rate of benefit discontinuation. Additionally, it again shifted how disability was determined through revisions of the criteria to meet “*Mental Disorders*” and by rejecting claimants’ declarations of pain or other symptoms as evidence of disability (Kearney, 2006). These amendments exemplify the social construction of disability and its interplay with cultural, sociopolitical, and economic factors. Public perceptions of disability, welfare, and work – all imbued with moral and religious frameworks – also contributed to the politics of defining disability through legislation (Berkowitz & Wolff, 1986).

Still, the contexts of disabled people’s lives have not shifted policy definitions of disability as could the perceptions of society had large. In all of its formulations, the policy-based characterization reflects a deficit-based understanding of disabled people by defining people based on what they cannot do in an able-bodied society. Thus, in order to access basic needs as received through the welfare state, disabled people must frequently shift their self-concept and portray their disability as a deficit rather than a cultural identity associated with pride (Dorfman, 2015). Moreover, disabled people receiving disability benefits must navigate the

process of obtaining and maintaining them on their own, or perhaps with the help of a caseworker. This process reifies the individualization of disability as a deficit that can be located within an individual rather than as a result of biased social environments and attitudes (Chaudhry, 2018; Dorfman, 2015).

As the principal social welfare agency for disabled people in the US, SSA operates as one of the most influential bodies shaping perceptions and treatment of disabled people. Indeed, the very definition of disability, which is in constant flux as is any other socially constructed identity, is often decided based on the right to protection under the Americans with Disabilities Act (ADA) or eligibility for benefits under the SSA disability programs (Weber, 2000). SSA's current definition of disability is individualistic and medical impairment-centered, closest to the medical model of disability, and defines it in counter distinction to participation in the labor market: "You cannot do work that you did before; We decide that you cannot adjust to other work because of your medical condition(s); **and** Your disability has lasted or is expected to last for at least one year or to result in death," (SSA, 2017). As the late historian and disabled activist Paul K. Longmore writes of SSA's disability policy, "Millions of other Americans with disabilities find their attempts at productivity and pride blocked by these same segregationist work penalties and the social prejudice those policies express" (2003).

The SSA definition of disability focuses on impairments or functioning as they are related to paid work; a deficit-based understanding of disability that essentializes disabled people to their (lack of) participation and production in the labor market. Yet in describing "the poverty trap" for disabled people, Stapleton et al. (2006) note unemployment among the disabled persists, despite the fact that "nonmedical characteristics of the individual and environment have become increasingly important to determining a person's ability to work." Much discrimination towards disability stems from this conceptualization of disabled people of incapable of working and integrating into the mainstream, particularly for employers seeking effective, efficient producers (Jammaers, Zanoni, & Hardonk, 2016).

Defining Poverty Among Disabled People in the U.S.

Disabled people are disproportionately represented in poverty and extreme poverty rates, despite the long-standing safety net programs (Batavia & Beaulaurier, n.d.; Buettgen et al., 2012; Stapleton et al., 2006; Yeo & Moore, 2003). From a critical intersectional perspective, the prevalence and degree of poverty increase dramatically when taking race and gender into account, with Black women facing the most severe circumstances (Shavers, 2007; Williams, Mohammed, Leavell, & Collins, 2010). There are multiple aspects to take into consideration in understanding the cause of persistent poverty in this population including sources of income, social services, social inclusion and social welfare support. Multiple studies show that the leading cause of unemployment for disabled people is disability-based discrimination by employers and a lack of accommodation-provision for disabled employees (Gold, Oire, Fabian, & Wewiorski, 2012; Jammaers et al., 2016; Nevala, Pehkonen, Koskela, Ruusuvoori, & Anttila, 2015; Sayce, 2003; Wilton, 2004). In an analysis of the inefficacy of anti-discrimination policies focused on disability, Sayce (2003) emphasizes the need for policies to address multiples levels of discrimination sources – structural, institutional, legislative, etc. – in order to achieve a positive cumulative impact. Access to the labor market for disabled people clearly manifests on all levels from interpersonal to legislative (Weber, 2000; Wilton, 2004).

