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REASONABLE ACCOMMODATION, REHABILITATION, AND INSTITUTIONALIZATION: THEORIZING DISABLED CITIZENSHIP

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BY
MATTHEW GABRIEL BORUS

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To my parents,

Judy and David Borus

Contents

List of Tables

Abstract

Disability, as a social construct, is embedded in a wide range of social systems. Beginning from the premise that different laws and institutions define disability in divergent, often contradictory ways, this dissertation asks how individuals and organizations in the Chicago metropolitan area experience, navigate, and contest the meanings of disability and the policies through which these meanings are institutionalized. I refer to the nexus of social and political structures through which disability is defined as *disabled citizenship*, drawing on T. H. Marshall's conceptualization of citizenship as a matter of social belonging and as built on interconnected categories of rights. I argue that contemporary disabled citizenship is the product of a process of *policy sedimentation*, whereby policies crafted in different eras, reflecting different approaches to disability, sit unevenly on top of one another. This contributes to an unstable and inherently contradictory construct that is bound up with tensions between disabled people's civil, political, and social rights.

The empirical chapters of the dissertation are structured around a comparative case study of four manifestations of disabled citizenship: 1) labor market participation with rights protections through the ADA; 2) income support through Social Security Disability Insurance and Supplemental Security Income; 3) institutionalization in putatively therapeutic settings such as nursing homes; and 4) activism by disabled people seeking to expand and transform the boundaries of citizenship. Many of my informants have experienced more than one of these policy regimes, creating tensions between conflicting policy logics. The fourth area of focus is clearly distinct from the other three, and its inclusion reflects my argument that disabled citizenship is fundamentally contested.

I argue that disabled people, facing the uneven terrain created by policy sedimentation, engage in a process of *policy navigation from below*, which I define as their active labor to secure accommodations, benefits, or services while also addressing their material needs. For disabled workers, this can mean requesting disability accommodations, maintaining relationships with bosses and supervisors, and ensuring that one can maintain health insurance and, in some cases, eligibility for other benefits. In the case of SSI and SSDI beneficiaries, the process involves interpreting and understanding program rules, navigating conflicting policy logics, and at times performing paid work where possible. For residents of Medicaid-funded nursing homes, it can mean keeping one's head down and maintaining friendly relations with overworked staff, pursuing the complex process of transitioning out of a facility, and advocating for better treatment. For disabled activists, policy navigation involves maintaining the external presentation of a campaign as a sympathetic appeal to nondisabled decision-makers who may view them through an ableist lens, while also sustaining internal commitment and creating space for defiant expression. While each chapter focuses on one policy arena, navigational work often takes place often across policy systems, reflecting the fragmented character of disabled citizenship. By illuminating these processes of policy navigation from below, I shed light on overlooked forms of labor that disabled people must perform in order to engage with systems of work, social provision, care, and political action.

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At this point, I have mentioned only a few of the friends and colleagues who have been essential to this period of my life. I count myself deeply fortunate to have a community of people with whom I can both discuss ideas and trade jokes, whom I can organize alongside, and on whom I can rely in a crisis. Any list is incomplete, but in rough order of when they entered my life, I want to thank Duff Morton, Aron Marie, Katie Gibson, Theresa Anasti, Julian Thompson, Kristen Ethier, Ashley Cureton, Lance Keene, Mary Bunn, Kathryn Bocanegra, Angelica Velazquillo Franco, Alabún'mí A.M. Jones, Rob Eschmann, Alison Kopit, Brian Heyburn, Allison Reed, Alicia Riley, Justin Harty, Dylan Bellisle, Tonie Sadler, Sneha Annavarapu, Karlyn Gorski, Haitong Xu, Hong Jin Jo, Hanock Spitzer, Tadeo Weiner Davis, Dani Adams, Hannah Obertino Norwood, Emily Ellis, Lauren Peterson, Shruti Vaidya, Lauren Beard, Jeffrey Parker, Melissa Osborne, Bellamy Mitchell, Lester Kern, Frania Mendoza Lua, Simon Shachter, Ilana Ventura, Shannon Morrissey, Kit Ginzky, Anna Fox, Hyojin Cho, Eunseok Jeong, Pratiti Deb, and Durrell Washington.

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Park Minyan, created on an ad hoc basis early in the pandemic, has become the center of my Jewish community. The Jewish Council on Urban Affairs and JCUA Votes have also been important political spaces for me, particularly in the difficult yet hopeful work of attempting to engage with Chicago's electoral politics. And while I am, once again, reluctant to name specific organizations so as not to compromise the anonymity of groups appearing in this dissertation, I am grateful for the welcome and camaraderie I have found in Chicago's disability communities.

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Chapter 1

Disabled Citizenship: A Historical and Theoretical Sketch

Disability, as a category of social structure and interaction, contains remarkable breadth and variation. Government estimates suggest that as much as 20-25% of the population has a disability of some kind (US Census Bureau, 2012; CDC 2018). The range of disabilities is as vast as the array of interactions between an individual's body and mind and the elements of society with which they come into contact. Disability is embedded in multiple social institutions, including the labor force, the welfare state, medicine, and policing and incarceration. Disability is a basis for political identity and social movement action, a justification for rights-based claims upon the state, and simultaneously a cause for social and political exclusion and marginalization. So perhaps it is not surprising that the array of approaches to disability within these systems, both in their definition of the concept and their response to it, are wide-ranging and contradictory. If we understand states to categorize people in order to make populations administratively legible (Scott, 1998), the category of disability remains difficult to read.

Disabled people in the US can easily find themselves at a juncture between several contradictory strands of disability policy. Consider a woman who qualifies for Social Security Disability Insurance (SSDI) because she is blind. The program is premised on the assumption that disability prevents one from working; early Social Security policy entrepreneurs likened it to an early retirement program for those whose disabilities forced an early exit from the labor force. But our hypothetical woman may also work; SSDI allows one to earn up to a certain amount before losing eligibility for benefits. And based on the policy history of categorical programs for the blind, that threshold is higher for blindness than for other disabilities. So she may regularly work a limited number of hours each week. Under the Americans with Disabilities Act (ADA), she is entitled to "reasonable accommodation" for her disability in the workplace, though her success in securing those accommodations, as well as the job itself, are contingent on her employer's attitudes, her bargaining power, and countless other factors. However things turn out, she is situated within two directly contradictory sets of disability policies: one that defines disability as exclusion from the labor force, and another that seeks to protect against disability-based discrimination in the workplace. And as multiple cases described in this dissertation will show, she will also need to be vigilant to ensure that one set of policies does not invalidate the other, not allowing her income to reach a level that leads the Social Security Administration to reduce or cut off a source of cash assistance upon which she relies. This is but one of the potential contradictions that disabled people navigate.

But despite such contradictions, the concept of disability remains salient in the lives of millions of people, as well as a broad array of organizations and policies at all levels of government. Much as Althusser (1970) writes that ideology interpellates subjects through everyday interactions that enact a complex ideological apparatus, so too are individuals interpellated into the conceptual frameworks that recognize them as disabled through their interactions with one another, with arms of the state, with employers, with non-governmental organizations, and even with mundane features of the built environment such as a ramp—or the lack of a ramp—between sidewalk and street. Social recognition as disabled is deeply intertwined with the ideology and structural manifestations of ableism, which produce disability as a form of marginalization (Mauldin, 2021). Though the legal and social meanings of disability are complex and internally contradictory, they are no less real.

I theorize this nexus of contradictory political and social structures as *disabled citizenship*, which I describe in the next section of this chapter. Beginning from the premise that different laws and institutions define disability in divergent, often contradictory ways, I ask how individuals and organizations in the Chicago metropolitan area experience, navigate, and contest the meanings of disability and the policies through which these meanings are institutionalized. This dissertation is structured around a comparative case study of four manifestations of disabled citizenship: 1) labor market participation with rights protections through the ADA; 2) income support through Social Security Disability Insurance and Supplemental Security Income; 3) institutionalization in putatively therapeutic settings such as nursing homes; and 4) activism by disabled people seeking to expand and transform the boundaries of citizenship. Many of my informants have experienced more than one of the three policy regimes on which I focus, highlighting important questions about how they navigate the tensions inherent within disabled citizenship. The fourth area of focus is obviously distinct from the other three; rather than a discrete policy regime, it is a more inchoate form of insurgent citizenship (Holston 2008). But as I will argue, disabled citizenship is fundamentally contested, and so the project would be incomplete without a focus on contemporary activism.

In my theoretical approach, I also consider an additional policy regime, constituted by carceral programs of so-called “therapeutic jurisprudence” such as mental health courts and police response to mental health crises. While I went to significant lengths to solicit interviews with disabled people who had experienced such programs, I found few informants willing to sit for interviews. Thus, while I discuss such programs in the historical development of disability policy within this chapter, and while my substantive chapters maintain reference to some informants’ experiences with such systems, I have shifted my plans for empirical analysis of carceral disability policy to future research.

DISABLED CITIZENSHIP

In conceptualizing disabled citizenship, I build on TH Marshall's concept of citizenship as both a matter of social belonging, and as built on three categories of rights. I also draw heavily on subsequent theorists of citizenship, particularly in the United States, who have worked to address Marshall's theories for a society without the social rights guaranteed in the UK, let alone in more social democratic countries. I argue that disabled citizenship is characterized by a *temporal* structure that brings together layers of policy from different historical periods, bearing the echoes of conflicting conceptions of disability that are found is disparate social systems. I point out that disabled citizenship is *contested*, as social movement actors have long sought to claim citizenship rights and counter systems of marginalization. I also argue that disabled citizenship is fundamentally *intersectional*, closely intertwined with the structures of race, gender, and capital that stratify society. Finally, I argue that a focus on disabled citizenship centers the varied experiences of a group that has often been presented as fundamentally outside the boundaries of citizenship.

Marshall (1950) describes citizenship as "a status bestowed on those who are full members of a community" (28), a status that bestowed a measure of both rights-based equality and social belonging. Marshall conceptualizes citizenship as based loosely around three categories of rights. Civil rights, in his formulation, are individual freedoms within classical liberalism, such as the right to own property and to enter into contracts, including free access to participate in the labor force. Political rights are centered around electoral enfranchisement and participation in systems of government. Social rights bestow a measure of economic security, and they are most associated with schools and the provision of social services. All three forms of rights contribute to the sense of belonging as a full member of a community. Marshall's approach is deeply influential, particularly in the sociology of welfare states with which disability policy is closely intertwined. Esping-Andersen writes that Marshall's "proposition that social citizenship constitutes the core idea of a welfare state" is a claim with which "few can disagree" (1990).

Notably, Marshall argues that rights may be guaranteed outside of the structures of citizenship. He presents the 1834 British Poor Law as a case where social rights were provided, in minimal form, without citizenship. Paupers who entered the workhouse "forfeited in practice the civil right of personal liberty" and suffered political disenfranchisement. To accept relief was to "cross the road that separated the community of citizens from the outcast company of the destitute." Similarly, the Factory Acts provided some measure of protection from long hours and dangerous working conditions. But Marshall notes that this protection was extended specifically to women and children, "because they were not citizens." To accept poor relief or workplace protection, under these logics, was to claim not the rights of a citizen, but an "alternative" status (23-25). Fraser and Gordon reiterate this point: dependency, like that of the pauper, "was deemed antithetical to citizenship" (1994, 315). Reuben Miller and Forrest Stuart (2017) elaborate on the concept of alternate citizenship status in their concept of carceral citizenship. Those who have been convicted of a crime, mostly poor and Black, are marked for exclusion by both state and non-state actors, while also gaining access to very limited systems of provision for basic needs that bear some resemblance to those afforded to paupers nearly 200 years earlier. The idea that the provision of social support or protection can result in the forfeiture of other rights, or create an alternate form of citizenship, is essential to understanding the trade-offs involved in multiple aspects of disabled citizenship.

Elsewhere, Fraser and Gordon argue that the civil rights of contract developed in such a way as to mitigate against social citizenship in the US, where social provision instead came to be framed as a matter of charity. With the rise of civil citizenship, normative social relations outside of the family unit were increasingly understood in contractual terms, ranging from the sale of one's labor for wages to liberal ideals of the social contract. This left less space for norms and practices of collective responsibility or social reciprocity outside of the concept of contract and exchange. Thus, they write, "Charity came to appear a pure, unilateral gift, on which the recipient had no claim and for which the donor had no obligation" (1992, 59). The distinction between contract and charity informs a central dichotomy in US social provision. Fraser and Gordon argue that beginning in the early 20th century, so-called earned benefit programs like workman's compensation emphasized a contractual logic, whereby recipients received support from systems into which they had had putatively "paid in" earlier, valorizing their status as workers. Meanwhile, "unearned" benefits like mother's pensions and subsequent cash assistance programs like AFDC, have carried the stigma of charity. Chad Alan Goldberg argues that the roots of this dichotomy in US policy trace back to the 19th century in the distinction "between citizens and paupers" that informed social provision in the wake of the Civil War (2007, 281).

Wherever one traces its source, the persistence of a contractual civil citizenship, with only residual social provision, stands as an ironic counterpoint to Marshall's optimistic proclamation that social citizenship would characterize the 20th century. The dichotomy between citizen-worker and aid recipient was incorporated into key elements of disabled citizenship. SSDI was presented to Congress and the public as an earned benefit program, explicitly modeled on Social Security retirement, and available only to those who had "paid in" with an eligible work history. Supplemental Security Income (SSI) is administered by the same federal agency and applies the same strict definition of disability, but it requires no comparable work history. Accordingly, it is more widely understood as a form of welfare, and benefit receipt is subject to strict asset caps (Erkulwater 2006).

Marshall acknowledges that social provision under poor law was largely inadequate to meet people's material needs. Much of the task of addressing poverty thus fell to private charity, and it was generally the "view of charitable bodies that those who received their help had no personal right to claim it" (33). This sentiment was echoed decades later by disability journalist Anne Peters. Writing in the May 1982 issue of a grassroots periodical called the *Disability Rag*, Peters offered a similar assessment of charity as restricting the space for political claims-making. She condemned Jerry Lewis-style telethons, with their parade of grateful disabled children, writing that such pageants were "the sanctioned way of dealing with the needs of this nation's disabled," providing funding for wheelchairs and "other things we can't get any other way." And because charity telethons met these basic needs, Peters wrote, "They keep us quiet. We still need the things telethons can give us, so we cannot afford to criticize them too much…We don't bite the hand that feeds us" (1982, 2). Outside of the structures of citizenship, or even the state, social provision was not an arena in which to claim political rights.

The previous paragraph, with Marshall's description of 19th century poor relief beside a 1982 critique of charity fundraisers, may seem at first to present an awkward juxtaposition. But disabled citizenship is characterized by a particular temporal quality whereby policies from different political moments, rooted in divergent definitions of disability, exist uneasily alongside one another in the present. Programs from one era locate disabled people outside the workforce, while more recent laws seek to guarantee accommodations at work. The US Department of Health and Human Services houses an Administration for Community Living, which is dedicated to supporting disabled people in living independently. Meanwhile, the Center for Medicare and Medicaid Services, another agency in the same department, is criticized for its "institutional bias" that steers people into nursing homes rather than the broader community. Understandings of disability with echoes of late 19th century eugenics sit alongside medical approaches that seek individualized rehabilitation and cure, as well as more contemporary social models of disability (e.g., Oliver 1990) that locate disablement in physical and social structures.

I call this temporal aspect of disabled citizenship *policy sedimentation*. The tensions between policies crafted in different eras are bound up with the tensions between civil, political, and social rights, contributing to an unstable and inherently contradictory construct that is disability in the contemporary US. The experience of these contradictions, and the work that disabled people must do to manage them, is an essential characteristic of disabled citizenship. The tradition of all past disability policy weighs on the brains of the living. But contra Marx (1852|1978), past policy does not only manifest as nightmare; programs like SSDI, despite their stringent conditions, offer crucial measures of material support. Activists and policy experts know all too well that if similar programs were proposed today, they would be unlikely to come into being. And so disabled people seek to navigate the contradictions of programs from different eras. Even among disability policies originating from the same era, different policy realms may take contrasting approaches to disability. A key example, discussed in detail in Chapter 2, is the divergence between the approach to accommodations for disabled students in schools, and that for disabled workers on the job.

The concept of policy sedimentation overlaps to some extent with the process of layering, a term first used by Eric Schickler to describe institutional development in the US Congress (2001) and elaborated by Kathleen Thelen in her cross-national study of occupational skill formation. Thelen argues that "institutional layering," which "involves the grafting of new elements onto an otherwise stable institutional framework," serves as a key mechanism of institutional transformation (2004, 35). Jacob Hacker subsequently presents layering as an approach to policy change pursued by welfare state opponents who, confronting opposition to formal policy reform, have instead created new private benefits that erode support for public programs (2004). But while this literature on layering discusses change within discrete institutional fields, policy sedimentation encompasses the many fields that bear on disability, even incidentally or residually. Rather than building on a stable institutional framework, to borrow Thelen's words, policy sedimentation can be unstable and contradictory. While the concept of sedimentation may evoke images of stones that are smoothed by the passage of eons, a better image is of a craggy landscape, marked by boulders deposited unevenly by the advance and retreat of policy glaciers.

Despite the political weight of accumulated layers of policy, disabled citizenship is fundamentally contested. Disabled people in the US have challenged marginalization in multiple eras, advancing claims for material support, civil rights, and political belonging. The contemporary disability rights movement emerged in the 1970s, with multiple overlapping initiatives. The model of the Berkeley Center for Independent Living (CIL), which advanced a paradigm of disabled self-determination in contrast to prevalent models of medicalization and institutionalization, spread across the country, particularly after they became eligible for federal funding in 1978. The political vision was facilitated by services grounded within the disabled community, including peer support, wheelchair repair, and attendant care (DeJong, 1983). Legislation supporting disability rights in the 1970s was largely due to the work of elite policy networks, but advocates and organizers subsequently sought to implement, defend, and build on new legal protections, in a dynamic that David Pettinicchio describes as "a demand for action *following* legislative victory" (2019, 7).

The 1980s and 1990s saw continued advocacy around a range of issues. Access to transit became a rallying point, leveraging the reluctance of authorities to be seen arresting wheelchair users, as well as the sheer difficulty of moving heavy power wheelchairs, to maximize disruption. But protests and advocacy campaigns also targeted a range of other issues, including legal protection, accessible public spaces, government support for independent living, media portrayals of disability, and more (Barnartt and Scotch, 2001, Pettinicchio 2019). Geographically dispersed activist networks emerged, woven together in part through print periodicals (Borus, in progress) and in subsequent decades, online platforms. The passage of the Americans with Disabilities Act in 1990 marked a significant victory, though many of its promises remain unrealized, and organizing has continued on a broad range of issues in the following decades. Alongside issue-based demands, activists also formulated new conceptions of disabled citizenship. What came to be known as a social model of disability (e.g., Oliver 1983, 1990) located the roots of marginalization not in disabled people's bodies or minds, but in social structures. The social model has itself been the subject of critique, in particular for minimizing impairments and pain that many disabled people experience (Shakespeare 2013, Price 2015). More recently, activists led by disabled queer people of color have advanced a more radical, multi-issue framework of disability justice (e.g., Sins Invalid, 2019).

Disabled citizenship must also be understood intersectionally (Crenshaw 1989). This is true of all citizenship, though race and gender are mentioned little in Marshall's account. Fraser and Gordon argue that as the ideal of the independent citizen-worker emerged in the 18th and 19th centuries, he had three main foils, two of which were explicitly based in constructs of gender or race: the housewife, a non-citizen dependent on her husband's family wage, and the colonial native or slave, a quintessential political non-citizen. Their third icon of dependency, the pauper, came to be increasingly gendered and racialized, develoing into the archetype of welfare dependency that became hegemonic in the late 20th century and beyond (1994). Elsewhere, Fraser and Gordon point out that coverture of married white women was essential in elevating their husbands from the status of dependent workers to their emergent civil citizenship as heads of households. They similarly argue that the "free labor" of white workingmen was specifically defined in contrast to the degraded labor of enslaved workers. Again, the creation of civil citizenship, with its archetypal white male citizen-worker, was contingent on the contrast with a non-citizen other (1992, 54-55). Goldberg further points out that the racialization of citizenship categories is not a given, but reflects the active symbolic work performed in mobilizing racial backlash against social welfare programs. In analyzing efforts to claim the status of rights-bearing citizens by beneficiaries of the Freedmen's Bureau, the Works Progress Administration, and workfare programs on the 1990s, he argues that both past and contemporaneous racial mobilization were key factors in the failure of such claims (2006, 281-283).

Evelyn Nakano Glenn (2002) elaborates on the gendered and racialized nature of citizenship in the US. She points out that the Supreme Court's infamous 1857 *Dred Scott* decision was fundamentally a denial of Black citizenship, and that long after passage of the Reconstruction Amendments to the US Constitution, African Americans were denied property rights and the franchise, Marshall's key civil and political rights. White women were also denied federal voting rights until the passage of the Nineteenth Amendment in 1920, and the property rights of civil citizenship remained out of reach for many women long after this. Glenn argues further that alongside the laws and policies that constitute "formal citizenship," scholars must also account for the uneven terrain of "substantive citizenship," whereby boundaries are enforced and schemes of gender, race, and belonging are both challenged and reinforced, in ways that may not match official policy (52-53). Her approach not only underscores the importance of race and gender in constituting citizenship, but it also informs my emphasis on disabled citizenship not only as a set of rules and politics, but of experiences. Even encounters with the physical environment can serve as stark rejoinders to disabled people's sense of belonging. Kevin Sullivan, a Chicago-area wheelchair user, attested to this in a comment to a reporter on his experiences of public transit, saying, "The elevators are broken constantly. If the elevators are running they could be filled with human urine and they're disgusting. *It makes us feel like we don't matter*" (Rebik 2023, emphasis added).

Finally, my effort to articulate a theory of disabled citizenship seeks to center a category of people who have often been understood, by definition, to be outside the boundaries of full social belonging. Historian Douglas Baynton writes that disability was a key factor in what he calls "the three great [US] citizenship debates of the nineteenth and early 20th centuries: women's suffrage, African American freedom and civil rights, and the restriction of immigration" (2001, 33). In each of these struggles, those seeking to restrict citizenship often cast a targeted group as somehow disabled: of inferior intelligence, weak or nervous constitution, and lacking the capacity to provide for oneself and engage in a larger polity. Just as importantly, the response from marginalized groups seeking to claim full citizenship has often been to distance themselves from such imputations of disability, leaving unquestioned the idea that those to whom such descriptions apply are indeed worthy of exclusion. For instance, Baynton writes, activists for women's suffrage and subsequent historians of their campaign rightly rejected claims that women were "too delicate" for political activity. But he adds that "just as it was left unchallenged at the time, historians today leave unchallenged the notion that weakness, nervousness, or proneness to fainting might legitimately disqualify one for suffrage" (43). This mode of response, Baynton argues, "tacitly accepts the idea that disability is a legitimate reason for inequality" (51).

Such tacit acceptance of disability as a basis for exclusion is present throughout formulations of citizenship. This stretches back to the classical liberal theory on which civil citizenship is based. Locke wrote that "lunaticks and ideots [sic] are never set free from the governance of their parents," while John Stuart Mill understood liberty "to apply only to human beings in the maturity of their faculties" (both quoted in Gong, 2019, 665). Allison Carey demonstrates how such ideological currents justified the denial of rights to people with intellectual disabilities in the US during the twentieth century, relegating them to "the margins of citizenship" (2009). Marshall portrayed schooling and the creation of an educated society as a key duty of citizenship, and while he did not pursue the matter in greater detail, this must be understood within the context of an educational system in which some potential pupils would have been presumed to be unable to learn, and thus actively excluded from the classroom. Marshall more directly invokes what would now be recognized as the language of disability in his discussion of poor relief, writing of "those who, through age or sickness, were incapable of continuing the battle, and to the other weaklings who gave up the struggle" to survive in the free market (1950, 23). By virtue of receiving public assistance, they faced the curtailment of their civil and political rights. In contemporary society, care for sick or disabled people, as well as the elderly, is widely understood as a private matter. Sandra Levitsky calls this the "ideology of family responsibility," which understands caregiving for family members as a moral obligation. Levitsky points out that the emphasis on family care leaves other forms of support, including public services, as minimally funded systems of last resort to be used when family resources are exhausted (2014, 4-5). Putting these pieces together, if we accept Glenn's argument that citizenship is characterized by twin dichotomies of independent/dependent and public/private (2002, 20), conceptions of disability across historical periods have often fallen within the least favored quadrant. Disabled people have been understood to lack the capacity for independent self-sufficiency, making them dependent, and thus relegating them outside of the public sphere, often reliant on either family or stigmatized aid. In theorizing citizenship, disability has often served as a limit case where exclusion is justified.

I seek in this dissertation to invert that logic, to make the citizenship of disabled people the subject of inquiry. Doing so means taking seriously disabled people as members of society, even when political personhood is often assumed to be limited or nonexistent. It begins from an understanding that disabled people themselves have different ideas of what the concept means in their own constructions of self, as well as in law and policy. It also means probing the processes through which street-level bureaucrats (Lipsky 2010) and community members recognize disability and expand or constrain the boundaries of political belonging in response, in what Glenn refers to as the "local practice" of substantive citizenship (2011, 3). And it means taking as a starting point the fragmentation and conflict between different policy regimes that disabled subjects find themselves navigating. In the next section, I offer a limited history of disability policy in the US, with a focus on the manifestations of disabled citizenship discussed in the opening pages.

THE PROCESS OF POLICY SEDIMENTATION: A BRIEF HISTORY

Several of the multiple, fragmented realms of contemporary disability policy can be traced to historic processes during the 19th century. A key development was the rise of what

Lennard Davis calls “an industrial mentality that saw workers as interchangeable and therefore sought to create a universal worker whose physical characteristics would be uniform” (2013, 6). In materialist accounts of the emergence of contemporary conceptions of disability (e.g., Oliver 1999), the drive for interchangeable bodies to suit the needs of mass production played a significant role in the exclusion of non-normative bodies from the labor force. As Sarah Rose (2017) writes, while some people with disabilities would have relied on public aid or the care of their families, for many survivors of disease or injury, “variations in bodily function and appearance were common and rarely prevented people from continuing to work.” Even as late as the early 20th century, missing fingers among Pittsburgh steelworkers were common; rather than being stigmatized, “such injuries were often seen as indicating manly mastery of a dangerous workplace.” But by the 1920s, the same disabilities had become reason for workers to be denied employment in many industries (5-7).

Rose links this rapid transition not only to the ongoing trend toward standardization, but to perverse incentives from the introduction of workmen’s compensation laws in the 1910s. The structure of compensation schedules paid larger amounts to workers with more severe injuries, understanding, for instance, the loss of both hands to be more catastrophic than the loss of one hand. This meant that a worker who was already missing one hand was seen, by both employers and insurance companies, as a greater compensation liability than one without any “defects.” This so-called “second-injury problem” made employers less willing to hire disabled workers. Along with targeting visible conditions like missing limbs, many employers enlisted growing numbers of industrial physicians to examine workers and screen out those with ailments. Moreover, employers and safety advocates often placed responsibility for workplace injuries on workers themselves, so that the fact of disability came to be seen as an indication that a worker was careless or more at risk. A Packard Motor Car official in 1914 said of employers, "They think that a man by reason of some physical defects is more liable to accidents than others" (162-167). With such logic, disabled workers were increasingly pushed out of the labor force.

At the same time, disability was also understood in some cases to make work impossible, and thus to justify the provision of income support. 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, Deborah Stone points out that "all but the first are part of today's concept of disability" (40). A similar logic applied in the US, where disability often served as a key signifier of the deserving poor. Josiah Quincy wrote in 1821 of "the impotent poor; in which denomination are included all, who are wholly incapable of work, through old age, infancy, sickness or corporeal debility." This group was deserving of assistance, unlike "the able poor…who are capable of work, of some kind, or other" (quoted in Katz, 1989, 12). Disabled veterans constituted a particularly deserving group, with Civil War pensions providing a wide-ranging system of social provision. By the passage of the 1890 Dependent Pension Act, pension eligibility was extended to Union veterans who had served more than 90 days and who were, or might come to be, "suffering from a mental or physical disability of a permanent character… which incapacitates them from the performance of manual labor" (Skocpol, 1992, 128).

But the identification of the disabled poor as deserving was not clean-cut. In the same 1821 report, Josiah Quincy wrote of the difficulty of distinguishing the deserving poor from the undeserving, a tension that Katz argues has troubled US poverty policy since then (1989). This points to fundamental difficulties in measuring the impact of disability—whether it truly left one "incapable of work." Moreover, some conditions that would now be classified as disabilities were not viewed as deserving, due both to their nature and their cause. Alcoholism and addiction, for instance, were markers of vice and poor character. The 1890 Civil War pension act quoted above specified that to qualify, a veteran's disability must be "not the result of their own vicious habits" (Skocpol, 1992, 128). Moreover, the broad eligibility criteria for pensions formed a major reason for opponents of the program to label it as corrupt. The employer view of workplace injuries as caused by worker carelessness provides another example of the very fact of disability casting doubt on a disabled person's character. In short, while one ideological tradition regarded disability as an ideal type for those who deserved public aid, this category ran headlong into various reservations and suspicions in practice, leaving the actual provision of assistance limited at best. Thus, we already see conflicting conceptions of disabled citizenship. Disabled people had once been understood as workers, but over time were increasingly pushed out of industry. They had also been cast as unable to work, for reasons understood to make them deserving of aid—but that deservingness was often contested in practice.

The late 19th century also saw the rise of eugenics, a development that Davis links to the emergence of statistics and associated conceptions of normality. Eugenic thinking was not merely the province of a right-wing fringe, but informed the mainstream of both medicine and policy, including Progressive reformers and even radicals like Emma Goldman. Eugenics was not only intertwined with scientific racism, but it also grouped a wide variety of traits as "undesirable." Statistician Karl Pearson, for instance, listed the "unfit" as including "the habitual criminal, the professional tramp, the tuberculous, the insane, the mentally defective, the alcoholic, the diseased from birth or from excess" (quoted in Davis, 2013, 6). Notably, this list explicitly included both congenital and acquired disabilities ("from birth or from excess"), and it demonstrated how illness ("the tuberculous") could signal not that one deserved aid, but that one was of poor stock. Similar dynamics were also apparent in immigration restriction, where "poor physique was a common justification for restriction of entry "(Baynton, 2017, 29-39). Pearson's list also reflects the close linkage between disability (particularly mental disability) and criminality, or in the language of eugenics, mental defect and moral defect. Such disabilities not only marked people as undeserving of aid, but as threats to property and public safety. These linkages were not solely the product of eugenic thinking, particularly when they were racialized. Andrew Dilts demonstrates that the conflation of mental disability, criminality, and Blackness animated restrictions of the franchise in the 1864 Maryland state Constitution (2012). But with eugenics, the link between disability and criminality was reinforced.

Increasingly, the policy response to those deemed defective was institutionalization. This, too, is an approach to citizenship, denying disabled people their rights and relegating them outside of broader society. Institutions, of course, were not new; workhouses and jails had been features of the 18th century landscape. But with reform movements of the mid-19th century came an increasing emphasis on classifying their residents, distinguishing the asylum from the workhouse from the juvenile reformatory, in what Andrew Scull calls "the specialization of the social control apparatus" (1984, 21-22). With the rise of eugenics in subsequent decades, institutions also took on a new function: preventing their inmates from passing along their undesirable traits to future generations. Leaders in the emerging field of social work were quite forthcoming about this goal. Josephine Shaw Lowell of the New York State Board of charities pressed her case for a custodial asylum for women of child-bearing age by expressing two goals for its targets: "to reform them if that be possible, but if that cannot be done, at least to cut off the line of hereditary pauperism, crime, and insanity now transmitted mainly through them." Alexander Johnson, the secretary of the National Conference of Charities and Corrections in

1897, argued that in light of the "sad fact of incurability, or incorrigibility, of unreformability," the "mother-state" should set its "weaker children" apart in settings where they would be cared for but pass along their defects, a position shared by Conference presidents of the period (Lieby, 1978, 109-110). In addition to preventing reproduction by means of institutional separation, forced sterilization became increasingly common, gaining the endorsement of the US Supreme Court with the 1927 *Buck v. Bell* ruling. The prevalence of institutionalization as a social response to intellectual and psychological disability would continue well into the 20th century. The population of state mental hospitals peaked in 1955 at 559,000, which Liat Ben-Moshe points out was "nearly as large on a per capita basis as the prison population today. A separate population lived in large state institutions for people with intellectual and developmental disabilities; this number peaked as late as in 1967, at 194,650 (2020, 40).

Thus, by the early 20th century, key sedimentary layers of disability policy that echo to the present day were in place. Disability was increasingly associated with pauperism rather than citizenship, with growing numbers institutionalized in asylums, state hospitals, and prisons. The job market was becoming increasingly inaccessible to disabled workers, particularly as workplace medical screening grew more common. Following World War I, new vocational rehabilitation efforts sought to help limited numbers of veterans and disabled people enter or return to the workforce. But these programs were often separate from labor bureaucracies, and their limited scope led them to focus only on those who were seen as the best candidates for successful rehabilitation, dampening their impact. Workers' compensation provided some monetary support for those who were excluded from the labor market by workplace injuries, but because payment levels were largely structured around principles of less eligibility, the program was generally inadequate to make up for lost wages or the costs associated with disabilities

(Berkowitz 1987, Rose 2017). Other sources of income support prior to the New Deal were largely limited to the poorhouse and state and local programs of outdoor relief.

The disability policy landscape saw significant development in the 1950s. One of the most significant developments was the creation of Social Security Disability Insurance (SSDI) as a national program of disability-specific income support. Two elements of SSDI are particularly important, as they have continued to shape policy through the present: the program's embrace of a medical approach of disability, and its definition of disability as fundamentally excluding work. Social Security policy entrepreneurs had expressed intentions to roll out a form of disability (or "invalidity") insurance soon after the initial passage of the Social Security Act in 1935. But having seen earlier attempts at private disability insurance schemes, as well as the history of worker's compensation and more narrow disability insurance programs for groups such as railroad workers, many were concerned with restricting program growth. This was, in many ways, a New Deal-era continuation of 19th-century questions of determining who was truly "wholly incapable of work" and thus deserving of assistance.

Policymakers attempted to resolve this dilemma by appealing to the impartial and scientific judgement of medicine. Physicians had already played a role in screening workers for disability, as mentioned earlier. Models of rehabilitation, particularly for veterans of World War II, were also increasingly defined in terms of the medical repair of injured bodies (Williamson 2019). For Social Security policymakers, medical judgement seemed to offer clear delineation of whether a disability claim met the program's "strict eligibility requirements." A 1948 Advisory Council report, warning of the "danger of malingering," recommended "that compensable disabilities be restricted to those which can be *objectively determined by medical examination or tests*" (quoted in Stone, 1984, 79, emphasis in original). Notably, many doctors argued that such objective determination of disability was not possible, and that clinicians often disagreed on the likely prognosis of a disease or injury. Many also rejected the role envisioned for them, pointing out that their job was to diagnose and treat patients, not to attempt to assess whether their patients could work. But they were rebuffed by legislators like Senator Alben Barkley, who rejected the claims of a doctor testifying to the limits of medicine in assessing disability, saying,

> "I am not willing to concede that after all the years of experience and growth and investigation and practice in the medical profession that they cannot with some reasonable degree of certainty arrive at a medically determinable point where a man is totally and permanently disabled" (Stone, 1984, 83).

There thus developed an extensive apparatus to certify disability, involving reviewers from the Social Security Administration and state-level Disability Determination Service, and often courts. To qualify, an applicant's disability also had to prevent them from working beyond a minimal threshold known as substantial gainful activity (SGA). Such criteria were meant to limit the number of beneficiaries. But for disabled people unable to find sustainable employment, demand for income support remained. Moreover, as Stone points out (and as doctors warned), assessment of the severity of disability remained a subjective and interactive endeavor, with various forces that could lead more people to gain benefits than the program's framers intended. SSDI became an important feature of mid-century US social provision.

The creation of Supplemental Security Income (SSI) as part of the limited welfare reforms under Nixon in the early 1970s further liberalized the process of disability determination. SSI nationalized state-level assistance to those deemed Permanently and Totally Disabled, as well as programs for the elderly and blind. The program adopted the same criteria and disability determination system as SSDI. But while SSDI required a work history (due to its structure as a contributory social insurance scheme), SSI did not. This made the assessment of an applicant's ability to work even more challenging, as prior jobs could not serve as a yardstick by which to measure the severity of an impairment. SSI also covered many with highly stigmatized disabilities, such as mental health issues or drug or alcohol addiction, whose claims to political and social citizenship were highly tenuous. In another expansion, SSI, unlike SSDI, covered children, so long as a child had a disability that was "of 'comparable severity' to one that would disable an adult," a standard that the SSA was "at a loss to define" (Erkulwater, 2006, 83-84). Unlike the "earned" benefits of SSDI, SSI specifically targeted at the very poor, conditioning eligibility on low income and a strict asset limit (currently $2000 for individuals, or $3000 for couples) on beneficiaries that arguably serves as a modern-day analogue to a pauper's oath. But despite their differences, both programs have remained features of an increasingly austere social welfare landscape. Their models of disability—as medically defined, and as precluding work—have become central to many disabled people's day-to-day survival, constituting a key element of disabled citizenship.

The 1950s and '60s also saw a move toward deinstitutionalization, first in the area of mental health, and then for those with intellectual and developmental disabilities. Liat Ben Moshe (2020) points to multiple factors in bringing about this sea change. Some are well known, like class action lawsuits and exposés of hideous institutional conditions in large institutions as early as World War II (facilitated, in part, by conscientious objectors performing alternative service in such facilities). Ben Moshe also points to more easily overlooked factors, including self-advocacy by the formerly institutionalized, and shifts in social attitudes toward about mental illness, normality, and institutions. She and others (e.g., Winant, 2018) also point to the creation of Medicaid in 1965, which provided a new funding mechanism for long-term care in settings such as nursing homes. Great Society programs around community mental health seemed to promise additional supports that could aid the newly deinstitutionalized, and advocates pressed for a vision of "a dense web of public programs replete with income support, housing assistance, sheltered work initiatives, and social services" (Erkulwater, 2006, 59). But many such supports never came to be, and others existed only in a drastically underfunded form. Moreover, because of what advocates refer to as an "institutional bias" in Medicaid funding, much of the support available went not to in-home care, but to nursing homes and similar congregate facilities. This contributed to the emergence of the contemporary nursing home industry, which some critics view as institutions in a new guise, often run as for-profit enterprises, propped up by Medicaid revenue.

While disabled advocates played limited (but real) roles in deinstitutionalization, they were central to the emergence of the movements for independent living and disability rights movement in the 1970s and '80s. Disabled protest had happened before, in multiple historical eras. One example was the 1935 sit-in and picket by members of what would become the League of the Physically Handicapped at the New York City office of the Emergency Relief Bureau, demanding that they be hired for Works Progress Administration jobs rather than funneled into cash relief programs (Longmore and Goldberger 2000). But it was in the 1970s that a wave of disabled contention managed both to sustain itself and to gain elite support. The movement challenged the authority of doctors and the medicalization of disability itself, as well as rehabilitative and social service professionals. The very term, "independent living," offered a contrast to institutional living, and to the paternalism encountered among many non-institutional service settings. The emphasis of Centers for Independent Living on community-based peer support and self-help reflected this ethos, as did sociologist Gerben Dejong's declaration that, "The dignity of risk is at the heart of the IL [Independent living] movement" (1983, 20).

Activists called, in the words of one article in the *Disability Rag*, for their opinions and needs to carry weight as "valid members of society," rather than being categorized AND dismissed as "invalid" (January 1983, 13). This reflected the emergence of a form of insurgent citizenship (Holston 2008) with a more contentious orientation toward the state and society.

Disability activism in this period also sought to assert a status of full members of a community—Marshall's very definition of citizenship. Activists' focus on demanding accessible public transit in the 1980s reflected not only a savvy choice of tactics (though savvy it was, as blockades of buses by wheelchair users spread to multiple cities and attracted headlines). They also demanded access to the same public good that abled riders used, asking, in the words of organizer Wade Blank, "Is the disabled community part of the public, or not part of the public?" (*Disability Rag*, October 1983, 9). With the passage of the ADA and the successful establishment of accessible buses as a standard, the organization that had led the public transit campaign shifted its name and focus. Originally known as American Disabled for Accessible Public Transit, they kept their acronym, ADAPT, but announced that it now stood for American Disabled for Attendant Programs Today. They sought to redirect Medicaid funding to provide support services that would allow nursing home residents to leave their facilities and move "into the community," continuing their emphasis on full social integration (Barnartt and Scotch, 2001, 182).

