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“Playing the Game” on SSI and SSDI Benefits: How Social Security Administration Policy Shapes the Individual, Societal, and Communal Disability Experience

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By

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Professor Tina Sacks, Chair
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Abstract

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Over 13 million adults in the U.S. under the age of 65 receive SSI (Supplemental Security Income) and/or (Social Security Disability Insurance) benefits as their primary source of income, yet over 40% of these individuals live in poverty. In order to make ends meet, SSI/DI beneficiaries must navigate a complex web of social welfare policies, interlocking benefit programs and social stigma. This study seeks to deepen understanding of the impacts of living on SSI/DI benefits through the experiences of beneficiaries alongside the specific policies they must navigate.

Employing a qualitative methodology, this study explores how disabled people in California’s Bay Area make ends meet on SSI/DI benefits and investigates how these experiences impact beneficiaries’ sense of self and identity. Over two phases of research, 33 working-age adults (ages 18-65) are interviewed in an in-depth semi-structured format followed by four member-check groups. A constructivist grounded theory approach to data analysis is used to analyze findings using the qualitative data analysis software, Dedoose. Throughout, a Critical Disability Studies (CDS) theoretical foundation guides the study.

Findings from this study are organized into three main themes entitled; (1) the administrative burden of “playing the game;” (2) the Social Security model of disability and (3) a total institution without walls. In the first theme, participants’ individual experiences of SSI/DI are marked by precarity, struggles for basic needs and burdensome paperwork for and communication with the SSA. They use creative workarounds to navigate SSA policy that they often perceive as working against them in their efforts to make ends meet. Next, the Social Security model of disability refers to the iterative process experienced by participants in which SSA policy shapes society’s perception of disability identity as non-participation in the workforce, participants feel devalued by society at large due to their disability, and participants limit their own development of families and careers in order to abide by SSA policy and maintain their benefits. Thirdly, participants’ experience of SSI/DI benefits also exists on a communal level, wherein the trauma of one beneficiary penalized by the SSA with loss of benefits or an overpayment reverberates through a community of beneficiaries. Further, participants experience of communal restrictions, support and resistance all contribute to a sense of being encompassed by SSA policy as if in an institution without walls.

Discussion of these findings are followed by three sets of implications for social welfare policy, practice and research. Policy recommendations address SSA policies that disincentivize SSI/DI beneficiaries' labor market involvement; create rigid and encompassing conditions set on benefit maintenance; and other aspects of SSA policy such as eliminating differential treatment of SSI versus SSDI beneficiaries. Implications for social workers include attending to the psychosocial issues that arise in navigating benefit policy, providing support to reduce administrative burden, and developing infrastructure to support confidential peer-based networks of SSI/DI beneficiaries. Lastly, future disability policy research would benefit from employing the CDS framework that emphasizes the narratives of disabled people in research and seeks to assess policy efficacy through their experiences of it.

DEDICATION

To Dana Kaplan-Angle, in loving memory.

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CHAPTER 1: INTRODUCTION

Over 13 million adults in the U.S. under the age of 65 receive Social Security disability benefits as their primary source of income and still over 40% of these individuals live in poverty (ORES, 2020). The Social Security Administration (SSA, hereafter) is a 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 health status, past education, employment and job skills, and factors such as age and current level of activity (SSA, 2019). Social Security disability beneficiaries navigate a complex web of social welfare policies, interlocking benefit programs and social stigma to survive and maintain benefits (K. Charmaz, 2019; Olney & Lyle, 2011; H. Whittle et al., 2017).

More broadly, in the United States, disabled people experience disproportionately high rates of unemployment, poverty, homelessness, incarceration, and other poor social outcomes in comparison to their non-disabled counterparts (Barnes & Mercer, 2005; She & Livermore, 2007; Vornholt et al., 2018). The SSA is an institution with significant power to shape the disability experience. This power ranges from determining who is deemed disabled, setting income levels, providing income and making rules disabled beneficiaries must follow in order to maintain their cash benefits, to encoding a widely accepted definition of disability as a status in contradistinction to participation in the labor market. By defining disability as an inability to work (due to medical reasons), the SSA creates a binary of labor market participation that precludes disabled beneficiaries from participating in it. Outside of the formal labor market, disabled beneficiaries must develop their own informal strategies to make ends meet.

Problem Statement

SSI, a public assistance program for disabled[1] children and low-income adults in the United States, provides a maximum monthly benefit of $783 per month for an individual or $1,175 per month for a couple in 2020 as well as health care through the recipient's state's Medicaid program (ORES, 2021). Almost eight million people receive SSI, over half of whom are working-age adults, 14% of whom are children under age 18, and 28% of whom are older adults

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[1] Throughout this dissertation, the term "disabled people" is used rather than "people with disabilities." There is lively debate regarding the proper nomenclature with which to refer to the disability community. The current dichotomy is known as person-first (e.g., person with disabilities) language vs identify-first (e.g., 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 et al., 2019). As with many marginalized communities, preferred language changes over time and differing opinions are inevitable. This dissertation is informed by critical disability studies and disability activists which both recognize disability as a status marginalized by society. All writing therein is consistent with this theoretical framework; language used by research participants; and me, which is identity-first language.

above 65 years. SSDI, a social insurance program for people who have previously worked and paid into payroll taxes, provides a monthly payment that is determined based on how long the individual has worked and how much money they earned during that time, with a 2019 average of $1258 (ORES, 2021). SSDI recipients are eligible for Medicare after a two-year waiting period. Almost 8.4 million disabled workers received SSDI in 2019 along with 1.4 million of their spouses and children. Approximately 1/3 of people on SSI or SSDI receive benefits from both programs simultaneously, since SSI comes into effect if an individual's SSDI benefit does not reach the SSI benefit amount.

SSI and SSDI function as the primary means of income replacement for disabled people in the United States, yet beneficiaries suffer significant economic and social consequences living under program policies including institutionalized poverty and stigma. People who are SSI and SSDI beneficiaries are broadly perceived as unemployable and must regularly prove their unemployability in order to maintain their benefits (Stapleton & Livermore, 2011). For the majority of people on SSI/DI, Social Security disability benefit amounts range from below to just above the federal poverty level. This very low income coupled with the higher costs of living disabled people typically have (aka the "crip tax") and SSA policy limits on beneficiaries' savings and assets all contribute to the disproportionately high rates of poverty in the disabled population (Batavia & Beaulaurier, 2001; Kraus, 2017; Mitra et al., 2017). The institutionalized poverty and expectations of non-contribution to the labor market create economic and social conditions that can be harmful for disabled people.

The experience of living on Social Security disability benefits involves ongoing surveillance of beneficiaries' bank accounts and requires the tracking and management of a tight budget. There are many circumstances when life cannot bend to the confines of SSA policy, thus people must find ways to maintain the appearances of rule-following. This bind can result in people's decisions to engage in informal economies, to hide cash if savings go over the $2,000 SSI asset limit, or to go without necessities such as food, toiletries, or electricity. Only through talking to disabled people in a safe and confidential manner about their experiences on SSI/DI can these experiences be illuminated. Financial dependence on SSA programs heightens the consequences of threats from SSA on people who commit benefit fraud, with consequences ranging from disenrollment to felony conviction (Dorfman, 2019). This dynamic discourages public conversation about the reality of beneficiaries' lives. Moreover, a lack of systematic investigation into these disability experiences masks the institutional nature of problems with SSI/DI, which allows them to be cast in an individualistic and aberrant light.

In their article on disability and austerity, Goodley et al. (2014) describe the precarious environments disabled people live in in a society "in which poverty and disability are once again being cast together as inseparable categories (p. 982)." These conditions include severe material deprivation, homelessness, social isolation, food insecurity, shame and stigma (Caplan, 2014; She & Livermore, 2007; Stapleton et al., 2006; Whittle et al., 2017). Altogether, systematic exclusion from social and economic life has prompted scholars to characterize the disabled experience as, alternatively, a denial of social citizenship (e.g. Barton, 1993; Erevelles, 2011; Russell, 1998); a state-driven slow death (e.g. Goodley, Lawthom, & Runswick-Cole, 2014; Puar, 2017); and a social death (e.g. Cacho, 2012; Priestley, 2000).

Although there is essential consensus that poverty and unemployment are significant medical and social issues that disproportionately impact disabled people, the causes and consequences of disablement and unemployment are contested in the literature. Causes of disability have been framed as a biomedical, individual problem (referred to as the medical model of disability in disability studies) by many rehabilitation sciences and social welfare scholars (Caplan, 2014; Franche et al., 2005; Gold et al., 2012; Retief & Letšosa, 2018). An economic perspective describes a conundrum in which over 90% of disabled people on SSI and SSDI express a desire to return to work yet fewer than 1% successfully transition and remain in the workforce (Stapleton & Livermore, 2011). A political perspective views disability through the lens of the social institutions and policies that create the category of disability (Stone, 1986). Through the political lens, the complex web of policies that SSI and SSDI beneficiaries must adhere to are the unifying experiences that characterize disability. This disability experience is plagued with contradictory messages around work and social exclusion, persistent poverty, and social stigma.

In this dissertation research, the political model of disability is employed to conceptualize anyone participating in the SSI and SSDI programs as disabled, regardless of impairment type, in order to explore the effects of SSA policy on the disability experience. The policies SSI/DI beneficiaries must follow to maintain benefits such as income and asset caps, work-reporting mandates and limitations, policy ramifications of marriage, as well as the process of accessing and maintaining benefits, create the unifying experiences that characterize this group of disabled adults. In addition, the bureaucracy set up to implement these policies and the street-level bureaucrats who implement them, which have been characterized as obstructive, stigmatizing and intrusive, further characterize this disability experience (Dorfman, 2017; Titchkosky, 2020; Whittle et al., 2017).

Purpose and Aims

This dissertation explores how disabled people survive under SSA programs and policies and what strategies they use in the struggle for everything from food to social inclusion through qualitative data collection and analysis. The transdisciplinary critical theory known as critical disability studies (CDS), which spans disciplines in the humanities, social sciences, and health sciences, is the theoretical perspective through which this study is conceptualized and its data analyzed.

This research aims to explore how SSI/DI beneficiaries make ends meet in the Bay Area and if they are able to do so while adhering to SSA policies; understand what underground and makeshift economies and practices develop in beneficiaries' attempts to make ends meet; understand the impact of SSA policies and bureaucracy on SSI/DI beneficiaries; and investigate how the experience of being on SSI/DI impacts beneficiaries' sense of identity, disability and otherwise, and their occupational decision-making. The study focuses on the Bay Area in order to assess how a federally based policy that does not take into account regional cost of living impacts beneficiaries living in a particularly high-cost area. Additionally, the area is known for being the birthplace of the Independent Living Movement and the Disability Rights Movement in the 1960-70's and continues to be a place that draws disability culture and activism.

The following research questions are posed to explore these research aims:

1) How do SSI or SSDI beneficiaries in the Bay Area make ends meet under the confines of Social Security policy?

2) How do beneficiaries experience Social Security disability programs and policy and the bureaucracy that carries them out?

    (a) In particular, what impacts does SSA and welfare-related stigma have on its beneficiaries' sense of worth, self-concept, and identity?

Findings from this study have implications for enhancing social welfare policies and programs aimed towards disabled adults, particularly those of the SSA. They also provide an opportunity for policy to be informed by the actual lived experiences of SSI/DI beneficiaries, rather than relying on decontextualized data points beneficiaries must report in order to maintain benefits. These findings reveal a disability narrative that remains largely untold in mainstream society. In addition to guiding SSA reform, findings reflect systemic calls to reimagine a new relationship between disability and the welfare state.

This dissertation is organized into seven chapters. After this introduction, Chapter Two provides a review of the existing literature related to this research and describes the theoretical orientation of the research analysis. Chapter Three details the methods used to collect and analyze data. Chapter Four explores how participants make ends meet on SSI/DI benefits and the strategies they use to navigate the SSA policies, referred to therein as “playing the game.” The chapter also discusses the impacts of administrative burden on study participants. In Chapter Five, the psychosocial sequelae of living on Social Security disability programs are depicted. These include issues of stigma, stereotyping, and how SSI/DI policy can alter participants' sense of self and their life trajectory. Chapter Six discusses how effects of SSI/DI policy is felt on a communal level, wherein the trauma of one beneficiary penalized by the SSA with loss of benefits or an overpayment reverberated through a community of beneficiaries. Further, participants' experience of communal restrictions, support and resistance all contribute to a sense of being encompassed by SSA policy as if in an institution without walls. Lastly, Chapter Seven summarizes the findings of this study, discusses its limitations, and provides implications for future social work practice and research.

CHAPTER 2:

REVIEW OF THE LITERATURE AND THEORETICAL FOUNDATIONS

Review of the Literature

This dissertation draws on scholarship from a number of disciplines including social welfare, sociology, economics, public policy, rehabilitation sciences and disability studies. Thus, the review of the literature integrates previous research from across these fields as they are relevant to issues facing disabled people on SSI/DI. First, in order to establish a common understanding of framework for key concepts in this dissertation the history and development of SSI/DI benefits are discussed followed by perspectives on defining disability. Next, SSI/DI benefits are examined more closely in a review of literature on the benefit structure, benefit amount, trends in benefit purchasing power, and the differences between SSI and SSDI. Four central topics related to the beneficiary experience of SSDI across rehabilitation, public policy, social welfare, and disability studies fields are explored next. Lastly, gaps in these sets of literatures as they relate to the economic and social impacts on SSI/DI beneficiaries are identified.

History and Development of Social Security Disability Benefits

The Social Security Administration (SSA) is part of the welfare state 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, 2020a). Though too politically contentious to pass in the initial Social Security Act of 1935, the two programs were added in subsequent amendments after much controversy. The first, very limited, iteration of SSDI became law in 1956 under the Eisenhower administration and almost two decades later, SSI was created by the Nixon Administration in 1973. SSI's creation combined the three existing programs; aid to the elderly, aid to the blind, and aid to the totally and permanently disabled (Berkowitz & DeWitt, 2013; Smalligan & Boyens, 2019).

SSI and SSDI policies have been routinely amended and debated over, thought the structure of the programs remains largely unchanged. In the Social Security Amendments of 1967, the definition of disability was changed such that an individual must not only 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). The current administration has provoked backlash from disability advocates in its 2019 proposal that would require continued eligibility reviews on beneficiaries with permanent disabilities. Controversy over the validity of beneficiaries' disability status has characterized the politics of the programs since their inception.

Today, there are over 13 million SSI and SSDI beneficiaries under the age of 65; 7.6 million receive SSDI alone, 4.4 million receive SSI alone, and 1.4 receive both benefits simultaneously (SSA, 2020). The SSA characterizes beneficiaries by their inability to earn an adequate income (known as a "substantial gainful amount" or SGA) due to a permanent condition that is expected to last until death, or at least 12 months. This characterization has come to define, in many contexts, the complex biopsychosocial experience of disability.

Defining Disability

The definition and conceptualization of disability varies depending upon context, particular policy, and theoretical or activist perspective. A medical or psychological model conceives of disability as an individual problem that involves a defect in one's biology or psyche. The problems presented by disability, in this case, must be addressed medically on a case-by-case basis. An economic perspective on disability views it as a social status with an accompanying income stream and role in the market economy. A sociological, or social, model of disability defines it as the result of a misfit between institutions or other components of society and people whose impairments are not planned for. The social model also explores the stigma of disability and how society functions to maintain and reproduce this stigma. Political scientist, Deborah Stone (1986), presents a political definition of disability that best represents how the concept is employed in this dissertation. The political approach views disability as a category created by the welfare state that is simultaneously entitled to certain social exemptions (namely, participation in the labor market) and deprived of some rights of social citizenship (such as freedom to marry, save money, and own a car). The two key pieces of federal policy that shape the political approach to disability are the Americans with Disabilities Act (though Stone's definition preceded its passage in 1990) and the Social Security Act. 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).

The disability experience is influenced by factors such as visibility of disability, or whether or not one is perceived as disabled upon sight, conversation, or other facets of routine interaction. Visible disability is a common target of stigma and discrimination, while invisible disability is often disavowed and denied necessary accommodation. The nature of disability, e.g. physical, psychiatric, developmental, sensory, etc., also impact the social and political interactions. For example, people with developmental and psychiatric disabilities are subject to significant restrictions of their basic rights such as forced hospitalization and conservatorship. For the purposes of this dissertation, the nature and visibility of participants' disabilities will not be explicitly discussed unless their salience emerges during data analysis, as the focus of the research is on the social and political experience of disability as created through welfare state policies and practices.

Structure of Benefits

SSI and SSDI serve people of all ages, from disabled children to low-income older adults. The largest group of beneficiaries, which are the focus of this dissertation, are working age (18-65) adults with disabilities. The programs are administered to individuals by the Social Security Administration (SSA) rather than local or state welfare offices using uniform eligibility criteria and benefit calculus across all states. However, 46 states and the District of Columbia provide supplemental payments through the State Supplemental Program (SSP), a monthly cash benefit for SSI beneficiaries who do not have other forms of income. States that do not provide this supplement are Arizona, Mississippi, North Dakota, and West Virginia. Since only 1/3 of state supplement are administered through the SSA and the rest are administered separately by state, the state SSP amounts are not uniformly tracked. They range from approximately $10-$600 depending on the state and an individual's living situation (ORES, 2020). In California, the 2019 SSP monthly benefit is $160.72 (CBPP, 2020).

SSI and SSDI provide monthly cash benefits to beneficiaries typically via direct deposit. SSI benefit amounts are based on a federal standard maximum monthly amount which in 2019 was $771 for an individual and $1,157 for a couple (CBPP, 2020). The monthly benefit can be reduced if the beneficiary is living in a Medicaid-funded long-term care facility, living rent-free with family, or if they have other sources of support or income such as alimony or income from working (ORES, 2020). As a result of these reductions, the average monthly benefit for SSI beneficiaries in 2019 was $567 (CBPP, 2020). SSDI monthly cash benefits are calculated based on the amount of time (or, number of work quarters) an individual has worked and how much they earned, or how much they have paid in FICA taxes -- the federal income tax that is effectively the premium of the social insurance program. There is no minimum amount of SSDI payment, and it is not related to cost of living. Thus, if an individual applies to SSDI and receives less than the federal SSI amount of $771, they can also receive SSI for the remainder.

When receiving SSI or SSDI benefits, the SSA requires that beneficiaries earn no more than a benchmark known as "substantial gainful activity" (SGA), or its equivalent to how much income one needs to be self-sufficient. This amount is adjusted for increases in the national average wage index and in 2019 for non-blind disabled individuals is $1,220 / month (SSA, 2019). Thus, if an SSI beneficiary were receiving the maximum federal monthly payment of $771 and worked as much as possible without going above the SGA, they would earn under $2,000 monthly. This same individual, if able to continue to work up to the SGA monthly while receiving SSI, would have a total income just under 200% of the FPL. Scholars such as Caplan (2014) have analyzed beneficiaries budgeting methods and find that individuals who take advantage of other social services such as housing programs and have high financial literacy are more likely to make ends meet and avoid debt accrual. However, these analyses assume that beneficiaries will remain in or near poverty and out of the labor market. Scholars such as Goodley, et al (2014) might characterize this approach as a conflation of disability, poverty and unemployment that naturalizes oppressive conditions for SSI/DI beneficiaries.

People receiving SSI are automatically enrolled in Medicaid (Medi-Cal, in California). SSDI beneficiaries receive Medicare after a two-year waiting period from their disability determination date (the date the eligibility workers determine marks the official onset of an applicant's disability onset when they are no longer able to work), though they must pay a monthly premium for non-hospital services. SSI and SSDI beneficiaries, after an additional application process, may be eligible to receive their state's benefit for Home and Community-Based Services (HCBS). In California, this program is In-Home Support Services, or IHSS. Known as "linked benefits," these health and home care benefits are often critical to survival and independent living for disabled people. Since the receipt of these services can be prohibitively costly outside of the scope of the benefit programs, many beneficiaries cite these benefits as primary reasons they must remain on SSI or SSDI instead of joining the workforce (Olney & Lyle, 2011).

Benefit Amounts and Buying Power

SSI/DI benefits increase annually for a stated goal of keeping up with increases in national costs of living, known as the cost-of-living amount, or COLA (SSA, 2019). However, SSA has been criticized for not keeping up with inflation and leaving disabled beneficiaries with progressively, relatively lower benefit amounts. A 2018 policy brief found that the buying power of social security benefits has decreased by 34% since 2000 (Johnson, 2018). Analysts have found that the largest contributor to this loss of buying power is due to the quickly rising costs of healthcare – an issue that disproportionally impacts disabled people (She & Livermore, 2007; Stapleton & Livermore, 2014). Despite the SSA's stated goal of the SSI program to aid "aged, blind, and disabled people, who have little or no income . . . to meet basic needs for food, clothing, and shelter," its monthly checks provide beneficiaries with an income that amounts to approximately 75% of the federal poverty line. For beneficiaries living in high-cost areas such as coastal California or the Northeast, their relative degree of poverty is even greater.

Still, the programs have a significant effect on poverty reduction. A 2019 report from the Urban Institute found that SSI reduces the number of households in poverty from 63 percent to 42 percent and reduces the number of households at 150 percent federal poverty level from 77 percent to 67 percent (Smalligan & Boyens, 2019). Without SSI and SSDI, 75% of current beneficiaries would be in poverty. While the two programs reduce the incidence of households in poverty and extreme poverty, the income and asset restrictions that are conditions of benefit receipt simultaneously prevent many households from achieving standards of living beyond near-poverty levels. Given the high level of influence the programs have over poverty levels among disabled communities and the numerous anti-poverty efforts at the federal, state, and local levels, it is striking that the intended benefit amounts leave such a high percentage of people in or near poverty.

Comparing SSI and SSDI

The majority of this prospectus will refer to SSI and SSDI together as SSI/DI for parsimony, however it is important to note their distinct roles in the welfare state. SSDI is a social insurance program that is designed for people who have become disabled after a period of participation in the workforce. As a result of this designation, there is less stigma attached to its beneficiaries and fewer regulations once on the program (Weber, 2009). However, for beneficiaries and the general public, the distinction between these two programs is often unknown and for people with shorter work histories and those whose prior work earned low wages, it can be just as difficult to survive on. Additionally, many people whose SSDI payment does not reach the federal maximum SSI benefit amount are eligible to receive both SSI and SSDI (SSA, 2020). This can result in a burdensome amount of paperwork and tracking different policies attached to each respective program. In 2017, 1.3 million (33% of SSI and 14% of SSDI beneficiaries) were receiving benefits from both programs. These beneficiaries must adhere to the SSI policies regulating work activity and savings caps.

The amount of money that SSDI beneficiaries receive varies widely depending upon the number of quarters they've worked and how much they earned in that time, since the program's aim is not redistribution of money but an insurance policy for income replacement (SSA, 2019). In 2018, the average monthly check amounted to $1,234. Perhaps more significantly, SSDI beneficiaries do not have an asset limit, which allows them to accumulate wealth and retain it while receiving benefits. This also exempts SSDI beneficiaries from the routine bank account surveillance that people who receive SSI are subject to.

SSI, or Supplemental Security Income, is a means-tested, public welfare program funded by general federal revenues, not a dedicated tax as in the case of SSDI. In order to be eligible for SSI, people must not meet the SSDI previous work earnings requirement; meet criteria for disability; and have an income less than the SSI benefit amount in the year of application; and have no more than $2,000 in assets at any point. SSI's population differs starkly from the older SSDI population. People with congenital disabilities or who have been disabled since childhood and people who have no formal work history make up the SSI rolls. (SSA, 2019; Webber, 2009).

Intrinsic Contradictions Around Work

Literature on policy impacting disabled people frequently characterizes the impact of these policies its intrinsic contradictions that simultaneously punish and reward disabled people's labor. Social security benefit policies and their accompanying work incentive programs are rife with tensions that complicate and often overrun disabled people's desires to (re-)enter the workforce after being on disability. SSI and SSDI are designed for people with "permanent" disabilities, yet beneficiaries of these programs are encouraged to seek vocational rehabilitation as soon as they join the rolls. A small literature exploring SSI/DI beneficiaries' decision-making processes regarding employment and use of SSA work incentive programs reveals that the policy paradox regarding work leads to so much fear and anxiety that it can dissuade people from entering the workforce.

The application process for SSI and SSDI is very challenging and can involve negotiating with health care providers for paperwork and supporting letters; an arduous application with confusing directions; high likelihood of denials; multiple rounds of appeals; potentially seeking legal counsel; and the psychic challenge of portraying oneself as unable to participate in the workforce (Dorfman, 2017; Olney & Lyle, 2011; Sosulski et al., 2012). After all this, only about ¼ of applicants have their SSI/DI applications approved and over 1/3 are denied for technical reasons (SSA, 2019). Thus, once a disabled person has successfully proven themselves unable to work and received disability benefits and the accompanying medical benefits (which can involve a two-year waiting period for those applying to SSDI), the prospect of losing them can be terrifying and opting out of them to return to work unimaginable (Olney & Lyle, 2011).

In their research entitled “The Benefits Trap”, rehabilitation scholars Olney & Lyle (2011) use a phenomenological approach to analyzing a series of 12 in-depth interviews with SSI/DI beneficiaries about their decision making process around engaging in work. Their primary finding was the limiting effects of social welfare policies on using work incentive programs, a phenomenon they name “the benefits trap.” For example, earning exactly up to the SGA is a concern for many beneficiaries who quickly learn that a small and not infrequent miscalculation by SSI or slight overpayment by an employer could result in being removed from the SSI rolls. This sets off a domino effect of benefits that immediately strips the individual of their health insurance (Medicaid for SSI or Medicare for SSDI) which also pays for any in-home support services – the critical program that allows disabled people who require assistance with activities of daily living to live in their communities and homes rather than a nursing home (Batavia & Beaulaurier, 2001; Caplan, 2014; O’Day & Killeen, 2002; Olney et al., 2014; Olney & Lyle, 2011; She & Livermore, 2007). Thus, while up to 90% of working-age people on SSI/DI express a desire to work, less than 1% of them actually transition back into the work force[2] (Olney, 2011). Living on a program that requires continual proof of inability to work through Continuing Disability Reviews (CDRs) and significantly caps allowable income forces beneficiaries to remain poor and not working. In this way, SSI and SSDI policies require beneficiaries to reproduce the disability and poverty SSA exists to alleviate in order to maintain benefits, or have the medical, economic, and psychic security of the program.

Deservingness and Stigma

Traditionally, disabled people have been typified as among the “deserving poor” in the welfare state. Disability status has provided an exemption from the expectation of work, leaving only the veracity of the disability up to scrutiny – both public and institutional. Yet, this exemption comes with a cost: The “disability con” (Samuels, 2014) refers to the notion of faking a disability, typically for some secondary gain, and can be observed in cultural works, legal frameworks, and public policy. Legal scholar Dorfman (2019) examines the disability con in the context of disability law and observes how fear of the disability con, or fear that people will abuse programs such as social security disability benefits by faking a disability in order to receive them, can result in barriers to accessing disability accommodations and rights. In the context of SSI/DI, the disability con serves to mitigate the deservingness of disabled people in the welfare state through a complex application process with high appeal rates and a medicalized disability verification process. This phenomenon can be observed in public discourse about disability benefits, particularly in times of rising disability application (K. Charmaz, 2019; Rabinovich, 2020).

