



'Live in Our Shoes for a Day':

A Study of Hoosiers Leaving the Workforce Due to Disability



INDIANA
COMMUNITY ACTION
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Research and Public Policy

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Introduction

A car accident. A cancer diagnosis. Any event causing severe post-traumatic stress disorder. A disabling condition could happen to any of us, at any given moment. A young worker at the age of twenty has approximately a one in four chance of experiencing a significant disabling condition before retiring.ⁱ Whether temporary or long-term, disabling conditions that take an individual out of the workforce can lead to months, years, or even a lifetime of financial instability.

“We’re separated from the average person in America. It’s two different worlds here.”

-Marcus

This study examines the experiences of individuals who leave the workforce due to disabling conditions. It centers their voices and experiences, adding statistics and research studies to illustrate the need for further policy attention to ensure that a disabling condition does not equate to financial ruin for the one in four Hoosiers who will experience them. It offers policy recommendations that rest largely on the experiences of Hoosiers and the gaps they see in our system. These recommendations prioritize strategies that would enable more Hoosiers to remain employed, assist with income during their transition out of the workforce, prevent poverty and hardship, and provide support to re-engage in the workforce for individuals who are ready and able to do so.

What Do We Mean When We Say Disability?

Disability can be broadly defined as a condition an individual is born with, acquires, or obtains due to injury that impairs certain activities and/or interactions with society.ⁱⁱ Definitions of disability have evolved, and while there have been attempts at standardization in research (e.g., International Classification of Functioning Disability & Health), variation remains and concepts continue to change over time.ⁱⁱⁱ To illustrate, Table 1 shows the different ways in which three government agencies – the Social Security Administration, the Centers for Disease Control and Prevention, and the U.S. Census Bureau – categorize disabilities. In 2023, the U.S. Census Bureau announced plans to change how it classifies disabilities in the American Community Survey (ACS). Due to an outpouring of feedback, they decided to keep the current classifications for 2025 and to meet with disability community stakeholders in September 2024 to better understand challenges in data availability and access for their community.^{iv}

Table 1. Categorization of Disabilities by Government Agencies

Social Security Administration		Centers for Disease Control & Prevention	U.S. Census Bureau
Immune System Disorders	Musculoskeletal Disorders	Hearing	Hearing
Cancer (Malignant Neoplastic Diseases)	Special Senses and Speech	Vision	Vision
Mental Disorders	Respiratory Disorders	Cognition	Cognition
Neurological Disorders	Cardiovascular System	Mobility	Ambulatory
Congenital Disorders that Affect Multiple Body Systems	Digestive Disorders	Self-care	Self-care
Endocrine Disorders	Genitourinary Disorders	Independent Living	Independent Living
Skin Disorders	Hematological Disorders		

Sources: Social Security Administration (2024). Listing of impairments – adult listing. <https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>; National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (2020). Prevalence of disabilities and health care access by disability status and type among adults. <https://www.cdc.gov/ncbddd/disabilityandhealth/features/kf-adult-prevalence-disabilities.html#:~:text=1%20Hearing%20%28serious%20difficulty%20hearing%29%3B%20%20Vision%20%28serious,or%20%20Independent%20living%20%28difficulty%20doing%20errands%20alone%29>; U.S. Census Bureau (2021). How disability data are collected from the American Community Survey. <https://www.census.gov/topics/health/disability/guidance/data-collection-acr.html>

Understanding the depths of how a disabling condition affects one's health and daily experiences can be minimized by check boxes and survey columns. We recognize the challenge of measuring the scope of these experiences. Within the context of this study, included are individuals diagnosed with cancer, bipolar disorder, post-traumatic stress disorder, genetic disorders, significant injuries, and other conditions. To better understand these experiences and create more equitable systems, those who are disabled must be included in policy conversations and research that impacts them. Exclusion from research has been commonly due to the personal discomfort of researchers and evaluators, biases towards accommodations or through intentional lack of inclusion. Individuals with disabilities need to be engaged in the planning of public health programs and services, and more exploratory work is needed to examine aspects related to disability policies and structures centering on firsthand experience.^v Those with direct experience bring awareness of critical points of needed change to our society; rethinking how systems function is valuable for improving access and processes for the broader population.^{vi} That is the aim of this study.

Disability by the Numbers

While fully acknowledging the limitations of available numerical data, the following statistics offer a snapshot that speaks to the prevalence of disability within our country and state as well as the challenges that arise from the use of differing definitions. In the United States, the CDC reports that one in four adults (28.7%) in the United States has a disability and in Indiana, 29.3% of individuals report having a disability.^{vii} The majority of disabilities in Indiana reported by the CDC for adults eighteen and older are cognitive disabilities (13.7%) followed by mobility-related disabilities (12.8%).^{viii} Similarly, the U.S. Census Bureau reports cognitive disabilities (5.9%) and then ambulatory disabilities (5.1%) as the most common for individuals aged eighteen to sixty-four in Indiana. While the highest prevalence of disabilities is among individuals over age sixty-five, nearly one in ten Hoosiers ages 18 to 34 and more than one in seven ages 35 to 64 is identified by the Census Bureau as having a disability.^{ix}

Table 2. Disability Statistics in Indiana

Indiana	With a disability	Percent with a disability
Label	Estimate	Estimate
Total civilian noninstitutionalized population	958,855	14.2%
SEX		
Male	462,505	13.9%
Female	496,350	14.6%
RACE AND HISPANIC OR LATINO ORIGIN		
White alone	761,513	14.6%
Black or African American alone	92,145	14.9%
American Indian and Alaska Native alone	3,240	14.0%
Asian alone	11,553	6.7%
Native Hawaiian and Other Pacific Islander alone	585	23.4%
Some other race alone	24,511	11.2%
Two or more races	65,308	13.8%
White alone, not Hispanic or Latino	751,490	14.7%
Hispanic or Latino (of any race)	54,443	10.3%
AGE		
Under 5 years	3,337	0.8%
5 to 17 years	79,140	6.8%
18 to 34 years	149,752	9.7%
35 to 64 years	352,693	14.1%
65 to 74 years	171,281	25.3%
75 years and over	202,652	46.0%

Source: U.S. Census Bureau, 2022 American Community Survey, 1-year estimates

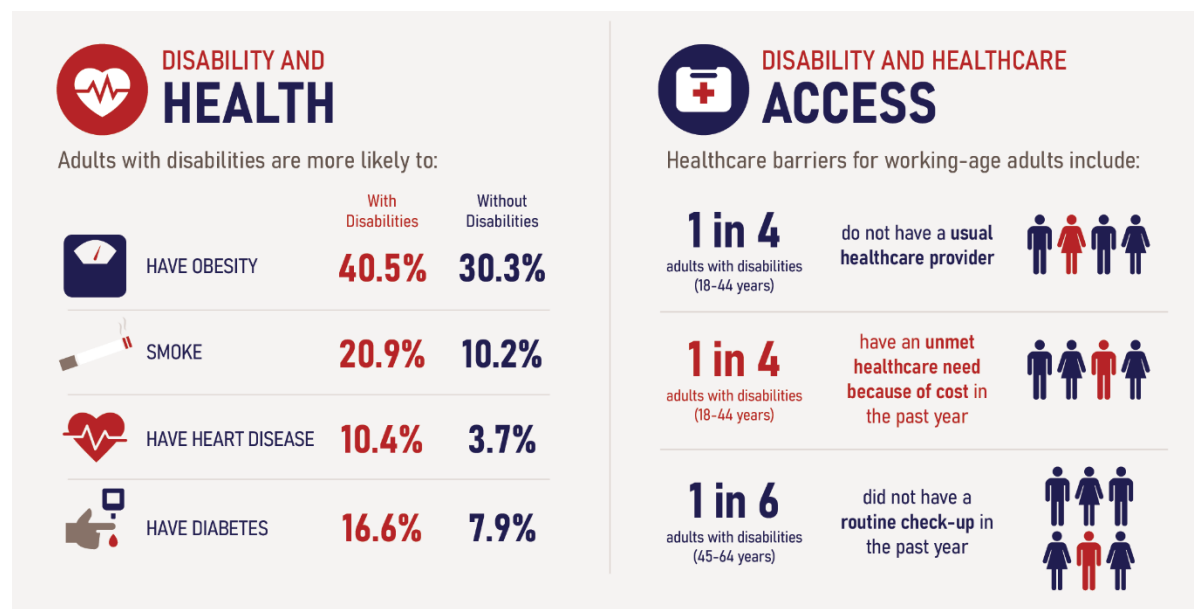
DISABILITY TYPE OVERALL & FOR WORKING-AGE HOOSIERS

With a hearing difficulty	248,382	3.7%
Population 18 to 64 years	85,527	2.1%
With a vision difficulty	173,449	2.6%
Population 18 to 64 years	94,045	2.3%
With a cognitive difficulty	381,208	6.0%
Population 18 to 64 years	238,053	5.9%
With an ambulatory difficulty	450,265	7.1%
Population 18 to 64 years	205,242	5.1%
With a self-care difficulty	153,597	2.4%
Population 18 to 64 years	68,028	1.7%
With an independent living difficulty	311,596	6.0%
Population 18 to 64 years	172,489	4.3%

Source: U.S. Census Bureau, 2022 American Community Survey, 1-year estimates

The CDC reports that adults with disabilities are more likely to suffer health disparities than those who do not have a disability. Nationally, individuals with a disability are more likely to be obese, smoke, have heart disease, or have diabetes. One in four adults with disabilities ages eighteen to forty-four reported they do not have a usual healthcare provider, and in the past year they had an unmet healthcare need because of cost. For adults forty-five to sixty-four years old, one in six did not have a routine check-up in the past year.^x These disparities require further research of the lived experiences of individuals with disabling conditions to understand the causes and consequences associated, along with effective solutions.