A capitalist society that values hard work, expediency and able-bodiedness among other means of conformism, is intrinsically at odds with the inclusion of the disabled population in the

labor market. Wilton's (2004) analysis of trends in the labor market point to an exceptionally challenging environment for disabled people; one that may "disable" those otherwise considered healthy enough to avoid the label. These trends include corporate and employer expectations of employee capacity for rapid adaptation to job changes, increased flexibility to work extra or unusual hours, and minimal need for on-the-job training. Moreover, there is increased expectation that employees will be able to multi-task, carrying out multiple job tasks simultaneously to enhance overall speed and efficiency. All of these expectations may render people disabled by a job that they would otherwise be able to perform, for example due to cognitive or processing impairments. Trends in the labor market have changed since Wilton's (2004) research was conducted, such as decreased overall unemployment rates that increase rates of employment for disabled people – however the employment gap between disabled and non-disabled people continues to grow (Kraus, 2017). While issues may vary, such as the increased need for social skills to be successful in today's labor market, the larger concern of a workforce that is particularly challenging to disabled people persists (Vornholt et al., 2018; Kraus, 2017).

These labor market changes are focused on expediency. Reasonable accommodations enshrined under the ADA Title I (Employment) are a threat to this market, given that accommodations recognize embodied diversity and often require time and funds that employers may be reluctant to invest (Nevala et al., 2015; Wilton, 2004). The flexible and changing nature of contemporary jobs can pose additional threats to the ADA's employment protections. Without explicit boundaries and expectations based upon a set of job skills, job descriptions can problematize the notion of "essential job functions." For example, if a company receptionist is a job category that a disabled person can fulfill, yet company expectations are for all clerical staff to assist with office equipment repairs, then the "essential job functions" may have just been altered slightly yet sufficiently to disqualify this otherwise capable disabled person. This is a critical alteration given that disabled job-seekers ought to be able to apply for, obtain, and make requests for reasonable job accommodations under the ADA *unless* they do not qualify for the "essential job functions" or their accommodations would "fundamentally alter" the nature of the job (Wilton, 2004). As such, disabled job candidates are systematically excluded from the labor market and remain embedded in contexts of deep impoverishment.

Literature on the interaction of disability and work under the welfare state is abundant in addressing descriptive statistics, barriers to employment, programs and policies to enhance employment, causes of disability-related entry and exits in the labor market, and what welfare state programs are indicated when disability precludes participation in the workforce. However, there is a paucity of literature that seeks to understand the lived experience of disabled people and the nuances of how and why they engage in particular occupational and economic behaviors. In particular, this review found just one article that addressed the use of the informal and underground labor markets or other creative and extra-institutional practices that disabled people rely on to survive amidst higher costs of living and fixed-income, policy-driven, poverty (Hall & Wilton, 2011). Yet, disabled people do find ways to survive and largely do not participate in SSI/SSDI work-incentives programs because of threats to their benefits and health insurance coupled with the public's perception of the capacity for disabled people to work, a barrier left unaddressed in the Ticket To Work program (Stapleton et al., 2006). An exploration of how disabled people pay for essential costs of living could fill this gap in knowledge and guide policy recommendations on poverty reduction based on existing and therefore feasible strategies for making ends meet.

Methods

Theoretical Motivations

This research design is informed by a critical realist epistemology and critical social theoretical perspectives. This means that as a researcher, my proposed research does not seek to identify a singular truth nor believe that a single truth exists. Moreover, it is impossible to separate the self as researcher from the research itself, meaning that the identities and perspectives of the researcher will inevitably impact the research process and outcomes (Collins, 2002; Morris, 2017). Rather than trying to eliminate this bias, this approach contends that it is impossible to remove the effects of one's humanity on research so instead strives to account for this impact through reflexive practices such as reflective memo writing. This epistemological approach stems from DuBois' original, though rarely credited, social science research methods that he pioneered in *The Philadelphia Negro* (DuBois & Eaton, 1899). The approach to this research, which is critical in nature and seeks to de-naturalize the standards of whiteness embedded in the White medical enterprise, is modeled from DuBois' innovative sociological research methods epistemology. He argued that human agency and context would always be necessary to scientific understanding, as there are no universal laws upon which to identify a singular truth (Marable, 2000; Morris, 2017).