From the 1980’s to the mid-2010’s, the number of SSI and SSDI beneficiaries, both total and as a percentage of the population, increased. The most significant increases took place in the early 1990’s when SSI eligibility policy changed and more recently in the late 2000’s during the Great Recession (Whittle et al., 2017; Smalligan & Boyens, 2019). In this same time period, the reorganization of welfare in the change from Aid to Families with Dependent Children (AFDC) to Temporary Assistance to Needy Families (TANF) alongside General Assistance (GA) cutbacks shrank non-disability-based cash benefits. Thus, SSI and SSDI are among the last of the

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[2] These figures were initially discovered in Olney, 2011 and after a backwards search of the references to a policy report and original SSA data, I was unable to locate more recent information.

long-term cash benefits available in the U.S. welfare state. Unsurprisingly, this shift has observed a corresponding increase in stigmatizing rhetoric; efforts to move beneficiaries in to return-to-work programs; and anti-fraud programming.

The pressure to counter the disability con motivates efforts to “perform limitations” as discussed in the qualitative research of recent disability studies scholars (Chaudhry, 2018; Dorfman, 2015, 2017, 2019; Emens, 2012). This literature speaks to the more nebulous yet consuming detrimental effects of SSA policy on disabled people’s experiences of surviving its confines. In their research, participants discussed the feeling of being constantly monitored before, during, and after the social security application process. The need to present as disabled in precisely the manner dictated by SSI/DI eligibility criteria in order to receive life-sustaining benefits clashed with their otherwise more hopeful, positive self-concepts as disabled people (Dorfman, 2015). The interaction of public perception and mixed-incentive policies create enormous stress in people’s daily lives. The labor of performing disability to self-advocate requires constant attunement to the perceptions of others such as bureaucrats and employers and can amount, along with other activities to meet one’s basic needs, to a full-time job (Chaudhry, 2018; Dorfman, 2015, 2017; Olney & Lyle, 2011; Whittle et al., 2017).

Thus, public sentiment and public policy have shifted away from the associations of benefit generosity and reduced stigma that has characterized welfare state depictions of disabled welfare beneficiaries. Some scholars, such as historian and disability studies scholar Paul K. Longmore, have argued that a deep stigma has always existed towards disabled beneficiaries since they are not expected to make any contribution towards the labor market in their lifetimes (2003). Literature (e.g. Whittle, et al, 2017) exploring the interplay between near poverty-level benefit amounts and high degrees of suspicion and stigma is emerging in the context of disability benefits.

In a qualitative study of 64 working-age, low-income, adults with chronic illness, physician researcher Whittle, et al (2017) detail the experience of navigating complex bureaucracy which included SSI/DI for the majority of their participants. Through participant observation and in-depth interviews with the individuals and providers from their medical teams, the research highlights the confluence of social welfare cuts, complex social policies to navigate, and stigma resulting from accessing social services. The authors characterize the stigmatization of disability benefits as “the latest manifestation of age-old stigmatization of the ‘undeserving poor,’ and go on to discuss how the SSI/DI systems and their surrounding stigma significantly marginalize and dehumanize lives of the participants (Whittle et al., 2017). In their discussion, Whittle, et al (2017) note that “to [their] knowledge, this study is the first to document in depth this interconnected web of poverty and stigma centered on the receipt of disability benefits among individuals with chronic, work limiting poor physical health (p.13).” To my knowledge, this study is the closest in design and research questions to the dissertation I propose herein.

Workfare and Social Security in the TANF Era

SSI/DI and TANF are both social welfare safety net programs designed through federal policy that keep many of the program beneficiaries in poverty through a combination of benefit amounts and benefit conditions on income and assets, though there are clear differences in the programs' goals, eligibility criteria, and benefit determinations. Critical welfare scholars such as Edin & Lein (1999) in their canonical work, *Making Ends Meet*, have done exhaustive quantitative and qualitative analyses of beneficiaries that portray the severe poverty and hardship families endure while living on TANF and under the scope of its policies. Their work highlighted the increasing challenges face by families after the transition from AFDC to TANF upon enactment of the 1996 welfare reform laws which tightened restrictions on beneficiaries while increasing programmatic focus on resources for entering the work force.

As SSI/DI benefits have become among the last remaining cash benefit provided by the welfare state, the national focus on transitioning off of the rolls and into the workplace through workfare has increasing turned to social security disability beneficiaries. Workfare programs are government-sponsored programs that aim to provide beneficiaries incentives and resources to transition off of welfare benefits and into the workforce or educational or vocational training. For SSI and SSDI programs, the SSA collaborates with local departments of rehabilitation to promote two such programs; the Plan to Achieve Self-Support (PASS) program for people on SSI to save money towards achieving employment-related goals and the Ticket to Work (TTW) program for people on SSI or SSDI to access jobs and create a plan to transition into employment. TTW attempts to alleviate beneficiaries' concern about losing medical insurance and going off the hard-won disability benefits by providing a nine-month period when people can both receive benefits and earn any amount of money as well as 60-month period of eligibility for Medicaid/Medicare after initial earnings. Despite these programs, the SSA's research and policy efforts towards increasing use of them, and the widely held desire to return to work by SSI/DI beneficiaries, actual return to work and transition off of benefits remains at less than 1% (Dekkers-Sánchez et al., 2011; Franche et al., 2005).

Several qualitative studies provide depth and nuance to the portrayal of TTW use found in the low program participation rates alone. In general, people do have an interest in returning to work and consider that working would be an improvement in quality of life over living on SSI/DI, however the work disincentives created by the same SSA policies enumerated above render beneficiaries unable to work (Olney et al., 2014; Olney & Lyle, 2011; Whittle et al., 2017). Further, research has found that mistrust of SSA extends to work programs such as TTW, and that fear of losing benefits is a strong deterrent to attempting work trials (Livermore, 2003; Olney, 2007).

Edin & Lein's (1999) research led them to develop a number of welfare policy recommendations based on the reality they discovered in existing strategies that were being used by the identified mothers on welfare. Both TANF and SSI/DI recipients experience barriers to the formal labor market, such as unpredictability due to disability or childcare needs. They must straddle the codified work incentives and work disincentives to retain benefits and make ends meet. In order to examine the barriers and motivations to work that disabled people face, insight may be gained by investigating work and income strategies that are unaccounted for within existing SSA structures. This research, while investigated in some groups of welfare program participants such as single mothers, has been largely absent among SSI and SSDI beneficiaries.

Motivation to Work

In the setting of policy and programmatic efforts to move people off the SSI and SSDI rolls and into the workforce, the concept of motivation is frequently invoked. There is a perception that if beneficiaries had adequate motivation, they might overcome their work-limiting disabilities and return to work. Research into this topic suggests conflicting relationships between motivation to work and actual return to work. There is a large body of literature on rehabilitation and motivation to work, that suggests the chronically low rates of SSA work incentive program participation are due to a lack of internal, individual, psychic resources. Yet, in the consistent albeit small qualitative research with disability beneficiaries, motivation remains consistently high. This motivates further research with input and participation by disabled people to define the barriers to work for themselves.

In a subset of research stemming from rehabilitative fields, researchers have investigated the non-economic losses of exiting the labor market for disabled working-age adult (Milner et al., 2015; Saunders & Nedelec, 2014; Vooijs et al., 2018). These studies start from the implied premise that the meaning of work to disabled people is unknown and investigate what role employment plays in their lives pre- and post- disability onset. In two qualitative studies and scoping review article of 52 studies on the topic, the findings are consistent that the meaning of work is largely consistent across disabled and non-disabled people. Themes include work as a source of financial independence and ability to care for oneself and loved ones; feelings of normality; a source of identity; a sense of being valued and worthwhile; and a site for socialization. One meaning of work that can shift for disabled people is identity and sense of purpose. When disabled people must exist the workforce due to their disability and/or lack of work accommodations, some report that their sense of purpose in life shifts to a more inter-personal, family and community-centered one.

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 et al., 2012; Jammaers et al., 2016; Nevala et al., 2015; Sayce, 2003; Wilton, 2004). In an analysis of the efficacy, or lack thereof, 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).

Gaps in the Literature

Despite research showing structural barriers to employment, social welfare policies often presume that motivation is the missing link between people receiving cash benefits and employment, which implicitly characterizes, for example, disability benefit usage as a matter of choice. The stigma assigned to benefit receipt, both SSI and SSDI, is coupled with the stigma of being disabled for SSI/DI beneficiaries. Beneficiaries may find themselves impacted by stigma, motivated to work, yet stuck in the intrinsic SSA policy contradictions that both incentivize work and penalize it. At the same time, they are typically faced with immense bureaucratic responsibility to maintain benefits that can require time and energy to complete in order to receive near poverty level income. This set of circumstances is likely to impact the lives of people receiving SSI/DI benefits in psychological, social, and economic spheres. Yet, social welfare policy literature, as well as scholarship in related fields, has yet to investigate these spheres of impact. This exploration and identification of issues facing SSI/DI beneficiaries is necessary in order to develop appropriate policy and practice interventions for disabled people in the U.S.

Literature on the interaction of disability and work under the welfare state is abundant in addressing 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 small subset of literature that seeks to understand the lived experience of disabled people, the impacts of SSA policy on their self-concept, and the nuances of how and why they engage in particular occupational and economic behaviors. In the few articles that have used qualitative methods to engage with disabled people, the difficulty of managing the conflicting and contradictory directives to be unable to work yet try to work emerge (Caplan, 2014; Olney & Lyle, 2011; Whittle et al., 2017). Issues of stigma and feeling stuck in persistent poverty are additional themes from these studies.

Additionally, this review did not identify research studies that sought to understand how SSI and SSDI beneficiaries were impacted by the SSA policies and survived that were conducted from an insider-perspective in the disability community and a former SSDI beneficiary. Perhaps for this reason, themes in related research did not arise regarding the use of the informal/underground labor market or other creative and extra-institutional practices that disabled people use to survive amidst higher costs of living and fixed-income, policy-driven, poverty (Hall & Wilton, 2011). I believe this is a core aspect of the social exclusion and economic deprivation that marks the disability experience and could provide critical insight into the impacts of SSI/DI policies on its beneficiaries.

This research proposes to build on the nascent body of research exploring the social and economic impacts of persistent poverty and unemployment, and their conflation, among disabled people through a qualitative, phenomenological approach to understanding the lived experiences of SSI/DI beneficiaries. The contestations in contemporary literature regarding the causes, consequences, and conflation of disablement, poverty, and unemployment create space to emphasize a disability studies perspective. Employing a key disability studies and disability justice maxim, “nothing about us without us,” the study seeks to deepen understanding of the impacts of living on SSI/DI beneficiaries through their experiences alongside the specific policies they must navigate. How people survive under harsh conditions and as targets of stigma, and what strategies they use in the struggle for everything from food to social inclusion will be explored in a series of qualitative interviews with working-age adults living on SSI and SSDI in the Bay Area of California.

Theoretical Foundations

Using critical social theories, in particular critical disability studies and intersectionality theory, this research will use qualitative methods to deepen understanding of how social security disability policy reproduces poverty and disablement in its recipients and how they survive through resistance and work while living in California’s Bay Area. The following section discusses the theoretical foundations upon which this study has been designed.

Critical Theory

Critical theory widens our understanding of concepts commonly assumed to have fixed, or essentialized definitions, such as race, gender, disability and sexuality. Mainstream research often collects demographic information such as the aforementioned characteristics and explores their correlations with dependent variables. From a critical theory perspective, these identity markers are social constructions that are connected to their histories and are continually redefined by structural power sources with the goal of ongoing oppression. Thus, critical theoretically informed research takes into account the iterative nature of demographic information and the social phenomena with which it is associated.

Co-Construction of Race and Disability

Medicine, illness and disability have been used as tools to both justify and carry out discrimination in the United States since the country’s inception. Casting a social group as somehow biologically, physically, or mentally defective has been a tactic for relegating them to a second-class citizenship while attempting to evade accusations of bias throughout history (Baynton, 2013).

For example, attempts to legitimate racism through science (i.e. scientific racism) depended upon the assumption that variants from an able-bodied norm were undesirable features rooted in the biological, rather than sociopolitical, environment (Dirth & Branscombe, 2017; Obasogie, Harris-Wai, Darling, Keagy, & Levesque, 2014). This is seen in in the U.S. from slavery to today when practices such as enslavement, torture, and systematic undertreatment of pain in the Black community are rationalized by a white research and medical enterprise that espouse that Black people have lower intellect and less capacity to feel pain. The historic linkage of racism and ableism is increasingly recognized by scholars and intersectional activists with the recognition that one institution cannot be dismantled without working in sync with the other (Annamma et al., 2013; Dolmage, 2018; Ferri, 2010; Nelson, 2010; Obasogie, 2013).

Critical Race Theory

Critical Race Theory (CRT) is a critical theory that deconstructs essentialist ideas of race and shows how social, cultural, political, and historical rules continue to construct and redefine race to uphold white supremacy and systematic racial oppression. It was coined by legal scholars including D. Bell, Kimberlé Crenshaw, and Richard Delgado as an alternative means of legal analysis that refuted the fallacy of ‘neutrality’ in written law. They underscored ways in which U.S. law reinforced white supremacy when it ignores the historical and contextual information necessary to interpret its actual impact. CRT is employed in multiple fields and settings as a way to analyze race and its intersection with other social identities such as gender, socio-economic class and sexuality. Critical race theorists unmask the way race and racism are constructed alongside power into everything from word choice to research methods (e.g. Bonilla-Silva, 2008).

The five primary tenets of CRT are 1) counter-storytelling; 2) the permanence of racism; 3) whiteness as property; 4) interest conversion; and 5) critique of liberalism (Heraldo, 2010). CRT emphasizes a highlighting of power dynamics in order to dismantle them, such as intentionally creating counter-narratives to build knowledge outside of white institutions. CRT guides the methods of this dissertation in ways that have also guided the formative concepts of critical disability studies. Emphasizing the narratives of SSI/DI beneficiaries as sources of knowledge about the benefit programs intentionally shifts the perspective away from the SSA, an administration built on white supremacy and neoliberalism that has largely had the power to define the disability experience in the U.S. Analysis of the words of participants through an intersectional and historical framework is informed by CRT and will be discussed further in the context of critical disability studies.

Critical Disability Studies

Critical disability studies (CDS) is a transdisciplinary field that is informed by CRT as a field and its focus on deconstructing essentialized norms and systems of power. CDS deconstructs a mainstream, medical model of disability by focusing on the lived experience of disabled people. Instead of perceiving disability as either a biological defect, pitiful tragedy, or object of charity, disability studies emphasizes socio-cultural conditions that create disabling circumstances. The subsequent social oppression of disabled people is referred to as “disablism.” Employing Crenshaw’s theory of intersectionality, disablism is considered alongside other facets of identity and other forms of social oppression (Crenshaw, 1991). A CDS perspective has the goal of seeing how people’s multiple identities and sources of oppression come together. This is necessary for a complete understanding of disability as well as of a disabled person’s experience, and particularly so for interpreting the complex disabling processes on multiply marginalized people. Disability becomes a lens through which critical disability studies perceives political, practical, and academic social events and issues. Like other critical theories, critical disability studies emphasizes a de-professionalization and de-centralization of knowledge, centering information derived from people’s lived experience of disability.

The *critical* in CDS reflects several key points of departure from the disability studies of the 20th century which was characterized by the prominence of the social model of disability (Goodley, 2013). The social model of disability was developed in the 1970’s by British disabled activists and scholars with primarily physical and visible impairments (Oliver, 1990). It contrasts itself with the medical model of disability, the perspective considered dominant in western society, by viewing the location of disability in society itself as opposed to an individual and posits that a mismatch between society and an individual creates disablement. The model identifies ‘impairment’ as an individual’s feature that places them outside of the mainstream in mainstream society, such as quadriplegia. If a quadriplegic uses a wheelchair to ambulate and is unable to enter a building with only a set of stairs leading to its entrance, the social model of disability indicates that the disability is located in the stairs, or the absence of a ramp. It is a political reframing of disability that emphasizes the material conditions of disablement (Oliver, 1990; Goodley, 2013).

CDS has emerged in the early 21st century to move forward from the “materialist social model of disability” not to refute it, but to widen its scope and complicate its concrete explanation of disability. CDS is intentionally self-reflective and self-appraising, continually assessing itself as an academic field and its relationship to the activist movement of disabled people without which it would cease to exist. In his five conventions of CDS, Goodley (2013) explains one aspect of the emergence of CDS as a response to the dominance of materialism in the social model. He highlights the relational nature of marginalization and the deep psychic wounds it beholds, that compound and exist beyond the socioeconomic focus of the social model. Disability, he argues, has further outgrown the social model in its role as a cultural trope that reduce disabled people into manufactured narratives including pity, disgust, violence, and deceit (Mitchell & Snyder, 2014).

The social model's dichotomy of impairment and disability is also critiqued by CDS scholars who, in recognition of the multiplicity of harms wrought by ableism, perceive a more complex interplay between an individual's body and their social environment than a process in which one might disable the other (Goodley, 2013). Further, the impairment-disability dichotomy implies that one's impairment, clearly situated in one's embodied existence, cannot be a source of distress or disablement. Disabled people with chronic pain and progressive chronic illnesses, among others, decry the theoretical disembodiment as incongruent with their experiences.

In addition to critiquing the social model of disability and other conventions of disability studies, CDS strives to be a site of inclusion for multiple voices (critically, disabled activists and community members in concert with academics) to co-create frameworks that can fit all people regardless of disability. Through its perception of disability as polar ends of a spectrum of human variation, CDS considers that disabled communities can be models of social inclusion for every variation of person: "We primarily intend these concepts to signify the ways in which disabled people pursue the invention of alternative cultures of living as a foundational value of navigating life in an able-bodied world created for a narrow range of bodies, aesthetics and capacities" (Mitchell & Snyder, 2018, p. 190). In this way, the benchmark for a disabled person's success does not necessarily remain as assimilation or acceptance into mainstream society, as the societal embrace of disabled cultures uplifting inclusion and interdependence become a broader goal. In widening its lens and explanatory modeling to all people, CDS does not restrict its study to disabled people. Instead, by emphasizing the process of disablizing, non-disabled people can become a topic of critical analysis ripe for de-essentializing (Flynn, 2020).

CDS has also been argued to be better suited as a methodology than as a field of study (Minich, 2016; Schalk, 2017). Given the long history of using disabled people as objects of research and subjects of writing wherein disabled people's own perspectives were overlooked, scholars such as Minich and Schalk warn of the risks of an emphasis on studying disabled people. CDS does not promote its own goals by studying disabled people who are identified as such by individual impairments. Instead, the processes by which people are deemed to be disabled and the social conditions that accompany this label are of interest and merit further study in this field.

Significantly, the emphasis on disabling processes does not require people to identify themselves as disabled in order to merit study through a CDS framework (Minich, 2016; Schalk, 2017). One critique that CDS holds of itself and seeks to redress is its lack of emphasis on race as a co-constitutive element of disability, particularly given the ways in which racism and ableism can magnify each other in the context of structural oppression (Bailey & Mobley, 2019; Bell, 2010;

Erevelles & Minear, 2010). Further, disability studies has strong roots in white and colonialist perspectives that result in framings of disability that capture primarily white reflections. For example, scholars such as Puar (2017) have critiqued disability studies for its “disability pride” (over)emphasis that can erase the violence and debility that can both cause and result from disability. Other scholars have noted the surprising absence of trauma in the field of disability studies which, for one example, results in further marginalization of the experiences of African American disabled war veterans. There are many experiences of embodied subjugation for which people do not necessary identify as disabled yet still resist the same essentializing and pathologizing frameworks as a CDS perspective, such as is common in medicalization. Thus, if CDS only studied disabled people who identified as such, it would continue to over-focus on the white, disabled experience. This is not to suggest that an academic employing CDS can determine for someone else that they are disabled when they do not identify as such, rather it is a means of analyzing people who are the targets of and in resistance to overlapping hegemonic systems.

In this dissertation, the Social Security Administration’s definition of disability is examined as the unifying factor amongst study participants. No particular physical, psychic or neurological features or spectrums are identified in my methods as constituting disability. The ways in which people navigate the policies of the Social Security disability programs and survive along with and in spite of them are taken to be the ways in which people navigate disability, in concert with the Stone’s (1986) political model of disability. CDS is employed here as a framework for interpreting disability and examining the iterative sociopolitical processes through which the U.S. deems people disabled.

CHAPTER 3: METHODS

Overview

This study employs qualitative methods to explore the lived experience and survival strategies of Social Security disability beneficiaries. While there is little research investigating this subject, a pilot study was used alongside existing literature to formulate the following research questions:

1) How do SSI or SSDI beneficiaries in the Bay Area make ends meet under the confines of Social Security policy?

2) How do beneficiaries experience Social Security disability programs and policy and the bureaucracy that carries them out?

(a) In particular, what impacts does SSA and welfare-related stigma have on its beneficiaries' sense of worth, self-concept, and identity?

Interviews and member-check groups exploring these topics were carried out in Phase I, a pilot study conducted in 2018-2019. Subsequently, the Phase II study consisted of further interviews and member-check groups using a slightly revised interview guide and the above research questions. This chapter describes the methods of these two phases together as one study and notes where there were any changes between Phase I and Phase II.

Theoretical Orientation

This research is informed by a critical realist epistemology and critical social theoretical perspectives. As such, the 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 axiology 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 whiteness embedded in the white medical enterprise, is modeled off of DuBois' innovative sociology research methods epistemology that contended human agency and context would always be necessary to 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).

Axiology

This section will describe aspects of myself, as primary researcher for this proposal, that are likely to be relevant in engaging in this research. Black feminist theorists emphasized the importance of identifying one's positionality, or standpoint, from which a researcher's perspective developed (Collins, 2002[3]). This is especially important for white people such as me whose perspectives are often naturalized and claimed as universal which contributes to the violent oppression of marginalized voices, Black women's in particular (Collins, 2002).

I consider myself as a chronic patient. I have numerous chronic conditions and have since early childhood. My time in the hospital and spent dealing with doctors has increased as my disabilities have progressed and complicated. For a few years I worked as a social worker in the ER, ICU and palliative care. This gave me a terrifying glimpse into the 'other side' of the false dichotomy between patients and providers; terrifying because everything I'd feared doctors judged and discriminately determined appeared at least as bad as imagined, a phenomenon described in Collins' (1986) article *Learning from the Outside Within*.

I collected and analyzed this data in my role as a disabled PhD student who has previously worked in the formal labor market as a medical social worker and has lived on disability benefits including SSDI and the California-based State Disability Insurance (SDI). While on SSDI, 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 on SSDI as the 60-month period of earning over the Substantial Gainful Activity (SGA) dollar amount has passed, since my doctoral fellowship exceeds the SGA. These details are included to communicate the intimate familiarity I have with the research aims and interview participants' narratives. Reflexivity via reflective memoing, consultations with a faculty advisor, peer-debriefing with a research assistant and colleagues, triangulation in data analysis via team coding, and member-check groups are utilized to identify and account for the multiple lenses I wear as disabled researcher in order to remain faithful to participant interview responses as my source of data (Fine, 2006).

Research Design

This research project follows the Phase I study and uses qualitative methods in interview and focus group formats to explore the social and economic experiences of people living in the nine-

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[3] Collins' seminal text, *Black Feminist Thought* (2002) builds theory from a multitude of Black women's voices. Collins incorporates other Black women scholars as well as the Black women participants they interview, building theory from the expertise of Black women in and outside of the academy. For this reason, one cannot cite Collins alone for the theories elucidated in her book (Paschel, Course Lecture, 9/6/2018). Yet, I am doing just that here in order to focus on how her theories informed my research proposal. This footnote serves to acknowledge the many Black women beyond Collins who contributed to the theorizing in *Black Feminist Thought.*

county San Francisco Bay Area who receive SSI and/or SSDI benefits. Twenty people were interviewed in an in-depth semi-structured format for approximately 60 minutes. Phase I interviews (n=13) took place in a variety of locations arranged individually with participants to meet both my and participant's access and transit needs. Locations included an office in Haviland Hall (the School of Social Welfare building on campus), coffee shops, my home, and a public seating area in the local Ed Roberts Campus. Phase II interviews (n=20) took place after the start of the Coronavirus pandemic and thus were conducted remotely through a combination of phone calls and Zoom video conference calls.

Participants were recruited from the nine-county Bay Area in Northern California. This area 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 very high and rapidly increasing cost of living, particularly for accessible housing (Whittle et al., 2015). Since SSA benefits are federally designed and do not account for geographic differences in cost of living (SSA, 2019) 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. In Phase I, participants primarily came from San Francisco and Alameda counties. Thus, in Phase II, more intentional recruitment was focused on the other seven counties in the Bay Area. I shifted the focus of recruitment location without changing the eligibility criteria for three reasons: (1) to expand upon the existing data set in Phase I which is based in Alameda and San Francisco counties; (2) to learn about strategies people use to make ends meet in an area with a high cost of living when subsisting on fixed, federally determined, low incomes; and (3) to allow for a slightly wider pool of potential participants with more varied environments than the two counties in Phase I without altering geography to the point of changing any major or political forces that may significantly impact participant responses. Life in the Bay Area varies in degrees of urbanicity and therefore also varies in degrees of access to public transportation, number of social services available, and costs of living. While no participants lived in a rural setting, some participants lived in more suburban areas than others. Still, survival for SSI and/or SSDI beneficiaries in the Bay Area is amidst the shared backdrop of the Bay Area labor market, high housing costs, and rapid gentrification.

Participants were eligible for the study if they were (1) between the ages of 18-65; (2) receiving SSI or SSDI; and (3) English-speaking. The age restriction intended to include working-age adults, excluding children and older adults, both groups of people who do not face the same social expectation to work and who may have additional sources of income support and benefit programs. Participants were not recruited based on any particular type of disability and only needed to report SSI or SSDI program participation to be eligible. In this way, the defining feature of disability for the study was a political one which considered disability to be associated with a set of program eligibility guidelines rather than biomedical criteria, diagnoses, capacity to perform activities of daily living, or other metrics which might capture the general public conceptualizing of disability. This criterion was intentionally designed to allow for analysis of SSI and/or SSDI participants and to explore ways in which living under the program policies and restrictions themselves became defining features of disability for the participants (see Stone, 1984 for discussion of the political model of disability). However, this choice meant that people who were not deemed eligible for SSI or SSDI could not participate, which excluded people such as undocumented immigrants, legal permanent residents with fewer than five years or residency, and people whose disabilities were not deemed sufficiently incapacitating by the Social Security medical evaluators.

Recruitment and Sampling

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. 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 race, gender, sexual orientation, work history, socio-economic status, and type of benefit.

