

Navigating Policy from Below: Managing on SSI and SSDI in Greater Chicago

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Abstract: The Social Security Administration's income support programs for disabled people serve millions of beneficiaries each year. But the literature on social programs has paid limited attention to these programs, particularly to the lived experience of claimants. This paper draws on in-depth interviews and participant observation with disabled people in the Chicago area to argue that they manage their benefits through a process of *policy navigation from below*. With limited resources and information, clients devote considerable mental and emotional labor to maintaining their eligibility, earning enough money to meet their needs, and dealing with the uncertainty and precarity that frame those tasks.

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US disability policy is a complex web of programs across multiple federal and state level agencies, each with their own definitions of disability, eligibility criteria, and internal incentives. Two of the most important elements in this web are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), serving 9.2 million and 7.6 million people respectively in 2021 (Social Security Administration 2022a and 2022b). SSDI, created in 1956, offers disability insurance to those with sufficient work history, paying at rates that are tied to beneficiaries' incomes when they worked. SSI, created in the early 1970s, is a poverty program open to those with little or no work history, with eligibility conditioned on income and assets limits. Despite these key differences, both programs provide income support to limited sets of disabled people who meet strict requirements. Both are under the purview of the Social Security Administration and have similar acronyms, leading even scholars and policy experts to comment that they are easily confused. For beneficiaries, programmatic decision-making can feel opaque, leaving many in fear of losing crucial supports upon which they rely. In the face of this uncertainty, those receiving SSI and SSDI perform unsung administrative labor managing their benefits and personal budgets.

This paper explores the precarious work of benefit management by SSI and SSDI beneficiaries, which I call *policy navigation from below*. Drawing primarily on in-depth interviews with beneficiaries of both programs in the Chicago area, I find stories that defy neat distinctions between disabled and nondisabled, or simple calculations around work disincentives. Beneficiaries struggle to get by, often supplementing benefits with other social programs and/or limited work, while they are unsure how Social Security Administration (SSA) decisions are made and fearful of jeopardizing their means of support. While there is a robust literature on the experiences of social service beneficiaries, much of it focuses on more broadly-available programs like Aid to Families with Dependent Children (AFDC) and its successor, Temporary Assistance to Needy Families (TANF), rather than programs premised on serving disabled clients. Related literature centers the administrative burden (Herd & Moynihan, 2018) that different programs impose on beneficiaries, but pays less attention to beneficiaries' voices. This paper thus addresses multiple gaps, with a client-side view of SSDI and SSI.

BACKGROUND

Social provision is an interactive process, and sites of service delivery and authorization shape relationships between beneficiaries and the state and/or other service providers. Interactions in these settings do not only deliver benefits or services, but they also serve to place applicants into various categories of citizenship, situating them in within social hierarchies and in relation to other systems such as the labor market. A persistent theme in studies of programs is that many eligible clients are not served. Piven and Cloward write that even in 1965, during the height of the War on Poverty, surveys in New York and Detroit found large numbers of families in severe financial need who did not apply for benefits. Many of them either thought themselves likely ineligible, did not know that aid was available, or did not wish to repeat earlier humiliating experiences at the welfare office. The authors argued that this was by design, with invasive and degrading aspects of benefit receipt intended to warn others away from pursuing benefits and keep them in the low wage labor market (1993, 165-173). In their study of low-income mothers 30 years later, Edin and Lein found similar attitudes toward Aid to Families with Dependent Children (AFDC). Though their main wages covered only about two thirds of most informants' expenses, many preferred work to the experience of welfare offices. One said that government

agencies “treat you like an animal.” Another former welfare client, discussing her refusal to go back, said, “They make you feel like dirt in the street” (1997, 139-140).

As AFDC was replaced with Temporary Assistance to Needy Families (TANF), studies reflected the new program’s emphasis on work as an alternative to benefit receipt. Scholars documented how this was enshrined not only in the 1996 legislation, but in program practice. Peck (2001) writes that Riverside County, California’s Greater Avenues to Independence (GAIN) program, which became a model for TANF administrators nationwide, was carefully structured to urge beneficiaries to seek paid work, even if it was part-time or irregular, above all other priorities. This “‘employment message’ permeate[d] every aspect of the program, from its internal staffing practices to the management of its basic education services, from induction seminars to case closures” (p. 172). Brodtkin’s (2013) study of TANF offices in Chicago argued that clients were referred to service providers that failed to place them in paid employment, put through empty rituals purporting to offer skills and job readiness, and discouraged from making claims of their own on the state. Caseworkers were evaluated according to rates of participation in the above-mentioned programs, and caseload reductions, which could be due to placement in low-wage work, program sanctions, or sheer discouragement. By 2017, Tach and Edin argued that public assistance should now be understood primarily as a set of work-based programs.