The theory driving the research question and methodological choices is critical theory. Critical social theories are particularly useful for making explicit power structures and unpacking the implicit goals and impacts of social policy. They also drive a critical analysis of key constructs in this research such as disability and poverty by examining who creates the definitions, when the definitions change, and whose lives the changes impact (Ford, 2016). Further, critical theory implicates a qualitative approach to the research by answering research questions using voices of those impacted by SSA policies. Lastly, critical theory informs the identifying of intersectional lives that participants live and how other aspects of identity such as race and gender impact their lived experiences and context for the meaning-making of disability and poverty (Choo & Ferree, 2010).

Study Design

The research project is an original, empirical study using qualitative methods to conduct semi-structured, in-depth interviews and focus groups with 13 disabled adults (ages 18-65) receiving SSI or SSDI and living in the Bay Area. An interview guide was used to explore strategies that participants utilize to live in the Bay Area and meet basic needs while acting with reference to the SSI and SSDI income and asset guidelines (see Appendix 1 for details). Interviews also explored participants' motivation and desire to work, participation or lack thereof in SSI/SSDI work incentive programs, gaps between cash benefits and income needed for basic needs, and the various work-arounds including unreported income and participation in the informal economy. Interviews were transcribed and analyzed for emergent themes as they took place November 2018 and February 2019. This allowed me to assess for domain saturation as interviews progressed. At the end of 13 interviews, domain saturation was achieved, and transcripts were analyzed a second time for common themes.

In order to mitigate researcher-bias in interpretation of interview data that could result from being the sole coder in the research process, a member-check focus group was held to review interview data, emerging themes, and allow for participants to expound on key issues.

Five participants participated in the moderated focus group, which was beneficial in refining some themes and in demonstrating the variety of opinions for others.

Participants predominantly lived in the Northern California Bay cities of Oakland, Berkeley and San Francisco. The “Bay Area,” as its colloquially called, is a particularly apt location for this research because there is a large, engaged disability community, due in part to the history of disability activism and the higher than average number of programs and affirming municipal policies dedicated to the disabled population (Bender, 2007). Additionally, it is an area with a high and rapidly increasing cost of living, particularly for accessible housing (Whittle et al., 2015). Thus, since SSA benefits are federally designed and do not account for geographic differences in cost of living (SSA, 2017) disabled people in this region are particularly likely to seek earning opportunities in informal and underground markets, in the hopes of maximizing their income without forfeiting their disability benefit eligibility. Participants were compensated for their time in accordance with local minimum wage laws. Participants received \$15 for participating in the interview and another \$15 for participating in the focus group.

Recruitment and Sampling

Participants were recruited from personal networks in the disability community as well as community centers such as the Ed Roberts Campus and online spaces for disability community engagement. A physical paper flyer was posted in community spaces and an electronic version with accompanying image descriptions was shared online. My phone number and email address were provided for interested parties to contact, thus all participants actively reached out to participate with the exception of one key informant who was recruited at the beginning of the study. Interest in the study was reflected in the rapid response rate from participants. Twenty-three individuals contacted the researcher to participated, resulting in a sample size of 13. Out of the ten people who did not ultimately participate in the study, two moved out of the area before their scheduled interviews, five were lost to follow-up after at least three rounds of voicemail exchanges, two were ineligible for the study due to geography, and one did not show up at his interview and did not return follow-up calls.

The study utilized a purposive sampling strategy, starting with a few key informants identified for their leadership in the disability community and relevance to the study topic complemented by a subsequent snowball sampling approach. After initial interviews were conducted, a grounded theory approach to qualitative data analysis was employed to inductively identify core domains (Charmaz, 2006; Glaser & Strauss, 1967). These core domains were used to refine the semi-structured interview guide for clarity and salience.

The sample sought to balance the homogeneity intrinsic to the research questions and logistical constraints (e.g. geographic location) with heterogeneity in other intersecting identities such as age, gender, race, and ethnicity. Further data collection was concurrent with transcription and data analysis in an iterative analytical process.

Axiology and Reflexivity

I conducted this research in my role as a disabled doctoral student who has previously worked in the formal labor market as a medical social worker and has received disability benefits including SSDI and the California-based State Disability Insurance (SDI). While an SSDI beneficiary, I participated in the Ticket to Work work-incentive program to transition back to work and benefited from the expedited reinstatement program when impairments worsened. I am no longer receiving SSDI benefits, as the 60-month period of earning over the Substantial

Gainful Activity (SGA) dollar amount has lapsed and I am a full-time graduate student. These details are included to communicate the intimate familiarity I have with the research aims and interview participants' narratives. Reflexivity via reflective memoing and bi-weekly consultations with my ARDRAW faculty mentor were utilized to identify and account for the multiple lenses I wore as disabled researcher in order to remain faithful to participant interview responses as my source of data.