Figure 1. Disability and Health



Source: Centers for Disease Control and Prevention. Disability and Health Data System (DHDS) [Internet]. [Updated 2024 July; cited 2024 July 15]. Available from: <http://dhds.cdc.gov>

Background on Key Policies: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)

All participants in this study were asked to describe their experiences with Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). These programs are run by the Social Security Administration and, among other goals, are intended to support the financial stability of individuals experiencing disabling conditions. This section provides a brief overview of both programs.

The initial Social Security Insurance (SSI) program was born on August 14, 1935, through the signing of the Social Security Act by President Franklin D. Roosevelt. The program was developed to pay benefits to retired workers ages 65 and older. Over the past 89 years, the Social Security program has expanded to include benefits to spouses, minor children, as well as disabled adults and children. One of the most notable changes to Social Security occurred in 1954 with the establishment of the Division of Disability Operations. The legislation that established this new division allowed individuals or their survivors to receive retirement benefits without them being reduced or wiped out if the worker had a period of disability. This 'freeze record' program did not provide cash assistance but provided some level of additional security. In 1956, President Eisenhower signed an amendment that included cash benefits to disabled workers aged 50-64 and to adult children of retired, disabled, or deceased workers if the child was disabled before age 18. In September 1960, President Eisenhower signed an amended law permitting paid benefits to disabled workers of any age and their dependents.^{xi} This legislation ushered in the establishment of Social Security Disability Insurance (SSDI).

Figure 2: Timeline of Major Disability-Related Social Security Changes



While SSI and SSDI are similar systems that each pay benefits to individuals who are disabled, they vary in their qualification process and functionality. Both SSI and SSDI pay benefits to adults who are disabled only for total disability, meaning an individual's disability is expected to last for at least one or more years or result in death. They also each generally use the same medical requirements and process to determine entitlements.^{xii}

The major difference in the programs is related to the work history requirement. SSI recipients who receive benefits due to a disability are not required to have paid into SSI through previous employment; however, their income and other financial resources must not exceed a strict cap.^{xiii} SSDI is considered an earned benefit that an employee has paid into through payroll taxes. To qualify for SSDI, individuals generally need 40 work credits, with 20 of those being earned in the last 10 years. Younger workers may qualify with fewer credits. A worker can earn up to four credits per year. These are based on average wages and changes annually.^{xiv} For example, a worker earns one credit for each \$1,730 in wages or self-employment income. When an individual has earned \$6,920, he or she has earned four credits for the year.^{xv} Recipients can receive both SSI and SSDI at the same time. In this study, SSI and SSDI will be discussed from the participants' vantage point to assess their adequacy in promoting financial well-being.

Methods

The concept for this study originated in discussions with the Indiana Community Action Poverty Institute's Advisory Council, as members who experienced disabling conditions urged the leadership team of the Institute to engage in deeper study and advocacy related to these experiences. To counter the longstanding history of exclusion of people with disabilities from designing research and programs that affect their well-being, the Institute prioritized the implementation of a trauma-informed research design that centered the voices and experiences of individuals with disabling conditions. The study design began with the research team learning and planning to implement trauma-informed research practices. The research team also committed to including individuals from the disability community in the research process by using a trained interviewer with a disabling condition and establishing a design team that included members who identified as having a disability. Table 3 describes the members of the design team and their roles in the community. Design team members were asked to commit to attending three of five monthly meetings over the research period and providing feedback on the draft publication. Design team meetings typically consisted of a one-hour meeting where the research team updated the design team of the study's progress and asked for guidance in the research study's development.

Table 3. Design Team Members

Name	Organization
Wendy Wright*	Advisory Council Member for Indiana Community Action Poverty Institute
Kendra Cuyler*	Advisory Council Member for Indiana Community Action Poverty Institute
Amber O'Haver*	Chief Revolutionary Officer, Disability Revolution
Emily Munson*	Policy Director and Senior Attorney, Indiana Disability Rights
Ashley Ellingwood	Family Development Counselor, Community Action Program of Western Indiana
Amber Armstrong	NeuroResource Facilitator, The Indiana NeuroResource Facilitation Program
Megan Stuart	Director of Advocacy, Indiana Legal Services
Quinn Kissane	Volunteer Member

**Indicates that the individual identifies as having a disability.*

The Institute recruited individuals with connections to Community Action who identify as having a disability. Ninety-six unduplicated individuals completed the study interest form and twenty were ultimately interviewed. Selection was based on a desire to secure diversity in work history, location within the state, experience with SSI/SSDI, and demographic characteristics. Interviews were conducted over the phone or by Zoom. To compensate them for their time, interview participants were offered a \$25 Visa gift card. To supplement these perspectives and answer clarifying questions, four professionals who work with the disability community were also interviewed.

Interview recordings were uploaded to NVIVO transcription software, and transcripts were edited by hand for accuracy. The research team developed common themes through a thorough process of listening to transcripts and extracting quotes. Quotes were categorized by topic, and themes emerged from these topics. To protect participants' identities, pseudonyms were used. Participants were invited to choose their own pseudonyms.

Members of the design team and interview participants were invited to provide feedback on a draft of the resulting report. Their feedback was incorporated into this final report.

Participants

Our research team interviewed twenty individuals who left the workforce due to a disabling condition and conducted four supplemental interviews to better understand the systems these individuals frequently interact with when navigating this experience. Supplemental interviews included a former state investigator for a township trustee's office, an attorney, an executive director of a Community Action Agency that is also an Area Agency on Aging, and a case manager for Child and Family Services.

Table 4. Demographic Characteristics of Participants with Disabilities

Gender	
Male:	4
Female:	16
Race	
White:	11
Black or African American:	4
Bi- or Multi-Racial:	2
American Indian or Alaska Native:	1
Other:	2
Hispanic/Latinx (of any race)	1
Median Age: 57	Age Range: 36-68

Participants answered open-ended questions about their work experience prior to leaving the workforce. Their answers are categorized in Table 5 below. Some offered more than one occupation.

Table 5. Participant Work Experiences Prior to Disabling Condition

Factory work	6
Health services	2
Administrative assistant / "Office work"	6
Cashier	2
Management	2
Animal care / Veterinary services	2
Sales	2
Research	1
Landscaping	1

Figure 3. Participant Locations



All participants were asked about their experiences with SSDI and/or SSI. While a more in-depth look at these is presented in the findings, summary data is presented in Table 6 below.

Table 6. Participant Experiences with SSI / SSDI

Receiving SSDI	13
Receiving SSI	2
Applied and Currently Denied SSI or SSDI	2
Awaiting Determination	3

Key Themes

Themes are drawn from the participants' experiences as they navigated departing the workforce, seeking support, adjusting to new financial constraints and mental hardships, and weighing returning to the workforce. Throughout, quantitative data and findings from research supplement participants' perspectives, largely indicating that the experiences of these twenty individuals are not unique. Rather, they speak to the experiences of a community of Hoosiers who have left the workforce due to a disabling condition and live through unnecessary hardships created by systems that do not permit Hoosiers to exit the workforce with dignity.

Departure from the Workplace: The Mental Toll

"Given all that I've gone through, it was really hard to understand I still have a purpose. Even when I didn't feel like getting out of bed."

-Shirley

Employment is not simply a means of financial security. Work plays a central role in the development, expression, and maintenance of psychological health.^{xvi} Many draw purpose and meaning for life through their occupations and the skills that we offer to others. Employment in the U.S. is highly prioritized as an essential component of "the American Dream." It is a social norm we are conditioned to work towards during our adolescent years and believe will be our future until we retire. James spoke to this social norm of employment as he shared his upbringing and perspectives on work: *"It's not fun to just stop work. My mom raised me to work."*

Losing the routine associated with employment was devastating to some participants. Without employment, participants lost social ties and a sense of personal worth and value. Amy, describing how unemployment affected her self-image, shared:

"[Not being able to work] definitely showed me how much I was depending on my ability to work as a definition of my worth as a person. I just felt like, 'Oh, my God, I'm...I'm a failure. I'm a lazy bum.'"