But SSI and SSDI stand as exceptions to that work-oriented logic. A key to eligibility for both programs is that an applicant’s disability must prevent them from working beyond the level of Substantial Gainful Activity (SGA). This reflects a longstanding view of disability as fundamentally exempting people from the labor force. Deborah Stone writes that the 1388 British statute regulating beggars, known as 12 Richard 2, distinguished between “‘those *impotent to serve* and those able to serve or labor” (1984, 35, emphasis added). The 1834 English Poor Law defined five categories of paupers who would be exempt from the labor regulating principle of less eligibility: “children, the sick, the insane, ‘defectives,’ and the ‘aged and infirm.’” Of these five groups, Stone points out that “all but the first are part of today’s concept of disability” (40). Because of this implicit assumption, Stone argues, people with disabilities are considered deserving of aid, meaning that programs like SSDI and SSI do not carry the type of stigma attached to other cash assistance programs like TANF. But the fundamental assumption of incapacity raises other questions about the experience of beneficiaries and their relationships to social structures. This paper seeks to shed light on those questions.

Another approach to understanding client experience lies in the burgeoning literature on administrative burden (Moynihan, Herd, & Harvey, 2014). Herd and Moynihan present this concept as “an individual’s experience of a policy as burdensome,” a concept they expand as account for “the learning, psychological, and compliance costs that citizens experience in their interactions with government” (2018, 39). This concept is helpful in its focus on the phenomenology of participation in government programs. But while applying for SSDI and SSI is unquestionably burdensome, the academic literature on administrative burden has paid noticeably little attention to these programs. Herd and Moynihan devote a book chapter to the Social Security Administration, but they focus on Old Age and Survivors Insurance (OASI), with disability programs mentioned only occasionally as contrasts with the low burdens imposed by OASI. OASI was intentionally designed to be a “near universal” program (238), with objective criteria that are relatively free of potentially invasive or debatable processes of eligibility determination. This is not the case in SSI and SSDI’s disability determination process. While Herd and Moynihan rightly call attention to SSA budget cuts since 2010 and the impact on client

wait times (251-253), they do not address the particular impact of these cuts on clients of disability programs. Subsequent academic work applying the concept of administrative burden has also left SSI and SSDI largely unaddressed; where the programs are relevant to studies, it has often been where benefit receipt is already established. For instance, Herd (2015) points to the use of SSI eligibility to promote applications for the Supplemental Nutrition Assistance Program (SNAP). Hammond et al (2020) similarly study the expansion of eligibility for California's SNAP program to SSI recipients in the state. But in both cases, receiving SSI, or simply interacting with SSA, is more of a precondition than an outcome of interest. This paper brings a focus to SSI and SSDI.

But this study is not a direct application of the concept of administrative burden to SSA disability programs. Nor is it a study of safety net programs in general. By focusing specifically on SSI and SSDI as programs specifically designed to serve those whose disabilities prevent them from working beyond SGA, I ask a broader set of questions. How do beneficiaries feel about the programs? How does this interact with their understanding of, and feelings toward, their disabilities? How do they understand their eligibility in relationship to paid work? Are they familiar with SSA work incentive programs? If so, what has been their experience with those? These questions are not only matters of measuring burden, but also of opportunity and political interpellation. They deal not only with direct interactions with government, but also with beneficiaries' daily lives outside of those interactions—including, as I will discuss in the following pages, active avoidance of government interaction for fear of negative consequences.

To understand my findings, I present a theoretical framework that I call *policy navigation from below*. This framework acknowledges that programs like SSI and SSDI are built on multiple layers of complexity. This begins with the fact that two distinct programs have similar names, leading some beneficiaries to be uncertain which they received. On top of this are complex and often time-consuming methods of eligibility determination, policies around work and SGA that can vary by disability type, asset limits in the case of SSI, exceptions to those policies under a range of work incentive programs, and access to health insurance that varies by state. Beneficiaries perform near-heroic work to keep up with these policies and manage their benefits. But they still operate with far-from-perfect information and may make mistakes. With the possibility of such mistakes comes the fear of loss of benefits on which they depend. By exploring how beneficiaries navigate SSI and SSDI policy from below, this paper offers insight on how clients understand the program and their disabilities, how they deal with the precarity in which they live, and how the Social Security Administration might alter its policies and procedures to provide clients with greater security and clarity.

METHODOLOGY

I approach these questions qualitatively, drawing on interpretive frameworks (Alford 1998). Rather than pursuing a statistically representative sample, this study goes into depth to understand beneficiaries' thoughts and experiences. Data is drawn primarily from 12 in-depth, semi-structured interviews, as well as a participant-observation of organizing meetings, both of which I discuss in the following paragraphs. I developed my research plans in consultation with, and with the approval of, the University of Chicago's Crown School of Social Work, Policy, and Practice and Chapin Hall Institutional Review Board (IRB).