While disability rights activists challenged medicalization and institutionalization, movement leaders had less to say on expanding or defending income support. This may have reflected a mismatch between program logics and movement logics. As Jennifer Erkulwater writes, the medical definition of disability on which SSI and SSDI were built "was not easily adapted to the 'human rights' or 'social' model of disability championed in the 1970s by advocates" (2006, 19). But some important community figures appeared to view such programs not merely as a poor fit with current thinking, but as the objects of scorn. A 1982 paper, widely circulated in independent living circles, "explicitly opposed the independent living agenda to the '"give me" socialist' view 'that "society" should and can provide benefits to each human with no corresponding obligation." Instead, according to Samuel Bagenstos, leaders stressed "the need for people with disabilities to move off of the disability benefit rolls and into the workforce" (2003, 999-1000).

Gaining access to the workforce was indeed a major focus of the disability rights movement. In formal policy, it accomplished significant gains, laying down a new sedimentary layer of policy that sharply diverged from prior practice. Following the passage of the ADA in 1990, to dismiss a worker or deny employment on the basis of disability constituted discrimination. The ADA also created an affirmative obligation on employers to provide "reasonable accommodations" for disabled employees. After court rulings limited the scope of these protections, Congress passed legislation in 2008 specifically seeking "to carry out the ADA's objectives…by reinstating a broad scope of protection" (quoted in Emens, 2012, 211). But despite this impressive legislative history, labor market exclusion persists. One of the ADA's leading 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). A recent report found that in 2021, 40.7% of disabled people ages 18-64 were employed, compared to 76.6% of people without disabilities (Houtenville et al, 2023). The ideal of the disabled citizen-worker has been invoked in policy, but it is more difficult to locate in practice.

The relative failure to gain access to the workforce must also be placed in the context of the transition from Fordism to neoliberalism. Disabled leaders made history, but not under circumstances of their own choosing (Marx 1852|1978). As activists pressed for access to the work force, the economy and broader society were in the midst of a transformation marked by deindustrialization, deregulation, and increasing income inequality (Bluestone and Harrison 1982, Harvey 2005). Indeed, Bagenstos argues that the ADA itself can be understood as part of the broader neoliberal agenda of welfare reform. He points out that in addition to making their case on the "dignitary grounds of equal employment and full citizenship," many of the bill's strongest supporters "sold the statute as a means of avoiding the social costs of dependency by moving people off of benefit rolls and into the workforce" (2003, 954-955). The 1999 Ticket to Work and Work Improvement Act, discussed in detail in the next two chapters, reflected a similar conjuncture of rhetorics of citizenship and austerity. While the most drastic enactment of "welfare reform" came with the 1996 elimination of AFDC, disability-specific income support programs were also targeted for retrenchment. This first came in Reagan administration with an aggressive review of SSI and SSDI cases which cut of benefits to hundreds of thousands and generated considerable backlash before the initiative was suspended in 1984 (Erkulwater 2006, 106-112). The 1996 welfare reforms cut SSI and SSDI, though in more limited ways than initially proposed. The legislation eliminated addiction as a primary reason for benefits, restricted the language defining SSI eligibility for children, and cut SSI for legal immigrants, though it was later restored for many (194-217). The drive for fiscal austerity also helped to propel deinstitutionalization, as Ben Moshe writes, "The push to close down state institutions came as an attempt to cut down public expenditures on social services more generally." But, as she adds in the following sentence, "This same move [toward austerity] would also make services in the community and affordable housing scarcer than ever" (2020, 57). And in an irony reflective of the uneven and adaptable development of neoliberalism, Medicaid, a crowning achievement of the Great Society, came to subsidize for-profit nursing home operators.

Scholars (e.g. Wacquant 2009) have also linked neoliberalism to racialized policing and incarceration, which serve to manage those who are displaced and impoverished by austerity and restructuring. And the link between disability and perceived criminality has persisted into the present day (as discussed in many sources, such as Russell and Stewart, 2001|2019). Police respond to calls for mental health crises, and to the public presence of homeless people in distress with no place to go. The 1990s saw the emergence of mental health courts and other programs within correctional systems aimed specifically at people with disabilities. To proponents like Risdon Slate, such programs of "therapeutic jurisprudence" are innovative approaches to what he calls the "criminalization of mental illness," which he links directly to deinstitutionalization and the lack of community supports (2017). Michael Perlin is more effusive in his endorsement of such programs, writing, "Therapeutic jurisprudence supports an ethic of care" (2013, 8). Liat Ben-Moshe, in contrast, critiques such initiatives as examples of "carceral ableism," which she defines as "the praxis and belief that people with disabilities need special or extra protections, in ways that often expand and legitimate their further marginalization and incarceration" (2020, 17). Such programs also raise questions as to the level of surveillance to which they subject participants, and to whether those facing jail sentences are truly free to choose whether to participate. Without taking a specific side in these debates, I argue that these programs must be understood as another category of state response to disability, both drawing on long-standing conceptions and introducing new practices, sitting uncomfortably within the fragmented landscape of contemporary disabled citizenship.

POLICY NAVIGATION FROM BELOW

While Marshall offers a narrative of progress in which civil rights are successively joined by political and social rights in a flowering of full citizenship, political development in the US has been far more complex. Advances in civil and political rights have been accompanied by retrenchment in social rights. The process of sedimentation presents disabled people with an uneven and conflicting set of policy regimes, which may vary in their rules, logics, and definitions of disability. As new programs are layered on top of the old, the same disabled citizen may be called on to demonstrate, for instance, both their value to an employer, and the constraints that their disability places on their ability to work. The policy landscape is treacherous and uneven.

At the center of this dissertation is the question of how disabled people make their way across this landscape as they experience and manage the contradictions generated by policy sedimentation, and how they understand themselves as members (or non-members) of society. In trying to answer this question, I turned to various literatures. Michael Lipsky's conceptualization of street level bureaucracy (2010) makes the crucial intervention of focusing not on policy as it is written, but as it is carried out, reflecting both the discretion and constraints of the titular bureaucrats. But Lipsky and those writing in his tradition tend to focus on the street level bureaucrats themselves, not on those who are subjects of policy. More recently, the burgeoning literature on administrative burden has turned an eye toward on the phenomenology of participation in government programs. Herd and Moynihan argue that whether policy is experienced as burdensome can be understood in terms of "the learning, psychological, and compliance costs that citizens experience in their interactions with government" (2018, 39). Related literature has flourished in the field of public administration, as scholars have identified opportunities to reduce burden. But I learned that disabled citizens did not solely experience policies through the unidirectional imposition of costs. To be sure, several of the policy regimes I studied do impose burdens, some of which might be alleviated through changes in program design. But my informants also described the difficult and active work of managing these costs, often across policy domains.

To describe this work, I present a theoretical framework that I call *policy navigation from below*. I define policy navigation from below as the active labor performed by disabled citizens, often across conflicting policy systems, to secure accommodations, benefits, or services while also addressing their material needs. This work is tied up in disabled citizens' feelings about the policies or programs they deal with, their understanding of their disabilities, and their relations to the workforce and polity. To understand it is not only a matter of measuring burden, but also of agency and political interpellation. Policy navigation can take obvious form, as in the act of applying for benefits or formally seeking workplace accommodations. But it can be more subtle, involving, for instance, the agentive decision not to seek a government benefit for fear of negative consequences.

In the following chapters, I sketch out the contours of policy navigation from below within each policy domain on which I focus. For disabled workers, navigation can involve mean requesting disability accommodations, maintaining relationships with bosses and supervisors, and ensuring that one can maintain health insurance and, in some cases, eligibility for other benefits. For SSI and SSDI beneficiaries, the process involves interpreting and understanding program rules, navigating conflicting policy logics, and at times performing paid work where possible. For residents of Medicaid-funded nursing homes, it can mean keeping one's head down and maintaining friendly relations with overworked staff, pursuing the complex process of transitioning out of a facility, and advocating for better treatment. Finally, for disabled activists, policy navigation involves maintaining the external presentation of a campaign as a sympathetic appeal to nondisabled decision-makers who may view them through an ableist lens, while also sustaining internal commitment and creating space for defiant expression. As the following chapters make clear, all three policy regimes on which I focus can be isolating, hailing citizens as solitary actors. By including activism as a form of disabled citizenship, I seek to trouble that individuation, arguing that policy navigation from below can also be a collective process.

A taxonomy of disabled citizenship

Examining the various forms of navigation demanded sheds light on how each policy regime generates particular manifestations of disabled experience. The workplace offers the best means for disabled people to approach the hegemonic ideal of the self-sufficient citizen-worker. But to achieve this, they must align multiple factors, including the knowledge of their rights under the ADA, accommodation needs that their employers deem reasonable, and positive relationships with managers and supervisors. Because their success is dependent on so many elements, I call this *conditional citizenship*. Those collecting SSI and SSDI face programs that can be baffling in their complexity, administered by an understaffed agency that is hard to reach with questions. Errors, including overpayments by the Social Security Administration that are no fault of beneficiaries, raise the specter of loss of benefits, generating a form of *precarious citizenship*. Nursing home residents must navigate institutional, often for-profit contexts in which staff operate under time and resource constraints, where neglect and even abuse are dangers. But residents' concerns are often ignored or treated as unreliable narrators of their own experience, making it more difficult for them to advocate effectively for themselves. Reflecting such limitations on their political standing, I describe the situation of facility residents as one of *constrained citizenship*. These three forms of disabled citizenship can be understood as a taxonomy, descending in social status from conditional to constrained. All three may be disrupted by the *insurgent citizenship* enacted by disability activists. This term, borrowed from anthropologist James Holston (2008), describes an orientation toward state and society that challenges unequal social relationships and puts forth defiant alternative visions of society that foster disabled belonging and well-being.

It is crucial to emphasize that each form of citizenship described above—conditional, precarious, constrained, and insurgent—is one aspect of the larger construct of disabled citizenship. A central element of my argument is that disabled people often operate *across* these and other policy regimes. Examples of such overlaps are numerous. The same person may work while maintaining their eligibility for SSI. A nursing home resident may be careful to maintain friendly relationships with staff while also organizing to improve facilities. Disabled workers may draw on past experiences seeking accommodations in schools. SSDI beneficiaries in nursing homes face pressure to turn their benefits over to facility management.

Such cases reflect the uneven development of policy sedimentation. In order to navigate policy, disabled citizens must at times leap between policy regimes, or balance tenuously between them. A citizen may benefit by applying lessons from one area of policy to another, or they may risk be weighed down by stigma from past experience with a lower-status policy regime. By focusing on the process of navigation below, we can see both the agency of individual disabled citizens and the fragmentary policy context amidst which they do their best to operate. We can ask how these systems situate disabled people as citizens, how disabled citizens act in in turn to manage conflicting roles, and how they understand their relation to multiple systems, and to society at large.

METHODOLOGY

I approach this project qualitatively, drawing on interpretive frameworks that emphasize the experiences of disabled people as political actors and citizens. (Alford 1998). I ask how individuals and organizations in the Chicago metropolitan area experience, navigate, and contest four overlapping forms of disabled citizenship. Rather than pursuing a statistically representative sample, this study goes into depth to understand informants' thoughts, experiences, and conceptions of both policy systems and their place within them. I draw primarily on in-depth, semi-structured interviews with forty disabled people in greater Chicago who had direct experience of policy systems that are the focus of this project. Those conversations are essential to Chapters 2, 3, and 4. I also conducted participant observation of two disability organizations in the Chicago area in 2022 and 2023. I draw on this data in Chapters 3 and 4, and it is the main focus of Chapter 5. Finally, I incorporate two sets of archival documents, as well as an interview with a policy advocate who was involved in the passage of legislation relevant to work and Social Security disability programs. These sources are woven throughout the dissertation.

Why greater Chicago?

I based this study in the city of Chicago, and the surrounding cities and towns in Illinois. While several of the policies I study in this dissertation are national in scope, they are still shaped by state and local policy. For instance, experiences of SSI and SSDI are shaped by factors including the presence or absence of state supplementary benefits, and state Medicaid policy. Access to the labor force can depend on reliable and accessible public transportation. By focusing on the Chicago metropolitan area, I sought to ensure a measure of local variation, while also holding state-level policy constant.

The Chicago area presents an excellent context for this study, due both to its strengths and its contradictions. A multiracial metropolis of millions of people, Chicago is also the site of persistent segregation that has been the subject of scholarly research for decades (e.g., Drake and Cayton 1945, Hirsch 1983, Chaskin and Joseph 2015). Chicago has one of the nation's largest public transportation systems, but its coverage is uneven, leaving neighborhoods and towns underserved. Over the years, Chicago has been a center of disability culture and activism, playing a major role in the wave of activism over accessible transit and other issues in the 1980s. But even today, multiple train stations in the city are still not wheelchair accessible, underscoring the limits of progress toward full disability access.

How Illinois compares to other states in disability policy varies with the specific policy in question. In some cases, the situation is dismal. In 2023, state lawmakers wrote in one of Chicago's major newspapers that the state ranked 49th in funding and support for residents with intellectual and developmental disabilities and their families, contributing to a crisis in the recruitment of support workers due to low wages (LaPointe et al, 2023). For SSI beneficiaries, the situation is somewhat better. Those who receive SSI in Illinois can also collect additional cash benefits through a state program called Aid to the Aged, Blind and Disabled. Calculated through a detailed formula, the benefit is usually no more than $70 each month in addition to a federal SSI grant (Illinois Legal Aid Online, 2024). This benefit is more generous than the six states that provide no state supplement to SSI (Social Security Administration, 2024b). But it is difficult to navigate, requiring applicants to file separate paperwork through the state, rather than offering automatic eligibility to all who are approve for federal SSI. The $70 monthly benefit also pales in comparison to California, which provides a monthly supplement of $632.07 (California Assisted Living Association, 2024). In other policy realms, data is simply not collected, suggesting limited interest from officials. The Bureau of Labor Statistics, for instance, only offers disability employment data at the national level, citing small state sample sizes (2015).

In-depth interviews

I began in early 2022 to recruit interview subjects in the Chicago area with experiences of at least one of the disability policy regimes I set out to study. Because this overlapped with the omicron surge of COVID cases, initial 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, particularly at first. I presented the project at meetings of several organizations, and I circulated the call for interview subjects on multiple channels including email, Twitter, and Facebook. Many people circulating the call beyond my immediate networks, leading to further online circulation. I also displayed flyers in public spaces such as libraries, and I distributed them through contacts and at events such as Chicago's Disability Pride festival. I asked those interested in participating in an interview to contact me through a dedicated email address and phone number. Each completed a brief screening questionnaire, either by phone or an online form. All those who participated in interviews provided their formal informed consent. I developed my research plans with Institutional Review Board (IRB) approval.

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 tell them that I was testing 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, the COVID pandemic, relationships with disability-focused organizations, and sense of disabled community. Based on their responses to my screening questions, I focused my questions on the policy regime(s) with which they indicated having experience. For instance, if they indicated that they had received or applied for SSI, I asked about that benefit, as well as related policies like Social Security work incentive programs. At the same time, people's screening responses did not always reflect their full experience, and so I might ask the same informant about their work history and whether they ever sought accommodations, about whether they had ever experienced a long-term hospitalization or other institutionalization, and about interactions with police.

Most interviews took between 1 and 5 hours. The majority took place in one sitting, though three extended over more than one da according to the informants' wishes. While I provided the option of in-person interviews when COVID case rates had declined, all but two chose to conduct the conversation remotely. For many, this seemed to be a matter of convenience, though there may have been other reasons; one nursing home resident indicated that she wasn't happy with how she looked, and conducted our interview over the phone so that I couldn't see her. One interview was conducted with American Sign Language (ASL) interpretation; all of the rest were in English. 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. I compensated all participants $50, both as an incentive and to reflect their labor in sharing experiences with me. All of them are identified with pseudonyms.

Soon after beginning recruitment, I received three inquiries from potential participants that were only a sentence or two long. All three completed my screening form, which at that point was on a Google Form, and their answers indicated that they were eligible. I subsequently scheduled interviews via Zoom. When I conducted the first interview, elements of the informant's personal story did not match her screening responses, and dates of events that she recounted were inconsistent. Thinking that this might be a matter of faulty memory, I continued with the interview and provided compensation. The next day, I had another Zoom-based interview scheduled, and the contradictions between the subject's screening responses and his comments that day were more glaring. I was more guarded after the previous day's experiences, and so I posed additional questions, revealing more inconsistencies. I cut the interview off after ten minutes and paused recruitment, telling others who had emailed me that interviews were on hold. It was clear that I was dealing with imposter research participants who likely sought to make money through incentive payments, a phenomenon recently described by Martino, Perrotta, and McGillion (2024). I discarded data from those interviews; they are not reflected in my description of informants or in any of my findings. Working with the IRB and colleagues, I restructured the screening process to weed out imposters. This included moving my screening form to Qualtrics, a platform that can log a respondent's IP address, offering a clue as to whether someone was falsely representing themselves as being based in the Chicago area. I also learned to identify and disregard inquiries that were from likely imposters.

Most of the forty interview subjects had experience with at least two of the policy regimes that became the focus of the dissertation. This reflects the extent to which disabled citizenship is built on policy sedimentation. An SSDI beneficiary may also work a limited amount, while also trying to maintain the balance of services that allow them to stay at home rather than moving into a nursing facility. Of my forty respondents, 28 were in the workforce, making them the focus of Chapter 2. 23 had experience with Social Security disability benefits, informing Chapter 3, and 11 had spent time in nursing homes, which are the focus of Chapter 4. I describe the demographics of these overlapping subgroups in each chapter. Of the complete set of informants, 26 lived in the city of Chicago, and 14 lived in a suburb. They ranged in age from 18 to 70, with one in her teens, seven in their twenties, fourteen in their thirties, six in their forties, six in their fifties, five in their sixties, and one in her seventies. 25 identified as white, eight as Black, 3 as Latinx, and four as Asian or Asian American. Nine were men, 23 were women, and eight were nonbinary.[1] Because I sought to use the broad range of characteristics that can be defined as a starting point, I sought out—and spoke with—informants with a wide range of physical, psychological, sensory, and developmental disabilities.

In presenting my findings, I introduce each informant with information on their age, race, gender, and disabilities. I regard these characteristics as important background data for how each informant moves through the world. As this is a small-n qualitative study, I generally avoid making explicit causal arguments that, for instance, an informant experienced a particular situation because of their race or age. At the same time, I believe that it would be negligent to omit such information. In some cases, informants themselves specifically point to aspects of their identity in shaping an incident they recount. In other cases, while recognizing the limits of my data, I point to trends within my data; one example comes in Chapter 2, where I point to the age and racial identity of the subset of informants who have been excluded from the work force.

The racial composition of this set of informants is worthy of discussion. While this is a qualitative study that does not seek to be statistically representative, my cases are whiter than I would like them to be. This is partly a matter of social networks and my own social location. As

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[1] One informant identified as a nonbinary trans woman, using feminine pronouns for herself. I have grouped her with other women. Another informant identified as a nonbinary woman and used both she and they pronouns; I list her here among women.

I wrote earlier, having begun data collection around the peak of the omicron wave of the COVID pandemic, much of my recruitment took place online. While I did reach out to disabled organizations and individuals of color, my own identity as a white academic surely shaped the reach of my recruitment and how my materials resonated with potential informants. It is also possible that by recruiting through disability-specific spaces, I skewed toward a whiter set of respondents. Critics and organizers have pointed out for some time that many disability spaces are disproportionately white, including disability rights movement (e.g. Sins Invalid 2020) and academic disability studies (e.g. Bell 206). As I continue to develop the project further, I will take further steps to recruit informants of color.

The gender composition of my informants also merits discussion; the group includes nearly as many nonbinary people as men. This is, in part, also due to my personal social networks and those in which my recruitment materials circulated. As I learned from one informant toward the end of the time when I gathered this data, my materials were posted on a queer and LGBTQ+ social networking app. I considered this a positive development, and I was flattered to know that interviewees had deemed me trustworthy enough to circulate study materials in their community. In my online screening materials, I also used a broad prompt with a free-response format for people to describe their gender, which may have led respondents to feel more comfortable reporting a nonbinary identity than they might have with other formats. The responses from transgender and nonbinary informants enriched my data, with accounts of both positive and negative experiences. One told me of how the hostile work environment and denial of accommodations she faced seemed to stem both from ableism and transphobia, while another spoke of being buoyed by a "built-in community of queer and trans people being more likely to have chronic conditions or disabilities, creating more community." The latter comment is bolstered by academic literature, which finds that disabilities are more common among transgender people than their cisgender counterparts, for reasons that are likely tied to social marginalization (Smith-Johnson, 2022). But while the presence of nonbinary informants is welcome, the relative paucity on male informants is a shortcoming, which I intend to address in future recruitment as I develop this project further.

Participant observation

In addition to interviews, I also draw on participant observation with two groups, which I pseudonymize as Chicago Disability Action (CDA) and the Nursing Home Emergency Response Group (NHERG). CDA is a long-standing disability activist group in the city, with a reputation for confrontational protest on multiple issues. NHERG is a newer group that formed in 2020 in response to the toll of the COVID pandemic in congregate settings. Over time, it evolved to organize residents and their supporters to push for improved nursing home conditions. I had been active in both groups before I began to gather data, which allowed me to build trusting relationships. When I asked for permission to observe them, I also made clear that I would not end my involvement if they said no, so that members would not feel that they had to support my research in order to hold onto an active member. Both groups granted their formal permission, and I engaged in both as a participant observer. I periodically mentioned my role as a researcher, and several of my interview subjects had some connection to one or both groups. At NHERG organizing meetings, I agreed to serve as a note-taker, providing the group with meeting minutes that I recorded while taking field notes. While I was specifically asked not to attend one NHERG training, and people in both groups occasionally asked how my project was going, I was generally a familiar presence whose role as a researcher seemed relatively unremarkable.

Both groups met primarily on Zoom, though I also saw members in person at rallies, lobby days, and organized social gatherings. As an ethnographer, I was aware that Zoom meetings made some data unavailable. Backstage interactions that might have taken place in shared space, such as meaningful looks or side comments between participants, might be replaced by private chat messages that I would never see. At the same time, being at my computer while the meetings took place allowed me to take detailed notes, writing down conversations in detail and at times capturing precise quotes. The NHERG residents' group was never large; attendance was often between 4 and 8 participants, some of whom were organizers or supporters rather than current or former residents. But by attending over an extended period, I was able to observe processes that couldn't be captured in a single one-on-one interview: a concern from one resident that drew commiseration from another; one resident's excitement as she drew closer to transitioning out of a facility, another's frustration as he realized that he would not be leaving before the winter as he had hoped. I also developed relationships with many group members, building trust and allowing me to ask follow-up questions and continue conversations in ways that enriched my data. I tried to reciprocate by supporting informants where I could, including reviewing one member's school application essay.

Archival sources

Alongside interviews and participant observation, I also turned to archival sources in order to illuminate both the roots of current policy and the alternate visions imagined by earlier disability activists. One source for this data was the archive of the *Disability Rag*, a grassroots publication which circulated in the 1980s and 1990s. As part of a separate project, I studied every issue of the *Rag* from throughout the 1980s, which provided a window into the hopes and frustrations of radical disability activists at the time. References to the publication are woven throughout this dissertation. I also studied the passage of the 1999 Ticket to Work and Work Improvement Act (TTWIIA). I interviewed Susan Prokop, a disability advocate involved in the passage of the bill, who also provided me with a number of documents surrounding its passage, including organizational memos. This legislation, which seems to have received little scholarly attention, sits at the juncture of Social Security disability programs and work. While backers, ranging from disability advocates to President Clinton, hailed it as promising a new day to beneficiaries who wished to work, its impact has been far more muted. The tension between its promises and its impact highlights the contradictory construction of disabled citizenship.

As my interviews and observations progressed, I iteratively reviewed transcripts and notes. I wrote out summary notes of relevant portions of interview transcripts organized by general topics, 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. In preparing Chapters 2 and 4, I iteratively coded my interview summaries using MaxQDA software. 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 sometimes influencing prompts in subsequent interviews. After poring over the results, the findings that follow reflect the most important themes to emerge from data collection.

CONCLUSION AND PLAN OF SUBSEQUENT CHAPTERS

This introductory chapter offered a limited genealogical sketch of how contradictory policies and conceptions of disability, reflecting different eras and philosophies, came to constitute the uneven and fragmented contemporary landscape of disabled citizenship. Antidiscrimination and reasonable accommodations policies have come to replace overt exclusion from the workforce, but the employment-to-population ratio for disabled people remains at nearly half that of their nondisabled peers. SSI and SSDI offer limited support to those who can prove that their disabilities prevent them from working, according to medical criteria that conflict with more current understandings of disability. While large state hospitals and asylums are mostly closed, 3.12% of people with disabilities still live in institutions (Houtenville et al, 2023), many of them in facilities like Medicaid-funded nursing homes. Jails and prisons, as institutions of another kind, also hold large numbers of disabled people, and police and courts have developed new programs specifically targeted at criminalized individuals with certain disabilities. Finally, disability activism continues on a range of issues, offering new visions of both citizenship and community.

In the pages that follow, Chapter 2 focuses on disabled people's experiences in the workforce, including the management of both formal and informal accommodation requests, which I described as a form of conditional citizenship. Chapter 3 turns to SSI and SSDI, and the work that applicants and beneficiaries must do to maintain eligibility while making ends meet, generating a form of precarious citizenship. Chapter 4 focuses on nursing homes as a form of congregate housing for disabled people, where their political standing is restricted in a case of constrained citizenship. Finally, Chapter 5 examines contemporary disability activism through a case study of an ongoing grassroots campaign for nursing home reform as an example of insurgent citizenship. The different manifestation described in each chapter is an aspect of the larger construct of disabled citizenship, which is both fragmented and internally contradictory. Woven through separate chapters are accounts of people navigating overlapping sedimentary layers of policy. Informants spoke with me about, for instance, collecting SSI while working, even though policy is structured to suggest that one would either work OR collect benefits. The contradictions between the programs, and the work necessary to navigate those contradictions, constitute important aspects of disabled citizenship.

Chapter 2

Disability in the Workplace

When I interviewed Rebecca in November 2022, she was applying for accommodations at work. A white woman living on the North Side of Chicago, she worked for a large research organization, performing her duties remotely from her home. At age 39, the experience of seeking accommodations wasn't new to her. Having lived with chronic pain since childhood, she had been diagnosed at 30 with Ehler Danlos Syndrome (EDS), a genetic disorder that affects connective tissue. At one point prior to her diagnosis, she had experienced pain so severe that it led to surgery on her back. She also had other conditions that can co-occur with EDS. She was hard of hearing, using hearing aids. And she experienced postural orthostatic tachycardia syndrome (POTS), a condition causing an accelerated heart rate when standing up after sitting or lying down, which can also lead to dizziness and fatigue. Rebecca found herself dealing with dizziness severe enough that it had begun to interfere with her work.

As an elementary and high school student, she had experienced symptoms that may have been related to EDS, but she simply made her way through the pain and discomfort. Looking back, she said, "I think that there were definitely some accommodations that could have been in place, but I didn't know to ask for them." As she grew older, and her symptoms intensified, she had sought accommodations in various contexts. One employer, a disability rights organization, had permitted her to work from home, long before the COVID pandemic made such arrangements more common. This meant that when her POTS required her to work lying down, she could do so easily. Before that, while working in a university's disability service office, she had faced a period of flaring pain that made sitting for eight hours in her office difficult. But in that instance, her employer had denied an accommodation allowing her to work from home, even for the administrative portion of her duties that she could have handled effectively outside the office. While she knew that officially she could make a strong argument under the Americans with Disabilities Act (ADA), she had chosen not to risk antagonizing those in authority at a job that also provided her health insurance and tuition assistance in graduate school. Instead, after taking a period off work under the Family and Medical Leave Act (FMLA), she accepted a reduced schedule and lower pay.

At the time of our interview, her dizziness had grown more severe. Seeking to address it, she was taking medications that could sap her energy, and she was pursuing physical therapy that sometimes made her symptoms worse. As a result, she sought a temporary reduction in her work hours. Her supervisor, whom she'd kept apprised of the situation as her dizziness developed, had told her that she would need to request a partial leave through the organization's human resources (HR) office, filling out both a formal accommodation request and a request for short-term disability benefits to cover the hours she wouldn't be working. I reviewed both forms after our interview. As she thought about how she would complete this paperwork, Rebecca was uncertain how her application would be received. "Because my accommodations are not traditional accommodations," she said, "there's always a risk for me. There's always a concern and a risk that it's not going to be approved." The forms that she had to fill out created their own dilemmas, as she asked, "Are they looking for certain buzzwords? Are they looking for certain language to be in here for approval, or do they just want me to be super honest, and be like, 'I feel dizzy all the time. Sometimes it's bad enough that it prevents me from being able to use the computer.'" She needed to strike a balance between demonstrating need and performing competence, saying, "I don't want them to think like, 'Oh, she totally has her shit together. *She* *doesn't need this*' [emphasis added]. I also want them to know, 'She put thought into this, and that she has a clear explanation for why she needs this.'"

Further heightening the uncertainty surrounding this request, reduced hours did not constitute what Rebecca called "traditional accommodations." An employer might argue that to employ someone who could not work full hours went beyond the ADA's promise of reasonable accommodations. In contrast, in order to accommodate her hearing impairment, Rebecca had simply requested that the organization enable captioning on Zoom for all meetings. Her employer had made this accommodation easily, even informally. Rebecca said, "hearing loss is so much easier. I can show you the form that shows you my level of hearing loss from my last audiometry test, and please turn the captions on, you know what I mean? That was super easy. I made actually just an informal request, and I was like, 'I'm happy to request this more formally, if that's required.' They turned captions on across the organization. I was like, 'Awesome, this is super easy.'" Her request for reduced hours, in contrast, was "turning into a much more difficult thing."

Rebecca's experience encapsulates key themes within this chapter. The ADA forbids employers of 15 or more workers from discriminating against an applicant or employee on the basis of disability. Moreover, it defines disability to include the failure of an employer to make "reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability who is an applicant or employee." But an employer may not be obligated to provide accommodations if they "can demonstrate that the accommodation would impose an undue hardship on the operation" of their organization (Americans with Disabilities Act of 1990). In short, the system allows for considerable ambiguity, which workers are often left to navigate on their own.

Rebecca navigated this system with many advantages. She was more fluent in the laws and regulations surrounding accommodation than many workers; not only had she navigated the systems herself, but she had worked for a time in facilitating accommodations under similar frameworks for university students. The ability to work from home, for which she had previously fought unsuccessfully, was at this point considered relatively standard after the early days of COVID had changed perceptions in certain fields, including her world of research. But still, she faced an uneven terrain. She knew that some accommodations, like those for her hearing impairment, might be secured relatively informally. But others, like the reduced hours she was seeking when we spoke, still left her uncertain. The precarity around this request was heightened by the process of documenting her request, forcing herself to demonstrate both that she needed the accommodation, and that despite this need, she remained an "otherwise qualified individual." As I reviewed the forms, I noticed that one of them, which centered on short-term disability, was provided by a private insurer with which her employer presumably contracted to provide coverage. This was a form of occupational welfare (Titmuss 1969) that could cover her lost income if she was granted a reduced schedule: a benefit that was not required by the ADA, and which she might consider herself lucky to have. But this was also the more intimidating of the two forms, requiring assessments of her abilities in a range of areas that she told me she had little idea how to answer, underscored by warnings of penalties for perjury lest some unscrupulous malingerer attempt to misrepresent herself. The document offered Rebecca the prospect of maintaining employment, allowing her to hold onto a key element of citizenship, but it also reflected how fervently that allowance was guarded.

This chapter asks how disabled workers understand and experience the uncertain terrain of workplace accommodations as they seek to make a living, secure essential benefits like health insurance, and ideally perform meaningful work. The archetypal citizen, for Marshall and many other theorists, is a self-sufficient citizen-worker. I thus ask what type of disabled citizenship is produced by the difficult process of navigating employment and accommodations, and how it is enacted in the strategies through which disabled workers navigate this fraught policy landscape. In an economic context in which power is concentrated on the side of management rather than workers, and where many workers already face precarity and marginalization on the basis of race, gender, and other axes of stratification, disabled workers face additional obstacles. Despite protections promised by the ADA, these obstacles begin when a disabled worker seeks employment. As mentioned in the previous chapter, the employment-to-population ratio for working-age disabled people is roughly half that of their nondisabled peers (Houtenville et al, 2023). Among those in the labor force, the unemployment rate for people with a disability in 2023 was 7.2%, compared to 3.5% for those with no disability (US Bureau of Labor Statistics 2024). At both the point of application and after being hired, those who need accommodations face the task of negotiating with employers whose attitudes and procedures can vary widely, often with limited outside support, under the context of a legal framework that many see as difficult to enforce. Workers must engage in a form of *policy navigation from below* that involves both identifying and advocating for possible accommodations; proving that these adjustments are needed, often at the cost of personal privacy, without endangering one's employment; ensuring access to health insurance and, at times, other benefits; and maintaining relationships with managers and co-workers who can have an outsized influence on whether a job is tenable.

I explore this process in the following pages, drawing largely on in-depth semi-structured interviews with disabled workers in greater Chicago. My informants include those who are securely employed, others who are only precariously or partially in the workforce, and still others who have been pushed out. I find that the concept of accommodations is not familiar to all disabled workers, with some learning of it over time from peers, teachers, and even their own online research. Workers seek accommodations both formally and informally, at times waiting until they are ready to quit if working conditions can not change. When they do seek them, they may have to document their disabilities, a process permitted under the ADA but often in conflict with both self-conception and expectations of privacy. And while some accommodations are granted with little problem, others may be rejected, often leaving the worker with few practical means of redress.

This creates what I call a form of *conditional citizenship*. The ADA holds out the promise of full incorporation into the labor force for disabled workers, and with it, the status of citizen-worker. But achieving this status is premised on many factors that are outside of the control of any individual. Even those who are able to secure employment must then navigate complex processes in order to request accommodations, and the outcome of their requests may hinge significantly on the whims of an HR office or a single supervisor. Disabled workers' continued employment, and thus a key element of their citizenship, is marked with a form of conditionality that is not faced by nondisabled coworkers.

I approach this chapter with a dual theoretical focus, looking both through a lens of citizenship that asks how disabled workers are situated within the workforce and society, and through a materialist lens that understands disabled workers, like other workers, to sell their labor. The obstacles that disabled people face in the labor force are both a form of exclusion from a key institution of citizenship, and a reflection of their perceived (lack of) value in the labor market, both of which lead to the forms of immiseration that are the focus of the two chapters that follow this one.

BACKGROUND

TH Marshall wrote, “In the economic field the basic civil right is the right to work, that is to say the right to follow the occupation of one’s choice in the place of one’s choice, subject only to legitimate demands for preliminary technical education” (1950, 15-16). The establishment of such a right in 18th century Britain, alongside related rights to own property and engage in contract, established a baseline of individual liberty in Marshall’s analysis, sweeping away remnants of feudal systems and customs that tied peasants to certain categories of work. These rights together, he wrote, were “essentially the status of freedom” (18). The centrality of work to citizenship was further cemented over time in the US as the independent white workingman came to be valorized as a prototypical citizen, standing in sharp contrast to the dependency and curtailed citizenship of women, people of color, and the poor (Fraser and Gordon 1992, 1994; Glenn 2002).

This meant that disabled workers who could not secure employment were also less than full citizens. While gender and disability are widely divergent constructs, close reading of feminist analysis is instructive. Ann Shona Orloff, assessing literature on the welfare state in the early 1990s, writes that analysis of social democracies tends to center an archetypal male citizen worker. Quoting Carole Pateman, Orloff writes that employment “bestows the independence that is the ‘central criterion for citizenship’ and is associated with men” (1993, 308). Orloff calls for new avenues of analysis that address whether and how women, who have been excluded from the paid workforce, are able to access paid work as a means of autonomy within patriarchal family structures. She writes, “For many women and others excluded from paid labor, commodification—that is, obtaining a position in the paid labor force—is in fact potentially emancipatory" (318). The same can be said of disabled workers, for whom access to paid work can be both a means to basic subsistence beyond residual income support (discussed in the next chapter), and to a status of social belonging that marks a fuller citizenship.

Employment was not actually the central focus of the disability protest cycle that peaked in the 1980s and 1990s; that distinction went to transportation, and particularly the demand for accessible buses. But activists framed accessible transit as a means to unlock a wide range of social institutions, the workforce chief among them. ADAPT organizer Wade Blank cast accessible transit as essential to disabled workers, saying, "If I hire somebody in my office who uses a wheelchair, and he needs to go downtown to pick up some papers, or run across town to attend a meeting," he would need access to an accessible transit system, rather than unwieldy paratransit that required planning rides days in advance (*Disability Rag*, October 1983, 15). Representative Tony Coelho of California, arguing for the ADA on the House floor in 1988, "testified that some 28 percent of Americans with disabilities attributed their unemployment to transportation barriers" (Pettinicchio, 2019, 110).

The Americans with Disabilities Act, passed in 1990, sought not only to improve the accessibility of transit and other public accommodations, but also to address the exclusion of disabled workers from the labor force directly. As stated in the opening of this chapter, Title I of the ADA specifically defines the failure to provide accommodations to otherwise qualified workers as a form of discrimination. As legal scholar Samuel Bagenstos (2009) writes, this has been portrayed by both supporters and opponents of the ADA as a qualitative break from other antidiscrimination laws, though he argues that the distinction is often overstated. Bagenstos also points out that under the ADA, workplace disability discrimination, much like other forms of employment discrimination, is far easier to prove against an incumbent worker than a job applicant. This blunts the impact of the ADA in opening up the workforce, and it could even be understood to create a perverse disincentive against hiring disabled workers who might later bring a complaint (123).

Following the ADA, legislators presented the Ticket to Work and Work Incentives Improvement Act of 1999 (TTWIIA) as another effort to facilitate disabled workers' access to the labor force. In addition to work incentive programs and vocational rehabilitation services for SSI and SSDI clients discussed in greater detail in the next chapter, the law sought to allow disabled Medicare and Medicaid beneficiaries to maintain their public health insurance coverage, even if they began work and their earnings exceeded eligibility thresholds. Several policymakers argued that resolving this conflict between social and occupational welfare systems was key to boosting disabled employment. Senator William Roth of Delaware testified that "millions of Americans" were "waiting to be freed" from "a system that tells individuals with disabilities that if they leave their homes and try to find productive employment they will lose their access to health insurance." Senator James Jeffords of Vermont, following his colleague from Delaware, said that "the promise of employment rights under the ADA was an empty one for millions of Americans" who feared loss of health care coverage. But with TTWIIA, he said, "we are making good on that promise" (Congressional Record 1999, S14971-S14973). These promises, too, stand unfulfilled. In our 2023 interview, policy advocate Susan Prokop, who was closely involved in passing TTWIIA at the time, told me that implementation was hindered by complex program rules and a patchwork of state policies in administering Medicaid. In retrospect, Ms. Prokop told me, "There may have been a certain degree of naivete about the seriousness of all of the barriers that remained to help people go back to work." While the ADA and TTWIIA evoked the prospect that disabled citizen workers could be full members of society, including as equal participants in the labor force, that goal has not been achieved.

In her analysis of disability and labor, Marta Russell argues that the exclusion of disabled people from wage labor, and the lack of progress under the ADA, is rooted not in issues of policy design or implementation, but in the fact that employers regarded the labor power of disabled workers as a less valuable commodity than that of nondisabled workers. In a market society, she wrote, “disabled persons perceived to be of less use to the competitive profit cycle were excluded from work” (2001, 89). Whether accurately or not, employers see the hiring of disabled workers as the source of additional production costs, whether through accommodations, health care coverage, or other means. In this analysis, a liberal civil rights framework, such as that enacted in the ADA, can only go so far. In a separate essay written soon after the passage of TTWIIA, Russell suggested that Congress and the Clinton administration sought to bring disabled workers into the workforce in part to address the tight labor market of the late 1990s. She predicted that any gains would be fleeting, however, as many disabled workers would not find secure long-term employment, but would instead be drafted instead into the “reserve army of labor,” serving to reduce pressure for wage growth before losing their jobs when labor market pressures eased (2001|2019).

Wherever one locates the root of the issue, data makes clear that disabled workers in the US continue to face structural barriers to full workplace participation. Recent analysis shows that disability status intersects with race/ethnicity and gender in employment outcomes, creating multiplicative “spillover” effects that entrench systems of social stratification (Brooks 2021). But there is relatively little research that explores how disabled workers experience and navigate the workplace. Studies of workplace accommodations are often based on large data sets (e.g.

