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Place and Disability Program Enrollment: Comparing Two Rural Counties

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Abstract

Enrollment in disability programs is shaped by both individual- and community-level factors. How does the process of getting on Social Security disability assistance differ between places? To answer this question, we draw on interviews with 47 disability assistance recipients or heads of households and 21 community experts in two rural counties with high rates of disability claims: Clay County, Kentucky, and Humphreys County, Mississippi. There are notable differences between the two sites. Clay County is over 90 percent non-Hispanic white, and Kentucky adopted Medicaid expansion in its implementation of the Affordable Care Act. Conversely, Humphreys County is majority-Black, and Mississippi has yet to adopt Medicaid expansion. In our analyses, we find that most recipients in Clay County followed an *institutionally supported model* to claim disability benefits. Potential claimants were encouraged to enroll by different organizations—schools, hospitals, healthcare clinics, and government agencies—and were often approved quickly. In Humphreys County, people largely followed a *self-help model* for receiving benefits. They were encouraged by friends and family members to apply but frequently experienced long wait times and multiple rejections. Most respondents in Humphreys County hired lawyers. Our results highlight how the institutional infrastructure of communities shapes the burdens of applying for disability assistance. Changes to disability programs can make a difference for recipients, but policies and programs that support the viability of healthcare systems and social service providers in rural areas are also highly consequential.

Keywords: Administrative Burden, Rural, Disability, Place
JEL Codes: I1, I3

1. Introduction

In 2023, nearly 8.7 million Americans received Social Security Disability Insurance (SSDI) and 7.5 million Americans received Supplemental Security Income (SSI) (Social Security Administration 2023). In 2021, the combined expenditures for these two programs were over $200 billion (Center on Budget and Policy Priorities [CBPP] 2023a; CBPP 2023b). While disability assistance plays a central role in the lives of many households, it remains a somewhat contentious form of social policy. Critics have denounced it as a backstop income guarantee for people who cannot or do not want to find work (Fang and Huber 2020; Plumer 2013). In addition, the number of disability beneficiaries grew substantially between the 1990s and the early 2010s. While this growth in enrollment reflects demographic factors such as the aging of baby boomers and growth in women's labor force participation (CBPP 2023a; 2023b), it has also generated anxiety about the financial sustainability of the programs. The rejection rate for both programs has increased significantly in the last 20 years.

Both programs also impose significant *administrative burden*—or the cost of seeking public benefits—on applicants, making the application process both onerous and time consuming to navigate. Administrative burden is not experienced equally among applicants; it is influenced by both individual- and community-level characteristics. In this analysis, we examine how place-based factors shape the administrative burden of applying for disability benefits. To examine this question, we draw on 68 interviews from two rural communities with exceptionally high rates of disability benefit program enrollment: Clay County, Kentucky, and Humphreys County, Mississippi. There are notable differences between the two sites. Clay County is over 90 percent non-Hispanic white, while Humphreys County is approximately 78 percent non-Hispanic Black (U.S. Census 2020a; 2020b). In addition, Kentucky expanded Medicaid as part of the implementation of the Affordable Care Act in 2014. Mississippi, meanwhile, is one of 10 states that have yet to adopt expansion, as local lawmakers remain at odds over the ideal scope and structure of any potential expansion (Ganucheau, Pender, and Harrison 2023). Medicaid expansion (or lack thereof) has certainly impacted rural healthcare systems in both states (Aron-Dine 2017; CBPP 2023c).

In our analysis, we found that administrative burden was perceived to be significantly greater for applicants in majority-Black Humphreys County, Mississippi, than it was in majority-white Clay County, Kentucky. In Clay County, most recipients followed an *institutionally supported model* for enrolling in disability benefits programs. Potential claimants were encouraged by different local organizations—schools, hospitals, healthcare clinics, and government agencies—to apply for disability benefit programs. These organizations helped diagnose their conditions and assisted them in claiming benefits. In Humphreys County, on the other hand, most recipients followed a *self-help model* for claiming benefits. They sought support from their personal networks—family members, friends, and neighbors—to enroll in disability programs. When their networks failed them, they turned to (often out-of-state) lawyers or disability representatives to help them navigate the process. While most of our respondents in Kentucky were enrolled in the program within a year, respondents in Mississippi often waited two to eight years before receiving benefits, typically receiving multiple rejections in the process. The long wait periods and multiple rejections took a financial, physical, and psychological toll on applicants; many respondents experienced significant material hardship living without income as they waited for their application to be processed, and the conditions for which they sought disability often worsened during the wait period.

This analysis contributes to our understanding of both administrative burden and disability benefits programs. For one, scholarship on administrative burden often focuses on the relationship between citizens and the state (Herd et al. 2013). Such work argues that the state can create (or reduce) burdens as a policy lever that is typically wielded toward political or ideological ends. While universally accepted programs frequently impose few administrative burdens on citizens, programs that engender less political support can construct administrative barriers for prospective recipients (Barnes 2021; Carey et al. 2021). However, we argue that there are other institutional actors that influence the process. Social service providers—even those unrelated to the administration of the program itself—can also impose or alleviate administrative burden. We find that policies and programs that support healthcare systems (and other social service providers) in rural areas indirectly have the effect of reducing the administrative and psychological costs of getting on programs such as SSI or SSDI.

Second, our results confirm that the local labor market is an important factor shaping disability enrollment: disability assistance is, by nature, related to the availability of jobs (O'Brien 2013). However, our analysis highlights that labor markets are not the only "local" factors that contribute to disability benefit program enrollment. The two pathways highlighted above—the institutionally supported model and the self-help model—illustrate the importance of local institutions in reducing administrative burden, thus demonstrating how places shape the ability of residents to access extra-local resources.

