

# Welcome and Introduction

## **The Power of Disability Literacy**

Presented by  
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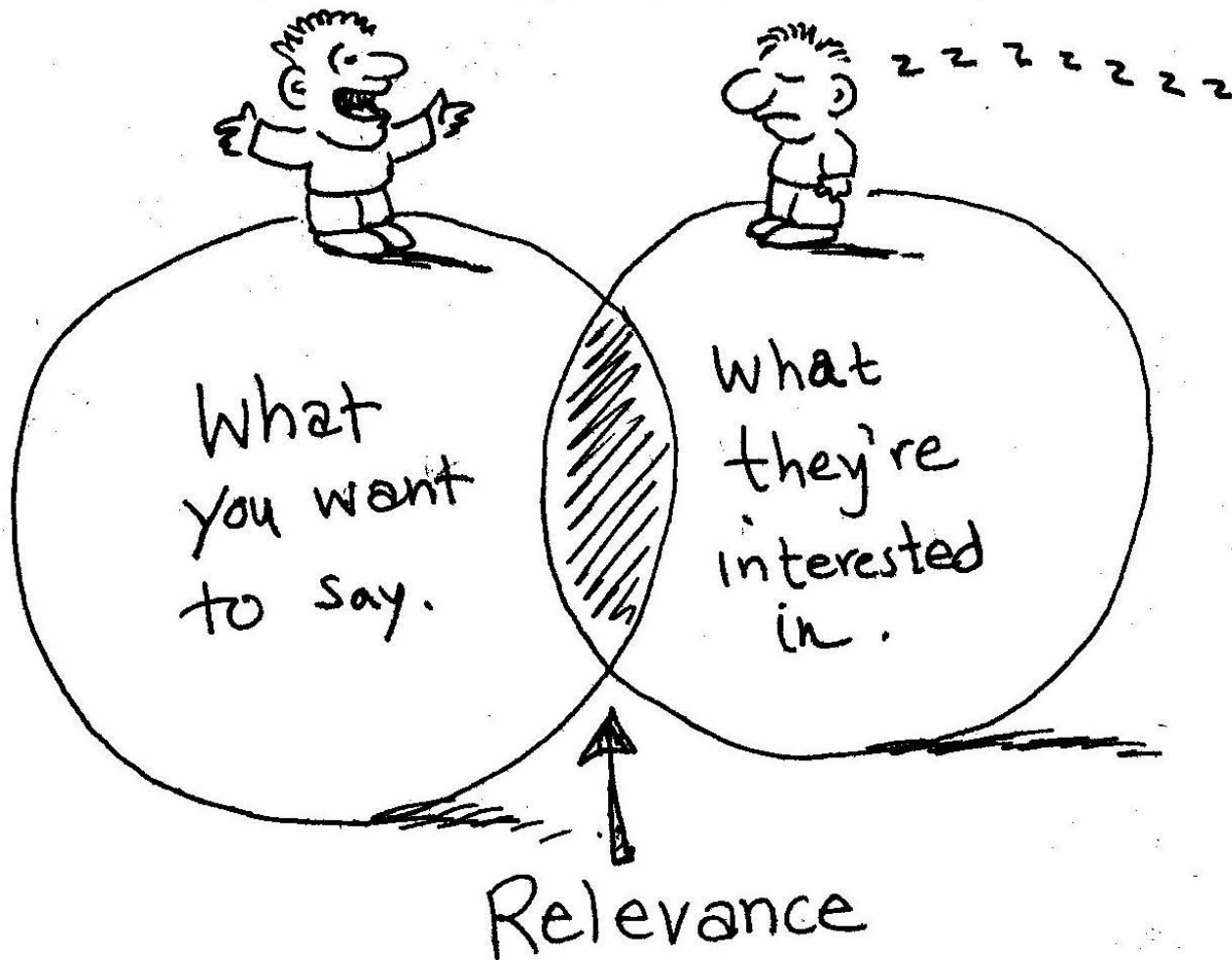
**HCBS Conference**  
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# Overview

Today we will:

1. Define “Disability Literacy”
2. Discuss Social Security Disability Insurance (SSDI)
3. Discuss Supplemental Security Income (SSI)
4. Examine SSDI claimant experiences and outcomes.
5. Identify strategies and tactics to increase disability literacy and improve claimant outcomes.
  - Financial
  - Physical/Mental
  - Social/Relational
6. Review disability literacy resources

# Does Disability Literacy Matter to You?



# It Matters to:

## **People who work(ed) and their dependents**

- Today's 20-year-old has a 1 in 4 chance of becoming disabled before reaching retirement age.
- Less than less than a third of American workers have private sector long-term disability insurance.