Data Analysis

Qualitative data were collected during in-depth, semi-structured interviews and one moderated focus group. Discussions were largely exploratory in nature as this study aims to understand the impact of SSA policies on disability and poverty in the lives of its beneficiaries through exploring their quotidian survival strategies. It does not seek to draw causal inferences or enumerate phenomena which might be better addressed via a quantitative approach (Marshall & Rossman, 2010; Padgett, 2008).

Analyses of interview and focus group data began with verbatim transcription of the digitally-recorded discussions, and were then imported into the analytic software package, Dedoose. Grounded theory, or the approach that develops theories through the analysis of data without preconceived categories, was used to develop a codebook in Dedoose based on inductive analysis to understand phenomena raised in the interviews and explore relevant aspects of participants' lives I did not anticipate or explicitly ask about (Charmaz, 2006). Interview transcripts, that ranged from 8-25 pages each, were each read multiple times. First, they were read through for accuracy of transcription and to review the interviews. The second reading took place prior to the focus group to develop a working list of emerging themes. The third (and in some cases, additional) readings took place as the interviews were coded and re-coded in Dedoose. For example, some codes emerged halfway through the third reading, in which case interviews were re-read to incorporate the new codes into the analysis.

Additionally, a deductive analytic strategy, or one that relies thematic categories created prior to data analysis, was utilized to look for common themes in answers to specific questions asked to all participants based on the interview guide (Creswell, 2007). For example, all participants were asked about their use of work incentive programs such as TTW, thus it was added to the codebook in advance of the theme emerging from the interview data. These original domains were expanded and revised to reflect the lived experiences of all participants while striving to capture themes amongst them.

Lastly, participant descriptors including demographics and Social Security-specific facts were collected from the transcripts. These were separated out to analyze alongside code frequency and to provide some context for the different intersectional identities that existed amongst the participants and how those identities shaped their responses.

Findings

Numerous common themes emerged with varying degrees of relevance to the study questions. This section focuses on codes most pertinent to the original goals of the study and a complete list of codes and representative quotes is included in the appendix for reference. The codes are organized in the following discussion of findings by research question that they respond to.

[Figure 1: Codebook with Representative Quotes]

Research question 1: *How do beneficiaries experience Social Security disability programs as safety net programs with an intended goal of poverty reduction?*

This question explored participants lived experiences as SS(D)I beneficiaries. Relevant codes include “financial precarity,” “income,” “perceptions of fairness in SSA policy” and “communication with SSA.” Possessing sufficient finances to meet basic needs was of significant concern for all 13 participants; “I think about it 24/7,” said Melvin², a Black, 51-year-old man with cerebral palsy. Participants described the extent of their concern about making ends meet as both a practical matter and a psychic weight. In discussing an experience of being unknowingly overpaid and subsequently having her benefit amount shrink monthly to compensate, Coral, a Black middle-aged woman with spastic cerebral palsy, expressed the toll the experience had taken on her every waking moment: “I write down everything I pay money for. If I get coffee, if I go to Walgreens, I write everything down so I don’t mess up. I don’t like that I don’t want to live like that. I’m tired of it.” This type of worry was experienced all the more intensely for participants with psychiatric disabilities, particularly involving anxiety. As reinforced in the member-check focus group, SSI/SSDI beneficiaries felt that they could never satisfy SSA rules. Stevie, a 55 year-old, white, multiply-disabled, man advised the group; “Never believe them if they tell you they don’t need some paperwork because you know the next person you talk to will. [group members nodded and murmured their assent] You have to take your paperwork into the office and talk to someone and ask them to put it in your file no matter what.”

While for some participants the lack of certainty and consistency regarding SSD administration created constant concern, others – particularly those who had been receiving benefits for longer – seemed to have adapted with a more fatalistic and practical approach: “You report earnings and they screw you over and you don’t report earning and they screw you over, so I just stopped... sure it’s a worry, but it’s not one I can do anything about.” Out of all interviews and the member-check group, only one participant denied financial concerns and did not seek external sources of income. Jonah, who identified as a multi-racial, gay, man with schizophrenia, stated that his low-cost housing in a wrap-around services program provided him with all of his needs. He did not need to leave the building for food, psychiatric care, or socializing and preferred to stay in walking distance of his home. While he acknowledged wishing he could “spoil himself a bit from time to time with cigarettes... or a new outfit,” he denied any material deprivation of financial concerns.