2. Literature Review

2.1 Administrative Burden

Administrative burden occurs when the state imposes burdens on citizens who are seeking public services. It includes the costs that people encounter when they search for information about public services and comply with rules and requirements, as well as the stress and loss of autonomy that come from such encounters (Herd and Moynihan 2018). As Herd and Moynihan (2018) argue, burden matters because it shapes whether government is experienced by citizens as accessible or opaque, simple or bewildering, respectful or antagonistic. Administrative burden is also unequally distributed (Chudnovsky and Peeters 2021); Herd and Moynihan (2018) argue that administrative burden affects poor Americans more than wealthy Americans. For example, relative to the near 100 percent take-up of universal programs such as Social Security and Medicare, take-up rates of means-tested programs—like Temporary Assistance for Needy Families (TANF)—aimed at poor people are much lower and vary widely across states (Giannarelli 2019). While burdens are inevitable, they often disproportionately disadvantage low-income populations. And certain programs, like disability insurance, can be particularly prone to administrative burden, given the necessity of documenting the severity of physical or mental impairments. As Liebman (2015) argues, "[d]etermining whether an individual is eligible to receive disability benefits is much more complicated and requires significantly more administrative judgment than the determination of eligibility for other large social insurance programs" (125-126).

Herd and Moynihan (2018) argue that burden can be alleviated through creative policy designed to shift burdens away from citizens and onto government. While they argue that the responsibility of reducing administrative burden ultimately falls on the state, other social actors can contribute to both imposing and alleviating administrative burden as well. Social networks—which are strongly shaped by both race and poverty—influence program applicants' ability to navigate complex applications and bureaucracies. For example, Browne (2015) describes how a rural Black community in southern Louisiana struggled to access FEMA resources after Hurricane Katrina because residents lacked "weak ties" to people who might help them navigate applications and appeals. Other third-party actors and institutions matter as well. Barnes (2021), for example, highlights how the actions and attitudes of third-party actors such as retailers can make it more cumbersome for mothers to use their Special Supplemental Nutrition Assistance Program for Women, Infants, and Children (WIC) benefits. By not stocking and selling WIC-approved food items, retailers increase the "redemption costs" for mothers.

This analysis focuses on the role of non-governmental actors in the disability enrollment process, particularly how they can increase or reduce administrative burden. Social service providers like schools, hospitals, mental health clinics, and other community-based organizations can act as mediators between potential recipients and the state. Looking at public and private social service providers at the local level expands our understanding of how people experience, and overcome, administrative burden to access needed resources.

2.2 Rural Access to Healthcare

Individuals living in rural areas, compared to their urban counterparts, have higher morbidity and mortality rates (Gaffney et al. 2022; Zeng et al. 2015). They also report fewer visits for preventive screenings, less access to specialists, and more preventable hospitalizations compared to people in urban areas (Bennett et al. 2008; Chan et al. 2016; Laditka et al. 2009; Larson and Correa-de-Araujo 2006). These disparities stem from the lack of access to healthcare in many rural areas of the US, which has been exacerbated by increased closure of rural healthcare facilities. Hospital closings in areas with minimal healthcare infrastructure can have far-reaching economic impacts as well, further exacerbating health challenges for residents. Indeed, some estimates suggest that hospital closings in rural counties—an increasingly frequent phenomenon (Kaufman et al. 2016) —are associated with decreased per-capita income and increased unemployment (Holmes et al. 2006).

Rural disparities in access to healthcare are often compounded by racism. Anderson (2017), for example, finds that the clustering of Black and Latino residents is inversely related to the presence of various types of health organizations, including physical fitness facilities, social service providers, and health clinics. Studies of disability resources offer similar conclusions, as the proportion of non-Hispanic Black residents is inversely associated with the presence of disability and aging services (Pendergrast and Rhubart 2022). Further, whereas 65 percent of rural counties are designated Health Professional Shortage Areas—a designation used to increase the number of health professionals practicing in the area—81 percent and 83 percent of

Hispanic- and African American–majority rural counties, respectively, have that designation (Probst et al. 2004). Historical particularities also matter in understanding the relationships among race, health, and geography. For generations, large concentrations of Black Americans have resided in the rural south, reflecting historical legacies of slavery and racial oppression (Lichter et al. 2012; Burton et al. 2013), and these rural areas have been especially deprived of hospitals and other healthcare amenities (Barry-Jester 2017). These areas, often referred to as "resource deserts," can exacerbate administrative burden by limiting residents' knowledge of and access to public resources (Heinrich et al. 2022).

Finally, there are state variations in access to healthcare. Our study was conducted in Kentucky and Mississippi, two states that rank in the bottom 10 percent of all states in measures of healthcare quality (Agency for Healthcare Research and Quality 2018). Yet, Kentucky is a Medicaid expansion state, while Mississippi is not. Studies show that Medicaid expansion was associated with improved hospital financial performance, especially in rural markets (Lindrooth et al. 2018), leading to a reduction in hospital closures (Carroll et al. 2022). The Affordable Care Act eliminated programs that reimbursed rural hospitals for costs associated with uninsured patients, under the assumption that Medicaid expansion would fill that gap. In Mississippi, a state that has not expanded Medicaid, a third of rural hospitals are at risk for closure, compared with only 11 percent in Kentucky (Center for Healthcare Quality & Payment Reform 2023).

For our study, healthcare infrastructure—which we define broadly as not only health and mental healthcare institutions but also any social service organizations that promote the physical and mental well-being of residents—is important for several reasons. First, fewer healthcare providers means less access to healthcare and, subsequently, worse health outcomes (Gaffney et al. 2022). The strength of a community's healthcare infrastructure plays an instrumental role in residents' health, which means it can prevent—or at least slow—the process of residents developing impairments severe enough for them to seek disability assistance. In other words, access to healthcare institutions helps keep people healthy.

But healthcare infrastructure also plays an important role in helping residents with impairments to enroll in disability assistance, as the Social Security Administration requires verification from specialists. This includes organizations and institutions that might not be strictly defined as "healthcare providers." Social service organizations, for example, can connect residents to resources through formal referrals or by facilitating informal information sharing

(Small 2009). The increased privatization of many public services over the past three decades has also empowered private community-based organizations to become key intermediaries between the state and disadvantaged communities (Levine 2016; Marwell 2004). As such, local institutions and organizations not only distribute resources to the poor but also have the potential to reduce the administrative burdens they face as they interface with the state. Yet, as highlighted above, not all communities have equal access to these types of organizations (Allard 2009).