In Phase I, 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 with my contact phone and email address was posted in community spaces and an electronic version with accompanying image descriptions was shared online. After this phase and reflection on the strong disability identification among my sample, I opted not to rely solely on disability-specific organizations for my recruitment since they often attract a more homogenous group of disabled people (e.g. white with a strong socio-cultural identification with disability, tends to be higher resourced and more system-savvy) than I sought. Further, many people receive social security disability benefits for chronic illnesses or injuries and may not identify as a part of the disability community. Thus, my recruitment strategy pivoted in Phase II. I still used a study flyer with an accompanying image description to recruit via email, social media, phone and snail mail. In this phase, along with a research assistant, I sent the flyer to organizations that serve disabled people (e.g. Centers for Independent Living), social services (e.g. affordable and accessible housing units; food pantries), and college and university disabled student programs in all of the nine bay area counties. I emailed the flyer to leaders in the disability community for dispersal to community group and non-profit list-servs and posted the flyer in Facebook groups that provide resources, information, and community to local disabled and chronically ill communities. While this shift to remote research was necessary to adhere to public health measures, particularly in this setting of interviewer and participants who were at high risk of serious complications from COVID-19, it may have introduced a selection bias amongst Phase II participants.

These outreach methods were adopted to reach as wide a pool of potential participants as possible while adhering to the limitations of social distancing. While there was some success in reaching participants who did not have regular online access (e.g., one participant received the study information from her case manager in a homeless shelter), there was a shift in the general participant characteristics that is likely attributable to the shift in recruitment strategy. The proportion of participants who were white and/or who had a college education or higher was greater in Phase II, including one participant with a PhD and three with graduate degrees.
My phone number (a Google voice 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 directly at the beginning of the study. Interest in the study

was reflected in the rapid response rate from participants and supporting organizations. Leaders from two organizations that provide disability-related services contacted me in response to the study flyer with interest in learning more about the study and shared what they had observed as issues among their membership related to SSA policy in informal conversations.

In total, 33 people were interviewed for this study and 23 of them participated in the follow-up feedback groups. 47 individuals contacted the researcher to participate initially. Ten of those people did not ultimately participate in the study because 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 (see Table 2).

Across the two phases of the study, the sample contained 33 people participated in total (see Table 1 for participant characteristics). They ranged in age from 24-64, with the majority of participants (18) falling between ages 45-64. Participants self-identified their gender: seven participants identified as men, 20 participants identified as women, two participants identified as trans-women, and four participants identified as non-binary or gender queer. Participants were also asked to self-identify their race/ethnicity. 19 participants were white, two were multiracial, three were Latinx, seven were Black, and two were Asian. 10 participants received SSI benefits, 17 participants received SSDI benefits, and 6 participants received both SSI and SSDI benefits. Their educational attainment ranged from less than high school (three participants) to a graduate degree (five participants), with 17 participants completing some or all of a bachelor's degree. None of the participants were married at the time of the study, though five of them had been previously and were divorced or separated. Participants' housing statuses varied greatly: two of them owned their own homes; five lived in homes owned by their families of origin; four rented at market value; 21 (the majority) rented their homes using a subsidy program such as Section 8; and one participant lived in a shelter.

In order to address participant concerns around confidentiality, participants were merged into composites that obscured their identities. This allowed me to incorporate the richness and contextualization from their backgrounds into the descriptions of study findings without disclosing specific details about any individual participant. 10 composites were developed based on shared characteristics and perspectives across the 33 participants. The composites are described briefly in a chart in Appendix F and described in detail in a series of biographical sketches in Appendix G.

Data Collection

I communicated with interested potential participants via email or phone, per their preference. After screening for eligibility in the study in the initial contact, I set up live meetings (either in-person or via Zoom or telephone) with participants to conduct the consent process and, if consented continue on into the interview. The study was approved by the Internal Review Board (IRB) at the University of California Committee for the Protection of Human Subjects as IRB protocol number 2020-07-13431. An oral consent was used since the IRB waived written consent to avoid compromising participant identity when discussing potentially illegal activity. Some participants requested the consent form in advance of meeting so they could read it first due to sensory processing and/or visual impairments.

Interviews ranged from 20 minutes to 2 hours with an average of about an hour based on the level of detail participants opted to go into in answering questions. I audio-recorded the interviews and took occasional notes throughout, documenting non-verbal communication in particular as it would not have been picked up on an audio recording. Three participants had speech impairments that transcriptionists were unable to decipher. In anticipation of this, I took much more detailed notes during these interviews as it was easier to understand the speech in the context of the interviews, participants were present for me to check and confirm what they had said, and since I am accustomed to communicating to people with speech impairments and was more likely to understand them. However, these two interviews were not transcribed completely and verbatim as the other transcripts were. Interviews were often emotional, with several participants becoming tearful and many expressing the catharsis that they experienced in discussing the issues that arose. As a researcher, community member, and former clinician, I balanced empathizing and responding humanely with maintaining my role as qualitative researcher.

During Phase II, I asked participants who had access to a camera-enabled device to use the video conferencing platform, Zoom, to participate in the interview. Six participants did not use video conferencing and called in to the Zoom conference line so that I could continue to use the encrypted cloud storage system to record their audio. For three of these six participants, they did not have the technology needed for video conference and the other three were all blind and therefore the video feature was inaccessible to them. Zoom records audio files separately from video files, thus video files were never saved in order to protect participant privacy. Audio files were destroyed following transcription.

The shift from Phase I in-person research to Phase II online research also brought about a shift in the visibility of my disability. In Phase I, I met participants in-person where I used a wheelchair, clearly indicating my status as an in-group member of the disability community. During Phase II, I met participants via Zoom or telephone, where I was visible from chest up and displayed no visible signs of disability. While I occasionally overtly or covertly disclosed my disability to participants in my interactions with them about disability, the dynamic did shift in Phase II such that I found it a bit more difficult to quickly establish rapport.

Participants were compensated in recognition of their time and expertise they provided to this study. During Phase I, participants received \$15 in cash for participation in the interview and another \$15 for participation in the member-check groups. I decided to increase the amount of compensation for Phase II based on (1) recognition that the amount of time participants spend coordinating study visits with me and participating in study activities was longer than I had initially anticipated and (2) increased availability of funds due to my receipt of the Institute for Research on Labor and Employment student research grant. For Phase II, participants received \$20 for participating in the interview and another \$20 for participating in the member-check groups. \$10 reimbursement was provided to all participants to reimburse them for costs of participation (e.g. phone bills or internet data). The \$10 amount was chosen based on the average interview length (one hour) which uses up approximately 1 gigabyte[4] of data which costs about $10. This additional compensation was intended to mitigate the barriers to participation intrinsic to a study carried out remotely. Participants received their $30 for interview participation and $30 for member-check group participation via electronic visa card or a physical visa card, mailed via visa website, per their preference. Blind and visually impaired participants requested a description of the physical envelop (e.g. envelope size and location of envelope windows) in order to be able to identify the visa card when it arrived in the mail, which was accomplished with the assistance of sighted participants who had received them.

After a preliminary data analysis was complete and initial themes were developed from the coding of qualitative data, member-check groups were organized in each phase. Member-check groups are a technique for ensuring accuracy in qualitative analysis and mitigating researcher bias through soliciting feedback from participants on the data analysis prior to finalizing themes and reporting them out. In addition, member-check groups reflect principles of community based participatory research (CBPR) by involving participants in the research process beyond the initial data collection phase (J. O. Andrews et al., 2012).

In Phase I, the group was held in a conference room in downtown Oakland that was wheelchair accessible and near multiple public transit options. I prepared 7 main themes from the data analysis to discuss with them and provided pen and paper for anyone who wished to comment privately. Refreshments were also provided. Five participants took part in a lively and dynamic member-check group, framed by a semi-structured group guide (see appendix D), which often took the form of a support group when participants expressed relief that others shared their experiences and at times providing each other advice on dealing with the Social Security Administration. This discussion took almost two hours and was also audio recorded and transcribed. One participant who could not attend in-person requested to participate in an accommodated form via email. The group was beneficial in refining some themes, in demonstrating the variety of opinions for others, and in shaping this dissertation's research questions and Phase II protocol.

In Phase II, member-check groups were scheduled according to interest and availability of participants. There were 20 participants in total and 17 participants joined 3 separate member-check groups allow everyone ample opportunity to provide feedback. A higher proportion of participants joined the member-check groups in Phase II, likely due to the fact that they did not have to travel to join the group since it took place remotely. These groups took place via Zoom with some members calling in by phone. The online format made crosstalk a little more challenging than during the in-person groups, which made them more efficient but did not allow for as much of a support group environment to develop as had occurred during Phase I. Groups lasted about 90 minutes each and were audio recorded and transcribed for analysis. I facilitated the discussions using the same guide as in Phase I and presented preliminary findings organized into three main findings areas. In all three groups, the majority of the participants affirmed the findings along with some clarifications and additions. Some participants voiced differing opinions and experiences. The findings in this dissertation are organized into three chapters that

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[4] Source for gigabyte approximation: https://www.whistleout.com.au/Broadband/Guides/How-much-data-does-Zoom-use

parallel the three main findings areas and have incorporated the clarifications and differing opinions raised by participants.

Data Collection Instruments

An interview guide was used to structure the interviews in exploring 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 C). Interviews also explored participants' motivation and desire to work, participation or lack thereof in SSI/DI work incentive programs, gaps between cash benefits and income needed for basic needs, and the various workarounds including unreported income and participation in the informal economy.

The Phase II interview guide had a few additions to the Phase I interview guide based on discussions with my qualifying committee, the onset of the COVID-19 pandemic, and policy changes between the phases. I added one question to explore more purposefully how multiple social identities inform participants' lived experiences as social security disability beneficiaries. In addition, I added one question related to the impacts of the COVID-19 pandemic to the interview guide. Given the dramatic effects the pandemic has had on everyone, and in Black, Brown, poor and disabled communities in particular, it was important both to acknowledge participants' current realities and leave space for possible discussion on how their social and economic coping may have shifted in this new context. Further, some social services programs expanded their reach to meet the rising needs in response to the pandemic provided additional resources, while others were no longer be accessible.

Lastly, I added a question to address a significant policy change that took place after Phase I: CalFresh, the California SNAP (Supplemental Nutrition Assistance Program), became available for otherwise eligible adults who receive SSI and/or SSDI. Previously, the state had considered its Supplemental Security Payments (SSP) payments to include the equivalent of the CalFresh cash amount and thus excluded these recipients from participation. Participants' awareness of this policy change and CalFresh enrollment status would change their experience of food access and therefore be important to include. In addition, ongoingly since the onset of the COVID-19 pandemic in March 2020, CalFresh recipients have their benefits increased to the maximum monthly allotment based on household size ($194 for an individual), which for some people could amount to a 20% income increase (CalFresh.gov, 2020).

A member-check group guide (see appendix D) was developed to aid in facilitation of these groups alongside the preliminary data analysis. The guide contained a brief script to set guidelines and explain the purpose of the group. Next, it provided probing questions to ask in the context of each theme. A separate document listed each theme from the data analysis with an explanation of that theme and an example from the data.

Data Analysis

Qualitative data were collected during in-depth, semi-structured interviews and four moderated member-check groups. Discussions were largely exploratory in nature as this study aims to understand the impact of SSA policies on finances and psychosocial experiences among 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).

In particular, constructivist grounded theory was used to guide the data analysis process. Constructivist grounded theory, rooted in an interpretative tradition, contrasts itself with objectivist grounded theory through perceiving the data collection and analysis process as a social action, or construction, that is co-created amongst study participants and researchers. Thus, unlike in positivist research where researcher bias is assumed to be fully eliminated, the researcher's perspective and values are assumed to be non-neutral and to shape the study findings (Charmaz, 2014). A constructivist grounded researcher's task is similar to that of the clinical social worker entering a client's room: They must recognize and take responsibility for their own values and biases in order to prevent them from entering the research or the client room masked as neutrality or objectivity. In this study, I have included techniques for taking this accountability that are described throughout this section, including the use of team-coding and member-check groups. Still, findings from constructivist grounded theory are taken to be an interpretation rather than a presentation of a solitary truth.

Constructivist grounded theory seeks to build theory based on a contextualized understanding of how study participants create their own meaning and participate in the world they live in. In her seminal text on constructivist grounded theory, the sociologist Charmaz (2014) describes the type of inquiry that is best suited for this grounded theory method: "The logical extension of the constructivist approach means learning how, when, and to what extent the studied experience is embedded in larger and often hidden structures, networks, situations, and relationships," (p. 240). Since this approach emphasizes dynamic relationships and how power differentials between people can be couched in language of objectivity, it is also effective at unpacking this process between institutions and individuals. Thus, the constructivist grounded theory approach is well suited for this research that explores the impact of the institution of the SSA on individuals as it relates to their finances, psychological, and social experiences. Further, the approach is consistent with the critical theoretical foundations described in Chapter 2, since both critical social theories and constructivist grounded theory emphasize the importance of reflexivity and of highlighting naturalized and entrenched systems of power.

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 (Kathy Charmaz, 2006). Interview transcripts 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 subsequent additional readings took place as the interviews were coded and re-coded in Dedoose. Since grounded theory emphasizes data collection and data analysis as an iterative, ongoing, process, codes emerged at varying timepoints in the analysis process which prompted continuous re-reading and re-coding of transcripts to incorporate the newest codes (Charmaz, 2014).

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 Ticket to Work, 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.

Alongside coding, participant descriptors including demographics and Social Security-specific facts were collected from the transcripts and uploaded into Dedoose (see Appendix A: Table 1). 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.

Coding Process

Interviews were transcribed using the NVIVO automatic transcription tool, which allowed me to upload audio files to the platform and access their automated transcriptions shortly afterwards. The transcripts were about 80% accurate and required me and my research assistant to go through each one along with the audio to correct them; redact any identifying information that participants may have disclosed; and add back in non-verbal sounds such as laughter or long pauses. This process of data preparation allowed us to begin to familiarize ourselves with the data and begin to identify common themes. Memo writing started at the data preparation phase in a shared Google spreadsheet that allowed both coders to process our personal reactions to the data, initial interpretations, and preliminary ideas about relationships between the data.

Once the data was prepared into transcripts and uploaded into Dedoose, the process of “open coding” began (Charmaz, 2006). In open coding, which took place during Phase I, I read through the data line by line and identified segments of text that seemed relevant or interesting to the research questions. In this phase of coding, codes were often more literal and less interpretative as the data was being reduced into more manageable parts (Charmaz, 2006). In addition to more literal or descriptive codes, I identified codes for the deductive analysis. In this case, where it was inevitable that participants would discuss similar topics such as the Ticket to Work program or the existence of financial stress, codes were applied to capture areas of intended analysis alongside the grounded theory driven, inductive, coding. The Dedoose coding program permitted creation of “root codes” or “parent codes” and “child codes” or “subcodes” that served to organize layers of analysis and helped group codes together as they emerged into themes. The process of elevating codes into themes is an important juncture in grounded theory wherein theoretical concepts are developed through researcher analysis of codes’ centrality and their relationship to other codes or categories (Charmaz, 2014). In the codebook (see Appendix E), the term “grandchild code” is used to denote subcodes of child codes. In all, there were 103 codes with 28 root codes. Analysis in this dissertation ultimately did not make use of all codes. Some, particularly codes related to the root code “work activity,” will be analyzed in a separate paper at a later date.

While Phase II took place after I had finished an analysis of Phase I data, I continued the iterative process of data collection and data analysis by starting Phase II analysis with the same codebook I had left off with after Phase I analysis. This meant that I already had a set of codes to expand upon, refine, and confirm that shaped my ongoing analysis. Phase II coding allowed me to confirm and build upon the findings I present in Chapter 4 with a new framing gleaned from the code, “playing the game.” It also allowed me to look deeper into areas that I had started to code in Phase I, such as “social death,” which the Phase I member-check group members had highlighted as particularly salient. Themes that expand upon “social death, represented in codes such as “stigma” and “institutional humiliation,” are presented in Chapter 5 along with other psychosocial issues experienced by participants. The additional participants and qualitative data in Phase II led to the emergence of a new theme that I had not identified in Phase I, identified first in the codebook as “communal experience” and discussed as “an institution without walls” in Chapter 6.

Codes were applied by identifying I completed the initial coding of all the coding independently at first, which included recoding the 13 interviews from Phase I. Then, my research assistant, an undergraduate student who also identifies as part of the disability community, coded half of the 33 interviews using the team-coding feature of Dedoose that allowed us to view, compare and contrast each other’s work. We both used memo writing as a way to process our reactions to the interviews as we coded individually. Additionally, we met weekly for a few months to discuss the coding process and emerging themes, including areas of discrepancy or disagreement between our codes. Discussions about the precise meaning of codes in order to communicate how to apply them aided in refining codes and their relationship to one another. Further, questions that the research assistant brought up throughout the process such as why I asked certain questions during the interview or why I had applied a particular code to a given transcript excerpt prompted my reflexivity and consideration of how my role in this research may have shaped the findings.

For example, there were a few participants who did not describe any significant economic or psychosocial distress related to their status as SSI/DI beneficiaries. My initial reaction to these interviews during analysis was to consider them outliers and I did not apply many codes to their transcripts. Upon reflection in our coding meetings, I realized that as a former SSDI beneficiary I had allowed my semi-insider status to prevent me from fully absorbing responses from participants that did not align with my experiences and what I had expected to hear from participants. These discussions prompted increased reflexivity and by extension the introduction of new codes to better track and capture differing experiences, such as “financial stability (relative);” “networking/social capital;” and “food access strategies.” (see Appendix E for codebook). In addition, these discussions shifted our application of some codes from unidirectional to bidirectional such as “family support” and “social support” to include participant references to the presence and absence of these components. This shift in coding to analyze differential experiences allowed for a discussion in Chapter 4 of the factors that were main contributors to participants’ whose experiences were in the minority. After coding, refining codes, and categorizing codes along with my research assistant, the analysis seemed to reach theoretical saturation, meaning that coding new interviews no longer produced new codes or themes (Charmaz, 2014).

CHAPTER 4:

PLAYING THE GAME:

ADMINISTRATIVE BURDEN AND SURVIVAL ON DISABILITY BENEFITS

You know, that's the way you play the game. Am I writing off the printer ink that I have to print the copious receipts for Section 8 housing? You betcha. Am I writing off, you know, the batteries for my adaptive equipment? Yeah, you know. Whatever I think I can justify and I'm pretty good at justifying.

- *Louise, age 46*

Introduction

Respondents like Louise described how surviving on SSI/DI was akin to a playing game in which one has to study the rules and skillfully operate within the constraints presented by them. Her experience helps to answer the central research question: *How do SSI or SSDI beneficiaries in the Bay Area make ends meet under the confines of Social Security policy?* In doing so, the chapter examines participants' lived experience as it relates to their interactions with the state through a variety of benefit programs, with a focus on SSI/DI. Further, it lays the groundwork for the subsequent two empirical chapters that analyze how these experiences relate to participants' sense of self and their roles in society, on both individual and community levels.

The routine experiences of SSI/DI beneficiaries and how they make ends meet has remained largely out of the public eye or discussion up to this point. Yet, it is difficult to truly assess or understand these two massive federal public assistance and social insurance programs and the policies that dictate them without understanding the concrete administrative activities and the experiences of the people who engage with them (Ting, 2017). In order to demonstrate how the qualitative data illustrate daily life for SSI/DI beneficiaries, this chapter will describe the theme of how SSA shapes individual behavior and experiences. Theories and scholarship that lend to this illustration of participants' quotidian survival will be described along with data to show how these concepts emerged from the raw data and coding process.

First, the overarching framework that participants described as a mechanism to navigate benefit systems, "playing the game," is described. The following section goes into more detail as to what survival strategies look like for SSI/DI participants as they "play the game." In discussing the negative impacts of "playing the game," most participants brought up the challenges they experienced with the bureaucracy associated with systems they navigated. This emerged as the code, "bureaucratic burden." The public policy concept of "administrative burden" is discussed in the third section as a framework to understand the harm participants' experienced as they interacted with the SSA and other benefit systems. The next section focuses on work activity and its associated administrative burden for SSI/DI beneficiaries. Next, the section focuses on a specific example of a key contributor to administrative burden for SSI/DI participants, overpayments. The experiences of administrative burden and "playing the game" contributed to participants' loss of trust in the SSA. This connection is the topic of the following section, Institutional Distrust. Finally, this chapter ends with a discussion of findings that were divergent from the main themes and an exploration of how SSI/DI policy might impact individuals differentially.

Playing the Game

When participants were asked about strategies that they used to make ends meet living on SSI/DI benefits in the expensive Bay Area, several of them responded using the same metaphor referred to herein as "playing the game." Playing the game referred to a collection of behaviors and strategies aimed solely at surviving on SSI/DI and various other public benefits in the Bay Area. Other public benefits are included here in addition to the disability benefit programs since the SSI/DI monthly payments necessitate supplemental resource support. For example, the average monthly rent in any Bay Area county easily exceeds an average monthly payment of $1,277 on SSDI or a maximum monthly payment of $944 on SSI, requiring people who cannot live with family to use Section 8 or other public housing options to access housing (SSA, 2020a). Thus, the benefit programs needed for survival and how they interact with SSI/DI are included in this analysis.

In addition to obtaining and managing benefits, playing the game acknowledged the lengthy and varying rule book that one must live by to maintain enrollment in the different programs as set by policy, such as adhering to work and asset limitations. The rules of the game are the varying ways in which SSA workers implement SSA policy. As participants perceived it, the game is set up such that benefit recipients are on one side seeking to maximize benefits and benefit administrators, such as SSA workers, are on the opposing side, presumably seeking to minimize benefits. Yet, the game is not fair since the opponents, or administrators, have the power to set and change the rules of play. As Sam, a 61-year-old white, gay, man from San Rafael explained, *"I always have to be mindful that the rules of the game are not written in my favor [laughs], that I'm not supposed to win the game, that I need, that I must cheat to win the game. That's something that I have to do if I want to survive . . ."* Not only were the rules of the game unfair, the game had very different stakes for the opponents when compared to participants' depictions of game playing as survival. In this framework, the objective of the administrators is simply to win, or minimize benefits, and the rules are written to aid this outcome. This reflects how many participants perceived SSA; as an administration with arbitrary rules and unpredictable communication about their rules, not one grounded in ideas of equity or resource redistribution.

Survival on Disability Benefits

Almost all participants reported feeling worried about their ability to make ends meet, and all participants engaged in very strict budgeting processes. Most participants' incomes ranged from below to slightly above the federal poverty level (the California SSI monthly benefit equates to 89% of the federal poverty level) and additionally they incurred extra costs of living due to their disabilities. Thus, participants were routinely making difficult decisions about where to cut costs. For almost 1/3 of participants in the sample, making ends meet entailed skipping meals. For still other participants, food budgets were cut very low through strategies such as eating the same thing every day or buying meal replacement drinks in bulk to curb their hunger. Many participants were ruthless in determining what was a "want" versus a "need" in order to make ends meet, for example several avoided transportation costs whenever possible, even with low-fare public transit cards. Tili, a 40-year-old, Black, transwoman from San Francisco explained,

> *Yeah, because you want to go places. Say, I might want to go see my friend over in Oakland, see? So that's still a want. When you look at that, you can look at your wants, but you also need to pay more attention to your needs. You need toothpaste, you need a toothbrush, shampoo, conditioner, and sometimes you just don't have the money for that. So what do you do? You take pennies out.*

What Tilly describes illustrates the mental calculations that go into surviving day to day for disabled people living on SSI/DI benefits. Further, she notes that her extremely tight budget requires to her to consider human connection as a luxury. This was particularly hard on Tili, who was in recovery from years of trauma, addiction and mental illness. Connection was key to her recovery, and she knew that she had a tendency to isolate when her stress levels rose.

She was not alone in this, as several participants also cited going out without socializing as a strategy to make ends meet. Most participants prioritized paying their bills first, such as rent and utilities, and split up whatever was remaining into food and basic necessities for the month. This left some participants going without what many would consider to be necessities, such as body lotion, and finding creative ways to obtain other necessities, such as sewing reusable menstrual pads and finding discarded household items such as pots and pans on the street.

Participants also engaged in a number of informal economic activities to make ends meet. For example, some participants bartered their skills and resources for things they needed and could not afford. One participant, a 52-year-old white woman from Oakland named Victoria, explained that marijuana was the most effective way to treat her chronic symptoms, yet was not covered by health insurance. In order to afford it, she drew on her baking skills and her network of other SSI recipients who participated in a barter economy:

> *. . . mostly what I use, because I mostly medicate with edibles or with tea, is [marijuana plant] trim, the leftovers. Now that can be used to make other things, but very often people will trade that [trim] for edibles down the road or something like that and so it just has worked out through the barter economy that exists within the black market to trade mostly for my weed. . . and I actively, you know, tried to establish a network in order to make that a possibility.*

Victoria was not alone in depending on a community of people who also had to be careful about how much money they took in that could be traceable through bank accounts. Other participants worked in a purely cash economy in order to earn money that would not be reflected in bank accounts that Social Security surveilled. These income mechanisms included informally renting out a part of their homes, babysitting, cleaning houses, doing odd jobs, and busking. A few participants reported that they used to engage in sex work to make ends meet but were no longer at the time of the interviews for reasons including disability progression and associating sex work with a substance from which they were in recovery. Participants emphasized that they engaged in unreported and off the books work in order to survive and that these efforts still left them barely scraping by financially.

The high regional costs of living in the Bay Area were another focal point for many participants, who decried SSI/DI policy for providing uniform benefit amounts regardless of geographical location. While several noted that the Bay Area was a great place to live as a poor person because of the many social services available, they still felt that geographical variation was important for the SSA to take into account when considering cost-of-living amounts. Concerns over high costs of living were particularly pronounced when participants discussed their housing status. While a few participants lived in houses that they or their families owned, the majority rented and participated in housing subsidy programs such as Section 8 or lived in supportive housing units. The degree of financial precarity or stability that participants experienced was frequently tied to their housing status. For example, a few participants lived in apartments owned by supportive housing organizations which had specific eligibility criteria they were concerned about maintain. One such participant, Melvin, a 40-year-old Black man living in a suburb of Oakland, recounted applying to Section 8 in every single county in California in hopes that he could afford to live somewhere in the state by the time he was kicked out of his current housing.

Administrative Burden Among SSI/DI Recipients

Participants made ends meet in part by making use of Social Security disability benefits as well as other county, state and federal benefit programs such as CalFresh (the California Supplemental Nutrition Assistance Program, or SNAP, benefit), Section 8 (the federal housing benefit program), Medi-Cal (the California version of Medicaid), or IHSS (In-Home Supportive Services, the California Home and Community-Based Services benefit). Participating in as many additional public programs as possible was generally necessary to make ends meet as disabled adults living in California's expensive Bay Area. These benefits programs are administered at varying levels of government and have distinct criteria for eligibility and program recertification. Further, the benefit systems do not have internal processes for coordination amongst each other - or, as Momo explained it, *"Social Security and Medi-Cal do not speak."* Hence, participants described spending significant time applying for, obtaining, recertifying, and managing these benefits. Momo is a 30-year-old Japanese man from Solano who works a full-time job for a small company, but maintained his SSI in order to receive IHSS through Medi-Cal. Though he could not receive monthly cash benefits, he needed the medical benefits which would otherwise not be available to him. As one of the younger participants, Momo hoped to eventually move off of SSI and develop a career for himself in consulting. He reviewed his to-do list as of our meeting: *"Right now, I have income papers for my landlord, I'm expecting income papers for my Section 8, and I also have to turn in paperwork for Medi-Cal."*

This process was especially burdensome given policies requiring extensive documentation, presumably aimed at reducing fraud, to prove one's eligibility and particular expense categories, such as medical expenses. Still further labor was required to access less formal supports for basic needs, such as food. Reese, a genderqueer and multiracial 25-year-old community activist living in Contra Costa, described their strategies for making ends meet at the end of the month when their disability 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. [Local non-profit] has produce on Mondays. They try and encourage healthier eating. Sometimes I'd go to [local town] Plaza for some produce. It's a little cheaper. So yeah, one was finding the cheap and free food.*

For some participants, disability-related symptoms made these complex processes even more challenging. Participants with cognitive symptoms such as brain fog described instances of missing forms, or even missing components of a single form, leading to benefit delays.

