

# 'Live in Our Shoes for a Day':

A Study of Hoosiers Leaving the Workforce Due to Disability

This study and webinar were generously funded by

# incoa Dae

#### Indiana Housing & Community Development Authority

And developed in partnership with



I N D I A N A COMMUNITY ACTION POVERTY INSTITUTE Research and Public Policy

# Warning



This presentation discusses the life and experiences of Hoosiers, and may trigger deep emotions. The quotes and videos shared may be difficult to listen to.

# Our Mission

The Indiana Community Action Poverty Institute engages in research promotes public policies to help Hoosier families achieve and maintain financial well-being.

- We believe that when Hoosiers are financially stable they can achieve their full potential and better contribute to their communities.
- We recognize that historic and ongoing discrimination on the basis of race, gender, ability, and other social identities contribute to economic inequities for Hoosier families.
- We know that policy plays an important role in dismantling inequities and in creating financial well-being for all.
- We value, gather, and share stories, statistics, and research studies to illuminate the opportunities and challenges that Hoosiers experience.
- We promote evidence-based solutions and build coalitions to engage in direct and strategic conversations with policymakers and the public to advance change.

### Why is this important to all of us?

- A 20 year old has a **1** in **4** chance of experiencing a significant disability before retiring at age 65.
- The average income from SSDI income in Indiana is \$1,480.12 which is a total of \$17,761.44 per year.
- Younger recipients, and entry-level lower-paying jobs recipients under 25 years old receive an income closer to \$831.49 per month.

"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." -Tammy

• How would your life change if you had to adjust to this income?

Source: Maleh, J., Bosley, T. (2023). Disability and death probability tables for insured workers who attain age 20 in 2023. U.S. Social Security Administration. https://www.ssa.gov/oact/NOTES/ran6/an2023-6.pdf. Source: Social Security Administration. SSA. (2023, October). Annual Statistical Report on the Social Security Disability Insurance Program, 2022Social Security Administration. SSA. (2023, October). Annual Statistical Report on the Social Security Disability Insurance Program, 2022Social Security Administration. SSA. (2023, October). Annual Statistical Report on the Social Security Disability Insurance Program, 2022 https://www.ssa.gov/policy/docs/statcomps/di\_asr/2022/di\_asr22.pdf

# What is SSI & SSDI?

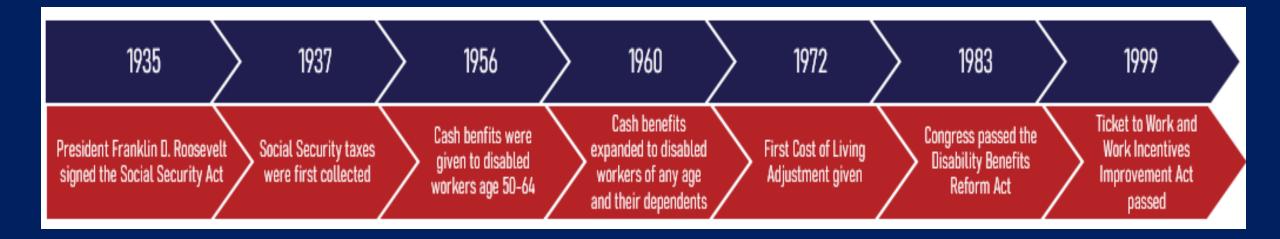


- These programs are run by the Social Security Administration and, are intended to support the financial stability of individuals experiencing disabling conditions.
- Both SSI and SSDI pay benefits to adults that are disabled
  - only for total disability
  - disability is expected to last for at least one or more years or result in death.
  - each generally use the same medical requirements
- The major difference in the programs is related to the work history requirement.
  - SSI recipients that 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.
  - 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.

Source: Social Security Administration. SSA. (n.d.). Historical Background and Development of Social Security. https://www.ssa.gov/history/briefhistory3.html

Source: Markowitz, A. (2023, December 15). Social Security SSDI and SSI are different programs ARP. ttps://www.aarp.org/retirement/social-security/questions-answers/ssdi-ssi-how-each-works Source: Social Security Administration. SSA. (n.d.). Disability Benefits How to Qualify. https://www.ssa.gov/benefits/disability/qualify.html

# Timeline of Major Disability-Related Social Security Changes



Source: Social Security Administration. SSA. (n.d.). Historical Background and Development of Social Security. https://www.ssa.gov/history/briefhistory3.html