2.3 Disability Assistance Programs

The number of people enrolled in SSI and SSDI has increased significantly in the last few decades. While similar, the two programs differ in important ways. Supplemental Security Income (SSI) is a monthly cash benefit that is available to children and adults with a disability and without significant work histories. Only low-income applicants qualify; applicants must have less than $2,000 in resources to be eligible. In 2022, approximately 1 million beneficiaries were children (CBPP 2023b). Since SSI is only available to those who have very low incomes and few assets, more disabled children become eligible for SSI when the poverty rate rises. In 2023, the basic monthly SSI benefit for individuals without any other source of income is $914. SSI recipients are also automatically enrolled in Medicaid.

Social Security Disability Insurance (SSDI), on the other hand, is a disability benefit program funded by Social Security payroll tax contributions. Applicants must have worked for at least one-fourth of their adult life and five of the last 10 years to qualify for benefits. Estimates suggest that only 36 percent of applicants for SSDI are approved after their first evaluation, and only 35 percent of denied applicants choose to appeal (Liebman 2015). While SSDI allows (and encourages) beneficiaries to supplement their benefits through work, the vast majority cannot work. One study of beneficiaries who were tracked for 10 years found that only 28 percent did any paid work (Mamun et al. 2011). If denied benefits from either program, an applicant can choose to appeal the decision, which almost always requires hiring a lawyer.

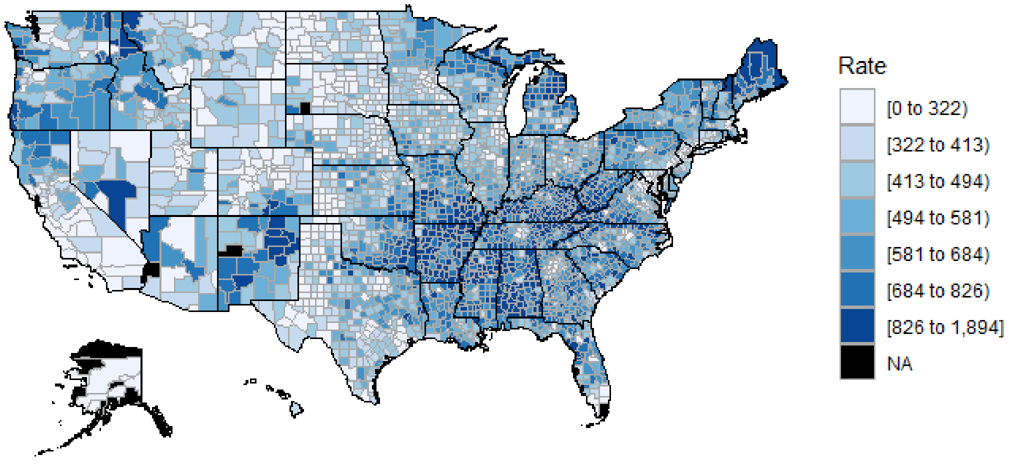
The literature on disability assistance programs makes a distinction between *impairment,* the physical/mental limitation, and *disability*, a condition created by a social context. One dimension of that social context is the labor market. O'Brien (2013), for example, argues that an individual's self-perceived disability status is strongly shaped by labor market conditions; that is, where and when employment is less secure, self-reported disability should be greater. Indeed, national trends in applications for disability assistance programs provide some evidence for this claim: between 2008 and 2009, at the start of the “Great Recession,” the number of applications for Social Security disability benefits increased by 21 percent (Johnson, Smith, and Haaga 2013). O’Brien tested this at the state level and found a link between state GDP per capita and reports of disability status. As state GDP increases, self-reported disability decreases. Similarly, as unemployment increases, the probability that a working-age person identifies as having a disability also increases. Such results highlight the contextual nature of disability claims. The local labor market, however, is not the only “local” factor that creates temporal and spatial variations in enrollment in programs like SSI and SSDI across places. There are also the logistics of enrolling in these programs as well as maintaining benefits over time, processes that are far from straightforward (Carey, Malbon, and Blackwell 2021; Hemmeter et al. 2017).

3. Data and Methods

3.1 Research Site Selection

This analysis examines the connection between local healthcare infrastructure and disability enrollment. We draw on data from 68 interviews in two rural counties with high rates of disability benefit program enrollment. Clay County, Kentucky, has the third highest enrollment rate in the nation (139 per 1,000 people), while Humphreys County, Mississippi (115 per 1,000), ranks seventh. Clay and Humphreys Counties also lie in two of the largest “clusters” of disability in the US: Southeast Appalachia and the Mississippi Delta (Mathematica 2018). These clusters can be clearly seen in Figures 1 and 2. Figure 1 shows SSDI recipients per 10,000 residents in 2020, while Figure 2 shows SSI recipients per 10,000 residents in 2020.

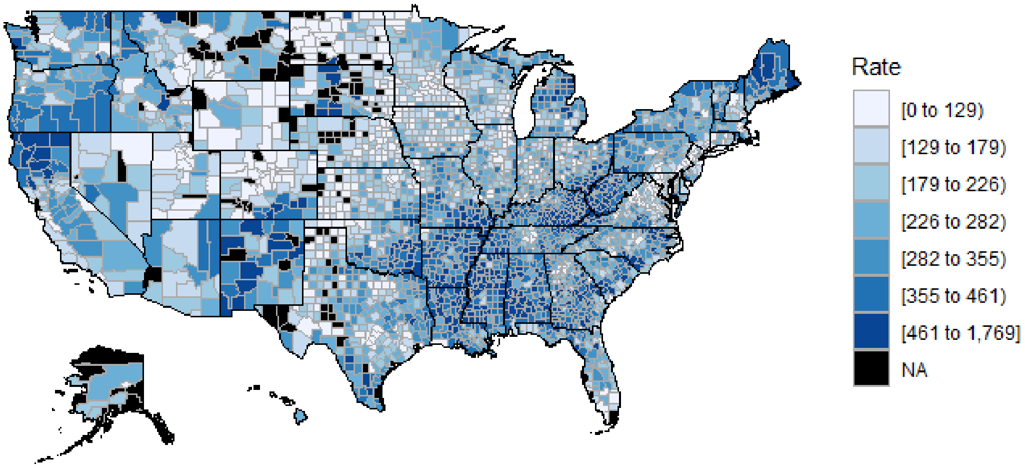
Figure 1: SSDI Recipients per 10,000 Residents in 2020