Research Question 2: *Within the context of the particularly high cost of living in the Bay Area, compounded by the incurred costs of disability, and Social Security-based income and asset restrictions, how do SSI or SSDI beneficiaries make ends meet to afford their basic needs?*

All other participants had either external sources of funding beyond their benefit amount (e.g. two interviewees had family financial support), worked part-time and earned under the SGA, worked off the books, worked in various underground economies, or some combination of the above. These codes reflected Research Question 2 that explored strategies employed by participants to make ends meet. Seven out of the 13 participants reported routinely skipping meals as a result of their poverty. Often, these participants spent all of their check on their rent or had disabilities that made it difficult for them to buy cheap, bulk food and do their own preparations, hence leaving them the option of cheap prepared food or nothing. Towards the end

² All names are pseudonyms.

of the month, many participants reported having run out of money and staying home to avoid incurring any costs and the embarrassment of their abject poverty.

However, there were also many creative uses of resources that participants described, many of which were arduous and took up almost as much time as a full-time job. Reese, a self-described mixed-race-white-passing, genderqueer, 36-year-old participant discussed their routine for accessing nutritious food even when their monthly check had run out: "I'd look online into the free produce, the pantries. Every place had a different rule. You have to bring a different form of identification, address or whatnot, some places by address. Ed Roberts [Campus] has produce on Mondays. They try and encourage healthier eating. Sometimes I'd go to Oscar Grant Plaza for some produce. It's a little cheaper. So yeah, one was finding the cheap and free food." Melvin discussed the amount of work put into managing benefits and resources as contrary to the idea that disability beneficiaries cannot or do not work, "'Being on SSI—I just want to get that clear—people think you're not working. Being on SSI is work. For me, it's like I have to go to SSI office to give papers. Then I have to go..."

In the context of the Bay Area, housing strategies were key to making ends meet. Housing costs, subsidized housing programs, and concerns over the shrinking affordable housing market touched each interview. Participants' housing status was a key factor in determining their financial security. This was acknowledged by Jonah, the participant who represented an outlier in his lack of financial stress and sources of outside income as a likely explanation towards his sense of security: "Well my rent is still just \$200, but the people who don't have reduced rent like me, they really have it tough." Stevie, while stably housed at the time of the interview, was aware that the housing program he was a part of might not survive the local housing market and was already strategizing for this potential issue; "I have my name on every waiting list for a Section 8 voucher, for every county in the State of California that has an open list, so that's about a third of them. If they give you a Section 8 voucher, you have to live there for a year, then you transfer it back here." Out of the 13 participants, six of them reported periods of either homelessness or unsafe housing while living in the Bay Area and receiving SS(D)I benefits. Only one participant actually had her name on the lease where she was living.

Research Question 3: *Are there any strategies this population uses within or outside of the formal economy to survive? And, if so, what are the drivers that shape the decision to engage any of those alternatives?*

Strategies participants described to make ends meet outside of the formal work economy addressed this question. Codes in this category included "legal but unreported" work as well as "underground economies" which were both unreported to the SSA and illegal labor activities. All but one participant described sources of income outside of their SSA checks that they considered integral to their survival. Many of these income sources included off the books work or other criminalized work activities, sex work in particular, that participants feared reporting to authorities to avoid losing SSA cash benefits and corresponding health insurance. These informal labor market activities were often connected to impairments and their progression, and thus insecure, as they were often physically demanding (e.g. house cleaning) and required a certain degree of physical desirability (e.g. sex work).