Shuey and Jovic 2013, Chow et al 2014) that paint a broad picture but lack experiential detail. Balser's (2007) study of accommodations offers important insights, including finding that full-time permanent employees were more likely than their part-time counterparts to secure accommodations to the physical set-up of their workspace, but less likely than part-timers to secure scheduling flexibility. But as a study based on regression models using survey data, the mechanisms behind these findings remained inaccessible. This chapter helps to fill a gap in the literature by analyzing detailed interview data to illuminate the process of navigating policy from below in the workplace, and the conditional citizenship that this process produces.

DATA SOURCES

All of the 40 disabled people in greater Chicago whom I interviewed for this project had some experience in the labor force, ranging from highly precarious short-term work to stable careers. But not all were currently attached, even tenuously, to the labor force. I classified 12 informants as out of the labor force, though many of them had worked earlier in their lives. Of the remaining interviewees, 13 of 28 were securely attached to the workforce at the time of our interview. All were securely employed in jobs ranging from customer service to social work, corporate human resources to academia. One had worked previously as a professional adaptive athlete in a basketball league in Europe, though he was now working in another field in the Chicago area. Those who worked less than full time had chosen to do so as a form of accommodation. The other 15 interviewees were tenuously or precariously attached to the workforce. Some worked multiple part time jobs or performed gig work through online platforms. Many expressed a desire for full-time work, but they had not been able to secure it. One lived in a nursing home where she sold chips and soda out of her room, a self-described side hustle that social workers had tried unsuccessfully to shut down. None of the 28 reported working in positions covered by a union contract.

I also attempted to draw a distinction between whether these workers had formal or informal accommodations. As Rebecca's story at the beginning of this chapter demonstrates, a worker may have both; for instance, she was able to secure captioning in Zoom meetings through an informal request to her supervisor. She also worked from home, which made her work much more accessible (as it did for many other workers, as I discuss later in this chapter). Because this was a norm at her workplace, I consider it an informal accommodation in this case. Had a worker specifically requested remote work an accommodation, as Rebecca did (unsuccessfully) at an earlier job, I would categorize that as it a formal accommodation. Applying this framework to the 28 informants who are the focus of this chapter, I counted ten who had, at most, informal accommodations. The other 18 had formal accommodations, often accompanying informal arrangements. Putting together the two classifications—formal or informal accommodations, and secure or precarious labor force attachment—I generated a 2x2 table, which appear as Table 1. As the table demonstrates, I counted eight precarious workers whose accommodations had been informal at best, two who were securely employed with informal accommodations, seven who were precariously employed but had current or previous formal accommodations, and eleven who were securely employed and had secured formal accommodations.

Table 1: Security of Employment and Accommodations

	Informal accommodations at most	**Formal accommodations**
Precarious/partial labor force attachment	8 workers	7 workers
Secure employment	2 workers	11 workers

I offer this table not to attempt causal arguments about whether the formality of accommodations is linked to the security of a worker's employment, but as descriptive data on my informants. At times, the distinctions were debatable. Three of the informants classified as precariously employed were boundary cases whom I considered classifying as out of the labor force. Two were not working at the time of our conversations, and the third was making very limited money selling crafts online. But all three still spoke of work in their future, and one was actively applying for jobs, and so I chose to place them in this category. Even categorizing whether someone was granted or refused accommodations created tensions at times. For some workers, accommodations were offered grudgingly, or with a snide comment or an element of condescension. Others knew that their accommodations could be better, but they accepted what they had as good enough. Laurel, a legally blind massage therapist, relied on co-workers to take care of computer-based work like managing client bookings. She knew that with adaptive technology, she could do that work. Reflecting on the arrangement, she said, "The computer situation at work, should that be accessible to me? Absolutely. Is it fine the way it's working? Big time." This reflects not only the challenges of any coding scheme, but the contradictions that many workers face as they attempt to navigate disability policy in the workplace.

Of the 28 workers who are the focus of this chapter, 21 were white, two were Black, one was Latinx, and four were Asian or Asian-American. Four were men, 17 were women, and seven were nonbinary. Seventeen lived in the city of Chicago, concentrated primarily on the North Side, with others in various South Side neighborhoods. Eleven others lived in various suburbs surrounding the city. They ranged in age from 18 to 65, with one in her teens, seven in their twenties, thirteen in their thirties, five in their forties, one in her fifties, and one in her sixties. Nine of them received SSI, SSDI, or a similar form of income support for disabled people from the Social Security Administration. The tensions of doing so, despite those programs being premised on the idea that beneficiaries can not work beyond a minimum threshold, are discussed in depth in the next chapter. As with my overall set of informants, this group reported a wide range of physical, psychological, cognitive, and sensory disabilities. Seven used wheelchairs, and five more used other mobility aids such as canes, crutches, or walkers.

The racial, gender, and age composition of this set of informants are all worthy of discussion. While a qualitative study built on the concept of sequential interviewing (Small 2009) can not seek to be statistically representative, I wrote in the introduction that my pool of informants was whiter and less male than I would have liked. This is likely reflective of my social location, and shortcomings in my recruitment. The informants for this chapter, in particular, skew younger than my informants as a whole.

It is worth comparing the racial and age composition of this group to that of the 12 informants who were out of the workforce. Of those 12, four were white, six were Black, and two were Latinx. They were also an older group, ranging from 38 to 70, with one in her thirties, one in his forties, five in their fifties, four in their sixties, and one in her seventies. Offering the caveat once again that this data is not a suitable basis for causal arguments, the difference between these groups may reflect the forces that shape whether disabled workers can maintain employment. As Brooks (2021) has documented, disabled workers of color face intersectional barriers to hiring and job retention. And as disabled workers age, they may face greater obstacles to remaining in the workforce than their nondisabled counterparts, both in attending to their personal needs and in marketing themselves to potential employers. Jackie, a 58-year-old Black woman with cerebral palsy who was no longer working, reflected on this during our interview. While she had worked in many jobs, the one where she felt most at home had lasted only five years before she was laid off due to upper-level mismanagement. She had hoped for a long-term job that would lead to retirement, but such positions seemed rare, and as she aged, she had found it more difficult to keep up with her able-bodied co-workers. She said,

> “I was always looking for that job that you could just keep until you retire. It took me a while to realize, and then I started hearing it on the news and I felt better. That world doesn't exist anymore, people are not staying in jobs until they're retiring. The world has changed, and people go from job to job to job. *The hardship on people with disability is sometimes we're limited to the type of jobs that we can do. We can't always make that transition easily*” (emphasis added).

FINDINGS

In the general context of advanced capitalism and the specifics of US labor law, most workplaces are structured to advantage employers over workers. Disabled workers face particular obstacles, both as job-seekers and as employees. Once hired, if workers need accommodations, it generally falls to them to learn that such arrangements are even possible, to identify what adjustments to the work environment might benefit them, and to request those accommodations. Making such a request can mean both disclosing details of one’s disability in order to justify an accommodation, while also managing relationships with bosses and supervisors, who can hold outsized power in both judging the request and shaping a worker’s experience in general. At the same time, workers need to ensure that they can maintain the health insurance coverage they needed, and in some cases, described in more detail in the following chapter, maintain their eligibility for other supports such as SSI or SSDI benefits. Together, these tasks constitute a form of policy navigation from below, which disabled workers must juggle alongside the labor of their jobs. Success and belonging are conditional on managing all of these elements.

“I think they just didn't know what to do with us.”

This chapter focuses primarily on the 28 informants who were connected to the labor force at the time of our interview, however precariously. But before turning to them, the remaining 12 informants are worthy of discussion, as their situations reflect processes by which disabled people may be excluded from work. Nine of them were current or former nursing home residents, which may at first seem to suggest that their disabilities were simply too severe to allow them to work. And indeed, several informants in this group said that the pain they experienced and the demands of frequent medical appointments made work impractical or impossible. But these ostensibly biomedical needs are mediated through social processes. Emily, a 64-year-old white nursing home resident, had left the workforce and started collecting SSDI when she was in her thirties. She had been working more than 40 hours a week as an executive assistant, experiencing severe pain from fibromyalgia and attempting to “tough it out.” She worked a limited amount after that for a time, but she said that returning to the workforce didn’t feel feasible. This was not simply a matter of her disabilities, but of the instability that came with poverty, as she sought to manage multiple moves and maintain her sobriety. When I asked about programs like Ticket to Work, she said, “I was moving so often. I was never settling down enough to actually do something like that. I lost my belongings about five times over.” Her disability certainly made work difficult, but so did the demands of daily survival in a context of poverty and instability.

Others had attempted to work and been turned away. Carmen, a 38-year-old Latina wheelchair user with cerebral palsy, lived with her family in Chicago’s south suburbs and collected SSI. She had studied early childhood education in college, hoping to become a teacher. But when it came time to complete her student teaching, the teacher to whom she’d been assigned “was not very comfortable having someone with a physical disability in as a student teacher.” From her chair, Carmen had limited ability to reach the blackboard, and so she wanted to have a personal assistant (PA) to write on the board, stressing that she would still be the one teaching. Carmen already had PA services to help her with activities of daily living, and this seemed like a logical extension, but the teacher treated this as if “it was unheard of.” Though Carmen later learned that this was far from an unusual accommodation, at the time, as a first-generation college student, she didn’t feel that she had other options. After two weeks of trying to make things work, Carmen said, “I wanted to leave with whatever dignity I had left,” and she completed her bachelor’s degree without becoming licensed as a teacher.

Despite this frustration, Carmen enrolled in a master’s program at the same university, this time with a focus in school counseling. Her internship at a high school was the most exciting part of her program, and she became certified as a licensed professional counselor. But after graduating, she spent five to seven years applying for what she estimated to be 50 different jobs. None hired her. Over that time, she attended continuing education programs in order to maintain her licensure, but this became financially untenable, and she fell away from the field. She said, “It just got so expensive for me to not be practically using it. It just took a bite out of my budget where there wasn't one. I just actually had to let those go eventually because I just wasn't using them, and I started to fall out of practice as far as what the techniques were and things like that.” She continued seeking work, volunteering alongside paid staff at a hospital scheduling office where she hoped in vain that she would be hired. After several years, she applied for student loan forgiveness on the basis of disability, a process that she described as one of the most painful things she had ever done. Reflecting on it, she said, “I went to school with—and again, maybe it was me being cynical or naive, but—the idea of promise and a future just like everybody else, and a career, and here I am saying in writing that this may not be the case, and that to me was the hardest part."

Others had been steered out of the workforce in ways that were less dramatic, but just as real. Howard, a 45-year-old Black man with cerebral palsy, used a walker and spoke with a stutter. During high school, where he had been in special ed, he had a job at a grocery store, bagging and pushing carts. He liked it, but he said he wouldn't want to return to that work. When I asked why, he told me, "When I got used to it, they turned around and let me go with no reason why," despite not having expressed any dissatisfaction with his work. But Harold said that he, his mother, and his sister believed that they knew the real reason: it was because of his disability. After high school, he worked for about four years at a sheltered workshop, a work site governed under Section 14(c) of the Fair Labor Standards Act, which allows disabled workers to be paid less than minimum wage (National Council on Disability, 2012). As at many sheltered workshops, Howard was paid a piece rate. He said that he liked it, and the staff were nice. But eventually, there came to be days with no work for him and his co-workers to do. Sometimes, they would show a movie in the break room on these days, but otherwise, he said, "We'd just sit around and do nothing." Howard soon stopped going, considering it a waste of car `fare. At the time of our interview, Howard lived in an assisted living facility in Chicago, and said that he wasn't sure if he would work if he found a job; he hadn't really thought about it for a while.

While he did not say so directly, I would argue that Howard had learned though experience that he didn't have a place in the workforce. Why would he wish to engage with an institution that had unfairly fired him, an experience that still seemed upsetting years later, and had then left him to sit idly in a workshop? His experience was reminiscent of comments from Joanne, a white 61-year-old genderfluid woman who had cognitive and developmental disabilities related to brain injuries and illnesses, who lived in a subsidized apartment in a Chicago suburb. Though she occasionally was paid for work with various organizations she was involved with, she didn't see work as feasible for her. In part, she attributed this to her medical needs; when I first asked about work programs, she pointed to the number of doctor's appointment she had, asking, "How many people have two neurosurgeons?" As she considered the matter, she added that she hadn't been prepared for work or college, saying, "Those of us who've been disabled really long time and have cognitive disabilities just never were given really a chance to work or to go to college and then work." When I asked if institutions had prepared her for anything, her blunt reply was "No. Death." She added, "I think they just didn't know what to do with us. I don't think they had any thoughts about it." Joanne attributed this in part to her generation, as someone born decades before the ADA passed. But it is not hard to see how the same exclusion of disabled people from work and other social systems, and thus from full citizenship, would persist in practice for Howard, who was 16 years younger, and for other disabled people today.

"If someone doesn't hire me because I can't walk, I don't have any proof that that's why."

Applying for a job can be a nerve-wracking process for any worker. But for disabled workers, particularly those whose disabilities were readily apparent, the process can also bring to the fore questions of whether one was less likely to be hired on the basis of disability. Several of my informants raised this, though they were often reluctant to state definitively that they had been passed over because they were disabled. It was more common for me to hear the possibility raised, along with a caveat that one couldn't be certain. But living with that uncertainty was part of navigating the world of work.

Mikoto, a nonbinary 34-year-old Asian autistic wheelchair user, had earned a master’s degree in education, and had spent some time looking for teaching jobs. When we spoke, they were planning to start a position soon as a guest teacher, a role much like a frequent substitute teacher, for three to five days a week at a private school. But before securing that position, ten to twelve phone interviews had not led to any job offers, and Mikoto’s disclosure of their wheelchair use had seemed to be a key reason. Interviews would go well, but then, said Mikoto, “I'm like, ‘Hey, I don't have a car, but my husband can drive me, so it's fine.’ They were like, ‘You don't drive?’ I'm like, ‘Yes, I'm on the wheelchair.’ They're like, ‘Okay, we need to have more physical fit person, so thank you, bye.’” At first, Mikoto said, they felt hopeless at this. They knew other teachers who used wheelchairs, and they felt that disabled students could benefit from having a visibly disabled teacher. But ultimately, they decided, “If you're not able to work with me because of my wheelchair situation, I'm glad I didn't get your job.”

Maureen, a 32-year-old white nonbinary person, walks with a cane due to chronic pain. They also experience depression and post-traumatic stress disorder (PTSD), and when their symptoms flared, causing the worst year they had ever faced, they dropped out of a master’s program in social work. With limited access to health insurance, and thus to therapy, they were out of school and work for an extended period until their symptoms abated. When we spoke, Maureen had been without steady work for about seven years. They had found some short-term app-based gig work as a tutor and a pet-sitter, but securing even that work had become nearly impossible. Speaking of one platform, Maureen said that when a job was posted, “The first person who clicks it gets it, and literally, those would disappear in five seconds. You could sit there for a few hours hoping desperately to click fast enough and still not get anything.”

Instead, Maureen preferred to devote their time to applying for longer-term jobs, estimating that they had sent out thousands of applications over the years. Their symptoms had improved to a point where they felt that they could work full time, especially if part of the job could be done remotely to reduce the physical demands of commuting by public transit. But they had been invited to a decreasing number of interviews, which may have been in part because their resume had “started looking staler” due to gaps in work. When I asked if their disabilities had played a role in how employees perceived them, Maureen said, “Explicitly, no. Implicitly, I've noticed hospitals seem to be very unhappy with it.” When I probed further, they said that in such settings, “there have been times where I saw the interviewer walk in and mentally check out from the rest of it” after seeing that they were visibly disabled. Maureen didn’t know why this seemed particularly true of hospitals, theorizing that ableism might be particularly intense in medicine (an idea that another informant had independently expressed as well). They felt that their use of a cane was irrelevant to the jobs they were seeking, asking, “For things like data entry or reception, what do you care if I'm going to be sitting at a desk for eight hours?” When I asked if they felt that the ADA provided any protection, they voiced low expectations, saying, “If someone doesn't hire me because I can't walk, I don't have any proof that that's why. They're just going to say, ‘No, we had a better candidate.’ There's no enforceability from my end that I can do anything about.”

Carla, as 26-year-old white woman, uses a power wheelchair due to cerebral palsy. After graduating from a highly selective university, she went about a year and a half before finding a job, applying to an estimated 300 positions in that time. Looking back, she said sardonically, “There were a lot of job applications, a lot of rejections. I do a first interview, they see me roll up in a wheelchair, and then they don't call me back. I wonder why.” In addition to using her wheelchair, Carla also has other accommodation needs; when working at a desk or table, she needs the surface to be at least 33 inches high, so that her legs can comfortably fit under it. She also has moderate low vision, and at times uses a magnifier for small print. When she applied for a position in the accessibility office at a state university, she learned that she would have to take an exam as part of the assessment process. She attempted to find out the details of the test, thinking, “Do I need a higher table? Do I need to bring my magnifier? Is the print small?" The hiring manager dismissed her inquiries with sexist condescension, saying something along the lines of, “Just relax, sweetheart. You're getting way too keyed up over this." Ultimately, she found someone who would give her the information, and the test was not a problem. Still, she said, “I did the test and never got called back. Wonder why.” Dealing with such rejections, and wondering if they are due to one’s disability, is part of the work of policy navigation for disabled job-seekers.

For most workers, regardless of disability, seeking a job is a process of trying to match one’s skills to an employer’s demands. For disabled workers, navigating this process can also involve matching one’s access needs to available jobs. Some, like Rebecca, sought jobs with flexible schedules, or that allowed them to work from home. Of all my informants, perhaps the best outcome of matching access needs to the job market was Chea’s. A 31-year-old Asian-American leg amputee, he had played wheelchair basketball competitively throughout high school and college, and he had gone on to play professionally for a year in France. In a tone that suggested a level of happy astonishment that this had been his life, he recounted how he “just played basketball every day and got to enjoy the life of a professional athlete. They paid me a salary, they paid for my food, they paid for my travel, my housing, anything I truly needed.” He was, at the same time, very much aware that he could not have done so in the US, which lacks the structure of adaptive sports leagues found in Europe. And he did not see professional sports as a long-term career, pointing to a friend who reminded him, “You can’t play sports forever.” Upon returning to the US, he had spent several years coaching adaptive sports, seeking to provide others with some of the joy and camaraderie he had found in athletics. When we spoke, he had begun a new job with a company working to make people’s homes physically accessible, a significant shift, but one that didn’t require him to work nights and weekends the way that coaching had. While he was only one of a few disabled workers both in his new job and as a coach, and pointed to some issues with accessibility in both, he was happy with his work.

For others, matching access needs to the job search can be more limiting. As I wrote earlier, Maureen avoided jobs that required walking, or that had a commute that would mean walking long distances—which eliminated many positions due to Chicago’s “patchy” public transit system. Leah, a 24-year-old white woman with obsessive-compulsive disorder and an eating disorder, worked as a consultant when we spoke. The role allowed her to pursue her interest in data science, and she said that “as far as consulting firms go,” hers was “very hospitable.” But her anxiety symptoms made it very difficult for her to meet expectations around billable hours, which in turn created more anxiety. She said, “I like it, but I really just can't keep up with [it]. I don't have the stamina for that kind of job, I think.” She planned to seek other jobs where she could work at a more manageable pace. Lee, a 23-year-old white nonbinary autistic person with an autoimmune disease, had also recently adjusted their career trajectory. After college, they had begun a graduate program but had been pushed out, due in part to low grades during a period when administrators had not yet approved testing accommodations. After leaving the program, they began a position as a lab manager at another university, and while they were clearly not happy about how they had been treated as a graduate student, this position was also more accommodating. It involved fewer of the interpersonal dynamics that were particularly stressful to Lee as an autistic person, and it didn't have the long hours that had exacerbated their autoimmune disease and taken a toll on their body. On the whole, they said, the new position "doesn't really put me up against my limitations as much."

"At that point, the term 'accommodations' was not really on my radar."

Once hired, many disabled workers navigate the process of seeking accommodations, whether formally or informally. But to do so, they must know that accommodations are an option! While this may sound like a truism, it is actually essential step in navigating workplace disability policy. In political sociology, John Gaventa's third dimension of power describes whether subordinate groups see even the possibility of challenging the status quo (1980). Analogously, the power of employers, in a single workplace and in society at large, can shape whether disabled workers know that accommodations are possible, let alone a legal entitlement. As Parvati, a 29-year-old South Asian non-binary woman with ADHD said, "It [the possibility of accommodations] certainly was not advertised, it was certainly not something that anyone ever talked about. I think I know it because I'm in disability spaces, I got lots of homies that are disabled."

Tanya, a 37-year-old white woman on the North Side of Chicago, lost her hearing abruptly while working as a pharmacy technician. "At that point," she said, the term 'accommodations' was not really something that was on my radar." She didn't have any specific requests because she didn't know what she needed in order to navigate a new set of life circumstances. Instead, she said, "The only thing I really remember being on my radar was just asking my boss, 'Can I just keep working while I figure this out without being able to hear?'" Fortunately, her supervisors and coworkers at what she called a "small independent neighborhood mom and pop pharmacy" were willing to support her. She wrote things down and had customers write their orders for her. While some customers were less accommodating, her co-workers proved willing to come to her defense and say, "No, it doesn't matter how loud you speak. She's not going to hear you. Either I'll help you or you can write it down."

Tanya's creativity in fashioning makeshift accommodations was not unusual. As a college student in summer 2020, when demand for food delivery workers was high, Mikoto was a regular customer of Uber Eats delivery service. They reasoned that if some workers delivered food by bicycle, they could do the same with their power wheelchair. Mikoto signed up as a bike-based Uber Eats gig worker. In the field where they were asked to list what kind of bicycle they had, "I put wheelchair and brand of the wheelchair. I submitted and they were like 'approved.'" Once this jury-rigged accommodation was authorized, Mikoto had to make other adjustments, memorizing which restaurants were more accessible. At times, they would encounter unhappy customers, particularly those who wanted a delivery to an inaccessible doorstep. But they worked in the position for three months, making reasonable money.

Some workers, despite not being familiar with the ADA's concept of accommodations, found other legal frameworks in which to advocate for themselves. Anica, a 44-year-old white woman with complex PTSD (CPTSD), ADHD, and a set of symptoms that pointed toward an autism diagnosis, has worked for decades in engineering management. When we spoke, she had only recently sought formal accommodations. But, she said, "I didn't think of it this way at the time, but I did have an accommodation" roughly twelve years earlier. Her CPTSD treatment had "hit a wall," and she was in desperate need of respite. "Through desperation and needing to figure out what I could possibly do," she said, "I learned that under FMLA [the Family and Medical Leave Act], I could take a leave. I could take a break from work and not lose my job.

That's what I was so scared of, of like losing my job, losing my career…I didn't really understand what other options might exist." Her therapist, who filled out required paperwork, said that he had never done so before. She approached her supervisor to make the leave request very apologetically—more apologetically than she needed to, in retrospect. Had she understood this to be an accommodation, she might have been more secure in making the request. But as she said, "I didn't have much language for it. I think that's partly why it was as terrifying as it was."

Hannah, a 40-year-old white woman, had developed central pain syndrome, along with associated bladder and bowel issues, roughly three years before our interview. She worked for an international non-governmental organization focused on education, where she was accustomed to working 60-hour weeks. Much of her career had been based outside the US, though when her symptoms began, she had returned to Chicago in response to the onset of the COVID pandemic. In order to deal with her symptoms, she had limited her hours and restructured her work schedule, trying to work at times of day when her pain tended to be less severe. But she made these adjustments informally, with permission from the organization's CEO, to whom she reported directly. While her boss assured her that she was still meeting expectations and getting her work done, Hannah felt very guilty at first, even suggesting that she be paid less. At the same time, her pain persisted, and she, like Anica, needed to take a period off in order to focus on her well-being. She wasn't sure if she would be permitted to take leave, but her pain had reached the point where she was ready to quit her job if needed. A further impetus for her to request time off was a colleague taking maternity leave. She drew a connection to what she needed, saying, "Maternity leave is basically medical leave and it's paid. I should be allowed to do that too, and it made me feel not bad about it anymore." Like some others, Hannah was not entirely unfamiliar with the concept of accommodations; she pointed out that she worked with disabled students, and believed firmly that they should have the accommodations she needed. But until recently, she had not seen either disability or accommodations as concepts that applied to her personally. She said, “I think that if I had self-identified as having a disability, that then I might have viewed accommodations at work differently, whereas it just felt like, I'm sick and you're doing me a favor kind of thing.”

The role of education

The fact that education was a reference point in Hannah’s conception of accommodations points to a key factor shaping how disabled workers navigate workplace policy. Disability in education in the US is governed not only under the ADA, but also under policies such as the Individuals with Disabilities in Education Act (IDEA). This is another sedimentary layer of disability policy, which creates different forms of disabled citizenship in the classroom than in the workplace. Schools have far greater obligations toward their students than employers have toward their workers, including the obligation to provide accommodations and individualized instruction. Educational policy creates its own set of political actors, including parents (Cowhy et al, 2024). For workers who had disability accommodations in school, the classroom can serve as a space in which they learn that accommodations are possible. In addition to robust literatures on the impact of educational attainment on future earnings, and on education as a source of social capital, we can also look at education for students with disabilities as a potential source of *navigational capital*, on which they can draw when seeking workplace accommodations.

Several of the workers discussed in the previous section had not experienced accommodations as students. Tanya lost her hearing in her twenties, and Hannah developed central pain syndrome in her thirties. Anica speculated that some of her disabilities had been present as a student, but she did not receive a diagnosis until adulthood. Moreover, her schooling was cut short when she dropped out of high school due to domestic violence, which also caused her CPTSD. As adult workers, none of them could draw on experience of classroom accommodations as a point of reference. In contrast, Mikoto had experienced accommodations in college not long before fashioning their wheelchair-based Uber Eats job. As a student who had recently come to the US, classroom accommodations were still new to them. While the university had particularly strong accessibility programs, including accessible dorm rooms and a campus paratransit service, Mikoto didn't know about these for their first two semesters. They recounted being asked by a disabled teaching assistant why they didn't have accommodations, replying, "What do you mean, accommodation?" After learning of the possibility, they still had to identify specific adjustments that would be beneficial and navigate academic bureaucracies to obtain them. But ultimately, they were able to secure accommodations, which may have made them more confident in claiming legitimacy as a wheelchair-based delivery worker.

Other informants also described learning of the possibility of accommodations in school, and some drew direct comparisons between education and the workplace as sites of disability accommodations. Carol, a 43-year-old nonbinary autistic person with Ehler Danlos Syndrome, was a practicing social worker when we spoke. But in their twenties, they had gone to school to learn to be an acupuncturist, and said, "That was where I really learned about the ADA." Acupuncture training often involved students practicing needling and bodily manipulation on one another, and for Carol, this could trigger intense physical pain. Someone pointed them to the ADA, which they researched online, eventually learning that at the school's other campuses, students with physical disabilities were able to have body doubles stand in for them in practical training. They had to advocate mightily to win this accommodation for themselves, but even in what they called a "predatory trade school," there were grounds to make the claim. In retrospect, Carol said that while implementation was usually poor, classroom settings were far more amenable to accommodations than workplaces, because academic "institutions know their fucking obligation, and they know that there's lawsuits, and that the government can come after them." Workplaces, in their experience, were less accountable.

Jackie, a 58-year-old Black woman introduced earlier in the chapter, offered a similar comparison between work and school. As a college student in the 1980s, even before the ADA had passed, she had accommodations and supports "because that was a school, see, that was different." Colleges, she explained, operate "under different law, under government help, all of that, but when you got into the real working world, we had to fight for our accommodations if you want a job and you want to keep your job." While Jackie's assessment may have been rooted in part in her generational experience, having finished college in the 1980s before the ADA, her sentiments were echoed by Jean, who was less than half Jackie's age. A 24-year-old white nonbinary person who is legally blind and has cerebral palsy and arthritis, Jean had accommodations throughout primary school, community college, and the university where they were enrolled when we spoke. Jean also had worked in various short-term roles, including house cleaning, tutoring, and corporate product testing. While they had managed to secure accommodations in these jobs, often informally, Jean offered a comparison of education to the workplace that was much like Jackie's, saying, "The accommodations in the workplace aren't nearly as well used as they are for collegiate stuff because the workplace doesn't really know how to do accommodations." The classroom and the workplace generated different forms of disabled citizenship, and those who had benefitted from the comparatively more robust approach to accommodations in schools could draw that experience in navigating policy on the job.

Navigating accommodation requests

Once a worker knows that they may be entitled to accommodations, the arrangements do not simply fall into place on their own. Workers must still secure them, in an interactive process of policy navigation that is shot through with the power dynamics of the workplace. Asher, a 30-year-old nonbinary social worker with mood disorders, said during our interview, “People with disabilities don’t receive the accommodations they need without a lot of emotional labor.” While their conversational use of the term was not fully in line with the sociological conception of emotional labor (e.g. Hochschild 1983), their point was clear. Securing accommodations can demand that disabled workers perform emotionally taxing labor outside of their job duties, which might be termed *navigational labor*.

Anica, introduced previously, ultimately came to understand herself as having a disability but still wasn’t sure what kinds of accommodations might be helpful. Her therapist referred her to an ADHD coach, who in turn referred her to multiple online resources listing possible accommodations. She was cautious in choosing what to ask for, weighing, “What would really help me and be worth asking for, and worth spending whatever clout I might have with this leadership team?” Ultimately, she formally requested that she be permitted to reserve blocks of time on her calendar when she wouldn’t be disturbed, which would help her to absorb information and accomplish her detail-oriented work. Even with this moderate request, she said, the HR department asked her more than once for clarification, leading her to say, “I can't tell if they were just being incredibly dense or if that was almost an intimidation tactic to make it seem like I was asking for something strange and unreasonable.” Ultimately, they granted the accommodation, though Anica noted that she still had to enforce it on her own in the day-to-day, continuing to navigate policy by carefully guarding her time.

Janet, a 42-year-old white woman in a Chicago suburb, had dealt with various disabilities early in her life, including ADHD and generalized anxiety disorder. About five years prior to our interview, she fell down a set of stairs on her first day on the job at a long-term care facility, injuring both legs and developing lymphedema (a form of swelling) in one leg that limits her mobility. It was after this injury that she started getting formal accommodations. These included adjustments to the dress code to accommodate her lymphedema, as well as simply being understood to move more slowly than many of her coworkers. She was also permitted, until there was a change in management, to call in to the first meeting of the day instead of attending in person. She noted that early morning commitments had been difficult for her for many years, which she attributed in part to her ADHD. But when her physical disability made it more difficult to get in on time, her desire for an accommodation was treated with greater legitimacy. She said, "If I could attach that to my leg hurting, having a hard time moving [in the morning] was far more acceptable than if I were to say, 'I was having a hard time moving because I have ADHD and I don't experience time the same way that you do.'" This fact that the same accommodation generated different responses, depending on which disability she attributed it to, reflects the conditional and arbitrary character of navigating such requests.

For many workers, securing accommodations depends on documenting the need for them. While an employer is permitted to require documentation under the ADA, it can mean subjecting oneself both to an invasion of privacy and to an administrative gaze that frames one's disability in a pathologizing, disempowering light. Parvati, introduced previously, works for a large public agency. In previous positions, she had found ways to manage her ADHD, but since beginning this job about a year and a half before our interview, she had found it more difficult. She felt that working from home would be helpful, for multiple reasons. Parvati stressed to me that her supervisor was supportive, but also strictly rule-abiding, with an approach that Parvati summarized as, “Let's make sure that every single thing is documented the way it needs to be documented before I as your supervisor feel comfortable letting you do the thing that we all know that you need." This meant, in part, being formally diagnosed with ADHD; while her symptoms had been clear for some time to her and to those who knew her well, she had never taken this step. The clinician she saw then had to document Parvati’s diagnosis, filling out a certification form for what her employer called its ADA office, which would evaluate her accommodation request. The process cost nearly $700 in fees to the diagnostician.

For Parvati, the form that her clinician filled out was the most injurious part of the process. She read part of it to me during our interview, reciting the instructions to detail a patient’s diagnosis, their impairment, and the limitations on their daily life activities and ability to perform their job. While she assured herself that the form was a necessary step to securing accommodations, she said, “I think it has the potential to be very, very harmful. The language and the way that these things are talked about. To be reduced to a diagnosis, the severity of a diagnosis, the length of a diagnosis, and even that language of, ‘What are all your impairments? List them off, rattle them off.’” She cited her supervisor’s support as a key factor in helping her through the process. Ultimately, she did secure an accommodation that allowed her to work from home twice a week. Soon afterward, however, her agency began a pilot program allowing all employees to work remotely half of the time. While she stressed that she was glad that others would also have access to telework, this added insult to injury. With palpable frustration, she said, “I'm like, I just have to look a fool in front of this entire thing. Get this whole fucking gnarly thing, pay $700 out of pocket, get this whole gnarly thing, have my disability read to filth in this whatever, only to find out that everyone else gets this accommodation…I felt very dehumanized through the process overall. Then to feel like it was for nothing…" Over time, however, agency-wide telework policies became less certain, and Parvati was glad that her accommodation remained in place, despite her feelings on navigating the process.

The tension between accommodations and privacy played out in other ways as well. Carla, as a wheelchair user with cerebral palsy, needed an accessible bathroom at work, with a door that could open automatically and a stall with grab bars. After more than a year of job searching after college, with no offers, she was beginning to think that she might never get a job. When she interviewed for a position as a credit counselor at a credit union, things went well, but the biggest sticking point was the bathroom, which had a heavy door that she couldn't open on her own. Without physical renovation, she would have needed someone to wait outside the bathroom to open the door for her, compromising her privacy on a daily basis. Nearly three months after discussing her bathroom needs with a potential employer, she had largely given up on the position when she was told that they had an opening at another branch. There, a previous employee had used a wheelchair as well, and while his needs were not identical to hers, it was close enough to be adapted. After hearing this account, I asked Carla how she felt about discussing bathrooms in a job interview. She said, "I really wish I didn't have to talk about my bathroom habits to HR. I wish that didn't have to be a thing, even among a really accepting workplace, but they need to know." To some extent, she added, making use of PA services throughout much of her life had "not given me access to the traditional modesty or things around privacy that most people would take for granted." Discussing her bathroom needs with an HR department was another manifestation of her limited access to privacy as she doggedly navigated her job search.

Regardless of legal obligations, some employers refuse to make accommodations. Beth, a 44-year-old white trans woman, has chronic regional pain syndrome stemming from a neck injury, as well as myalgic encephalomyelitis (also known as chronic fatigue syndrome, and abbreviated as ME/CFS). An academic, she moved to the Chicago area after earning her doctorate to begin work as an assistant professor. She initially sought accommodations including an ergonomic desk chair with a headrest that would support her neck, and a lightweight laptop computer. She also had a service dog who carried her things in saddlebags, allowing Beth to avoid exacerbating her neck pain. None of these are unusual or particularly costly accommodations. When she met with the team at the university who evaluated accommodation requests, she provided an annotated collection of medical records, with a bulleted summary at the beginning. But members of that team appeared not to believe her, suggesting that based on appearance, she couldn't have the kind of pain she described. While she obtained the chair she needed, she was denied the laptop, and she was told that instead of her service dog, she should bring a rolling suitcase to campus. She ultimately was permitted to bring her service dog, but this began to create conflicts with other faculty; a few insisted on trying to pet or interact with Beth's service animal, while others began bringing in their pet dogs. Eventually, her department chair urged her to stop bringing in her service dog. Alongside the hostility of colleagues, this made working from her office largely untenable.

Because of her ME/CFS, Beth was also dealing with significant fatigue and exhaustion, and asked that her tenure clock be paused due to illness. While she ultimately won this accommodation, she did so only after a months-long process that involved filing a formal grievance, undermining what respite she might have gained from the tenure hold. By the time of her third-year review, she was told that she had not made sufficient progress, and her contract was not renewed. As she recounted this ordeal, Beth stressed that the obstacles she faced seemed to stem not only from ableism, but also from hostility to her as an outspoken trans woman, reflecting one mechanism producing the intersectional marginalization documented by Brooks (2021). Her story speaks to the conditional nature of disabled citizenship at work. Her belonging depended on the support of colleagues and decision-makers, and without that in place, she was pushed out of her job.

“One person can really change the course of your life when you have a disability.”

Beth’s experience reflects a persistent theme across many accounts from many of my informants: the power that management, often a single boss or other supervisor, held over the lives of disabled workers, particularly when seeking accommodations. To point out the power of employers is not novel. Elizabeth Anderson writes that free market ideology obfuscates the ways that workplaces operate as “private governments,” wherein bosses “don’t merely govern workers; they *dominate* them” (2017, xxii, emphasis in original). Eidlin and Uetricht write that most workers in the US “check their deeply held democratic rights at the door every day when they show up for work,” and they locate campaigns for workplace democracy within the history and potential future of labor movements (2018, 1). But discourse on the arbitrary power of employers has paid less attention to their role in facilitating or hindering workplace accommodations. As disabled workers navigate policy in the workplace, they do so within the context of this lopsided power relationship. A good relationship with management can be an essential condition for securing and maintaining accommodations.

Several of my informants gratefully emphasized the support they received from their supervisors. Tanya said that when she lost her hearing, she was “lucky” to be working for a mom and pop pharmacy, rather than a chain, where her boss was willing to work with her as she figured out how to adapt. Parvati emphasized that her boss supported her and understood her frustration with the documentation process. She said, "I think that it helped me to have a supervisor who was like, 'Yes, I get that this is not the language that you would have used, or this is not how you would have talked about it, but just stay on top of this.'" Some informants who had highly accommodating jobs attributed their situations in part to being fortunate enough to have supportive management. After working at the credit union, Carla had found a job at a nonprofit organization where she hadn't had to fight for accommodations, and many of her access needs were treated as standard protocol. Everyone was permitted to work from home, work schedules were flexible, and there was unlimited sick leave. When staff gathered in person for a work retreat, she had an accessible room, and the presence of her PA did not seem to cause any problems. Carla expressed wonderment at her luck in having found such an accommodating workplace, asking "How did I end up here? This is amazing."

But for several workers, maintaining beneficial relationships with supervisors was not simply a matter of luck; they worked at it. Hannah's supervisor and coworkers had supported her in adjusting her schedule, reducing her work hours, and taking time off. But she stressed that she was still perceived as producing high quality work. She also pointed to her long tenure with the organization as a source of credibility, saying, "I worked such crazy hours for so long, and everyone saw it… I think I've built up a lot of goodwill. If, I think, I were just starting at [the organization], it would be really different." Anica expressed more uncertainty in her relationship with her supervisors, but she spoke of a similar dynamic of trying to justify accommodations by working hard and making herself essential. For many years, she said, "I felt like if I'm going to be the person that is going to break every five years and need to take a medical leave so I don't jump off a bridge, then I better be really fucking good so that they think I'm worth disappearing for three months every few years. I don't feel like that's how it should be, but… I'm putting a lot into the piggy bank so that *when I need to ask for this extra accommodation, they feel like I'm worth it*" (emphasis added).

The power of managers to grant accommodations also meant that they could revoke them. When a new executive director took over at the long-term care facility where Janet worked, she lost the accommodation that had permitted her to call in to early morning meetings rather than attending in person. Around the same time, a worker who reported to Janet faced a health crisis that required her to stay seated for a period of roughly six weeks. Janet attempted to make an accommodation, offering this worker the opportunity to fill in for an open secretarial role for that period. But upper-level human resources staff rejected the proposal. During our interview, Janet's voice grew incredulous as she told me how she was told, in writing, that the company was "not in the habit of providing accommodations to anyone who is not currently pregnant." Indignant, drawing both on the organization's religious affiliation and her identity as a preacher's daughter, Janet responded with what she described as a sermon, citing both biblical passages and the ADA, which she sent not only to the HR representative, but her supervisor, the new executive director, and the CEO of the company. She soon found herself facing a disciplinary write-up for a facially unrelated matter, and her supervisor warned her, "You've got a target on your back." After discussing finances with her husband, she gave notice of her resignation.

The arbitrary power of management also shaped Beth's experience. She said, "Even before my hire date, after having been offered the job, I got told that if I needed accommodations," she should be in touch with a specific university office that handled those requests. This was the office that was dismissive of her medical history and skeptical of her reported pain levels. Beth did not demonstrate the kind of cautious deference that Anica showed to her managers, instead asserting what she needed, and pointing out that the people judging her were not specialists in her condition. Her relationship with them deteriorated; she described one member of that team even resorting to name-calling. She later learned that in another department of the university, faculty brought service animals to campus regularly, without problems. But, she said, "they don't ever tell [the accommodation office] because that entire department knows that [the accommodation office] is dangerous." But Beth didn't know that, and without that knowledge to guide her navigation process, she ran afoul of managers who blocked her accommodations, even in an office putatively designed to facilitate them.