Sources: American Community Survey 2020; Social Security Administration 2021

These two sites share many similarities: they have experienced large-scale economic dislocations that began during the Great Depression and accelerated in the 1960s. The decline of the coal industry has been devastating for Eastern Kentucky. In Mississippi, mechanization of agricultural production, combined with the Great Migration, precipitated persistent depopulation. However, the two sites also provide key sources of variation that allow us to explore how disability status and program enrollment play out at the individual, household, and community levels, which are explored below.

Figure 2: SSI Recipients per 10,000 Residents in 2020



Sources: American Community Survey 2020; Social Security Administration 2021

3.1.1 Clay County, Kentucky.

Clay County is located in Central Appalachia and has an estimated 20,345 residents, with approximately 92 percent identifying as non-Hispanic white (U.S. Census Bureau 2020a). In the antebellum era, Clay County was famous for its salt works; after the Civil War, the lumber and coal industries took over. In recent decades, it has become an economically depressed and depopulating region. It has also suffered acutely from the opioid crisis. In 2016, 2.2 million doses of prescription opioid medications were dispensed in Clay County over a 12-month period, a stunning 150 doses for every man, woman, and child (Galewitz 2017).

Compared to other states, Kentucky is relatively generous when it comes to spending on basic assistance programs for residents. In 2020, for example, the TANF-to-poverty ratio in Kentucky was 21—as in, for every 100 families living in poverty in Kentucky, 21 received TANF cash assistance. For a family of three, the maximum TANF monthly payment was $262, which is about 13 percent of the poverty line (Kentucky Health Benefit Exchange 2022). Overall, approximately 75 percent of the state's TANF funds were spent on basic assistance to families (U.S. Department of Health & Human Services 2022). Kentucky has also expanded Medicaid, which has made a significant difference in the health of residents. Estimates suggest that after expansion there was a 35-percent increase in the share of residents who had gotten a check-up within the past year, a 39-percent increase in the share reporting excellent health, and an 18-percent increase in the share receiving regular care for chronic conditions (Aron-Dine 2017; Sommers et al. 2016). Kentucky established its own insurance marketplace under the ACA under the branding "Kynect," a strategy that distanced the marketplace from politically charged discussions of "Obamacare" and led to a surge in enrollments. Today, the Kynect platform facilitates enrollment in a range of benefit programs (Thomas 2017).

3.1.2 Humphreys County, Mississippi.

Humphreys County is in the heart of the Mississippi Delta. According to estimates from the 2020 Census, Humphreys County is home to 7,785 residents, more than three-quarters (75.8 percent) of whom identify as Black or African American (U.S. Census Bureau 2020b). Humphreys County remains a place where disability rates are exceedingly high, but it differs from Clay County in both its racial composition as well as the broader state-level policy environment in which it is embedded.

By almost any measure, Mississippi would be classified as one of the least generous states in the country when it comes to welfare spending (CBPP 2022). In 2020, the TANF-to-poverty ratio in Mississippi was four—as in, for every 100 families living in poverty in Mississippi, four received TANF cash assistance. For a family of three, the maximum TANF monthly payment was $170, which is about 9 percent of the poverty line (U.S. Department of Health & Human Services 2022). Approximately 6 percent of the TANF block grant was spent on basic assistance to families, with the majority going towards programs such as work and education training activities (34 percent) and fatherhood and two-parent family programs (18 percent) (U.S. Department of Health & Human Services 2022). Further, the state recently made national news for misappropriating TANF funds. In recent years, state auditors discovered that the Mississippi Department of Human Services allowed well-connected people—including prominent athletes—to squander tens of millions of welfare dollars (Fausset 2020). Unlike Kentucky, Mississippi is not a Medicaid expansion state, although expansion remains an ongoing topic of debate in the state legislature (Ganucheau, Pender, and Harrison 2023). Estimates suggest about 96,000 uninsured adults in Mississippi would become eligible for Medicaid if the state were to expand the program. Of the individuals who fall within this so-called coverage gap, 17 percent are individuals with disabilities and more than half (53 percent) are Black or African American (CBPP 2023c).

3.2 Interviews

During the summer of 2022, six fieldworkers interviewed a total of 68 respondents in the two sites, with 34 respondents coming from Kentucky and an equal number coming from Mississippi. Forty-seven respondents were disability benefit recipients or the head of a household that included a benefit recipient. The rest were community experts, including elected officials, school administrators, lawyers specializing in disability claims, faith leaders, and social service providers. Disability recipients were recruited through local institutions (e.g., libraries, churches), public spaces (e.g., laundromats), and referrals from community members and other respondents. We attempted to achieve maximum heterogeneity in our sample by recruiting from different spaces (Edin and Lein 1997). Each disability recipient, or head of household, was provided $50 as compensation for their participation in the study. Disability recipients and heads of household were asked a variety of questions about their experience navigating the enrollment process, household income and expenditures, health history, social relationships, and local civic life. To bolster our understanding of these places, we also analyzed the economic and social histories of each region, maintained subscriptions to local newspapers, and accessed current and historical census and administrative data on each region. Table 1 provides an overview of the demographic of respondents in the study.