As Reese explained, "'To be honest, I'm always looking for other ways to make money that are under the table, like hustling. . . I've done sex work. I would do it again. I'm just a little mentally disorganized, honestly, under the recent threat of SESTA-FOSTA³. Sex works takes a

³ SESTA-FOSTA is an expansion of federal criminal law that opened online platforms to criminal and civil liability for any content related to sex work. The bill, Allow States and Victims to Fight Online Sex Trafficking Act

lot of fucking skill to put it together." Participants also described income mechanisms that were not illegal and also not designed to be integral to one's income, most notably participating in market surveys and finding organizations with paid incentives. Lolly, a white, 45-year-old, transwoman with intellectual and learning disabilities, explained that she had learned where in the city she could go to get "gift" (visa) cards; "I do gift cards. I do these surveys, too. Surveys—I just get—I was at testing yesterday for HIV/AIDS. I made a gift card, \$20." Three separate participants described running small, informal, business in which they sold their artwork. While none of them reported satisfactory earnings, they each continued because they enjoyed the work and needed to take advantage of any possible extra income.

Research Question 4: *How might beneficiaries' reported efforts to ensure economic viability inform SSI/SSDI work incentive programs, e.g.:*

- (1) Substantial Gainful Activity amounts;*
- (2) length of time in the Ticket to Work program when an individual may return to receiving benefits; and*
- (3) length of time in the Ticket to Work program when access to Medicare/Medicaid is guaranteed?*

This question explored existing work efforts both within and outside of the SSA work incentive confines. There were many codes that fit into this question which may inform optimizing use of work incentive programs for beneficiaries. Several participants had either attempted or already participated in the (TTW) program. The TTW program was noted for allowing only one nine-month work trial period over a lifetime. This was of particular concern for those who initiated SSI at young ages; for if someone used up their TTW at age 19, they had no option to reattempt workforce entry two decades later. Moreover, participants noted the issue of employer discrimination in hiring as a barrier to return to work, particularly salient amongst people with low levels of education and thus fewer work opportunities. Yet, even for those who had not had success in work incentive programs, work remained a desired goal. Most participants talked about previous work lives with nostalgia and sadness. They described missing the income, the respect, the craft, and the many other monetary and social aspects of belonging to a workforce. For some, the nostalgia was so strong that they continued to work as much as they could without having to risk losing benefits by volunteering.

The code "education" responds more broadly to the question of securing economic viability in describing participant aspirations, if not explicit efforts. SSA typically does not expect individuals on disability to gain more skills after disablement (ARDRAW webinar, 2018). However, two participants had specific plans to pursue higher education while on SS(D)I and one had already completed a college degree while on SSI. Participants referenced the relative flexibility in school as compared to in the labor market as well as the desire to participate in a fulfilling activity and gain skills that could lead to potential work that would be feasible in context of disability. This brought up the question of how individuals on SS(D)I might be supported in their educational pursuits as part of a wider conception of work incentive programs, particularly when disabled people face access-related barriers to education. Larissa, a blind, multiply-disabled, middle-aged white woman, noted that the lack of braille materials was directly

(FOSTA) was signed by President Trump in April 2018. It combined existing law with the U.S. Senate's Stop Enabling Sex Traffickers Act (SESTA). Many sex workers and advocates against sex trafficking have voiced concern that they are subject to increased danger under the new law, citing online platforms used to organize, educate and protect sex workers and prevent trafficking. Critics have referred to the new law as censorship that violates the First Amendment (Cole, 2018; Polich, 2019).

related to her inability to finish her degree, which narrowed her future work potential: “. . . I was only a few units away from an AA {Associate’s degree}” she explained. “I couldn’t finish because I couldn’t get the math in Braille. There were a couple of other issues, too, but I could have gotten rid of those. It was the math in Braille that doomed it.”

Discussion

Implications

This research begins to address both knowledge and methodological gaps in the literature. For example, the participants’ understandings of work incentive policies and reactions to them that were elicited in the in-depth interviews bring more depth to the simple fact of how many SS(D)I beneficiaries use these policies. Specific policies that were raised in interviews were the lack of regional cost of living adjustment and the related policy on monthly check. All participants received checks which, in sum were insufficient to lift them out of poverty (based on the Federal Poverty Line for 2019⁴) and expressed experiencing financial stress. This research suggests that further thought on the determination of benefits is warranted to address the many social concerns brought up in interviews as a result of living in poverty or extreme poverty.

The interviews did reflect a lack of use of work incentive programs, yet they simultaneously reflected a desire to work, as well as actual work activity. This suggests that the fear of losing benefits is not adequately addressed in the TTW, and/or that there may be room for work incentive programs that do not intend for participants to transfer entirely off of benefits. For example, given the tendency for most disabilities to wax and wane over time, it is likely that there are multiple beneficiaries who share the concern of the respondent who has already “used [their] ticket to work.” Consideration of a TTW renewal every seven years, or every time someone’s disability is reviewed, may make the program more accessible to a wider network of beneficiaries.