### 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.



Source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (2024). Disability

# 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. <u>https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm</u>; 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. <u>https://www.cdc.gov/ncbddd/disabilityandhealth/features/kf-adult-prevalence-</u> <u>disabilities.html#:~:text=1%20Hearing%20%28serious%20difficulty%20hearing%29%3B%202%20Vision%20%28serious,or%206%20Independent%20</u> <u>living%20%28difficulty%20doing%20errands%20alone%29</u>; U.S. Census Bureau (2021). How disability data are collected from the American Community Survey. <u>https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html</u>

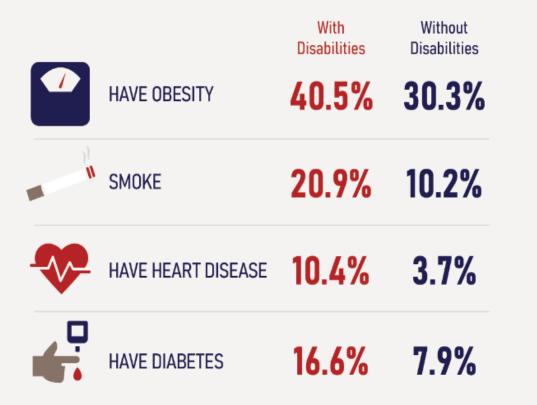
# A Study of Hoosiers Leaving the Workforce Due to Disability

This study examines the experiences of individuals who leave the workforce due to disabling conditions.

- Applied and received social security disability insurance, were awaiting a decision, or had been denied benefits
- Centers their voices and experiences
- Adding statistics and research studies to illustrate the need for further policy attention
- It offers policy recommendations and 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 supports to re-engage in the workforce for individuals who are ready and able to do so.



Adults with disabilities are more likely to:





Healthcare barriers for working-age adults include:

1 in 4 adults with disabilities (18-44 years)

do not have a **usual** healthcare provider



**1 in 4** adults with disabilities (18-44 years) have an unmet healthcare need because of cost in the past year **ŤŤŤ** 

1 in 6 adults with disabilities (45-64 years)

did not have a routine check-up in the past year



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

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						

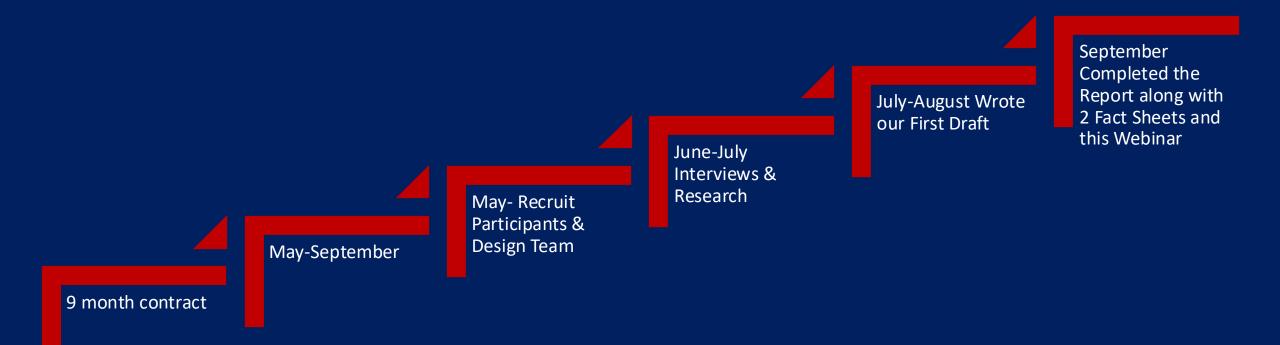
Source: U.S. Census Bureau, 2022 American Community Survey, 1-year estimates

#### 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 Research Process



# Methodology

- Research Team
  - Trauma-informed research design
- Design Team
  - Five meetings
  - 8 members
- Interview Participants
  - 96 unduplicated individuals signed up
  - 20 participants were interviewed; 4 professionals
  - Phone or Zoom interview
  - \$25 Visa gift card