Table 1: Respondent Characteristics

	Clay County, KY	Humphreys County, MS
Recipients		
Direct recipients	21 (88%)	22 (96%)
Head of household (someone else receives benefits)	3 (12%)	1(4%)
Average Age	54	56
Female	19 (79%)	11 (49%)

White	24 (100%)	3 (13%)
Black or African American	0 (0%)	20 (87%)
Type of Benefits		
SSI	18 (75%)	10 (43%)
SSDI	6 (25%)	13 (57%)
Use of Lawyer	5 (21%)	18 (80%)

During the fall of 2022, the team of six fieldworkers developed a codebook of 56 codes based on initial themes from interviews, observations, and archival analysis. Researchers utilized this initial set of codes to analyze all interviews using MAXQDA, with fieldworkers from Mississippi coding the Kentucky interviews and vice versa. The authors then reviewed the codes and wrote memos based on emerging themes. A primary goal of this process was to make comparisons across the two sites, in terms of not only how residents viewed disability programs but also how they navigated the application process.

4. Results

4.1 Importance of Social Networks

In both Kentucky and Mississippi, social networks played an important role in validating the physical and mental ailments of prospective applicants as a form of disability. Networks were also important in helping applicants ultimately receive disability benefits. Living in communities with high rates of disability enrollment meant that people were regularly exposed to others who were already participating in the programs. As such, enrolling in a disability benefit program was seen as a viable path for survival. There was also some—albeit limited—local knowledge on how to enroll in the program. This did not preclude stigma around receiving disability benefits, but residents in both counties recognized that they lived in places where many people were enrolled in disability benefits programs.

Many respondents in both counties applied at the encouragement of friends or family members. Jewell, a 71-year-old white woman in Clay County with chronic foot issues, was prompted to apply by conversations with friends and neighbors. As she explained, “I signed up because I just wasn’t doing well, and I signed up because everybody said I could probably draw it because of my, you know, the way things were with me.” Similarly, Bruce, a 30-year-old white

Clay County resident suffering from depression, was encouraged by a family member to apply: "[w]ell, actually, my mom, like she's the one that told me about it or whatever. Because she was on it too, you know?" Indeed, as Bruce highlights, his mom not only encouraged him to apply but also helped him with the application process because she had been through the enrollment process before. Without her help, he reflected that "I wouldn't probably have been able to get it." Other respondents reported receiving informal help or encouragement that proved instrumental in their ability to enroll. For Ruby, a 61-year-old Black woman from Humphreys County suffering from diabetes, psoriasis, and chronic back pain, it was her daughter who pushed her to apply. "At the time, my oldest daughter, she was just saying, 'Well, mama, if you're not able to sit and work … you might need to try disability and see what they help, allow you with disability,'" Ruby recalled.

While respondents in both Kentucky and Mississippi relied on social networks, these networks were not equally efficacious in helping residents navigate the process of applying for SSI/SSDI. We argue that these differences relate—at least in part—to the healthcare infrastructure, or lack thereof, in each county. In Kentucky, a constellation of institutions created conditions for an institutionally supported model of navigating the disability process, leading to comparatively short wait times and fewer setbacks in Clay County. Conversely, the lack of a similar infrastructure in Humphreys County led most prospective SSI/SSDI recipients to rely on a self-help model for navigating the application process, leading to long wait times, multiple rejections, and reliance on lawyers to get applications approved.

4.2 Kentucky: Institutionally Supported Model

In Kentucky, most respondents relied on public and private social service providers to learn about disability programs. These organizations included Social Security offices, schools, hospitals, healthcare clinics, and psychiatric facilities. Such local institutions provided residents with information about SSI and SSDI, encouraged them to apply, helped them navigate the application process, and even provided support as applicants faced setbacks. In other words, institutions reduced the administrative burden residents faced in applying for disability benefits programs by helping alleviate the psychological, compliance, and learning costs of enrollment.

Kimmie, for example, is a 57-year-old white woman in Clay County who received help from a local mental health clinic. Kimmie grew up in an unstable, abusive home—her father was an alcoholic who sexually abused the girls in the household. Her mother, Kimmie recalls, was sweet but suffered from schizophrenia and experienced paranoid hallucinations. When Kimmie was eight, she was taken by social workers and placed in a foster home, which unfortunately proved to be an abusive environment as well. Then, as an adult, Kimmie began experiencing chronic pain. She has thyroid issues and struggles with seizures and severe “nerves.” Eventually, she entered Cumberland River Comprehensive Care (“Comp Care”), a facility that provides care for individuals with mental disorders, because she was experiencing seizures and nerves and her sister was already there. Comp Care did almost all the work to coordinate her SSI enrollment:

> **Kimmie**: My sister got me in [to Comp Care], because she was in there. And they wanted me to... Well, at the time, I was having a lot of problems, seizures. Nervous disorders. I needed something to do through the day, and so I got in there. I enjoyed it. I was there a year. We would, we would make stuff. I made quilts.
> **Interviewer**: So they helped you get your social security?
> **Kimmie**: Yeah. My SSI.

Kimmie was certainly not the only Clay County resident to benefit from the presence of Comp Care in the community, even if their initial interactions with the clinic were unrelated to applying for disability benefits. When asked how he would advise someone interested in applying for SSI, George, a 62-year-old white man, explained, “I told you go to Comp Care.” Indeed, after being referred to Comp Care because he was struggling with “nerves,” a term residents used to describe a variety of mental health conditions, George received help from a specialist at the clinic and was approved for SSI 30 days later.

Comp Care was far from the only institution in Clay County that encouraged residents to apply for SSI/SSDI and helped them navigate the application process. For example, Mel, a 35-year-old white woman, had a doctor recommend she apply for SSI. In seventh grade, she had a seizure while holding a pair of scissors. Her principal called her mother, accusing Mel of being on drugs. Mel found out she had epilepsy only after a medical screening in the emergency room. She continued to have an active life, playing softball in high school, taking classes for dual credit, and starting college. Yet, her seizures continued to plague her into adulthood, eventually making it impossible for her to live a stable life. Her doctor recommended that she apply for disability insurance benefits and offered to help her with the process:

> I had a blood clot … a blood clot that would never go away, because after five days old it does not go away. And between that and my seizures … but I try not to let it get the best of me. I just, you know, I just keep on going day to day, like just trying to overcome it. But I was just taken back by like when [the doctor] asked me [about the disability program] and then my response was like, "I'm not very happy about this." [The doctor] was surprised by my response … I end up breaking down 'cause I'm like, I feel like I'm gonna be trapped for the rest of my life. Like all my hopes, my dreams, everything has been crushed at this point.