The exercise of arbitrary power over disabled lives is not limited to the workplace. The quote at the beginning of this section actually came in response to the actions of a school administrator. Wendy, an 18-year-old white woman with Down Syndrome, worked part time scanning tickets at a sports venue. She enjoyed the job, specifically pointing out that she made the same minimum wage as other workers, rather than the subminimum wages that local law has only recently begun to phase out. But she was also in an ongoing fight with her school district, about providing transition services as she became an adult. After our interview, she allowed me to speak with her mother, who said, "I guess that was the thing we were most surprised at that one person can really change the course of your life when you have a disability. You just need one special ed director that either believes in you or doesn't, and everything either falls apart or goes really well." As I reviewed the interview, I was struck both by the truth of this comment, but also by how much the same dynamic was amplified by the structures of at-will employment and management prerogative that that operate in most US workplaces, generating a form of citizenship for disabled workers that is conditioned on maintaining relationships with decision-makers who can change the course of their lives.

Pushing the bounds of reasonable accommodations?

The promise of reasonable accommodation in the ADA begs the question of what is "reasonable." While there is government guidance on the topic, this is also a fundamentally unstable category with changing definitions. This, in turn, can generate uncertainty for disabled workers seeking accommodations. There may be no better example of this than remote work, which has been the subject of massive shifts in popular conception over the past five years. When many employers began remote operations early in the COVID pandemic, some thought that an increased acceptance of remote work could be, in Schur et al's words, "a 'silver lining' for workers with disabilities" (2020). Using three sources of pre-pandemic survey data, they found that disabled workers were more likely than nondisabled workers to work from home, and they expressed optimism that "employers may find that home-bound workers are a valuable pool for reimagined jobs" (534). But Brooks and von Schrader, comparing 2019 and 2021 data, found that the increase in remote work was greater among workers *without* disabilities than among those with disabilities. They argued that this might be attributed both to employers viewing remote work requests from abled workers more favorably than those from disabled workers, and to occupational segregation that makes disabled workers more likely to hold low-wage jobs that can not be performed remotely (2023).

Many of my informants worked remotely for at least some portion of their work week. Several framed this as a matter of reducing the likelihood of contracting COVID, which posed a high risk to many of them, particularly early in the pandemic. But, in line with other research like the articles cited in the previous paragraph, remote work was also a key accommodation for numerous other reasons. The anecdote that opened this chapter described how working from home made it easier for Rebecca to deal with her dizziness, working while lying down when necessary. Carla said that when she worked from home, she needed “drastically less accommodations because I'm not physically going to a bathroom I can't access.” Maureen said that she hoped to find hybrid or remote work because of “pain and mobility,” as walking long distances could exacerbate her symptoms. Lee, who is autistic, said that working from home at least one day a week was essential; working in a crowded office with lots of noise and activity was draining, making it more difficult for them to cook and take care of themselves when they got home. Remote work was not without its drawbacks, of course. Hannah said that she felt like less of a member of the organization where she worked, recounting a time when she was the only person participating remotely in a three-day senior management retreat. She said, “Remote participation when everyone's in different places is fine and works well, but if everyone is together in a room and you're the only one on a computer, it just falls apart.” Still, she emphasized that remote work had been vital in allowing her to manage her pain and medical care.

But workers could not assume that employers would consider it reasonable to permit them to work remotely. Prior to the pandemic, Rebecca had been denied an accommodation to work part time from home, on the grounds that if she could do so, “other people would want it then.” She chose not to “antagonize” her supervisors by filing a formal ADA complaint. In the current moment, many workers took advantage of the recent expansion in remote work; they worked from home not as a formal accommodation, but because their jobs allowed them to do so. But for some, those arrangements were precarious. Leah knew that management wanted her to come in a couple of days each week, but she said, “That really just doesn't work for me very well. I don't like coming in, I can't do my therapy when I come in. I do better at home." Her consulting firm was in a "transition period" when we spoke, deciding whether to require people to work from the office. Lee was not sure how much they were allowed to work from home, but thus far hadn't run into problems working remotely one day a week. Still, they said, "if I could not work from home at my job one day a week, I would probably quit."

If remote work reflects shifting perceptions of what accommodations might be possible and reasonable, a reduction in work hours seemed to push even further at the limits of what could be asked of an employer. From a Marxian perspective, employers purchase labor power; a worker who can offer fewer hours of labor risks being replaced by one who can work full time. In the opening anecdote, Rebecca expressed her uncertainty over how her employer would receive her request to reduce her hours, saying that it went beyond the limits of "traditional accommodations." Still, she was in a better position than many; her workplace offered short-term disability benefits through a private insurer, which held the potential to cover her lost wages if she were granted the accommodation. Forms of occupational welfare, such as short-term disability and health insurance, were particularly salient for those who would benefit from working fewer hours.

Carol, who was introduced earlier in the chapter in the context of their accommodations as an acupuncture student, had established themselves as a social worker at the time of our interview. They served as clinical director for a small therapy practice and intentionally structured their work in order to accommodate their autism and chronic pain. They said, "I've had a long time to figure out what I can do. I don't work more than 18 hours a week. I don't see more than five clients in a day. I don't see more than three or four in a row because I know what makes me miserable, and I don't want to be miserable." This had financial consequences; Carol had moved each of the past three years in search of affordable housing, because their limited work schedule meant that they earned less money. But as the clinical manager of their practice, Carol was able to structure their work according to their access needs.

Most workers do not have that power in the workplace. For those who would benefit from reduced hours, the main option seemed to be finding part-time work, which can come with its own forms of precarity, particularly because many part-time positions don't provide health insurance. Barbara, a 31-year-old Asian-American woman with ME/CFS, had worked at a nonprofit organization several years earlier, where her full-time position was reduced to 30 hours a week due to funding constraints. This turned out to be beneficial for her, particularly with a supportive supervisor; when her fatigue became intense, she could do things like go home and take a nap in the middle of a workday. Asher felt that working part time would be better for their mental health, but it didn't seem feasible in terms of income. They added that their agency had once allowed people to work 80% time, but management appeared to have withdrawn that policy, even denying it to a coworker who had hoped to ease back into work after being on maternity leave. Alex, a 25-year-old autistic white nonbinary person with bipolar disorder and hypermobility spectrum disorder, was working three part time jobs when we spoke, as a children's dance teacher and a Hebrew School instructor. Even with all three jobs, they worked significantly less than full time. This actually seemed beneficial to their well-being; while Alex had missed many days of work due to mental health issues, they said that they had only called out of work once in each job in the previous two and a half months, which they called "huge for me." But working part time was also not tenable in the long term, particularly given their need for health insurance. Alex said, "Partially what's fueling my depression is that I am really unhappy when I'm working full-time, and you have to work full-time to survive and have health insurance and stuff. I'm about to turn 26 so I'm going to lose my health insurance" under their parents' plan. At the same time, they believed themselves to make too much to qualify for Medicaid, and mustering the executive function to sit down and navigate insurance options under the Affordable Care Act had proven difficult. But in terms of what might be considered an accommodation, they saw reduced hours as "not something that people are open to talking about."

DISCUSSION

Paid work is an essential element of citizenship in the US, both as a means to some measure of economic security and as bestowing a social status, as a worker, shared by full members of the community. For disabled workers, that citizenship is conditional, bracketed not only by the precarity that is fundamental to capitalist wage labor, but also by dilemmas that are specific to disability. Statistics show that more than three decades after the passage of the ADA, many disabled workers are still unemployed. Those who manage to secure employment must navigate a new set of policies if they seek accommodations. To do so demands additional forms of labor as workers learn of their options, weigh and craft their requests, document their disabilities, and nurture their relationships with decision-makers, often by going above and beyond to prove their economic value and moral worth to their employers. This is mentally and emotionally taxing work, and it still provides no guarantee that accommodations will be granted or that, once granted, they will remain in place. Workers can be remarkably creative in their approach to accommodations, even when they do not know their rights under the ADA, making informal arrangements or seeking relief in policies like the FMLA. Nonetheless, making demands of an employer can be an intimidating prospect, and some informants delayed their requests until they had reached a breaking point and were ready to quit if their working conditions couldn't change.

Three themes in this chapter are particularly relevant to understanding disabled citizenship. The first concerns the arbitrary power of employers. Even while the ADA offers formal protections, defining the failure to provide accommodations as a form of discrimination, much depended on an employer's support or hostility. For many of my informants, this worked out well, thanks both to their relationships with supervisors and to the individual bargaining leverage of each worker. But this could not be taken for granted; as Janet learned, an HR representative might even openly declare in an email that they were not in the habit of providing accommodations. A comment from Anica summarizes the situation for many: "In theory, there are protections. In reality, I've been mostly scared to make use of those things." This is one reason why I write that disabled citizenship at work is *conditional*: the effective right to accommodations depends to a large extent not only on workers' willingness and effectiveness in pursuing them, often at considerable risk, but on employers' willingness to grant them.

The second theme is that some accommodations are more easily arranged than others. This is baked into the structure of the ADA, which offers *reasonable* accommodations that don't create "undue hardship" for an employer. But as the shift in attitudes toward remote work shows, conceptions of what is reasonable are matters of social understanding, and they are highly mutable. The example of remote work also highlights the extent to which accommodations can be job-specific; even at the peak of COVID-based work-from-home policies, large numbers of workers, from hospitals to grocery stores, had no remote option. My data made clear that some accommodations were often seen both as more justified and as more feasible than others. For Rebecca's employer, turning on Zoom captions was easy; providing her with a temporary reduction in hours was less certain. Still, a reduced schedule was more feasible for her at a large research organization that offered short-term disability coverage than it was for Alex, who didn't see reduced hours as a realistic accommodation request and who wondered how they would find health insurance while working part time. This is another aspect of conditionality: disabled citizenship at work depends on the type of accommodations that a worker needs, and the way that those accommodations are understood in their workplace.

A third theme, which elucidates the character of policy sedimentation and disabled citizenship broadly, deals with the role of schools in generating navigational capital for some disabled people, introducing them to the concept of accommodations and potentially socializing them to be more comfortable making demands. I had not expected to hear comments from multiple informants comparing their experiences seeking accommodations as students to their experiences as workers. To be clear, many were highly critical of the process of seeking accommodations in school, with several reporting accommodations granted grudgingly if at all. But critics still learned about accommodations in school. This put them in contrast with several informants who had become disabled later in life, who were either initially unfamiliar with the concept of accommodations, or who didn't see themselves as eligible to seek them. I argue that this is fundamentally a matter of the types of the citizenship generated by two different policy contexts. Broadly speaking, schools provide greater disability protections than the workplace, interpellating students into a position where they are more willing to make accommodation demands of the educational system than workers often are of their jobs. But for workers who had accommodations in the classroom as students, their prior experiences may help them to navigate the accommodation-seeking process on the job.

The chapter obviously has limitations. Data is drawn primarily from 28 workers in the Chicago area. As I wrote earlier, the cases tended to be more white and less male than I had hoped, and I intend to address that in future data-gathering. None worked in unionized jobs, eliminating one potential source of support in accommodation-seeking. Notably, the twelve other informants who were out of the workforce, whose comments I discussed briefly earlier in the chapter, included larger proportions of men and people of color. The chapter also focuses on workers who had accommodations, even informally. This was by design; I sought to understand the forms of belonging generated by the ADA's promise of accommodations for workers who had previously faced exclusion from the labor force. But this also means that this chapter may have paid less attention to those who were denied accommodations or didn't seek them, and who either muddled through as best they could or were pushed out of the workforce altogether.

CONCLUSION

Work is central to Marshall's conception of citizenship. Many disabled people continue to face exclusion from the labor force, even with the passage of the ADA and other policies meant to boost disabled employment. Those who are hired and seek workplace accommodations can face a complex and demanding combination of bureaucratic, interpersonal, and practical hurdles. This creates a form of conditional citizenship, with accommodations dependent on the alignment of multiple factors and subject to change. Those who are unable to secure steady work that meets their economic needs may choose to apply for assistance through SSI or SSDI. For the limited number who qualify, this introduces a new set of policies to navigate, to which I turn in the next chapter.

Chapter 3

Disability and Income Support: SSI and SSDI

When I spoke with Jackie, a 58-year-old Black woman with cerebral palsy, she was living in a nursing home on the North Side of Chicago. During our interview, which lasted roughly four and a half hours over the course of two afternoons, she shared stories from many periods of her life in Chicago, beginning with her upbringing in the South Side neighborhood of Englewood. At one point, she told me of a job where she had worked between 1995 and 2000 as a receptionist in the health care industry. She loved the job, where she felt valued as a member of a team that she likened to a family. But due to mismanagement, she was laid off abruptly. At that point, she says, her life "literally fell apart." She was terrified of being evicted, and her finances were so tight that she reached a point of eating a piece of toast and an egg each day. She saw two possible sources of support: unemployment insurance, or Social Security Disability Insurance (SSDI). But to collect unemployment benefits, she had to document that she was seeking work, while for SSDI, she had to prove that she couldn't work. The contradiction fueled her distress, as she recounted,

> "I was really worried, like what if…it looks like on one hand that I'm unemployed looking for work. And the other hand I'm saying I'm not able to work, I have a disability. I was so afraid that it was going to catch up with me, and then I was going to get in trouble and have to pay money back or have a fine or be put in jail or what."

While the dire consequences that Jackie imagined may have been exaggerated, she had insightfully identified the conflicting policy logics between work-oriented systems, including unemployment insurance, and disability-specific income support programs like SSDI and its companion program, Supplemental Security Income (SSI). Together, SSDI and SSI are two of the most important sources of cash assistance to disabled people and their family members in the

US, serving 9.2 million and 7.6 million people respectively in 2021 (Social Security Administration 2022a and 2022b). SSDI, created in 1956, is an earned benefit program that offers disability insurance to those with sufficient work history, paying at rates that are tied to beneficiaries' income levels when they were employed. SSI, created as a federal welfare program in the early 1970s, is open to those with little or no work history. Eligibility for SSI is also conditioned on low income and strict asset limits. While there are exceptions for items like a car and a home, individuals may only have $2000, and couples may only have $3000, to collect SSI benefits, which max out at $943 per month in 2024. SSDI does not impose income or asset limits, and benefits can go as high as $3822/month, but millions of its clients are still poor. According to 2013 data, 19.7% of beneficiaries had family incomes below the federal poverty level, and additional 18.1% had family incomes between 100 and 150% (Bailey and Hemmeter, 2015). A limited number of claimants, whose wages were low enough when they worked that their SSDI benefits still leave them below the relevant income threshold, can also collect SSI as so-called "concurrent" beneficiaries (Social Security Administration 2024)

Both programs restrict eligibility to those who meet a stringent definition of disability, defined in terms of a medically documented inability to work more than a minimal amount, known as Substantial Gainful Activity (SGA). In 2024, this means that most beneficiaries may not earn more than an average of $1550 per month.[1] The process of applying can be onerous and invasive, and some applicants wait years for a final decision (Government Accountability Office, 2020). The duration of the process is partly fueled by applicants who appeal initial denials. Even after appeals, though, one analysis found that 61% of SSI applications were denied, as were 67% of SSDI applications (Center on Budget and Policy Priorities, 2023a and 2023b). Once

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[1] The SGA threshold for those who qualify because they are blind is $2950/month.

approved, many beneficiaries are subject to periodic Continuing Disability Reviews to document that their disabilities continue to prevent them from working, and they must also ensure that they do not run afoul of program rules by, for example, working beyond the SGA threshold. At the same time, they may be invited to take part in a host of "work incentive" programs designed to transition beneficiaries back into the workforce, sending conflicting messages around their place in the labor force.

These are, in short, complex programs. This chapter asks how beneficiaries experience SSI and SSDI, how the programs' approach to disability fits or conflicts with beneficiaries' daily lives and material needs, and what sort of disabled citizenship this produces. I find that for beneficiaries, program rules are often unclear, leaving many in fear of losing crucial supports upon which they rely. The differences between SSDI, as an earned benefit program, and SSI, as a welfare program, seem to blur in the face of a shared approach to disability and a common administrative apparatus. In the face of this uncertainty, those receiving SSI and SSDI perform stressful administrative labor in managing their benefits while also making ends meet and maintaining basic health and well-being in the context of disability. I argue that the ongoing work of applying, interpreting and understanding program rules, performing paid work where desired and possible, and negotiating conflicting policy logics constitute a process of *policy navigation from below*.

Identifying this process has sharp implications for the understanding of disabled citizenship. In her foundational 1984 book *The Disabled State*, Deborah Stone argues that a key "innovation of the modern welfare state" lay in what she calls the "categorical resolution" to dilemmas of resource distribution, whereby the creation of concepts such as disability allowed for the provision of social assistance "to categories of citizens without having to define them as lesser citizens" (24). But forty years later, the accounts of SSI and SSDI beneficiaries reveal a form of *precarious citizenship*, marked by the conflicting meanings embedded within disability as a category, that indeed produces a lesser form of belonging. Beneficiaries struggle to get by, often supplementing benefits with other social programs and/or limited work. The complexity of program rules leaves beneficiaries unsure how Social Security Administration (SSA) decisions are made. Many devote considerable mental energy to ensuring that they do not violate program rules, so as not to jeopardize the benefits on which they depend. But even if a beneficiary makes no mistakes, they may learn that they were overpaid by SSA, resulting in painful clawbacks. The opaque rules and looming threat of benefit loss contribute to a pervasive sense of precarity.

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. 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). But TANF stands apart from SSI and SSDI in several ways, not least in orientation toward work. Related literature on administrative burden (Herd & Moynihan, 2018) shines an important light on the costs that different programs impose on beneficiaries, but it has less to say about the work that beneficiaries do to manage those costs. Administrative burden literature has also paid limited attention to disability benefits than to other government programs. This chapter thus addresses multiple gaps, with a client-centered view of SSDI and SSI that emphasizes how clients actively navigate these programs, situated within the concepts of rights and belonging that constitute citizenship.

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 situate applicants and beneficiaries within social systems, hierarchies, and categories of belonging. This process can promote social solidarity; Marshall, for instance, wrote of the "common experience" of going "to collect children's allowances or pensions from the post office" (1950, 56). Sykes et al point to similar dynamics of social inclusion among low-income workers collecting the Earned Income Tax Credit, (EITC) which they obtained through tax preparation agencies as customers, an experience that one beneficiary celebrated as a chance to be "side by side with all the other hardworking taxpayers" (2015, 258).

But social provision can also make clear who is not a full citizen. Marshall presents the 1834 British Poor Law as a case where social rights were provided, in minimal form, without citizenship. Paupers who entered the workhouse "forfeited in practice the civil right of personal liberty" and thereby suffered political disenfranchisement (1950, 24). And while Marshall, writing in post-World War II Britain, foresaw a new era of social citizenship, US policy has unfolded along a drastically different path. Many scholars have argued that the New Deal heralded a dual or "two-track" welfare system. So-called "earned benefit" programs, such as Social Security retirement, were valorized as entitlements, while "welfare" programs, such as Aid to Families with Dependent Children (AFDC), were stigmatized, with the Social Security Board actively working to sharpen the contrast between the two programs (Fraser and Gordon 1994, Cates 1983). Building directly on Marshall's approach to citizenship, Chad Alan Goldberg

(2007) points out that in the US, the stigma attached to welfare programs continued to diminish the citizenship status of beneficiaries, much like poor relief of earlier eras.

Considerable literature on US cash assistance programs underscores this argument. 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 (1993, 165-173). In their study of low-income mothers 30 years later, Edin and Lein found similar attitudes toward AFDC. Though their main wages covered only about two thirds of most informants' expenses, many still 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).

One function of such degrading experiences, along with low welfare benefit levels, has been to push poor people into the low-wage labor market. As Temporary Assistance to Needy Families (TANF) replaced AFDC, 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). Brodkin'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. As neoliberal work-first logics grew entrenched, Tach and Edin argued that public assistance should now be understood primarily as a set of work-based programs (2017).

SSI and SSDI stand, in large part, as exceptions to that work-oriented logic. As mentioned earlier, 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 draws on a deeply rooted understanding of disability as fundamentally placing people outside the labor force, an ideology that is essential to the form of disabled citizenship produced by these programs. 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).

But this insulation from the logic of work is inconsistent. A March 1982 article in the *Disability Rag*, the grassroots activist periodical, pointed out that SSI and SSDI existed alongside vocational rehabilitation programs that sought to return people to the workforce, writing, "You would think, at least America is consistent—America believes disabled people can't work. But this isn't true either. The truth is that American's OTHER official program targeted at us disabled people [vocational rehabilitation] says we all have to be able to work, ultimately" (1982, 3). These questions are further complicated by newer policies that seek to encourage beneficiaries to work. One of the most significant such programs came about in 1999, when Congress passed the Ticket to Work and Work Incentives Improvement Act (TTWIIA), which sought to create more options for beneficiaries seeking to return to work (Social Security Administration, n.d.a). Through Ticket To Work and other work incentive programs, people already receiving SSI or SSDI can maintain their Medicaid or Medicare benefits while returning to work, as discussed in the previous chapter. Some participants can also maintain their cash benefits for a period, even if they earn more than SGA. The program also enables beneficiaries to work with vocational rehabilitation services to explore employment options, and it offers a process of "expedited reinstatement" of SSI or SSDI payments for those who attempt to return to the workforce and lose their benefits but find that they are unable to maintain paid employment (Social Security Administration, n.d.b).

Documents from the period when the bill was passed, as well as Susan Prokop's first-person recollections of the process, show that Ticket To Work reflected a fusion between the disability rights movement's ongoing demand for social inclusion, including access to the workplace, and the neoliberal welfare-to-work logics of the 1990s. President Clinton signed TTWIIA in a public ceremony at the Franklin Delano Roosevelt Memorial, where he highlighted Roosevelt's use of a wheelchair. He simultaneously called for inclusion and presented the bill as a reduction in the welfare state, saying "It doesn't make sense for people to be denied the dignity of work and for the taxpayers to pay the bills" (White House, 1999). An advocate who helped to pass the bill framed it as liberatory, saying in an interview soon after it passed, "The disability community has learned what the other civil rights movements have learned--that a person is not truly free unless they have economic independence" through policies that allow them to work without losing necessary supports like health insurance (National Industries for the Severely Handicapped, 2000).

Despite these lofty goals, the programs have been constrained by their cost-cutting logics, with limited funding for the services that promised employment. As examples of policy sedimentation, these work incentive programs sit awkwardly across the basic logic of SSI and SSDI, emphasizing work in the context of programs premised on a putative inability to work. This is another example of the uneven and internally contradictory nature of disabled citizenship. As they attempt to navigate this treacherous policy terrain, beneficiaries spend months or years documenting their inability to work in order to obtain benefits in the first place, but then find themselves subsequently urged to return to work by program administrators.

I ask in this chapter how beneficiaries experience these programs, including their contradictory logics. As I wrote in the introductory chapter, I initially approached this question by applying the concept of administrative burden. But while applying for SSDI and SSI is unquestionably burdensome, the academic literature on administrative burden has paid less attention to SSI and SSDI than it has to other 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 in stark contrast to SSI and SSDI’s complex 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. It may be that these complex policies do not easily lend themselves to the straightforward calculation of costs. There may also be limited policy levers by which to reduce these costs, particularly without greater funding for SSA personnel or significant changes to program rules.

Instead, I approach the policies through the active framework of *policy navigation from below*. In relation to SSI and SSDI, I define policy navigation from below as the active labor performed by beneficiaries to achieve and maintain eligibility for complex programs while also addressing their material needs. The process involves interpreting and understanding program rules, navigating conflicting policy logics, and at times performing paid work where possible. This framework acknowledges that programs like SSI and SSDI are built on multiple layers of complexity. This begins with the simple fact that two distinct programs have similar names, leading some beneficiaries to be uncertain which they received. On top of this are complicated 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 different work incentive programs, and access to health insurance that varies by program (and for SSI beneficiaries seeking Medicaid, 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. The Social Security Administration itself may also make mistakes, overpaying beneficiaries and then informing them that they must repay large sums, often by having subsequent benefits withheld in a “clawback” process that even the SSA Commissioner has described as “cold-hearted” and promised to address (Government Accountability Office 2021, 2023; Classen-Kelly, 2024). It is thus no surprise that beneficiaries fear the loss of benefits on which they depend. By exploring how beneficiaries navigate SSI and SSDI policy from below, this chapter offers insight on how clients understand the program and their disabilities, how they navigate complex program rules, and the precarious citizenship that is generated by this set of programs.

DATA SOURCES

Data in this chapter is drawn primarily from 23 in-depth, semi-structured interviews with disabled people in greater Chicago who had direct experience of Social Security disability programs as beneficiaries or applicants. I set out to recruit interview subjects in the Chicago area who received SSI or SSDI. I interviewed 18 current beneficiaries of SSA disability programs. These included eight receiving SSI, seven receiving SSDI, two with dual eligibility collecting benefits from both programs, and one collecting benefits as a disabled adult survivor of a Social Security beneficiary. Two more had received SSI as children and/or during their college years, but they had since left the program and were working full time when we spoke. Another had received SSI for a period as an adult, but he had lost it when he went to work and his earnings exceeded the SGA threshold. When we spoke, he was no longer working, but he had not been able to get back on SSI. Another two interview subjects had applied for benefits but not received them. One of these two was still waiting for a decision after close to a year, while the other had applied unsuccessfully on two occasions, with one application generating a follow-up phone call but then appearing to be lost, and their other application never receiving a reply. I also interviewed a 24th 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, for reasons that suggested possible cognitive psychological issues. In the interest of accuracy, I have excluded her comments from this chapter. Finally, data from several other interviewees who considered the programs but did not pursue them add depth to the analysis.

Of the 23 main respondents, twelve lived in the city of Chicago, and eleven were in the suburbs. Thirteen identified as white, six as Black, three as Latinx, and one as Asian American. Eight were men, twelve were women, and three were nonbinary. Ages ranged from 18 to 65, with one in her teens, three in their twenties, eight in their thirties, one in his forties, five in their fifties, and five in their sixties. They had a range of disabilities that impacted mobility, mental health, speech, hearing, vision, and other aspects of life. Eleven used wheelchairs, and six others used canes, walkers, or similar mobility devices. At the time of our interviews, four lived in nursing homes, two lived in an assisted living facility, while the remainder lived in the community in various arrangements.

In addition to interviews, I also draw on my observations of discussions, primarily on Zoom, among members of the Nursing Home Emergency Response Group (NHERG), particularly in weekly residents' meetings. While I initially approached the group with an eye toward other parts of this project, I soon learned that questions around Social Security benefits for those in facilities were not uncommon. The topic might arise by chance, as when one member asked whether his assisted living facility was entitled to a portion of his recent SSI backpay award, or with formal planning, as when Social Security disability programs were the topic of a weekly training series on financial literacy.

FINDINGS

Contrary to popular images of beneficiaries as passive recipients of aid, most SSI and SSDI clients I interviewed 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 characterized the precarious citizenship produced by these programs. Choices that may appear from the perspective of outside observers to fail to take advantage of programs and policy opportunities, were reasonable strategies for dealing with uncertainty and managing confusing and complex programs. Together, these actions constitute a form of policy navigation from below. In the pages that follow, I share key aspects of how this process plays out.

The application process

The process of navigating SSI and SSDI arguably begins in earnest when one applies. As mentioned earlier, studies show that a majority of applications for both programs are denied, even when accounting for appeals. Because I sought to focus on the experiences of beneficiaries, my data reflects an element of survivorship bias. But my informants still painted a picture of a complex and opaque determination process. There is a pervasive understanding that benefits are hard to obtain; one informant who was approved for SSDI without difficulty described herself as "probably the luckiest disabled person you're going to meet." Most beneficiaries fell into three overlapping categories: those who had assistance from an expert or advocate, those who had extensive documentation that facilitated their applications, and those who faced invasive and difficult application processes. All three categories attest to the onerous work of even accessing these programs, and to the fundamental precarity of this form of disabled citizenship.

Jason, a 50-year-old Black man, collected both SSI and SSDI after falling down a set of stairs and becoming quadriplegic. After his injury, he spent an extended period in a well-respected Chicago rehabilitation hospital, where a social worker applied on his behalf. He understood the process to have been relatively simple, saying, "They immediately approved me because I was there, and it was obvious that I had an injury or whatever." Steve, a 37-year-old white man, had spent time in the same rehab hospital after having surgery for a brain tumor. When I asked about the process of applying, he also spoke of staff handling the process, saying that he had been "pretty out of it" at the time. Others pointed to the assistance of outside programs. Julio, a 61-year-old Latino man, has severe arthritis in his knees and hips, as well as severe depression. Having been in the homeless shelter system, he was able to access assistance from a caseworker at a local Center for Independent Living who worked through SOAR, a federal initiative designed to assist those who are homeless or at risk of homelessness (Substance Abuse and Mental Health Services Administration, n.d.). In all of these cases, the work of navigation was led by experts. The very existence of a specialized form of advocacy focused on these programs testifies to the complexity of SSI and SSDI.

The second group was able to access the program thanks to their own extensive record-keeping. Carla, a 26-year-old autistic white wheelchair-using woman with cerebral palsy, chronic pain, and other disabilities whose job search I discussed in the previous chapter, applied for SSI after turning 18. While she hadn't qualified as a child due to her parents' income, she pursued benefits as a legal adult so that she could start covering some of her own expenses, and because she was not sure if she would ultimately be able to secure full employment. Her pediatrician, a physical therapist with whom she had worked since childhood, and those she called “my high school team” from her suburban school district all attested in writing that she could qualify for benefits. With such documentation, she was approved in four to six months. Jackie, introduced at the start of this chapter, focused in our interview on the second time she successfully applied for SSDI, which came after abruptly losing her job. She said that because she had worked successfully for several years, she was initially rebuffed when she went to the Social Security office. But she had carefully kept records from her previous period of benefit receipt, recounting to me confidently, “I had a whole file. I never threw Social Security papers away.” She was also able to find an advocate, whose name she still remembered, to assist with her application. Between the documentation and the advocate, she was able to get SSDI within about a month. Despite successfully navigating the process, Jackie said that she “hated” applying, but she “had no choice.” When I asked what she hated about it, she replied, “The stigma. Another Black woman in public housing on Social Security.”

Jackie’s negative feelings toward the process were amplified by those who described a frustrating and invasive application process. Shana, a 38-year-old white woman with various physical and mental disabilities, told me of applying for SSI roughly ten years earlier. She was in a semi-formal transitional living program, where residents were urged to apply for benefits in order to pay their rent. She described the process of filling out her application as “grueling,” saying, “I didn’t know whether what I was answering was, like, right.” She figured that she should use medical terminology to describe her condition, but didn’t know the appropriate language, grasping at terms she did know like “morbidly obese.” She added, “It was just page after page of asking about what does this feel like? Can you do this? Does this hurt?” Some questions offered binary yes/no choices, while others asked her to rate her answers on a scale. After three to four months of "hoping and praying," she was ultimately approved.

In contrast, Wendy, an 18-year-old white woman with Down syndrome, was still in the midst of her application process about ten months after it started. She and her mother, with whom she allowed me to speak about some of the details of the process, recounted how Wendy had applied for SSI soon after turning 18. But while she, like Carla, had extensive documentation of her medical needs as well as a clear diagnosis, she had run into multiple roadblocks, even with her family supporting her application process. An initial appointment was in the wrong division, delaying the start of her case. Although she and her family understood Down syndrome to be an automatically qualifying condition, the Social Security Administration acted as if this wasn't the case. "Finally," Wendy's mother said, "I just made a copy of their own manual and sent that in." Then a trust, which her parents had carefully set up with a lawyer so that it would not impact her eligibility, was viewed as an asset that disqualified her from receiving benefits. When we spoke, it had been nearly ten months since Wendy's initial application, and it was still not clear if she would be approved.

Jean, a white 24-year-old legally blind nonbinary person with cerebral palsy, arthritis, fibromyalgia, and mental health issues, had collected SSI as a child but found the experience of re-applying as an 18-year-old extremely invasive. Their visit to the Social Security Administration involved physical tests of their range of motion, along with endurance tests of whether and how far they could walk. Jean was asked to verify that they were indeed wearing braces by showing them to the evaluator, who seemed to view them with suspicion because they were so old—which Jean explained to me was not a matter of faking a condition, but of their insurance not approving new ones. As the examination continued, Jean said, "it was so invasive that they had me show them the scarring from surgeries that I had." On top of these intrusions, Jean faced questions that were difficult to answer because of the variability of their chronic conditions. For instance, when asked about how far they could walk, they said, "I might be able to walk that distance, but not for work every day. I'd be exhausted by the time I got to work." I heard similarly from other informants, that such questions essentially compelled them to describe how things played out on their worst day, even when that led to presenting themselves in a way that felt demoralizing or inaccurate. When one's condition is inconsistent, making employment prospects similarly inconsistent, there is a compelling logic to presenting the most severe situation when navigating the application process, lest one be left in an even more precarious situation if a disability becomes more severe. "As long as I can get SSI and they'll give it to me," Jean said," at least I know I have an income and I'm not on the street."

A two-track welfare state?

A powerful framework for understanding US social provision understands there to be what Fraser and Gordon call a "two-track welfare system," bifurcated between earned benefit programs and so-called welfare programs. The former, like Social Security retirement benefits, are valorized and built on the premise "that beneficiaries merely [get] back what they put in." The latter, like AFDC and TANF, are stigmatized, gendered as female, racialized as non-white, means-tested, and continue "the private charity tradition of searching out the deserving few among the many chiselers" (1994, 321). Under this framework, we would expect beneficiaries' experiences of SSDI and SSI, particularly after they have been approved, to be markedly different. SSDI is an earned benefit, while SSI is a means-tested welfare program. And indeed, such assumptions have informed past research; Joe Soss, for instance, compared SSDI and AFDC (a welfare program like SSI) in a study of how government programs shaped beneficiaries' beliefs about the efficacy of political participation. He found that that SSDI clients were more likely to believe that they could influence government (1999).

But for many of my informants, there was not a clear distinction between the two programs. Indeed, some were unsure whether they collected benefits from SSI or SSDI. Rhonda, a Black woman with lupus in her mid-50s living in a Chicago nursing home, told me 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.

Her uncertainty was not unique. Carmen, a 38-year-old Latina woman in a Chicago suburb who used a wheelchair due to cerebral palsy, said, "I am on Social Security disability. I don't know how you would identify it as SSI or SSDI. I always have an issue discerning the two or distinguishing the two as far as what's the difference between one or the other." Maureen, a 32-year-old white nonbinary person in Chicago with both physical and psychological disabilities, had applied unsuccessfully for benefits using the Social Security Administration's website. But they were not sure which program they had applied for, saying, "I would've chosen [which program to apply for] based on sitting on their website and looking at the difference, and I don't remember what it was." Caitlin, a 27-year-old white woman with osteogenesis imperfecta who lived in one of Chicago's suburban counties, had indicated on her screening form that she received SSI and SSDI. She didn't know details of the program through which she collected benefits, and she suggested at one point that it might have to do with her father's military service. It ultimately became clear, as we spoke, that she actually collected benefits as a disabled adult survivor of a Social Security beneficiary.

Such uncertainty was not universal. Some beneficiaries were consistent in describing which program they were enrolled in. Joanne, an SSI client, spoke of being looked down on by other disabled people who collected SSDI, adding "SSDI is disability. SSI is welfare." But a two-track welfare state framework suggests that the distinction between an earned benefit program and a welfare program would be much more consistently understood and felt by those who depend on the policies. To my surprise, my informants suggested that the distinction was not nearly as clear as the two-track framework would predict.

The confusion points to structural factors that blur the distinction. Unlike Fraser and Gordon's contrast between retirement and AFDC, SSDI and SSI are both administered through the same agency, with complex rules and even similar names. Both operate in the context of ableism and stigma, subjecting clients to the same lengthy application and disability determination process, which seeks to screen out those who are not truly deserving. The suspicion of cheating is amplified, for both programs, by periodic media stories about "startling" trends in disability program enrollment and how beneficiaries allegedly "game" the system (e.g., Roy 2013, Joffe-Walt 2013). SSI and SSDI thus serve to complicate the dichotomy between earned benefits and welfare, suggesting that disabled citizenship is precarious even for those whose SSDI benefits are theoretically based on getting back what they put into the system when working.

"I don't know how government things work."

As Caitlin and I discussed the uncertain source of her benefits, she said flatly, "I don't know how government things work." Caitlin is not uneducated; she had 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 view of government as opaque and monolithic was not unique. Now that Jason was managing his benefits on his own, he also expressed frustration with, “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.”

Gabriela linked this sense of opacity to her interactions with multiple government agencies, including the Medicaid coverage alongside her SSI receipt. She said, “The system is so complicated. It's like a big suit with many pockets and the money just comes and goes out of different pockets, so it's so hard to keep up with.” She soon repeated the metaphor of a suit with many pockets, adding, “You end up going to so many different offices trying to get an answer on just one question, and you end up talking to 20 different people and that question that you asked was never answered or you get 20 different answers not knowing which one was the right one.”

Up until a few years before our interview, Carmen’s father had served as her representative payee, and she told me of a visit to the Social Security office for a Continuing Disability Review in 2019. During the meeting, to Carmen’s shock, the agency representative directed questions to her father, rather than to her, even though Carmen was more than capable of answering. She called the experience “very dehumanizing,” and added that she decided during that appointment to transition to serving as her own payee, so that she wouldn’t have to go through it again. But that, too, ran into bureaucratic obstacles. She had questions and called Social Security frequently, but she found that if she didn’t call early in the day, she faced extraordinarily long wait times, adding, “I actually ended up hanging up a couple of times simply because I was exhausted, or hungry, or had to go to the bathroom and didn't want to wait on hold." When she did reach a worker, she had to wade through conflicting guidance from semi-anonymous SSA representatives. She said, "They [SSA phone line workers] don't give you a last name. They give you a first name…How am I supposed to reference that back to someone else who's telling me something different?" Her experiences echo the degrading treatment reported in studies of other income support programs such as AFDC, as discussed in the background section of this chapter. The inaccessibility of support from the phone center, where anonymous workers offered inconsistent advice with no means of referring back for clarification, underscore the uncertainty and precarity under which she was forced to operate.

Some were able to navigate the programs relatively successfully even when program rules were unclear. Sarah, a white woman in her mid-50s with depression and cerebral palsy, collected SSDI, and explained to me that SSDI clients could work a limited amount, while SSI beneficiaries could not. This was incorrect, as those on SSI can also work below the SGA threshold. But the misconception had little bearing on Sarah's day-to-day life. For others, though, unclear rules could create major crises. Carla had been collecting SSI for about three years as a college student when the Social Security Administration informed her that they had overpaid her by $4000, which she now owed. As mentioned previously, overpayments are an ongoing issue in both SSI and SSDI. For Carla, nothing had changed in her income or living situation, but after three years of living primarily in her dorm, she was suddenly reclassified as receiving in-kind support from her parents, which reduced her benefits retroactively. She told me of crying during her internship at a Center for Independent Living. Colleagues there were sympathetic and seemed unsurprised, saying "Man, that sucks, I hate SSI." She consulted with a lawyer, who advised her that she might not be able to win a case, and so she reluctantly set up a payment plan, accepting a reduced monthly benefit. But that, too, ultimately ran into problems when she was told that she had to pay back the full amount or risk a negative mark on her credit report. Throughout this process, Carla tried in vain to get clear information from the Social Security Administration. But despite her social capital as a college student interning at a disability organization, she hit bureaucratic walls. Like Carmen, she received conflicting information from whichever agency representative answered a call. She said, “There was a lot of like, you talk to person A and get one answer, you talk to person B and get a completely different answer. No one knows, there's no paperwork, there's no written policy, there's no guidance…. I kept a written record of what I could, but sometimes people wouldn't give you their names. Sometimes people would hang up on me.”

Laurel also spoke of the difficulty of getting consistent information from within the program bureaucracy. 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.” Like Carla, 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.” For beneficiaries like Carla and Laurel, opaque administration had very real consequences, creating a deeply felt sense of precarity around their benefits. Even for those who didn’t personally experience overpayments or abrupt benefit cuts, stories of it happening to others could help to spread the perception of insecurity, contributing to the broad experience of precarious citizenship.

"Don't poke the bear."

Laurel developed a strategy for dealing with uncertain instructions and the fear of loss of benefits. She summed 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 for a disabled home ownership tax deduction. But despite having owned property with her spouse 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." This decision to forgo a possible benefit reflects not only the tensions of policy navigation from below, but a fundamental aspect of this precarious form of disabled citizenship, characterized by a fear that making claims on the state can backfire, and so it may be wiser to stay quiet and avoid calling attention to oneself.