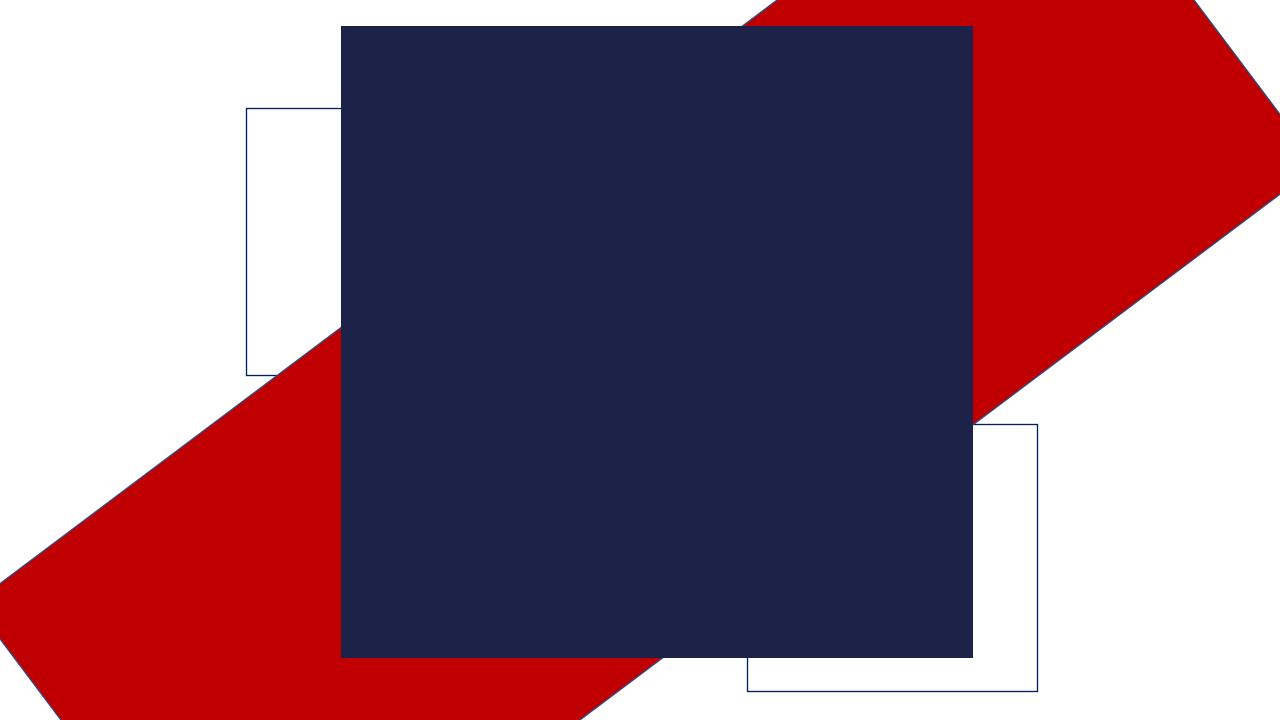
- NVIVO transcription software
- Quotes were categorized by topic and themes emerged
- Pseudonyms were developed for participants



### 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 OHaver*	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 a having a disability.



# Participant Demographics and Locations

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



Participant Work Experiences Prior to Disabling Condition			Participant Experience with SSI/	'SSDI
Factory work	6		Receiving SSDI	13
	Ŭ			
Health services	2		Receiving SSI	2
Administrative assistant/ "Office work"	6	Applied and Currently Denied SSI or SSDI		2
Cashier	2			
Manager	2		Awaiting Determination	3
Animal care/ Veterinary services	2			
Sales	2			
Research	1			
Landscaping	1			

# Themes

- Departure from the Workforce
- Navigating the Benefits Gauntlet
- Financial Hardships
- Mental Health and/or Social Supports
- Re-engaging in the Workforce?
- Policy and Practice Recommendations



### Departure from the Workforce:

"It's not fun to just stop work. My mom raised me to work." - James

- Work plays a central role in the development, expression, and maintenance of psychological health.
  - Financial
  - Social
  - Purpose

"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." - Christine

# Trying to Stay on the Job

"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 rendering because I loved my job. I loved what I was doing and the people I was doing it with." - Ellen



"[I] tried to take a leave of absence, and they immediately fired me."