Mel's narrative highlights the profound psychological costs many applicants face as they evaluate their own impairments and consider applying for disability benefits. For Mel, the feeling of being "trapped" and having hopes "crushed" led her to break down. While she did not welcome the news, her doctor's suggestion provided her with options and gave her a realistic pathway to getting the assistance she needed.

Loretta, a 40-year-old white woman from Clay County, also benefited from the assistance of a local medical institution. "[I] was a slow learner and … really wasn't up to date and where I was supposed to be, my age and stuff like that," she explained when talking about her experience in school growing up. Her mom noticed Loretta's struggles and enlisted the help of First Steps, a local organization that provides pediatric therapy, to assist her in getting Loretta approved for SSI. "I guess, you know, she had First Steps and all them people work with me," Loretta explained. Kitty, a 63-year-old white woman, also knew very little about SSI when she applied on behalf of her daughter. "I knew nothing of that kind of stuff, you know, when (my daughter) was born," she said, "It was a social worker there who first asked me about it." When first approached with the idea, she remembered telling the social worker, "I have no idea what you're talking about." But, fortunately for Kitty and her daughter, the social worker helped them with the paperwork for enrollment and prepared Kitty for potential rejection. As Kitty recollected, "[t]hey first told me, 'let's get started with [the application], because even if she gets denied the first time, if we keep going and she does get approved, then she'll be back paid all the way to the first time she was applied.' " This advice proved consequential; Kitty's daughter's first application was approved after a three-month wait.

Non-medical institutions, like schools, provided invaluable assistance to Clay County residents as well. Green, a 39-year-old white woman, has a child who receives SSI. For children under the age of 18, schools are important mediators: they help identify children who could benefit from receiving SSI and help them enroll in disability programs. As Green explained:

> **Green**: My little girl has a learning disorder. She sees things backwards, so it makes it hard for her to learn, and I have to be with her 24/7 to help her out.
> **Interviewer**: Really? Wow. How did you find out that you could sign her up and get some help?
> **Green**: The school helped me.
> **Interviewer**: Did they suggest it?
> **Green**: Mm-hmm. One of her teachers, her, uh, special ed teacher. The school helped her get in … After she was denied the first time, it went longer, but after that, she got approved.

The fact that many of these institutions were local to Clay County residents reduced the cost of visiting them. Most respondents in Clay County reported receiving disability benefits within a year of the time they first applied. They were encouraged to enroll in the program by professionals who guided them through the process. A small number of people hired lawyers to help them, but many saw lawyers as useless—they explained that they felt like they could have done it themselves and the lawyers did not add much. Reba, a 67-year-old white woman with chronic pain in her legs and back, explained, "I got a lawyer, but he never helped me none." For others, lawyers were seen not just as unhelpful but even potentially exploitative. "I don't like lawyers," Shania, a 58-year-old white woman with a heart condition, explained. "They're so corrupt." Fortunately for women like Reba and Shania, they had other nearby resources that helped them avoid being reliant on legal intermediaries. Having a nearby institutional infrastructure of healthcare providers with knowledge of the disability process helped reduce the need of Clay County residents to rely on other types of intermediaries, ultimately saving them both time and money during the enrollment process.

4.3 Mississippi: Self-Help Model

Unlike residents of Clay County, most respondents in Humphreys County followed a self-help model as they applied for SSI or SSDI; in other words, people were left to fend for themselves without help from public or private service institutions. This seemed to be one of the many consequences of the dearth of local service providers in the area. The only hospital in Humphreys County, for example, closed in 2013. This meant that any medical emergency required a trip to Yazoo City, a city roughly 30 miles from the Humphreys County seat of Belzoni. For more serious or complex emergencies, people often went to Jackson, the state capital, which is roughly 70 miles from Belzoni. A medical emergency could therefore become a life-or-death situation very quickly. This was certainly true for Harmony Stribling, a Belzoni woman who tragically died of a heart attack—only five days before she was due to give birth—because her husband was unable to make the 30-minute drive to Yazoo City in time for her to receive treatment (Clark 2021). Humphreys County was certainly not the only place in the Mississippi Delta that had been impacted, or could soon be impacted, by the closure of a hospital (Clark 2021). Nearly all respondents in Humphreys County knew someone or had heard stories of people who had died while waiting for an ambulance.

The lack of healthcare and social service agencies in Humphreys County meant respondents were, for the most part, responsible for figuring out how to apply for disability benefits on their own. While some received help from friends or family members, this often took the form of emotional encouragement rather than practical guidance. Bridget, a 70-year-old Black woman, spent years helping others enroll in disability benefits programs. She was the second of 10 children, growing up in a large household full of extended family members. Her mother worked as a cleaner for a plantation owner; she also helped chop and pick cotton. “I used to help people get on disability, I just started doing it when I was in high school,” she said. “There was an old lady. She said, ‘Look there, come in. You know I can’t read and write … I need the social security form. I want you to help me get on disability.’ She got on, and she brought a couple more friends. They got on.”

As an adult, Bridget struggles with diabetes, high blood pressure, kidney issues, and back pain from herniated disks, a condition exacerbated by a car accident. Her primary care doctor works at a clinic in Belzoni, but her kidney specialist is in Greenville, a city 50 minutes away that she visits four times a year. She worked at a local Jockey factory until her back injury became so severe that she had to quit. Eventually she decided to apply for disability benefits herself. Much to her surprise, particularly as someone with considerable experience helping others apply, the process was a nightmare—she was rejected four times over a period of six years. After getting repeatedly denied, she went back to work as a home health aide and a crossing guard.