Grace, an RN facing terminal cancer, struggled to make sense of her life 'from the other side of the bed,' as she described it. *"I loved helping others. I don't like to be on this side of the bed. I felt like I made a difference. How can I make a difference now?"*

Permanent or prolonged absence from work created major disruption in participants' lives. Participants expressed not wanting to leave the workforce and missing their jobs and the socialization that accompanied it. *"It was difficult [leaving the workforce],"* said Max. Jessica echoed the same sentiment saying, *"I really miss it. Working...my colleagues...having that, you know, because it isolates you, it isolates you.... If I could have had it my way, I would have loved to continue being working."* Additionally, Christine also spoke about work as a highly valued and desired aspect of life. *"It's not like I don't want to work,"* she says while crying. *"I used to work three jobs. I used to work at the post office, I was a medical receptionist, and I was working at a factory. I was going to school and now I am not working at all."*

Individuals who develop disabling conditions can experience significant barriers to continued employment. However, beyond the conventional metrics of labor force participation or unemployment rates, we know very little about the workplace experiences of people with disabilities.^{xvii} Individuals with disabilities may be adversely affected by the degree of acceptance and flexibility afforded by co-workers and supervisors. Disability may be perceived as disruptive to the workplace's operations and structure, resulting in the resistance to provide, or the denial of, accommodations.^{xviii}

Participants desired attention and resources to support enforcement of existing nondiscrimination laws and to increase tolerance for diversity in the workplace. Shirley, a former dog groomer, needed more flexibility, tolerance, and education in the workplace. “[My employer] thought I was slowing down because I was on drugs or something and I was having to be monitored.” Even when participants took proper steps to exercise their rights, such as by requesting reasonable workplace accommodations or the use of accrued leave, they found themselves unemployed. Ellen recalls asking for accommodations

...and they would agree on paper, but not physically. And so it would show that they agreed to work with me, but then they would come out and say, ‘You got to do this and you got to do that.’ And I would say, ‘I’m sorry, I can’t because of my physical disability and my mental disability.’ And they’d say, ‘Well, you either do it or you find another job...’ And it was very heart-rending because I loved my job. I loved what I was doing and the people I was doing it with.

Tammy, a healthcare employee, also tried to follow the proper protocol and was fired. “[I] tried to take a leave of absence, and they immediately fired me.”

When employers are not willing to work with employees around their emerging health conditions, it can lead to disruption in the employee's life, but can also affect their work performance, potentially creating unsafe work environments for both the employee and those around them. Grace, an RN, shared that she

...had a lot of symptoms...I was calling off for and I don't really know why I was having all these other symptoms and it was related to the cancer. And so when I was finally diagnosed, I couldn't take any time off of work. So I had the surgery on Thursday, and I went back to work on Monday after having my right kidney removed.

She worried about the quality of care she was able to provide at that time and described her managers as rude and felt that they wanted to fire her. Ultimately, she resigned and found another position before additional complications led her to seek Social Security Disability Insurance.

Not only can workplaces become hazardous when accommodations aren't granted, but they can become the cause of disabling conditions. Nationwide, workplace injuries and illnesses resulted in days away from work totaling 1,184,200 million nationwide in 2022, the most recent year for which we have data.^{xix} Lisa developed multiple conditions working in factories.

I started at a factory that produced gas line antifreeze and charcoal lighters with no ventilation...and then I worked at a place for 8 years that made rubber...they used an electric welder, and it cut patterns into the foam for car seats and stuff...They ended up with a lot of carpal tunnel because they had to work with your hands at such a fast pace. And there was no taking your time to do it. That's just the way it was... My first surgery from them was for heel spurs on both feet. I could not do standup work anymore.... I got COPD from all the chemicals and secondhand smoke."

Not all participants experienced negative departures from their employers. Several participants reported experiences with understanding employers, and they expressed gratitude for their employer's willingness to provide accommodations. Karen, a receptionist at a dental office, describes her employer holding her position and working hard to make it possible for her to continue in her role.

"Even months and months into it, he was like 'if you just want to come into my office. You don't even have to see or deal with patients or anything. You just want to come to my office.' Like his personal office. 'You can, like shut the door in there....' [He] Was offering like, could you maybe do this? Or we could bring in a special chair. We could do all these things."

Even when an employee's job couldn't be held for them, a show of care went a long way. *"I was very grateful to have the employer at the time because I know sometimes employers don't care and you're just a job to them... my employer was very heartbroken for me having a stroke and having to leave and not being able to come back,"* Elaina, a factory worker, acknowledged.

The decision to leave the workforce – temporarily or permanently – can be extraordinarily difficult as employment is a primary source of income, social interactions, and one's sense of value and purpose. Being forced to leave or feeling unwelcome within workplaces further exacerbates a demoralizing experience. While legislation like the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (Figure 4) have attempted to support workplace engagement, participants' experiences speak to the need for greater support to claim their rights. In addition, policies that increase workplace flexibility or provide medical leave through paid family and medical leave programs or short-term disability policies are needed. Finally, more employers could connect employees to resources if an employee ultimately must leave the workforce and apply for disability benefits – especially in light of the stories shared under the next theme, "Navigating the Benefits Gauntlet."

Figure 4. Nondiscrimination Legislation Related to Individuals with Disabilities

Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 is a federal law that protects individuals from discrimination based on disability. The nondiscrimination requirements of the law apply to employers and organizations that receive financial assistance from federal departments or agencies. Section 504 forbids organizations and employers from denying individuals with disabilities an equal opportunity to receive program benefits and services. It defines the rights of individuals with disabilities to participate in, and have access to, program benefits and services.

The Americans with Disabilities Act (ADA) of 1990

The Americans with Disabilities Act (ADA) of 1990, as amended, protects the civil rights of people with disabilities, and has helped remove or reduce many barriers for people with disabilities. The legislation required the elimination of discrimination against people with disabilities. The ADA has expanded opportunities for people with disabilities by reducing barriers, changing perceptions, and increasing participation in community life.

Source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (2020). Disability and health inclusion strategies. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-strategies.html>

Navigating the Benefits Gauntlet

Navigating the process of applying for Social Security is a grueling gauntlet of confusing questions and paperwork that participants described as a process that is designed for people to “give up.” Max described the process as having to “go through a lot of hoops.” If SSDI is a benefit that individuals have paid for and are entitled to upon becoming disabled, then why is it so hard to access? The answer to this question is complex and stems from disjointed systems that are not easily accessible or navigable, especially during a health crisis.

“It’s such a humiliating process.”
-Karla

Nearly every interviewee expressed frustration over being denied benefits after their initial application and having to appeal the process, adding unnecessary stress and financial strain. Jeff shared that after applying for benefits he “had a phone interview and the guy said, ‘They always will decline on the first attempt.’” When James first applied for SSDI, this was his experience as well. “I applied in 2002, I got denied, and then I applied again. About a year later, I tried to go back to work and it just got hard...hard on me. I applied again and I got approved around 2003.”

The Federal Social Security Administration denial rate for initial worker applications in 2019 was about 65%, with 49.2% of **all** applications eventually being approved. Applicants can appeal a denial decision, but the appeals process is lengthy and can add years to the wait for a final decision. There are four levels to the appeals process. Table 7 offers summary statistics of Social Security Disability approval rates.

Table 7. Social Security Disability Benefits Determination Approval for Workers

Initial Application Approval Rate	2022	2021	2020	2019	2018	2017	2016	2015
Indiana	34.9%	33.4%	32.0%	32.2%	31.1%	30.4%	30.7%	31.5%
National Average	38.8%	37.7%	38.3%	37.6%	35.3%	34.4%	33.5%	32.8%
Reconsideration Approval Rate	2022	2021	2020	2019	2018	2017	2016	2015
Indiana	11.0%	10.1%	10.7%	9.2%	9.8%	9.6%	9.4%	7.2%
National Average	15.0%	13.2%	13.6%	13.4%	12.4%	12.9%	12.6%	11.7%
Hearing Approval Rate	2022	2021	2020	2019	2018	2017	2016	2015
Indiana	53.7%	54.6%	53.4%	52.5%	54.3%	60.3%	56.7%	55.4%
National Average	54.2%	54.7%	51.1%	52.9%	53.9%	56.8%	54.7%	53.4%

Source: U.S. Social Security Administration (December 2023). Annual Statistical Report on the Social Security Disability Insurance Program, 2023

Having access to supportive medical providers, an attorney, and other professionals aware of the process of applying for disability helped applicants move through the slow and tedious process of applying for benefits. According to the Government Accountability Office, individuals who had representation from an attorney or even a friend or family member at an appeal were granted benefits at a rate nearly three times higher than those who did not.^{xx} This was true for Lisa, who received assistance from an attorney. *“I didn't have as much trouble as some people have. I think it took me a little over 18 months. But thank God I had my mom and dad, and my lawyer was a retired Social Security judge. He came up from [Name of Town] Kentucky and took my case.”*

Most participants sought the help of an attorney, therapist, or family member to assist them with the appeals process. Tammy, who had previously applied for SSDI on her own, had the support of her therapist and an attorney the second time around. *“[My therapist] helped me and I think it was just probably less than a year after she helped me that I applied and I got it. She got this lawyer. Her and I went to him, and as soon as she talked to him and she wrote a letter, I immediately within that year got my disability.”* Legal services were often instrumental in not only getting benefits but also correcting errors, as in Elaine’s case. *“That lawyer helped me tremendously because he told the judge that they should have been the ones to tell me that I applied for the wrong thing. So in the court, he fought for me to get that backdated, and the judge agreed.”*

The importance of legal services is dual: while, as reflected in the experience above, legal services can be crucial for gaining access to wrongfully denied benefits, it also is a space that some members of the community have noted is inaccessible and difficult to navigate with a disability.^{xxi} Stephanie also got an attorney after being wrongfully denied benefits. She described the process of applying for disability as frustrating and later hired an attorney to assist with her appeal.