While the term is Laurel's, the concept of not poking the bear is a key part of policy navigation from below, and it was echoed in many informants' accounts of their interactions (and non-interactions) with government. 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 in 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, collects SSDI while working part time in childcare in a Chicago suburb. Shortly before we spoke, her employer decided to give $2000 bonuses to employees. In response, fearing for her benefits, Sarah asked her employer, "Miss Amanda,[2] 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, so great was her fear that it would draw the proverbial bear’s attention and put her at risk.

“There’s a chance I can still do a little better than poverty.”

If some beneficiaries are disciplined into not poking the bear while they collect benefits, other disabled people avoid the programs altogether due to their stringency. In addition to the 23 beneficiaries and applicants who are the focus of this chapter, I also asked other interview

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[2] The name of the employer here is a pseudonym, but Sarah used this mode of address, to “Miss [first name].”

subjects about their familiarity with SSI and SSDI and whether they had considered applying. Several said that they had considered it, but chose not to, feeling that they wouldn't qualify. Such reactions reflect the intentional policy architecture of the programs. As I wrote in Chapter 1, policymakers who crafted SSDI as the first Social Security disability program intentionally designed narrow criteria, tied to putatively objective medical judgement, in order to screen out those who they wouldn't deem truly so disabled as to deserve public assistance. Some of my informants who had considered the programs also felt that even if they could qualify, program rules would be too restrictive. This, too, is by design, with long historical precedents. English Poor Law of 1834 sought to deter paupers from seeking relief through the application of the "principle of least eligibility," which stipulated that the conditions of the workhouse were required to be less appealing than "the situation of the independent laborer of the lowest class" (Stone 1984, 39). In their assessment of social provision in the US, Piven and Cloward argue that outside of periods of social upheaval, assistance to those deemed "without economic utility," among whom they count the disabled and "insane," is delivered in such degraded conditions that the worst employment would seem preferable (1993, 33).

Comments from various interview subjects indicated that the conditions of SSI and SSDI had successfully deterred them from pursuing benefits. Lee, an autistic white 23-year-old nonbinary person introduced in the previous chapter, told me of their experience working at a full-time office job the summer after graduating college. While Lee had worked in other capacities before, aspects of the office environment were a difficult fit with their autism. Feeling the strain, knowing of other autistic people who were burned out, they wondered if they could manage fulltime work for the rest of their life, thinking "That's going to make me so miserable and so unhealthy." So they looked into SSI, which a close friend received. But Lee quickly decided that it wasn't an option, saying, "Not only would I have to be navigating this very scary bureaucracy with big boy consequences…if I were to misstep," but they would also have to give up things they enjoyed in order to meet income guidelines. Carol, a white 43-year-old nonbinary social worker with physical and mental disabilities who was also introduced in Chapter 2, recounted how, roughly ten years earlier, they had lost a job at a marijuana dispensary, in part due to its failure to provide accommodations. In the wake of that, they said, "I was like, 'Oh, should I just fucking suck it up, and get a lawyer, and apply for SSDI?' But then I was like, 'I don't want to be in poverty forever, and…there's a chance I can still do a little better than poverty.'" In addition to being deterred by the poverty-level benefits, Carol was wary of the requirement to limit their work to stay below the SGA threshold, saying, "I think I would be very bored if I were on disability."

Tanya, a white 37-year-old woman introduced earlier who abruptly became Deaf in her mid-20s, looked into applying for disability benefits when she lost her hearing. 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 based on 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."

Barbara, a 31-year-old Asian-American woman with myalgic encephalitis/chronic fatigue syndrome (ME/CFS) exacerbated by long COVID, was also introduced in the previous chapter.

Like others, she had observed through friends that Social Security means-testing and continuing review created an "incredibly dehumanizing" process that, she said, "I don't really want to go through." When we spoke, she had recently completed a master's degree in social work, and she hoped to find a job that could accommodate her disability. Still, she noted, if securing work didn't seem feasible, "then I'll need to explore the Social Security stuff."

Beneficiaries struggle to balance paid work with program rules

For those who collect benefits, a fundamental premise of SSI and SSDI understands beneficiaries to be situated outside of the labor market. Deborah Stone 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" (1984, 21). Work that falls below the Substantial Gainful Activity threshold is treated as incidental and of limited significance. But for multiple informants, work still played an important role in their lives, both as a source of income and a meaningful activity. Even for some who had been out of the labor force, the desire to work was still present. When we spoke in 2022, Jason had not worked since becoming quadriplegic in 2014. He 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."[3]

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[3] 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.

Few 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. The conflict between work and the rules of SSI and SSDI is a key example of the contradictory nature of policy sedimentation, and the uneven terrain of disabled citizenship that it produces. To navigate this treacherous ground, disabled people must step between clashing logics, ensuring that their efforts to make ends meet, and to pursue meaningful work, do not turn out to undermine the benefits they rely upon. This can take the form of quotidian monitoring of income to ensure that one is not going over SGA, and of feeling that one must perform an ongoing balancing act. It can also involve the frustration of feeling stuck between contradictory policies, as Jackie recounted in the opening to this chapter and as other share in the following pages.

Multiple informants described keeping careful track of their income to ensure that they didn't go over SGA. Sarah's attempt to decline a $2000 bonus is arguably an extreme example of this. Alice, a 65-year-old white woman, 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 at the time 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. Laurel, who has a higher SGA threshold than many because she collects SSDI for blindness, 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." Lee, within the first minutes of our interview, explained that "Even though technically through SSI, you can work and have X amount of income," they still needed to account for eligibility thresholds not only for SSI, but for other programs like housing assistance. Lee added, "It's a very tedious balance of what you can and can't do as a disabled person needing money." In order to strike that tedious and precarious balance, each informant was navigating policy as best they could.

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, many knew that they might not be able to secure and maintain long-term employment. This leaves people in a double bind. Steve, a 37-year-old white man introduced in Chapter 2, had expected to work as a contractor before becoming disabled due to a brain tumor. When we spoke, he was actively trying to find steady employment, but with limited success. With his voice conveying his irritation with the situation, he 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." But as a wheelchair user whose disability also impacted his speech, he had not been able to secure the job he desired. As discussed in the previous chapter, he was far from alone in finding employers unwilling to hire him as a disabled worker. But it left him feeling stuck.

Laurel, while continuing to work as much as she could, 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." Sarah spoke poignantly of feeling caught between programs, saying, "It's like they keep us in a box…I can't make more money and I have to be the way I am." When I probed into what she meant by "the way I am," she spoke of her medical needs and the importance of health insurance. She 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. Sarah makes minimum wage, and while she takes pride in her work, she says that her employer liked her because she is "cheap." She tracked her hours at home, and at times, in order to keep below the SGA threshold, she didn't record all the hours she worked in a day, leaving her literally working for free. The fear of violating program rules, as well as the pressure to work when her employer needed her, placed her in a profoundly exploitative box.

Work incentive programs undermine themselves

As discussed at the beginning of this chapter, programs like Ticket To Work sought to facilitate access to the labor force for SSI and SSDI beneficiaries. The 1999 passage of the Ticket To Work and Work Incentives Improvement Act (TTWIIA) constituted a key episode of policy sedimentation. The basic structure of SSI and SSDI remained in place, but policymakers added new programs to them. This reflected two shifts in popular thinking: changing assumptions around the capacity of disabled people to work, and decreasing acceptance of income support amidst the neoliberal restructuring of safety net programs in the 1990s. Susan Prokop, the policy expert with whom I spoke, recalled the discussions as the legislation was crafted. She told me that there had been proposals of a so-called "options program," which could have served potential beneficiaries outside the framework of SSI or SSDI. But ultimately, Ticket to Work was directed at those who were already receiving disability benefits. This created a conundrum, in her words: "Here, people have fought and battled, sometimes for years, to try to get on disability benefits. They're on benefits and they get sent a letter saying, 'Congratulations, here's your ticket to go back to work.'" But while acknowledging those conflicting logics, she said that there did not seem to be a way around them. In her assessment, "there was no way to overcome that. If this was going to be a Social Security disability work incentive, it had to be offered to the people who were on Social Security." A key promise of such programs, listed first in some policy documents from the time, was to allow continued access to Medicare and Medicaid for beneficiaries who went to work, in hopes of avoiding dilemmas like the one Sarah faced when she considered leaving SSDI. There were also other affordances and resources, including connections to vocational rehabilitation services that can, in theory, assist beneficiaries in securing employment. But a wide gap remains between what the programs promise, and the reality of securing steady employment as a person whose disability is so impactful that they have managed to qualify for SSI or SSDI.

To pursue Ticket To Work is to take on another dimension of policy navigation from below. One must attempt to traverse across uneven layers of conflicting policy while engaging the intricacies of complex programs. While many of my informants had heard of the work incentives, some weren't sure exactly how they worked. Shana had heard of Ticket To Work, but she quickly said that she didn't know enough about it, saying, "I know it's out there, but I don't know what I would need to do in order to get it." She added, "I feel [these programs are] very mysterious and they're not very well explained, and they're always very much clouded with, 'Oh, come and see us and we'll explain more.'" Laurel, as discussed earlier in this chapter, was already working, and Ticket To Work might have helped her to ensure that her earnings didn't threaten her benefits. As mentioned earlier, that was not a theoretical fear for her, as she had lost benefits for several months not long before we spoke. But she explained that while she had received information about the program in the mail, and had received a phone call about it, "Again, no one tells me the same information twice." In the end, she "never made sense out of it." So while she may have been an ideal candidate for the program, she didn't apply, sticking to her strategy of not poking the bear.

Raúl, a 39-year-old Latinx man with multiple disabilities who collects SSI, was active in Chicago's disabled communities when we spoke, and he was familiar with workplace accommodations and services. But he hadn't been nearly as familiar with them years earlier, when he had participated in Ticket to Work. His efforts in that period to find work in low-wage service industry jobs had not lasted long; he guessed that his longest tenure was a six-month stint at Burger King. Thinking back, 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 added, "I wish I would've waited and not given my Ticket to that employer back then. I wish I would have waited 'til now. Back then I did not understand the job I was doing." Without clear information on what Ticket to Work could provide, he was not in a position to navigate it successfully.

Steve had found a rehab counselor through Ticket to Work who he liked very much. But she left the position, and he was transferred to a new counselor who, he said, "basically doesn't want to do anything." So 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." When we spoke, he was in the process of trying to switch to yet another a new service provider. The impression that Ticket To Work's job services would generally seek placements in low-wage and unfulfilling jobs was shared by some other informants. Lee felt that they would rather pursue work providing services to other disabled people, even part time or as a volunteer, than take a likely Ticket To Work placement, saying, "I would rather have less money and make people's lives better than sit in a red uniform on a stool and be like, 'Hi, welcome to Target.'"

Under Ticket To Work, both public agencies and private organizations can provide job placement services. This creates additional layers of organizational dynamics that beneficiaries must navigate. After losing her job and enrolling in SSDI, Jackie secured job coaching though a disability service provider, which found her a job at a small call center in Chicago. She took the position, answering the phone with about a half dozen coworkers. But dynamics with those coworkers soon soured, as she found herself unfairly accused of stealing people's lunches from the office refrigerator. To avoid conflict, she started leaving the office during lunchtime, but the situation became unbearable. She ultimately found another job with a minister at a church and resigned. She wrote to her call center supervisor saying that while she appreciated the opportunity to work there, the accusations she had faced meant that "there was not a camaraderie that you would like to see in a working environment for a person with a disability, so therefore, I thank you, but I respectfully resign."

The reaction to this polite letter was striking. The call center cancelled its contract with the disability service organization that had served as her job coach, citing her letter as the reason, and implying that the organization had coached her to write it. The organization, in turn, contacted Jackie, angry that she had lost a placement site for them. As Jackie recounted this years later, she was indignant, both at the implication that she didn't write the letter on her own, and at the reaction to her speaking up for herself. She asked, "'Why do you think I can't think for myself and write my own letter?' When I wrote it, it was not with malicious intent. I wanted to let them know that [sic] why I wasn't happy, but that wasn't meant to keep them from hiring other people with disabilities." But rather than being understood as an individual worker, Jackie's participation in Ticket To Work implicated her in a complex web of organizational relationships, with their own incentives that she had to navigate. Moreover, even though she was working, she was not recognized as an independent citizen-worker. Instead, having secured the job as a disabled SSDI beneficiary, she was expected to be grateful and not to upset the proverbial apple cart. The disability service provider's expectations of her, and their dismay at her self-advocacy, echoed Marshall's description of the dynamics of private charity. As Marshall wrote, it was generally the "view of charitable bodies that those who received their help had no personal right to claim it" (1950, 33), and docile gratitude was the appropriate response. When Jackie did not demonstrate such docility, her former employer's over-the-top response demonstrated the precarity facing not only her, but the disability service organization that had placed her there and its other potential clients.

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. Insofar as SSI and SSDI are analogous to what earlier eras of social provision called outdoor relief, then Medicaid-funded nursing homes are more akin to poorhouses, where civil and political rights are even more sharply curtailed. SSI and SSDI beneficiaries living in these facilities face another situation in which two different forms of disabled citizenship come into contact, each with its own logics and rules. Informants living in these congregate settings, which are the focus of the next chapter, 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 was also the Personal Needs Allowance required for nursing home residents in the state of Illinois until the beginning of 2024, when it rose to $60. SSDI policy is less clear, but clients generally understood that any benefits allocated to them had to be redirected to facility management, often by designating the facility as a representative payee. SSDI beneficiaries in nursing homes with whom I spoke also had only $30 per month on which to live. When I asked Shana, who had lived in multiple nursing homes, whether anyone discussed refusing to sign their checks over to the facility, she said simply, "If you refused to sign your check over, you would be kicked out." Emily, a 64-year-old nursing home resident in Chicago with multiple disabilities who had collected SSDI 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 like Medicaid, 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.”

Notably, one research analyst at the Social Security Administration, reading of this finding, said that if beneficiaries were pushed into such arrangements, it might run counter to official SSA policy. She wrote, “There is no rule from SSA that people have to make nursing homes their rep[resentative] payee. In fact, SSA policy is that a rep payee should only be assigned if an individual lacks the capacity to handle their own finances, as determined by a medical provider” (L. King, personal communication, December 9, 2022). But their residents felt that their position in relation to management allowed little space to contest such policies. As I write in the next chapter, a common strategy for navigating policy from below within nursing homes is to keep one’s head down.

So residents were left to manage the demands of facility management on their own. In the Nursing Home Emergency Response Group’s resident meetings over Zoom, Social Security disability programs were a recurring topic on which people hoped to find resources and clarity. Residents attempted to advocate for themselves without knowing what their rights were in regard to their Social Security benefits. At a meeting in February 2022, Julio logged in. He had recently moved into an assisted living facility, a different category of institution, which he had hoped would be better than the nursing home that he had left. Before moving in, he had been approved for SSDI, and had received back pay in a sizable lump sum. But now, apparently citing those assets, the assisted 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 group did not have clear answers to his questions. When I interviewed Julio the next year, he reported that he had paid the amount, fearing what might happen if he didn't. But he'd been asked to pay more the next month, and the nursing home he had left sought to collect a portion of his benefits for the months he had lived there after being approved. He decided not to pay either of them, and the demands eventually ceased.

Julio's situation starkly illustrated the challenges of navigating complex and uneven policy terrain. Putatively therapeutic institutions like nursing homes and assisted living facilities may see a resident's cash assistance as an additional source of revenue for the facility. The status of SSDI beneficiaries in congregate facilities evokes Marshall's discussion of paupers who entered the workhouse under English Poor Law, who forfeited civil and political rights. For beneficiaries who enter a congregate care setting today, their citizenship shifts from that of a poor but independent person to that of a facility resident, a status that overrides their individual agency and means of support.

DISCUSSION

This chapter presents a picture of the precarious citizenship generated by the demands of SSI and SSDI receipt in the context of conflicting policy logics. Through the active work of policy navigation from below, 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, both as applicants and as beneficiaries. 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.

Precarity is a key theme of this chapter. The people I spoke with did not know all of the rules and feared loss of benefits—which had happened to two informants. 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 few other means of support for a host of reasons, the fear of losing what aid they had loomed large.

The data in this chapter is, of course, limited. It draws primarily on interviews with 23 informants, 21 of them current or former program beneficiaries, as well as observation of a small organization. While interview subjects vary around a number of important axes, including race, gender, disability type, and living situation, this is still a limited sample. But one of the chapter's limitations actually underscores the finding of persistent precarity. Because of the social and organizational networks through which I recruited, as well as the activist orientation of the NHERG, respondents may have also tended toward politicized views of disability more than their average peers. (This was certainly not uniform; one respondent, for instance, told me that she didn't believe in voting, believing that fixing the world was a task for the Almighty.) 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 stark insecurity.

A second key finding is that many SSI and SSDI beneficiaries worked to a limited extent. As discussed in the previous chapter, work is intimately tied to models of citizenship from which large numbers of disabled people are excluded (Rose 2017, Fraser and Gordon 1994). SSI and SSDI are ostensibly premised on the definition of disability as inability to work beyond the minimal threshold of Substantial Gainful Activity. And indeed, informants reported being careful to keep their earnings below SGA. But their receipt of SSI and SSDI is not solely a matter of incapacity, not of a lack of interest in working more. Steve's frustrated declaration that he had applied for over 200 jobs, for instance, attests to his desire to work more. While programs like Ticket To Work were ostensibly designed to make it easier for beneficiaries to work, these work incentive programs essentially undermined themselves, with their complex policy apparatus and conflicting logics making many potential participants wary of losing what supports they had. The fact that multiple SSI and SSDI beneficiaries described working serves as a prime example of the uneven results of policy sedimentation, which disabled citizens must navigate as best they can.

A third important implication of these findings is to trouble common understandings of a two-track US welfare state. The common two-track heuristic suggests that earned benefit programs, where beneficiaries are understood to have "paid into the system," are valorized, while welfare systems, providing unearned benefits, are denigrated. If this were so, we would have expected beneficiaries to know clearly whether they received SSDI, an earned benefit where they would have more favorable experiences, or SSI, a stigmatized form of welfare. Instead, many were uncertain. This suggests that the stigma or valor attached to a program reflects not only its funding structure, but the experiences of applicants and beneficiaries. SSDI, as an earned benefit program, certainly has some rules that are more favorable to beneficiaries than SSI, such as the absence of asset caps. But it still puts applicants through the same denigrating disability screening process as SSI, and it sends beneficiaries with questions to the same overburdened call center. These are all factors that shape the overall experience of beneficiaries, in which stigma may outweigh valor.

This finding suggests that scholars seeking to understand a government benefit should ask whether its administration situates beneficiaries as full members of society, or whether it separates them out for specialized processing. The former, like Social Security retirement beneficiaries or the EITC claimants at a commercial tax prep agency, are likely to have far more positive experiences than SSI and SSDI beneficiaries who must navigate a specialized bureaucratic maze. Scholars should also ask how closely a program guards against the specter of chiselers or cheats, erecting complex ordeals to determine eligibility. While focusing on these factors, it may be best to acknowledge that whether a benefit is “earned” is in many ways a fiction; those who don’t qualify for SSDI still “pay in” to government revenues through a range of taxes. More important than whether a program is categorized as an earned benefit or as welfare is how it treats beneficiaries and applicants.

CONCLUSION

As disability-specific income support programs, SSI and SSDI are not only sources of much-needed financial assistance to millions in poverty 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. By approaching these programs experientially, and understanding them within a broader framework of disabled citizenship, 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. These findings stand in contrast to the argument, advanced by Deborah Stone (1984) and others, that people with disabilities are broadly considered deserving of aid, and that SSDI and SSI are therefore not marked by type of stigma attached to cash assistance programs like AFDC. Instead, we can still see how stigma and ableism manifest through onerous verification processes and complex program rules that treat beneficiaries as potential cheats, generating a form of precarious citizenship. Beneficiaries' difficult interactions with the Social Security Administration, as well as their frustration with inadequate benefits, underscore the extent to which these income supports are a form not of social citizenship, but of a dynamic more reminiscent of T.H. Marshall's depiction of nineteenth century Poor Law. We can also see how they constitute the broader fabric of disabled citizenship in their interactions with the labor force, as discussed in greater detail in the previous chapter, and congregate care facilities, which are the focus of the next chapter.

Chapter 4

Disability Institutionalized: Nursing Homes

On a bright fall day in 2022, I joined roughly a dozen members and allies of the Nursing Home Emergency Response Group (NHERG) in a Chicago-area park. We were gathered in support of Keisha, a group member living in a nursing home on the city's South Side. A 39-year-old Black woman, Keisha had lived in various nursing homes since becoming quadriplegic nearly 20 years earlier. She called her current facility the second-worst in which she had ever lived, and while pursuing the slow process of transitioning out, she also sought to improve conditions. That Fall, she had created an online petition to management, seeking redress for issues that included rationing of linens, inadequate food, deteriorating physical facilities, and staff being owed back wages. The Group had come together to deliver petition signatures to the offices of the corporation that managed her facility, one of about 20 in its portfolio in Illinois. While she had considerable experience in advocating for herself, this was Keisha's first demonstration, and she later told me that she had been anxious.

After a short march, with periodic stops to narrate to supporters watching online, the group arrived at a nondescript brick office building and entered. The entryway was richly appointed, with a nice rug in white, beige, and black splotches by the door leading to a tiled floor that one might find in an expensive home. A stylishly scalloped wood table stood to the left of the doorway in front of a glass wall etched in a design evoking prairie grass, behind which was a conference room with a large monitor. Off to the right, behind another glass wall, we could see a decorative suit of armor. After being told that no one was available to meet with us, the group chanted "Bring out the owners," and ultimately, a man emerged from the back and identified himself as an owner. His tone was brusque, repeatedly asking who we were, at one point saying, "This is my space. I want to know who I'm talking to."

After taking the petition without looking at it, he said that he would have the administrator address whatever concerns we had. After further exchanges, he told us to leave and retreated back to his office, as one of his staffers called the police. Our group remained. When two suburban police officers arrived, they told us that this wasn't our property, and we could make our case on the sidewalk outside. I could feel my anxiety rise, fearing that the situation would grow confrontational. But as our group reiterated the issues that had brought us, the officers seemed reluctant to physically remove us, perhaps because our numbers included two wheelchair users, a third person with a walker, and a fourth with a cane. Ultimately, even as a third police officer arrived and we were treated to periodic reminders that we *could* all be arrested, one of the officers served as an intermediary between our group and the owner. They negotiated plans for a meeting between the owner and NHERG members, including Keisha, to take place the next month. With that success, our group left.

Afterward, I accompanied Keisha, along with a personal attendant whom the NHERG had hired for the day, back to her nursing home in a paratransit vehicle. As we entered the gray building and turned to the two passenger elevators that served the seven-story facility, we encountered a long line of residents extending from the cafeteria nearby. We missed one elevator, making our way onto the second after someone else called out to make way for a wheelchair. After bringing Keisha to her room on the fifth floor and saying our goodbyes, I walked back down the hall to the elevator, noticing the institutional beige walls with floral prints. One display offered a cliché assurance that "If you believe, anything is possible," according to your attitude and motivation. While waiting back at the elevators, a nursing home worker commented that it would be packed because residents were smoking, reflecting the scheduled nature of one of the small pleasures of nursing home life. When an elevator going up arrived, we rode it to the top floor, and then back down to the entrance, crowded amongst people with masks on their chins, as well as a worker wearing no mask at all.

The sharp differences between the two sites I visited that day reflect key themes in this chapter. While the corporate office was comfortable and spacious, even with some dozen protestors in its lobby, the nursing facility was crowded and institutional. The owner, clearly offended by our intrusion, asserted "This is my space" before leaving the lobby, in contrast to nursing home residents who, as this chapter will show, complained of their lack of privacy. When his staff called the police, they arrived promptly and removed us from the premises; while they did so through negotiation, I had little doubt that had the owner been willing to risk the bad publicity, the police would have made arrests. In contrast, as I discuss, residents in nursing homes spread across Chicago reported that when they called 911 to report theft or abuse, they were often denied services because they were nursing home residents; whether through formal policy or the attitudes of dispatchers, they lacked the standing to call on the city's emergency response system. The crowded elevators served as a reminder of the ongoing risk of COVID transmission in nursing facilities. While the owners could decide with whom they would interact in their offices, residents had little choice but to cram cheek to jowl in small spaces like those elevators if they wanted such diversions as a smoke break, a cafeteria meal, or time in a recreation space on the first floor. This fundamental reality of institutional life, even in a setting putatively devoted to care, contributed to the disproportionate toll of the pandemic in nursing facilities, particularly in 2020.

In this chapter, I focus on the conditions of institutional life in nursing homes, several of which were thrown into sharp relief in this vignette. I ask how congregate care settings shape the lives of disabled residents, and what kind of citizenship they produce. While the previous chapters have focused largely on disabled people's relationship to work and income support, this chapter engages with citizenship in terms of housing, and whether one is situated as an independent householder in a broader community, or as the ward of an institution. This distinction reflects the role of property ownership as a key part of Marshall's conception of civil rights. It also reflects the genealogical links between nursing homes, particularly those serving low-income people, and the state hospitals, asylums, and almshouses of the 19th and early 20th century. Like earlier institutions, nursing homes also serve as sites of poverty governance, interwoven with social processes such as eviction and homelessness. But they also differ from earlier public institutions in key ways, one of the most significant being that many nursing homes operate as for-profit businesses, despite their reliance on government revenues from programs like Medicaid. Nursing homes are, of course, also distinguished from almshouses or shelters in that they specifically serve those needing various types of support, which range from medical nursing care to assistance with activities of daily living that might also be performed by a personal attendant (PA). If we examine nursing homes in terms of policy sedimentation, we can see threads of continuity in the basic practice of placing people within congregate settings as a social response to disability.

Contemporary nursing home residents, unlike the 19th-century British paupers whom Marshall described, do not lose the franchise. I heard from multiple sources that they had been able to vote with relative ease.[1] But their standing to make political claims, whether of the facility or of society at large, is eroded in myriad ways. One small but telling example lies in the practices of the Census Bureau, which does not enumerate residents individually, but gathers data individually (US Census Bureau, n.d.). In daily life, residents' reliability as narrators of their own experience, their capacity to make decisions and to contest mistreatment, and their access to public services all face constraints in both mundane interactions and moments of crisis. Meanwhile, their daily lives are bracketed off from public life, behind institutional walls. Nursing home life is discursively juxtaposed to life "in the community," in contexts ranging from daily conversation to the name to the Administration for Community Living, an agency of the US Department of Health and Human Services. Such terminology is a regular reminder that facility residents are not, in Marshall's terms, "full members of a community" (1950, 28). Reflecting the limitations on their political standing, and their symbolic and practical exclusion from broader public life, I describe the situation of nursing home residents as a form of *constrained citizenship*.

While disabled people are funneled into a wide range of residential settings, including group homes, psychiatric hospitals, and those state residential facilities that survived the deinstitutionalization movement of the late 20th century, I focus in this chapter on nursing homes. Of course, the category of "nursing home" is still a broad one, encompassing facilities that allow both short-term rehabilitation and long-term stays. There are nursing facilities attached to expensive retirement communities, where residents put considerable wealth toward high-quality care. I focus here primarily on facilities funded, at least in large part, by Medicaid, which is not

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[1] Some political actors may wish that this weren't the case. A Senate candidate in neighboring Wisconsin recently questioned the legitimacy of voting by nursing home residents, saying, "Almost nobody in a nursing home is in [sic] a point to vote." (Eberwein 2024).

only a source of health insurance for low-income people, but also the main funder of long-term support services. For a nursing home bed to be Medicaid-funded indicates that the resident is most likely both poor and staying in the facility for an extended period. One recent assessment, using data from 2019, counted roughly 1.3 million people who stayed in nursing homes for 60 days or more. Nearly 210,000 were under age 65, constituting a significant minority of younger disabled residents in a context that is popularly associated with seniors (Ne'eman et al. 2022).

In the following pages, I situate nursing home life within the literature, tying it to past practices of institutionalization, to contemporary poverty governance, and to the work of disability activists who pursued (and continue to pursue) independent living as an alternative. I then turn to my own data, drawing on in-depth interviews with current and former nursing home residents, and participant-observation with an activist group focused on nursing home conditions. With their rich stories, I illustrate the overlap of nursing homes with other mechanisms of poverty governance, the function of residents as revenue streams for facility managers, and the institutional nature of nursing home life, with its slow rhythms, lack of privacy, and power imbalances that create the potential for neglect and abuse.

Within this setting, I then turn to the work of *policy navigation from below*, which takes on specific meanings in nursing homes. Residents face complex questions of how they are categorized by multiple institutions, reflecting the fragmented landscape of disabled citizenship. One set of dilemmas was presented in Chapter 3, with SSDI beneficiaries compelled to direct their benefits to the institution. Another web of bureaucratic complexities faces residents who seek to move out of nursing homes, a process referred to as "transitioning". There are formal programs to facilitate transition for residents, but eligibility depends on whether one lives in a facility covered by a relevant court order. If residents are eligible to participate, they must then prove that they have the capacity to live on their own, navigating multiple gatekeepers in a process that can feel infuriatingly slow. And while still in a facility, residents must strike a delicate balance between advocating for themselves and asserting their dignity while maintaining relationships with often-overworked staff, on whom many rely for such personal needs as toileting and bathing. When they find themselves mistreated, residents may pursue various means of redress: speaking up individually, turning to family or friends, seeking the support of the state through a regulatory hotline or 911, or even—in rare cases like Keisha's—turning to organized protest. But success is never guaranteed, and speaking up presents the risk of retaliation, leaving residents uncertain about how best to navigate a dilemma that is rooted in fundamental questions around their *constrained citizenship*.

BACKGROUND

Institutional settings are largely absent from Marshall's treatise on citizenship. Their sole mention is a sentence I reference previously, which reads in full, "For paupers forfeited in practice the civil rights of personal liberty, *by internment in the workhouse*, and they forfeited by law any political rights they might possess" (1950, 24, emphasis added). In other words, to enter an institution was to abandon key elements of citizenship. The lack of attention is unsurprising; Marshall's optimistic focus was on the development of a robust social citizenship, not on its exceptions. But his language makes clear that to enter a congregate institution was to remove oneself from the polity, giving up both rights and belonging. This is bound up in a key aspect of Marshall's conceptualization of civil rights as tied to contract and property ownership. While much of my discussion of civil rights thus far has dealt with employment as a contractual relationship, it also includes securing stable housing where one can enjoy privacy and some level of control over one's space. Paupers who moved into an institution like the workhouse or almshouse were defined by their lack of property, unable to exercise this key civil right.

Disability scholars have drawn genealogical lines between the institutions of the 19th century, particularly the almshouse, and contemporary nursing homes. Nancy Crewe and Irving Zola write that many residents of almshouses were moved into differentiated facilities including "experimental schools for the mentally retarded, the blind, the crippled" (1983, 2). This echoes Andrew Scull's description, referenced in the introductory chapter, of the "specialization of the social control apparatus" (1984, 21-22). Crewe and Zola also draw a direct link to the establishment of the contemporary nursing home. They write that modern social welfare programs replaced some congregate institutions such as the almshouse. But they continue, "For the severely disabled who needed physical care in order to survive, however, the only public solution continued to be institutionalization. Nursing homes eventually provided an alternative to hospitals" (3). Timothy Diamond's research in nursing homes in Chicago, conducted in the early 1980s, reflects this institutional lineage. Some residents in a Medicaid-funded "public aid" ward of a facility he studied "were former inmates of state hospitals living out the consequences of the deinstitutionalization programs of the 1970s, moved from state hospitals to the community and then to nursing homes" (1992, 67). Despite the drastic reduction in the population of large institutions like state hospitals, which Ben-Moshe describes as "the largest decarceration movement in US history" (2020, 2) practices of institutionalization persisted in various forms, including that of nursing homes. For some, like the residents Diamond describes, the link between institutional contexts was not only theoretical, but biographical.

Like the almshouse, some nursing homes also serve as sites to concentrate and manage the poor. Recent literature on poverty governance, much of it based in California, has highlighted the role of several medical and medical-adjacent social institutions. Josh Seim writes of the role of ambulance services in regulating “bodies in spaces,” moving the poor out of public spaces like streets or businesses (2017). Armando Lara-Millán describes a process of “redistributing the poor,” documenting the practices of both public hospitals and urban jails in Los Angeles in managing the flow of people coming through their door, in part by shifting the categorical definitions through which they are processed in order to relieve pressure on system capacity (2021). Neil Gong describes the “tolerant containment” of mentally ill homeless people in the same city, which sees the poor moved into housing first programs or Board and Care homes that share certain similarities with nursing homes, where residents have basic shelter and are removed from public view, but they receive limited if any care or treatment (2019). Anthony DiMario offers a theory of “palliative governance,” based on his study of a Los Angeles syringe exchange program, whereby programs seek primarily to keep the poor alive, even while doing relatively little to alleviate their suffering (2022). I argue that nursing homes serving the poor should be understood within this literature as similar sites of poverty governance, in which poor disabled and elderly people are contained outside of public view with limited care, often relieving pressure on adjacent systems such as homeless shelters. This understanding not only adds to the literature on urban poverty governance, but it helps to contextualize the constrained citizenship experienced by residents.

The institutional nature of nursing homes is not only a reflection of their policy genealogy. Institutional logics also shape their operating structures, and the nature of daily life and citizenship for their residents. In Goffman’s classic discussion of total institutions, he posits that they fall into five categories. The first of these consists of “institutions established to care for persons felt to be both incapable and harmless; these are the homes for the blind, the aged, the orphaned, and the indigent." (1961, 4). Nursing homes, as spaces for the aged, indigent, and disabled, clearly fit this description. Other aspects of Goffman's depiction of total institutions are easily found in a nursing home. It is both a residential community and a formal organization, with an unmistakable divide between staff and residents (whom Goffman would call inmates). While admission to a nursing home does not involve the extent of mortification that Goffman describes in prisons or military barracks, there are still indications that one surrenders a measure of individual autonomy, from being thrust into a living situation with a roommate to the gradual loss of clothes and other belongings as they make their way through institutional laundry or risk being stolen. Daily life is built around a bureaucratic rhythm which can structure not only meals and smoke breaks, but also the arrival of staff to patient rooms for such intimate but essential activities as bathing residents, changing their diapers, and assisting them in getting out of bed. Nancy Foner writes of how the bureaucratic structure of the facility she studied could harm patients, rewarding staff who operated harshly but quickly, while punishing those who devoted more time to "emotional work" (1994, 53-68). The institutional character of the facility renders residents as bodies in beds rather than full members of a social or political community.

Many nursing facilities are not only institutions, but for-profit businesses. Analyses highlight the profit motive and economic logic of the nursing home industry. Marta Russell writes that nursing homes "have commodified disabled bodies so that the least productive can be made of use to the economic order" (2001, 93). The title of Diamond's ethnography, *Making Gray Gold*, refers to the process by which caregiving is made into an industrial commodity. His section headings reinforce this theme, situating both residents and staff within the process of "Mining the Raw Materials," "Forming the Gold Bricks," and "Melting the Gold Bricks Down" (1992). Government revenues constitute a key source of that gold. The contemporary system of nursing homes was established on government subsidies and loans for facility construction in the 1950s and 60s. Even more important were the establishment in 1965 of Medicaid, and to a lesser extent, Medicare. Both served as funding sources for long-term care stays, with Medicaid funding indefinite institutionalization (Foner 1994, 10; Winant 2018, 101). Estes et al write that the presence of these government funding streams contributed to the commodification of old age, creating profit opportunities for an emergent "medical-industrial complex," the development of which included "dramatic" growth in the number of for-profit nursing homes (2001, 50-51).

This historical trajectory has reached a point where for-profit nursing facilities are widespread, and their economic logics shape the citizenship produced within their walls. According to 2019 data, 71.5% of long-term nursing home residents lived in for-profit facilities (Ne'eman et al 2022). A recent journalistic/academic collaboration by Campbell and Harrington, focusing on a highly profitable mid-sized nursing home chain, presents a system in which the pursuit of shareholder profits contributes to inadequate staffing and deplorable conditions. Despite the high level of public subsidy through Medicaid and other sources, the authors portray government regulation as largely inadequate, pointing out that a proposed federal rule around minimum skilled staffing levels would establish a *lower* minimum staffing level than one suggested by the Center for Medicare and Medicaid Services in 2001 (2024). From the start of the COVID pandemic in 2020 until April 2022, the national long-term care workforce dropped by 15%, losing nearly 245,000 nursing home jobs. Only about 55,000 jobs had been recovered by April 2023, in what even industry groups called a "historic labor crisis" (AHCA NCAL 2023).

Campbell and Harrington also point out that infection control was "the most frequently cited deficiency in nursing homes" between 2013 and 2017, providing clear but unheeded warning of the disaster that came with COVID (2024). There were also indications that short-staffing contributed to infection rates; one analysis early in the pandemic found that California facilities with lower nurse staffing levels were more likely to see COVID infections between March and early May 2020 (Harrington et al, 2020). The overall toll of COVID in nursing homes was devastatingly grim. Analysis from the Department of Health and Human Services estimated that 40% of nursing home residents in the United Stated contracted COVID in 2020, and that the overall mortality rate in nursing homes increased 32% over the previous year. In over 1,300 facilities, over 75% of residents contracted the disease that year. Because of data limitations, this analysis focused largely on Medicare beneficiaries, most of whom are over 65. But it found that those who were also eligible for Medicaid, i.e., those who were low-income and/or long-term residents, were at greater risk, having contracted COVID at nearly twice the rate of those who were only eligible for Medicare (HHS Office of the Inspector General, 2021, 2023). By early 2024, 170,000 nursing home residents were estimated to have died of COVID, more than 10% of the total US death toll (Cirruzzo and Payne, 2024). These figures are not only tragic; the policy regime that led to this concentration of suffering reflect the diminished citizenship of nursing home residents, and their lack of status as "full members" of the broader community.

Finally, nursing homes have long been a focus of opposition from many disabled activists. In the passage cited previously from Crewe and Zola, they present independent living as a response to nursing homes, writing, "Nursing homes eventually provided an alternative to hospitals, but it remained for the Independent Living Movement to suggest options that offered real autonomy" (1983, 3). ADAPT, the organization that had led the direct action campaign for accessible buses during the 1980s, changed its name after the passage of the ADA from

Americans Disabled for Accessible Public Transit to Americans Disabled for Attendant Programs Today. Its new focus was "a demand for personal assistance services to permit people with impairments who need assistance to live at home *instead of in nursing homes*" (Barnartt and Scotch 2001, 182, emphasis added). While they may not have used the language of citizenship, activists recognized that nursing homes constrained the rights of their residents and placed them outside the larger community.

Legal advocacy eventually won the 1999 *Olmstead v. L.C.* case in the US Supreme Court, where a majority ruled that under the ADA, "undue institutionalization qualifies as discrimination 'by reason of…disability.'" While the two women who brought the case were confined in a psychiatric hospital, the case formed the basis of subsequent lawsuits on behalf of nursing home residents. In the Chicago area, two of these cases led to ongoing consent decrees that have created structures by for residents to transition out of facilities and into community settings. The Colbert consent decree, filed in 2011 covers nearly 20,000 class members in nursing homes in Cook County, while the Williams decree, filed in 2010, covers more than 4,000 class members in a subset of facilities called Specialized Mental Health Rehabilitation Facilities (SMHRFs), which also provide nursing care. The discourse around the settlements reflects an acknowledgement of the diminished social status of residents; a report from a court-appointed monitor, for instance, refers to the *Colbert* settlement as enabling those who transition "to rejoin and fully participate in society" (du Pree 2023a, 28).

Despite the large numbers covered by these decrees, relatively few people have transitioned under their provisions. Recent reports by the court-appointed monitor show that since implementation began, the targeted number of transitions had only been achieved in one out of eleven years for Williams, and one out of ten years for Colbert. Numbers had also dropped sharply with the onset of the pandemic, a change reflected in accounts from my informants, though they had increased by 2022. That year, 358 people in Illinois moved into the community under Williams, and 431 in Cook County transitioned under Colbert (Illinois Department of Human Services, 2023; du Pree, 2023a and 2023b). This policy history, which continues today with the ongoing implementation of the consent decrees, provides crucial context to the constrained citizenship of nursing home residents, as well as their efforts to navigate the policies that structure institutional life.