Communication lapses seemed prevalent between local social service agencies who serve many beneficiaries as well as municipal agencies such as the Department of Rehabilitation regarding ticket to work. For example, one participant had never heard of TTW and was thrilled when I told her about it in an interview and confused about why the many city agencies she’d spoken to never mentioned it to her. Another participant described facing ableism and classism at the DOR in San Francisco due to her learning disability and illiteracy. Multiple participants suggested the “if the right job was available” they would be eager to attempt work. In an economy with fewer low-skilled jobs, a particular concern in the Bay Area, coordinating with DOR’s for job placement not just job training may be beneficial. Additionally, participants expressed an interest in learning new skills and in accessing higher education. Increasing partnerships with city and state universities, which would require increasing openness to disabled students at these universities, could provide a path towards labor market inclusion as beneficiaries could receive training in fields that would be accessible to them. Education may be an important intervention in the poor and disabled population as means of access to work that could be more flexible, remote work (e.g. from home), and available in a high-skill demanding labor market.

⁴ The poverty guideline in 2019 for the 48 contiguous states and the District of Columbia is \$12,490 for an individual (Federal Register: Annual Update of the HHS Poverty Guidelines. Retrieval from <https://www.federalregister.gov/documents/2019/02/01/2019-00621/annual-update-of-the-hhs-poverty-guidelines>)

Respondents reported that having the opportunity to illuminate the behaviors of people receiving SSI/DI benefits provided an empowering experience, many of whom alluded to feeling “heard” and eager to communicate to policy makers whose decisions impact their daily lives. Moreover, participants’ economic survival strategies exemplify feasible approaches to achieving economic self-sufficiency that could provide fresh ideas regarding work incentive and related SSI/SSDI policy-making. For example, providing renewed opportunities to use the TTW program every seven years, when continuing disability is assessed, may assist more younger SSI/SSDI-users to engage with the program. Further investigation in other geographical areas is warranted to deepen understandings of these phenomena and assess their relevance in urban areas outside of the Bay Area as well as non-urban settings.

There is minimal research using qualitative methods among directly impacted disabled people to inform disability policy in the welfare state, let alone conducted by disabled researchers. Yet, evidence that the perspective of the researcher or policy-maker has an impact on the outcome of policies for disabled people suggests that it is important to expand literature informed by participatory ideologies (Dirth & Branscombe, 2017; Yeo & Moore, 2003).

Study Limitations

The interview data revealed a set of frequently mentioned themes and consistent patterns among participants who had little in common other than their geographic location, disability status, and benefit status. The study’s location in the Bay Area is important since the large and active disability community, disability services, and social services availability has made it a desirable home for many disabled people. Still, this field study site might limit the generalizability of this study’s findings. Data patterns may have transferability to other urban, liberal areas with higher rates of social services. However, suburban or rural areas, areas lacking public transportation, more conservative parts of the country and states that spend less on social services are likely to provide less in the way of supplemental supports that participants described in this dataset. Additionally, it is hard to find a more expensive housing market than the Bay Area, CA in 2019, so the impact of financial strain would likely be less focused on housing, may be less overall, or may shift to areas such as food if there are fewer social service agencies providing it.

Additionally, there may have been some sampling bias as the recruitment methods were by and large through disability related community centers. Thus, people who were recruited may have been more informed and politicized around their disability, more connected to resources, and more in touch with their disability identity and community than the average beneficiary.

Despite the focus described in the methods section on axiology and reflexivity, with the qualitative researcher as the research instrument, or the one posing the questions and building rapport with participants, I inevitably had an effect on outcomes. Participants were likely more apt to discuss their difficulties with their benefits as several described the interview experience as “getting a weight off their chest” in the opportunity to discuss what was distressing to them. While many participants did describe illegal activities after feeling assured that their personal information would be kept in confidence, it is likely that some were nervous to disclose this type of behavior to a research funded by the SSA. Thus, the degree to which participants discussed unreported work may in fact be underrepresented.