You know what, it was frustrating, you know. And the reason it was so frustrating is that I did the application online. And I was denied. Then I did talk to someone at Social Security, and they said that, you know, I didn't classify. You know, I was not really disabled, you know, what I put into the system. So that's why I went on ahead and I got a lawyer.

Stephanie was later approved for SSDI after hiring an attorney.

Ruth was equally frustrated as she recalled the medical evaluation she underwent when she applied for benefits.

I got to see this guy and to bring all my medical equipment, which was a huge freakin' ordeal. I mean, I had the car filled with bags of stuff, and I walk in and they're like, oh, you didn't have to bring any of that. And I was like, 'What? Really?'

Next, she went on,

they put me in a room and he tells me to touch my nose with my arms and hands, you know, and touch my feet. And I could do that. And out the door I went. It didn't matter that there's days I can't do that. Like, every day is different. And, you know, then I got denied. Then I hired a lawyer for the appeal. The appeal took three years.

Applying for Social Security disability benefits is often a years-long process if an individual needs to appeal an initial denial. Karla, spent over two years engaging in the appeals process. When asked about it, Karla describes it as

Horrible. You know, they denied and they denied. And then I got an attorney and.—oh— it ended up going through. But it took two and a half years during which time I quit work. I have a piece of paper where they said you can be a dishwasher. And that was just humiliating, you know? And it's like, I wish I could, you know..... it's just a horrible stigmatizing process. And then they granted it and said they would review me in one year....then they denied it and they took it away. And so then I had to fight for it for another two and a half years. And the attorneys wanted me to stop my disability payment so that they could take 30% knowing it would take them 2 to 3 years and then they can make a lot of money on it..... So, yeah. I mean, that's five years of my life, right?

Figure 5. Average time from submission to decision



Source: USAFacts Team. (2023, December 12). Wait times for Social Security Disability Benefit Decisions Reach New High. USAFacts. <https://usafacts.org/data-projects/disability-benefit-wait-time>

Note: Each time duration displays represents the most recent public data for wait times at each level. Because these data come from different agencies or are updated at different frequencies, the most recent update at each level varies.

Marcus hired two attorneys and then struggled to make ends meet as he waited for a decision. Speaking of the first, he shared that *"this lady did not know what she was doing and therefore I was denied."* A second attorney helped him get benefits – nearly two years after he started the process. Surviving required him to *"beg, borrow, do side work. Whatever I could."* He leaned heavily on his mother and *"wouldn't have made it without her."*

Marcus' financial struggle while applying for disability benefits was similar to other participants. The toll of maintaining basic needs led some individuals to give up without appealing. As mentioned by Shirley,

I just applied once and I was going to appeal, but I was going through an eviction process at the time and I didn't make the appeal in time. I've been determined by the FSSA to be medically frail. But that wasn't enough for the disability office to approve my disability.

To mitigate situations like Shirley's, individuals with qualifying conditions undergo an expedited review process through the SSA. Grace, who had a terminal cancer diagnosis, reported getting a timely appointment and approval. *"I took the interview October 2nd, and I believe around November 7 [or] November 8 they had come to a decision, and they approved the Social Security and it was quite timely, but it was because of the terminal diagnosis that it went through so quick."*

The SSA is aware of the hardship that decision wait times create. In September 2022, the SSA released a letter to the public remarking that the increased wait time on initial application decisions is "unacceptable" and "cause[s] significant financial hardship for the most vulnerable people." SSA attributed increased wait times since 2020 to challenges maintaining staff.^{xxii} Applicants wait an average of seven months for an initial decision and have 60 days to appeal if denied. Once denied, applicants who appeal wait months and sometimes years before getting a final decision.^{xxiii}

Applying for benefits poses a plethora of challenges for applicants, aside from hiring attorneys, completing lengthy paperwork, experiencing long wait times, and attending medical exams – all while experiencing debilitating health conditions.

Health Needs Complicate the Process

Participants found the process of applying for SSDI/SSI competed for their attention as they struggled to manage their health needs and loss of income. In particular, the required paperwork was overly cumbersome for several applicants. Karen recounts the paperwork being stressful and her intellect being clouded by pain.

It's a good thing I'm very detail-oriented because I can see how some of those things could trip you up. So that part is very stressful because again, it's like I'm in a level 8 to 10 pain all over my body. Everything was crazy. I couldn't sit or stand for long trying to fill out documents. Trying to do this. You know, pain clouds your intellect. That part was very stressful.

Ellen also recalled how her health needs complicated the process of applying for SSDI.

Honestly, I don't remember much cause I was in a full blown PTSD episode... I just felt like crying. Every split second. It just was overwhelming to me. But my attorney was wonderful.... So, between him and my husband, who was my only support, I felt. I thought I had enough strength to go through the procedure, but I really, really just felt like I wanted to just cry and cry in a hole.

The process of applying for SSI or SSDI created stress for participants. It was bigger than just applying for a benefit, as the result would shape their future financial state either temporarily or permanently, and not knowing when they might be approved or hear back about their application status added to their stress.



Lack of Communication Adds Frustration

Participants disclosed that there was a lack of clear and consistent communication when applying for benefits. This barrier is reinforced by the intensive processes required by each applicant for completing paperwork, which has them answering many personal and in-depth questions. Conversely, participants expressed that those accepting the applications failed to provide in return the bare minimum support for an applicant's questions. Shirley recalls, *"There's just no communication with any... Being able to answer any of my questions...I could answer all of their questions, but they couldn't answer any of mine."*

Communication difficulties also arose in the application process, as participants explained that there is little to no communication between approval and denial letters. The lack of communication made it difficult for participants to understand what they should do to meet their needs or, often, the needs of their children. When asked how long it took to receive a response from the SSA, Shirley said, *"What really was difficult was waiting on them to process everything that they would turn in or waiting for them to schedule an appointment with their doctors or just waiting without any inkling of, of, a yes or no or a screw off, you know?..."*

Crystal, a social worker, who has assisted her clients with applying for Social Security benefits, describes the process as not being user friendly.

It's frustrating and the wordings on the applications are not friendly to those that are less educated, or that have any sort of comprehension issues. It's not user friendly at all. And they don't explain the process. So you don't know. Like, am I waiting a week? Am I waiting a month? When am I going to know something?

She later explained ways that the process could be improved by simplifying the language, providing *“more communication and streamlin[ing] the process in general. It's a lot. And then nothing. And then a lot more. And then nothing. And if you miss one thing, it just throws it all off.”* When asked about streamlining the process she suggested,

There's been a couple of times I'm having to resubmit the exact same paperwork to different people....It's super frustrating. Everybody has to do everything from scratch all over again. Part of me feels like they're probably doing it to frustrate people so they just go away.

Even upon receipt of notice that benefits had been approved, beneficiaries shared that they were given insufficient information about the amount of benefits to which they were entitled and when those benefits would be dispersed. Roxanne, who was recently approved for Social Security benefits prior to her interview, felt conflicted by the terms of her approval.

They said I was approved. I'm approved, but I have to basically stop working completely. And I'm still trying to work bare minimum at [retail store] as a cashier, which I'm hanging on.... I just got back-approved for my Medicaid yesterday. I've been without insurance and without insulin since February. That's going to risk me being homeless or my kids being under a bridge. I really don't have resources to fall back on. They don't want to tell you what you're entitled to. They just say you're approved. But I'm scared to wait for social security because when are they going to push the button? Are we going to be homeless waiting? I'm in a big bind if you ask me.... I am kinda stuck between a rock and a hard place.

On the other hand, those applicants who were denied benefits were given little information as to why. Ruth was denied benefits and, asked whether she would appeal or re-apply, thought, *“I don't know what they were thinking. And so...the idea of applying again. You know, it's like you can't solve a problem if they don't tell you what the problem is.”* Ruth believed there was a misunderstanding about information in her application, but the lack of transparency in the decision-making process left her feeling lost.