I set out to recruit interview subjects in the Chicago area who received SSI or SSDI. While both programs are obviously national in scope, they are shaped by state and local differences in access to benefit offices, the presence or absence of state supplementary benefits,

and state Medicaid policy. By focusing on the Chicago metropolitan area, I sought to ensure a measure of local variation, while also holding state-level policy and regional culture constant. I began recruitment in early 2022. Because this overlapped with the omicron surge of COVID cases, opportunities for in-person recruitment were limited, as both individuals and institutions sought to reduce the risk of transmission. Thus, my recruitment largely took place online through multiple channels. I presented the project at meetings of multiple organizations, and I circulated the call for interview subjects on multiple channels including email, Twitter, and Facebook, with many people circulating the call beyond my immediate networks. This summer, I also distributed recruitment flyers at Chicago's Disability Pride Festival. This led to further online circulation. At one point, a prospective subject informed me that she'd seen information about the study on LinkedIn, which I barely use and where I had not shared it.

Those interested in participating in an interview were asked to contact me through a dedicated email address and phone number. Each the completed a brief screening questionnaire, either by phone or Google Form. After the first several interviews, I received an uptick in interest from potential subjects saying that they had learned of the project online. Unfortunately, the first interview of this set raised several troubling signs that the informant had falsified their qualifications in order to receive the incentive payment. In order to protect the integrity of my results, I discarded that interview and, upon encountering similar flags in a subsequent interview the next day, I cut off the conversation and suspended recruitment. After consultation with the IRB and others, I updated my screening methods, including moving from a Google Form to a Qualtrics survey that could track the approximate geographic area from which someone responded. These changes were effective, screening out one other respondent from outside the Chicago area, and confirming the eligibility of others. All those who participated in interviews provided their formal informed consent.

I interviewed 10 disabled SSA beneficiaries from a variety of programs. Specifically, these included 4 receiving SSI, 4 collecting SSDI, 1 with dual eligibility collecting benefits from both programs, and 1 collecting benefits as a disabled adult survivor of a Social Security beneficiary. Of these respondents, half lived in the city of Chicago, and half in the suburbs. Six identified as white, three as Black, and one Latinx. Four were men, and six were women. Ages ranged from 27 to 65. They had a range of disabilities that impacted mobility, mental health, speech, hearing, and vision. Two lived in nursing homes, while 8 lived in the community in various arrangements. One interview was conducted with American Sign Language (ASL) interpretation; all of the rest were in English. I also interviewed an 11th subject who was 70 and said that she had received SSDI prior to becoming eligible for retirement benefits, but a number of her comments were of questionable veracity, which seemed to be related to some psychological issues. In the interest of accuracy, I have excluded her comments from this paper. Finally, I also draw on 2 additional interviews with two people who looked into the programs but did not apply. One, a white man with multiple disabilities, was told that he would likely not qualify; another, a white woman who had abruptly become Deaf as a young adult, decided not to apply.

Most interviews took between 1.5 and 3 hours. While I provided the option of in-person interviews when COVID case rates had declined, all chose to conduct the conversation by phone or over Zoom. All were audio-recorded, and, where it was feasible and subjects gave permission, video-recorded. Recordings were subsequently professionally transcribed, and I intermittently spot-checked transcripts for quality. All participants were compensated \$50.

I structured the interviews as open-ended conversations. Following the advice of Jiménez and Orozco (2021), I emphasized flexible prompts rather than a set of direct questions. I did not state a particular hypothesis so as not to lead interviewees to tell me what they thought that I wanted to hear—a risk of interview-based research that Jerolmack and Khan (2014), among others, caution against. Topics covered included subjects' general biographies, the nature of their disabilities, and their educational and work experiences. I inquired about their experiences applying for Social Security benefits, their interactions with the programs, and both the assistance and any difficulties the programs provided them. I made a point of inquiring about their familiarity with work incentive programs, and any relevant experiences. I also covered a range of other topics relevant to other areas of my research which shed further light on their Social Security experiences, including interactions with nursing homes and other congregate care settings, encounters with police, the COVID pandemic, relationships with disability-focused organizations, and sense of disabled community.

In addition to interviews, I also draw on my observations of discussions, primarily on Zoom, among members of an activist group (which I pseudonymously call the Nursing Home Emergency Coalition) seeking to organize residents from a handful of area nursing homes to push for improved conditions. This group, formed in the early days of the COVID pandemic in response to the toll of the disease in congregate settings, evolved to have weekly meetings of nursing home residents and supporters. With permission, I observed dozens of hours of the group's conversations. While I initially approached the group with a different set of research questions in mind, I soon learned that questions around Social Security benefits for those in facilities were not uncommon.

As my interviews and observations progressed, I iteratively reviewed transcripts and notes. I wrote out summaries of interview transcripts, coded by general topics and themes, and then reviewed these summaries in sequence, seeking to identify emergent themes. I wrote memos and identified key topics and issues that were voiced by multiple subjects. The small N of this study reflects its qualitative nature and is not intended to be statistically representative. Instead, guided by Mario Small's (2009) concept of sequential interviewing, I treat each new interview as a case, framing the set of interviews and observations not as a sample but as a multiple-case study. Each case built on the previous, with responses in one interview often influencing prompts in subsequent interviews. After poring over the results, the findings that follow reflect the most important themes to emerge from data collection.