## **Veterans**

- VA disability benefits and SSDI Wounded Warrior and 100 percent Permanent & Total VA rating programs.

## **Caregivers**

- Nearly one in ten caregivers receives disability benefits and 27 percent report caring for family members receiving disability benefits.
- SSDI is the most common disability coverage reported among these caregivers and the individuals they care for.

## **People living with mental illness and chronic diseases**

- People with mental illness are the largest and fastest-growing group of people receiving public disability income (NAMI, 2014).
  - One out of four Americans experience mental illness
  - People who suffer from a chronic disease are more likely to also suffer from depression
  - Caregivers are at elevated risk for developing mental health disorders.

**More than 50 million people living in the U.S. have some type of disability.**

# Health Literacy

**The ability to obtain, process and understand basic healthcare information and services to make appropriate health decisions is essential to maximizing personal health.**

- Research shows that currently available health information is too difficult for average Americans.
- Limited health literacy affects adults in all racial and ethnic groups.
- Limited health literacy is associated with worse health outcomes and higher costs.
- Even people with strong literacy skills can face health literacy challenges, when they are diagnosed with a serious illness and are scared or confused.

# Health Literacy

Even people with strong literacy skills can face health literacy challenges, when

- They are diagnosed with a serious illness and are scared or confused.
- They have complex conditions that require complicated self-care.
- They are not familiar with medical terms or how their bodies work.
- They have to interpret numbers or risks to make a healthcare decision.

**Individuals with severe disabilities who can no longer continue working often face all of these challenges at once.**

# The Power of Disability Literacy

Disability literacy is the ability to obtain, process and understand basic information regarding finances, healthcare and **available resources** needed to adapt to change and anticipate, prepare for and overcome physical, financial, emotional and mental challenges resulting from a disability.



# The Power of Disability Literacy

- With severe disability, crisis is compounded by lost employment and lost income.
- Many people are not aware of or do not understand the programs provided at local, state and national levels designed to support people with disabilities.
- Other aspects of their life change, including the need to plan for worsening physical and mental condition. Depending on their situation, they may need to consider:
  - a living will
  - an advance directive for their healthcare
  - employing personal assistance
  - relying on family and caregivers
  - setting up a power of attorney
  - writing a will
  - establishing a trust for dependents



# Increasing Disability Literacy

Increasing an individual's knowledge and understanding of these five content areas will increase their Disability Literacy.

1. Long-term disability insurance (LTD)
- 2. Social Security disability programs (SSDI/SSI)**
3. Personal finance/Disability life planning
4. Healthcare
5. Government and community resources

# Disability Literacy-Available Resources

Today

- Social Security Disability Insurance (SSDI)
- Supplemental Security Insurance (SSI)

**According to the Urban Institute, fewer than half (47 percent) of adults who meet the disability criteria receive public disability benefits at some point between ages 51 and 64.**

# About SSDI

- Established in August 1956.
- Payroll tax-funded, federal insurance program. It provides income to people unable to work because of a disability.
- FICA taxes include 6.2% for Social Security, a small portion of which is allocated to SSDI.
- To qualify, you must be both “currently insured” and “fully insured”—that is you have earned 20 “work credits” in the last 10 years. Usually, if you have worked five out of the last 10 years you are currently insured.
- If you are under age 31 when you become disabled, it is possible to be currently insured with less than 20 quarters of coverage.
- SSDI is not “means-based.”

# Benefits of SSDI

- **Monthly Income:** A regular monthly payment based on your lifetime earnings, adjusted annually for cost-of-living. A portion may be tax-free. Average benefit in 2014 is **\$1,148** for an individual and **\$1,943** for a disabled worker with a family.
- **Medical Benefits:** 24 months after date of your SSDI cash entitlement, you qualify for Medicare. This includes Medicare Advantage, often a better option for those with disabilities.
- **Drug Coverage:** Medicare coverage includes Part D.
- **COBRA Extension:** If you receive SSDI, you may be able to extend your COBRA benefit coverage an additional 11 months.