Not understanding the differences between benefit programs further complicated the process for interviewees. A particularly salient experience shared by Marcus involved the confusion he had trying to apply for SSI benefits and accidentally applying for SSDI benefits instead. *“I applied for the wrong thing. I applied for the one that you pay into when you're working. Obviously being so young, I didn't have enough work credit for something like that. That's why I kept getting denied.”* Marcus is not alone in this experience; other young participants did not understand work credits and how they played a role in benefit program eligibility. As noted above, the application process is long and tedious, and applicants applying for the wrong benefits suffer even longer wait times, and further flood SSA with unnecessary benefit applications. A transparent denial process could assist both applicants and the SSA.

Due to his long wait time, like many other applicants, Marcus turned to other benefit programs as he awaited a decision from the SSA. Support during the application process is scarce, however. Richard, the executive director of a local Community Action Agency and Area Agency on Aging shared a vital resource that could have helped Marcus understand what benefit he should have applied for.

We have a program on the [Area Agency on Aging] side called the ADRC. It's the Aging and Disability Resource Center. And all of your AAAs in all counties in Indiana have the ADRC, and it's a very good entry point into the system. If they have disabilities or think they qualify for disability assistance, they can call the ADRC and schedule an appointment with the case manager in the case manager can walk in and say, 'Oh yeah, yes, you probably qualify or no, you don't qualify.'"

ADRCs were not mentioned being used by any participants, which may suggest that they were unaware of this resource.

Aside from difficulties applying for and maintaining benefits, participants described the negative effects of the systems not working in harmony with one another. Karen describes this as she shared the consequences of receiving a Cost-of-Living Adjustment (COLA).

When we have that fixed cost of living adjustment increase like two years ago, it just put me literally I think it was \$5 or \$8 over a month to where I lost the bulk of my health care....That happened last June of last year. I was devastated because I go to countless doctor appointments still every week on a weekly basis."

Social Security COLA adjustments can push individuals like Karen over the financial eligibility threshold for other benefits, such as Medicaid or SNAP. Benefit programs must work in unison to ensure that benefits are not lost when the beneficiary's status has not changed, such as when the SSA addresses inflation through annual COLA adjustments.

One specific but important theme that emerged from this study is that individuals who work in caregiving roles are, arguably, not fairly compensated within the Social Security system. Hope was a stay-at-home mother for a significant portion of her working career. Because she did not receive payment for her caregiving work in the home, Hope was eligible for a lower SSDI benefit than she would have had she been paying into the system during that period.

I was able to be with my children until they went to school but then that's a ding to me. When I do need help and they're like, 'Well, you've only paid this much money in so this is what we're offering you...' There's got to be something better.

Since men typically earn more than women, men’s monthly SSDI benefits are higher than women’s. Nationally, men receive an average of \$1,628.22 in SSDI while women receive \$1,337.53.^{xxvi} This is nearly an 18% difference in income, which correlates with the 16% national wage gap between men and women.^{xxiv} Stay-at-home mothers and other unpaid caregivers have generally paid less in Social Security taxes, which can disadvantage them if and when such benefits are needed. This inequality is important because it highlights the lack of value ascribed to unpaid labor that women disproportionately provide even when such labor enables others to work or relieves the burden on taxpayer-funded caregiving programs. In addition to sacrificing time, unpaid caregivers also sacrifice potential future security because the present system fails to acknowledge the value of their work.

Overall, participants felt overwhelmed, confused, and experienced a lack of understanding and control over the process of applying for benefits. For many participants, these difficulties compounded with financial instability from their change in income and led to financial hardships.

Financial Hardship



“I’ll never own a house. I’ll never have a car again. I’ll never have, you know, anything. I’m 57 years old. I’ll never have anything worthwhile because of this again.”

-Tammy

According to the U.S. Census Bureau, in 2022, 24.0% of adults aged 21-64 living in Indiana with a disabling condition are living in poverty, compared to 9.5% of adults without a disabling condition.^{xxv} The average income from SSDI income in Indiana is \$1,480.12 which is a total of \$17,761.44 per year.^{xxvi} As noted previously, SSDI is based on work credits. Younger recipients have a shorter work history, and entry-level lower-paying jobs mean that recipients under 25 years old receive an income closer to \$831.49 per month.^{xxvii}

While awaiting benefits, participants reported significant financial challenges and often lose assets and any sense of financial security. Shirley described losing everything as she applied for benefits. *“[I] lost my house and my car and my dog... I still have outstanding bills from that time that I’ve not been able to get paid.”* Early in his disability journey, Marcus became homeless and suffered frostbite while sleeping in an abandoned building; he recently became homeless again due to a rent increase he couldn’t afford. *“Right now, I’m...I’m back in that homeless position,”* Marcus shared.

Jeff’s stroke and the subsequent economic fall-out meant the loss of a \$500,000 home and sports car and transition into subsidized housing and a \$1,800-a-month benefit. *“So while I was unemployed. I ended up losing my car, my home, and everything - all of my physical possessions.”* He connected with Habitat for Humanity and now has a home that costs \$300/month.

Tammy also noted a significant difference in her income after leaving the workforce. *“It drastically changed it. You know what I make in a month, I used to make in a week...You don't have enough to provide when you get \$935 a month. You cannot realistically live on that. That does not provide rent, utilities and basic needs, food and toilet paper the things that you need.”*

Research has found that applicants for Social Security are increasingly likely to begin using SNAP benefits the longer they wait for approval. In addition, an estimated 8,000 applicants file for bankruptcy, and 10,000 die each year while awaiting a decision on their disability benefit application.^{xxviii} People with disabilities are also disproportionately likely to experience homelessness. Today, only 37 affordable homes are available for every 100 extremely low-income renters. As a result, 70% of the lowest-wage households spend more than half their income on rent, placing them at high risk of homelessness when unexpected expenses (such as car repairs and medical bills) arise.^{xxix}

Even while receiving benefits, affording the basics is extremely challenging. Hope reflected on how insufficient supports force people with disabilities to prioritize their most essential needs, explaining, *“It's a struggle [to meet my basic needs].”* Before he became homeless again, Marcus's budget was extremely tight: Of his \$943 monthly SSI benefit, he allocated *“\$600 a month for rent, paying my utilities was just about \$100 apiece. Gas. Electric. I haven't thought about buying toilet paper [or] hygiene items, nothing like that. So that's another hundred. So that's \$900 right there. That's \$43 left.”* This budget echoes existing research that finds individuals with disabilities have to triage their needs, such as foregoing nutritious food to afford more pressing needs, like medications.^{xxx} Lisa, who receives \$1,380 a month, reported, *“By the time I actually pay my bills, I have between 50 and 75 dollars left for whatever for the month. Indiana decided that I could have \$24 a month food stamps - that should be enough.”* Elaina similarly described the stress of maintaining a meager budget.

My household budget went from I didn't really have to budget beforehand, to now I'm on a very strict budget. I have to make sure I plan for each individual month because things do change things getting a little more expensive or things coming in cheaper.

Meeting the cost of basic needs was a challenge for many participants, and the compounding stress of varying medical bills created another source of financial stress.

Medical Bills and Other Debts Compound Financial Hardship

Medical debt disproportionately affects individuals with disabilities. Nationwide, 15% of adults with disabilities report having medical debt of \$250 or more as compared to 6% of adults without disabilities.^{xxxii} For low-income Hoosiers on a fixed income, even a relatively small medical bill can decimate one's financial well-being. Ellen described this well.

I have numerous hospital visits and a lot of them were not covered. We had no insurance: my husband was working at a job that had insurance, but the premiums were so high for a family that we could only afford for him to have insurance. And so I would be without insurance and I would have all these hospital visits that weren't being covered and would come out of pocket and just destroyed us.