RESULTS

I found that, contrary to popular images of beneficiaries as passive recipients of aid, most were performing significant mental and emotional work to manage their benefits, maintain their health, earn enough money to meet their needs, and deal with the uncertainty and precarity that framed those tasks. Choices that may appear, from the perspective of outside observers, to fail to take advantage of programs and policy opportunities, were actually reasonable strategies for dealing with uncertainty and managing confusing and complex programs. Together, these actions constitute policy navigation from below. In the paragraphs that follow, I share key aspects of how this process plays out.

“I don't know how government things work.”

For those who research and work in policy, it can be tempting to take for granted that clients are familiar with the rules and procedures of the programs on which they rely. But this is

not a given. Caitlin,¹ a 27-year-old with osteogenesis imperfecta who lived in one of Chicago's suburban counties, had indicated on her screening form that she received SSI and SSDI. But during our interview, it became clear that she actually collected benefits as a disabled adult survivor of a beneficiary. She didn't know details of the program, and she suggested at one point that it might have to do with her father's military service, before saying flatly, "I don't know how government things work." Caitlin is not uneducated; she recently completed a master's degree, and she hoped to pursue a career in higher education disability services. She also had advocacy experience. But when it came to navigating the complexities of her benefits, she simply said that it was beyond her.

This lack of clarity was not uncommon. Rhonda, a Black woman with lupus in her mid-50s living in a Chicago nursing home, said in her screening that she received SSDI. During her interview, she was able to offer details of the questions she'd been asked when her application went to a hearing years before. But when I sought to clarify which type of benefit she received, she said, "I'm not sure. SSI, yes. Social Security Disability," using the terms for both programs. Based on her benefit level, and her further comment that she didn't work enough to get benefits that were available "after you work a long time," it became clear that she collected SSI. But her confusion reflected the complexity of the programs.

One common response to this complexity, of course, is for social workers and other advocates to assist people in their interactions with SSA, particularly when they first apply. Jason, a 50-year-old Black man who had recently moved from a series of nursing homes into his own accessible apartment in a Chicago suburb, collected both SSI and SSDI after falling down a set of stairs and becoming quadriplegic. He had little to say about the process of applying for benefits, explained that a social worker applied while in a rehabilitation hospital after his injury, and "They immediately approved me because I was there and it was obvious that I had an injury or whatever." But now that he was on his own, he found interactions with government frustrating. When I asked him to elaborate, he pointed to "Just dealing with the government, period. And then I sent them what they asked me for, they had to come right back around and ask the same thing."

Laurel also found her interactions with the program frustrating. A 39-year-old white woman collecting SSDI because she is blind who also lives with chronic pain, she said bluntly, "Their communication sucks. You could call somebody on a Tuesday, get all the information that you think is correct. Everything's solid. You're writing down notes. They're sending these paperwork forms and great. You call back on a Thursday and all the information you got is different. There is no continuity. There is no communication between offices or departments, and it's just crazy." This was not a mere bureaucratic headache for Laurel. In 2021, she lost her benefits for 8 months, for reasons that were not clear to her. She was ultimately able to get back on, though amidst the turmoil of a year that also included the loss of a pregnancy, she wasn't sure of whether she appealed her denial or applied anew. She described the experience as "very, very scary."

"Don't poke the bear."

Laurel developed a strategy for dealing with uncertain instructions and the fear of loss of benefits. She sums it up in four words: "Don't poke the bear." In other words, she seeks to limit her interactions with SSA for fear that they could have negative consequences. This has very real opportunity costs. For instance, she lives in suburban Cook County, where she could qualify

¹ All informant names in this paper are pseudonyms.

for a disabled home ownership tax deduction. But despite having owned property for six years, she has never applied. To qualify, the county needs “your award letters of the amount that you get every month to and verify that you are on disability and you are a disabled homeowner.” And out of fear that requesting those could somehow put her benefits at risk, she has never sought out that documentation. Instead, she said, “I’ve taken the hit, because again, don’t poke the bear.”

While the term is Laurel’s, the concept of not poking the bear is a key part of policy navigation from below, and it echoed in many informants of their interactions (and non-interactions) with government. For Laurel, it also had led to her not pursuing the Ticket To Work program, even though she already worked and the program might have helped her to ensure that her earnings didn’t threaten her benefits. She explained that she had received information about the program in the mail, and had received a phone call about it, adding, “But again, no one tells me the same information twice.” In the end, she “never made sense out of it” and didn’t apply, partly because she didn’t want to poke the bear.