DATA SOURCES

I draw data for this chapter from two main sources. First, I conducted eleven in-depth semi-structured interviews with current and former nursing home residents in the Chicago area. They included four Black women, three white women, two Black men, one Latinx man, and one white man. Informants ranged in age at the time of our interviews from 38 to 70, with two in their thirties, one in his forties, five in their fifties, two in their sixties, and one who was 70. They had a range of physical and mental disabilities; some needed assistance with activities of daily living, while others were able to operate more independently. Four used wheelchairs, and four others used mobility devices like canes or walkers. When we spoke, five of them were living in nursing homes in the city of Chicago, while six were former residents recounting past experiences. Seven of them had spent time in more than one nursing home in Chicago or its suburbs, allowing our conversations to plumb consistencies and differences across facilities. Three informants had also spent time in assisted living, a category of facility that allows a greater level of autonomy than a nursing home, which provided further grounds for comparison. Two were living in a Chicago assisted living facility when we spoke, having moved directly from a nursing home. A third had gone from assisted living, where she lived with her husband, back to a nursing home several months earlier on the instructions of her doctor. Alongside these informants, I also spoke with a former nursing home staff member. While our conversation focused largely on her experiences as a disabled worker, her insights shed light on the accounts of nursing home residents.

Some of these eleven informants had also spent time in other types of congregate care facilities, including psychiatric hospitals and group homes. One had spent several years in psychiatric facilities but had only short stays in nursing homes; he had also worked for some time in group homes. Beyond these eleven informants, four other people I interviewed had experienced mental health hospitalizations, three of them for roughly a week, and one for several months. While their accounts provided important data with which to contextualize this chapter, particularly in terms of the role of police in relation to institutionalization, for the sake of focus I have chosen to craft this chapter primarily around nursing facilities. Another informant spent several years in an institution in another country before moving to the US. While many elements of their experience were similar to those recounted by informants from the US, I have set their data aside for this chapter, as it took place within a different policy context.

I also draw on my ethnographic participant observation in the work of the NHERG. While recruiting informants behind facility walls presents challenges, the NHERG's network of residents provided a key avenue by which to reach people. I regularly attended both the NHERG's biweekly organizing meetings and the weekly meetings of its residents' group, the latter of which provided the most relevant data for this chapter. Between early 2022 and mid-2023, I attended and took notes on over 50 group meetings or events where facility life and conditions were topics of discussion, and those field notes inform this chapter. NHERG meetings took place over Zoom, a practice from the early days of the COVID pandemic. While the online format allowed current and former residents of different facilities to connect with one another, it also posed its own challenges, requiring both access to and familiarity with relevant technology. The NHERG worked to bring phones to interested residents, and it was not uncommon for members to coach one another on how best to use them.

FINDINGS: INSTITUTIONAL LIFE

Over the course of my research, I found that informants entered nursing homes through unexpected paths, including eviction and the homeless shelter system, reflect the facilities' complex genealogies as sites of both medical care and poverty governance. Once inside, they are subject to for-profit logics that treat them as institutional revenue streams, even at the cost of basic needs. They are simultaneously subject to institutional logics that situate them as passive objects of care from overworked staff, set within an institutional power dynamic that can generate mistreatment and abuse. In the following pages, I describe the constrained citizenship within nursing homes that flows from these policy logics, before turning to the strategies by which my informants navigate them.

"Who knew that the eviction teams have a social worker?"

When I spoke with Jen, a white woman living in Chicago, she was 57 years old. She had dealt with both depression and diabetes for much of her life, but she didn't think of these as disabilities, and she had kept them well managed, with a long career in software development in the financial industry. But after a contract ended, as she struggled to find her next position, she sank into a deep depression. After four years without income, her house went into foreclosure, and she was evicted on a January day. At that point, her electricity and water had already been shut off; she told me how a neighbor allowed her to plug an extension cord into an external outlet, and to collect water from a spigot on the outside of their house. She had known that eviction was likely coming, and she estimated that she had called twelve to fifteen organizations that addressed homelessness. But she was told that they couldn’t help her, as she was not (yet) homeless. She didn’t know where she would go next. As she recounted the events of her eviction, Jen said, “When they came, basically, the social worker—who knew that the eviction teams had a social worker?” I replied that it was news to me, and she continued, “I was shocked.”

When the social worker asked where she was going, Jen told him bluntly that she was homeless. He expressed concern, pointing to her diabetes, saying, "That's not good for a Type 1 diabetic that needs an address so that they can get their pump supplies." The social worker offered to call a homeless services provider, but it was one of those that Jen had already called. He said that he would see what he could find, and he soon returned with the news that there was a nursing home that would take her because of her depression, and she could move in immediately. This, too, was a shock for Jen; she associated nursing homes with 80-year-olds. But, as she said, “it was go [to the nursing home] or go sit on a bench somewhere. It was January. The bench was going to be frozen.”

Jen was one of the first people I interviewed for this project, and this story initially surprised me. But I soon learned that nursing homes occupy a space within the constellation of organizations serving the homeless and marginally housed. This reflects both their genealogical connection to almshouses described previously, and the practical fact that, as residential spaces, they offer a form of housing that may be preferable to other marginal spaces such as homeless shelters or the streets. Julio, a 61-year-old Latino man with depression and severe arthritis who was introduced in Chapter 3, had worked for many years in hospital security. But after a change of management, he lost his job, eventually going through his savings and becoming homeless.

He stayed in various shelters that placed 90-day limits on how long he could stay there. During that period, he developed a hernia, and a worker referred him to a medical respite care shelter, where he could recover from hernia surgery under more hospitable conditions than a standard shelter. But that promise of care turned sour; he contracted an antibiotic-resistant infection while there, which put him in a hospital. The hospital then discharged him to a nursing home. While he came to be very critical of the facility after spending four and a half years there, he was initially glad "that at least I was not having to change the address every three months or so." With a chuckle, he told me, "For the first year, I was scared, man. I thought I was going to have to leave and that they'd be moving me to a shelter and stuff. After being homeless, I really didn't want to have to go through that."

Shana, a white woman with bipolar disorder and other disabilities who was 38 when we spoke, had been working the night shift at a pharmacy chain about ten years before. Her mental health declined, and she spent six months in a residential treatment facility, which she described as helpful. When she was discharged, she said, "They told me to basically start my life over." Because she had some addiction issues, she moved into what was billed as a transitional living facility in an inner-ring suburb of Chicago. What she found there "was just scary." From her description, the facility appeared to be a largely unregulated form of marginal housing, with a structural model much like the Philadelphia recovery houses described by Robert Fairbanks II (2009), but with significantly worse conditions. Women slept five to a room on bunk beds. Rent was $500 a month, and she was urged to apply for public benefits to cover the cost. Some residents exchanged sex with the male house manager in place of rent, which could put them in positions of power among other residents. She moved to another facility that was supposed to be better, but she described it as largely the same. In contrast to Fairbanks' account of careful adherence to 12-step models in Philadelphia, Shana said that she was the only sober person in that house.

Her psychiatrist told her of a “new program where you can get an apartment in six months if you’re in [a] nursing facility. He may have been referring to the Colbert and Williams settlements, which were relatively new at that point. Regardless of what he had in mind, it is clear that he, much like Jen’s social worker, turned to nursing homes as a housing option. For Shana, this began a seven-year odyssey through multiple nursing facilities in the city and suburbs. She pondered seeing that psychiatrist again and asking, “How'd that workout for me, the six months thing?"

Two other interview subjects mentioned having spent time in homeless shelters, though neither said that they went directly from there to a nursing home. Sam, a middle-aged white man who regularly attended NHERG meetings, told of being evicted early in the COVID pandemic. While he frequently expressed interest in an interview, he never scheduled one, and so my knowledge of his story is limited. But Jen, who knew him well, said that he had been hospitalized after his eviction, and had gone from the hospital to a nursing facility. Like others, without stable housing as a basic condition of citizenship, he had few other options but to enter a facility.

Others entered nursing homes due to different kinds of housing crises. Keisha, introduced at the beginning of this chapter, had become quadriplegic due to what she called “a random act of violence that I was not involved in.” For the next two and a half years, she was in and out of hospitals, a rehab facility, and “step-down” facilities that provided near-hospital-level care. She joked that everyone in the emergency room knew who she was, and she knew the staff by name. But when her condition stabilized, she faced the difficult question of where she could live. She had been 19 when she became disabled, and she had four younger siblings. Her family had moved in with her grandmother after a fire in their apartment building, "and that made it a full house." Ultimately, she said, "I didn't want to put all of that on my mom because I had younger siblings that she needed to take care of and focus on…I was just like, 'Okay, it's time to start adulting.'" In this context, acting as an adult meant moving into a nursing home. Jason, a 50-year-old Black man introduced in the previous chapter, had spent seven months in a rehabilitation facility after becoming quadriplegic. When his time there came to an end, he said, "They tried to find me somewhere to go, but I couldn't go up my mother's stairs or anybody else that I knew, so they had to send me to the nursing home." Without accessible housing, he had no other option.

Jason described this transition as a time of anxiety; he had been warned of "how bad the situation was at nursing homes." He was not alone in this fear. Even among those who had never lived there, some informants spoke of them with a mix of fear and disgust, particularly in relation to the toll of COVID among residents. Carmen, an SSI beneficiary quoted in previous chapters who lived at home with her aging parents, said that living in a nursing home was "a big no" for her. As the conversation continued and I probed as to the source of her negative impression of nursing facilities, she said,

> "A lot of it I learned through COVID because when COVID hit, everything shut down including nursing homes and you hear these horror stories of people that were basically left there to die because no one knew how to respond to what was happening. That to me was just like no, I don't even want to think about putting myself in that situation. I'll fight it tooth and nail till I can't fight any more."

For Jackie, a 58-year-old Black woman with cerebral palsy introduced in the previous chapter, the path into a nursing facility was not a matter of housing, but of the failure of systems that she relied on for such essentials as a working wheelchair and personal attendant (PA) services. The problems began when her power wheelchair broke, and her efforts to have it repaired through her insurance or doctor were unsuccessful. Jackie didn't have a manual chair, and without her power chair, she was bedbound. During this period, she had PA services through the state. Attendant programs are often cast as an alternative to institutionalization, allowing disabled people to get whatever assistance they need in their own homes. But some of Jackie's PAs would miss shifts or leave early, leaving her without meals or medicine that she couldn't get on her own. After a while, she deconditioned to the point of a health crisis, leading her to be hospitalized. She was discharged to a nursing home, where she had physical therapy and was soon back home. But once again PA services were inadequate, and she soon faced another health crisis. After another hospitalization, she was discharged to another nursing home, where she had lived for roughly eleven months when we spoke. Without reliable PA services that she could rely on as a right, she had nowhere else to go.

"There's no point to it other than somebody is making money off of it."

In the previous chapter, I wrote of how nursing home residents were compelled to turn over their SSDI benefits to facility management, leaving them with only a $30 Personal Needs Allowance (PNA) each month.[2] As I wrote in that chapter, this exemplified the conflict between abutting policy regimes that is characteristic of disabled citizenship, and the difficulty of navigating policy in such settings. In looking closely at constrained citizenship within nursing homes, it is also important to understand that the practice reflects an institutional dynamic in which residents served as revenue streams for facility management, means to an economic end rather than full members of a community.

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[2] In early 2024, this amount was raised to $60. As I had concluded this phase of data-gathering by then, my discussion focuses on it at the $30 level.

`The effort to extract resources from residents was not limited to monthly benefits. As I wrote in Chapter 3, when Julio moved from a nursing home into an assisted living facility, he had recently been approved for SSDI, receiving back pay that amounted to roughly $22,000. The assisted living facility demanded $4400—far more than one month's benefits—which he paid. They soon demanded the same amount again, while the nursing home where he had previously lived demanded "3000 some odd dollars" for the last three months that he lived there. Julio refused to make either payment, and the extra demands eventually ceased, leaving a sense that both facilities simply wanted to claim whatever they could. He kept his money in an online bank account and believed that the nursing home hadn't known how much he had, saying, "I wouldn't want them to know that I had the $22,000 because they would've said that they could have claimed that."

Julio was not the only one to tell me of the facility taking even more than their monthly SSDI benefits. Emily, a 64-year-old white woman with hypokalemia, spoke in the previous chapter of her frustration with the fact that her facility claimed both her SSDI and her pension from her late ex-husband. She also told me that the facility had taken $7,000 out of her savings and applied it to her care.[3] She had learned this in early 2020; when we spoke in mid-2022, she was still clearly upset, describing it as an issue she wanted to resolve. Such experiences contributed to a sense for several informants that unless they were disruptive, facility management wanted to keep them there as a source of income, and that economic logic crowded out questions of care or recovery. Shana spoke to this after I asked about daily life in a facility,

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[3] It wasn't entirely clear where this money had come from; Emily referred to it being "released by Social Security," which suggests that it may have been a lump sum payment after benefits were delayed or adjusted. She ended our interview when she grew tired after nearly two hours, leaving some details uncertain.

saying, “Where people are living in nursing facilities for years on end like I did, it's wrong. There's no point to it other than somebody is making money off of it.”

Residents stressed that facilities did not meet all of their needs, and that the $30 a month allowance was far from adequate. The NHERG called for the PNA to be raised to $90, and members agreed that this was a top priority for residents that could tangibly improve their living situations. When discussing this demand, it was common to hear that the PNA hadn’t been raised for decades. While I didn’t find clear records to corroborate that, Timothy Diamond wrote of a $25 monthly allowance during his field work in the early 1980s. Even then, he said, it “didn’t go far” (1992, 61). One of my informants, Ellen, a 70-year-old Black woman with multiple disabilities, said, “Some people think when you're in a nursing home, that facility takes care of all your needs. That's not true…Only $30 in Illinois comes back, and with that $30, you might not like the food. And a lot of it is pork. I'm half Jewish and I was brought up Jewish. If you're wanting another meal plus your toiletries or what—it's not right. They don't take care of all your needs.”

Rhonda, a Black woman with lupus in her mid-50s, echoed these sentiments in her interview, saying, “Our income is $30 a month. Who can live on $30 a month?” She went on to itemize potential costs, saying, saying, “The food is not the best. It's horrible sometimes. Sometimes we just get a sandwich, a tomato 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.” She also pointed to the precarity that led many residents to the facility, saying, “A lot of people came from the hospital here that didn't have anything to begin with. You're going to start all over building up these things. You never going to get anything with $30. Maybe you'll get one or two things, and the way things are now? Oh wow. You can't afford anything. It's getting worse and worse. We need so many things, so I see a lot of things from churches."

The "things from churches" that Rhonda mentioned were donations, and she was not the only person to bring them up. Emily spoke of a local food pantry bringing in food early in the pandemic. During an NHERG meeting, in discussing what a PNA increase would mean to residents, Jen spoke of being able to buy clothes rather than picking through donations trying to find something to wear. In all three conversations, these comments were made in the context of a larger point, and I almost missed them. But they underscore the extent to which facilities failed to meet residents' needs, leaving them to depend on the vagaries of charity, with its stigma and diminishment of citizenship.

Jackie's situation was even more extreme. Her understanding was that after moving to a long-term floor of her facility, management was legally "entitled to get everything," including her full SSDI check, because of the care they provided. She did not receive a personal needs allowance at all. When I asked, she said that she might have been able to receive $30 a month if she set up an "account" with the facility, whereby the business office would hold that money and give it to her for specific expenses when she asked. But she had seen her roommate try to access this money, only to face bureaucratic obstacle. Confident that she would eventually go home, Jackie had decided not to set up an account, leaving her without even her PNA. She was vigilant in keeping some money out of the facility's hands, saying, "if somebody sends me $20, I just keep it hidden." When we discussed her compensation for participating in the study, she told me that she would like it on a gift card, so that the finance office couldn't take it. When I asked about this during our interview, she said, "The money that I'm getting from here from you, that's why I chose to put it on a Walmart card, because I can have a gift card and it's not considered an asset. That way, I could spend the money the way I see fit, and I don't have to give it up." Because of my research design, I didn't speak with facility management. It is quite possible, even likely, that staff at Jackie's nursing home would have said that she should have had an account to collect her PNA. But whether by design or bureaucratic error, she was left without even that meager resource, guarding what funds she was able to obtain.

The institutional nature of nursing home life

Goffman wrote that on entering a total institution, one gives up some level of autonomy. This erosion of self-determination constrains one's citizenship. In nursing homes, one form this took was the loss of privacy. When Jen entered her facility after her eviction, she said, "They put me in the room that I was going to. It was a four-person room. That was a shock to me." Her only point of reference for nursing homes was where her grandmother had lived, and she'd had a private room. Jen hadn't lived with another person since her divorce seven years earlier. The loss of privacy was a point of contention for others as well. At one point in our interview, Emily was telling me of her frustration with being in a nursing home, faulting herself in part for not successfully managing her hypokalemia. As she gave voice her shame and anger, she said, "It's a terrible feeling being in a nursing home. Being in this tiny space with a roommate with who you share a bathroom and just looking at everything that's going on around you saying, 'This is not right, there's something wrong with this picture.'" The fact that she mentioned sharing space with someone, at a point in the interview when we hadn't discussed roommates for over half an hour, speaks to the emotional power of this standard aspect of institutional life.

With institutional life comes institutional food. Food service was a common complaint. At one point in an NHERG meeting, a member who had recently been forced out of her facility told the group about the new nursing home where she had landed. She said that she had no complaints except for the food; Jen knowingly replied that this was typical. While complaints about institutional food service can be found in settings ranging from school cafeterias to military mess halls, Rhonda pointed to specific issues with nursing home food. She pointed to "the pureed food for people can't swallow that's in a nursing home, and they have to have it like, ugh, like baby stuff." She recognized that some people might need that. "But," she said, the majority that I see here with me could eat regularly. When I asked the guy that's the cook, and the guy over the food [for better food, they said], 'Oh, this a nursing home. We don't have that there.' Well, what about—can we get something good some of the time? Can the people have something good, a treat, some of the time? You know? Some of the time, you know?"

Nursing homes also operate according to institutional rhythms, which can be particularly slow in the current context of widespread short-staffing. Jackie's experience is illustrative here. I should note that Jackie offered the most positive comments about nursing homes of any of my informants. After being neglected by PAs and deconditioning at home, she praised the facility for providing "all the basic three meals a day here, all the shots, all the medicine," as well as "phenomenal" physical therapy when she first arrived. Knowing that many disabled people feared nursing facilities, harboring sentiments like Carmen's, Jackie spoke of using her experience "to share with other disabled people that being in a skilled nursing home is not such a scary experience." Still, many of her other comments spoke to the slow pace of services. She regularly got out of bed only once every two weeks, on Fridays, when she went to a music therapy session, after which she met with an insurance representative. At times, she also got up on Wednesdays when there was bingo. When I asked how often she'd like to get up, her reply was almost painfully reasonable: "I'd love to get up at least every other day."

The issue, Jackie explained, was that to get up, she needed to use what she called a sit-to-stand machine. To do so, she needed two staff members to support her; at one point, she had injured her leg using it with only one worker's assistance. One might argue that this is precisely the sort of skilled care that a nursing home should provide. But Jackie said that there were not enough workers who knew how to use the device for her to get up more often. She also went without the restorative physical therapy that would have helped her to maintain the improvements that she had made after entering the facility. Jackie said that staffing issues had grown significantly worse after her facility went under new ownership about three months before we spoke. On the second day of our two-part interview, which took place in mid-December, she told me of a holiday "shopping spree" event in the dining area, where people who had the funds could purchase gifts. She would have liked to go, she said, "because I'm not a person that's good with just being in bed all day." But she was governed by the work schedule of an understaffed institution, and that day, like most days, she had been left in her bed.

Residents also spoke of arbitrary rules. Shortly before our interview in August 2022, Emily had spent several days visiting a group home where she was considering moving. Upon returning to her nursing home, she had to go to the store, and so she requested a pass allowing her to leave. To her surprise, a social worker said that she wouldn't be allowed out for two weeks as an infection control precaution, saying, "You've been gone. We don't know what you brought back." Emily was shocked; she understood the policy only to require residents to quarantine if they had been in a hospital, and even then, only for 72 hours. Fuming, she spoke with the Director of Nursing, as well as a nursing supervisor whom she'd known for four years. Within half an hour, the nursing supervisor sent her back to the social worker, saying, "We've addressed your concern." The social worker told her that she could leave the facility as long as she took a COVID test. When I asked where this alleged policy had come from, Emily said, “He makes things up as he goes along.”

She was not the only one to complain of such arbitrary exercise of authority. Jen, who served as president of her facility’s resident council, asked repeatedly for a set of written policies but never received them. At one point, a manager said that the policies were “in her head and an administrator’s head,” which Jen interpreted to mean that no written version existed. Jason had spent time incarcerated before becoming disabled, and I asked him how he would compare being in a nursing home to being locked up. To my surprise, he said, “I would rather be in a penitentiary.” He pointed to various reasons, including his discomfort among people who were sick or dying, as well as food that was “80%, 90% better than it’s in the nursing home.” But the first reason he cited dealt with whether rules remained consistent. He said, “Because you've got more freedom, you've got more room to run around. You've got set rules at the penitentiary like, ‘This ain't going to change.’ If you do this, this is what's going to happen. If you do this, if you're found guilty or whatever, this is the punishment for it.” Sites of incarceration are rarely described as free of arbitrary rules, making his comment all the more striking. Such stories constitute a key reason why I describe nursing homes as producing a constrained citizenship. If residents are governed by a set of rules that can change at the whim of a manager, their ability to engage with the institution as any sort of rights-bearing citizen is severely restricted.

Residents also described being treated less as individuals than as bodies in beds, with staff attitudes and practices marked by a clear power and status imbalance. Chris, an autistic white transgender man in his mid-fifties who used a wheelchair, described how in one of his short nursing home stays, he informed staff that his roommate was blind, “because they kept giving her *Time* magazine as her leisure activity. She was definitely blind enough to be unable to read, and they hadn't realized that yet." Julio described a roommate who was always left in his bed; workers said that when he was brought out into common areas in a wheelchair, he would lie on the floor. In the staff's eyes, this seemed to be a hassle at best, and perhaps a form of troublemaking. Julio, who had lived with the man for over a year, suspected that he actually found sitting in a manual wheelchair for hours on end uncomfortable, leading him to end up on the floor after trying to make himself more comfortable. Julio suggested using another kind of chair, designed for older patients, that could recline to a near-horizontal position, so that his roommate could be more comfortable but still have time out of their room. No one took up his suggestion. Julio also spoke of general disregard for residents, which could be worse when the main day shift was off duty. "Friday," he said, "the place would smell like normal, but by the time Sunday night came, the unit reeked of urine every weekend because starting after five o'clock, it was like nobody cared."

Shana told a story of a worker entering her room at night to change her elderly roommate's diaper. The worker was on the phone, and she didn't stop her phone call or speak to Shana's roommate to wake her. While the sections of their room were separated by a curtain, Shana could hear the worker punctuated her phone call with periodic instructions, "just like, 'Move, turn, do this, do that.'" As she recounted the shame and embarrassment she felt for her roommate, Shana interrupted herself to acknowledge, "Workers, they're not paid enough." But, she continued, "you're paid to have an ounce of fucking compassion, excuse my language, but compassion when you're going in and doing something as delicate as changing someone's private areas." The tasks that nursing home workers perform are often intimate; for Shana, the worker's failure to acknowledge this was a violation of her roommate's dignity.

Jackie, who had spoken of her efforts to convince other disabled people not to be afraid of nursing facilities, still recognized the power dynamic between staff and residents. At one point, she told me how staff would “do little things like they'll tie your call light around your bedpost where you can't possibly get it,” putting it out of reach. When I asked her why, she said. “They just want to go to the next person, and you're slowing them up” by asking to be positioned more comfortably in bed or making similar requests. Speaking more generally, she said, “When you're living in this situation, they do have the power over you and the authority, so unfortunately, they're going to exercise that power, and they sometimes will use it in the wrong way.” Accepting this imbalance in authority, and the likelihood that it would lead to misuse of power, attested to her constrained citizenship as a resident. Jen also spoke of an uneven power dynamic, which she interpreted in terms of respect. When I asked her to compare her experience at work to her experience in a nursing home, she said that despite the presence of some good nursing home workers, “in large part, there's an attitude [toward residents] of, you don't matter… [At work,] I had a lot of respect. There was no respect in that nursing home.” As social institutions, Jen’s workplace and her nursing home produced profoundly different forms of citizenship; she was a valued colleague in the former, and a trouble-making case to be managed in the latter.

This lack of respect arguably had its most dire impact in the toll of COVID in facilities. Most of my informants were in facilities in 2020, and several recounted trying to get information as the pandemic began, with little assistance from management. Fear and confusion were widespread, while precautions were inconsistent. Shana said that masks in her facility were initially for staff only, and so residents started stealing them from bins where they were kept. Multiple informants contracted COVID, and many spoke of the deaths of people they knew in their facilities. Toward the end of our conversation, Julio turned from another topic to mentioning people who had died of COVID. I asked whether the facility had done anything to recognize those who died. His reply, which spoke to his impression of the concern that management held for residents, is best reproduced in full from the transcript.

> **Matthew:** When COVID-19 was at its worst and so many people were dying, did the nursing home do anything to recognize those losses?
>
> **Julio:** Recognize the losses?
>
> **Matthew:** Yes.
>
> **Julio:** No, I think they totally didn't want to acknowledge it at all. [laughs] Are you kidding me? Most of these places didn't even want to report the deaths and shit.

Amidst this power dynamic, several of my informants reported abuse. Some made brief references to their experiences, indicating directly or indirectly that they didn't want to go into details. Jackie said of an incident early in her stay, “It was abuse. I did ask for help, but my calls for help were not heeded.” She then added, “That's all I can say on that.” Keisha told of being sexually assaulted by another resident, whom management then moved to another floor of the facility. She brought this up while describing her confrontation with management over their inadequate response, and I chose to respect her choice of focus rather than returning to the topic and asking for an account of the assault. During my interview with Rhonda, I asked a general question about how the facility where she lived at the time compared to others where she had been previously. She replied with stories of mistreatment. The worst, she said, was when a CNA “pushed me so wouldn't anybody see in the room, behind my door.” There, Rhonda said, “She slapped me. She slapped me so hard. I had a welt all on my face…There's been some bad experiences in the nursing home.”

Jason offered a more detailed account of the abuse he suffered, and the circumstances leading to it. While difficult to read, I recount it here. One night, he said, the CNA who was supposed to change him came toward the end of his shift. Perhaps in a hurry to leave, the CNA "left everything that was soiled on the ground." The next day, his nurse was unhappy to find this. Jason presumed that the CNA had faced some kind of rebuke, because the next night, he was upset. As he changed Jason this time, the CNA threw a rag that he had been using to wipe him off "right on the table where my food stuff was." Jason, upset, pointed out what he had done, saying, "You better take that off my table." The CNA replied, "F that, you want to get changed?" The CNA and another worker then pushed him up against the guardrails of his bed, and while he shouted that they were hurting him, "He started pushing the towel all the way in my butt." In response to Jason's yelling, a nurse came into the room, but his response was to scold Jason for creating a disturbance. Jason lay on his bed, uncovered and still not changed, for an hour. The next morning, Jason planned to report what had happened to the administration. Instead, a staff member told him, "We got a report that you was cursing nurses out, was acting up all night," and Jason found himself the subject of disciplinary action.

While my focus is on residents, I should note that the profit-seeking and understaffing that harm residents also create difficult working conditions. Nursing home work is a form of care work that is almost axiomatically undervalued and performed largely by women of color. Several residents recognized the low status attached to the work. Rhonda asked, "Who wants to do this? It's just a steppingstone from beginners. Who wants to change people and the things that you have to do in here? Nobody wants to do it even on a good day." The work also carries the risk of mistreatment; Foner detailed physical attacks and racial slurs directed at aides at the facility she studied, where residents were mostly white, and the staff was entirely Black and Latina (1994, 36-38). And the risks from COVID were not confined to residents; the pandemic claimed the lives of nursing home staff as well (CDC 2024). On the whole, structural conditions are not conducive to quality care. But an understanding of the structural forces behind resident mistreatment does not justify the mistreatment, nor does it mitigate the extent to which residents are situated at the bottom of an institutional hierarchy, far from any claim to full citizenship.

FINDINGS: NAVIGATION STRATEGIES

While the previous section describes policy logics that constrain personal agency, nursing home residents still choose how to respond to their settings. This constitutes another form of policy navigation from below, as residents seek to maintain dignity and well-being while securing the care and support they need, despite complex and often-unclear policies. I identified three distinct navigation strategies. These approaches were not mutually exclusive, and it was not uncommon for the same resident pursue two or all three. First, some keep their heads down, expecting little from a nursing home and trying not to draw attention to themselves. Second, they may attempt to navigate the transition process, working with agencies that may eventually place them in their own apartment if they are deemed to have the capacity to manage it. Finally, they may seek to advocate, whether as individuals, with support from family or friends, or even by calling state hotlines or engaging in protest. While organized collective advocacy is rare, the response to residents who attempt to navigate policy by asserting their rights underscores the constrained citizenship that facility residents experience. All three strategies mean facing arbitrary or unclear policies, whether those are at the level of institutional decision-making, eligibility for aid in transitioning into the community, or calling on systems that claim to provide protection against abuse or mistreatment.

“I don’t expect anything more from the nursing homes.”

The first navigation strategy was to keep one’s head down, expecting little from the facility. In many ways, this resembled Laurel’s strategy, discussed in the previous chapter, of not poking the bear. But nursing home residents must deal with staff and management more regularly than SSI and SSDI beneficiaries engage with the Social Security Administration. And so in nursing homes, this strategy placed greater emphasis on maintaining low expectations and not provoking negative reactions. This strategy accepts that one's citizenship is constrained and seeks to manage that as best as possible.

For instance, when I asked Rhonda how things were at the nursing home where she lived at the time of our interview, her reply was telling. She said, "Well, they do what they want to do. I have to fuss sometimes, but people know me now. You know how you get to know people after a long period of time?…I just try to go with the flow. I don't ask for much. This is a nursing home. I don't expect anything more from the nursing homes." Her low expectations were also reflected in her earlier quote about workers, of whom she asked, "Who wants to do this? It's just a steppingstone from beginners." Rhonda shared many strong opinions with me, on topics including the quality of food and the inadequacy of the Personal Needs Allowance. And when she was slapped by a CNA, or faced similar serious mistreatment, she was willing to "fuss" and advocate for herself. But for the most part, she didn't ask for much.

Jackie seemed to have higher expectations of the nursing facility than Rhonda, and she was quick to praise the ways that her stay had benefitted her. She also told me of ways that she advocated for herself, both in day-to-day interactions and in responding to mistreatment. But at the same time, it was Jackie who told me, in a matter-of-fact tone, how rarely she got out of bed because there weren't enough skilled workers to support her. She related her situation in the nursing home to the social fact of her disability, saying, "When you are born disabled, the society has been taught to treat you less than." She framed the nursing home as a space where she gave up autonomy, but one she was willing to endure, saying,

> “When you signed up to be in a nursing home for the time that you're here for rehabilitation, you also signed up for them to take full authority over your body, your mind, over how you're talked to. All of that is part of this. I'm not saying I agree with it. I don't agree, but once again, going back to my heritage, the reason I'm able to deal with it is because this is what our ancestors went through. It's not right, but it is life.”

Emily also pursued a version of this strategy as she worked to managing her relationships with nursing home staff. Her facility had gone under new management roughly a year before our interview. While she’d had a good relationship with the previous administrator, she said that she had nothing in common with his replacement, and they didn’t talk. Stressing her point with repetition, she said, “We don't have anything to talk about. I just stay under the radar. Stay under the radar.” At one point, she mentioned that she had a community pass, which made it easier for her to have cigarette outside of scheduled smoke breaks or to take a walk. But, she said, “If anything happens, like if I fall, or if I act out or if there's a behavior problem, I get my privileges taken away for two weeks.” As a result, she said, “I’m minding my Ps and Qs.” She repeated that she was minding her Ps and Qs later in the conversation when she recounted her experience with the social worker who seemed to make up a quarantine policy on the spot. While she was frustrated, she was careful to “talk sensibly and reasonably.” The arbitrary nature of the rules he imposed underscored the challenges of this navigation strategy; it is difficult to adhere to rules that may change on the spot, or that exist only in the mind of the person enforcing them.

About two months before our interview, that same social worker had come up in conversation during an NHERG meeting between Emily, an intermittent attendee, and Sam, who logged in most weeks. Before this social worker had been hired at Emily’s facility, he had worked at Sam’s nursing home, where he had been a problem for Sam. Sam warned Emily that the social worker would retaliate if she provoked him, and she seemed to agree, asking, “What’s the point in arguing?” Sam, too, regularly said that he wanted to keep his head down and avoid conflict with management. He would periodically offer praise for management of his facility, reporting in June that they had provided ice water during a hot spell, and mentioning a few months later that he'd been assigned a new roommate who was quiet. While he was a regular presence at NHERG meetings, Sam generally deferred when asked to participate in the group's activism. He would frequently say that he was wary of retaliation from management, and so he was keeping his head down rather than "fighting the good fight." Sam's fear was tied in part to a desire not to jeopardize his effort at transitioning into his own apartment. He also spoke often of how he had previously attempted to stand up for himself, objecting to a search of his room, and had suffered for it. I look at each of these in turn as I describe the other two key navigation strategies.

Transition to community living: "When it takes so long, you can get so depressed."

A second strategy for navigating nursing home life was to focus on transitioning out. The systems set up under the Colbert and Williams consent decrees, described earlier in this chapter, allowed residents to work with nonprofit social service agencies to move out of nursing homes into less restrictive settings, including subsidized private residences. The process can also help them to set up PA services and income support, and even obtain basic assistance with needs such as furniture. At the time of our interviews, both Shana and Jason had moved into their own apartments through this process. Rhonda spoke of having moved out of an earlier nursing home into an assisted living facility, though when I asked if it was through Colbert or Williams, she didn't remember. Jackie was in the midst of a transition at the time of our interview, and she contacted me several months later to say that she had moved back to her previous apartment, which her brother had helped her to continue to rent while she was in the nursing home. But she was once again finding it difficult to arrange for the level of PA services, which put her future living situation in doubt. Keisha and Emily were both working to transition out when we interviewed, though both also shared their frustration at how slowly the process seemed to be moving. Sam and Julio also attempted to transition into stable housing, but as I will describe, their attempts ended abruptly when their eligibility for the programs changed.

The process of transitioning under these consent decrees presents a complex policy navigation challenge. The process involves court orders based on legal criteria, and actors from multiple organizations, creating layers of complexity that can be opaque to residents. I wrote in the previous chapter that some informants were unsure whether they collected SSI and SSDI; analogously, it was not uncommon to hear informants refer to Colbert and Williams not as court cases, but as companies or organizations. Beyond the specific settlement under which one tried to transition were a host of other elements. Shana offered a helpful narration of the process. After a point of contact with the nonprofit agency assigned to them, called a “prime agency,” there would be an occupational therapist who “evaluates the ability to do things around the house,” with whom the resident would visit a “practice apartment.” Then came a social worker who “texts you a lot about your social supports,” asking “who's going to do what when you get out.” Only after that would a resident and their support team begin the process of trying to find an affordable, accessible apartment. Shana spoke positively of the process, saying that while a resident was evaluated, “it’s not really like pass or fail,” but a matter of identifying issues on which a resident needed to work. Jackie also praised her prime agency, calling them “the most professional team” that was “working diligently to make this a safe transition.”

But those positive feelings were not universal. Keisha described being told that her process would be delayed because she was not meeting her prime agency’s benchmarks to demonstrate that she could live independently. One example they cited was that she missed a doctor’s appointment. Keisha found this absurd, saying, "Why am I being penalized because the transportation company canceled the ride? I have nothing to do with that.” The housing locator assigned to her was largely inactive, and had recently sent listings in Chicago’s western suburbs, despite the fact that Keisha’s mother, whom she hoped to live with and rely on for support, worked in the city. Keisha, like others, was also frustrated with how long the process took. When I asked if her prime agency had adhered to the timeline they had set in her initial meeting, she laughed. Jason said that he had first met with his prime agency in 2017, had heard that he’d been approved in 2019, and then had finally moved into his own home in 2022.

My notes from NHERG meetings reflect people’s frustration with the slow pace of the process. At one meeting in summer 2022, Sam announced an upcoming meeting with someone from a prime agency, and he was cautiously optimistic that the person would be his transition coordinator. He had begun the process earlier, and he hoped that it would pick up speed, “because when it takes so long, you can get so depressed.” Months later, he said that while had had indeed been assigned a transition coordinator that summer, there had been no movement, dashing his hopes of being out before winter, when he wouldn’t have the outdoors as a respite from nursing home life. At another meeting that summer, Emily said that she had been in contact with an advocate from an area Center for Independent Living, who she hoped would “light a fire under [her prime agency]’s butt” to hurry her ongoing transition. Nearly nine months later, she told the group that she was working with a new housing locator. She hoped that he would be a better match, saying that she needed to work with someone who “doesn’t have a shitfit when I say that a place has too many stairs, and I can’t take the rollator [a mobility aide] down them without taking a header.”

The transition process is based on a complex policy apparatus that seemed unclear to most residents. This meant that the navigation process was fraught, and residents risked inadvertently undermining their transitions. Colbert and Williams are judicial consent decrees, offering transition services only to those who live in facilities within parameters of the cases. If a resident leaves a facility through another process, they forfeit their access to the transition system and its supports. There is an administrative logic at work here, but the opacity of the process could create bureaucratic snares. As a sedimentary policy layer, court orders have sharp edges, and residents attempting to navigate them can abruptly fall off. Julio had lived in a nursing home for four and a half years. He had a very good relationship with someone from his prime agency, but one day, he was told that they had been assigned by the state to cover other nursing facilities. Julio called the news "crushing," and said that he was holding back tears on the phone after learning this. His contact from the new prime agency didn't seem as helpful. Ultimately, Julio worked with his insurance company (which contracts with Medicare and Medicaid) to move into an assisted living facility, which he hoped would be better than the nursing home. But he was still unhappy there, and he tried to get back in touch with his prime agency, seeking to resume a transition process. But his calls went unreturned. Julio wondered if he'd been "blackballed," but as I reviewed our conversation, a more likely explanation became clear: he was no longer a nursing home resident, and thus ineligible for transition services.

A similar process with a more dire outcome played out for Sam. After a confrontation with staff, which triggered a trauma response based on past experiences that I discuss in the next section, he left his nursing home against medical advice. His prime agency dropped him, as he was no longer a Colbert class member. At an NHERG meeting soon afterward, he discussed the possibility of entering another facility and starting over, but he was apprehensive about beginning another multi-year process. A month later, Sam joined a meeting from a sober living house, which had been his best option for housing. His attendance at meetings grew less common, and I learned a few months later that he had become homeless again.

Advocacy and its challenges: "Might as well be talking to the air"

The third navigation strategy is to advocate, whether for oneself or with other residents, to improve nursing home conditions. This is the strategy that most starkly raises questions of citizenship, asking whether a resident is a full member of a political community, or an unreliable narrator who doesn't know what is best for them and whose voice should be disregarded. Too often, the response is to demonstrate the constrained nature of residents' political standing. Some forms of advocacy take place in everyday contexts, with residents acting on their own. One example is Emily's success in challenging the social worker's arbitrary restriction of her permission to leave the facility. On a similar note, Jackie told me how, when she received a paper menu on which to circle her choices for a meal, she would write in specific requests, asking, for instance, for blueberries and strawberries in a fruit salad. Sometimes, she said, "I got some of the things that I wanted, and my roommates would notice," and so she would urge them to make similar requests. Ultimately, nurses told her to stop telling other people, citing possible dietary restrictions. But, said Jackie, "like John Lewis, I'm always in good trouble." Her reference to Lewis speaks to her willingness to advocate, but also to the baseline level of restriction in her facility, where encouraging special food requests can be compared to civil rights activism.

Advocacy is often more effective when a resident has outside support from family members or friends. Residents who had these networks were particularly likely to call on them in extreme circumstances. After Rhonda was struck by a CNA, she said, "I called my daughter and my sister, and they came immediately." Similarly, after the incident of abuse that Jackie referenced but did not elaborate on, she said, "I have let family members know and appropriate action has been taken." She later told me how she kept notebooks to record issues she faced, which she subsequently gave to her family, saying "I got family members that do come in and advocate and say they have the information, so that they can find the right person, and they can advocate for me. Because no matter how good you are at communicating…when you are in this situation, everybody needs an advocate." Jason took a similar approach. While he said that nursing homes were likely to treat white residents with wealthy families better, for residents of color like him, it was particularly important to have support networks. That way, he said, if a staff member considered mistreating him, "They know oh, I can't do that to him because his mama going to call, his sister going to call next, then his baby mama going to call next. Then I'll be getting a phone call from his lawyer."