# Benefits of SSDI

- **Protected Retirement Benefits:** SSDI “freezes” your Social Security earnings record during the disability period. These years aren’t counted when computing future benefits, so your retirement benefit may be higher.
- **Return-to-Work Incentives:** Social Security will provide opportunities to return to work while still paying your disability benefits.
- **Protecting other income benefits:** Most long-term disability (LTD) policies require claimants to apply for SSDI. If you do not, your LTD benefits often are suspended, resulting in a reduction in income.
- **Dependent SSDI Coverage:** Dependents under the age of 18 typically also qualify for SSDI.

# SSDI Eligibility

## **The SSA defines a person as disabled if:**

- A physical or mental impairment prevents you from engaging in any substantial gainful work.
- Your condition is expected to last 12 months or longer or result in death.

## **To qualify:**

- You meet the criteria above.
- You have worked (and paid FICA taxes) 5 out of the last 10 years (in most cases).
- You have not reached retirement age (65-67).
  - Over 21 years of age and less than retirement age
- You have medical proof of disability.

# Adult Disabled Children and SSDI

## **Adult children with a disability may be eligible for SSDI based on their parents' work record if they are unmarried AND:**

- Their medical condition was diagnosed before age 22.
- They meet SSA's disability criteria for adults.
- They are not doing any substantial work (earning more than \$1,070 a month).
- Either parent has worked long enough to be insured under Social Security and is receiving retirement or disability benefits or is deceased.

An adult child who is receiving SSI may apply for SSDI benefits once a parent is deceased, or once the parent begins receiving Social Security retirement or disability benefits.

# SSA Profile

## SSA profile of disabled-worker beneficiaries:

- Workers accounted for the largest share of disabled beneficiaries (87.5 percent).
- Average age was 53.
- Men represented just under 53 percent.
- **Mental disorders was the diagnosis for about a third.**
- Supplemental Security Income payments were another source of income for about one out of eight.

Source: [Annual Statistical Report on the Social Security Disability Insurance Program, 2012.](#)



# Supplemental Security Income (SSI)

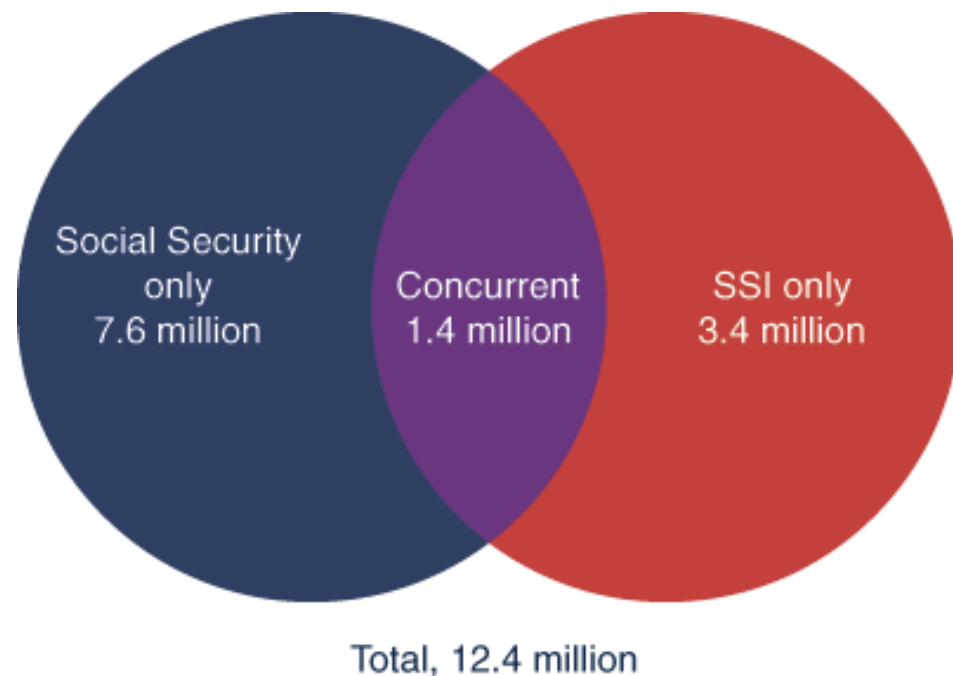
- Supplemental Security Income (SSI) is a welfare, or social assistance, program.
- Provides monthly income to people who are 65 or older, disabled, or blind (including children under 18) and have little/no work history.
- Funded through general tax revenues.
- Must meet SSA's disability criteria **AND** have limited income and resources (needs based).