Laurel was not unique in her fear that participation in SSA’s own work incentive program could poke the bear. Andrew, a 63-year-old Deaf Black man, has collected SSI for some time, and is very active in local Deaf and disabled communities, as well as his church. When I asked if he knew of programs like Ticket to Work or the Trial Work Program, he replied that based on the experience of people he knew, the programs were “no good.” He had researched them but didn’t want to risk the loss of benefits. He explained that even receiving income from work and a reduced SSI benefit was “not enough money to survive on.” He further feared that making money from a job could lead to the loss of SSI altogether, “and then, if you lost your job or whatever, then you had to reapply for SSI and start the process all over again. There went another six months that you had to wait before you started getting money every month from SSI.” Despite SSA’s efforts to promote work, he understood the job market to be too precarious to justify that course of action. Participating in a work incentive program could upset the bear in a fundamental way, jeopardizing the benefits on which he relied.

Another form of not poking the bear could be found in how people managed their work. As I will discuss in the next section, many of my informants worked a limited amount, with care not to go over SGA. Sarah, for instance, a white woman in her mid-50s with depression and cerebral palsy, collects SSDI while working part time in child care in a Chicago suburb. In August, her employer decided to give \$2000 bonuses to employees. In response, fearing for her benefits, Sarah asked her employer, “Miss Regina don’t pay me the \$2000, please don’t pay me the \$2,000.” But her employer, insisting that it would be unfair not to do so, gave her the bonus. When we spoke in October, Sarah was anxiously waiting for the other shoe to drop, wondering if she would hear from Social Security. Much as Laurel passed on the opportunity to seek a tax deduction for fear of drawing SSA’s notice, Sarah attempted to turn down a workplace bonus, fearing that it would draw the proverbial bear’s attention to her.

Not poking the bear can also mean deciding that the costs of engaging with Social Security override the benefits one might gain, leading people to choose not to apply in the first place. Tanya, 37, looked into applying for benefits when she abruptly became Deaf in her mid-20s. She ultimately decided not to, though she stressed that she had previously collected benefits through the Supplemental Nutrition Assistance Program (SNAP) and had no problem with receiving public aid. Her decision not to apply for SSI or SSDI was in part because of the experience of her child’s father, who had fought a six-year effort to qualify for benefits and passed away before a determination was made. But she also saw the program as a catch-22,

saying, “I’ve heard from different people I’ve met in the disabled community who do get disability benefits, how small those benefits are and these are people who maybe could work five hours a week, but if they did, they would lose their disability and lose their health insurance. All these things that they have to rearrange their lives just to make sure they’re getting the bare minimum of government benefits. It’s not a system. I don’t think that is working for anyone.”

Work

There is a strong thread of academic and policy literature that understands disability programs to place beneficiaries outside of the labor market. Deborah Stone’s canonical book, *The Disabled State*, argues that debates over the definition of disability, and struggles over who qualifies for SSI or SSDI in particular, stem from the unique nature of these programs as bestowing a “categorical exemptions from the labor market,” with disability understood to “render people automatically incapable of participating in the wage labor system” (Stone 1984, 21). The work that is allowed under SGA is treated as incidental and of limited significance. But for a majority of my informants who received Social Security benefits, work still played an important role in their lives. Six out of ten respondents reported working. Of the four who did not, two were in nursing homes at the time of our conversations, reflecting both the extent of their medical needs, and living situations that would make a job near-impossible. Jason, who appeared in the previous section, had not worked since becoming disabled in 2014. But he, too, had spent much of that time in nursing homes, moving into his own home only months before we spoke. When I asked him if he was familiar with SSA work incentive programs, he said, “No, I never heard of them, but I would love to work.” Nearly half an hour later, as we concluded the interview, I asked if there was anything else that we should discuss, he said, “If you could just send me that information about getting a job, that would be really helpful.”²

None of my informants who worked gave any indication that they neglected to report income or comply with program rules. But maintaining their benefits while working was an ongoing challenge, and a source of stress to many. This is another aspect of policy navigation from below: ensuring that one’s efforts to make ends meet, and to pursue meaningful work, do not turn out to undermine the benefits one relies upon. This can take the form of quotidian monitoring of income to ensure that one is not going over SGA. It can also mean the disappointment of being poorly served by programs that are meant to foster greater employment. And for many, it can also involve the frustration of feeling stuck between contradictory policies. I discuss each in the following paragraphs.

While Sarah’s attempt to decline a \$2000 bonus is arguably an extreme example of this, multiple informants described keeping careful track of their income to ensure that they didn’t go over SGA. Alice, 65, had planned to “die at her desk” rather than retire, but she lost a long-time job at a disability-focused nonprofit in a suburban county suddenly in 2017. Roughly 60 years old with cerebral palsy, she was able to get on SSDI, but when offered a job with another organization in 2020, she took it eagerly. Still, she earns only as much as she can without crossing the SGA threshold, noting, “I need to make sure I’m still legal” as we spoke. Sarah makes minimum wage and said that her employer liked her because she was “cheap.” At times, in order to keep below the SGA threshold, she didn’t record all the hours she worked in a day, meaning that she was essentially volunteering a portion of her time. While she likes her work, she said that she felt “terrible” about how she handled her hours—which she attributed not to

² While I share this story as an example of his interest in work, I should add that I did email him information that afternoon about work incentive programs. I do not know whether he pursued it.

being exploited, but to feeling dishonest. Laurel, despite her reluctance to apply for Ticket to Work, works four days a week as a massage therapist. She said, “I have to watch what I make all the time...I Uber to and from work. I Uber to and from doctor appointments, so all of that's deductible. My medications are deductible. If I have any adaptive software which I do need on my phone, and I need my phone to communicate with clients, that's deductible. I think that they want to make it helpful, but they make it tricky in the process.” Each of them is navigating policy as best they can.