Ellen's situation is not uncommon. While approximately three in four individuals (76%) without a disability have private health insurance, only an estimated one in two individuals (49.9%) with a disability have private health insurance. Lacking private health insurance may not seem significant—after all, public health insurance rates are comparable for individuals with and without disabilities—but an individual's type of medical insurance often determines whether they will bear co-pays and whether physicians will agree to accept them as a client.^{xxxiii} Additionally, the implications of being uninsured are more severe for individuals with disabilities than for those without disabilities. Six times more uninsured individuals with disabilities report difficulty accessing necessary care or medicines than those without disabilities.^{xxxiv}

Lack of insurance or inadequate insurance coverage can lead to spiraling costs of medical care and ultimately medical debt, which is particularly harmful for individuals with disabilities as it can create further barriers to accessing necessary care. In Indiana, available data suggests that households that have a member with a disability are more likely to have medical debt in collections and to have higher amounts of medical debt, compared to families with a disabled member, reflecting the compounding issue of how low benefits interact with needing healthcare that is not made affordable, ultimately inflicting harm on Hoosiers.^{xxxv}

Medical debt can be considered part of a broader category of financial drain from debt that individuals with disabilities experience. *"I had a credit card that I basically had to live off of a little while, while we were homeless,"* said Tammy. Tammy reported barely keeping up with the interest fees associated with their period of time without income. Elaina experienced something similar, and shared, *"I have had to take out loans and then [was not] able to pay those loans. And then at one point, I had to get a title loan against a vehicle, and I wasn't able to pay off that loan."*

Financial Hardship Affects Relationships

Financial hardships also negatively affected participants' personal relationships. For more than one participant, having limited income contributed to reliance on abusive relationships. *“Due to my disability, I have allowed men to take advantage of me and it did not end well. It ended in domestic violence,”* Elaina reported. Nationwide, individuals with disabilities across genders are at higher risk for intimate partner violence (IPV).^{xxxvi} According to the American Psychology Association, survivors of domestic violence with disabilities can endure unique forms of abusive behaviors with complicated dynamics, such as:

- Removing or destroying a person's mobility devices (e.g., wheelchairs, scooters, walkers),
- Denying access to and/or taking prescribed medication from someone,
- Forcing someone to take medication against her will,
- Forcing someone to lie in soiled undergarments,
- Preventing access to food,
- Inappropriately touching a person while assisting with bathing and/or dressing,
- Denying access to disability-related resources in the community and/or to health care appointments, and
- Controlling or spending disability and social security benefits.^{xxxvii}

Even when survivors with disabilities leave an abusive situation, it may be hard for them to find a shelter that can accommodate their needs.^{xxxviii} IPV also disproportionately affects women experiencing poverty, potentially due to increased economic needs.^{xxxix} The intersectionality of poverty and disability poses a heightened risk for IPV indicating a need for increased supports and resources to assist those with different needs in exiting violent home situations. Research suggests that more generous TANF policies may serve as a protective factor against IPV.^{xl} Policies that assist with creating greater independence for individuals with disabilities should be further explored.

Financial Drains Limit Mobility & Access to Supports

Transportation difficulties, coupled with low income, reduce the capacity of individuals with disabilities to be independent. Like other participants, Grace, who received benefits relatively quickly due to a terminal cancer diagnosis, still lost her car to repossession during the time she couldn't work and was awaiting benefits. Even with benefits, the math didn't add up to allow a car payment again – even if Grace could have found one that was affordable.

I get \$1716, I think, a month. My rent is \$1250. I have renter's insurance, electricity bill, my phone bill. And because of the amount I get, I don't receive any food stamps [SNAP benefits]. So with any money left over, I have to buy food. And in the meantime, my vehicle was repossessed because I could not afford – I mean, I had no income until Social Security started, even though it was approved right away. So now I have no vehicle and not even really living month to month because I just don't make it every month.

Lack of transportation made seeking out other resources that could supplement limited incomes extremely difficult. Rachel was evicted from her home and lost her car while applying for benefits. *“Even if I could get somewhere where they're giving away, you know, food from a food bank or clothing in a clothing bank, there's no way to get there and get the stuff home. So that's even more difficult,”* she shared.

Lisa, who still had a vehicle, described not being able to maintain insurance but saw no other option than to try to make it last as long as possible.

I feel like I'm going to have to see if I can find a trustee to help me. I have no insurance on my trailer. I have no insurance on my car. I can't afford it. I have a car that doesn't run very well. There is no means of public transportation anywhere.

Tammy also expressed how the lack of reliable transportation impacted her.

I live in a small town and it's hard, even though the [health] insurance provides transportation. You can't get them to come out to my town to take me, because it comes from the big city...and sometimes the transportation won't come out there just to go, you know, two miles away to my cancer center. And sometimes I would have to miss my chemo because I couldn't get transportation to it.

The experiences described by Lisa and Tammy are echoed by millions of other Americans with disabilities, who are overall less likely to own a car and more likely to live in a “zero-vehicle household.” Hope, facing a similar issue, reported using rideshare services to compensate for their lack of a vehicle, a solution utilized by 10.1% of individuals with disabilities aged 18 to 64.^{xii} *“If I decided to drive, I wouldn't be able to afford a vehicle. So, I have to depend on Lyft or Uber to go anyway,”* said Hope. Although rideshares can be useful resources, they are often not available in rural areas, or to individuals with disabilities, especially those who stay in their wheelchair during transportation or who are accompanied by a service dog, due to limited wheelchair-accessible rideshares, and despite it being illegal to deny entry of a service dog. The lack of accessible transportation options experienced by many individuals with disabilities is particularly an issue in Indiana, where many individuals with disabilities live rurally.

Other Safety Net Programs Present Barriers

Individuals with a disabling condition who receive SSI in particular may incur additional financial hardships due to limits put on the amount of assets they can have. This is called “countable resource limits.” Per the SSA, countable resources include cash, savings and checking accounts, financial investments such as stocks and bonds, vehicles (one vehicle is non-countable if it is used to transport the beneficiary to medical appointment), real estate (generally other than the family home), life insurance, personal property, or anything else a person owns that could be changed to cash and used for food or shelter. For an individual, the countable resource limit is \$2,000 and for a couple, it is \$3,000.^{xliii} Tammy worried about how her children would afford her end-of-life expenses, believing this limited her ability to save for her burial.

"I can't even afford life insurance," she says through tears. "What are my kids going to do with this cancer and stuff if I pass away? My kids can't even afford to bury me." Indiana does allow SSI and Medicaid beneficiaries to have a modest burial trust of \$10,000 to pay for a pre-arranged funeral, however on a tight fixed income, for many participants, this is not an option. Without the ability to save or have any type of investments or sizeable life insurance policy, individuals on SSI have a small margin for financial error.

Kirstin, a township trustee investigator, shared that trustee could be a key component to assisting individuals financially through the application process and beyond. She also notes that trustees could work better with the community by changing some of their policies. In her trustee's office, applicants seeking assistance had to come in-person during limited business hours and needed to fill out the 10-page application before being considered for assistance. She noted that this created barriers for individuals with disabilities if they had health-related difficulty traveling or trouble obtaining transportation.

One individual...recalling them is difficult. Not that it's difficult to remember. It was quite the opposite. He had schizophrenia...they were forced to come to us. They had to take a taxi to get to us. And I remember at the time, she [his mother] told me that she only had X amount in her bank account. And I remember being absolutely shocked that she even had enough for the taxi in the first place. If you need assistance, people can use their last few dollars to get there and they're riding on a chance because, it's not absolute.

Kirstin suggest having a designated fund through the trustee's office to assist individuals with disabling conditions and allowing them to not leave home to get assistance.

Participants did recount getting financial relief from family members, religious institutions, and township trustees. Amy recalled the support her parents provided. *"I am so incredibly lucky that I have caring and supportive parents that also have the means to support me when I can't support myself. Otherwise, I would have been out on the street a long time ago."* Elaina also shares a positive display of support through her church. *"It has also allowed me to get closer and gain a relationship with God and a church that loves me and supports me and my disability, and the decisions I now know how to make. So, I'm grateful for that."* Karen, who learned about support from township trustees through her electric company, talked about the assistance she received from her trustee. *"She helped me pay my rent every single month. Pay my electricity. You know, they just help pay all of those things."* Her local trustee also informed her of other benefits programs. She recounted her trustee saying, *"You're going to need to do X, Y and Z to get some money coming in. You are going to have to apply for disability."* Karen's connection to her township trustee assisted her with applying for programs she qualified for and assisted her with financial stability as she applied for SSDI.

The need for support during the application process was described in every interview. The support of family members, community programs, local and state agencies proved to be instrumental for participants to gain financial stability and resources.

Need for Mental Health and/or Social Supports

“My goal is to still live with a purpose and live with dignity and you know, go through this disability and this life change with dignity and grace.”

-Grace

According to the SSA 2022 Annual Statistical Report on the SSDI Program, the majority of SSDI benefit recipients have a musculo-skeletal system or connective tissue related disabling condition. However, in the same report, the majority of disabling conditions in Indiana for SSDI recipients is mental disorders, which are classified together as intellectual disorders or mental health disorders (depression, bipolar, and related disorders).^{xliii} Whether the disabling condition is an injury, illness, or chronic condition, the potential effects of disability, such as departing the workforce, losing income, relationships, and having trouble addressing significant health needs can be significant triggers for mental health needs. The element of mental distress emerged as participants spoke about feeling abandoned and isolated from society. Losing employment, a sense of worth, and experiencing chronic pain and mental conditions that others could not relate to led to severed ties with family and friends.

Ellen who experienced trauma, spoke about her disabling condition affecting every relationship she had.

I became a recluse... I couldn't trust anyone. Every relationship I have has been affected by it. My personal family stays away completely. I've lost contact with my children. I was a recluse and I would stay in month after month. So, I couldn't maintain relationships.

Karen explained the surprise she feels by the abandonment she's experienced since her disabling condition.