Others with psychiatric disabilities described experiencing significant anxiety over bureaucratic processes that were difficult to understand yet had potentially severe consequences -- namely, losing benefits -- if they were not completed in an accurate and timely manner. As Penelope, a 55-year-old white woman from Alameda who receives SSI and SSDI, described it: "*There's paperwork every year. They send you paperwork and stuff and you fill it out. And so, it's very stressful because it's hard to understand some of the stuff on the forms and things.*"

These bureaucracy issues are conceptualized by the field of policy administration as administrative burden, which is defined as the "learning costs, psychological costs, and compliance costs" born by individuals in their interactions with the state (Moynihan et al., 2015). Moynihan et al. (2015) have argued that the amount of administrative burden placed on an individual in an interaction with the state, such as receiving SSI/DI benefits, reflects a "hidden politics" of policy makers. This is particularly salient in the current era of welfare retrenchment, where SSI/DI represents one of the remaining cash benefits available to adults in the U.S. Since an increase in administrative burden results in a decrease in program uptake, as individuals are unable or unwilling to engage with the required bureaucracy, and vice versa, it is an area ripe for channeling political dislike of the welfare state. Rather than overtly widening or shrinking the eligibility of given state programs, policy makers can use a hidden lever of administrative burden.

Yet, administrative burden that may result from subtle policy changes tends to take place away from public scrutiny; in private, among harried and overworked bureaucrats and overwhelmed recipients waiting long hours in welfare offices, as discussed at length in Lipsky's *Street Level Bureaucracy* (2010). Thus, it is important to render such administrative burden and its human implications visible (Chudnovsky & Peeters, 2020; Moynihan et al., 2015; Ting, 2017). This visibilizing work has been done in some areas of social welfare policy, such as in Eden and Lein's seminal work on single mothers receiving TANF, yet remains largely obscured for the experiences of adults receiving Social Security disability benefits (Edin & Lein, 1997).

Two components of administrative burden, "compliance costs" and "psychological costs," are particularly resonant with participants' experiences. Compliance costs are bureaucratic requirements to maintain benefits that usually take the form of paperwork to demonstrate continued eligibility for a program. Examples of compliance costs include annual benefit recertification processes and requiring extensive documentation as evidence of income. Psychological costs refer to negative social and emotional experiences as a result of social program participation such as stigma, loss of autonomy, uncertainty, frustration and stress. Psychological costs often take place when participation in a public program involves public identification, such as standing in line outside of a pantry (Moynihan, et al., 2015).

Both compliance and psychological costs can have strong deterrent effects and numerous studies have demonstrated how an increase in either type of cost leads to a decrease in program take-up rates (Moynihan et al., 2015). Melvin described this exact phenomenon when he explained why he did not use IHSS services, even though they would have benefited him:

> *Yeah, I tried it. I tried it twice. It's just so much paperwork in the beginning, and you don't hardly get enough in it. For me right now, I don't want another bureaucracy in my life. I said I don't want to do that with another agency. A lot of people ask me why you don't use support services. I just don't want to fill out another stack of papers for a little bit of service.*

Melvin was not alone in eschewing a helpful public service due to administrative burden. Several participants cited "paperwork" and a general sense of bureaucratic overload as the reason they did not apply for CalFresh, or why they gave it up after finding out they received a low monthly allotment such as $12 per month. Bureaucracy took a clear toll on participants, thus engagement with it had to be worthwhile.

Given the inverse relationship between administrative cost and program take-up, bureaucratic discretion can be used to increase the administrative burden on program participants, particularly when a group is viewed as undeserving (Moynihan et al., 2015), which could provide insight into the relative increase of SSI bureaucracy as compared to SSDI bureaucracy. Sunstein (2018) has described the excessive paperwork requirements to maintain benefits as "sludge," and called for deregulation of many social programs to increase their accessibility. Deregulation in the context of SSI could involve waiving the requirement that recipients have no more than $2,000 in assets. Critically, this would not only waive the asset requirement, it would also waive the constant asset testing via monitoring of recipients' bank accounts.

Administrative Burden and Work Activity

Working while receiving SSI/DI benefits brought in a whole new realm of administrative burden and game-playing. Some participants found themselves in situations where, due to the fluctuating nature of some disabilities, they had periods of time where they had both motivation and capacity to work more hours than permitted by SSA. Since they knew they still had to rely on SSI/DI to receive cash benefits as well as benefits such as Medi-Cal and IHSS, disclosing a higher number of work hours was not an option. Maxine, a 45-year-old Black woman from Contra Costa, characterized this dilemma as being "locked in[to]" her disability benefits:

> *"Ideally, you know, if my condition allows, I definitely want to work more. I want to be self-sufficient. And I wish, you know, I didn't have to depend on Social Security so much, but yeah, definitely it keeps you in a... it's a limitation, you know, because you can't go over that SGA amount without your benefits decreasing, you know, eventually. But then you have to think about, wait, my condition may change and then I may have to do this process all the way over, you know? Yeah, you're definitely locked in. Definitely locked in."*

Maxine's reflections point to a common concern among participants; that the SSA definition of disability did not mirror their own experience of disability. In SSA policy, disability is a binary state and one can either be disabled or able-bodied, with no further options. Yet, whether or not a participant could work was much more complicated than this binary.

For some participants, work was possible when they received appropriate accommodations from their employer, yet due to limited education and work availability, it was difficult to find an employer willing to make appropriate accommodations when they could just as easily hire another non-disable low-skilled worker. Others experienced weeks to months when they could be productively engaged in a work environment but needed to be able to take leaves of absence when disability flares took place. This left many participants feeling frustrated that there wasn't a system that could allow them to work when they were able and provide a safety net when they were not. It was particularly frustrating for those on SSI who felt that due to the asset limit, they were prevented from even trying to develop their own safety net. Stevie, a 48-year-old, Puerto Rican woman from Solano, explained how she and others in her position navigated this conundrum of working while maintaining benefits:

> *Well, I'm working for a nonprofit, right. So, yeah, every time there's a cost-of-living increase, they and I have a little chat beforehand and make sure it's not going to do evil things to me. And if it is, then we figure out a way. For example, they may reimburse me for a phone bill or something on a monthly basis. Which brings extra money to the table that doesn't get counted as income. Many people may do something to the effect of having an assistant and having them get hours and then actually having several hours be yours. But that's not going on your paycheck. It's going on theirs. So that's, that's another coping mechanism that some people may use.*

Stevie described ways that she was able to earn money through working without actually earning money through a paycheck. The irony of this work, or game-playing, to navigate a system that is designed to provide income to people unable to access the labor market was not lost on Stevie. She reflected on the flawed perception of SSI/DI recipients as people who "game systems" or seek to exploit public benefits, as distinct from a system so replete with administrative burden that it results in game-playing:

> *Then the system... you know, is set up for people to* haaave to *widely interpret it, in a way that, you know, that they can, that they can make work to their benefit and still play the game. And you know what a different system it would be if they just said, OK. You can make what you make. You turn in your receipts to offset. The rest is gravy. And you know, we're going to work with you to figure out how best to do that. We're going to raise the ceiling on the two-thousand-dollar assets. We're going, you know, we're going to do it differently. And, you know, I mean, I get that there are people that game systems. I understand that. But to think that everybody is going to this set up to do that and to think that we all are kicking back here making the big bucks and it's, you know, we're doing nothing -- it's not the case.*

Here, playing the game was distinguished from gaming the system through the outcome. Gaming the system was reminiscent of welfare queen ideology, the stereotype of malingering people who live lavish lives based on deceitful exploits of government programs. Instead, participants saw themselves as trying to make the best of a flawed system in order to survive in a game stacked against them. Recognizing the thin border between this distinction, Sam would later playfully refer to himself as a "*disability queen*."

Participants who were participating in SSA work incentive programs and working in addition to receiving benefits took on additional bureaucratic responsibilities. Penelope explained, *"when I was working, myself and my attendant would go in [to the SSA office] once a month before the 10th of each month, sit to wait to see somebody, show them all the receipts and everything, my check stub and all that."* Prior to the COVID-19 pandemic, SSA beneficiaries were required to complete routine reporting tasks in person, at an SSA office. The quick shift to phone and internet interactions with SSA prompted a few participants to question why it was ever necessary to go to the SSA offices. The trips required the time, funds, access support, and energy to travel between home and the nearest SSA office as well as to sit and wait long periods of time to be seen between the hours of 9am-5pm on weekdays. Adding this logistical and time-intensive challenge to their schedules presented additional barriers to work for disabled beneficiaries who sought to enter the labor market.

Further, tasks that required going into SSA offices contributed to psychological costs of administrative burden (Moynihan et al., 2015). Participants described feeling humiliated when they entered SSA offices due to stigmatizing aspects of these appointments including security screens, high levels of surveillance and suspicion. Worse still, they rarely felt that their questions were answered through these oft degrading encounters. Tili described a series of frustrating encounters with SSA offices:

> *It's not fair. You know, workers say one thing and then the other. They all should be on the same page because they had me thinking that they're going to help me, you know what I'm saying, but instead they said to me, oh, no, you got to go to the next one. Your branch now is all over there on [name omitted] street because of where I live, so I go over there.*

In this instance, while frustrated, Tili was able to eventually sort out her issue after multiple trips. Some participants experienced this type of run-around as a more severe barrier to service, such as two participants with psychiatric disabilities who each endorsed being agoraphobic and struggling to get to the SSA office even when they anticipated that they might receive additional funds after straightening out bureaucratic issues.

Several participants alluded to the irony in the amount of work they had to do to maintain benefits provided in lieu of income from a job by referring to this labor as "like a [full-time] job." Melvin was one of these participants, and contrasted the actual and laborious experience of being on SSI with the common stereotypes assigned to SSI/DI recipients:

> *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 the SSI office to give papers. Then I have to go to sort out my Medi-Cal. Then I have to go to the Section 8 office. It's stressful. It's like a full-time job."*

Almost every participant described stressful components of survival on SSI/DI benefits. Some participants found psychic relief in reframing their work to manage and maintain benefits for survival as playing a game. Stevie explained:

> *... one day I was talking to a friend of mine and I said, I'm so stressed. I got to da-da-da-da and I was just rattling off all the stuff I had to do for all these different programs. And so she said to me, think of it as a game. At least if you think of it as a game, you'll figure out what you need to do and you figure out a way to beat the game - you know, and then it won't weigh on your head as much.*

Reframing the administrative burden of survival into playing a game seemed to help some participants to manage the pain they felt from needing to interact with systems that did not seem to have their best interests in mind. Lessening the psychic weight of decision-making and labor in completing administrative tasks to maintain benefits by "thinking of it as a game" helped some participants garner their strength to get their piles of paperwork.

The Burden of Overpayments

One area in which interactions with SSA workers was a particularly frequent topic among participants was in discussions of overpayments. Sam described an experience he had when he was first approved for SSDI and received his retroactive payment from the SSA-determined date of disability:

> *. . . so I did get my lump sum minus the general assistance money. And then I got like, six weeks later, I got a letter from Social Security saying, well, 'we miscalculated, like you owe us five thousand dollars' I was like, OK. And then about seven weeks ago, I got a surprise electronic deposit in my checking account from Social Security for twenty-four thousand dollars. And so [laughs] and so I was like 'You know what? Like, I'm just going to take this money. I'm going to put it in an interest-bearing account [laughs] and I'm just going to let it sit there till they ask for it back because they're going to ask for it back.'*

Here, Sam recognized his own limits on preventing overpayments from Social Security, particularly in the era of direct deposits, and seemed to cope with the stress of uncertain finances through humor, psychically, and with a separate bank account, fiscally.

Overpayments occur when the SSA sends SSI/DI beneficiaries more money in their monthly benefit than they are due. More than half of participants receiving both SSI and/or SSDI discussed experiences with overpayments and cited them as a source of administrative burden and considerable anxiety. This large number of overpayments is reflected in research on the prevalence of overpayments among SSI/DI beneficiaries, which shows that overpayments are particularly likely to happen when beneficiaries report their work earnings while receiving benefits (Hoffman et al., 2019, 2020; Kregel, 2018; Livermore, 2003). Overpayments brought palpable dread to participants who described feeling powerless over a situation which they knew they would be blamed for and required to solve. These situations departed from the psychological costs of administrative burden identified in the literature, since they did not result from policy administration but from administrative errors in policy administration, a phenomenon not identified as such in the literature. As Tili explained,

> *They are penalizing people for their mistakes, because, see, I had to pay back Social Security so much money because they said that they overpaid me. Well, I did not know that. That wasn't my fault; it was theirs. So I think Social Security needs to be more conscious of people's well-being, you know?*

Tili was frustrated by the lack of accountability the SSA was held to when it came to their not infrequent overpayments. Having funds withheld from future benefit checks had significant tangible consequences on her daily life, such as needing to cut her food budget for the month and take the bus to different parts of the city to access soup kitchens and food pantries.

Several participants described scenarios in which they were aware that SSA had overpaid them and yet they were unable to stop it, which often caused them significant stress as they anticipated an unknown future date when it would be requested back. Momo described a maddening scenario in which he was aware that he was going to receive an overpayment due a recent pattern and went out of his way to prevent it, to no avail:

> *A couple of times I submitted my pay stub late and they gave me about $200 because according to them my income changed . . . But once they recalculate everything, that $200 becomes an overpayment. . . . And even though I told them multiple times, PLEASE,*

> *do not send me any money because I don't want to increase my overpayment [laughs] because I do have an overpayment that I'm still paying. So last time I had, I went to the office and I asked the worker, 'please do NOT send me any money [laughs]. Even though my pay stubs come late to you, I don't want to add to my overpayment. Even though they told me, 'Ohh, you can use the money!" . . . But they'll want it back.*

This situation did result in Momo receiving yet another overpayment, though he was aware of it and could put the money aside in this instance.

A lot of policy literacy and vigilant monitoring of benefits and bank statements is required to be as aware of an overpayment as Momo was, and this was not common amongst participants. Further frustration came from the style of communication from SSA, that made participants feel like they were always in the wrong, even when it was clear that SSA had erred. Momo referenced these feelings after his last overpayment: *"They haven't sent me anything like 'OK, we're sorry.' I mean I know I'm never going to get an apology, but they never own up to the fact that they blew it either."*

The only successful strategy for preventing an overpayment was recounted by Stevie in reference to an incident decades ago when the SSA mailed paper checks as the primary mode of payment. She held onto the paper checks without depositing them and was able to return the physical checks to the SSA office. Yet, to be in the position of strategizing how to repay money from SSA before they deducted it from future benefit allotments required both sophisticated policy literacy, advocacy skills, and some degree of financial stability. Sam continued to discuss his overpayment and reflected on the larger issue it represented:

> *"Usually, they don't provide a mechanism for you to actually repay. They just deny, they just deny your future benefits, right. They say, "OK, for the next eight months, we're just not going to pay you because we've decided we've already overpaid you", which wreaks havoc with any ability to do financial planning. You know, you put this money in my account. You said this was my back payment. What do you mean I owe you five thousand dollars? You know, like just it's crazy. Luckily, I had it, but a lot of people are not in as privileged of a situation as I'm in. . . . And like I said, luckily, I'm in a privileged economic situation to be able to do that. People who live with food insecurity, you know, and go hungry or can't buy medicine or can't pay their rent. You know, they're going to use that money if it's sitting in their accounts [inaudible]. Rather than be evicted or go hungry like or be sick, like you're going to use that money. And then later to be told, like, "oh, that never belonged to you to begin with." It's just it's just so destructive to people's lives, to their sense of stability."*

Sam's decades in the workforce prior to receiving SSDI and ability to live cheaply in his family-owned home granted him more financial stability than other participants. He understood this and was very sensitive to how his circumstances differed to the average SSI/DI beneficiary. His discussion of the impact of overpayments on beneficiaries with less privilege bore out among many participants. For others, managing overpayments often looked like finding ways to make ends meet with even less money on an already stretched budget. These strategies included using credit cards for purchases, getting support from friends and family, and going without necessities such as fresh food and basic household items. This can go on for months or even years, as the SSA typically makes a payment plan and withholds a portion of the monthly benefit until the beneficiary's debt (overpayment) is resolved.

It seems reasonable to suggest that if a policy is too complicated or arduous for the SSA to accurately carry out, it is too complicated or arduous to subject beneficiaries to managing. Research into overpayments primarily investigates work-related overpayments, which refer to the overpayments resulting from the highly complex work incentive policies that allow beneficiaries to earn money while receiving benefits in various cases. Findings from (work-related) overpayment analyses suggest that they usually result from a mix of SSI/DI recipient error and SSA error (Hoffman, 2019; 2020). These errors often relate to delays in work reporting, complex rules governing benefit administration when beneficiaries are working, and insufficient administrative resources (Hoffman et al., 2019; Kregel, 2018). In a study exploring the experiences of SSDI beneficiaries who dealt with overpayments while participating in SSA work incentive programs, Kregel (2018) found that after an overpayment, half of respondents stopped working and additional respondents reduced their work hours. Thus, participants in this study and the existing literature suggest that overpayments act as a work disincentive, in addition to their financial and psychological implications. Recent research has identified an association between higher employment-population rates among SSDI beneficiaries and a great prevalence of overpayments. In their longitudinal analysis, Hoffman and colleagues (2020) suggest that this association may be due to an increase in work reporting by beneficiaries that the SSA does not have the administrative capacity to manage. Findings from this study lead to the recommendation that work reporting for beneficiaries be waived until the SSA has the administrative capacity to manage them and thereby avoid the unwarranted harm overpayments can impart.

Institutional Distrust

For some participants, the game playing metaphor belied a lack of trust in their government and its institutions, namely the SSA. At least half of the participants perceived the SSA as an institution that did not truly seek to help disabled people but instead to entangle them in a rigged game. While many participants frequently used humor to cope with the absurdity of situations they found themselves in, occasionally a deep sadness emerged underneath it. Sam grew quieter after joking about the game and its unfair rules and acknowledged, *“It's just sort of a sad part of my reality that this is an institution that I can't trust, that I can't be honest with. It's not fair. It's not a fair system. But I've just got to do what I can to survive.”* This loss of trust in government institutions is a clear example of how administrative burden can mediate citizen experience of the state, here as a negative rather than positive force, and shape how citizens perceive their own role with respect to the state.

For a few participants, the loss of trust in the SSA lead to a disengagement with “the game.” They felt so fed up with the inconsistent information from different SSA workers and the constant administrative errors, that it did not seem worth playing their own role as scrupulously. Melvin responded to a question about reporting his work earnings:

> *In the beginning, yes, but now I don’t. I don’t report it, so I know I’m taking a chance but I used to in the beginning, but I realized they would mess up constantly, and they would send me letters that I owe them. When I found out that they messed up. . . why am I doing that if you’re going to mess it up, so I just stopped doing it. I know I’m taking a risk, but yeah.*

Here, Melvin referred to issues of erroneous overpayments that arose when he submitted earnings information. As discussed throughout this chapter, dealing with an overpayment can be very disruptive and even harmful. Thus, if overpayments arise in relation to work reporting, it is not surprising that Melvin would lose trust in the reporting system. In fact, choosing not to report work is one of the few ways participants could find any control over their situations, even if it did leave them worrying about the risk of eventual SSA discovery.

Similarly, Reese described a sentiment they shared with their community of loss of faith in the SSA. Further, they linked their observations of the SSA and impacts on disabled beneficiaries suggesting that SSA not only is not trustworthy, but it in fact also seeks to do harm:

> *I guess I just want to say that it's clear to me and all of the disabled people I'm friends with and who rely on Social Security as their main means of income, it's incredibly difficult to be approved for this benefit. People die during the waiting process. They make it incredibly hard to be approved. If you do get approved, they make it incredibly hard for you to be able to live on the amount of money, poverty wages. It keeps people trapped in poverty and it's a way of slowly killing people, and I do know disabled people who have died waiting to be approved for Social Security. I know people who have died because they needed to turn to survival work while they were receiving their benefits. The system was designed, I think, to kill people. We deserve better.*

Reese was a part of a highly politicized community of disabled people in the Bay Area and seemed to have had spent a lot of time reflecting on these topics. They were visibly angered as they talked about people in their community who had died before their time due to poverty-related causes. While some participants thought that the SSA could be slow, inefficient, and gave poverty-level benefits because of how many people were on the system, people who were identified as disabled and considered themselves part of a disability community were most likely to express this view of the SSA inflicting intentional harm.

The sum total of participants' experiences and interactions with SSA and its representatives resulted in a deep mistrust that permeated every aspect of the SSA. Thus, administrative burden and institutional trust are important factors for SSA policy makers to consider, if only as factors to consider in motivating workforce participation. Participating in SSA work incentive programs such as TTW requires trust that the SSA will keep its word and allow participants to return to benefit receipt if working does not turn out to be a feasible option for them. The majority of participants interviewed described fear of losing benefits as a major barrier to working, even after learning about ways in which the TTW policy seeks to ensure a pathway to return to benefits. Thus, distrust of the SSA harms all players in the game and weakens adherence to its rules.

SSA Policy and Differential Survival Experiences

Not all participants had the same experiences playing the game nor felt the same degree of administrative burden. This section reviews some survival strategies and privileges that appeared less frequently in the data. Next, it presents participant demographics associated with differential experiences to lend an intersectional perspective to the findings. Current and historic SSA policies are discussed to explore how SSA policy impacts individuals differentially.

Several participants received intermittent financial support from family members and romantic partners that was essential to making ends meet and went unreported to the SSA. A few participants lived in homes that were owned by family members, which often made a dramatic difference in lowering the amount of routine financial stress they experienced. Living arrangements and familial relationships affect SSI benefit amount. Adults who rent or own their own home and are responsible for their own food can receive up to about 1/3 of the total benefit more than adults who live rent-free, or receive support on food or other household bills, or any combination of the above (SSA, 2020b). Married adults, or two adults living together as if married, also have their benefits deducted for the presumed cost-savings of cohabitation. In this sample, participants who lived in housing owned by family were typically far more financially stable than those who did not, likely due in part to the relative high cost of housing in the Bay Area. These select participants who lived in an owned home and experienced relative financial stability as compared to the sample were all white. This is one of many ways that participants' identities beyond their disability status affected their experience on disability benefits.

Experiences with administrative burden also varied among participants. Here, the starkest differences were among participants who had SSI or SSI and SSDI benefits, as opposed to SSDI alone. While most of this dissertation looks at these programs together and focuses on their overlapping elements, there are meaningful distinctions that I will briefly address here. SSI, as a means-tested public assistance program, has more programmatic restrictions on its participants and overall a greater administrative burden. SSI recipients have an asset limit of $2,000 and have their bank accounts regularly monitored to make sure they do not go over the limit. SSDI, alternatively, has no such asset limit. The six participants who received both SSI and SSDI provided unique insight into how the experience differed on the two programs. Louise had been on both SSI and SSDI and was currently on SSDI only. She compared the relative ease of administrative burden now that she was only on SSDI:

> *You don't have to worry about some bureaucrat looking over your shoulder and seeing how much money you got in the bank statement, you know. And there's still plenty of rules you gotta go by. But not - you don't have to worry too much about those resource restrictions and stuff, or have to constantly be hiding money, be thinking you're going to have hit too much or, you know, stuff like that.*

Here, Louise describes the psychic implications of the constant surveillance and asset-testing when on SSI. Other participants expressed similar emphasis on the burden of constant monitoring as the pain point when managing SSI rules as compared to SSDI.

Reese, who also received SSI and SSDI, was so tired of the monthly work reporting policy on SSI that she was considering giving up her SSI check altogether.

> *I'd like to get off SSI. I would keep my DI, but I'd like to get off SSI because for every damn dollar you make, first of all, they want to take a nickel, and it's not the nickel that's so bad, but every single month, and if you have a paycheck it's easier; but if you're like me and you're kind of a gigger and a hustler or seasonal worker, anything where things aren't stable throughout the entire year, you have to report every bleeping month. With SSI, they care. With SSDI, as long as you're below SGA nine months out of 12, they don't care about every bloody nickel and dime, but SSI wants every penny.*

The way that work earnings are addressed differs between the two programs, which meant that participants who received SSI in addition to SSDI had to adhere to both sets of rules. As Reese explained, on SSDI, individuals can earn up to a certain threshold (the Substantial Gainful Activity, or SGA, level which is $1,260 in 2020) each month without triggering additional SSA bureaucracy or benefit cuts. However, on SSI, individuals can earn up to just $65 per month before it is counted by the SSA. After the $65 threshold, SSI benefits are reduced by 50 cents for every one dollar earned. In addition, impairment-related and work-related expenses known through SSA as IRWE (impairment-related work expense), such as adaptive technology for using a computer or specialized transportation costs can be subtracted from earnings (SSA, 2020a).

Above, Reese explains that it is not just the loss of 50 cents per dollar earned that is difficult, it is the need to count "every penny" earned and account for it with the SSA "every bleeping month." As Momo put it, *"Starting out on SSI as a young person, there's no way out."* Momo refers here to the challenge of getting out of the SSI program and into the relatively less burdensome SSDI program. People become eligible for SSDI solely through participation in the workforce in a job that pays FICA taxes. Thus, for people become disabled either at birth or during their youth, they do not have the opportunity to work prior to receiving disability benefits. Thus, they are only eligible for SSI. Once on SSI, the previously described work disincentives apply, which makes it difficult to work enough to gain eligibility for SSDI. Several participants who started on SSI at a young age alluded to this problem and felt that they were penalized for something they could not control, i.e., childhood disability. For this reason, among others, policy recommendations in Chapter 7 include elimination of differential administrative guidelines for benefit eligibility and maintenance for SSI.

Conclusion

Participants made ends meet through a combination of public benefits, formal and informal work, going without basic needs, and social and familial support. Living under or near the poverty line in an area with a high cost of living lead to a high degree of food insecurity and heavy reliance on social benefit programs beyond just SSI/DI, such as Section 8 and CalFresh. Making use of these benefit programs required participants to learn the complex rules of multiple benefit systems that often were not set up to interact with each other. Participants' description of their survival strategies when compared to SSA policy suggests that they perceived programmatic rules as barriers to survival to be surmounted.

The compliance and psychological costs of the administrative burden participants experienced when obtaining, maintaining, and working while on SSI/DI benefits led to experiences of stigma, stress, anxiety and frustration. Participants wanted to be able to work without restrictions when the right opportunity came along with a period of relative improvement in disability and wanted to save up money in bank accounts over the $2,000 asset limit to cushion themselves in times of greater vulnerability. Since SSA policy generally did not permit this, a game was played out between beneficiaries and administrators where rules were largely barriers to life that evoked alternatively creative workaround strategies, simple nonadherence, or stress and anxiety. In this sample, many participants expressed a deep distrust in the SSA's intentions as well in their practices. The issue of overpayments is reviewed here as an example of SSA policy-related administrative burden that brought forth beneficiary-administrator clashes and multiple beneficiary survival strategies.