Others sought to enlist the support of state agencies. Under Illinois law, residents of nursing facilities are formally protected from abuse and mistreatment. As one means of putative protection, the state provides an abuse hotline, the number for which is displayed prominently in facilities. Jason called the state on various occasions to report mistreatment. When I asked how he had learned that this was an option, he said, "They have these abuse hotline numbers on all the doors in there, so I just wrote down these hotline numbers, and started calling them." There is also a team of publicly employed ombudspeople who can serve as resident advocates. Several informants told me about working with their ombudsperson, particularly one who was known to be especially supportive, even attending occasional NHERG meetings. She was the one Jen called in a particularly disturbing moment. It began when Jen and her friend Linda saw a third resident in their facility, a man with dementia, tied to a chair. Described the scene she and Linda encountered, Jen said that the man had a sheet around his waist, "tied in a knot behind the back of the chair. Now, it wasn't tied tight. It wasn't like he couldn't move at all, but he couldn't stand up. He was definitely restrained." Jen felt that this couldn't be justified, and she called the ombudsperson, who in turn called both the police and the state abuse hotline.

But in this case, like many others, little came of the complaints. Jen met the police outside, but when they reached the man's room, he had been untied. The man was unable to speak to what had happened, and staff denied Jen and Linda's accusations. Representatives from the Illinois Department of Public Health, which oversees nursing homes, came the next day. But they, too, saw no direct evidence of what had taken place the night before, and they ruled that the report was unfounded. Jen thought that she had raised the issue through the appropriate channels, only to find her concerns dismissed. Around this time, she also recounted the story to the NHERG seeking their support. The group sent a letter to facility management expressing concern, which led to a meeting. But management continued to deny the incident.

Soon, Linda began to face retaliation. Small requests for things like towels were denied. Her medications, which she needed to take according to a strict schedule, came erratically. The man who had been tied up was her friend, but soon staff restricted her visits to his room. Soon, they restricted her visits to yet another friend's room, supposedly for that friend's protection. Before long, after a confrontation that involved her being yelled at by a staff member for violating these new restrictions, Linda was "sent out" on a stretcher to the psych ward of a hospital, prohibited from returning to that facility. Jen, fearing she was "next on the hit parade," soon seized an opportunity to move out on her own.

Linda's story illustrates two key points. The first is that advocacy can bring retaliation, as many informants told me. It may come in relatively minor or subtle forms, like the denial of

Linda's request for towels, or Jackie's story of staff putting call lights out of reach. Or it could also be as severe as Jason's assault, which appeared to be triggered by his having had the audacity to object to what was thrown on his table. The pervasive risk of punishment for speaking up reflects the constrained nature of residents' citizenship. Second, as with Linda, several informants reported the misuse of psych wards as a form of punishment. Jason was in a nursing home because he was quadriplegic, not because of a mental health issue. But he reported being sent to psych hospitals three or four times, "because I refused to let them just walk over me." When I asked about one of those hospitalizations, he said, "I stayed there for two or three days, and the doctor said, 'There ain't nothing wrong with you.'" Shana did have mental health issues in her history, but her account of multiple trips to psych wards spoke more of punishment than care.

In Sam's case, the use of psych wards as a form of retaliation appeared successful in silencing advocacy. Early in my time in the field, after increasing tensions around privacy, including staff walking in on him in the bathroom, Sam was in a confrontation with nursing home staff over their insistence on searching his room.[4] This led to his being sent in an ambulance to a psych ward, for what he called "eleven days of hell." When he came back, he told other NHERG members that if staff wanted to search his room, he would not object in the same way. Over the following year, Sam would frequently refer back to this experience while emphasizing his desire not to make waves or cause problems. To the extent that Sam's punishment was meant to keep him in line, it largely succeeded. This was why he said so often that he was keeping his head down. It also seemed to do him real harm. When Sam left the facility abruptly a year later, it was because he was again being threatened with a mental health

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[4] In a later NHERG meeting, a member asked a lawyer, who attended as a guest speaker, if nursing home residents had a right to some level of privacy. She said that they did, despite Sam's experience.

hospitalization. Facing a repeat of that trauma, he chose to leave without a discharge plan, setting himself on a course that led to homelessness.

The outcome of Jen and Linda's attempt at reporting the crude physical restraint of a resident speaks to another larger point: Despite the existence of hotlines and ombudspeople, residents have few effective means of redress or protection from mistreatment by facility staff. When complaints are investigated, the accounts of staff seem to be granted more credibility. Jen said that complaints like hers were often dismissed as "attention-seeking." Jason estimated that he had filed 20 complaints during his seven years various facilities, but said, "They always found the nursing home was not liable," later adding, "might as well be talking to the air, because nothing's going to be done." The facility where Jason was assaulted tried to kick him out. But with assistance from a non-profit legal advocacy organization, he successfully contested it, with a judge finding that this was a wrongful eviction. But even this victory showed how few options he had; he did not win any damages, but only the right to stay in the nursing home where he'd been abused. Recounting a conversation with his lawyer, he said, "They found that they had no reason to kick me out. She asked me, 'Do you really want to go back there?'"

At one point when I visited Keisha, she spoke with an ombudsperson who offered a similar dubious assurance. He had come to her facility to meet with Keisha and an administrator, trying to address concerns that Keisha had raised. The administrator didn't show up, citing another emergency meeting. As Keisha and the ombudsperson spoke, he tried to mediate, though he did recognize that Keisha had grounds for complaint. But rather than promising that he would resolve the issue, he assured her that if the facility attempted to discharge her involuntarily, she would have ten days to appeal, and she should contact him. Like Jason, she was promised that she could stay in the facility where she was mistreated, but not that conditions would improve.

The limited nature of residents' means of redress were further manifested in the response to 911 calls. Access to a city's emergency services constitute a mark of citizenship; a full member of the community can call for assistance from first responders in a crisis. But I heard from more than one informant that their calls were dismissed when dispatchers learned that they were in nursing homes. Rhonda recounted an incident of serious mistreatment by a staff member that led her to call 911. But, she said, “It was really crazy to me. They just hung up. Three times, they hung up on me.” She understood this to be a rule that she hadn't been familiar with, saying, “I didn't know that you can't call the police for a nursing home unless you have to get the nurse, someone in the office, or something to call.” Ultimately, her sister called on her behalf. Keisha, who lived in another facility, told me of a time when she asked a nurse to push her bedside table closer to her. The nurse, annoyed by an earlier part of her interaction, shoved the table with enough force that it hit Keisha in the face. Shocked, she called her mother and sister, who both urged her to call the police. But, she said, “At first, when I dialed 911, they were like, ‘Oh, we can't dispatch your nursing home unless the nurse or someone calls.’ I'm like, ‘Since when?’ She's like, ‘Yes, that's our policy.’” Ultimately, she also asked her mother to call, and police eventually came, though at first they didn't come up to her room.

Anecdotal stories of similar encounters circulated in NHERG meetings and other conversations. One possible explanation, offered by Jen and others, is that 911 operators may assume that calls from nursing home residents come from people who are confused or delusional, leading dispatchers to disregard the calls as nuisances. But as this chapter demonstrates, there are plenty of residents with legitimate concerns who can articulate them clearly. (And, of course, there are also 911 callers living in the community, facing far less pressing situations, whose calls are still treated as valid.) Dispatchers may also be reluctant to send first responders to nursing facilities to avoid fruitless engagement with staff, who may insist that there isn't a problem and attempt to keep them from entering. A secretary at a police precinct seemed to suggest this to Keisha on a separate occasion, telling her "You're behind locked doors," and so police couldn't necessarily reach her if she called. But whatever the justification, Chicago's emergency response system appears to be another context in which claims made by nursing home residents are not treated as credible, highlighting the constrained nature of their citizenship.

DISCUSSION

This chapter makes two sets of arguments. First, I situate contemporary Medicaid-funded nursing homes in terms of three key aspects: their institutional character, their for-profit logics, and their role as sites of poverty governance. I illustrate how each of these characteristics manifest in the accounts of my informants, from their pathways into nursing homes to the slow rhythms of care to the dynamics that can generate mistreatment and even abuse. All three of these factors undermine residents' political status, setting the stage for the experience of constrained citizenship.

The chapter then turns to the strategies of policy navigation from below by which residents seek to make their way through facilities. They may keep their heads down, expecting little from a nursing home. They may concentrate on transitioning out, navigating the intricacies of a set of services based in judicial consent decrees. And they may try to advocate for themselves, whether on their own, with friends and family, or through state channels ranging from abuse hotlines to local police. These strategies are not mutually exclusive; several of my informants pursued all three. But it is notable that none reflect an assurance that facilities would provide the care that residents needed. Even Jackie, who spoke of trying to convince other disabled people not to be afraid of nursing homes, cautioned that "in this situation, everybody needs an advocate," and focused on transitioning out. Instead, there was a broad sense that one could not demand too much of a nursing home, and that pushing too hard could make things worse. This reflects the constrained citizenship experienced by residents, who like paupers in Marshall's almshouse, had given up a measure of standing to make claims on either facility management or the state.

Residents performed this navigational work while being situated within complex and cross-cutting policy categories that could create confusion and distress. Those who collected SSDI were told to sign over their checks to the facility, suggesting that living there placed under a new set of policies that they were hard-pressed to challenge. Nursing home residents also appeared to be categorized apart from the general public by 911 dispatchers, denying a means of redress—and a measure of social belonging—to those facing abuse. In some cases, there were profoundly different policy implications to those living in different types of congregate settings. While the PNA for nursing home residents was $30 per month, it was $90 for residents of assisted living facilities. Julio pointed to this as one reason for moving to an assisted living building. But by leaving his nursing home, Julio inadvertently made himself ineligible for transition services, a process so unclear that when we spoke, he was unhappily asking why his prime agency wouldn't return his calls. The structure of the Colbert settlement, which applies only to Cook County, means that a resident could also find themselves ineligible for transition if they moved to a nursing home in a neighboring county.

While I draw genealogical and functional links between nursing homes and contexts such as historical almshouses and contemporary homeless shelters, I should make clear that I do not mean to claim that these continuities are the product of intentional design. The social worker who referred Jen to a nursing home was, most likely, simply trying to find a resource for a woman with medical needs who faced homelessness in Chicago in January. In the moment, he likely gave little thought to how her situation situated her in a long history of disabled people facing poverty. But the fact that sending her there was an option reflects the historical development of Medicaid as a funding stream that has allowed nursing homes to become a large and profitable industry, even while some other institutions, including many state hospitals and asylums, have reduced capacity or closed. This development reflects the contingent, and at times surprising, manner in which policy sedimentation can unfold.

This chapter draws on experiences shared by eleven informants, whose accounts included some of the longest interviews in this project, as well as the regular meetings of a small activist group. This is obviously a limited number of sources. Because of my focus on disability rather than old age, my informants are also far younger than the overall long-term nursing home population. And in their willingness to advocate, the members of the NHERG are surely not representative of the average nursing home resident. Those willing to take part in activist work are a minority in most social groupings, and perhaps even more so in nursing homes, which are rarely hospitable to political agency. I addressed this in part through my interview structure, where instead of focusing solely on residents' grievances, I asked what they had hoped for in entering facilities and probed as to the benefits of their time there. And while they certainly had grievances, it would be a mistake to dismiss this group as complainers or malcontents. In their pursuit of official channels to issue complaints or seek redress, and in their insistence that facilities could improve, residents who advocated for themselves demonstrated a faith in state oversight systems and an optimism about how nursing homes could be. The resistance that they encountered in making those claims reflected both the structural characteristics of contemporary nursing homes and their constrained citizenship as residents, which made it easier for their claims to be dismissed.

Moreover, my focus on this set of residents fits with Zussman's assessment that the effective case studies focus on cases whose importance comes "not because they are representative but because they show a process or problem in particularly clear relief" (2004, 362). The daily life of institutions is thrown into sharper relief by the experience of those seeking to prove that they are capable of moving out on their own, or whose advocacy elicits a response that highlights the systems of power within a facility. If even those who were willing to advocate for themselves faced substandard conditions and policies designed to make them docile, it suggests that those with less capacity or inclination to speak up may have quietly borne similar treatment or worse.

CONCLUSION

Contemporary Medicaid-funded nursing homes set residents apart from the broader community. They do so both physically, as congregate institutions where staff can control entry, and metaphorically, by restricting residents' political standing. The facilities generate a form of constrained citizenship, whereby institutional rhythms and the pursuit of profit offer residents few options. Nonetheless, residents still pursue various strategies to navigate both daily life and the complex web of policies they face, at levels ranging from facility rules and the whims of individual staff members to emergency dispatch practices, judicial consent decrees, and Social

Security Administration rules. Some residents sought to advocate for themselves and for others by means including organized activism campaigns, to which I turn in the next chapter.

Chapter 5

Disability Insurgent: Contemporary Activism

In the previous chapter, I recounted a story from Shana, a 38-year-old white woman who had lived in various nursing homes for seven years before successfully transitioning to her own apartment. In one facility, she described listening as a staff member continued a conversation on her phone as she entered the room and changed her elderly roommate's diaper. Shana expressed her discomfort and outrage at the worker's failure to greet her roommate and engage with her as a person, let alone to acknowledge the intimate nature of the task she was performing. This incident, Shana said, played an important role in making her begin to think, "Something needs to be done in nursing facilities. This can't continue." She did not reach this conclusion in isolation. Not too long earlier, she had attended a financial literacy workshop at a local Center for Independent Living (CIL). On her first day there, a staff member had invited her to stay for a meeting that evening of Chicago Disability Action. Over time, she became involved in both the CIL and the activist group, and she found herself trying to reconcile the rhetoric of the organizations with daily life in her nursing home. Presenting the contradiction she faced, Shana said, "I'm going to these meetings…They're all about disability rights and disability pride, and I'm like, 'Disability pride, disability rights, disability this, disability that.' Then I see what's going on around me [in the nursing home], and I saw anti-disability. It's like, 'What the fuck? How can I put these two puzzle pieces together?' It's just—they don't fit."

Ideologies and practices of ableism—or in Shana's words, anti-disability—are pervasive throughout society. Ableism permeates the workforce, systems of income support, and nursing homes like the one where Shana lived at the time, structuring the policy regimes that disabled people must navigate and the manifestations of disabled citizenship generated therein. Disabled people are often positioned as the objects of benevolence or charity, and as Marshall wrote, charitable bodies have generally taken the view "that those who received their help had no personal right to claim it" (1950, 33). Those who receive charity are expected to be grateful and docile. But contrary to such expectations, ableism does not go unchallenged. Efforts to contest marginalization and exclusion have played fundamental roles in generating new layers of policy. Organized activist groups offer disabled people the opportunity to believe that ableist structures are, in Piven and Cloward's phrase, "both unjust and mutable" (1977, 12). In Shana's case, her relationships to activist groups were essential in bolstering her sense that "something needed to be done." After some time, in another nursing home, she and two other residents circulated a petition protesting conditions, drawing supportive attention from a local politician. At the time of our interview, she was active in the leadership of the Nursing Home Emergency Response Group (NHERG), trying to ensure that contemporary nursing home residents would live under better conditions than she had endured.

This chapter focuses on activist efforts as forms of *insurgent citizenship* (Holston 2008). I wrote in Chapter 1 that disabled citizenship was fundamentally contested. The process of policy sedimentation is driven in part by waves of activism that create new laws and programs that sit uncomfortably over the old. I pointed there to the passage of the Americans with Disabilities Act (ADA, with its promise of anti-discrimination protections in the workplace, as a contrast with income support programs created in earlier eras that understand disabled people to be located outside the labor force. But the ADA became law in 1990, and the protest cycle amidst which it was enacted is now in the past. In this chapter, I ask how contemporary disability activism challenges marginalization during a period when social protest is widespread, but disability-focused contention may be less prominent. I focus specifically on the work of the

NHERG, particularly on its efforts to change state law governing the operation of nursing homes, which have thus far met only limited success. This case highlights the challenges of claiming citizenship by a group that is widely seen, by virtue of their disability and policy location, as lacking the capacity to care for themselves, and thus as not worthy of recognition as full political actors. Within this context, I consider the group's campaign in two registers: as the instrumental, largely unsuccessful, pursuit of policy change, and as the defiant expressive enactment of alternate conceptions of disability and self.

This activism constitutes a distinct form of *policy navigation from below*. While much of the policy navigation discussed thus far has taken place individually, in contexts where citizens are often isolated from one another, the navigational work of insurgent citizenship tends to be performed collectively. Its goal is not only for one disabled person to secure care or benefits, but to change the broader structures through which resources are allocated. The disabled activists whose work I describe in this chapter faced the tasks of most organizing campaigns, i.e., communicating their issues to decision-makers and winning their support, while also sustaining group members' commitment over the course of a long campaign whose success was uncertain. They also faced additional, disability-specific access barriers and ableist attitudes that made common advocacy tactics unfamiliar and even impossible for some. All of this made participation more emotionally and physically difficult, even for those who could most benefit from the policy changes they pursued.

BACKGROUND

Insurgent citizenship is not a concept that appears in Marshall's discussion of citizenship and social class (1950). While he historicizes his account of the emergence of different forms of citizenship, his approach emphasizes the impact of new legal regimes in a progressive narrative of expanding citizenship. The work of political actors outside of government seeking to challenge or expand the bounds of citizenship is largely absent from his account. In contrast, Evelyn Nakano Glenn (2002) writes in depth of how groups who were denied political rights nonetheless pressed for full citizenship. Glenn argues that substantive citizenship, as a matter of belonging, includes “recognition by other members of the community” (52). She later discusses how this recognition was enacted by groups challenging their marginalization. In the US South during Reconstruction, she writes of the mass attendance of African Americans, including large numbers of women, at the Virginia Constitutional Convention in Richmond from 1867 to 1868. Citing historian Elsa Barkley Brown, Glenn argues that Black Virginians operated in two political arenas, one external and one internal. While the political rights of Black women were not formally recognized for decades, the internal arena became a space in which both men and women were deeply engaged in political life. And as white supremacists rolled back Reconstruction-era gains, this internal Black political community sustained resistance in the external political arena (93-98).

In a subsequent lecture, Glenn describes the political work of African American women during this period as an example of insurgent citizenship (2011, 9). She attributes the term to anthropologist James Holston, who uses it to describe an orientation toward citizenship that arose in the working class urban peripheries of Brazil. Holston (2008) argues that Brazil’s approach to citizenship has historically been marked by particularity and differentiation in status that offer privilege to a relative few. But while this system of citizenship still holds great sway, Holston writes that “an insurgent form of citizenship has arisen,” posing a challenge to the “entrenched citizenship of unequal social relations” (18). He portrays insurgent citizenship as a destabilizing force, one which “bubbles up from the past in places where present circumstances seem propitious for an irruption" (34). Glenn applies this concept in her analysis of the undocumented student movement in the US. Higher education students without formal immigration status face an uneven and contradictory policy landscape across federal, state, local, and even university levels. While Glenn does not use the term, this political terrain is rooted in a form of policy sedimentation. Past court rulings, like the 1982 *Plyler v. Doe* case that protected undocumented youth in public primary schools, operate in sharp tension with more recent anti-immigrant legislation. In this context, undocumented youth have supported one another while organizing for policy change at multiple levels. Glenn describes the activism of undocumented students as an enactment of insurgent citizenship, one which centers questions of belonging, as well as the role of education as a public good and social right (2011, 9-17).

Drawing on Glenn's application of Holston, I approach disability activism as a form of insurgent citizenship. Contemporary disability activism is situated within a longer historical tradition, including the rise of advocacy within the disability nonprofit sector in the 1970s and early 1980s documented by David Pettinicchio (2019, 85). The shift toward advocacy helped to sustain two waves of protest events, first targeting the federal government in the late 1970s and early 1980s, and then focused on accessible transportation and the nursing home industry in the late 1980s and early 1990s (111-114). Activists developed a repertoire of contention (Tilly 1995) with an emphasis on confrontational protest. Tactics made particular of use power wheelchairs as means of disruption; such chairs weigh hundreds of pounds and are difficult to remove from a street or office doorway. At the same time, police were often reluctant to arrest visibly disabled protesters; one officer at a Los Angeles transit protest in 1988 told reporters, "We look bad no matter what we do" (Pettinicchio 2019, 115).

Chicago was an important site of disability protests at this time, contributing to an organizing tradition with direct links to the work of CDA and NHERG in the current moment. The July 1984 issue of the *Disability Rag* reported that five members of ADAPT used their wheelchairs to block bus traffic outside Chicago Transit Authority (CTA) headquarters for over an hour, in protest of the CTA's plan to purchase buses without wheelchair lifts (5). The January-February issue the following year brought new of continued transit protests, this time citing the *Barrier Buster*, the Chicago ADAPT chapter's newsletter (1985, 9). Disability activism in Chicago took place in the courtroom as well as the street, winning a key victory in early 1988 when a judge ruled that the CTA had violated the state's Human Right Act in its treatment of disabled would-be transit passengers (*Disability Rag*, March-April 1988, 9). And transit was not the only realm in which disabled people pushed for full citizenship. The *Disability Rag* also reports on an ongoing lawsuit by a group called the Network of Illinois Voters with Disabilities over physically inaccessible polling places in the city (September-October 1988, 17).

Across the nation, many of the disability protests during this period were small by the standards of other movements. Barnartt and Scotch, in their encyclopedic assessment of US disability protests in the final three decades of the 20th century, write that the largest was reported to have 6,000 participants, and the largest quartile in their data set "had only 182 participants or more" (2001, 81). But social networks overlapped to create links between activists and more institutional organizations. Charlton, for instance, wrote of how Chicago-based Access Living, one of the country's largest Centers for Independent Living (CILs), both maintained ties to the Clinton administration and supported the local ADAPT chapter alongside other service provision and policy advocacy (138-139). CILs and activist groups together became sites for the cultivation of what Sharon Groch calls “oppositional consciousness,” whereby disabled people saw themselves as members of a group facing structural injustice that they could come together to oppose (2001). Such consciousness can be an essential element of insurgent citizenship.

The protest cycle of the 1980s and early 1990s also engaged a wider group of disabled people through the chronicling of action in print periodicals such as the *Disability Rag*. As I have written elsewhere (Borus, in progress), the *Rag* addressed its readership as participants in an ongoing movement, offering reports from protests as small as a picket against an inaccessible store entrance, and as large as ADAPT’s protests against the annual meetings of the American Public Transportation Association. Many narratives sought to evoke for readers the affective power of confrontational protest. A key example lies in a report by Mary Johnson, part of a ten-page spread detailing an effort to win final passage of the Americans with Disabilities Act (ADA). This account focused on a group of activists who, rather than making lobby visits or attending hearings, created a disruption in the US Capitol Rotunda that succeeded in bringing legislators, including then-House Speaker Tom Foley, to speak with them and hear their demands. Johnson wrote,

> “What must it be like to be an ADAPT member at such a time? Having lived in a nursing home, nobody paying any attention to you, nobody ever listening to your words? How must it be, having to use a communication board to be understood by the grocery clerk; avoided by the postman because you drool or shake, to have captured the heads of one of the most powerful legislative bodies on earth? To be holding them captive, before burning television lights, able to ask them anything you want? What must that power feel like? For that—before all else, before everything else—is what ADAPT is all about” (May/June 1990, 24).

Johnson emphasized that the goal of this confrontation, which ended with 104 arrests, was not solely or even primarily to offer input to legislators. It still demanded passage of an important bill; chants of “ADA now!” left no doubt of that. But it was also the intentional creation of a space in which disabled people stopped being polite or ashamed, and instead reveled in bold defiance of institutional power. The circulation of Johnson's narrative of the protest expanded its reach, enabling readers to imagine themselves into this instantiation of insurgent citizenship.

Pettinicchio writes that by the middle of the first decade of the 21st century, disability protests had become significantly less frequent, while the number of active disability organizations also declined (2019, 159-160). Still, he points out that disability organizations were central to many confrontational protests, including sit-ins at Congressional offices against proposed rollbacks of the Affordable Care Act early in the Trump administration (139-140), suggesting the persistence of the earlier repertoire of contention. Alongside rights-based disability activism, the period since 2005 has also seen the emergence of a disability justice paradigm, which has built on disability rights organizing and which organizers with the Sins Invalid collective call the "next stage in movement evolution" (2019, 11). Disability justice advocates point out that while the disability rights movement established essential legal protections, it tended to center the experiences, leadership, and needs of white disabled people, particularly those with mobility impairments, while overlooking the ways that disability intersects with race, gender, sexuality, and other axes of difference. The disability justice framework centers the leadership of disabled people of color and queer and gender-non-conforming people, with an emphasis on intersectionality and cross-disability solidarity.

Building on these principles, movement leaders with Sins Invalid call for organizing across movements, aligning disability justice activism with ongoing efforts for racial, reproductive, and environmental justice, opposition to police violence, and other liberatory campaigns. At the same time, drawing on disabled experience, they call for an organizing strategy that emphasizes sustainability, moving "away from urgency and into a deep, slow, transformative, unstoppable wave of justice and liberation" (25). Pointing to the isolation of many chronically ill and disabled people, Sins Invalid writes that disability justice is still a "developing framework" wherein movement work "is largely done by individuals within their respective settings," including online spaces and transient organizational structures (17). With this expansive definition of movement work, the disability justice framework suggests that disabled insurgent citizenship can be fostered beyond the bounds of traditional movement spaces. Akemi Nishida builds on this with her articulation of "bed activism," highlighting the work of sick and disabled people who spend much of their time in bed, including those who raise a fist in solidarity with street protests that they find themselves too sick to join. Nishida points to beds as spaces of writing, advocacy, and connection, but also as spaces of rest, where disabled people defy the mandates of capitalist productivity. She argues that bed activism constitutes a form of "ontological resistance," valuing people's existence rather than "their abilities and capacities to live closely aligned with social norm and capitalist demands" (2022, 166), thus locating expressions of insurgent citizenship in spaces that are easily overlooked.

The emergence of disability justice frameworks did not displace disability rights organizing. Indeed, both of the groups that I studied, Chicago Disability Action and the Nursing Home Emergency Response Group, are arguably constituted more around rights claims, though they also work to enact disability justice principles around intersectionality and leadership by the most impacted. But in this brief review from the heyday of the disability rights movement to emergent disability justice thinking, there is a continuity in the conviction that disabled insurgent citizenship can take multiple forms. It may be manifested through an established repertoire of contention in which power wheelchair users create disruption by placing their bodies and chairs in the gears of daily business, risking arrest. And it may also be found in the actions of those who can not join such protests, instead reading and writing about them, whether in a copy of the

Disability Rag that arrived via the mail 40 years ago, or on a laptop balanced on a pillow by someone in bed today. As in the case of the ADAPT activists in the Capitol rotunda in 1990, the work of activists today operates in two registers: as an instrumental effort to secure policy change, and as an affective expression of resistance of social marginalization.

DATA SOURCES

Unlike in previous chapters, I use my individual interviews primarily as background here. Instead, this chapter draws primarily on ethnographic observation of two organizations, Chicago Disability Action (CDA) and the Nursing Home Emergency Response Group (NHERG).[1] Chicago Disability Action has deep roots in the local organizational landscape, with connections to the protests for accessible public transit of the 1980s. A number of leaders and staff members of more mainstream organizations in the disability field, including area CILs and local and state government agencies, have worked with them or operated in coordination with them over the decades. The group has been through considerable change since then, though a shrinking number of movement veterans remains involved; one member happily refers to himself as part of the “old farts caucus.” While CDA works on a variety of disability-related issues, often based on what members or other groups bring to their attention, they maintain a reputation for confrontational protest, often situating themselves as a radical flank (Haines 1984) to bolster the demands of other groups. Before the onset of the COVID pandemic, the group met once a month in person; since then, those meetings have taken place over Zoom.

The NHERG, which I have already introduced, came together during the first wave of COVID in Spring of 2020, calling for nursing home residents to have the opportunity to relocate

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[1] I also spoke with leaders of a third organization, explicitly modeled around disability justice principles, which was working on a campaign to win a state supplement to SSI benefits. Unfortunately, this group folded soon after I began my field research.

to safer settings such as unused hotel rooms. It built on previously existing relationships, including some ties to CDA, but created its own organizational identity. By the time I began gathering data in early 2022, the group had largely moved on from its demand for resident relocation, shifting its focus to improving conditions within nursing facilities. In addition to the weekly residents' meetings that provided significant data for Chapter 4, the NHERG also held organizing meetings twice a month, also on Zoom, to plan and advance its campaign work. Both groups were majority white, but with significant leadership by members of color. CDA was roughly evenly split between men and women, with one nonbinary leader, while the NHERG was made up of more women than men.

Both groups took steps to make their meetings accessible to people with various disabilities, including providing captioning and, in some cases, American Sign Language interpretation for Deaf and hard-of-hearing participants. The culture of both groups was also marked by a measure of access intimacy, a term coined by disability scholar Mia Mingus. Mingus describes access intimacy as "that elusive, hard to describe feeling when someone else 'gets' your access needs." She goes on to write that it is "also the intimacy I feel with many other disabled and sick people who have an automatic understanding of access needs out of our shared similar lived experience of the many different ways ableism manifests in our lives. Together, we share a kind of access intimacy that is ground-level, with no need for explanations" (2011). The term first arose during my research in my interview with Joanne, who had been involved in CDA in the past. While she didn't remember with whom the term originated, Joanne described access intimacy as characteristic of most disability community contexts where she spent time, characterized by a level of familiarity that meant that "we don't have to explain needs or access needs. You just have to say I have an access need." I saw this playing out in understated quiet enactments of community norms in organizational spaces. For instance, one evening, a relatively small group was making casual conversation on Zoom before an NHERG organizing meeting. One member mentioned her lymphedema treatment, making note of compression garments that she had to wear to help her circulation. Despite the relatively intimate nature of the topic, everyone took her comments in stride, without expressions of discomfort or embarrassment. People sympathized with her sentiment that the compression garments were a pain, but notably did so without pity, while a few asked matter-of-fact questions. The exchange was soon swept to the side as the meeting began. The topic was treated as unremarkable, reflecting a level of access intimacy that allowed for casual discussion of an aspect of some disabled lives that would have created awkwardness in other social settings.

The work of CDA and NHERG must be understood in the context of both Chicago's organizing tradition, and the power dynamics of the Illinois state legislature in Springfield. Saul Alinsky, whose model of community organizing was once among the most dominant in the US, began his work in Chicago's Back of the Yards neighborhood before World War 2 (Alinsky, 1941). In recent years, many Chicago community organizers have embraced new approaches to their work, collaborating across racial and geographic boundaries while engaging directly with political economic realities that have changed drastically since Alinsky's time. Lesniewski and Doussard argue that these approaches have been effective, pointing to successful campaigns to protect workers against wage theft, raise the minimum wage, and provide workers with paid sick leave (2017). The strategies of disability activists have been shaped by both old and new organizing approaches. In my research, it was not unusual to hear older disability activists speak of working with Shel Trapp, an organizer trained in Alinsky's tradition who was best known as a founder of National People's Action, but who had also worked with ADAPT later in his career

(Marsico, 2010). But disabled activists also learned from and participated in contemporary organizing, and organizations operating under various models engaged with CDA and NHERG as coalition partners and collaborators.

While community organizing in Chicago is flourishing, many organizations still struggle to enact change at the state level. A telling example is the case of the Chicago Teachers Union, CTU. Since electing new leadership in 2010, CTU has established itself as a pillar of Chicago's left, collaborating with community organizations and advancing a broad vision of the common good. In 2012, CTU went on strike for the first time in roughly 25 years, invigorating city-wide organizing and inspiring other teacher's strikes across the country in subsequent years (Lesniewski and Doussard 2017; Blanc 2019). In 2019, under a different mayor of Chicago, CTU successfully went on strike again. Throughout this period, CTU was arguably the most powerful popular organization in Chicago. At the same time, Chicago was the only school district in Illinois where the school board was appointed, rather than elected. Winning an elected school board was one of the top priorities for the new leadership in 2010 (Pratt 2024, 105). But despite the union's power, it took until 2021 to pass the state legislation allowing Chicagoans to elect their own school board (179). That it took an organization as powerful as CTU more than a decade to pass state legislation offers one indication of the uphill battle that NHERG faced in its campaign.

This chapter focuses on the NHERG's ongoing effort to pass state-level legislation to improve nursing home conditions. I draw not only on regularly scheduled meetings, but also on four trips with activists to Springfield, the state capital, over a period of about six months. Springfield is about three hours from Chicago, allowing for day trips, albeit exhausting ones. On two occasions, I traveled there and back by train with other activists; on a third occasion, for logistical reasons, I drove on my own. The fourth trip included an overnight hotel stay, in hopes of facilitating an early morning protest the next day; I caught a ride with Tim, a middle-aged white man and long-time organizer who worked for the NHERG. All four trips offered the opportunity for longer, less structured interaction with activists than our usual Zoom meetings allowed. Crucially, these meetings also offered opportunities to observe activists' interactions with lawmakers and their staff. I was also able to join some online meetings between legislators and activists outside of their Springfield visits, as they discussed campaign strategy and legislative prospects. Encounters between activists and the legislative branch, whether in an in-depth meeting with a bill sponsor or a brief pitch to an aide at their desk, offered important windows into the work of making insurgent citizenship legible to policymakers and attempting to forge policy change, while also sustaining their movement.

FINDINGS

This chapter takes a different form than its predecessors, as I offer a more narrative account of the NHERG's thus-far unsuccessful effort to pass legislation. I begin with their efforts to win support through institutional channels and describe the roadblocks that they encountered. Some of these obstacles were not specific to disabled citizenship. The NHERG was a grassroots organization seeking to impose new regulations on a powerful and well-connected industry. It is almost unnecessary to write that they faced a significant power imbalance, particularly in light of the Springfield power dynamics described in the previous section. But they also faced structural barriers to participation by activists with deep stakes in the campaign, and ableist attitudes from both policymakers and opponents. The NHERG had to navigate these obstacles and make the experiences of disabled nursing home residents legible and compelling to state lawmakers. After some setbacks, while still seeking to build legislative support, the group turned to toward more contentious protest in an effort to escalate the campaign. This shift not only served as an external tactic, but it also helped to sustain the commitment of activists who otherwise felt dismissed and disrespected. Through both its external challenge to unequal social relations and members' knowing support of one another, this campaign constituted an enactment of insurgent citizenship.

The work that activists did to build support among lawmakers, circumvent ableist barriers, and sustain ongoing commitment constituted a form of policy navigation from below. Nina Eliasoph's concept of frontstage and backstage realms in the work of activist groups is useful in explicating this process (1998, 7). Eliasoph observed that, contrary to Goffman's expectations, backstage speech made room for broad political discussion, while frontstage pronouncements in public fora were characterized by narrow conceptions of personal interest, often framed as the fears of concerned moms. Among the NHERG, I found echoes of this dynamic; as I will discuss, personal narratives of mistreatment, framed around a direct interest in protecting oneself and one's peers, were among the most valued forms of frontstage speech. But the group's public presentation was also undermined at times both by structural barriers and by attitudes toward disabled speakers, who were not taken seriously or treated as credible. This frustrating dynamic was often brushed off, even in backstage settings, if it was remarked upon at all. But it took a clear emotional toll. When organizers turned to more confrontational protest, they created a space in which the rejection of those slights, and the insistence that activists would not be blown off, moved into the frontstage realm.

Campaign demands

In mid-2022, NHERG leaders developed a platform of demands, seeking to improve conditions for current residents while advancing a long-term agenda of non-institutional living.

Key elements included a tripling of the state-provided Personal Needs Allowance (PNA) for nursing home residents, discussed in the previous chapter, from $30 to $90 each month. Another important demand, informed by experiences of abuse and of being "sent out," as also discussed in Chapter 4, sought to bolster protections for residents against retaliation by facility management. While formal anti-retaliation protections already existed, the group sought to make them more enforceable. They proposed to create a private right of action, modeled on Chicago's landlord/tenant ordinance, that would assist residents in bringing legal claims against facility management. They also called for the state to fund a pool of on-call personal attendants (PAs) to help people avoid nursing home placement in the first place, a need reflected in Jackie's story in the previous chapter of a health crisis hastened by inadequate and unreliable PA services.[2] Longer-term measures included funding for disability-accessible affordable housing, and a task force to re-envision the state's long-term care system, which would be charged with reducing by half the number of people living in nursing homes.

These demands were the subject of much discussion, both as the platform was being crafted and afterward. I heard residents say on more than one occasion that the increase in the PNA would have the most tangible positive effect on them and others in nursing facilities. The call for a private right of action as an anti-retaliation measure came from Tim, who had previously worked in tenant organizing. The technicalities of how it would offer protection were initially unclear to many, including myself. But over time, members embraced it as a means to win greater standing for residents facing retaliation. On the whole, members saw the legislative package as a reasonable start. If passed, it could benefit residents, but no one seemed to expect that it would truly transform nursing homes in Illinois. For some, this meant that the demands

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[2] To be clear, while I point to her story to illustrate an issue, Jackie was not involved with either NHERG or CDA.

did not go far enough. I witnessed at least one interaction in which a long-time disability activist rejected any prospect of improving nursing homes, arguing that they should instead be shut down. This stance, which essentially dismissed any attempted improvements in nursing home condition as hopeless reformism, aligned with the longstanding position of CDA, and at the national level, of ADAPT. But CDA's membership overlapped with that of the NHERG, and in time, the two groups, including the activist who had initially objected to the platform, came to work together on the campaign.

Pursuing multiple forms of access

To pursue a legislative campaign, the NHERG needed to recruit lawmakers to sponsor and champion a bill. While the group had relationships with CILs, unions, and other organizations, it was clear from the beginning that this would be an uphill climb. My attempts to facilitate a meeting between NHERG leadership and one potential legislative supporter are illustrative. Following a request from organizers, I reached out to a progressive lawmaker with whom I had a limited connection, asking for his support for what I called "long-overdue nursing home reforms." He replied in ten minutes, saying that he would love to set up a meeting. That was the easy part. After making contact with his staffers in early January, I entered a weeks-long cycle of conveying proposed meeting times to the NHERG, ascertaining members' availability and setting a plan—only for the legislator's office to cancel and ask to reschedule. As this happened again and again, I found myself personally exhausted by the process. I could see that the process clearly sent a message to group leaders that even with a progressive and sympathetic lawmaker, they would have to fight for access. Upon hearing of another postponement, Shana asked me plaintively why he was doing this and if he didn't support us.

We finally met over Zoom on a cloudy January morning. The day before, organizers had planned out who would present different parts of the platform, linking it both to activists' personal stories and to other issues the lawmaker had championed during his career. When the meeting began, with the legislator in a car as a staffer drove him to an event, those careful plans were difficult to carry out. The lawmaker's State House expertise and inside view quickly contrasted with the NHERG's approach. He urged changes to the structure of the bill, and he pushed the group to identify what it would and wouldn't compromise on, which members were not prepared to do at that point. Still, he signed on as a supporter and helped to file a bill. The same themes surfaced again in a follow-up meeting three weeks later. He stressed that we would face opposition from the powerful nursing home lobby, which had already contacted him by then. His most emphatic message was that we needed to be in Springfield, lobbying for this bill. He urged the group to organize lobby days, and to collaborate with organizations that employed full-time lobbyists who could advocate for this bill. The NHERG saw its task as mobilizing constituents to contact their legislators, and it had found some success in winning initial bill sponsors through calls and online meetings with supportive lawmakers. But the legislative ally in these early meetings made clear that this was no substitute for face-to-face "everyday lobbying." It was a reminder that the state capitol was its own organizational field, and the NHERG was on the outside looking in. If the proposals were to have a chance of becoming law, the group would need to gain access to that field.

The NHERG recognized the challenge and began to plan lobbying trips to Springfield. Making the three-hour trip is no small feat, but it is one that countless organizations based in Chicago face each year, and which the NHERG had resources to facilitate. But the demand for face-to-face lobbying posed challenges that were specific to a disability organization. The concept of access is useful here. As a small grassroots group attempting to change policy, the NHERG sought institutional access to a relatively elite world of policymaking. At the same time, group members faced barriers to disability access that made their task all the more difficult. Lobbying in Springfield is a more daunting undertaking for disabled people whose bodies may make it more difficult for them to travel several hours in a car, move around the Capitol, or grab meals on irregular schedules. If they can go out safely, residents of nursing homes may face facility-level restrictions on their movements. These restrictions meant that key NHERG voices were absent from the Capitol. Keisha could speak compellingly of the retaliation she faced, but as a quadriplegic woman whose nursing facility was generally hostile, a trip to Springfield did not seem feasible for her. Sam had faced significant retaliation, including being forced out of his nursing home during the campaign. I attended a meeting where organizers tried to persuade him to accompany them to tell his story, stressing that he could have a significant impact by speaking to legislators. The appeals seemed to resonate with him, but his unstable living situation after being forced out, along with a general reluctance to rock the boat any further, led him to stay home.