A number of respondents had pursued work incentives like Ticket to Work. But the programs have not always met their promise. Raúl, a 39-year-old Latinx man who collects SSI, had worked a number of low-wage jobs in the service industry earlier in his life, but had not stayed at any of them very long, guessing that his longest tenure was a six-month stint at Burger King. Thinking back to them, he said, “I never spoke up, but I think that's what I needed, accommodations and I needed a job coach.” But at the time, he hadn't known that these were even possibilities. He had participated in Ticket to Work, but on reflection, he said, “I wish I would've waited and not given my ticket to that employe[r] back then. I wish I would have waited 'til now. Back then I did not understand the job I was doing.” Steve, a 37-year-old white man, also collected SSI after a brain tumor resulted in multiple disabilities. Through Ticket to Work, he had worked with a rehab counselor he liked very much, but who left the position. Steve was transferred to a new counselor who “basically doesn't want to do anything,” and after realizing that, Steve advocated for himself and sought to change counselors again. But this time, he was assigned to someone who he called rude and condescending. While Steve has a master's degree in social work that he would like to put to use, the counselor suggested that he apply for call center jobs. This was particularly irksome, Steve said, because due to his disabilities, “I have trouble speaking, and I told her that. The more I talk, the more tired I get.” He was in the process of trying to switch to a new service provider. Despite his very real frustrations, he continued to try to navigate the system.

Finally, many expressed frustration that their desire to work conflicted with the SGA threshold. While they wanted to earn more on their own, and viscerally felt the social stigma around benefit receipt, they knew that they might not be able to secure and maintain long-term employment, leaving them feeling stuck. Steve, who had expected to work as a contractor before acquiring his disabilities, said, “It actually bothers me at times. I try not to get down about it, but when they put so much importance on working, it's like, ‘Well, I didn't choose this. I didn't raise my hand to be disabled.’ ... I've got previous work history before I had a disability. Then also I've applied to over 200 jobs, so give me something with a living wage, and I'll get off Social Security, and I'll get off Medicaid.” Sarah told of a time in the late 1990s when she was working consistently and wanted a full-time job, but when she called Social Security, a staff member discouraged her from leaving SSDI. Recounting the conversation, Sarah said, “I remember it exactly. ‘You can't do that. You can't do that. You can't get off because what about insurance, you need it, you can't get off.’” The risk of losing health insurance—particularly at that point, prior to the passage of the Affordable Care Act, was compelling enough to change her mind. Laurel, while continuing to work as much as she can, summed up the conflict she felt, saying, “I really wanted to get off of it [SSDI]. I did not want to be under the thumb of anybody. I didn't want them saying you cannot earn this, you are less than, you can't earn whatever amount you're not able to. However, one of my physical issues is I have back surgery. There's nerve damage, and I have a very hard time being on my feet and working and I could not hack it. I am very thankful that SSDI was there for me.”

Navigating in Nursing Homes

If policy navigation from below is challenging for those living in communities, it is even harder for those attempting it within the context of nursing homes. Informants living in these congregate settings described monotonous, institutionalized life, without sufficient staff to care for residents' most basic needs. Official US policy, as expressed in the *Olmstead* decision and elsewhere, promotes independent living rather than restrictive settings such as these. But for those who qualify for SSI or SSDI, benefits that might serve as a resource to assist in moving back to the community essentially disappear. SSA policy states that SSI benefits when one is institutionalized are generally only \$30/month (2022c). This small amount is also the Personal Needs Allowance required for nursing home residents in the state of Illinois. SSDI policy is less clear, but clients generally understood that any benefits allocated to them were redirected to facility management. They too had only \$30/month to live on.

Residents seem to agree that \$30/month is grossly inadequate. While in theory, nursing homes cover the cost of basic needs, many expenses still emerge. Rhonda itemized some expenses, saying, "The food is not the best. It's horrible sometimes. Sometimes we just get a sandwich...probably people want maybe some snacks, or maybe pop every now and then. Maybe you want to eat out every now and then. Maybe want to get underwear if you don't have. Basic things, maybe just an extra pair of socks." Such a modest list does not even cover items costs like internet access (which can sustain crucial social ties), let alone items one might need in order to return to the community. In addition to its inadequacy, Emily expressed frustration that the SSDI benefits she'd earned were going to managers providing inadequate services. Aside from the \$30 allowance, she said, "They take it all and it's a good amount. I was making good money back then [when she worked]." She pointed out that as she understood it, the state already paid the nursing home through other funding streams, and now they were collecting her SSDI on top of that, adding "It's just unreasonable. Then they say they don't have enough money to fix this or fix that...can't even get a can of ginger ale when your stomach's upset."