# Supplemental Security Income (SSI)

- Federal SSI rates monthly maximum in 2014 =  
\$721/individual.  
\$1,082/couple.
- States have option of providing Medicaid.
- Must pass screening threshold of household income and resources. Limit = \$2,000/individual or \$3,000/couple.
  - Resources that **do not count** include a home where a person lives and one car (usually).
  - Resources that **do count** include bank accounts, stocks & bonds, 401(k), CDs (certificates of deposit), more than one vehicle.

# SSDI and SSI

Supplemental Security Income payments were another source of income for about one out of six disabled beneficiaries and one out of eight SSDI beneficiaries.

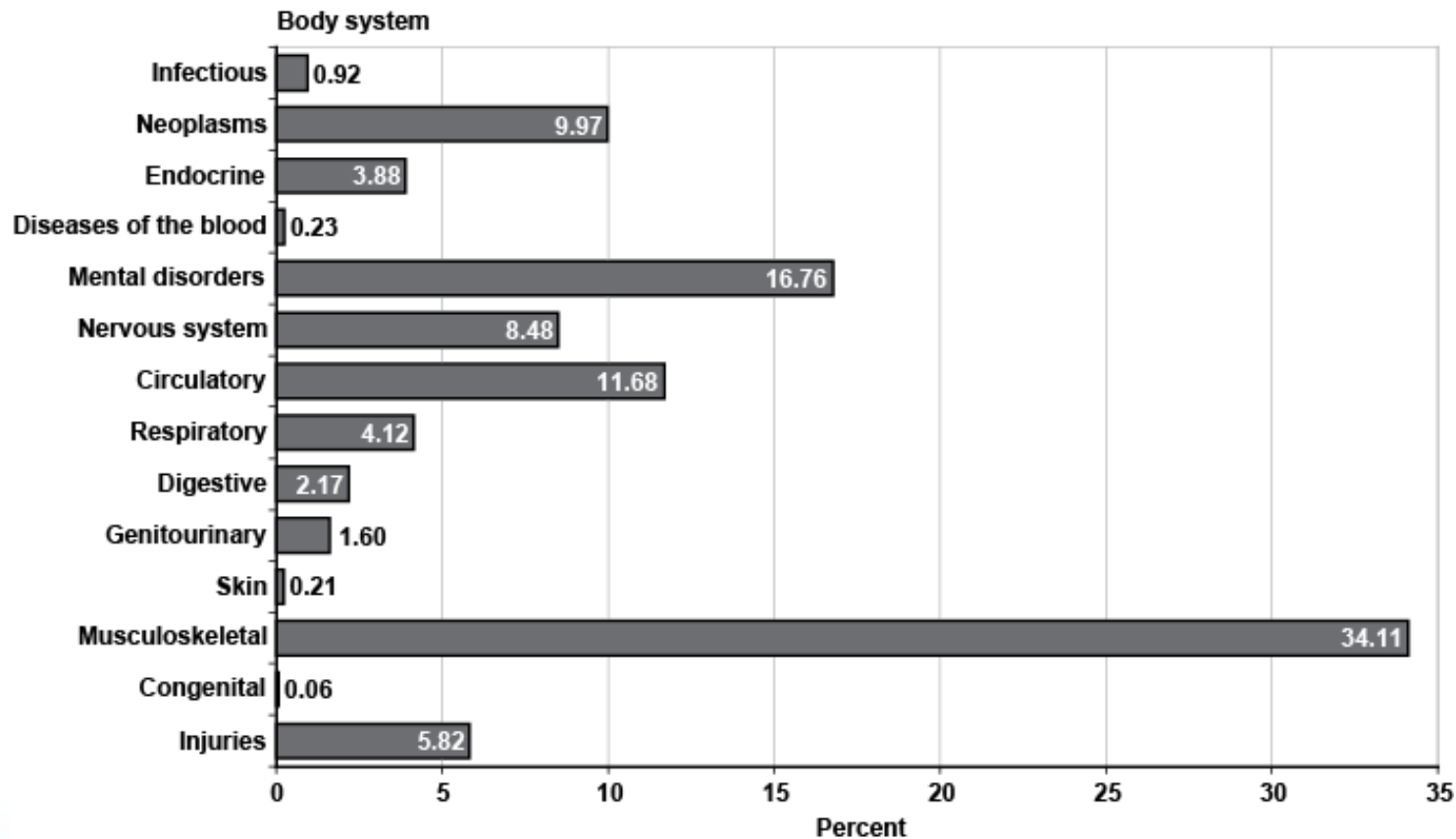


Sources: [Outcome Variation in the Social Security Disability Insurance Program: The Role of Primary Diagnoses](#) and [Annual Statistical Report on the Social Security Disability Insurance Program, 2011](#).

# SSA Claimant Diagnoses

## Percentage of claimants, by body system

(based on a representative sample of claims from 1997-2004)



Source: SSA, Outcome Variation in the Social Security Disability Insurance Program: The Role of Primary Diagnoses. 2013

# What is the SSDI Process?

- Consists of 5 levels within application process.
- Majority of individuals who file get frustrated with denial percentages and never continue with the process.
- Appeals process allows individual to request additional consideration at the hearing level.
- Most hearings involve a representative.

# Level 1 – Initial Application

- Application completed by claimant with SSA district office (or with representative).
- **Mandatory wait period for benefits is 5 months after date of onset.**
- District office prepares evidence for state-level Disability Determination Services (DDS).
- DDS compiles medical evidence, sends questionnaire, orders consultative exam.
- DDS determines if claimant should be awarded or denied.
- SSA reports time at this level = 107 days in 2013.
- Approximately 67% of claims are denied at this level.

# Level 2 – Reconsideration

- If claimant is not awarded at first level, seeks appeal with the SSA District Office.
- Claimant has 60 days to file and submit an appeal.