I was very surprised because it's pretty much been everyone in my life, friends, family and my church, everyone of [them], you just feel very abandoned. Okay, well 'cause you are abandoned.... And I've learned through just different doctors and physical therapists and such, they say the same thing....Patients of theirs who have chronic illness or suffer chronic pain, we have no explanation but, you're not the only one. I have tons of other patients who say the exact same thing. They're like, 'It's just the worse. Like if you're not fun or if you're sick and, or in pain.' I don't know.... It's not good, but it's not isolated to just me. Apparently, it's other people who have certain health issues. Debilitating health issues that a lot of people cut out.

Crystal, a social worker who was interviewed as field expert, is currently living with her own disabling condition. She has experienced work discrimination after asking for accommodations, and said *“I struggle on my hard days with feeling worthless and defeated. I have gotten better at making myself get out of bed on those days. But I have just stayed in bed and cried all day.”*

Challenges with mental health in Indiana are well known, however they are not well documented. According to a report published by FSSA in 2022, data collected from 2008-2018 shows that the Midwest has one of the highest Any Mental Illness (AMI) rates in the nation, and Indiana has a higher AMI rate than the Midwest.^{xliv} When asked if their disabling condition affect their mental health, many participants agreed that it did. Roxanna responded, *“A lot. It makes you feel powerless.”* Stephanie noted needing mental health support to overcome her mental health challenges. *“You know what, it did at one time, but I did get the needed help because I did have to see a therapist. And I got that needed help and that helped me out quite a bit. It really did.”*

Other participants found it challenging to access mental health support. Shirley tried to get support and, even though she was suicidal, she could not find help. She shared

I've even tried to get a hold of, you know, with my insurance, try to get hold of counselors, therapists, psychiatrists, anybody to help, you know, talk me through anything. Everything. All of it. You know, just, just 'cause there were too many times my aunt actually took me to the sheriff's department at one point because I was suicidal.... They then sent me to the hospital to have me evaluated for my mental health and they even told me at the hospital that given everything that you've been going through for the last three years, you're completely rational and reasonable in how you're feeling. Well, we don't feel like you need to be admitted anywhere, but you do need to talk to somebody. And they gave me a list of people that don't take my insurance or if they did their dockets were full.

Hope shared that worrying about money made her develop intrusive thoughts.

There are days that I just I have good cries that I do cause. I worry about things like, what if they stop paying me disability? What if something happens to my ex and he's not able to pay that money every week? What is going to happen to my daughter? What is going to happen to me? What is going to happen to the house? Intrusive thoughts.

Elaina believes mental health issues start for individuals as they exit the workforce. She suggested that support be given at the start of that exit. *“Maybe focusing on how they feel leaving work, helping them through the process of leaving with their mental health. Because I think, the biggest part of having to leave work for me did play a part in my mental health.”*

Whether mental health distress was due to financial, medical, or lifestyle changes, these issues at times compounded and led to a sense of hopelessness about the future. This experience, too, is borne out in the data, with adults with disabilities reporting mental distress at nearly 4.6 times the rate of those without disabilities.^{xlv}

Re-Engaging in the Workforce?

SSDI and SSI recipients are not a static group. Participants in our study shared a range of experiences with reentry into the workforce. At the time of our interview with her, Christine reported seeing improvement in her health condition and planning to ask about returning to work. *“I just recently had a scan and the blood clots are gone. So I'm going to have a discussion with my doctor to try to release me to work. So that's the next step....because I want to work.”* Others experienced a disabling condition, returned to work, and then needed disability again down the road. Elaina who overcame her anxiety disorder to successfully take on a role in a factory, noted *“I was supervisor of my line doing very well, and I had overcome the anxiety a lot. And when I had the stroke, then I had to reapply for disability.”*

“It's not easy to get a job that pays well knowing that your health is deteriorating, no employer wants to take a risk.”

-Roxanne

There are many entities that work to support and incentivize individuals with disabilities who wish to return to the workforce. The SSA, for example, allows individuals receiving disability benefits to “try returning to work” with a nine-month “trial work period” in which individuals can still receive benefits while earning.^{xlvi} Indiana also allows individuals with disabilities to retain Medicaid coverage through MEDWorks.^{xlvii} These offerings were not widely known to participants, who expressed fear of losing benefits by returning to work or securing earnings in other ways. Ruth wanted to work and earn but feared losing access to health care.

I think if I could...if everybody could just have health insurance. I think the fear...the fear of just always, how am I going to have health insurance would have left and I probably could have been an entrepreneur. And I think a lot of people could be. You know, I've got all kinds of business ideas and marketing ideas I could do at my pace and stuff like that.

Although Ruth dreamed of being an entrepreneur, she did work part-time.

I don't do very well when I don't work. And they said, but you can work on disability. Just part time. And I'm like, 'That's all I'm ever able to work is part time.' And so I was really excited after that. And they said 'that would take the pressure off of you financially a little bit.

Some saw the consequences of re-engaging as penalties that created a feeling of “Why try?” Christine, who “really miss[ed] working, you know, my colleagues, having that...” felt that

you can't go try to find something you could do for a couple of hours a week and make anything because they take it from you, and by the time you put your effort, energy, and gas out to try to go somewhere and work...they make it to where you can't rise above your circumstances at all without being penalized financially for it.

Others expressed fears about what re-engaging in the workforce might mean for their health or how they would cope if their condition returned or worsened. Tammy was among them.

There are days that I feel like I would love to go back to work, and I could handle it. And then sometimes I sit here and think, you know, 'Oh, my gosh, today's a bad day, what if I had been working?'

Still, whether through work or other means, it was clear that many participants craved engagement and purpose. Marcus started a bachelor's program.

I was like, 'I can't just sit back and do this.' And so something told me...just go to school because I always wanted to obtain my degree. I just feel that...I need to feel positive about things. I need to feel positive about myself....if I can just help one person before I leave this earth my life will not be in vain. That's what I live by.

His goal was to start a research firm to support wrongfully incarcerated individuals.

Following his stroke and two years of rehab, Jeff struggled with memory and movement. He took a position at his local Head Start. *“I just needed something to do to keep my mind busy. So I set up where I was what they called a grandpa. I would go in and help get their breakfasts and do the bathroom.”* After several years, though, his doctor advised him to stop due to the frequent illnesses he contracted.

Some participants who wanted to return to work found securing a job challenging, and their experiences are supported by workforce statistics and research studies: the unemployment rate for individuals with disabilities was 7.2% in 2023, nearly double the rate of those without a disability (3.5%).^{xlviii} A disabling condition can interrupt employment long before an individual applies for disability benefits. Often participants spent years fighting to obtain and maintain employment while enduring workplace discrimination, in spite of the Americans with Disabilities Act, which protects prospective and current employees from discrimination because of a disability. In 2023, the Equal Employment Opportunity Commission (EEOC) received 740 charges of disability discrimination (see Table 8) in Indiana.^{xlix}

Participants also reported experiencing discrimination that blocked re-engagement. Ellen described this as part of her experience, noticing that

when I would tell employers about my disability, I never got called back. And even though a lot of things I was overqualified or at least qualified, they wouldn't call me back. And I don't know why, but I'm assuming it's because I told them. Because the ones that I didn't tell about my disability would call me back. So it was obvious to me that it was me sharing my disability with them that was causing them not to hire me.

Table 8. Equal Employment Opportunity Commission Charge Receipts 2023

United States Total	81,055
United States Disability	29,160
Indiana Total	4,598
Indiana Disability	740

Source: U.S. Equal Employment Opportunity Commission (2024). *Enforcement and Litigation Statistics 2023*.

Nationally, workers with a disability are twice as likely to work part time.^l Part-time work, while economically helpful to balancing budgets, also means that employers are less likely to provide benefits like health insurance or retirement. Individuals with disabilities also tend to earn significantly less than their non-disabled counterparts. Table 9 offers a snapshot from the American Community Survey of the median earnings of individuals with and without disabilities, showing that most workers with a disability earns slightly less than 200% of the 2024 federal poverty guidelines^{ll} for a single person, a common benchmark for self-sufficiency.

Table 9. Median Annual Earnings in Indiana

With a disability	\$30,037	Without a disability	\$41,753
Male	\$35,973	Male	\$50,308
Female	\$24,134	Female	\$35,106

Source: U.S. Census Bureau, American Community Survey 2022, 1-year

Jessica offered an idea to support individuals who want to work that have a disabling condition.

[We need] programs like vocational rehab... when somebody can be identified, make a system that can identify people that are working, that suffer these disabling health events and make a case manager that can come out and see how best we can support that person in hopes to recover them back, not only for their benefit, but for the country's benefit.

Jessica's idea would create a system that would keep disabled workers working if they are able to, and assist employers in creating reasonable accommodations.