But precisely whether benefits went to facility management, or were simply reduced or suspended, was not always clear to residents. In the Nursing Home Emergency Response group's resident meetings over Zoom, clarity around Social Security was a regular topic on which people hoped to find resources. I attempted to offer what insight I could, but my own policy knowledge here was limited. Residents attempted to advocate for themselves without knowing what their rights were in regard to their Social Security benefits. At a meeting in February, a member named Julio logged in who had recently moved into a supported living facility, which he had hoped would be better than the nursing home where he had previously lived. Before moving in, he had been approved for disability benefits (whether SSDI or SSI was unclear) and had received a sizable lump sum. But now, apparently citing those assets, the supportive living facility wanted to charge him \$4400, and pushed him to name the facility as his representative payee. He sought the group's advice: could they do that? If they could, what resources would he have left? Members suggested a number of resources, including Legal Aid and the state's Protection and Advocacy agency. But the situation starkly illustrated the challenges of navigating complex policy from within a putatively therapeutic institution.

DISCUSSION

This paper presents a framework of policy navigation from below as the active processes through which disabled beneficiaries manage the complexity of SSI and SSDI and maintain a

very limited level of economic security. Working with limited information, many find the Social Security Administration difficult to engage with. The rules can be even more bewildering and inaccessible for those operating within the constraints of settings like nursing homes. Some actively decline to take advantage of programs designed to serve the disabled population, even programs administered by SSA, for fear of “poking the bear” and putting what benefits they have at risk. At the same time, these benefits are still often insufficient, pushing many to work to the extent allowed by the labor market and program guidelines. Together, these findings point to two key areas that should inform research and policy: the profound precarity that informs many beneficiaries daily lives, and the importance of work even in programs that has previously been understood to remove participants from the labor force.

This study has obvious limitations. It is based primarily on interviews with only 10 beneficiaries, as well as observation of a small organization. Interview subjects vary around a number of important axes, including race, gender, disability type, and living situation (whether suburban or urban, and institutional or community). But by no means do they cover the entirety of the beneficiary population in greater Chicago, which in turn is but one metropole in a large country. Because of the social and organizational networks through which I recruited, as well as the activist orientation of Nursing Home Emergency Response, respondents may have also tended toward politicized views of disability more than their average peers. (This was by no means uniform; one respondent told me that she didn’t believe in voting, believing that fixing the world was a task for the Almighty.) But the study was not meant to create a representative sample. Instead, following Small (2009), each interview served as a unique case. Each one involved a respondent sharing detailed experiences, often disclosing deeply personal information about their disabilities, their health, and their treatment—and too often, mistreatment—in moments of heightened vulnerability.

Indeed, one limitation of the study underscores the finding of persistent precarity. One might imagine that a group of respondents with ties to disability-oriented institutions, whose recruitment paths went through an activist organization and a disability pride event, would feel relatively secure around their program participation. With access to information and relationships with advocates, they might rest a bit more assured than the average SSI or SSDI claimant that they would not lose their benefit. But the majority of interviews were still marked by considerable precarity. The people I spoke with did not know all of the rules and feared loss of benefits—which had happened to one very careful informant for reasons she still was not sure of. Interactions with SSA were cause for anxiety and frustration, to the extent that many actively avoided them or put “government things” out of mind. This precarity was also intimately tied to the level of support that people received, which was largely seen as insufficient. But with consistent employment for a host of reasons, the fear of losing what aid they had loomed large. While much of this precarity is deeply structural, future research and policy action can seek ways to ease it, including stronger protections against loss of benefits.

The role of work is another key finding. As I wrote earlier, much of the academic literature on SSI and SSDI presents them as fundamentally exempting beneficiaries from the requirements of the labor market, with disability defined as inability to work beyond a minimal threshold. And indeed, informants were careful to keep their earnings below SGA. But their benefit receipt is not solely a matter of incapacity, nor of lack of interest in working more. Steve’s frustrated declaration that he had applied for over 200 jobs attests to that, as does Laurel’s acknowledgement that working too many hours a week could exacerbate her chronic pain. This raises the questions of how policies can be shifted to better serve those who are

passed over by hiring managers due to their disabilities, who can work more than SGA but less than full time, or whose chronic conditions threaten to flare up and cause the loss of a job. The promise of the Americans with Disabilities Act to prevent disability-based employment discrimination has not come to pass. One of its champions, Tom Harkin, commented in 2007 that “we really haven’t cracked the nut on employment,” estimating that over 60% of people with disabilities were unemployed, and more were underemployed (quoted in Pettinicchio, 2019, 147). Nearly 15 years later, only 38.4% of people ages 18-64 were employed, compared to 75.8% of people without disabilities (Houtenville and Boege, 2022). How to support those who seek to work, without jeopardizing the benefits on which so many rely, is an urgent question.