Indeed, given the lack of institutional infrastructure in Humphreys County, the costs of seeking help are often quite high. When talking about her experience navigating the application process, Sherry, a 51-year-old Black woman, explained, "It was horrible. I had to run back and forth to Greenwood, because the lady at Greenwood Hospital ... she's the one that started helping me ... Lord have mercy! And I don't even have a car."[1] For many Humphreys County residents, the various appointments with lawyers, doctors, and judges required considerable travel. Vern, a 64-year-old Black man and military veteran who suffered from chronic back pain and arthritis, was one resident who had traversed across multiple counties in the Delta to get his application approved. He summed up these struggles in explaining that, "[the] VA hospital is in Jackson, and in … Greenville. Now, they office are located in that same area, but I go to Jackson to the VA one day, and the next day, I'll have to go to Greenville to the VA. That's in two so totally different directions, and about the same distance in miles, you know, and that burns gas." Fortunately, Vern had a car; others were not so fortunate and were therefore reliant on the availability of family or friends to drive them to appointments. Some even reported paying neighbors or other acquaintances to drive them to medical appointments.

Norman, a 63-year-old Black man, also reported having difficulties receiving disability benefits. Norman's father worked at a cotton gin; his family also had hogs, chickens, and other livestock to feed the family. He went to school until 10th grade before leaving to work on a farm. He currently has rheumatoid arthritis and is blind in one eye. "The nerve went out in my right eye," he said. "I had to quit [my job], I had to retire." Norman applied for disability benefits but was rejected several times:

> I couldn't stand up long. I couldn't walk. And that's how I got my—I ain't get disability by my sight … [The judge] say you can work with one eye. They won't give me none. They deny ... Every time they deny me, I appeal it …. They told

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[1] Greenwood is a 45-minute drive from Humphreys County.

> me over there, at the Social Security office, like, "[Norman] they want you to stop appealing." [But my friend] say, "Every time they deny you, appeal. Every time they deny you, appeal it."

The steady stream of declined applications and long wait times between rulings meant that it frequently took a long time for Humphreys County residents to be approved for SSI or SSDI. It took most respondents in Humphreys two to eight years to be approved for their disability benefits. Waiting, and the setbacks often involved in that process, could exact a psychological toll on respondents trying to make ends meet. "It can be hard to get on disability. It's hard," Linda, a 52-year-old Black woman with heart issues, told us. "A lot of people have just given up. And some people's appealed it so much too, they just done got tired." Waiting for approval could often cause existing conditions to worsen, and some respondents even reported developing new impairments as the process played out. Although it was debilitating back pain that led Bridget to apply for disability, her application was ultimately approved for another condition: depression. Long wait times and frequent rejections of her application only exacerbated Bridget's depression, and the disability representative she eventually hired convinced her that her best chance at approval would come through citing her mental health as the primary factor limiting her ability to work.

Indeed, after multiple rejections, and with no one else to turn to, respondents often sought out lawyers—many of them out-of-state—for help. "I helped everybody, all these fools get on disability, couldn't get on it myself," Bridget said. "I had to have a [disability] representative help me. I had to have him to help me, because shoot, I couldn't, I couldn't get on." She was finally approved after she hired the representative. Norman also hired a lawyer and was amazed by how much that expedited the process:

> My friend, he told me to call disability [lawyer], they'll get me on disability…. He gave me the number. I called 'em. And they got me on. It was about two months. Well, I went two years and two months. Then I went to Greenville, I met the lawyer over there … After [the judge] talked to me and talked to the lawyer. Said he'll let me know in about five days. [The judge] wrote me a letter saying, "I approve." I got the lawyer, then [was approved in] five days.

While law firms were efficacious in providing help, their services often came at a considerable financial cost. Derek, a 66-year-old Black man with diabetes, hired a lawyer after his application was denied. “And within three weeks’ time I was back before the, another judge who granted the disability,” he recalled, “because it was a nurse on the lawyer’s staff who put the medical files in chronological order, where [the judge] could understand how this diabetes had progressed because of my medical records. And he granted it no problem.” The cost of three weeks of legal help—mainly putting Derek’s medical records in order—was about $5,000. Yet, Derek had no regrets about spending the money. “I could tell them about, you know, what some of the struggles and challenges I had,” he said. “Trying to drive and do all these things the doctor wants me to do. Something, [the judge] just wasn’t getting it … I didn’t have the benefit of that record either, that whole medical file like that … [the nurse] put it where he could understand it.” Similarly, Norman’s lawyer received $3,000 of the $11,000 he received in back pay. But he had no regrets either, especially given that he had “spent almost his entire” retirement savings trying to navigate the application process on his own.

5. Discussion and Conclusion

Enrollment in disability benefits programs is a social process, shaped by a variety of individual- and community-level factors (O’Brien 2013). Drawing on 68 interviews with disability benefit recipients (or heads of household) and community leaders in two rural counties with exceptionally high rates of disability claims, we highlight the importance of local institutional infrastructure in shaping the administrative burden that disability recipients must overcome to enroll in SSI or SSDI. Local factors beyond the labor market matter for disability benefit program enrollment, as they can shape who can access the program, how long it takes for them to enroll, and the types of conditions that lead people to seek assistance. In other words, everyone faces administrative burdens when they seek help from the state, but not everyone is equally equipped to overcome those burdens. Our analysis shows how places, and the institutions embedded within them, shape the ongoing relationship between individuals seeking disability benefit assistance and the state.

We have highlighted two “pathways” to applying for disability benefits, which are summarized in Table 2. The *institutionally supported model*, which was the most common pathway for residents of Clay County, Kentucky, was marked by low rates of rejection, short wait times, and the ability to get applications approved without hiring a lawyer, thereby maximizing the financial benefits of enrollment. This set of outcomes was made possible by a local infrastructure of healthcare and social service providers in Clay County. These organizations often served as primary mediators between the state and prospective recipients during the application process, reducing applicants' administrative burdens. Individual and institutional actors—ranging from nurses to social workers to disability advocates—helped reduce the learning, compliance, and psychological costs of "being disabled" for recipients. In other words, local institutions had what Masood and Nisar (2021) call "administrative capital," or an understanding of the "bureaucratic rules, processes, and behaviors" that comprise the disability application process (56).