Despite these barriers, many group members made multiple lobbying trips. They met with legislators and aides, testified in hearings, and "worked the rail" of the area outside the House chamber, where they competed with lobbyists and other advocates to catch the attention of passing Representatives. During the lobbying visits I joined, I accompanied members in groups or pairs as we went from office to office and desk to desk, pitching our campaign to legislative aides. As I observed these interactions, I noticed that activists who were noticeably disabled were not always taken seriously, particularly if their disabilities impacted their speech. At one point, a member with cerebral palsy, who uses a wheelchair and speaks in a non-standard way, was presenting the legislation to a staff member in the office suite for House leadership. He works as an organizer for a CIL, and toward the end of his pitch, as he fumbled for a business card to leave with the staffer, he mentioned that he'd met with the House Speaker in the past. Had he been an abled man in a well-tailored suit, this would have likely been interpreted as name-dropping: potentially obnoxious, but a relatively common display of one's connections. But in his case, the legislative staff replied, "How nice," in a tone she might have used if a child had told her that he once met a celebrity. No one commented on the condescension as we moved to the next office.

Amidst this dynamic, Jen emerged as one of the group's strongest advocates and spokespeople. As she approached each new legislative aide, she regularly mentioned her own two years in a nursing home. This seemed to surprise some staffers, for whom a well-spoken, ambulatory, middle-aged white woman may not have fit their expectations of a nursing home resident. Drawing on her experience, she assured her listeners that retaliation was a major issue, referencing stories that I had heard in meetings of the NHERG residents' group, and presenting the bill as an opportunity to even the power dynamics. Her use of these personal stories evoked Eliasoph's concept of "Mom discourse" (1998); like a mother expressing concern for her family, Jen expressed concern for the fellow residents she had lived alongside. But perhaps more importantly, she offered a direct, experiential connection to a world of nursing home mistreatment that was far outside the standard discourse of the state Capitol. Some aides seemed engaged, while others simply nodded along. One seemed reluctant to believe what Jen told her. As Jen recounted a story of a facility calling police to deal with a resident, the legislative aide asked, "This was a resident of the nursing home?" As the conversation continued, the staffer sought assurance that nursing home conditions weren't as bad as Jen portrayed them, saying, “They’re not all like that, right?” Later in the conversation, she referred to a facility in the small central Illinois town where she lived, suggesting that it must be better.

I found myself wondering how to interpret her reaction. On one hand, I could certainly relate to being distressed at hearing about mistreatment of vulnerable people. Abuse and retaliation in nursing homes are not only assaults on the dignity of residents; they are also a profound violation of social trust that people may find hard to accept. Over the course of my research, I periodically found myself not wanting to believe what I was being told, thinking that surely an account of abuse was exaggerated (before hearing similar accounts from others). At the same time, I might ask the legislative aide the same question that I asked myself: was that response rooted in the fact that the narrators were nursing home residents, whose status was tied to a lack of capacity to care for themselves, whose claims thus merited greater skepticism? I might also ask whether the nursing home industry, whose lobbyists were a regular presence in the Capitol offices, had already shaped her understanding of how facilities were operated. Perhaps the distinction was irrelevant; whether because the stories were distressing to hear, or because the storytellers did not carry the same credibility as the lobbyists who defended the nursing home industry, the NHERG faced challenges in convincing lawmakers that retaliation protections were necessary. While insurgent citizenship may be a destabilizing force, the everyday assumptions within the state legislative apparatus also served to rebuff challenges to established power relations.

Opposition and legibility

As the campaign started to gain traction, winning an early committee vote, the nursing home industry appeared to step up its opposition. After the second lobbying trip that I joined, we were led to believe that the bill would receive a full vote on the House floor the next day. While it would still need to make its way through the state Senate, the group was excited to have made such progress. Tim sent out a link to watch a live stream of votes on the House floor, and I sat at my desk watching as bills were called for a third reading. Their sponsors spoke to them briefly, and the chamber voted in quick succession, moving forward in a freight train of not-particularly-deliberative democracy. But our bill was never called. As I learned in an emergency meeting the next day, our legislation had been pulled from consideration by the Speaker's office. The bills we saw being approved so quickly approved were "consensus bills," with no major objections. Our bill was the subject of objections, including from the nursing home industry, which took issue with the proposed anti-retaliation protections. To move forward, the NHERG was asked to meet with industry lobbyists to try to reach a consensus on new language for the bill. Rather than taking sides, the state Democratic leadership sought to elide the conflict by framing it as a matter that could be negotiated into some sort of a win-win scenario.

Through this process, I learned that the nursing home industry actually had two lobbying entities in Illinois. One of them, the Health Care Providers of Illinois (HCPI),[3] met with NHERG representatives, and after a lengthy process, agreed to new language that activists were comfortable with. But the other body, the Health Care Industry Association (HCIA), took a much harder stance against the campaign. When they finally met with NHERG representatives after much delay, their position was simple: they opposed the anti-retaliation measure. There was nothing to negotiate. These attempted negotiations took months, and by the time the impasse with HCIA was clear, the legislature was close to adjourning for several months. In an effort to push the bill through, NHERG members returned to Springfield, and I joined them for my third lobbying visit.

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[3] The names of HCPI and HCIA, like the names of other organizations in this chapter, are pseudonyms. The depiction of the two lobbying associations—including their similar names and initialisms—is accurate.

There were small but noticeable differences in tone during this visit. The bill survived another committee vote, but with less support than before. As our group made our way through a set of legislative offices, an HCIA lobbyist walked past and greeted Jen by name. Jen later told me how he had stared her down during a hearing earlier in the day, saying that the was "all puffed up, like trying to intimidate me." We made our rounds to update legislative aides on the bill, seeking their support. Jen developed a rhythm, bridging her personal experience to the issue. She would open by saying that she had lived in a nursing home for two years, add that she facilitated a weekly conversation (in the NHERG residents' group) between current and former residents, and then stress that retaliation was a real problem. Jen seemed aware that some legislative aides might be skeptical of her accounts of retaliation. After telling one story about a resident who was threatened with being sent to a psych ward, she added, "That's not a wild, once in a lifetime story. I could give you legions of them."

Toward the end of the day, I found myself sitting beside Jen in the office of one of our key legislative supporters. Across the desk, the state Representative showed us her tally of supporters in the chamber, with only 25 confirmed YES votes from a Democratic caucus of 78. She also reported that one influential member had new concerns with a piece of legal language. And perhaps most notably, she asked for examples of retaliation, saying that she needed compelling cases to share with her colleagues to win their support. I shared a case from my research, and Jen began to tell stories of mistreatment that friends had experienced. Jen's accounts were complex, offering backstory and context, for which the Representative didn't seem to have patience. She wanted clear and compelling stories, delivered directly. At one point, she prompted, "What happened to you, Jen?"

My impression was that she wasn't only asking for her colleagues; even as a cosponsor and champion of the NHERG bill, this lawmaker didn't have a clear enough sense of the issue that she could easily communicate it to her colleagues. This was not unreasonable; pithy narratives are a common feature of any activist campaign. But this legislator was an early co-sponsor of the bill. NHERG leaders had met with her early on, along with supporters from her district. While I had not attended in order to make room for others, I suspected that the legislator had already heard Jen's story and others like hers. Indeed, I had stood beside Jen that day as she told legislative aides of finding a man tied to a chair in her facility. Still, the gulf between nursing home life and the state Capitol was wide enough that Jen needed to find new ways to make the group's issues legible. This was difficult and emotionally taxing work. After a day that had started around 4:00 am when she left Chicago for an early morning hearing, Jen pledged that she would try to translate accounts of institutional abuse into easily digested sound bites, in the hope of catching the sympathies of a few more legislators. The two of us moved to an empty office, where Jen borrowed my laptop to start drafting a set of anecdotes that she could email to the Representative. While I was careful not to make her feel that I was looking over her shoulder, she didn't appear to write much, attesting to the difficulty of the task. We soon left for the day, with Jen pledging to continue to assemble a list of stories.

But that effort was not enough. Over the course of Zoom meetings on each of the next three days, it became clear that there was not enough support to overcome HCIA's lobbying against the bill before the end of the legislative session. The Representative with whom Jen and I had spoken attended the last of these meetings, praising the group for its work, but reinforced this assessment. The only way for the bill to pass would have been to eliminate the anti-retaliation measures, which neither NHERG members nor the Representative wanted to concede.

One group member asked about the proposed increase to the PNA, and the Representative said that it might be bundled into the state budget, pointing to another proposal to raise the level from $30 to $60 a month. This was still markedly lower than the NHERG's proposal of $90, and a member argued that it was inadequate, comparing it to the $50 allowance in her home state of West Virginia, where the cost of living was much lower. As the meeting continued, Tim intervened to frame the setback as temporary, saying, "We're not pausing the campaign; we're changing the timeline." Members voiced their agreement. While some may have felt discouraged or frustrated, they offered praise for the Representative's support of the campaign. After the Representative logged off and the group debriefed, this praise continued. Whatever frustration members were feeling was directed instead at HCIA, along with a Representative who had voted against the bill in committee. A member reminded the group of the Representative's comments on the PNA increase, pointing out that some progress there was still possible.

Persuasion and pressure

As the group faced setbacks, internal discussion turned toward the possibility of protest as a means to advance the campaign. In one meeting, Tim pointed to HCIA's "money power," which it had used for years to make generous campaign donations, fund professional lobbying, and set the terms of debate around nursing home policy. In contrast, Tim said, "Our power is what we can do to get in their way." He pointed to the protest at the corporate office of Keisha's nursing home, recounted at the beginning to Chapter 4, as an example of how more contentious action could bring opponents to the bargaining table. Over time, discussions continued, centering on a protest targeting HCIA. In the dramaturgy of protest (Benford and Hunt, 1992), they would cast HCIA as an antagonist, framing the lobbying group's opposition to retaliation protections as support for abuse. Organizers hoped that this would negatively impact HCIA's image, making legislators less amenable to being seen as supporting them and more open to backing the NHERG bill.

Embracing protest tactics would be a change in tone for a campaign that had, thus far, focused on demonstrating positive support for its positions from individuals and organizations, and appealing to legislators on the merits of the proposal. At stake was a fundamental question of what disabled insurgent citizenship could look like, and how it would be perceived by those in power. At one point, NHERG members floated the idea of protest action targeting HCIA in a meeting with a few legislative supporters, including the Representative mentioned earlier. She urged against it, saying that instead, the group should rely on the power of its stories to win support. Though she did not draw the connection overtly, this seemed to tie back to her request to Jen in her office several months earlier, asking for accounts of abuse. In her vision of insurgent citizenship, the power of disabled people lay in narratives of their mistreatment, which they could mobilize to sway the sympathies of decision-makers who would not want them to suffer. In contrast, by raising the possibility of protest, NHERG members invoked a more defiant concept of insurgent citizenship. In doing so, they also drew on a repertoire of contention that disability activists in Chicago and beyond had practiced in protests around accessible public transportation and a range of other issues.

This turn to protest was also a matter of strategy. NHERG members saw their appeals colliding with entrenched power, which had thus far successfully stopped their campaign. One stark illustration lay in the Illinois legislature's practice of soliciting "witness slips" before hearings. This process allows members of the public to go on record as supporters or opponents of a bill being heard, even without offering testimony of their own. Each time there was a hearing on NHERG's bill, advocates consistently recruited over 100 supporters to file witness slips, while the nursing home industry stood alone in opposition. Still, the bill was not advancing. To organizers, this suggested that demonstrating popular support and marshalling compelling arguments was simply insufficient to overcome entrenched power. While members continued to organize support as grassroots lobbyists, they also saw protest as a means of escalation that might help the campaign to move forward.

“We came down here to do an action.”

Drawing on the group’s long history of direct action, NHERG appealed to CDA to join them in planning a protest. The group chose the HCIA office in Springfield as their target at a time when the legislature was gathered for its annual veto session. In addition to the dramaturgy and logic of escalation described above, they hoped to make it clear to HCIA that the campaign was not over, and to suggest to lawmakers that they, too, could face public protest if they opposed the bill. I rode to Springfield in Tim’s car, arriving the night before the planned action. He had hoped to have more information about the office that would be our protest site that could help with logistical planning. But the CDA member who was going to coordinate that had been supporting his disabled spouse as she dealt with a health issue. Once we arrived in Springfield, Tim and I walked past the closed office, noting with some concern that it was on an upper floor of a small office building, which we could easily be kept out of. Other activists from greater Chicago arrived that evening. They were later than expected; one of them explained in an email that paratransit—which he called “para-stranded”—had caused some of them to miss an earlier train, even after they allowed two and a half hours for a trip to the station that should have taken a fraction of that. Once we were all in Springfield, we worked together to finalize plans. The group would go to the HCIA office, where we would present a statement, calling on them to stop protecting abuse by blocking our bill, and stage a protest. If ordered out by police, we would leave to avoid arrest, but not before making our presence known. Discussing who would lead the group, Bryan, a middle-aged Black man involved in CDA who had previously lived in nursing homes, spoke to the tactical use of wheelchairs for disruption. Punching the armrest on his own power chair for emphasis, he said, "You can move an able-bodied, but you can't move a damn wheelchair."

When we arrived at the office the next morning, a top HCIA lobbyist and another staff member were standing on the sidewalk. Caught off guard by this apparent coincidence, and knowing that we might not have a similar opportunity if HCIA prevented us from entering their office building, three protesters sought to engage the lobbyist, approaching him on the sidewalk and voicing the group's demands that his organization drop its opposition to the bill. He deflected them as a skilled political operator, smoothly shifting between positions. He first said that he shared our concern with abuse from nursing home staff, and then claimed that he'd like to work with the NHERG to fix the problems with the bill. As the advocates tried to reply, he shifted to claiming that his group had already attempted to work with us. He finally pivoted to saying that the bill was unnecessary, because there were already legal protections in place. The entire interaction took minutes before he turned to enter his office, leaving our group on the sidewalk.

The activists found a spot a few blocks away where we could regroup. In this backstage space, the frustration was palpable. Sandy, a young African American woman who was there working as a PA, was in tears, telling the group, "You're human beings" who should not have been treated so dismissively. Others called it "bullshit." Tim said, "Clearly, these are people who disrespect us," who believed that they could deflect the group with four minutes of talking points. Still, it was not clear what the group would do next, with members feeling deflated and

HCIA staff now aware of our presence. I wondered if we would decide to move on to the Capitol, where the group had planned to make a round of lobbying visits after protesting. But after some discussion, a comment from David seemed to shift the sentiment of the group. A young white man with cerebral palsy who speaks slowly, David had served in the past as an elected co-chair of CDA. As the group deliberated, he said, “We came down here to do an action. That was not an action. In my mind, we should go in front of the building and make some noise and let them know that we aren’t going away and he’s not going to blow us off.” After a bit more discussion, the group agreed.

With that, we returned to the building that housed the HCIA office. Knowing that there was no chance of entering, Bryan and Sonja, an African American woman who also uses a power wheelchair, parked their chairs directly in front of the doors. The rest of us gathered around, a small but vocal group of ten making clear that, as David had said, we weren’t going away, and we wouldn’t be blown off. The group cycled through chants that members had learned through CDA and National ADAPT actions, making the message clear: “Our homes, not nursing homes,” “Up with attendant care—down with the nursing homes,” and “I’d rather go to jail than die in a nursing home.” At one point, a member called the HCIA office through the building’s intercom system, bringing the chanting into their office both from the street and through the phone. A UPS truck arrived with a package for someone in the building; after a short conversation with Tim, the driver left without making his delivery. While we had planned to protest for half an hour, the chanting lasted longer than that until the group chose to leave. As we made our way up the block, I looked back and saw HCIA staff exiting the building, as if they had been waiting for us to depart. This suggested that the group had indeed not been ignored, and that the protest had successfully claimed their attention. That afternoon, we made another round of lobbying visits.

These took a somewhat bolder tone as well, as the group refused to leave two offices until we were permitted to speak with a legislative staffer or schedule a meeting with an official. The defiant spirit of insurgent citizenship buoyed the group, even within the staid confines of legislative offices.

DISCUSSION

This chapter offers a brief narrative of the process of policy navigation in the context of an ongoing disability organizing campaign. In their pursuit of nursing home reform, the NHERG faced the challenge of making the context of contemporary nursing homes legible to skeptical lawmakers, while also challenging an entrenched and powerful corporate sector with a longstanding lobbying apparatus. To meet this challenge, the NHERG enacted two distinct yet complementary forms of insurgent citizenship. The first approach positioned them as citizen-lobbyists, seeking to present stories of retaliation against nursing home residents in ways that would be clear and compelling, swaying the sympathies of lawmakers. This was a difficult task, and while it won some progress toward passing the legislation, it also forced NHERG members to render traumatic stories into easily digested anecdotes that could enable legislators to understand the social world of Medicaid-funded nursing homes. It also meant finding their way around ableist barriers that made this work all the more difficult.

The second form of insurgent citizenship was marked by defiance, drawing on a longstanding repertoire of contention. Activists embraced their role as protesters, painfully aware that they were not fully accepted within the halls of power, but demanding that they not be overlooked. This was clearly the more emotionally rewarding enactment of citizenship. While I would not go so far as to describe the group's small demonstration as an example of collective effervescence, there was a palpable energy. David's declaration that we had come for an action, and the group's collective chanting, were reminiscent of a political enactment of Durkheimian ritual (1995/1912). The sidewalk outside a nondescript office building, where only a short-time before disabled advocates had been demeaned and dismissed, was transformed into a space of collective affirmation by the same advocates that they would not be blown off. In an echo of Mary Johnson's account of the ADAPT protest in the US Capitol rotunda in 1990, demonstrators insisted that the lobbyists who had successfully stonewalled their legislative proposals would at the very least be unable to ignore their presence for half an hour that morning.

While these two forms of insurgent citizenship contrast sharply in affect and tone, they are not incompatible. NHERG members made clear that they could operate in both registers as they went from protesting outside the HCIA office to lobbying in the state Capitol later the same day. At the same time, neither approach had succeeded in passing their proposed legislation, which was already only meant as a reasonable proposed start. After I left the field, I maintained contact with the NHERG, offering support where I could. By Spring 2024, after another round of committee votes and instructions to negotiate with the nursing home industry, the legislation had once again stalled. One might be tempted to dismiss this as a losing campaign, the outcome of which would be unsurprising in light of the balance of power between the NHERG and the nursing home industry.

But the campaign was not without its successes. The Personal Needs Allowance for nursing home residents increased to $60 a month at the start of 2024. While this was not the level that NHERG had demanded, it was the first increase in decades. The change was largely unpublicized, but Tim confirmed that it was due to the work of the NHERG and other advocates. Moreover, even if the campaign remained entirely unsuccessful, I would argue that the case remains worthy of study. The pursuit of this legislation, with leadership from current and former nursing home residents, challenges entrenched conceptions of who is capable of advocating for themselves. In order to enact disabled insurgent citizenship, activists have shown a nimble ability to shift between affective registers, pressing their claims while at the same time sustaining members' energy and collective commitment to a campaign that they may not ultimately win.

This chapter is significant in that it presents policy navigation from below as a collective process. In previous chapters, I have not argued that the work of navigation was necessarily individual. And several informants did mention informal, peer-to-peer support in securing accommodations or SSI or SSDI benefits. But across different sedimentary layers of policy, disabled people are often hailed as isolated individuals or through caregivers (who were often family). And so it is no surprise that across policy contexts, navigational work often seemed to be performed alone. Disabled workers were reluctant to disclose their disabilities to colleagues; SSI and SSDI beneficiaries sat alone, on hold, waiting to speak with a Social Security Administration staffer. In nursing homes, more informants spoke of the importance of assistance from friends, family, and advocates, reflecting residents' limited standing to be heard when speaking on their own behalf. This limited standing, and the isolation of nursing home residents behind facility walls, makes the work of the NHERG all the more remarkable. A comment from Ellen, a 70-year-old Black nursing home resident and intermittent participant in the NHERG, spoke to both the extent of isolation and to the power of activism in the face of it. In August 2020, when COVID vaccines were not yet available and many nursing home residents were under strict limits on movement and visitors, the NHERG organized a march on a main thoroughfare in Chicago that was home to multiple nursing facilities, seeking to call attention to conditions inside. Remembering the event, Ellen said, "When they did that march down Sheridan Drive…it was the most beautiful thing that they could do because it was getting attention…. They're trying to bring people from the outside world into this facility, all the facilities, so that they will know what is going on inside." When we spoke nearly two years later, Ellen was still moved by this collective action that recognized nursing home residents as members of society, acknowledging dire conditions and suggesting that they could change.

CONCLUSION

As I write in the introductory chapter to this dissertation, disabled citizenship is fundamentally contested. The persistence of disabled activism has helped to drive the creation of new layers of disability policy, contributing to the process of sedimentation. This chapter offers a narrative of an ongoing organizing campaign seeking to improve conditions in nursing homes, a site where disabled citizenship can be especially constrained. In pursuing the effort, NHERG members navigate policy while operating in two registers, seeking both to make themselves legible and compelling to lawmakers, while also drawing on a tradition of defiant protest as both a campaign pressure tactic and a means of sustaining commitment. Though their legislative success thus far is limited, the group's work constitutes a form of insurgent citizenship, pushing the boundaries of who is recognized as a participant in political life.

Conclusion

This dissertation begins with the argument that disability is embedded in a wide range of social systems with divergent, often contradictory meanings. The nexus of social and political structures generates *disabled citizenship*. While T. H. Marshall's conceptualization of citizenship emphasized civil, political, and social rights, disabled citizenship often involves trade-offs, with social provision conditioned on the erosion of political and even civil rights. Disabled citizenship is also marked by its temporal structure, whereby policies from different eras, reflecting disparate conceptions of disability, are awkwardly laid on top of one another in a process I call *policy sedimentation*, creating an uneven policy terrain. Contemporary policies are genealogically linked to structures from the 19th century, even as they have also changed through the development of the New Deal and post-war order, and subsequent neoliberal transition. Disabled citizenship is fundamentally contested, as the victories of activists help to generate new layers of policy. Finally, disabled citizenship is fundamentally intersectional, reflecting the racialized and gendered processes by which disability is constructed, and creating differential access to resources and services that contributes to structures of cumulative disadvantage.

In order to find their way through this uneven landscape, disabled people engage in a process of *policy navigation from below*. This term describes the active labor performed by disabled citizens, often across policy systems, to secure accommodations, benefits, or services while also addressing their material needs. Policy navigation from below is often lonely work, but it can also be performed collectively. It takes on different focus in different policy realms, but it also involves navigating *between* policy domains, as in the case of SSI beneficiaries who do a limited amount of paid work while protecting their eligibility for benefits. The concept of policy navigation from below stresses the active work of citizenship, in contrast to theoretical frameworks that cast disabled people as the passive objects of policy, to whom benefits are granted and on whom burdens are placed. While different policy regimes demand unique forms of navigation, the uneven process of policy sedimentation also compels citizens to navigate *across* overlapping areas of policy built on contradictory conceptions of disability. Thus, while the policy regimes described in chapters two through five generate different forms of citizenship, these are all aspects of a larger, fragmented construct of disabled citizenship.

Chapter 2 focuses on paid work, a central element of hegemonic conceptions of citizenship. While disabled workers have long faced exclusion from the labor force, the Americans with Disabilities Act (ADA) of 1990 offered hope for change, particularly by requiring employers to make reasonable disability accommodations. But reality has not lived up to this promise. Disabled workers experience a form of *conditional citizenship*, where employment and accommodations are subject to the arbitrary power of employers, the types of accommodations a worker needs, and whether those accommodations are perceived as reasonable in a particular field and workplace. As the move to remote work in many sectors early in the COVID pandemic demonstrated, conceptions of what is "reasonable" can shift with changing social circumstances. A disabled worker's social belonging is conditioned on aligning these factors, which are largely out of their control.

For disabled workers who are able to find employment, securing accommodations means engaging in a process of policy navigation from below. Despite formal legal rights, workers may not initially recognize that accommodations are an option, let alone know what specific arrangements might be beneficial to them and acceptable to their employers. Reflecting the process of policy sedimentation, some disabled workers are able to draw on prior experience navigating accommodations in school, where distinct but overlapping policy regimes structure disabled students' rights. Once they have identified potential accommodations, workers must make requests, whether formally or informally, which can involve an extensive process of documenting their disabilities in order to plead a case. While doing so, they must also maintain relationships with supervisors and coworkers, whose attitudes can determine whether their jobs remain bearable. Even if disabled workers fluently navigate this process, their accommodations may still be denied or undermined, reflecting the workers' conditional status.

Chapter 3 turns to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), income support programs serving millions of disabled people, many of them living in poverty. While SSDI is an earned benefit program and SSI is a means-tested welfare program, beneficiaries of each program recounted similar experiences, troubling the common academic framework of a two-track welfare state. Eligibility for both is based on a strict definition of disability, which in turn is based on medical diagnosis and an assessed inability to work beyond a minimum earnings threshold known as Substantial Gainful Activity. The programs generate a form of *precarious citizenship*, marked by a fear of running afoul of program rules, even unknowingly, and putting one's benefits at risk.

In the context of SSI and SSDI, policy navigation from below involves the work of interpreting and understanding complex program rules in order to secure benefits and maintain eligibility while also addressing one's material needs. Informants spoke of frustrating hours spent on hold with the Social Security Administration while attempting to find consistent program information. Some adopt a strategy of "not poking the bear," i.e., choosing not to pursue potential assistance for fear of jeopardizing benefits. Once again, policy sedimentation means that many beneficiaries engage with other policy regimes that can introduce contradictions. For instance, despite the formal assumption that beneficiaries can not work beyond a certain threshold, many informants do engage in paid labor, some through Social Security programs meant to promote work. This means navigating additional rules, as well as the conflicting institutional logics of the workplace and SSI or SSDI. Residents of congregate facilities unhappily find that their benefits disappear, as facility management claims their SSDI checks as an institutional revenue stream.

In Chapter 4, I consider nursing homes as sites of congregate care, a form of disabled citizenship that looms large in the imaginations of disabled communities because of the history of institutionalization. Contemporary Medicaid-funded nursing facilities function in part as spaces of poverty governance, reflected in accounts from several informants of how their paths to admission involved homelessness or other housing crises. Life in the facilities is structured around institutional rhythms, and the staff who provide essential services are pressed by resource and time constraints driven by managers and owners seeking to maximize profit. This confluence of factors creates fertile ground for mistreatment and abuse, as residents face a form of *constrained citizenship*, with their political standing diminished, making it difficult for them to seek redress for intolerable conditions.

Disabled nursing home residents are situated within a web of cross-cutting policy systems, ranging from the Social Security and Medicaid benefits that provide revenue to facilities, to the judicial consent decrees that offer some residents a path to transition back into the community. In this context, policy navigation from below takes on three overlapping forms. Some residents keep their heads down and their expectations low, in an approach reminiscent of not poking the bear. Some work to prove themselves to a parade of gatekeepers in hopes of transitioning through the Colbert or Williams consent decrees, though moving to the wrong facility can make one ineligible for these programs. And some, particularly when facing severe mistreatment, choose to advocate. They may speak up on their own, call on family, friends, or advocates, or even seek help from governmental entities. But those who call 911 may be told that public emergency services will not respond to calls from nursing home residents, providing yet another example of how their status constrains their political standing.

Finally, Chapter 5 focuses not on a policy regime, but on activism seeking to contest and transform disabled citizenship. Despite being situated so that their social belonging is conditional, precarious, and constrained, disabled people have forged a persistent activist tradition. This includes a history of confrontational protest with a distinct repertoire of contention, including the use of power wheelchairs as tools of disruption. And it includes more inchoate but no less real strands of oppositional consciousness like Nishida's concept of bed activism (2022). Together, these constitute a form of *insurgent citizenship* (Holston 2008), which I approach through a case study of a campaign by current and former nursing home residents, along with allies, to improve conditions through state-level legislation.

While policy navigation from below can be an isolated process in other settings, it is fundamentally collective here, as activists work together to pursue change. In the case study, members of the Nursing Home Emergency Response Group (NHERG) faced obstacles to advocacy that were specific to disability, including barriers to traveling to the state Capitol, and decision-makers who did not grant them the same credibility as abled lobbyists. Nonetheless, NHERG members nimbly pressed their campaign in two affective registers. As citizen-lobbyists, they built support by making the world of nursing homes, including its horrific aspects, legible to state lawmakers. And as protesters, they reveled in defiant confrontation that sought to pressure their opponents while also sustaining activist commitments, declaring their refusal to be ignored or dismissed.

Looking across the chapters, one persistent aspect of disabled citizenship is that programs for disabled people are made difficult to access. It bears emphasis that this is not an inevitability, but the result of specific policy choices. Arduous application and certification processes serve a social control function. Piven and Cloward write that outside of periods of social ferment, income support may be provided to residual groups, including disabled people, but they must be "degraded for lacking economic value," thus discouraging others from seeking the same support (1993, 33). My findings reflected this dynamic repeatedly. The experiences of SSI and SSDI beneficiaries bore out Piven and Cloward's argument, as informants recounted a reluctance to apply for benefits and told of degrading ordeals when engaging with the Social Security Administration. On the job, disabled workers feared asking for accommodations, with some telling me that they waited to do so until they felt that they would have to leave their jobs if something didn't change. More than one informant recounted supervisors who told them that if other workers learned of an accommodation, then "everyone would want it," leading them either to deny a request or to urge the disabled worker not to let others know. Nursing homes, despite their conditions, provide disabled people with desperately needed housing and care services. But these, too, are provided under degraded conditions, and residents who challenged these conditions risked retaliation, leading many to keep their heads down. Even in the activist realm, there are echoes of a similar dynamic at play. The same Representative who championed the NHERG's legislation urged them not to pursue a strategy of protest, arguing that a more positive appeal was the way to win change.

But if disabled citizenship is marked by an element of social control, that control is in dialectical tension with the work that disabled people perform in navigating policy. Disabled citizens pursue workplace accommodations and apply for benefits, despite discouragement.

They also help friends and peers to pursue their own accommodations or benefits, as several informants told me. Even in nursing homes, where the apparatus of control is frighteningly present, residents push back on mistreatment and call on others to support them in doing so. And traditions of disability activism are not only seen in discrete campaigns, but they sustain an insurgent citizenship that resists degradation and offers in its place visions, however distant they may be, of disabled community and resistance.

On a separate theme, a key argument of this dissertation, despite its chapter structure, is that disabled citizenship, as a product of policy sedimentation, encompasses contradictory policy domains. This means that disabled people must often navigate conflicting logics, which several informants spoke of doing. For some, like SSI or SSDI beneficiaries who work, this is a source of anxiety. Jackie, for instance, told of how, after losing her job, she collected unemployment benefits, which were conditioned on looking for work, while applying for SSDI, which meant claiming that she could not work. In the midst of a personal financial crisis, this contradiction led her to fear that she would have to pay back needed benefits, or even face criminal sanction. For others, experience across policy domains emphasizes the contrast between types of disabled citizenship. Jen, for instance, juxtaposed her professional experience with her time as a nursing home resident, saying that at work, "I had a lot of respect. There was no respect in that nursing home." And while schools were not a focus of this dissertation, multiple informants compared workplace accommodations unfavorably with educational accommodations, arguing that the laws governing public education offer more robust inclusion than the ADA provides on the job. Disabled workers who have benefitted from accommodations as students are able to draw on their experience as a form of navigational capital, demonstrating that experiences across policy regimes can provide important socialization that facilitates policy navigation in less hospitable contexts.

Policy implications

I am writing in mid-2024, at a time when the chances of passing new laws to benefit disabled people, particularly at the federal level, seem slim. Indeed, in my interview with Susan Prokop, the long-time policy advocate, she pointed to the passage of the ADA Amendments Act in 2008—an earlier political epoch—as the most recent major federal disability legislation, suggesting that she could not see such a law passing today. Despite these headwinds, there are multiple small steps that could tangibly improve disabled people's lives. At the federal level, SSI beneficiaries are only permitted to have $2000 in assets as individuals, or $3000 as a married couple, levels that have been in place since 1989. To raise these limits, or remove them altogether, would allow beneficiaries to live—and to marry—with a greater level of financial security (Stetler, 2014). Similarly shifting policy to prevent nursing homes from claiming residents' SSDI benefits, and to allow SSI beneficiaries in nursing homes to collect full benefits, could check the process of immiseration that too many residents experience. Federal and state Medicaid policy could change to mandate better pay for both nursing home workers and at-home personal attendants (PAs), which would address staff shortages, while policymakers could also institute more stringent minimum staffing levels and protections against abuse. At the state level, Illinois could embrace the NHERG's calls for a Personal Needs Allowance for nursing home residents of at least $90 each month, while also passing strong anti-retaliation protections and other parts of the group's proposals. Illinois could also increase its supplement to federal SSI payments, offering residents a greater measure of income support. In the workplace, while enforcement of the ADA has proven difficult, unions could push for strong language guaranteeing accommodations as part of the collective bargaining process.

Beyond these discrete proposals, this dissertation also provides a space to think more broadly about remaking disabled citizenship. As I wrote earlier, one common thread is that accommodations and benefits are difficult to access *by design*. Employers and government agencies demand disability documentation, which can be both invasive and degrading, to guard against the possibility that those deemed undeserving will receive accommodations, benefits, or care. This in turn generates precarity, as disabled people fear jeopardizing whatever resources they have cobbled together.

I propose a move away from this conditional model, with its emphasis on evaluating and proving disability, to greater universality. This is in part a call for decommodification, which occurs, in Esping-Andersen's words, "when a service is rendered as a matter of right, and when a person can maintain a livelihood without reliance on the market" (1990, 22). For services or benefits to be offered as matters of right stands in sharp contrast to the situations described in the preceding pages, where obtaining support requires complex policy navigation, and even those who are successfully able to secure work or benefits often struggle to maintain a livelihood. But the logic of decommodification presumes that workers have already been commodified within the labor market. This is not the case for many disabled people. As I wrote earlier, building on Orloff's feminist analysis of the concept of decommodification (1993), many are excluded from the workforce, denying them both a source of income and a social status (as a worker) that is key to dominant conceptions of citizenship. Nishida suggests that disabled people may encounter two forms of commodification. Alongside exploitation within the capitalist labor market for those who manage to achieve it, disabled bodies may also be commodified "as the targets of care, rehabilitation, and other medical industrial complex mechanisms," their bodies generating revenue for the institutions in which their beds are situated. She also points out that some disabled people fall into the "cracks between those two commodification schemes…and [are] sometimes ostracized from both" (2022, 162).

What, then, might be the features of a less conditional vision of disabled citizenship, one that provides for people's needs without treating them as mere commodities, while also facilitating inclusion as full members of society, including as workers? One major step could be to pursue full employment, including that of disabled workers, as a matter of US policy. This would include strengthening the ADA to require that jobs be designed to be accessible as a default, with accommodations granted unless an employer can convincingly demonstrate that they would somehow be detrimental to the functioning of a workplace. Such a policy would seek to shift the burden of navigation from a disabled worker seeking accommodations to an employer seeking not to provide them. A related reform would be to establish a shorter work week, an idea advanced by Senator Bernie Sanders, who has introduced legislation toward that goal, and the United Auto Workers, who have called for a four-day week in collective bargaining (Sanders and Fain, 2024). Taken together, these shifts in policy could make the workforce more accommodating to disabled workers, including those who recounted their difficulty working a 40-hour week. Rather than serving as a reserve army of labor (Russell, 2001|2019), it would allow disabled workers greater security on the job—and in their sense of social belonging.

Outside of the workforce, SSI and SSDI, in their current form, are more akin to poor law than to social rights. A fundamental change could be to supplement them with a social wage, a form of universal income that is not contingent on disability status. This would not only provide a means of financial security, but it would also serve as the basis of a universal experience that could generate social solidarity, much like Marshall's account of collecting children's allowances or pensions from the British post office (1950, 56). There is a case to be made that a universal income would not necessarily meet the needs of disabled people; Morris et al, for instance, write that a household that includes an adult with a work disability will need 29% more income, on average, to maintain the same standard of living as a comparable household without a disabled member (2022). This is why I propose the social wage as a supplement to SSI and SSDI, rather than a replacement for them. But the application process for SSI and SSDI would be made far less onerous, with benefits not so zealously guarded as they are now. These reforms would be paired with a truly universal health care system, providing coverage that would include durable medical equipment and specialty care that many disabled people require. While current SSI and SSDI beneficiaries fear the loss of Medicare or Medicaid if they move into the workforce, universal health care would obviate that risk.

What of those disabled people who would benefit from the sort of consistent services that are currently promised by nursing homes? The shorter-term policy steps I proposed earlier, such as improved pay for care and service workers and more robust protections against abuse, remain urgent here. But in formulating broader reforms, it is important to recall that many residents I interviewed had landed in nursing homes after facing homelessness or housing insecurity, or after the sudden onset of a disability had made a home no longer accessible. A significant increase in the availability of affordable housing, designed for disability access, could thus make nursing homes one option among many, rather than a form of last-resort housing. This universalistic step would benefit abled people as well, removing a source of separation between disabled citizens and the broader society. This would be paired with a broad increase in the availability of in-home PA services provided by well-paid workers, further reducing the need for institutional living. Currently, Medicaid is a key funding source for both PA services and nursing homes, reflecting both a medical model of disability, and a trend in social service provision that Hansen et al call an increase in “medicalized forms of support for indigent people” (2014, 76). But if we understand nursing homes as a form of housing, and PA services as housing supports, then these can be funded by general government revenues. This would make diagnosis less relevant in qualifying for services, alleviating the need for onerous medicalized application processes.

Together, these proposals would not fully knit together the fragmented landscape of disabled citizenship, nor completely eliminate the need for policy navigation from below. But by providing broad access to work, basic income, health care, and housing, they would offer disabled people significantly greater social stability that is not so dependent on heavily guarded eligibility criteria based in narrow conceptions of disability. As Esping-Andersen writes, decommodification is best understood as a matter of degree, not “an issue of all or nothing.” These proposals would improve disabled life by a qualitatively significant degree. Esping-Andersen further points out that decommodification facilitates collective action, making the development of labor movements possible (1990, 37). I would extend the same argument to disability movements. Proposals like those I elaborate here set the stage for further collective action and insurgent visions to continue to push the boundaries of disabled citizenship.

Research implications

For researchers, the analytic approach of this dissertation offers a means of understanding the fragmented and contradictory meanings that can be embedded in a single social construct. The concept of policy sedimentation offers a framework through which to assess how these meanings come to sit unsteadily on top of one another. Disability is a particularly potent area of focus, as a category that has often been defined in residual or indirect fashion. Even with the emergence of disability studies as a scholarly field, disability is too often defined tacitly and treated as a footnote. As I wrote in the introduction, I seek to invert that logic by centering disabled citizens as political actors navigating complex social terrain, drawing lessons from this analysis that can inform other social inquiry.

The analytic framework of *citizenship* emphasizes that policy regimes are not simply means of transferring resources, and their impact can not be assessed solely by counting the number of workers in jobs or residents in nursing home beds. Policies also situate citizens within society, communicating their standing as full members or as something less. To learn how this process unfolds, we must understand that policies are *experienced*. Perhaps the most telling example lies in the similarities between SSI and SSDI, to the extent that some beneficiaries were unsure which they collected. An analysis rooted in program structure would point to the fact that SSDI is an earned benefit program, whereas SSI is a welfare program, and assume a wide gulf between them. But by centering the experiences of beneficiaries, we see that the programs' shared disability determination process, their reliance on the same understaffed Social Security Administration call center, and the broader social context of ableism and resentment of government programs all lead beneficiaries of both programs to face similar social degradation. This point evokes a 2004 comment from Jacob Hacker. Responding to the increasing prevalence of decentralized policy structures, he wrote, "It may become increasingly difficult to judge policy effects simply by reading statute books or examining disputes over policy rules. We will need to look at what really happens on the ground" (247). I argue that even in centralized programs like SSI and SSDI, greater consideration of what really happens on the ground will illuminate important aspects of policy and society.

Finally, my approach to citizenship, particularly in the concept of policy navigation from below, also centers a fundamentally sociological argument: that policy is interactive. Benefits, accommodations, and services are not granted by default; citizens must actively pursue them, often through onerous processes. Citizens actively navigate policy, maneuvering across domains and managing contradictions, simply in order to meet their basic needs. And despite being situated as objects of charity or benevolence, disabled activists challenge the constraints of current structures and seek to claim more capacious forms of citizenship. The study of disabled citizenship, with an emphasis on policy navigation from below, offers both the challenge and the promise of a research approach that emphasizes the interactive and experiential character of contemporary policy.

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