Entrepreneurship may be a viable option for those who need to return to a different type of work or work environment than they had previously while offering increased flexibility and independence. Tammy expressed this desire, *“I would love to start my own business.”* Lisa already engaged in their own business, reveals, *“...once in a while, somebody will bring me something, like pants that need shortened or got a hole in their coat and I make a couple dollars off that.”* However, figuring out how to start a business was a barrier to many participants, including Elaina who expressed difficulty in starting:

The downside--I think the downfalls, like the cons of [entrepreneurship], would be the money aspect and the, you know, the startup of it. That's a huge thing for people to start up their own business. Yes. Stuff like that. Like just where do you start?

These perceived barriers are consistent with findings from a 2022 National Disability Institute study on small business ownership among people with disabilities, finding that while individuals with disabilities frequently turn to entrepreneurship because it “provides greater control, choice, and flexibility,” they also experience “limited access to affordable startup capital and a scarcity of supports, services, and programs tailored to their unique needs and challenges.”ⁱⁱⁱ This is in part due to disability status data not being collected on large national surveys.

While not a fit for all participants, those who sought opportunities to reengage sometimes saw its potential for something beyond financial measures and independence—it represented an opportunity to provide a hand up to others in similar positions: *“I can bring in people that have trouble getting jobs due to backgrounds and stuff like that. I could give people the benefit of the doubt.”* Elaina’s vision is to make

...a cafe type thing where anybody is welcome to just come in and talk about how they're feeling. You know, what are you struggling with today? Is there anything I can help you with? And a free and safe place to come and have coffee, to have something to eat, and just openly talk about your feelings.

Hoosiers with disabilities dream of an Indiana where they can return to the workforce with reasonable accommodations, seamlessly apply for social security benefits, and remain financially secure while doing all of this. From the thoughts and dreams of Hoosiers like Elaina, policy and practice recommendations emerged.

Policy and Practice Recommendations

Participants offered a wide array of recommendations that could improve the experiences of individuals with disabling conditions on the job, during the transition out of the workforce, and upon re-engagement. The results of the study indicate a need for supports and resources both informationally and tangibly to assist applicants and recipients. Financial, employment, and application assistance are key themes that should be further studied to develop programs alongside increased benefits that support financial stability. Future work should include the development of resources that:

- assist individuals with disabilities during times of financial hardship;
- assist individuals with disabilities with staying employed, or with exiting the workforce; and
- assist with the application process.

Further research should examine how these three supports improve the health outcomes, and relieve the burden of the SSA by keeping individuals employed and/or reducing applications filed in error or without complete documentation to efficiently make determinations. Faster determination times could significantly reduce the number of individuals who lose housing, transportation, or other assets as they wait to hear from the SSA. Faster determinations could also be obtained through a significant investment into state Disability Determination Services and Federal SSA to secure an adequate workforce to process applications.^{liii} Outlined below are additional recommendations from study participants and the study's design team.

Making it Possible to Stay on the Job

- Educate employees and employers about their rights and responsibilities under the Americans with Disabilities Act
- Offer programs or supports that facilitate the adoption of workplace accommodations

Promoting Financial Stability Outside the Workforce

- Offer paid family and medical leave to ease the financial strain of disabling conditions and allow more family caregivers to support loved ones without a significant loss of income
- Increase family shelter options
 - *"There was no shelter that would take both of us." -Tammy*
- Streamline and create connections between services
 - *"I think of a resource center. Where you can go and you can figure out what resources you need. And so if you need work accommodations, there would be someone there that would help with that. But you need medical advocacy because let's say if you have access to this medication, you're better able to do your job better." -Karla*
 - *"As far as recommendations go, having a better way to help when people are clearly confused or not following through." -Megan*
- Ensure people have access to information for support resources

- *“Let people know how to access these programs because a lot of people are not.... [they] don't have computers.” -Stephanie*
- Create support groups specifically designed for individuals with disabling conditions
 - *“I think the first thing would be just adjusting. A program to help you to just adjust your life.” -Stephanie*
 - *“Maybe just a group of people that we're all in the same boat and just where we listen to each other for a little bit.” -James*
- Assign social workers or other support personnel to individuals when they begin the process of applying for disability
 - *“Someone who is assigned to a newly disabled person who guides that person step by step through the process of getting everything they are eligible to do or may any of the help they can get.” -Max*
- Ask Township Trustees to set aside a specific fund that can assist individuals with disabilities or those applying for disability insurance
 - *“Make changes to help rise up, not keep down or not make their situation even worse because of some rule you have that you got to be without income for a month before a trustee can help keep you a roof over your head until you figure out what's going on.” -Christine*
- Ensure Township Trustees have a published phone number and online location to accept applications for support
- Create transparency about why someone was denied disability
 - *“Why was I denied? Because there are just too many people applying? Or do you really think I don't have what I say I have? Or is what I have not disabling enough?” -Ruth*
- Provide equitable support to those who were unable to pay into Social Security due to being caregivers
- Add a benefit for toiletries and/or include toiletries in food banks
 - *“I think there should be a benefit that we have over the counter is that we can buy toilet tissue, laundry soap, body soap, and stuff.” -Tammy*

Re-Engaging in the Workforce

- Provide case managers who can work with individuals and prospective employers to create a mutually beneficial work arrangement
- Support the development of small businesses/entrepreneurship among people with disabilities

Increasing Understanding

- Encourage policymakers and others in positions of power to take time to get to know people with disabilities
 - *“Just walk in our shoes for a day. Come see what it's like to live in our shoes for a day” -Tammy*

- *“I'd say, number one, listen and have compassion.” -Hope*
- *“I really feel like they [need to] talk to us and listen to our stories.” -Karla*
- *“Listen to us. We go through a lot of stuff emotionally and psychologically. And trust me, some days, you know, it's hard to even get up.” - James*
- Consider new classifications and categories for disabilities that make space for multiple disabilities and different levels of severity
- Put individuals in leadership roles who have direct experience or who have worked in the field, particularly when services are being designed or reconsidered
- Reconsider and align practices with the true goal of disability benefits
 - *“They need to ask themselves. What the goal of the process is? Is it to really help people? Is it to lift people up to the point that they can work? Is it to house the elderly in nursing homes? Is it? Like what? What are you doing?” -Ruth*

This study draws attention to the needs of Hoosiers leaving the workforce due to disabling conditions. The Indiana Community Action Poverty Institute is committed to advancing the needs of Hoosiers and encourages future research and action that examines and improves upon federal SSA processes. Due to the rise in disabling conditions, it is pertinent that legislators begin addressing issues related to the system and the individuals affected.

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Appendix

Interview Guide

We used a semi-structured and trauma-informed interview guide. This means that questions were asked depending on their relevance and follow-up questions and/or breaks or opportunities to skip questions may have been added by the researcher.

Life Story Experience:¹

- Do you mind sharing what caused your disabling condition?
- How has it changed your life and ability to care for yourself? And work? Financially?
- How has this affected:
 - Your household budget
 - Your ability to secure basic needs
 - Your relationships
 - Your access to healthcare
 - Your mental health
 - Transportation-related needs

Employment:

- Can you tell me about your career and life prior to your disability?
- How did your employer respond when that happened?
- What caused you to leave the workforce?
- Can you explain what the process of leaving work was like for you?
- Did you utilize FMLA, temporary or long-term disability, or COBRA Insurance? Did you receive workers compensation if hurt/disabled on the job? Or do you have supplemental disability insurance policies such as AFLAC?
- Did you ask for reasonable accommodations to continue working, or were you given a performance improvement plan?
- If you were given reasonable accommodations, would you have been able to remain working?

Working with SS Administration / SSI/SSDI:

- How long after your disability did you apply for disability?
- Can you tell me about your experience applying for Social Security Disability?
- [If applicable] How many times did you apply or appeal?
- How did you meet your financial needs while you went through this application process?
- Did anyone help you with your application? Family/friend/professional/attorney?
- What would have been more helpful during the process of applying for disability?

On Disability:

- From the time you applied how long did it take for you to get on disability?
- Are you willing to share how much you receive per month?

¹ Interview questions may have been eliminated depending on if an applicant was receiving, awaiting, or denied Social Security Benefits

Dealing with Other Benefits Programs / Supports:

- Does SSI/SSDI affect your access to other benefit programs such as SNAP, Medicaid, TANF, home health aide, etc.?

Working with other Government Agencies:

- Have you had to work with other state agencies like FSSA or IHCDA?
- What was your experience like with these agencies and were they helpful? To what extent
- Have you reached out to the state Centers for Independent Living for help? If so, what was your experience?

Return to Work:

- Since leaving work have you ever returned or considered returning to the workforce?
- Have you utilized state Vocational Rehabilitation services to access employment?
- [IF YES] What kind of support do you feel has been most helpful?
Explore the Return to Work Program (quantitative data/studies)
- Have you considered starting your own business as an alternative?

Catch All Questions

- What would you say to policymakers or other people who want to better support people who have experiences like yours?
- If you could imagine or create a program that would be helpful to people who must leave work due to a disabling condition, what would that look like?
- What else would you like to share with me about this topic?
- Do you have any questions for me?
- If you could give advice to someone applying for disability what would it be?

Thank you so much for being part of this process.

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