Conclusion

This research illuminates myriad areas of policy and administrative intervention as the day-to-day barriers and challenges faced by disabled recipients of SS(D)I were raised in the dialogue that can come about using a semi-structured interview format. Its primary limitation is its generalizability. Implications for future research would suggest repeating this study design in different geographic areas and different states. For purposes of comparison, the next step in this research might be to replicate the study in the same state but a different geographic context, such as the rural and generally more conservative Central Valley where the cost of living may be less than the Bay Area, yet social services may be less plentiful and accessible.

Further, there are many domains that could not be fleshed out for the purposes of this report but may give important insight into the day to day lives of disabled people living on disability benefits. Thematic codes that include “intrinsic (non-monetary) incentives to work;” the “moral authority of work;” “poverty worsens health;” and “social death;” while beyond the scope of this report, merit further exploration in order to help address knowledge gaps in the persistence of poverty among disabled adults in the U.S.

Lastly, research about disabled people that is conducted with disabled people and is qualitative in nature is far too rare an effort undertaken in social science contexts. While there are unique challenges to studying any vulnerable or isolated group, the challenges that arose in the process of carrying out this research were relatively minimal and certainly surmountable. Enhanced attention to the methods of this research that were unique to qualitative research with disabled people may be beneficial to flesh out in future writing, so that other researchers can access a template for ethically and generatively approaching this sort of research effort. Further, this work could enhance research about disabled people writ large by mitigating barriers to the illuminating potential of talking to disabled people about their lived experiences.

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Appendix I: Interview Guide

Protocol ID:2018-05-11074

Protocol Title: How SSI and SSDI Beneficiaries Work Around and Within Labor Incentive Programs

Interview Guide

Part I: Introduction

“Thank you so much for consenting to participate in this research. I’m really eager to learn more about the day to day strategies you use to make ends meet financially. We understand that living on Social Security disability benefits can be difficult, especially when you live in such an expensive area like the Bay Area. The Social Security Administration has some programs that allow people who receive benefits to do a little work and even to try to return to work. I’m interested in how you have or have not used these programs and why. I’d also like to hear about any other strategies you have, whether related to budgeting, support from family or working. The interview will last approximately one hour. Remember that at any point you are free to not answer my questions or to stop the interview altogether.

I’m going to start with some questions about how you identify and the nature of your disability, okay? So, first, how do you describe yourself?”

Probes:

- Age
- Race
- Gender
- Sexuality
- Education attained
- Family/social – married/partnered; parent of children (young or not)
- Nature of disability
- Amount of support needed for activities of daily living (ADL’s)

Part II: Economic Stability

“Thanks for letting me get to know you and your background a bit more. Now I’d like to move into questions about your finances which may feel a bit more sensitive. Can you tell me generally how stable you feel in your finances? E.g., do you worry about being able to pay your bills each month?”

Have financial struggles increased/decreased/stayed the same?

When did you go on disability?

If you worked prior to going on disability, did you feel more stable at that time?

If yes, what did you do?

What are your biggest concerns related to your finances?

Part III: Benefit Amount

Is your monthly benefit enough money to cover your basic needs (rent, utilities, food, healthcare)? Has this changed over time?

Follow-up questions/probes:

If yes, do you adhere to a budget/plan your spending carefully?

If no, what can you (not) afford based on your benefit amount?

Do you ever skip meals or health care expenses because of money issues?

Do you ever not pay your bills on time because of money issues?

Do you have any necessary costs that you relate to your disability? Examples?

Are any of your basic needs more expensive because of your disability?

Part IV: Income Strategies

*Only continue into this section if participant has indicated that they do have financial concerns.

Can you tell me generally how you make it through the month covering your basic needs?

Follow-up questions:

Do you do any paid work?

If yes, are you conscious of the Substantial Gainful Activity dollar amount? Does it impact your decisions about working?

Have you ever tried the Ticket to Work program? Why/why not?

Do you receive any support (financially or in-kind) from other organizations? Friends or family?

What other strategies do you use to cover your basic costs of living?

Part V: Conclusion

Is there anything else related to this topic that you would like to share with me?

Thank you so much for your time and sharing your insights and experiences. Do you have any questions for me before I go? Here is my card; feel free to contact me if you think of any questions later on.

[Appendix II: Codebook with Representative Quotes](#)

(attached in separate document as well as linked via pdf above)