CONCLUSION

As disability-specific income support programs, SSI and SSDI are not only sources of much-needed financial assistance to millions across the US. They also present a mentally and emotionally taxing set of requirements for beneficiaries seeking to secure and maintain eligibility, particularly for those who also earn money by working. Through in-depth qualitative research on the work that claimants do to navigate these policies from below, we can see beyond simple dichotomies around the relationship between disability and work, and we can understand clearly that beneficiaries are not simply passive recipients of aid. We can also gain insight into why many decline to participate in programs, such as work incentives, that could serve them well. As the disabled population grows with the ranks of those experiencing long COVID, these findings can help to guide policy changes that reduce the precarity in which too many disabled people live today.

(Implications for SSA follow on next page.)

IMPLICATIONS FOR THE SOCIAL SECURITY ADMINISTRATION

Many of the issues described in my paper are larger than the Social Security Administration. More than one respondent spoke of their frustration with “government” in general, rather than the SSA in particular. And SSA, of course, operates under very real constraints. But as the administrator of these essential programs, specific policy changes by the administration could also have profound positive impacts on the lives of beneficiaries.

Allow nursing home residents to keep their benefits

Informants in nursing homes had no source of income but a \$30/month personal needs allowance, a rate set by the state of Illinois. For those who qualify for SSI, this matches the maximum allowed to an institutionalized beneficiary. For those collecting SSDI, there is not a clear policy blocking continued receipt of full benefits. This suggests that facilities may routinely compel residents to designate management as their representative payee, even when this is not appropriate.

I thus suggest two policy steps. First, **significantly increase the cap on SSI payments to institutionalized beneficiaries, or remove it altogether**. As multiple informants pointed out, living in a nursing home does not mean that one is without expenses. A minimum of \$150/month is far more realistic than the current \$30. This would support residents in maintaining social ties (by paying for communication technology), addressing daily needs, and transitioning back into the community. If necessary, the funds can be stored in ABLE accounts. Second, working with the Department of Health and Human Services (which regulates nursing homes and provides significant funding through Medicaid), SSA should **investigate nursing home practices around representative payees** to explore the extent to which residents are being pushed to name facility management as their representative payees. SSDI was not created to fund for nursing homes. Even when a representative payee arrangement is appropriate, facility management should not view a resident’s benefits as a revenue stream. To do so creates a perverse incentive for managers to block beneficiaries’ return to the community while immiserating residents.

Increase SSA staffing

The rules governing SSI and SSDI are complex. When clients receive conflicting information from different agency representatives, or they feel that they are being asked for the same item repeatedly, it adds to that complexity can breed frustration and disengagement. But unclear or consistent instructions are a predictable outcome of understaffing. Cuts to SSA’s staffing budgets have increased wait times, harming both workers and clients (Herd & Moynihan, 2018, 251-253). Wait times faced by disability applicants have been the topic of attention from the US Government Accountability Office (GAO), as well as journalists (GAO 2018; GAO 2020; Rein 2022). By reversing recent funding trends and building up adequate staffing levels, SSA can create an environment where workers can give more time and attention to each question, and where clients seeking help will not have their patience taxed by long waits before an appointment or phone call even begins.

Enhance and universalize protections against loss of benefits

The fear of being cut off of SSI or SSDI shaped many people’s behavior. It led some to avoid opportunities, even for benefits as material as a tax deduction, for fear of “poking the bear.” And

the concern was not without warrant; Laurel, despite her careful accounting, had lost SSDI for an eight-month period. To whatever extent possible, SSA could better serve disabled clients by offering greater protections against benefit loss, such as grace periods or warnings. Some work incentive programs already offer income disregards, and SSDI beneficiaries who participate in the Trail Work Period can take advantage of the Extended Period of Eligibility. But as discussed in the paper, many are wary about participating in work incentive programs in the first place. If extended eligibility and grace periods were universal rather than restricted to subsets of beneficiaries, they could be sources of greater security, reducing the pervasive fear that a small misstep might lead to a catastrophic loss of support.

Evaluate how SSI and SSDI beneficiaries understand SSA communications

Nearly 20 years ago, the Government Accountability Office urged SSA to study how to improve general understanding of the annual Social Security statements sent to workers (GAO 2005). The rules governing SSI and SSDI are arguably more intricate than those governing retirement benefits, and the frustration expressed by many informants suggests considerable uncertainty as they attempt to navigate program rules. In the same spirit as GAO's 2005 recommendations, I urge SSA to study how beneficiaries understand the information they receive from the program, and how documents and other formal communications can be made clearer. This could ease the learning costs imposed on clients, and it has potential to reduce demands on caseworkers by reducing the number of errors and streamlining processes.

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