- Tammy

# **Disability Work Related Legislation**

#### 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

# 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.				

### 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."

"go through a lot of hoops" –Max

*"it was frustrating" – Stephanie* 

"it's such a humiliating process" –Karla

# Challenges Applying for Social Security Disability Benefits

#### **Health Needs**

"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." –Karen

"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." -Ellen

#### Communication

"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?" -Crystal

"there's just no communication... Being able to answer any of my questions...I could answer all of their questions, but they couldn't answer any of mine...just waiting without any inkling of, of, a yes or no or a screw off, you know?" -Shirley

# Average Time From Submission to Decision

	Initial Submission 2023 225 days
7 months, 15 days total	
	Appeal 1: Reconsideration 2022 183 days
1 year, 1 month, 13 days total	
	Appeal 2: Administrative Law Judge 2023 372 days
2 years, 1 month, 20 days total	
	Appeal 3: Appeals Council 2020 264 days
2 years, 10 months, 14 days total	
	Appeal 4: Federal Court 2023 316 days
3 vears, 8 months, 25 davs total	
3 years, 8 months, 25 days total	

Source: Social Security Administration

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.

Social Security Administration denial rate for initial worker applications in 2019 was about 65%, with 49.2% of **all** applications eventually being approved.

"So, yeah. I mean, that's five years of my life, right?" –Karla

"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." -Shirley

### Wait Times

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."

"beg, borrow, do side work. Whatever I could." -Marcus

# 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

### **Representation Matters**

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.

"[My therapist] helped me...She got this lawyer." - Tammy

*"That lawyer helped me tremendously." –Elaine* 

"That's why I went on ahead and I got a lawyer." -Stephanie

"But thank God I had my mom and dad, and my lawyer was a retired social security judge." -Lisa

Source: U.S. Government Accountability Office. (2018, January 8). Social Security Disability: Additional measures and evaluation needed to enhance accuracy and consistency of hearings decisions. Social Security Disability: Additional Measures and Evaluation Needed to Enhance Accuracy and Consistency of Hearings Decisions | U.S. GAO. https://www.gao.gov/products/gao

### **Financial Hardships:**

"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

- Homelessness/eviction
- Losing a vehicle
- Living off of credit cards



### COLA

### **Gender Wage Gaps**

"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." —Hope

Men's monthly SSDI benefit are higher than women's. Nationally, men receive an average of \$1,628.22 in SSDI while women receive \$1,337.53 (18% wage gap)

# **Tight Budgets**

"Right now, I'm...I'm back in that homeless position," —Marcus

Marcus's budget was extremely tight. Of his \$943 monthly SSI benefit:

- "\$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 \$100.
- So that's \$900 right there. That's \$43 left."

"So while I was unemployed. I ended up losing my car, my home and everything - all of my physical possessions." —Jeff



### Transportation



# Effects on 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

Nationwide, individuals with disabilities across genders are at higher risk for intimate partner violence (IPV). 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 forcing someone to take prescribed medication from someone,
- 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 and/or to health care,
- Controlling or spending disability and social security benefits.

Source: Breiding M. J., Armour B. S. The association between disability and intimate partner violence in the United States. Ann Epidemiol. 2015 Jun; 25 (6):455-7. doi: 10.1016/j.annepidem.2015.03.017. Epub 2015 Mar 31. PMID: 25976023; PMCID: PMC4692458.

Source: American Psychological Association. (n.d.). Women with disabilities: How to identify abuse and get help. American Psychological Association. https://www.apa.org/topics/disabilities/women-violence

### Mental Health & Social Support

"I struggle on my hard days with feeling worthless and defeated...I have just stayed in bed and cried all day." - Crystal

According to the SSA 2022 Annual Statistical 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).

"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." -Karen



Source: Social Security Administration (2023). Annual statistical report on the Social Security Disability Insurance program, 2022. https://www.ssa.gov/policy/docs/statcomps/di\_asr/index.html

### Access to Mental Health Support



# Re-Engaging in the Workforce

"I just recently have 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." -Christine

- The SSA, 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.
- Indiana also allows individuals with disabilities to retain Medicaid coverage through MEDWorks.

"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." -Jessica

Source: Social Security Administration. (n.d.). Try returning to work without losing disability. Social Security. https://www.ssa.gov/disability/work#:~:text=You%20can%20return%20to%20work%20for%20at%20least,much%20you%20can %20earn%20during%20the%209%20months. Source: Family and Social Services Administration. (2024, June 18). MEDWorks. Medicaid Policy. https://www.in.gov/fssa/ompp/med-works/

### **Barriers to Employment**

"There are days that I feel like that 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?" -Tammy

"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." -Ellen "I don't do very well when I don't work. And they said, but you can work on disability. Just part time...that would take the pressure off of you financially a little bit." -Ruth