Yet not all participants had the same experience, and some characteristics played a greater role in mediating their daily struggles. Participants who were part of families that owned homes experienced greater financial stability, particularly in the context of the Bay Area housing market. In a pattern similar to national trends, white participants were more likely to receive family resources such as housing or cash that they could fall back on. Whether participants received SSI, SSDI, or SSI and SSDI benefits shifted their degree of financial precarity and administrative burden, with SSI recipients shouldering the greater burden.

These findings render visible the concrete activities and experiences that result from SSA policy administration in the context of California's Bay Area. They explore the extent to which SSI/DI policies do and do not support the basic needs of disabled adults and how, when left without resources, people are essentially forced to create their own safety net. The following chapter will explore how participants' sense of self and their role in society is impacted by the conditions and strategies described in this chapter.

CHAPTER 5:

STIGMA, STEREOTYPES, AND SOCIAL DEATH:

THE SOCIAL SECURITY MODEL OF DISABILITY

*Sometimes I feel like everybody people think like, oh well you just like being disabled. Like I even had somebody say, oh, it must be nice to be disabled. You guys just sit at home and collect the check. Okay. 1) No, it's not [laughs]. And don't act like the check we collect is like a million bucks. Right. It's like bare necessities, dude. But the fact that society feels that way - it's maddening to me and makes me sadder too, because it's like how am I gonna get this across not only to the people that made the law, when you can't even convince mainstream society that you're worth a piece of sh*t, you know what I'm saying? [laughs] Like everybody in society is like, oh, you're disabled. Like they just kind of discount you. The minute they say disabled, you could just see it on their face. – Stevie, age 48*

Stevie, among other participants, describes her experience of stigma and exclusion as it relates to her identity as a disabled SSI recipient. She explains her view that the perception that disabled people do not work, which is reflected by the SSA policy definition of disability, drives mainstream ableism. Stevie's understanding of the relationship between SSA policy and her social experience of disability stigma help respond to the second research and sub question: *How do beneficiaries experience Social Security disability programs and policy and the bureaucracy that carries them out? In particular, what impacts does SSA and welfare-related stigma have on its beneficiaries' sense of worth, self-concept, and identity?* These questions explore the psychosocial sequelae of many of the conditions and coping strategies described in Chapter 4. As discussed in the previous chapter, participants often saw their interactions with SSA as akin to playing a game, given the oppositional nature of their relationship with and experience of the bureaucracy. In this section, I explore the implications of being a player in this game on participants' sense of self and their role in society. How SSI/DI participation impacts participants' sense of themselves and their role in society; their disability identity; their life trajectories; and their experience of being devalued in society is discussed. Taken collectively, these experiences form a disability experience referred to as the Social Security model of disability.

SSA Policy Shapes Disability Identity

In order to maintain access to disability benefits with strict eligibility and maintenance guidelines, participants must understand the eligibility criteria and in order to meet them. At times, this can mean that people present themselves in ways that do not feel authentic, such as playing up their challenges and playing down their strengths. Performativity has been discussed in disability studies literature in the context of performing disability in various social settings where societal perceptions of what disability looks like does not match people's own internal or external experience of disability. Applications for disability-related benefits (including but not restricted to SSI/DI benefits) are a particularly high stakes site for performing disability, since the cash benefits and medical benefits are essential for survival. In turn, acceptance into a disability program such as SSI/DI can feel like an acceptance into disability writ large, and thus holds high stakes for people's sense of self and identity.

As Dorfman (2015) writes of the SSA disability determination process, "This procedure holds a personal, intimate significance regarding a person's self-identity, which is known to be influenced by the cues an individual receives from formal and state institutions as well as from society at large," (p. 61). This finding was confirmed by participants who talked about both their struggles, first, to perform their disabilities in accordance with how SSA disability reviewers perceive disability, and subsequently, to reincorporate SSA's labeling of "disabled" back into their sense of self. Sam described the first phase of this process, performing his disability according to how it would be received by the disability determination process, thusly:

> *You know, even like when you go see your medical providers or your psychiatrist, you really have to reinforce your deficits and you have to refrain from talking about your strengths because they're going to document that. Social Security is going to use that documentation to make a determination. So even like interacting with my health care providers, who I'm supposed to be able to be honest with and say anything to, that's very much not the case. If I want them to document my conditions, then I have to be really selective about what I share or what I emphasize. Doing that is performative. So it's through that repetition of performances that you kind of become the role that you're playing. And you know, and it's not about deception or fraud, it's about [pause] . . . it's about a strategy for survival.*

Here, Sam acknowledged the gap between his own lived experience of disability and the SSA's process of disability determination. While his experience of disability is not necessarily characterized by his deficits, they are what he must emphasize in order to be eligible for essential benefits. Yet, while he describes this as a performance, he acknowledges the difficulty in separating the show from real life, as he needs to fully embody his disabled role. Thus, he is left with a sense of disability identity that is inextricable from an (in)capacity to work and is devoid of strengths, a hallmark of the Social Security model of disability. Sam spent three years applying for SSDI; in general people can spend anywhere from a few months to several years in the application process.

SSA's 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, 2020a). 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 that 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 of the discrimination toward disabled people stems from this conceptualization of disabled people as incapable of working and integrating into the mainstream, particularly for employers seeking effective, efficient producers (Jammaers et al., 2016). Embodying these contradictory messages about work is characteristic of the binds faced by beneficiaries through the Social Security model of disability.

The SSA's administrative definition reflects a deficit-based understanding of disabled people by defining people based on what they cannot do in an able-bodied, capitalist, 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 or community (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 or attorney. This process reinforces the individualization of disability as a deficit that can be located within an individual rather than as a dynamic, relational, process connected to societal environments and attitudes (Chaudhry, 2018b; Dorfman, 2015). In a member-check group, participants discussed the impact of receiving their benefit determination letter that deemed them "totally and permanently disabled." Melvin described the experience of seeing those words on letters from the SSA year after year: *"You feel like you're inferior to other people. . . like I must be different from everyone else. . . and as we've said, they [SSA] have a very narrow definition of it [disability]."* Sam, who was relatively new to SSDI, described his experience of trying to prevent his participation in SSDI from reshaping his sense of self:

> *It's just such a mindfuck… here's this expert government authority telling me that I'm totally and permanently disabled, whatever that means, just for someone to define your reality for you . . . it takes a lot of mental energy to keep your head screwed on right and to keep a sense of yourself, at least that's been that's been my experience.*

Sam spoke to the fine line between conforming to SSA's policies in order to receive SSI/DI benefits and starting to believe what the administrative language says about him as a person. While he needed to take up SSA's definition of disability to access benefits, he simultaneously needed to resist it for his own well-being, which was particularly important considering his psychiatric disabilities. This tension of needing to convince the SSA of a type of disability while simultaneously trying to dissuade oneself of the same representation of disability characterizes the experience of disability in the Social Security model of disability.

Momo voiced concern in this discussion that in shaping people's sense of disability identity, the SSA provided information selectively, which reinforced concerns that arise in the Social Security model of disability. In particular, he noted the lack of information about ways to work while receiving benefits. His insights were formed by his own experience in working while on SSI using the policy's provision referred to as 1619(b) as well as his those of his friends in similar circumstances: "Social Security doesn't necessarily let people know their options, like how they can work on while on benefits." Section 1619(b) of the Social Security Act was designed to address Medicaid coverage as a primary work disincentive for SSI recipients. Many SSI/DI recipients fear going back to work since their medical benefits (Medicaid/Medi-Cal and/or Medicare) are linked to their receipt of SSA disability benefits, thus earning money over the SGA could result in forfeiture of their medical insurance as well as their cash benefits.

By participating in 1619(b), individuals who maintain all SSI eligibility criteria except for the earnings threshold may continue to receive Medicaid benefits. In order to remain eligible, individuals must follow certain guidelines, such as maintaining a total annual income below a given threshold, which in California in 2019 was $37,706 (SSA, 2020). However, per the SSA's guide to social security disability benefits and work incentive programs, the Red Book, there is a process through which recipients can apply to raise their SGA to a higher individual threshold. Momo described his Kafkaesque experience trying to access an application for this process:

> *I tried to call the Social Security office and . . . they didn't even know what I was talking about! They told me to call Medi-Cal [laughs] to apply for that. So, I call Medi-Cal and they tell me, well you're on SSI right now even though you're not receiving money, you still qualify for Medi-Cal. And I'm like, 'well I want to apply to keep my Medi-Cal and then increase my SGA. And it was like, 'you need to talk to Social Security.' So, I'm like, 'okay, do you even talk to each other?' The person I spoke to said, 'well we don't talk, but if you're in the system we know.'*

Momo laughed throughout his accounting of this incident, clearly aware of the dark humor in the absurdity of the situation. A policy exists on paper that could have serious benefits to his career and his livelihood, yet the lack of process through which he could utilize the policy and the lack of knowledge of the policy by SSA workers rendered it nonexistent. This situation has a sizable impact on SSI recipients like Momo, who felt forced into a social role subsumed by disability and blocked from pursuing his career while remaining entangled in a web of policies and programs that he constantly engaged with in order to maintain poverty-level benefits.

In Momo's experience, SSA policy and its implementation create and reinforce its own definition of disability as someone who cannot work, even though his barriers to work were situated in the policy itself. This feature of disability identity as someone who cannot work is a key contributor to stigma among disability beneficiaries, despite the fact that beneficiaries may desire to work but prevented to by program guidelines. Moreover, the amount of work one must do to navigate these benefits is immense and requires continuous work that goes unrecognized by society, As one participant, Stevie, put it, *"imagine how much we could do with all of the energy we have to put into dealing with Social Security?"*

Like Momo, Stevie described extensive and frustrating interactions with SSA and the other benefit programs she needed to live on SSI, including Section 8, Medi-cal, CalFresh, and In-Home Support Services, and the toll that these interactions took on her sense of self: *"So it's at a certain point, my life is nothing but policies in my head that I've memorized, or I know, and deadlines and how to shield income, basically. And that's all it is."* Here, she explains how the work of survival and navigating these essential benefits not only take up a lot of time but begin to reshape her sense of herself and her own life. During subsequent member-check groups, the idea that receiving SSI/DI benefits could reshape one's sense of self was discussed at length. While it resonated with many participants, some felt that it went too far. For example, as Penelope responded to the idea:

> *"That doesn't resonate in our conversation in terms of reshaping . . . but it [SSA] does kind of make me a little leery or on edge. It's like, 'what do I say or what do I admit?' Kind of like, don't ask, don't tell kind of a mentality?"*

Penelope was leery of assigning too much malice towards the SSA. She tended to give them the benefit of the doubt, reasoning that there are so many beneficiaries and likely inadequate resources. Participants who shared Penelope's sentiment, that the effects of interactions with SSA may be unpleasant during the experience, but not enough to carry over into one's sense of self in other settings, tended to have less interactions with additional welfare programs such as IHSS, Section 8, CalFresh, and/or Medi-Cal.

In her interview, Maxine considered the relationship between playing the game and the game permeating her sense of self. She explained it with careful attention to neither over- nor understate the impact of bureaucratic interactions:

> *But yeah, I mean, it's I think, more than it being a sacrifice, is it's a psychic drain. Having to keep juggling all these different bureaucracies and having to be mindful of all of this on a daily, weekly, monthly, minute by minute, sometimes, you know, basis can be daunting and can be tiring and can be [pauses] - well, certainly limiting, but it's more than that. It's kind of . . . [pause] 'Soul obliterating' is too tough, but it is, it's you know, it has* impacted . . . *the way I think, on some level.*

While the performance process starts in the SSI/DI application period, research to date has not explored the extent to which people must continue to perform even after enrollment in disability programs and how that ongoing performance impacts their sense of self. The finding that people receiving SSI/DI experience themselves as performing a role for the SSA and grapple with their sense of self and disability identity even after the application period adds to our current understanding of the disability programs' psychosocial sequelae.

SSI/DI Shapes Life Trajectory

Career Aspirations

Some participants described ways that they saw their life trajectory shift as a result of living on SSI/DI and expressed sadness over the lives they were coming to accept as lives they would no longer be able to live. Some people described giving up dreams of marriage and children, home ownership, or careers, all stymied by SSA policy and its effect on their ability to make ends meet. Yet, when some participants expressed ways that SSA policy had been a barrier in their lives, they made sure to note that without SSI/DI, their lives would be much harder. Victoria described the benefits and consequences of receiving SSI and SSDI as well as the challenges of ever coming off of the programs in the Bay Area, despite her active work life:

> *Being on benefits is kind of a two-edged sword. You know, it has taken me, it's enabled me and empowered me in many ways. . . And it's disabled me and disempowered me in others. So, it's kind of a balancing act. I think I do it pretty well because I'm able to work - I've worked for the last 21 years. And, you know, I still have to stay on them cause you can't - The challenge is I would have to go from making what I'm making on SSI, SSDI, whatever to about probably six to eight thousand a month to cover my personal care attendant reality, my housing reality, and - you know it might even be more than that.*

Victoria explained how she found herself, for better and for worse, stuck on SSI/DI benefits due to the way they related to other necessary benefits such as homecare and housing. She worked over 30 hours per week and would have worked more if permitted by SSI/DI programs, thus her disability clearly did not meet the definition of "unable to work." Instead, due to her need for assistance with activities of daily living and the administrative mechanism for acquiring this care, she found herself limiting her work life, income, and assets to maintain disability benefits. Victoria was not alone in this situation.

People who found themselves in this position of wanting to pursue a career and work more than they were permitted while receiving disability benefits often fell into two categories: People who had long periods of symptom abatement between disability flairs and people who required in-home care support with activities of daily living. People who had long periods of relative functioning often wanted to take advantage of them by working as much as they could yet knew that disability flairs or recurrences were inevitable and could not risk letting go of their disability benefits altogether. Often these people had already used their Ticket To Work and thus were ineligible to use the program again, despite the relapsing and remitting nature of many disabilities.

The other participant subgroup, of people who required in-home care, needed to maintain their disability benefits in order to maintain access to otherwise very expensive in-home attendant care. This care was typically accessed through In-Home Supportive Services, which itself is accessed through Medi-Cal. Other health insurance programs, including Medicare and private, employer-based, health plans, do not offer home-based attendant care. Thus, many participants needed to hold on to their SSI and Medi-Cal to continue receiving this care which would otherwise cost upwards of $50,000 annually out of pocket. Stevie described how benefit policies interacted in her life to alter her career:

> *But it's also really complicated because, like on the other side of this, I have a master’s degree. You know, I am physically disabled. It's kind of apparent. I use an electric wheelchair. But the other side, this is that like, well, if you use Section eight housing to live in the bay or basically to live anywhere, but especially here in the bay, I'm income restricted. So, can I work? Yeah, not really, because you get sort of - I view, I feel I get trapped within systems, do you know what I mean? Because of my physical disability, I use attendant care, like and that's not even by choice. I wouldn't be able to function if I didn't use it, but in order to use it, you have to be poor.*

Stevie had a master’s in public administration, which was evident in her sophisticated policy analysis that was interwoven along with her personal story of making ends meet. She spent a lot of her time engaged in disability activism and had worked briefly in policy research years before our interview. She would go on to lament at length the fact that SSI/DI did not set disabled people up for success in their lives and was adamant in communicating the policy structures that shaped her and others’ career trajectories, regardless of their talent and drive.

This interlinkage of benefit programs, coupled with asset limits in SSI and Medicaid, has been described in the literature as a civil rights issue, contributing to the reproduction of the cycle of poverty among disabled people (Ball et al., 2006). Policy scholars have deemed this phenomenon “the benefits trap” or “the poverty trap” and noted it for its significant role in preventing SSI/DI beneficiaries from moving off of disability rolls and into the labor force (Olney & Lyle, 2011; D. C. Stapleton et al., 2006). Stevie’s accounting of her limitations while receiving SSI suggested that she also saw the administrative technicalities that kept her receiving home care through Medi-Cal and SSI benefits despite a desire to work as a disability civil rights issue:

> *I really struggle with the fact that everybody else gets to have the American dream, whether it's be a doctor and lawyer, you know, the president. But if you're disabled, ‘Oh, you can't make any money because, you know, we're going to take your benefits away from you.’*

Here, Stevie associated disability discrimination, in its administrative manifestations, as the barrier to working, rather than her disability itself. This analysis refutes the SSA definition of disability as an impairment-related inability to work, and instead affirms a political model of disability wherein disability refers to the collective experience of people who are categorized together by welfare policy and whose shared experiences result from living according to the rules of disability policy. Hereafter, I will refer to this model of disability identity that refers to the collective experience of people whose lives are dictated by the confines of SSA policy as the Social Security model of disability. In sum, the Social Security model of disability refers to the iterative process experienced by participants in which SSA policy shapes society's perception of disability identity as non-participation in the workforce, participants feel devalued by society at large due to their disability, and participants limit their own development of families and careers in order to abide by SSA policy and maintain their benefits (see Figure 1).

Participants who had higher levels of education (bachelor's degrees, master's degrees, and in one instance, a doctorate degree) were among those who were most vocal about the ways in which they had to limit their own career prospects. 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).

Developmental Milestones

In addition to altering work trajectories, participants described ways in which their aging process, or normative developmental trajectories, were impacted by SSI/DI polices and therefore characterize the Social Security model of disability. Reese was one person, among other younger participants, who described the existential loss of a carefree youth:

> *So, it's just if you're on disability, you have to, you know, make sure that, you know, you don't work, you don't work and earn over a certain amount. You don't have as much expenses. And, you know, that's kind of not fair for a [25] year-old who is just learning life and learning it, figuring out what [they] want out of life.*

SSI/DI beneficiaries struggle to work amidst the complex policies and guidelines they must navigate to maintain benefits. Reese poignantly noted that this difficulty was compounded by the more normative challenges of a young adult in the workforce: They had yet to figure out what type of work was a good fit for their talents and temperament and were overwhelmed by job-seeking with the barriers of strict income limits on top of it all.

Victoria described her experience of looking back from a lifetime of constantly advocating for her own and her community's rights for survival and realizing that she had not met some of the long-term, normative, experiences of adulthood she had wanted for herself:

> *I'm almost 60 years old - and I can't believe that - And admittedly, you know, I look at certain things differently now. But, having that lens there, holding everything up against. . . It's like I look at my life - as like, well, I would've liked to have owned a home. You know, I would've liked to have had a wife and kids.*

The nature of survival on SSI/DI as well as specific policies make it very difficult to marry, have children, and buy a house. Marriage can trigger a loss of SSI benefits based on the income of a spouse or can significantly lower the benefit amount for two disabled adults sharing a household (SSA, 2020).

Victoria's reflection made space for her to grieve her loss of a number of social roles, such as spouse and parent. These social roles were hard to obtain alongside the role of disabled adult for most of the participants. Only two of the participants were partnered at the time of their interviews, and neither of those partnerships were formalized by law. Several participants had been previously married and of those, participants described more extreme financial difficulties during the marriages due to SSI/DI policies. A few participants had children and emphasized how difficult it was for them to manage the frequent and unpredictable nature of their expenses while receiving disability. Further, unpredictable benefit changes from SSA such as overpayments, as discussed in Chapter 4, caused even more severe anxiety and material hardship for participants who tried to buffer the impacts on their children in addition to themselves.

Healthy Relationships

For a few participants, their marriages and relationships presented risks to their personal safety. While violence and abuse were brought up in just a handful of interviews, nothing in the interview guide (see appendix) broached the topics of violence, abuse, or even relationships; and it is likely that a great proportion would have endorsed these experiences if they had been asked about them. Maxine was one such participant who described a previous marriage characterized by intimate partner violence:

> *I even told my doctor, I was like, you hurt an animal, you have a harsher punishment than if you hurt a disabled person. I have disabled friends that have died, and you know, and that are in abusive relationships. And I was in an abusive relationship for [20] years. So, I know how people think of disabled people. They think that nothing's going to happen to them, so they don't have a problem hurting you. And that's unfortunate -- we need to send a different message.*

Here, Maxine disclosed her own personal history of an abusive relationship and suggested that this is a problem for disabled adults in general due to society's undervaluing of disabled people.

For some disabled adults including the ones in this sample, Adult Protective Services (APS) county offices can be a resource when in abusive situations. However, research suggests that APS efforts tend to focus more on elderly adults and less on working-age adults with disabilities that render them dependent on others for care. Disabled adults are at particularly high risk for sexual abuse and have been identified as a vulnerable group in need of further research and oversight to track, prevent, and lessen their victimization experiences (Basile et al., 2016; Haydon et al., 2011; Hughes et al., 2012; Smith, 2008). Being female, unemployed, and uncoupled are all variables that increase the risk for disabled adults of experiencing intimate partner violence (Smith, 2008). For disabled women receiving SSI/DI, benefit policy discourages both employment and partnership, placing them at high risk.

Social Security and Social Death

As Maxine suggested, disabled people often experience a negative feedback loop between how much society values disabled people and how they are treated (Cacho, 2012). Many participants brought up their perceptions of how they were viewed by society at large, and how this impacted and was influenced by the poverty conditions inherent in in their experiences of SSA policy. Cacho (2012) argues that through social and state-sanctioned processes, some groups of people - particularly poor, criminalized, and racialized communities, are rendered ineligible for personhood, their rightlessness is validated and naturalized, and thus they experience a social death. Cacho's scholarship on social death continued to come to mind as I listened to participants grapple with their destitution, their sense of stuckness, and the contrast between the lives they lived and the stereotypes and stigmas they encountered as disabled adults receiving SSI/DI.

An exchange with Reese exemplified how the concept of social death was evoked in these interviews despite the lack of any prompting questions in the interview guide:

> *Interviewer: Do you have something you consider your biggest concern financially?*
> *Reese: Well, overwhelmed with shit I owe, but that's still—I feel I've gotten to a pretty good space right now in terms of I know where to go to get the cheap food. I know where to go to get free produce. I've become incredibly resourceful based on a lot of things.*
> *Interviewer: Can you tell me a little about those strategies?*
> *Reese: Yeah, yeah, yeah. Well, you mean knowing where to go to get the produce, stuff like that?*
> *Interviewer: Yeah, in having a tight budget, how you manage to still survive.*
> *Reese: Good question. I don't know if I was surviving this time. I mean, maybe I had a pulse, but I don't think I was surviving. I don't know. I don't really know how to explain that descriptor, you know what I mean?*
> *Interviewer: Uh-huh. Like you weren't dead but you weren't alive?*
> *Reese: Yeah.*

Reese referenced a sense of feeling lifeless while still being technically alive, suggesting that the term "survival" ascribed more life than they actually experienced. Cacho (2012) argues that in the setting of American neoliberalism, people's value is assessed through a capitalist and economic lens in which people who do not contribute to the labor market are devalued. This logic is affirmed by many aspects of SSA policy; including the bifurcation of disability benefit programs into SSI and SSDI, in which people who have not paid payroll taxes prior to becoming disabled are funneled into SSI, a program with even more limiting guidelines than SSDI. For people who were disabled since birth, their participation in SSI is all but destined by the time of their infancy, for the sole reason of their inevitable exclusion from the labor market.

As is the case among other oppressed groups, such as undocumented immigrants, people receiving SSI/DI benefits have significant legal restrictions on their ability to work with high stakes consequences if they are caught working. Yet, since they still need to eat, this dynamic inevitably leads to working in underground economies which render them at risk of being exploited, underpaid, or abused due to lack of regulation and workers' precarious and rightless statuses. Later in the same interview, Reese discussed the underground economies they had engaged in to make ends meet while receiving SSI and used similar language suggesting their sense of their own marginal existence:

> *I mean, it has been more stable but still incredibly stressful because of the sort of, kind of—I feel like the world of hustling you have to do when you are at that low income is like so pushed underground that even, literally, like with statistics, it'll be, like, you are 300 plus below the poverty line—not even below the poverty line; you're 300 percent plus*

> *below the poverty line. It's like you don't exist, you know, so, like, a lot of our lives, I'd say, a lot of us are pushed underground to do a lot of different things.*

Reese describes a different sphere, or "world," in which their poverty and available work opportunities are so extreme that they seem to disappear from the mainstream world, existing so far outside of social processes and laws that "it's like you don't exist."

In this way, the significant amount of work that people do to first access work and then engage in the actual labor meant that many participants were very hard workers. Yet, despite policy that forces them into risky and underpaid work, disabled people are often most stigmatized for their lack of work and contribution to society. Stevie voiced her concern over this dynamic and how it reinforced the devaluation of disabled working-age adults:

> *Sometimes I feel like everybody thinks like, oh well you just like being disabled. Like I even had somebody say, oh, it must be nice to be disabled. You guys just sit at home and collect the check. Okay: One, no, it's not [laughs]. And don't act like the check we collect is like a million bucks. It's like bare necessities, dude. But the fact that society feels that way - it's maddening to me and makes me sadder too, because it's like how am I gonna get this across not only to the people that made the law, when you can't even convince mainstream society that you're worth a piece of shit, you know what I'm saying? Everybody in society is like, 'Oh, you're disabled.' Like they just kind of discount you. The minute they say disabled, you could just see it on their face.*

Stevie recounted a common stereotype of disabled adults, that they are somehow profiting off of disability checks and that they are not working and therefore lazy and worthless. She also connected the fact that the general public has this perception with the political reality that lawmakers seem to be driven by these misconceptions, showing the linkage of devaluation and poor treatment of disabled people in social policy.

Several other participants discussed a similar frustration with how they are perceived, and how different it was from their actual experiences of hard work and poverty. The notion that disabled people are somehow gaining an unfair edge on society from their social position, such as in the receipt of SSI/DI benefits, is widely explored in disability studies literature on the "disability con." First coined by Samuels (2014) and later applied to the SSI/DI application experience by Dorfman (2019), the disability con refers to fear of disability deception among fantasies that disability is a tangible, observable, feature of humanity that can be regulated, with fakers and the truly disabled clearly demarcated and classified as such.

Participants in the study encountered fears of the disability con in the many benefit systems they navigated, constantly having to produce evidence, receipts, and their own deference to maintain access to benefits. As if constantly on the defensive, many participants would introduce damaging societal beliefs that they were subjected to in order to present their alternative views of reality. Victoria expressed her frustration with the perception that disabled people get something for nothing, not only harmful for their stigmatizing effects but also for the denial of her reality in the daily bureaucratic grind:

> *I'm not somebody who's looking for a free ride. Never was. You know, there are people who have a perception of those of us on benefits as, 'Oh, yeah, they just -- I wish I could get paid for doing nothing.' Like, yeah, live in our world for about 30 seconds and then talk to me about that. I don't think those people would last a day.*

Adding an important caveat to the protestation that people on SSI/DI do in fact work, Reese reminded me that the neoliberal value of assigning worth based on work productivity was in itself reductive:

> *Because there's only one type of way to be productive in society and contribute, and that is by working a job that pays a paycheck into a certain thing. Plenty of people contribute work and aren't compensated. There's plenty of different types of work that aren't valued and respected as work but they're still working.*

Many participants were actively engaged in their communities in a number of ways from doing community organizing, to volunteering at their churches, to making art, and engaging in public education campaigns. Many were also engaged with each other in disability community spaces, as will be discussed further in Chapter 6. Reese claims a seat at the table along with other prominent critical disability studies scholars in critiquing an overemphasis on access to the workforce without questioning the currency with which neoliberal value is accrued.