Conversely, the *self-help model*—the pathway utilized by most residents of Humphreys County, Mississippi—was marked by high rates of rejection, a wide variation in wait times (two to eight years), and a high reliance on paid third-party facilitators like lawyers. While there were some medical clinics in Humphreys County, the closing of the local hospital in 2013, and the general lack of institutional infrastructure, meant that residents were forced to be self-reliant and self-motivated as they navigated the application process. As such, the "cost" —both in terms of real dollars paid to lawyers as well as administrative burden—of enrolling in disability benefits programs was high for many benefit recipients in Humphreys County. The case of Humphreys County also highlights how the private sector can benefit from administrative burden, as lawyers were often the primary beneficiaries of the long wait times and high number of setbacks experienced by residents.

Table 2: Institutionally Supported and Self-Help Pathways to Disability Benefits

Institutionally Supported Model	**Self-Help Model**
• Strong local infrastructure of healthcare and social service providers • Institutional actors as primary mediators in application process • Low reliance on legal counsel	• Limited local infrastructure of healthcare and social service providers • Paid lawyers as primary mediators in application process • High reliance on legal counsel

• Low rate of rejection of initial applications • Narrow range in wait times from first application to approval • Institutions pay learning costs for enrollment	• High rate of rejections of initial applications • Wide range in wait times from first application to approval • Individuals pay learning costs for enrollment

While we have highlighted how Clay and Humphreys Counties differed in terms of the pathways residents commonly followed to enroll in SSI or SSDI, there are other relevant differences between these two sites; namely, Clay County is predominantly white while Humphreys County is majority Black. Our data are limited in their ability to observe directly how racism shapes the disability enrollment process, especially given that the two focal counties had little racial diversity. Yet, past research suggests that racism influences differences in the enrollment process in two important ways. First, racial demographics are associated with the types of organizations that exist (or do not exist) in a community. Past research finds not only that Black communities have fewer health and social service organizations (Anderson 2017) but that organizations in majority Black communities located in rural areas tend to spend less on human services (Shapiro 2021). Second, race likely plays a role in shaping how doctors, social security office workers, judges, and other institutional actors assess the deservingness of applicants. Ray, Herd, and Moynihan (2022) refer to these assessments as "racialized burdens," or the types of administrative practice that "normalizes and reinforces patterns of racial inequality in public services, simultaneously reproducing disparate treatment while obscuring discrimination because bureaucratic actors are 'just following the rules'" (139). Indeed, experimental research suggests that the ways policies are enacted are not race-neutral, as Black applicants are more likely to be seen as undeserving of assistance than their white peers (DeSante 2013). These designations can be consequential; past research highlights how factors like political ideology shape the ways that street level bureaucrats evaluate the utility of administrative burden for determining the "deservingness" of potential applicants (Bell et al. 2021). One study, for example, found that Republicans were twice as likely as Democrats to believe that SSDI recipients were receiving assistance illegitimately (Fang and Huber 2020).

It is also important to acknowledge the different state-level policy environments across our two sites, and how they might shape the findings presented here. For one, the existence of healthcare infrastructure in Clay County is connected to Kentucky's expansion of Medicaid, which has allowed many low-income residents to receive medical care with greater regularity (Aron-Dine 2017; Sommers et al. 2017). Second, state-level logics around approval of SSI benefits might shape differences across sites. For example, Hemmeter et al. (2017) draw on administrative data from the Social Security Administration to highlight considerable variation in the proportion of child recipients who end up losing SSI benefits after turning 18. In Mississippi, 47 percent of children enrolled in SSI stop receiving benefits when they turn 18—the highest rate in the country. Conversely, only 36 percent of children on SSI in Kentucky stop receiving benefits when they turn 18. The authors highlight several potential explanations for these cross-state disparities, including economic environments, employment opportunities, and optional state supplements. This suggests that improving disability assistance programs can be approached in two ways. One is by directly tackling the federal and state-level policies that govern how applications for disability assistance are processed and approved. Another is by supporting local healthcare systems (and other social service organizations) that facilitate the application process for residents.

While our results point to social service organizations as key mediators between the state and individuals with disabilities, it is also important to recognize the broader implications of this arrangement. As Heinrich et al. (2022) point out, reducing the administrative burden for applicants requires placing "additional strain on the capacity of public and private nonprofit organizations that serve as the health and social safety net for those in most need, particularly in communities with more limited resources and social service infrastructure" (40). In other words, organizations are not always well-equipped to alleviate administrative burdens, and devoting time and resources to helping residents overcome them can limit organizations' ability to benefit communities in other ways. Given that disability benefit enrollment is concentrated in many rural areas that are persistently poor (Gettens, Lei, and Henry 2018) and that often have limited organizational resources (Shapiro 2022), the strain on local organizations in places like Clay and Humphreys Counties can be considerable.

Clay and Humphreys Counties are both places with very high rates of disability benefit program enrollment, located in geographic areas with high clustering of disability claims. Thus, while they make for an ideal comparison, they are somewhat exceptional when it comes to the proportion of residents receiving SSI or SSDI. Future research should explore whether similar or different pathways exist in areas of the country with much lower rates of disability benefit program uptake. Also, the potential link between local healthcare infrastructure and SSI/SSDI enrollment remains a fruitful area for future work. Limitations notwithstanding, our analysis shows how places shape the ability of residents to enroll in programs that are not place-based. While everyone would have equal access to disability benefits programs with the proper documentation, we have highlighted how the task of navigating the application process from start to finish is far from straightforward and is profoundly shaped by many local factors that ostensibly have nothing to do with the administration of SSI or SSDI. Our analysis also suggests that as rural hospitals continue to shutter their doors due to corruption or limited funding (Kaufman et al. 2016), the consequence is not only inadequate access to healthcare for residents but also inadequate administrative resources to help residents enroll in programs like SSI and SSDI.

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