# 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

### Policy and Practice Recommendations



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

# Promoting Financial Stability & Supports

- Paid family and medical leave to eases the financial strain of disabling conditions and allow more family caregivers to support loved ones without a significant loss of income.
- Streamline and connection between services
- Ensure people have access to information for support resources
- Township Trustees to have a specific fund that can assist individual with disabilities or those applying for disability insurance

- Transparency for why someone was denied disability
- Support groups specifically designed for individuals with disabling conditions
- Social workers assigned to individuals when they begin the process of applying for disability

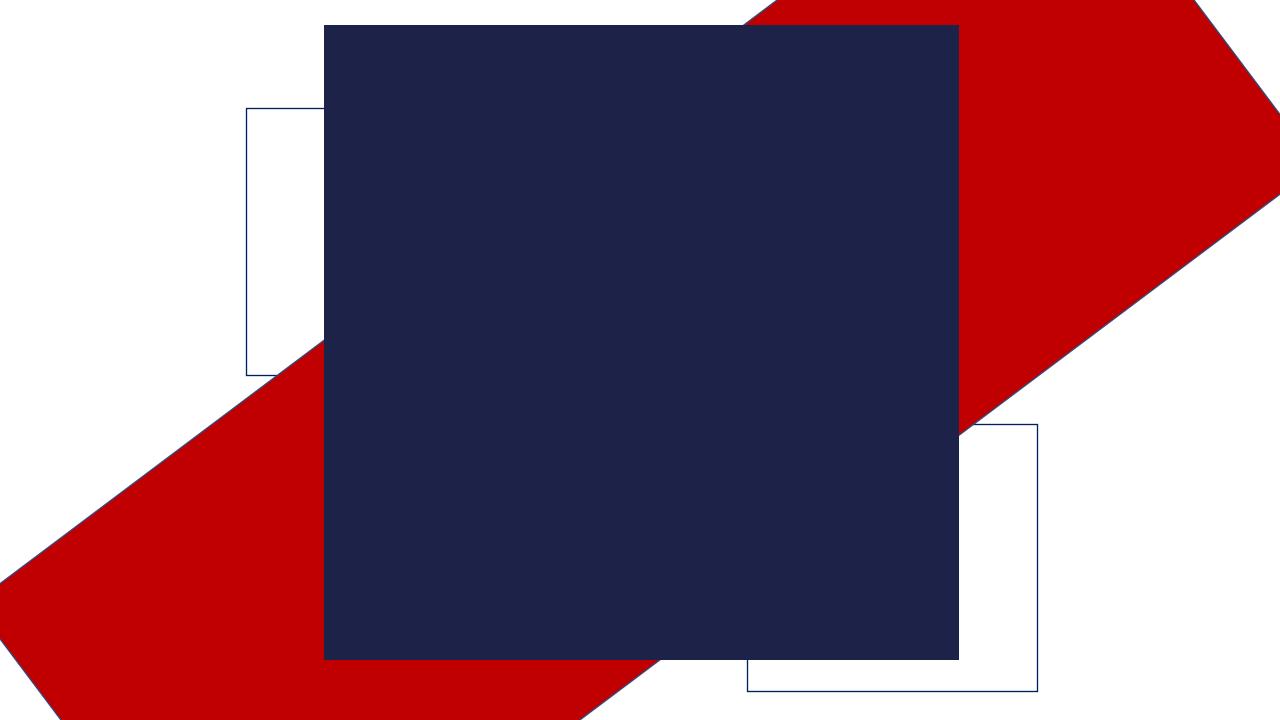


### Staying/Re-Engaging in the Workforce

- Case managers who can work with individuals and prospective employers to create a mutually beneficial work arrangement
- 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
- Support for the development of small businesses / entrepreneurship

### Increasing Understanding

- Politicians who will take time to get to know people with disabilities
- New classifications and categories for disabilities that make space for multiple disabilities and different levels of severity
- Individuals in leadership roles who have direct experience or who have worked in the field, particularly when services are being designed or reconsidered



### Acknowledgements

The Institute is incredibly grateful to the participants who shared their experiences, often taking an hour or more to talk with our interviewers about deeply personal and challenging experiences with the hope of seeing change. We also are appreciative of our design team and our Policy Fellow Mrs. Roshawn Neal for their commitment to shaping this work and sharing their expertise, as well as Jody Michele and Cierra Thomas-Williams from the Indiana Coalition Against Domestic Violence for their wisdom and counsel. Finally, we thank Tina Darling and the team at Indiana Housing and Community Development Authority for investing in and supporting this project.