Yet, many SSA policies operate under the assumption that in order to promote work amongst SSI/DI beneficiaries, beneficiaries must be assessed for desire to participate in the workforce and then aided on an individual basis to rejoin it. The Ticket To Work program, analyzed in this lens, is antithetical to the national labor market and the mixed economy welfare state. Several participants spoke about their experiences on SSI/DI with a similar skepticism of the possibility of truly supporting disabled people when operating within a capitalist system. Often in these conversations, the line between biological death and social death was blurred as participants questioned the motives beyond programs as restrictive as SSI/DI.

Sam discussed the slow application process and the fact that disabled people often spent years without income or health insurance while they submitted appeals to the SSA:

> *It's like that Audre Lorde quote, 'we were never meant to survive,' you know? And so I felt like I was up against a system that truly benefits by me not surviving. You know, if I don't survive while I'm on Social Security, they no longer have to make a payment. If I die before I get a Social Security decision, they don't have to make a payment.*

Sam's concerns about the impacts of lengthy application periods are supported by research that suggests that longer wait times are correlated with lower income, likelihood of being uninsured, and increased medical issues (Coe et al., 2013; Prenovitz, 2020). Sam, like other participants, perceived the SSA as using a ruthless and utilitarian approach to disability benefits. Their experiences with SSA involved such denial of personhood, that the leap to assuming that the system did not care if they lived or died was not a large one. Participants who brought up these concerns tended to be people who were engaged in activism of any sort and who had evidently spent time seeking to understand why SSI/DI programs operated as they did.

Tili was among these participants and clearly explicated why she saw SSA in a eugenic framework:

> *I guess I just want to say that it's clear to me and all of the disabled people I'm friends with and who rely on Social Security as their main means of income, it's incredibly difficult to be approved for this benefit. People die during the waiting process. They make it incredibly hard to be approved. If you do get approved, they make it incredibly hard for you to be able to live on the amount of money, poverty wages. It keeps people trapped in poverty and it's a way of slowly killing people, and I do know disabled people who have*

> *died waiting to be approved for Social Security. I know people who have died because they needed to turn to survival work while they were receiving their benefits. The system was designed, I think, to kill people. We deserve better.*

Tili's perceptions of SSI/DI reveal a complete lack of trust - not only in SSI/DI as programs, but in the motives of the SSA itself. The fact that several participants used explicit language of death or murder to describe their view of these programs, and that none of these observations were prompted by explicit questions, was striking. It suggests that the cumulative effects of navigating SSI/DI policies, interacting with street-level bureaucrats, and playing the game with multiple public bureaucracies, which are all features of the Social Security model of disability, take a significant psychic toll on beneficiaries. While there has been little research to date on the nature of psychosocial impacts of SSI/DI on beneficiaries, existing critical disability studies frameworks and theorizing on the disability experience through the perspectives of capitalism and the labor market align with participants' accounts of feeling invisible and devalued (Longmore, 2003; Puar, 2017; Russell, 2019).

Conclusion

The findings described in this chapter are an important empirical contribution that show how oppressive social security policy coupled with administrative burden can result in undesirable shifts in individuals' life trajectories; sense of self; experience of stigma, role in society; and experience of social devaluation. Taken together, these experiences make up the Social Security model of disability. Through personal and community experience, knowledge of the literature base, and theorizing, participants have portrayed the "economic violence" wrought on those excluded from the labor market as a form of state-sponsored debilitation, akin to Social Darwinism (Russell, 2019). The psychosocial sequelae of living on social security disability benefits are important to consider in exploring the beneficiary experience as they characterize the quality and nature of life that people experience as they make ends meet.

Participants' experiences also highlighted out SSA policy that devalues disabled people influences negative societal perceptions of them in a process akin to Cacho's (2012) social death. This negative feedback lops can have an iterative effect on disability policy and disabled people's relationships and sense of themselves. Lipsky describes a segment of this process in his discussion of the moderating effect of street-level bureaucrats:

> In another sense, in delivering policy, street-level bureaucrats make decisions about people that affect their life chances. To designate or treat someone as a welfare recipient, a juvenile delinquent, or a higher achiever affects the relationships of others to that person and also affects the person's self-evaluation. Thus begins (or continues) the social process that we infer accounts for so many self-fulfilling prophecies (2010, p. 9).

Considering these ripple effects, it is not surprising that social policy defining disability in contradistinction to engagement in the workforce could lead to negative social- and self-evaluations of disabled people in a capitalist labor market. Still, the motivation for policy change to improve disabled people's material lives and disrupt the "benefits trap" only grows when considering the psychosocial and societal effects sequelae of current policy that might shift, in turn.

Without the tools for lawmaking immediately in front of them, participants in this study were forced to creative and collective means in order to resist some of their negative SSI/DI experiences. In the next chapter, I will depict the community-level strategies that emerge in the struggle for survival and resistance under a Social Security Model of disability. Where Chapter 4 explored how SSA policy shapes individual strategies for survival on SSI/DI benefits and Chapter 5 described psychosocial and societal sequelae of that survival, Chapter 6 will examine how SSA policy shapes an entire community of beneficiaries and how the community responds in resistance.

CHAPTER 6:

LIFE IN A TOTAL INSTITUTION WITHOUT WALLS:

THE COMMUNAL EXPERIENCE OF SSI AND SSDI

"A lot of the stuff I've learned from other people. . . I have learned from other people who have gone through the hoops of Social Security. My stepmother deals with Social Security and she's also disabled. And so, we, you know, we all learn how to do the hoop jumping together."
- Victoria, age 52, on SSDI

Victoria describes her experience on SSDI as a communal one in which she learns how to interact with the SSA from other beneficiaries rather than an official information source. While SSA policy for administering the SSI/DI programs is designed to treat each beneficiary as an individual according to a set of common rules, this study found that beneficiaries' experience of SSA often takes place communally, as it does for Victoria. Participants cited other people receiving SSI/DI benefits as important sources of information and strategies for survival as well as sources of support and economic exchange. While this study did not pose research questions about the communal experience of SSI/DI and neither did questions in the interview guide, this theme emerged in multiple codes through the open coding process of grounded theory. After observing this pattern amongst participants of turning to each other to make sense of their worlds and access support and information, this theme was conceptualized and presented to the three member-check groups in Phase II where participants reported high levels of resonance. Further, they reenacted this theme during the member-check groups when the group discussion organically shifted towards information sharing about navigation SSI/DI benefits. The communal experience that emerged from interviews and member-check groups in this study amounted to a particular experience of disability in the U.S. Abiding by SSI/DI policies led to circumstances such as having severe asset and income limits and structural barriers to career advancement that became subsumed into participants' sense of disability identity, as described in the previous chapter. This shared experience of disability as resulting from life according to SSI/DI policies is first referred to as the Social Security model of disability in Chapter 5 and will be elaborated upon in this chapter. This chapter explores the community-level impacts of SSI/DI policy that allowed participants to share their trauma and fear as well as to access survival, humor and resistance.

Communal Trauma

While sharing SSI/DI stories with other beneficiaries was an important coping mechanism for participants, it also allowed people's horror stories to ripple widely into the community. In this way, when one person was harmed by a negative interaction with an SSA worker or experienced a costly administrative error, a whole community of people were impacted. Tili shared her rationale for bringing hard copies of documents in person to the SSA office*: "I would never mail anything into them, because I know too many people who have done that. And they've [SSA] lost their [SS(D)I recipients'] paperwork."* Tili explained here that she makes decisions about how to communicate with SSA not only based on her interactions but based on those of her fellow SSI/DI beneficiaries.

Being harmed by SSA's actions or policies is so ubiquitous among disability communities, it is seeped into disability culture. Stevie referenced an essay by the disability activist and historian Paul Longmore to demonstrate her point about SSA's ruthlessness:

> *There's a situation, I don't know if you've read about it, but where Paul Longmore talks about the fact that he was living on benefits and he published a book and they took it, they took all the money away from him because he published a book.*

Stevie gave pause to her ideas about creating her own website of her writing because of the experience of a well-known disability activist and scholar as he wrote about in his collection of essays, *Why I Burned My Book* (Longmore, 2003). In this example, Stevie, a policy wonk with an MPA, interprets SSA policy and decides on how she will navigate it through the experiences of her disabled community.

While these experiences may have increased participants' anxiety, they also provided important validation to participants who felt that their experiences with SSA were often unpredictable and nerve-wracking. In conversation with me during interviews, participants used the validation of their social network to highlight the significance of what they were telling me (not unlike the process of qualitative data analysis). Louise described her experience of fear related to her SSI benefits:

Louise: . . . it's just you're aware that it's a massive bureaucracy. And anytime you get a communication from them, you're not sure if it's going to, you know, just rip your lungs out. Because anything could go wrong.
Interviewer: That's a very vivid description.
Louise: Well, I have, you know, a number of friends on SSI and SSDI. And they all report the gut-dropping. You know, even if it's a perfectly innocuous, you know, about the time of the COLA [cost of living adjustment] letter every year, there's that moment of "ohhhh."
Interviewer: So, what is the fear?
Louise: Well, you know, that they could take your benefits just like that . . . that's pretty much a constant fear, that they'll decide your okay. . ."

The annual determination of the cost-of-living adjustment (COLA) by SSA is mailed out to beneficiaries to let them know how much their benefits will increase each year to keep up with the cost-of-living. This is not a high stakes or stressful occasion for beneficiaries. Louise uses this "innocuous" event to illustrate the severity of her SSA-related anxiety. Even though she gets the COLA letter at around the same time each year and logic might dictate that she could expect it, she feels fear at the mere the sight of a letter from SSA, always worried that her benefits could be terminated.

Louise went on to explain that the fear of losing benefits is always "in the background" since she receives periodic disability self-report letters and then spends a few months waiting to find out if SSA will require further review of her disability status. When I probed multiple participants about the origins of their SSA-related fears, they responded similarly, alluding to a constant background fear that they could lose their benefits. Louise seemed to recognize that her reaction could be considered extreme when she noted that *"a number of friends on SSI and SSDI ... report the gut-dropping... even if it's [a] perfect innocuous."* The fact that other people also experience gut-dropping fear lent credence to her own experience and suggested that fear was experienced on a community-level when it came to SSI/DI beneficiaries.

Participants described their experiences of SSA-related fear with phrases that were suggestive of post traumatic reactions. Several participants used the phrase, *"waiting for the other shoe to drop"* to describe their hypervigilant states while on benefits. For example, Stevie described her experience on benefits thusly: *"I'm sick and tired of waiting for that other shoe to drop. You never know when it's going to drop. And it's like, holy crap."* Just as a person who experienced trauma may have an elevated baseline state of arousal and remain on guard for any potential danger, participants who had either experienced or witnessed the experience of life upheaval as a result of an interaction with SSA lived in chronic anticipation of a repeat occurrence (Herman, 2015). As Louise explained, even when a letter from SSA was expected, as in her example of the annual cost of living adjustment (COLA) letter, it remained a trigger that set off her sensitized nervous system's trauma responses. As Louise aptly described the phenomenon, "*every social security applicant has a little, you know, Post Traumatic Social Security Stress.*" Louise voiced her understanding that the traumatic reactions to SSA's decisions that often felt unpredictable and uncontrollable impacted everyone on SSI/DI, starting as early on as the application phase.

Later, Louise described her mental process of deciding whether or not to create her own online business:

> *But I'm - honestly, I did my taxes and I'm waiting for Social Security to either email me or send me a letter going "Wait! You can't own a business." So, yeah, internally in the back of my mind, I'm like, okay, when's this letter going to come? Because. . . I'm freaked out about it. I'm like, what are they going to do to me?*

Louise went on to describe a friend of hers that received benefits and tried to start some part-time work when *"they took away her benefits."* Her decision about whether or not to pursue her online business idea was explicitly influenced by her friend's experience and how to avoid ending up in the same situation. The ultimate fear among participants, having their benefits taken away from them, could have lethal consequences. In this same discussion, Louise connected the dots between her business idea and her life being threatened:

> *And I'm just like, oh, my God, I don't want to be in that situation . . . where they're like, nope, you can't do that, you know, because what happens if I'm working? But something happens in my heart and I have to go to the hospital, and I can't pay for it. Then I'm kind of screwed in a different way.*

Since SSI and SSDI benefits are linked with health insurance (Medi-Cal/Medicaid and Medicare, respectively), losing benefits entails losing both one's income and one's health insurance. For disabled people who often rely on some sort of routine health care, health insurance takes on increased import. It is reasonable for disabled people to prioritize access to health insurance in this precarious environment with a privatized health care system, even when that means restricting oneself from engaging in part-time work that is permissible by policy but in practice can often result in benefit interruptions (see Chapter 4 on overpayments). Further, participants showed that the fear of losing benefits is so palpable that it can happen to someone else in their community and still result in their experiencing symptoms of post-traumatic (Social Security) stress.

In an environment filled with fear and unpredictability, where the mere sight of letters arriving in the mail from the SSA provoked hyperarousal, knowing that other people felt similarly seemed to provide some needed solace for participants trying to come to terms with the instability of their lives. In this way, participants existed in a state of communal trauma, where the same unpredictable administration guided their daily lives, and an overpayment or benefit cut-off that happened to one of them became community lore that sent fear rippling through all of them.

A Total Institution Without Walls

Although SSI/DI beneficiaries live scattered throughout communities across the U.S., the SSA guidelines that dictate their occupational, familial and economic choices in their daily lives create an alternate sphere of existence, as if they were living in an institution without walls. One participant strikingly spoke to this idea when she conceptualized a life on SSI as a life in a geographic space:

> *That being said, like I did my part, I went to a good school, I went on to get my master's thinking I'll get out of the ghetto, and that never really happened. Get out of the ghetto meaning I'm stuck on benefits, and it never really happened for me. And so, like, there are some people, like I said, that tell you "oh, you're just lazy, you don't want to da-da-da". And I'm like, "no. This is fear." Basically, it's fear, and security based upon what the system looks like.*

Here, Stevie reflected on her life in poverty on multiple benefits, including SSI, after having done all of the things she had always been told would help her succeed in life. She worked hard in school, went to college, and even received her master's degree. Yet, the maze of policies that linked her housing, home care and medical benefits to her SSI receipt while restricting how much she could work made it impossible for her to be in the workforce. Being stuck in this space of benefit navigation instead of employment felt to her like being ghettoized as a result of her disability.

While other participants did not speak so explicitly about a figurative place that benefits kept them in, they used language like *"locked in*" or *"stuck"* to described how they felt on benefits, which are also suggestive of a figurative space. This was striking to me, as these analogies brought to mind the institutions from which disabled people, over decades of activism centering around the Independent Living Movement, have struggled for liberation. While many more disabled people do now live in the community than prior to the Independent Living Movement in the 1970's, there were still disabled people in the movement's epicenter in the Bay Area, who felt that they still were not free. This section explores the communal SSI/DI experience as one akin to being institutionalized, though in this case the institution is a set of policies so encompassing that the effects transpire without walls to house the residents.

Goffman's (1968) description of the common characteristics of a "total institution" in *Asylums* provides a basis upon which to understand life on SSI/DI as life in an institution without walls. In a total institution, the dynamic between the small number of supervisory staff and the large group of individuals for whom the institution is designed is characterized by "narrow hostile stereotypes" and communication between the two groups is highly controlled. The large group of people that the institution is designed for are all treated the same way and are surveilled for compliance to institutional rules. Power dynamics between the supervisory staff and the people living under institutional control are reinforced by maintaining distance, socially, and restricting contact with the institution staff.

In participants' descriptions of interactions with SSA workers, communication was characterized by confusion, access barriers, and lack of accountability. Prior to the COVID-19 pandemic, participants reported that SSA required much of their communication to take place in the SSA local offices, with some rare medical exceptions. This introduced transportation barriers, time costs, and often involved humiliating scenes of being monitored and searched by office security. Power dynamics were reinforced by requiring participants to wait to see SSA workers, a technique also described in Lipsky's (2010) discussion of the street-level bureaucrat: "*You'd go down there and you just would have to - even if you had an appointment, you used to have to wait forever."* When a mistake was discovered to have been made by SSA, many participants noted the fact that SSA's response was to stop blaming them but never involved an apology or admission of error. Louise lamented, *"I mean I know I'm never going to get an apology, but they never own up to the fact that they blew it either."* SSA errors for participants could mean weeks to months of stress and administrative burden, going without sufficient funds to make ends meet, and a personal sense of betrayal. Participants worked hard to keep their benefits and navigate SSA rules and often felt personally affronted by false accusations that they had erred. These personal affronts were magnified by the lack of humanity in never receiving acknowledgments or apologies from SSA.

Participants described strategies of communication with SSA workers that they utilized and that they had learned from others. Common communication recommendations included: (1) Minimize communication with SSA as much as possible (*"... but like my whole thing about Social Security and I'm sure you've heard this from others, is that you only deal with Social Security when you absolutely have to [laughs]. Their not knowing is just fine unless they ask"*); (2) expect to receive incorrect and conflicting information from different SSA workers ("*Social Security is notorious . . . for not even knowing their own policies, not even following their own policies."*); and (3) never send SSA original documents because they will lose them (*"Never give the originals to anybody! Don't ever give original documents to Social Security. Always make copies! Give them copies. No originals because they're just going to lose them.*").

Two blind participants discussed the challenges of accessing SSA communications. Victoria talked about a time a few decades ago when she was kicked off of SSI because she had not been responding to paper letters that were inaccessible to her, assuming that if they were important they would have communicated in an accessible format. Both of them said that as of recent years, there seemed to be an increased effort towards accessible communication for blind beneficiaries, yet barriers remained. The SSA preference for hard-copies and in-person communication makes it difficult for blind people to use assistive technology, such as speech-to-text and text-to-speech computer features, to assist in their communication.

Overall, communication with SSA seemed to reinforce beneficiary fear of consequences of not following SSA policy and to remind beneficiaries that they were not in control of their relationship with SSA. As Stevie described the impact of any contact from SSA, *"There's a bit of terrifyingness that goes . . .you're like, oh my God, - I don't think you're going to help me [laughs] so like what is this all about?"* One participant, Penelope, did not have as strong reactions to SSA communication: *"Sometimes it's confusing, but I've been through it a couple times to kind of be able to navigate it pretty easily."* Penelope tended to give the SSA the benefit of the doubt. Perhaps due to her family support, she felt slightly less beholden to the SSA and was enrolled in fewer interlocking benefits.

A defining feature of Goffman's total institution is that the natural barriers between the spheres in which one sleeps, works and plays are broken down and the institution takes charge of all three, or "provides something of a world for them." (p. 4) In doing so, the institution disrupts core aspects of daily life: "There is an incompatibility, then, between total institutions and the basic work-payment structure of our society. Total institutions are also incompatible with another crucial element of our society, the family." (Goffman, 1968, p. 11). The work-payment structure of society is disrupted by the payment structures set up in an institution, where work may be endless, un- or underpaid, and restrictions on spending earned income may be in place, thus altering people's motivations and attitudes towards work itself. SSI recipients have their relationship to their earned income restructured through an explicit and fixed formula: After the first $65 earned, fifty cents of every dollar earned is subtracted from their monthly cash benefit, effectively halving whatever income they earn (SSA, 2020). For SSDI recipients, the relationship between income earned and income received is slightly less convoluted yet still restrictive: Earnings up to the annual Substantial Gainful Activity (SGA) amount, which is $1,310 in 2021, are allowable each month (SSA, 2020). Any amount earned in excess of the SGA violates SSA rules and places an individual at risk of having their benefits cut off and/or future benefits reduced. Thus, for SSI/DI recipients, an hour of work does not always equal an hour of pay and more work does not always equal more pay, thereby disrupting the societal structure that creates motivation to work.

Further, both SSI and SSDI participants have to avoid hitting certain thresholds, the $2,000 asset limit on SSI and the $1,310 SGA on SSDI, after which they are at risk of losing their benefits. As in the game blackjack, where a player's score increases as the sum of their cards increase until it reaches 21, after which point a player loses, whether their cards total 22 or any number above 22, people on SSI/DI must constantly watch out for hitting their policy threshold numbers, above which they lose their benefits. As anyone has tried the game blackjack can attest, avoiding the number 22 makes one nervous to keep accruing points starting well below 21. Maxine, a Black woman who receives SSI, described becoming nervous about losing her benefits when her bank account reached $1,700, knowing that with an additional $300 she would be over the asset limit.

This disruption of the work structure can impact a person's motivations and attitudes towards work itself. As Goffman (1968) explains of a total institution, "Whether there is too much work or too little, the individual who was work-oriented on the outside tends to become demoralized by the work system of the total institution," (p. 11). Several participants expressed a sense of demoralization as they explained how to fit their prior work experiences and educational experiences into the structure SSA policies created for work. Reese expressed frustration that the limit on hours they could work based on a near-minimum wage salary at a number of retail jobs made it difficult to find any work at all, since *"90 percent of the time they don't want to hire you for so few hours."*

For Stevie, who had a master's degree, issues arose around negotiating pay such that she could work the required number of hours without threatening her benefits: *"It's also weird to try to apply for a job and then go, 'you don't really need to pay me that much' [laughs]. So that's hard to negotiate. It's hard to say to a company, well... And so it's like, OK, do I work part time?"*

Despite her humor, which was a quality shared amongst the majority of participants when discussing the absurdist and frustrating aspects of SSI/DI issues, Stevie's subsequent tearfulness belied the toll this issue took on her.

When Momo's annual salary began to creep towards the limit in October of one year, he had to cut down hours in order to keep his job and Medi-Cal while on SSI's 1619b. Yet, working a full-time job for a small company, Momo's responsibilities remained unchanged. As he described it, this meant that *"the more I work less the more I have to maximize my hours."*

Victoria summed up what many participants expressed, and later would discuss in a member-check group: *"The effect of being on benefits is multi-pronged. You know it. It affects me in a way of self-limiting myself that I didn't used to do. And I don't like that. But I understand it."* Victoria went on to explain how she has less career ambition as her primary focus shifted away from climbing the management ladder at her organization and towards maintaining her benefits, which meant adhering to SSA guidelines around income and asset restrictions. The sky could no longer be her limit when $1,310 became her monthly income limit, which led to what she referred to as "self-limiting." This idea that SSA policies limited people from their potential was echoed by many participants, who cited both the psychic drain of navigating policy as well as the practical elements of curbed work hours.

Communal Resistance

In their individual struggles to survive, participants had to maintain at least a semblance of compliance with SSA policies and to stifle their frustrations in their interactions with SSA workers in order to keep their benefits. However, as a community, participants could demonstrate resistance to the SSA through teaching other beneficiaries their benefit navigation strategies, which was often accompanied by mocking the absurdity of SSA policies. This practice was also found to be a feature of Goffman's (1968) total institution: "In total institutions there will also be a system of what might be called secondary adjustments, namely practices that do not directly challenge staff but allow inmates to obtain forbidden satisfactions or to obtain permitted ones by forbitten means," (p.54). This system of secondary adjustments, like those described in this dissertation as "playing the game," are symptomatic of a system that denies personal freedom. It is telling of the stifling and rigid nature of SSI/DI policies that they might spurn an environment that participants felt required some degree of game-playing to survive in.

Participants unanimously attributed their strategies for SSI/DI navigation to the teachings of other beneficiaries, except in cases where they had developed the strategies themselves. They also offered up examples of how they would share insights on SSA workings and experiences of mentoring others on SSI/DI. For some, inter-teaching among SSI/DI beneficiaries was a matter of necessity, as Penelope explained: *"So people need to know all the ins and outs before they apply for Social Security. They know so they know what they're getting themselves into [laughs], you know. They need to know how to deal with this red tape."* Penelope went on to give examples of things that people need to know, starting with the common participant refrain, *"never give them your originals!"* Penelope understood the "ins and outs" of Social Security as the things that you learn as a beneficiary about how to work with the imperfections of the administration, even if they are not written anywhere in policy.

Victoria also spoke of the importance of passing forward information about the "playing the game" with the SSA, and noted that she saw it as a form of advocacy:

> *You know, I... coming at it as an advocate, of course there are many things I want to change. And of course, I've... I taught other people my tricks about, you know, what you do and how to do it, and you know?*

Victoria acknowledges that as an advocate for disabled people on SSI/DI benefits, she needs to operate on multiple levels. On a macro level, there are things that she wants to see change about SSA policy. And, while she lives in a world with SSA policy in its current form, she also needs to work on an individual level to support people surviving on SSI/DI, which she can do in part by sharing her "tricks."

The tendency for SSI/DI beneficiaries to look to each other for information on managing their benefits was on display during the four member-check groups. To varying degrees, in each group participants ended up asking for and providing advice to each other. This was often done alongside absurdist humor about the nature of SSA workers and bureaucracy as well as venting over the endless complexity of the paperwork. For those who were not part of a disability community, they seemed to have been yearning for this sense of recognition, validation, and support. At the end of the fourth member-check group Tili shared, *"I've learned more about SSI in the last couple of hours than I ever have from reading their [SSA's] pamphlets."*

Maxine found a volunteer position through which she could share her strategies for navigating systems at a local free health clinic. Thanks to her years of work reading the texts of laws and policies to optimize her participation in them, *("You have to read the actual law because they leave out all of the helpful information in those pamphlets they send you summarizing the code!"*) Maxine could help other SSI recipients enroll in interlocking benefits, such as CalFresh and Section 8, and receive the maximum benefits, by sharing her spreadsheet system with anyone who came to the clinic. She explained,

> *"I don't think many people do this or even realize that they could . . .I made up my own system - it's a lot of work and creates a lot of labor, if more people did it they might stop making people prove everything because they wouldn't have the time, and it would cost more to pay people to go through it than it would just go give people the benefit amount."*

Maxine knew that any medical expenses could be deducted from income amounts for both CalFresh and Section 8, which could significantly change the benefit amount. She, as well as a few other participants, put a lot of time and effort into identifying which items could be considered medical expenses and maintaining the required records of verifying doctors' letters and itemized receipts. Maxine's ideas about changing welfare administration practice by way of encouraging large numbers of people to take advantage of policy components that they were eligible for, such as medical expense deduction, is very similar to a welfare reform proposal put forth by the critical welfare scholars, Piven and Cloward.

In their article, "The Weight of the Poor: A Strategy to End Poverty," Piven and Cloward (1996) point out that there are millions of poor people in the United States who are eligible for benefits that, for various reasons, they do not receive. In order to create the political will to overhaul the highly inadequate welfare system, their strategy suggests creating a political and financial crisis through a mass effort to enroll the poor onto welfare benefits. Maxine's strategy also involves using people's welfare rights to overwhelm the current system and push it towards a less oppressive one with less administrative burden. Further, in both strategies, welfare recipients lead the efforts through their knowledge of how to receive and maintain benefits and whether or not the efforts are ultimately successful, in both scenarios, more people have been introduced to their rights and have gained access to public resources.

Through their teaching and learning from one another on how most effectively interact with the SSA, participants are exercising their rights to public welfare and social insurance as well as pushing the programs they interface with towards being less onerous and more humane systems. Not all participants who participated in this sort of teaching and learning activity considered themselves to be advocates or activists, though some did, others simply considered themselves to be surviving in community. Still, some did have broader visions for disability policy system change. Victoria described her vision for transformation for SSA and its encompassing effects on disabled people:

> *My problem with the system is that it doesn't, it doesn't expect people with disabilities to want or to become empowered. The system disempowers people, the system doesn't... you know, it's like, what do you mean you can't you know, you can make, you can have twenty dollars in unearned income, and sixty dollars and whatever or however that works. It's like, come on, you know, I mean, what do you mean you can only have two thousand dollars in assets, including what you make every month? You know, I mean, that's not that's not going to empower people. What do you mean if you get married? We're going to count your partner's income against you? I mean, God forbid, people get to pool their resources and actually have a better life. You know. Then the system from... you know, is set up for people to have widely to interpret it, in a way that, you know, that they can, that they can make work to their benefit and still play the game. And you know what a different system it would be if they just said, OK. You can make what you make. You turn in your receipts to offset. The rest is gravy. And you know. We're going to work with you to figure out how best to do that. We're going to raise the ceiling on the two-thousand-dollar assets. We're going, you know, we're going to do it differently.*

Conclusion

Participants' experiences with SSA extended into every area of their lives and psyches to the point that they felt stuck amidst its complex and rigid policies. As if they were physically institutionalized in one place, participants depicted a community of SSI/DI beneficiaries that served multiple functions in their lives. Their communal experience entailed sharing cautionary tales of SSA interactions; witnessing and becoming triggered by each other's SSA-related trauma; sharing tips on how to "play the game" with the SSA; and resisting the SSA's financial and psychosocial oppressive polices and practices.

While all participants in this study lived outside of institutions and in the community, many of them still experienced a curtailment on their freedom. They struggled to communicate with the SSA and as a result of accumulated negative experiences, many of them came to the conclusion that contact with the SSA should be avoided unless absolutely necessary for maintaining benefits. This meant that they had a lack of guidance for how to survive in a system that they had to live under, which was a shared need that they filled for each other. Through one-on-one conversations, social media, and organizational volunteering, participants developed systems to teach and learn from each other.

CHAPTER 7:

DISCUSSION AND IMPLICATIONS

"I don't think it's necessarily a question of benefits. It's a question of, at least the way I see it, it's a question of the fact that these benefits programs have us trapped and they're not meant for our success. They're built so that you get stuck. But I would like to see programs changed to build on success, not to keep somebody in failure. . . to build on work success or just success as a whole."
-- Stevie, age 48

Discussion

This chapter concludes the dissertation with a discussion of the study findings, study limitations and implications for future social work, policy, practice and research. This study sought to understand how disabled adults make ends meet day-to-day on SSI/DI benefits while living in the Bay Area, and how those survival experiences impact their sense of self and experience of stigma. Further, it sought to explore the possibility of survival on SSI/DI benefits while adhering to all programmatic policies and if not, to examine any sub-economies that developed in order to circumvent SSI/DI policy. Since the goal of this study was to understand the lived experience of this group of disabled adults, a qualitative methodology was utilized. 33 in-depth interviews were conducted with participants followed by four member-check groups during which participants provided feedback on preliminary findings. Employing a constructivist grounded theory approach, findings were analyzed into a set of codes that developed into broader themes. These themes were written up as three main findings that are described in Chapters four-six.

Finding 1: The Administrative Burden of "Playing the Game"

Perhaps the most striking aspect of my interviews was the depth and nuance of the policy discussions I had with my participants. Often, I found myself momentarily forgetting the role with which I had assigned participants, that of SSI/DI beneficiaries, in the context of these interviews and felt as though I was talking to a colleague about a policy brief. This is not surprising, although striking, since to survive on SSI/DI benefits in the Bay Area for the majority of participants entailed enrolling in a number of additional social benefit programs (e.g., Section 8 and CalFresh) and managing each of their distinct set of rules and eligibility criteria as well as their interactions with other, all while attempting to maximize their benefit amounts to meet the high costs of living in California's Bay Area. To do this required a depth of social policy comprehension and self-advocacy skills that could rival any trained social workers. Yet, the ultimate irony of these participants' lives filled with bureaucratic labor was that in order to remain eligible for these benefits, they could not work and had to routinely provide evidence of their incapacity to work.

Participant's efforts to make ends meet were, for the most part, against a backdrop of poverty and constant fear that an administrative error on the part of the SSA or themselves would kick them off of benefits which would lead to a cascade of problems including loss of health care coverage. When participants were successfully making ends meet, they lived highly precarious lives that were often budgeted down to the dollar. Changes in income or expenses were common and could easily wreak havoc in their lives, from minor changes such as a $5 increase in an electricity bill to major changes such as a $200 deduction to a benefit check because of an SSA overpayment. Participants met these challenges with a variety of strategies including skipping meals, engaging in underground work activities, accessing social and family support, and "playing the game." Playing the game referred to the collection of behaviors and strategies participants employed that were geared solely towards survival on SSI/DI benefits. Often, they entailed creative use of policy loopholes.

Many of these survival strategies were harmful to participants' health and well-being and most of them caused great mental distress. Thus, survival resulted in a reinforced cycle of poverty and poor health, potentially contributing to the documented health care inequities faced by disabled people (Krahn et al., 2015; Mahmoudi & Meade, 2015). An intersectional analysis was important in this context, since some participants faced greater precarity than others due to factors other than disability status, such as factors associated with structural racism.

There is an extensive literature that shows how structural discrimination through policies such as red lining has allowed white families to accrue wealth and home ownership over the generations and often denied these rights to people of color, particularly Black people (Jones, 2017; Oliver & Shapiro, 2013). White families, who are more likely to have significant extra resources such as a second home or large amounts of savings, may transform the experience of surviving on disability benefits from constant precarity to relative stability. These family and community resources are not taken into account in means-testing and are effectively invisible to social policies that allot government resources based on need, thereby reinforcing existing inequities. Within this limited sample, these broad, population-wide inequities were reflected in the racially disparate application of certain codes such food insecurity, skipping meals, financial stress, financial stability, and work activity. Of course, this was not true across the board and there were additional factors that complicated participants' relationships to their families of origin such as being former foster youth, adoption experiences, and interrupted family connections among LGTBQ participants.

In addition to stress faced by participants in their precarious financial situation and survival strategies, most participants referred to stress faced by the administrative burden of the SSI/DI programs as well as other social benefit programs. This administrative burden resulted from challenging experiences obtaining and maintaining benefits with restrictive conditions on earnings and assets. The constant surveillance of beneficiaries' bank accounts and disability status lent to a chronic stress of losing the benefits that could barely sustain them. For participants who received SSI, the stress and degree of administrative burden were heightened as a result of SSI's relatively more stringent earnings and asset limits and surveillance practices when compared to SSDI. The levels of administrative burden in SSI were so high as to have deterrent effects for participants who received both SSI and SSDI benefits, despite living near poverty. One participant voluntarily disenrolled from SSI to depend entirely on SSDI and two others reported considering doing the same in order to bypass the burdensome administration and surveillance associated with the program. In particular, the SSI asset limit was a significant contributor to the psychological and compliance costs of administrative burden experienced by SSI recipients. Thus, the bifurcation of Social Security into public assistance (SSI) and social insurance (SSDI) reproduces racial inequities among SSI/DI beneficiaries.

Black and Indigenous workers in the U.S. have been largely excluded from the social insurance components of the Social Security Act since its inception in 1935. At the time, most job sectors available to people of color were not part of the formal labor market such as agricultural and domestic work. Thus, using FICA taxes as an eligibility criterion excluded these workers from retirement and later disability insurance eligibility. Today, despite some integration in the labor market, the agricultural and domestic work sectors remain outside of the formal labor market and overwhelmingly performed by Black and Indigenous workers. Thus, the policies that make survival on SSI benefits significantly more arduous and challenging than survival on SSDI benefits, reinforce and strengthen existing inequities based on disability and race. Though there is some controversy, many social policy scholars interpret the exclusion of these agricultural and domestic workers as a way to intentionally leave Black people out of the New Deal, and the ongoing exclusion as evidence of current racism built into the structure of U.S. social policy (Perea, 2011; Stoesz, 2016).

Finding 2: Social Security Model of Disability

The second study finding covers ways in which SSA policy shapes the societal disability experience, which I refer to as the Social Security model of disability. This model of disability refers to the iterative process experienced by participants in which SSA policy shaped society's perception of disability identity as non-participation in the workforce, participants felt devalued by society at large due to their disability, and participants limited their own development of families and careers in order to abide by SSA policy and maintain their benefits. Thus, the societal disability experience includes both the way SSA policy impacts the broader public's perception of what it means to receive SSI/DI, e.g., stigmatizing attitudes, as well as how SSA policy influences beneficiaries' sense of themselves and their disability identities. Further, participants' experience of the reverberation between these three components - SSA policy, public sentiment and beneficiary sense of self -- are conceptualized as a form of social death (Cacho, 2012).

Critical Disability Studies (CDS) scholarship is replete with models of disability and varying constructions of the meaning of a disability identity, which is revealing of the challenge of identifying the causes, consequences, and location of disability itself. Disability is an elusive concept that moves among fissures in our society, differences in human biology and social tendencies to develop hierarchies as tools of oppression. Some CDS scholars, in recognition of these dynamic concepts, have suggested that disability be considered not an object of a lens but the lens itself; a way in which we can understand the world around us. This finding delimits the Social Security model of disability. This model is an offshoot of Stone's (1986) political model of disability, which views disability through the lens of disability as a welfare category. The administrative-, bureaucratic- and policy-defined experiences of people who fall into this category are the unifying features of the disability experience. This finding asserts that the cumulative psychic and physical effects of navigating SSI/DI policies, interacting with street-level bureaucrats, and playing the game with multiple public bureaucracies, are all features of the Social Security model of disability.

In the Social Security model of disability, there is ongoing tension and contradiction between the disability identity a beneficiary must present to the SSA and the disability identity a beneficiary tries to internalize about oneself and community. In order to meet the SSA definition and criteria for disability, a beneficiary must demonstrate that they cannot do their previous work nor adjust to any other work. Yet, as depicted in the first finding, the very task of maintaining SSI/DI benefits takes significant labor. Further, disability is rarely stagnant and can progress, wax, or wane; meaning that people's capacities may also vary. For many participants, it was painful to hold the SSA's determination of them as "totally and permanently disabled" even though it was their ticket to benefits. While some participants did not explicitly state any discomfort with this labeling, they expressed their disaffiliation with non-working in other ways. For example, a couple of participants referred to people who abused or worked the system and could actually work if they wanted to. Still, in these cases, the stigmatizing effects of the non-working designation were acknowledged in participants' desire to define themselves in contradistinction.

Additionally, facing barriers to work as SSI/DI beneficiaries further complicates the Social Security model of disability. Even when they wanted to work and chose to be transparent about this work to the SSA, many participants found themselves blocked both by SSA policy (e.g., earnings caps) and SSA policy administration (e.g., overpayments). This absorption in policy details that a beneficiary must navigate in SSI/DI became so ingrained in some participants that it further shaped their sense of self under the Social Security model. This constant psychic work of assessing one's finances that may be surveilled, managing paperwork for various administrations and abiding by multiple sets of benefit conditions is a feature of the model.

The ways in which participants had to limit their own life trajectories, from career aspirations to family planning to relationship building, were heavily influenced by SSA policy. Participants expressed the greatest amount of sadness when they described these impacts, as they paused to take in the extent to which SSI/DI policy governed their lives through benefit cuts for couples and work restrictions. Participants were largely single and some described violence in past relationships. The precarity of participants' financial and health-related lives and their sense of being devalued as disabled adults in the U.S. contributed to an extreme vulnerability among them. Navigating family and work are two of the most salient experiences of most adults' lives, thus emphasizing the degree of impact of the Social Security model of disability.

Lastly, the Social Security model of disability describes a dynamic experience wherein society's devaluation of disabled people, the material deprivation from SSI/DI programs, and their felt sense of invisibility and alienation all impact each other contributing to an experience described by Cacho (2012) of social death. Social death entails a denial of personhood through criminalizing a group of people's attempts to survive, such as through work restrictions. Here, the Social Security model is informed by Puar's (2017) theory of debility and disability as a result of state violence. Puar asserts that disability can be construed as the outcome of state efforts to oppress via protection of some people's bodies and debilitation of others.

Puar (2017) characterizes the U.S. labor market as a form of state violence. Jobs available to marginalized communities such as low-income communities of color are often unstable and debilitating, leading to premature illness, disability and death. The "essential workers," among whom a disproportionate number are Black and Latinx people, who have become disabled or died thus during the COVID-19 pandemic are a prime example of the disabling nature of the labor market. Puar invokes Berlant's notion of a "slow death" to critique a focus on disabled people and poverty for emphasizing a binary of ability; asserting that this binary masks the reality of ostracization, deprivation, and desperation impacting all those "populations marked for wearing out" (Berlandt in Puar, 2017). Thus, she attributes the poverty and unemployment endemic to the disabled community as a function of a capitalist labor market that is constructed to debilitate and then exclude people based on disability. Health, in this context, represents a lauded state of success in capitalism. Casting health and able-bodiedness as the normal state by marking disabled people as ‘other’ and on the fringes of society, the neoliberal individual is recentered as the cause of their own state of ability or disability, health or sickness, employment or unemployment.

Finding 3: An Institution Without Walls

Through their communal experiences of SSA policy, participants existed as if in a sphere unto themselves. This sphere is conceptualized in Chapter 6 as a total institution without walls. Based on Goffman’s (1968) concept of the total institution as a tightly controlled space that dictates inhabitants lives across domains, from work to family lives, the total institution without walls describes a similar experience with the dissolution of boundaries based on physical space. Instead, SSA policy is so far-reaching and invasive in the daily lives of beneficiaries, it does need the physical walls of an institution to regulate behavior. Through surveillance of bank accounts, benefit amounts that vary based on living arrangements and coupledom, restrictions on work hours, and mandatory reporting of changes in disability, earnings, and family support, the SSA achieves much of the social control found in an institutional setting.

The concept of an omnipresent yet invisible inspector that surveilles a populace was described by Foucault in *Discipline and Punish* (1975) through his concept of panopticism. In a process that was first described in the context of contact tracing during a plague, Foucault defines a panopticon as a mechanism of power applied to individuals through surveillance, supervision, control, punishment, compensation, and correction all performed towards the goal of instilling a set of normative ways of being (Foucault, 1975). In a panopticon, the inspector is invisible to the individuals being surveilled, yet their awareness of its presence, or omnipresence, is sufficient. As SSI beneficiaries’ knowledge itself of the SSA’s practice of surveilling bank accounts to ensure they are kept below the $2,000 asset limit prompted participants’ to cautiously monitor their own bank accounts for this limit, the goal of the panopticon was to instill discipline among the people such that they took over their own self-monitoring.

Foucault’s (1975) description of panopticism in all spheres of life, from penitentiaries, to hospitals, to schools, to charity organizations, show how this form of power can take place through the mundane intricacies of daily life without requiring physical forms of power such as bars or locks. Moynihan, et al. (2015) describe a similar phenomenon in the hidden politics of administrative burden. The intricacies of policy administration can be shifted in ways that are nearly imperceptible to the public and even politicians voting on legislation, yet that have significant impact on the targets of the policy or on program take-up as a whole. For example, requiring additional documentation to verify one’s income or increasing the frequency with which one must recertify for a social benefit are examples of increasing administrative burden that could be subtle enough to avert public scrutiny while being enough added bureaucracy to deter program participation. It is in this realm of the panoptic administrative sphere where SSI/DI beneficiaries exist, responding to demanding and unpredictable requests for information and verification, by a nameless, invisible, SSA. As in the hidden politics of policy administration, the agents of this surveillance can remain imperceptible and without attention, the experience of the beneficiaries can go unobserved.

This framing of SSI/DI beneficiaries living in an institution without walls frames SSA policy as a communal experience, which contrasts with the policy as written that intends to impact SSI/DI beneficiaries on an individual basis. A salient example of life in this institution is the communal trauma described by participants in which they either experience or bear witness to another beneficiary's experience of an SSA penalty such as an overpayment or expulsion from a benefit program. Many participants described a state of hyperarousal triggered by the mere sight of a mail from the SSA, in which they imagine that they, too, are suddenly denied their benefits. Thus, what happens to an individual on SSI/DI does not only impact that individual, but their whole community.

Participants also described ways in which they resisted the SSA's policies as a community. Many of them experienced either teaching, learning, or both, how to "play the game" through other SSI/DI beneficiaries. Advice on navigating the SSA was widely shared, unprompted, by participants to me during individual interviews and to each other during the member-check groups. The nature of the advice went beyond reiteration of SSA policies. Instead, advice reflected insider-only tips about how to manage the realities of interactions with SSA workers, such as admonitions to never send SSA original documents lest they be lost, as they frequently were. Some participants recognized and named this inter-teaching as a form of advocacy for disabled people, a way of making change in a system they perceived as unfair. While for most of the participants teaching their game-playing techniques happened informally as they were in community with other disabled people receiving benefits, a few participants actively volunteered in the community to support other SSI/DI beneficiaries.

One participant in particular was notable for her discussion of the potential impact that this community work could have on SSA policy and administration: She noted that if enough people made use of certain rights that could maximize benefits, the system would be so overrun with administrative work that it would have to change to reduce paperwork write large. This theory, written about by Piven & Cloward in their Strategy to End Poverty (1966), holds true for all of the participant information sharing. Indeed, participants resisted in the only way available to them under such oppressive conditions and found remarkably creative ways to reassert their own humanity in doing so. And as one participant expressed, the very struggle brought on them by the nature of SSA policy rendered mere survival an act of resistance. In her description of undocumented youth resistance to the criminalization of immigration in the mid-2000's, Cacho (2012) describes the unique nature of struggling from the place of social death:

> And yet the space of social death is always graced with hope, courage, and/or youthful idealism, where those who decide to take responsibility for the unprotected are always looking for and stepping on the pressure points that can barely manage the contradictions that their very presence, their very being inspires (p. 145).

In the precarious and controlled lives of SSI/DI beneficiaries, their presence in any space of community protection, service, and advocacy runs counter to the social narrative and policy edict that they be totally and permanently disabled, removed from the primary spheres of adult life through exclusion from the labor market.

Study Limitations

This study took place in two phases which were initially intended to have the same research design, yet restrictions on research due to COVID-19 shifted the design in Phase II so that it could be executed entirely remotely. Thus, study limitations differ in some cases between the two phases. Since the recruitment strategy for both phases of the study was primarily passive, participants were all people who chose to reach out to me after seeing the study flyer (See Appendix G). Thus, it is possible that participants who had particularly strong feelings about SSI/DI may have been more likely to respond to my study flyer. I sought to mitigate this limitation by offering compensation to participants for their time and advertising the study widely.

Some participants, particularly in Phase I, were from my personal network, either heard about the study directly from me or saw it advertised on my social media accounts. These participants may have felt pressured to say what they perceived that I hoped to hear or have otherwise altered their responses in reaction to our relationship. To mitigate this potential limitation, I avoided discussion of my broader research efforts with these participants and on social media and repeated to participants that I was most interested in whatever their personal experience was.

While Phase I recruitment and interviews took place in person, Phase II took place after the onset of the COVID-19 pandemic and therefore was completely remote. This could have reduced the diversity of participants who responded since the majority of them found out about the study online and engaged in a fully remote research process. I attempted to mitigate this by focusing recruitment efforts on agencies that reach disabled people with fewer resources, such as accessible housing units and social service agencies geared towards the disability community. Through agencies, I provided flyers that staff could physically post, thus increasing opportunities to advertise offline. While this practice did yield some participants, the majority of Phase II participants were recruited online.

The study had a relatively large number of participants with degrees in higher education and overall had a very high level of system-savviness. The fact that the study took place in California's Bay Area, while key to the formation of the study aims, could also introduce limits on the generalizability of the findings. There is a robust disability community in the Bay Area which tends to be highly politicized and well-informed on issues of disability. The degree to which participants had already engaged in reflection on some topics may not be representative of other parts of the state or country. Further, participants living in rural areas may have experiences that are not represented in these findings. Still, the Bay Area can be compared to other areas centered in and around large cities. While qualitative research is not intended to produce generalizable findings, the amount of transferability of the findings to other geographic areas is important to note.

In designing this study, I intended to compare degrees of urbanicity across the nine Bay Area counties to assess for neighborhood and regional impacts on SSI/DI participants ability to make ends meet. However, due to the limited sample size and the homogeneity of participants within some counties, this was difficult to assess. For example, participants in the counties outside of the more urban San Francisco, Alameda and Contra Costa counties were predominantly white and more likely to own or live in family-owned homes. Therefore, I am unable to discern whether differences based on geographic location can be accounted for by other factors such as race and home ownership. In future studies, the impact of education, race, and geographic location on the experiences of SSI/DI recipients ought to be investigated.

Lastly, this study did not interview SSA workers or policy makers to hear their perspectives of the policy and policy administration topics that SSI/DI beneficiary participants discussed. While this could provide an alternative perspective on what participants said in this study and is important to take into account, the majority of existing SSA policy assessment either explicitly or implicitly assumes these perspectives. The purpose of this study was to focus on the experiences of SSI/DI beneficiaries and their perspectives to contribute to this void in the current literature.

Implications for Social Welfare Policy

Throughout chapters 4-6, a number of policy recommendations are embedded in the presentation of findings and their discussion. Some recommendations came directly from participants and were coded as “policy recs.” Others were derived from analysis of the findings. These recommendations, including others that did not appear in previous chapters, will be presented here.

While some of these recommendations may seem politically infeasible, I have opted not to water them down in an anticipatory compromise in order to remain true to the participants’ words and to make plain the ideal outcomes. Further, I completed a full draft of this dissertation in the week that President Biden signed his $1.9 trillion COVID relief bill that provides historic levels of relief to individuals and families in poverty and marks a significant departure from the era of welfare retrenchment that has characterized social welfare policy in the U.S. for the past few decades. As FDR signed his 1935 Social Security Act into law on the heels of desperation cause by the Great Depression, the U.S. government today faces an opportunity in a post-COVID-19 era to rebuild the nation and its economy with an increased national understanding that poverty is not always the fault the of the pauper. Biden’s COVID relief bill did not include work requirements as a condition of aid, which perhaps, too, could be seen as further recognition of the multitude of factors that affect capacity to work, such as work availability, other than personal motivation. Codifying welfare restrictions, conditions, and penalties has been a hallmark of the US welfare system since the Elizabethan Poor Laws in the 1600’s. A significant reimagining of the relationship between the welfare state and its citizens is necessary to fully reverse these themes. These policy recommendations allow for some of this necessary imagination.

Work Disincentives

- End the practice of subtracting $0.50 for each $1.00 earned from SSI benefits.
- End the practice of cutting off SSDI benefits when earnings exceed the SGA (Substantial Gainful Activity) in a given month.
- Allow a 1-month grace period for submitting work earnings to SSA.

- Overall, shift from consideration of benefits as income replacement to that of disability income supplement, or allowance, as is the case in some European countries including Sweden, Finland, Denmark, the Netherlands, the UK, and Iceland.
- Waive annual salary limits for beneficiaries participating in the 1619(b) program

Benefit Conditions

- Eliminate administrative differences between SSI and SSDI.
    - While funds may still come from different sources, the guidelines for benefit administration and eligibility maintenance need not differ.
    - Eliminate the asset restriction on SSI (or, at minimum, raise it to $100,000 with annual cost of living increases) and the accompanying bank account surveillance.
- Raise the minimum federal SSI benefit amount with funding saved from eliminated bureaucracy in accompanying recommendations to, at minimum, eliminate the loss in buying power of 30% since 2020 (see: Johnson, 2020).
- Eliminate the “couple” benefit amount and treat each beneficiary as an individual, regardless of marital status.

Other SSA Recommendations

- Address rising cost of healthcare and its disproportionate inflation relative to the general economy through either 1) provision of a health savings account for beneficiaries who are not dual eligible or 2) allow automatic dual eligibility for all SSI and SSDI beneficiaries
- Fund local SSA office telephone support line staffed by existing SSI/DI beneficiaries
- Collaborate with the SSA Ticket To Work program to introduce a pathway to SSA-based employment for SSI/DI beneficiaries
- Waive any attempts to recoup overpayments after 6 months post-payment
- Waive any attempts to recoup overpayments under $1,000
- Introduce a strike system such that participants have three chances to err on SSI/DI policies before benefits are cut off

Implications for Social Work Practice

Study participants commonly expressed experiencing catharsis after participating in the study interviews. They described holding a lot of emotions related to their experiences as SSI/DI beneficiaries and carrying a lot of painful experiences related to the SSA, yet felt a general lack of societal recognition in this struggle. One way that social work practice can address this issue is for social work clinicians to be familiar with the common stresses facing SSI/DI beneficiaries and assess their presence with clients. This can serve to both normalize the experience, provide validation of the stressors, offer space for an experience that is often invisibilized and stigmatized, and provide further psychosocial intervention as indicated.

The administrative burden literature cites outside assistance with managing benefits as an important way to alleviate administrative burden and reduce its deterrent effects. Social workers who interact with clients receiving SSI/DI can inquire about administrative burden and offer resources to assist with organization, fill out paperwork on clients' behalf, and otherwise share their burden.

Social workers sensitized to the issues of work activity for SSI/DI beneficiaries can work with their agencies to create stipend-based programs for part-time work. Multiple participants in this study were supported by this type of program which offered SSI/DI beneficiaries a mechanism to contribute to a community they cared about; make use of their skills and talents; and earn much-needed income. This format can be particularly successful as a structure for peer support programs. The incidental finding that SSI/DI beneficiaries experienced support, validation, and practical information sharing suggests that intentional group spaces may be beneficial for this population. Social workers at agencies that serve SSI/DI clients could support beneficiaries in accessing peer support through the creation of confidential peer support groups in person and online. Further, in recognition of how SSI/DI beneficiaries may be uniquely situated to support other beneficiaries in navigating SSA policy, social workers could create stipend-based positions that provide in-person, phone, or online peer benefit support. This model, in addition to those that create part- and full-time positions for benefit navigation support, is in existence at some disability-specific agencies such as Centers for Independent Living. However, non-disability-specific agencies, such as substance abuse recovery centers or behavioral health clinics, may have large numbers of SSI/DI beneficiaries in their population and could extend this type of peer of programming.

In general, social workers can be agents of social change by being informed about SSI/DI programs and resisting a culture of stigma against SSI/DI beneficiaries. Whether among agency colleagues or in health care settings, social workers may be particularly likely to hear disparaging comments about people who receive disability benefits. Further, social workers may be part of program development that, impacted by this stigma, starts from a "disability con" perspective and places excessive emphasis on weeding out disability "fakes." Social workers who are informed about this tendency can provide education in their work environments about the pitfalls of overemphasizing fraud-detection in disability programs, the multiple presentations and progressions of disabilities, and the potential for harm in perpetuating stigma. They may recommend that programs start from the assumption that disabled people are not faking their disability and adopt an abolitionist stance on SSA fraud by not engaging in attempts to report it.

In March 2021, the California Public Health Department, after facing pressure by disability activists, decided to forgo concerns about "line-jumping" to increase COVID-19 vaccine access to disabled people by allowing individuals to self-attest to meeting eligibility criteria. This recent example of public service provision that did not start from a presumption of fraud sets a strong example for disability policy and programming moving forward that social workers may reference for application to their agencies.

Implications for Future Research

This study emphasized the importance of attending to the experiences of disabled people through its research design and research questions. In doing so, it uncovered many psychosocial issues that have previously gone unaddressed among SSI/DI beneficiaries and provided an important way for the people most impacted by SSA policies to inform its revision. Research conducted by and in consultation and collaboration with disabled people is implicated to inform future policy and administration research and to assess the experience of SSI/DI beneficiaries.

Other than the important work done by political scientist Lael Keiser (1999, 2001) on the exercise of state discretion through administrative burden and street-level, no prior research was identified that assessed administrative burden in SSI/DI policies. Given the degree to which administrative burden characterized participants experiences and the high costs of policy administration, further research on administrative burden in SSA policy is warranted. This research could explore the experiences of beneficiaries; assess impact of administrative burden on obtaining SSI/DI program goals; and interventions that could both minimize administrative burden and reduce the SSA's administrative costs.

While scholarship on stigma is robust for many areas of the welfare state and for disability in general, there is little research that explores the intersection of these two stigmatized categories: the issue of stigma in SSI/DI policy (Rabinovich, 2020; H. Whittle et al., 2017). Findings from this study suggest that stigma is a significant issue that impacts SSI/DI beneficiaries. Further research to explore stigma in larger samples of beneficiaries and intervention studies to explore stigma-reducing mechanisms are warranted here.

Lastly, disabled people's experiences in the U.S. are significantly shaped by policy, yet there is a dearth of research that applies a critical disability studies framework to disability law and policy (e.g. Dorfman, 2016, 2019; Russell, 2019). This study found the CDS theoretical foundation to benefit policy analysis, particularly as it focuses on the narratives of disabled people. Future research in disability law and policy that is informed by CDS may lead to key alternative legal, political and administrative insights.

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APPENDIX A: TABLE 1: PARTICIPANT CHARACTERISTICS

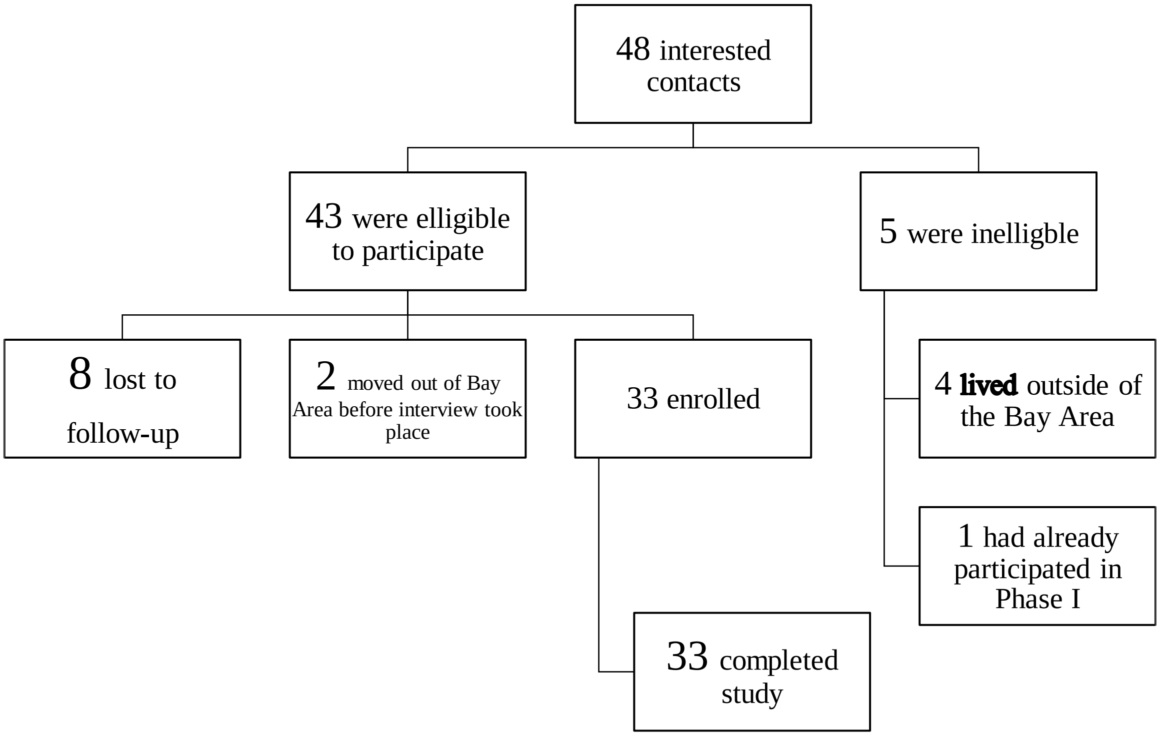
Table 1: Participant Characteristics

Participant Characteristics	**N=33**
Age	
18-25	1
25-34	4
35-44	7
45-54	10
55-64	8
Unknown	3
Gender	
Man	7
Woman	21
Trans-woman	2
Non-binary/bi-gender/gender queer	3
Race/ethnicity	
Asian	2
Black	7
Latinx	3
Multiracial	2
White	19
Benefit Type	
SSI	10

SSDI	17
SSI & SSDI	6
Educational Attainment	
Less than High School	3
High School or Equivalent	4
Some college	6
Bachelor’s degree	11
Graduate degree	5
Unknown	4
Marital Status	
Married	0
Widowed	0
Divorced/separated	5
Single / Never married	28
Housing Status	
Owns home	2
Lives in home owned by family	5
Rents – market value	4
Rents with subsidy	21
Shelter	1

APPENDIX B: TABLE 2: COHORT PARTICIPANT RECRUITMENT CHART

Table 2: Cohort Participant Recruitment Chart



APPENDIX C: INTERVIEW GUIDE

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 and timeline of disability
- Amount of support needed for activities of daily living (ADL’s)

Follow up question: What is your most salient identity?[5]

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?

Are you aware of the change in CalFresh policy and did you enroll in the program? (why/why not)

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[5] Italics indicate that a question was added between study phases I and II.

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 you biggest concerns related to your finances?

Part III: Benefit Amount

Is your monthly benefit enough money to cover your basis 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.

How have your financial resources and challenges shifted since the onset of the Coronavirus pandemic and shelter in place orders?

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 D: MEMBER-CHECK GROUP GUIDE

Member-Check Group Guide

Introduction:
“Hello everyone, thank you for participating in this second portion of my research project. Everyone here participated in a one-on-one interview with me. As a reminder, my name is Katie Savin and I am a student investigator from UC Berkeley studying how adults on SSI/DI manage to make ends meet in an expensive area like the Bay Area. Just like in the interview process, you never have to answer questions and are free to stop participating at any time. I anticipate that this group will take about one hour.

My goal for today is to report back to you on themes I found after analyzing all of the data from your interviews and to hear your feedback. I will never speak about any one person’s interview or information; I will discuss general themes that seemed to come up in multiple interviews. I am interested in your thoughts about these themes.

First, please consider everything that is said in this group to be confidential. Please do not disclose anything that is said here to anyone outside the group.

Second, please take care to not reveal anything about yourself or about other people that you would prefer to be kept confidential. Remember that while I ask you all to keep everything confidential, I have no control over what anyone here says to others about this meeting. Therefore, you should not assume that anything you say will be held confidential.

Third, you should of course feel free to avoid answering any questions which make you uncomfortable or you do not wish to share information with the group.”

[The following template will be filled in with 3-5 themes once the data is collected and analyzed.]

“One topic that came up in many of the interviews is ______.”

Probes for feedback on topics:
Does this resonate for anyone? How important is ____ in of how you make ends meet in your daily life on SSI/DI?
Does anyone have thoughts that might be similar to this but are not represented here?
If you were a policymaker for the SSA, what might ____ suggest to you?

Conclusion:

Is there anything related to this topic that feels very important to you that we did not discuss today?

Is there anything related to your experience participating in this study that you think went well?
- that you would change/ do differently?

APPENDIX E: CODEBOOK

#	Root Code	Child Code	Grandchild Code	Description
1	"Institutional humiliation" / performativity			Experiences with SSA and other welfare/government institutions that seem to have no purpose other than to humiliate (P016 quote)
2		"Mindfuck"		Absurd situations arising out of SSA policy, ableism, etc., that leave recipients speechless. (P016 quote)
3		"Playing the game"		Participants referring to the SSD/SSI as a game, trying to get their needs met through SSA as a game - winning / playing / cheating, etc. When SSA rules / actions don't make any logical sense so participant roles become learning what SSA moves are so they know how to move strategically.
4	Ableism / access issues			Participant references facing access barriers related to disability
5	Addiction and recovery			Participant references their own addiction and/or recovery process, programs they're partaking in related to substance use, and/or how their addiction/recovery has impacted their SSA application and benefits.
6	Advocacy Strategies			Strategies participants use to advocate for benefits, rights, access, etc.
7		Flexible Resources		see Link & Phelan "an array of resources, such as money, knowledge, prestige, power, and beneficial social connections that protect health no matter what mechanisms are relevant at any given time" - here as applies to disability benefit program participation vs health
8			Policy Literacy	Understanding how policy works, leveraging knowledge
9		Resistance		Participants resist SSA humiliation, oppression, policies through various psychic and practical strategies - resisting social death and poverty. More active than survival. Often has an edge to it - activism, mischievousness.
10			Networking / social capital	Use of one's network/social ties to advocate, e.g. contacting elected officials to appeal a SSA decision
11	Application experience			Experience with, perceptions of, influence of, SSI/DI application process
12	Cats			Cats are mentioned in interviews. Incorporated to assess interviewer impact on interview content.
13	Children			Challenge of having kids while disabled, expenses, CPS ableism, MIC ableism, etc.

14	Communal experience			SSA policy and administration (and other benefits systems) are carried out individually but often experienced as a community. People referencing other beneficiaries' experiences as their points of reference / meaning-making, sharing and receiving advice, tips on playing the game, developing fears based on others' experiences/community trauma, etc. - includes referencing the communal experience and specifying how one does not fit into it
15	COVID			Life situations changed as a result of COVID-19 pandemic
15	Culture			The sociality that emerges among disability beneficiaries - related to poverty, unemployment, disability, social exclusion - arising from sub-economies, day programs, and interactions with SSA workers. E.g. P033 - "get out of the ghetto means get off benefits"
16	Economic Strategies			Strategies participants used to make ends meet
17		Bartering		Participants barter and trade goods and services
18		Budgeting		Participants discuss use of budgeting to manage money, or lack thereof
19		Forgoing basic needs		Not being able to obtain things that one needs due to cost
20			Needs vs wants	Determining whether something is necessary for life or is more of a luxury. Often relates to addictions - e.g. cigarettes or social needs, e.g. socializing. At the crux of difficult decision-making when in poverty and making constant survival-oriented decisions.
21			Socializing	Forced isolation due to of lack of finances to travel, eat out, etc.
22			Wants vs needs	Determining whether something is necessary for life or is more of a luxury. Often relates to addictions - e.g. cigarettes or social needs, e.g. socializing. At the crux of difficult decision-making when in poverty and making constant survival-oriented decisions.
23		Discrimination/ Bias Impedes Strategies		Disability, race, gender, class bias - explicit and implicit - that raises barriers to strategies to make ends meet
24		DIY		E.g., clothes, cooking from raw ingredients, etc.
25		Participation in research/surveys for income		Participant in research or corporate surveys, using incentive funds to pay for basic needs
26		Social services		Involvement of social service organizations, typically governmental, includes social worker support

27			Labor to access services	Labor required on behalf of participant to access social services, e.g. Travel, bureaucracy, etc.
28	Education			Past educational experiences
29		Aspirations / career dreams		What people want to do with their lives - educationally, community advocacy-wise, occupationally, etc.
30		Financing education		Student loans, paying for higher ed, etc.
31	Financial precarity			Little-to-no room for financial shifts, barely making ends meet
32		Economic stress		Psychic weight of constantly worrying about finances, feeling anxiety about present and/or future finances
33		Financial stability (relative)		Compared to other participants, finances are relatively stable and not as precarious
34		Poverty worsening health		Health / disability worsens as a result of poverty, lack of affordability of housing, lack of income options, etc.
35	Food insecurity			Issues with access to nutritious food including limits to food storage and preparation
36		CalFresh		Enrollment in, decision not to enroll in, use of CalFresh (in phase 1, references to lack of eligibility for)
37		Food access strategies		How participants access food, strategies
38		Skipped meals		Participants going without meals/food they need due to lack of funds or access to food prep
39	Health Insurance			Medicare, Medi-Cal, eligibility for and coverage
40		Dental care		Lack of dental care, low quality Medi-Cal dental care, dental costs
41		Fear of losing health insurance		particularly as motivating force beyond other behavior, e.g., economic or occupational
42		Health and disability costs		Money spent out of pocket on expenses related to health and/or disability
43			Medical expenses as economic strategy	Tabulating medical expenses, turning things into medical expenses that might not obviously be them, using the medical expense deduction in various programs as a strategy to reduce costs or increase benefit amount (e.g., for Calfresh or section 8)
44	Housing Strategies			How participants access housing
45		Bay Area		Why do people want to be here, despite cost of living? + other implications of living in the Bay Area
46		Section 8		Receiving section 8 housing benefit: managing the benefit and how benefit interacts with SSA

47		Unsafe / inadequate / lack of housing		Homelessness, structurally or relationally unsafe living environments
48			Precarious housing	Concerns over finances because housing situation is temporary or precarious and knowledge that housing market is difficult
49	Income amounts			GA, SSI, SSDI , etc. participants share amounts of money from benefits
50	Pride, faith			Participants reference their faith and pride while discussing struggles, e.g. reframing not being able to have food as fasting; refusal to let dignity go bc of disability or poverty or faith
51	Policy Recs			Beneficiaries make policy and policy administration recommendations
52	Political anxiety			Fears re trump, future elections, status of social security, etc.
53	Quotable			Really striking quotes that are particularly emblematic of a certain code - to highlight them for potential inclusion in write up
54	Racial/racist conflations			Conflating race and disability, race and underground economies, race and drug use, race and poverty, race being conflated with any number of negative social outcomes
55	Social support			Resources from social networks, community, e.g. church
56		Family support		Resources, e.g. money or attendant care, from family
57	SSA Work Incentives			Participants reference SSA programs, policy, or communication related to incentivizing SSI/DI recipients to work
58		Perceived SSA work disincentive		Participants reference how SSA policy reduces their actual earned income, e.g., losing money from SSI monthly benefit when they work
59		Ticket To Work		References to specific work incentive program, Ticket to Work (TTW)
60			Barriers to using program	Barriers to successful experiences while on TTW program
61			DOR	Experiences accessing services through the Department of Rehabilitation, perceptions of and complaints about DOR
62	SSI/DI policy as lived experience			Participant experience of SSI/DI policies
63		"Post Traumatic Social Security Stress"		Fear of breaking rules accidentally, fear of being caught for breaking rules, fear that SSA will change rules suddenly, fear that SSA surveillance will catch participant in something, fear of losing benefits, the dread felt upon receiving mail from SSA, going to appts, etc.

64		"the system is seriously flawed"		Policies perceived as unfair/wrong
65			"I don't think you're going to help me"	Whether you follow the rules or not, they find a way to mess you up. So much confusing bureaucracy, rules always changing, the other shoe will always drop, don't believe what ssa tells you (a sense that the policy is not in fact intended to help beneficiary
66			"Not a lot of people know about it"	Policies that are not communicated (well) to beneficiaries, loopholes, ways to work the system that take a lot of work and policy savvy (quote from P020) - includes policy communication that is obtuse, unclear, confusing to all
67			Delayed benefit cuts	E.g., people earn money and then months later it is deducted from their check after they've stopped working again
68			Lack of accountability	SSA makes mistakes but does not own up to them; apologize; or accept accountability
69			SSI Asset Limit / Bank of REI	Issues resulting from $2k asset limit, participant work arounds to limit
70		"You're definitely locked in"		Participants describe the difficulty/impossibility of getting off disability benefits, alongside a desire to get off them.
71		Bureaucratic burden		Labor beneficiaries must do to maintain benefits - e.g. collect receipts, show pay stubs, annual reviews, etc.
72		Communication with SSA		Participant experience of communicating with the SSA via phone, mail, online and in-person
73			"Medi-Cal and Social Security do not speak"	Issues in inter-agency communication on federal, state and local levels (code includes any agencies, not just ones in title quote) - P033 p8
74		Disability identity		Conflicts / confusions / wonderings about disability identity as it relates to SSA policy, benefit eligibility, etc.
75		Legal action		SSA takes participants to court, participant appeals via court system, etc. Legal action presents the SSA as an adversarial and distrustful institution, rather than a beneficial social program.
76		Linked benefits		Benefit receipt is conditional upon another benefit receipt/eligibility (e.g. IHSS via Medi-Cal); frequently cite barrier to getting off of benefits
77			IHSS	Home care, managing employees, working IHSS system, benefit interaction
78		Regional costs of living		Perception that living in the Bay Area with its high cost-of-loving makes survival on benefits more difficult

79		Sense of self		Shifts in sense of self - due to requirements of SSA, exhaustion from fighting systems, resulting from playing the game, etc. Includes ideas of 'self-limiting' due to lifestyle necessary to follow policy Can also be more positive aspects of self - e.g., Creativity and resourcefulness includes weathering
80		Social death		Feeling invisible / barely alive / ignored and uncared for by society; ranges from "they don't get it" to "they're trying to kill me"
81		SSI vs SSDI vs SSA		examples of the contrast between the three programs, participants comparing/contrasting them
82		Street Level Bureaucrat Issues		Individuals representing the SSA make mistakes, don't implement policies correctly, don't listen to beneficiaries, demonstrate incompetence - "it seems like the more you explain it to them, the more complicated it gets"; based on Lipsky's work
83			Inconsistencies / "arbitrary rules and policies"	Different SSA workers provide conflicting information; includes evidence of use of discretion by SSA workers
84			"She's always just so reasonable"	Participants discuss the one good social security worker; the outlier / helpful person who demonstrates some competence and care (marked for low bar)
85			Overpayment / Backpay issues	Discussion of experiencing overpayments and struggles to cope with the debt and/or lower monthly payments
86			SSA incompetence	Participants share stories about SSA workers making mistakes, not knowing policies, displaying general incompetence
87		Surveillance		SSA asking about/ having access to/ knowing personal details of people's lives. Includes psychic effects of constant surveillance on daily decision making
88	Transportation			Participant access to transportation, accessibility of transportation options, use of personal car & payments for them
89	Welfare fraud & stereotyping			Welfare fraud discourse, discussion of "people on welfare" as monolith, including disability, food stamps, etc.
90		Stigma		Participants internalized welfare and disability related stigma and references to times others have stigmatized them; general awareness of stigma of SSI/DI
91	Work Activity			Participants discuss working
92		Job skills		Participants reference marketable skills that they have, or skills that they lack which makes finding

				work difficult, or areas that would be helpful for training.
93		Motivation to work		Participants talk about reasons that they would like to work, or work more
94			Moral authority of work	Discussion of work with moral implications - either explicit or implicit; e.g. references of self-respect and respect from others that may come along with a working status
95		Occupational decision-making		Participant's process of weighing the costs and benefits, possibilities and limitations, of returning to work; includes factoring in benefit policies, potential future health / disability flares, personal desires
96			Barriers to work	Reasons why [attempted] work did not pan out
97		Prior work experiences		Participants reminisce on their previous working lives
98		Unreported work/ income strategies		Work earnings that are explicitly not reported to SSA - includes informal and unregulated economies, e.g. sex work, busking, etc.
99		Volunteering		Participants discuss their volunteering and why they do it, including to have work-like experience and not risk their benefits, motivation to be 'productive' in society, includes advocacy, community work
100		Work activity based on SSA		When work activity is adjusted solely to adhere to SSA policy e.g. not working, working for more hours than getting paid for, volunteering to avoid SGA
101			1619(b)	Provision of SSI that allows you to work and still receive Medi-Cal, though you lose cash benefits and have an earnings cap
102			Work constraints	Labor market participation is curtailed due to SSA policy
103		Work availability		How availability of jobs impacts people's experience seeking and holding onto jobs, e.g., layoffs, economic recessions

APPENDIX F: PARTICIPANT COMPOSITES

Participant Composites and Sociodemographic Characteristics

Name	Ethnicity/Race	Gender	Age	County
Sam	White	Man	61	Marin
Tili	Black	Transwoman	40	San Francisco
Victoria	White	Woman	52	Alameda
Louise	White	Woman	46	Alameda
Penelope	White	Woman	55	Alameda
Momo	Asian	Man	30	Solano
Reese	Multiracial	Genderqueer	25	Contra Costa
Maxine	Black	Woman	45	Contra Costa
Melvin	Black	Man	40	Alameda
Stevie	Latina	Woman	48	Solano

APPENDIX G: PARTICIPANT COMPOSITE BIOGRAPHICAL SKETCHES

Participant Composite	Biographical Sketch
Sam	Sam is a 61-year-old, gay, white man who receives SSDI benefits. He became disabled as a result of his HIV/AIDS diagnosis later in life, which means that he spent a few decades in the workforce before he started his SSDI benefits. He rents a small cottage in Marin from his family, which allows him to pay a significantly subsidized rent without dealing with the bureaucracy and uncertainty of public housing. As a result of his housing and a small savings account from his years of work, Sam has some financial stability and is very aware of his privilege relative to most other people on disability benefits. As a gay man with HIV, Sam is also acutely aware of the politics of disability and has spent a lot of time thinking about SSA policy.
Tili	Tili, age 40, is a Black transwoman who lives in supportive housing in San Francisco. She is in recovery from a life of trauma, addiction and mental illness and working to build a stable life for herself. She receives SSI, Medi-Cal and Cal-Fresh benefits. As a result of her experiences on benefits, Tili often wonders if the SSA is actually trying to harm rather than help her and other disabled people. She has a lot of distrust of and frustration as a result of the interpersonal and systemic discrimination she has experienced in government systems due to her race, gender and disability. She can place trust in her service dog, Lolo, who is an important stabilizing force for her.
Victoria	Victoria is a 59-year-old, queer, white woman who is blind and has multiple chronic illnesses. She lives in Oakland with a few roommates and a beloved cat. Due to her blindness, Victoria requires assistance with activities of daily living which she receives through IHSS. She is a longtime disability advocate and outspoken activist. Her passion for this work is evident and as such, she is highly respected in her disability community. In addition, she works multiple jobs, on and off the books, in order to make ends meet. Victoria is aware of the irony of her heavy work schedule and the SSA definition of disability as someone unable to work. Still, without SSI and SSDI she would not be able to receive Medi-Cal and IHSS, leaving her stuck between the world of work and that of interlocking benefits.
Louise	Louise is a 46-year-old, straight, white woman who lives in Berkeley. She has been single for many years, though she once lived with a partner when she was younger. Her psychiatric disabilities qualify her for SSI and SSDI, and by extension, Medi-Cal. A few years ago she terminated her SSI benefits since the burden of SSI guidelines and associated surveillance outweighed the benefit of the very low amount of cash. She experiences a lot of severe anxiety, especially as it relates to benefit rules and maintenance, though she often makes witty, self-deprecating, remarks about it. In doing so, Louise coined the term “Post Traumatic Social Security Stress.” Along with her network of friends who are also on SSI or SSDI, she has developed many creative strategies for making ends meet.

Penelope	Penelope, age-55, is a straight, white woman who receives SSI and SSDI benefits. She lives in Alameda in a small home that her family owns, for which she pays a nominal rent. Penelope has a lot of anxiety and fear that the SSA will find a reason to kick her off of her benefits, and as a result works scrupulously to follow all of the guidelines for both disability programs. However, frustrated she is about all of the bureaucracy, she tends to believe that the SSA's rules exist for good reason. She quickly forgives mistakes made about her benefits, explaining that they are inevitable given how many people are served by the SSA.
Momo	Momo is a 30-year-old, straight, Asian man who recently graduated with his bachelor's degree and lives with his family in Solano. He utilizes the 1619(b) program in SSI which allows him to work full-time while maintaining non-cash SSI benefits (he needs the Medi-Cal). He has a neurological disability and uses a wheelchair and daily home care support. He hopes that he will be able to put his education to use through a career in consulting (disability-related). Right now, he is trying to stay in the workforce and work his way up, though it is frustrating for him to be bound by the restrictive program guidelines at the same time.
Reese	Reese is a 25-year-old, genderqueer, multiracial person living in Contra Costa. They have received SSI since age 18 and SSDI, in addition, for the last couple of years. They are deeply involved in a radical activist community in the East Bay area and have a highly critical and anti-capitalist perspective on the mixed-welfare state. They have psychiatric disabilities as well as multiple chronic illnesses which they attribute to their lifetime of trauma and poverty. In order to make ends meet in the Bay Area, Reese balances a part-time job, periodic gigs and side hustles, and a rigorous knowledge and use of resources for low-income people across the region.
Maxine	Maxine is a 45-year-old, straight, Black woman who lives alone in subsidized housing in Contra Costa. She receives SSI benefits in addition to Medi-Cal, IHSS, and Cal-Fresh and knows more about the ins and outs of benefit policy than any policy wonk or government employee. Several years ago, Maxine's niece set her up with a computer and a few lessons on how to use it. Since then, Maxine has used it to research the full text of benefit policy and develops systems to help herself and others navigate multiple, complex, benefit systems. Twenty years ago, Maxine was in abusive relationship that led her to reflect on the devaluation of disabled people. Today, her advocacy for community members who also receive public benefits gives her a sense of purpose.
Melvin	Melvin is a 40-year-old, straight, Black man who lives in a small suburb of Oakland. He receives SSI and Medi-Cal but has decided not to accept IHSS and Cal-Fresh benefits that he is technically eligible for because of the immense burden of documentation and other bureaucracy. His attitude towards the SSA is one of resigned pessimism. He has dealt with overpayments and other administrative errors that have caused him significant material harm as a result does what he can to avoid any government system.

Stevie	Stevie is a 48-year-old, lesbian, Puerto-Rican woman who lives in Solano. She has a developmental disability and uses a wheelchair. Her family of origin does not live locally; however, she has a close network of friends who support her. Most of her friends also identify as disabled and receive SSI and/or SSDI. Stevie is very involved in her disability community, including through her part-time work at a non-profit organization and her participation in disability advocacy and activism. She is highly politicized around her disability identity and is incredibly savvy on disability policy. Stevie received her master’s degree from a university with an excellent reputation and spend some years working in research. In addition to SSI, Stevie participates in the following benefit programs: Section 8, CalFresh, In Home Support Services (IHSS), and Medi-Cal. She is often frustrated by the ways that these programs interlock, which keep her beholden to all of them such that she is bound by a number of strict guidelines in order to maintain benefits.

APPENDIX H: FIGURE 1: THE SOCIAL SECURITY MODEL OF DISABILITY