- District Office submits evidence to DDS.
- DDS compiles medical evidence, sends questionnaire, orders consultative exam.
- DDS determines if claimant should be awarded or denied.
- Reconsideration level typically takes 3-5 months.
- Approximately 89 percent of claims are denied at this level.

# “Skip”/Redesign States

- New SSA policy adopted in 1999 that enables the disabled individual to skip the “reconsideration” and move straight to the hearing.
- Two offices in California (LA N 00057 and LA W 00056)
- “Skip states” include AL, AK, CO, LA, MI, MO, NH, NY, PA



# Level 3 – Hearing with ALJ

- Claimant files appeal with SSA District Office.
- District Office forwards request to Office of Disability Adjudication and Review (ODAR).
- Administrative law judge (ALJ) determines if claim can be awarded on the record or if it requires hearing.
- If hearing required, (ALJ) conducts hearing with claimant.
- Typically takes a year to get a hearing and wait times are growing. National average = 382 days in 2013, now taking 414 days for a hearing.
- Approximately 48 percent of claims are awarded at this level (2013), a huge decline from 62 percent in 2010.

# Level 4 – Appeals Council

- Claimant files appeal with Appeals Council.
- District Office forwards file to Appeals Council for review.
- Typically lasts about one year.
- Appeals Council awards, remands or affirms ALJ's denial
  - Remands = case should be reviewed again by ALJ
  - Awarded moves forward in process
  - **Approximately 98% are denied**

# Level 5 – Federal District Court

- Requires formal representation by attorney who will file civil suit in Federal District Court.
- Typically lasts 12 months.
- **98% of claims are denied at this level.**



# Why People Need Help

- More individuals applying for SSDI
- Process is complicated and intimidating
- Nearly 30 percent denied for technical reasons.
- Most individuals have representation at the hearing level.
- Fewer resources at SSA to handle incoming requests
- Most individuals do not have enough savings/ income to sustain them through the months- to years-long process.
- Nearly one-half of caregivers surveyed (46 percent) indicated an interest in receiving assistance with the SSDI application process.

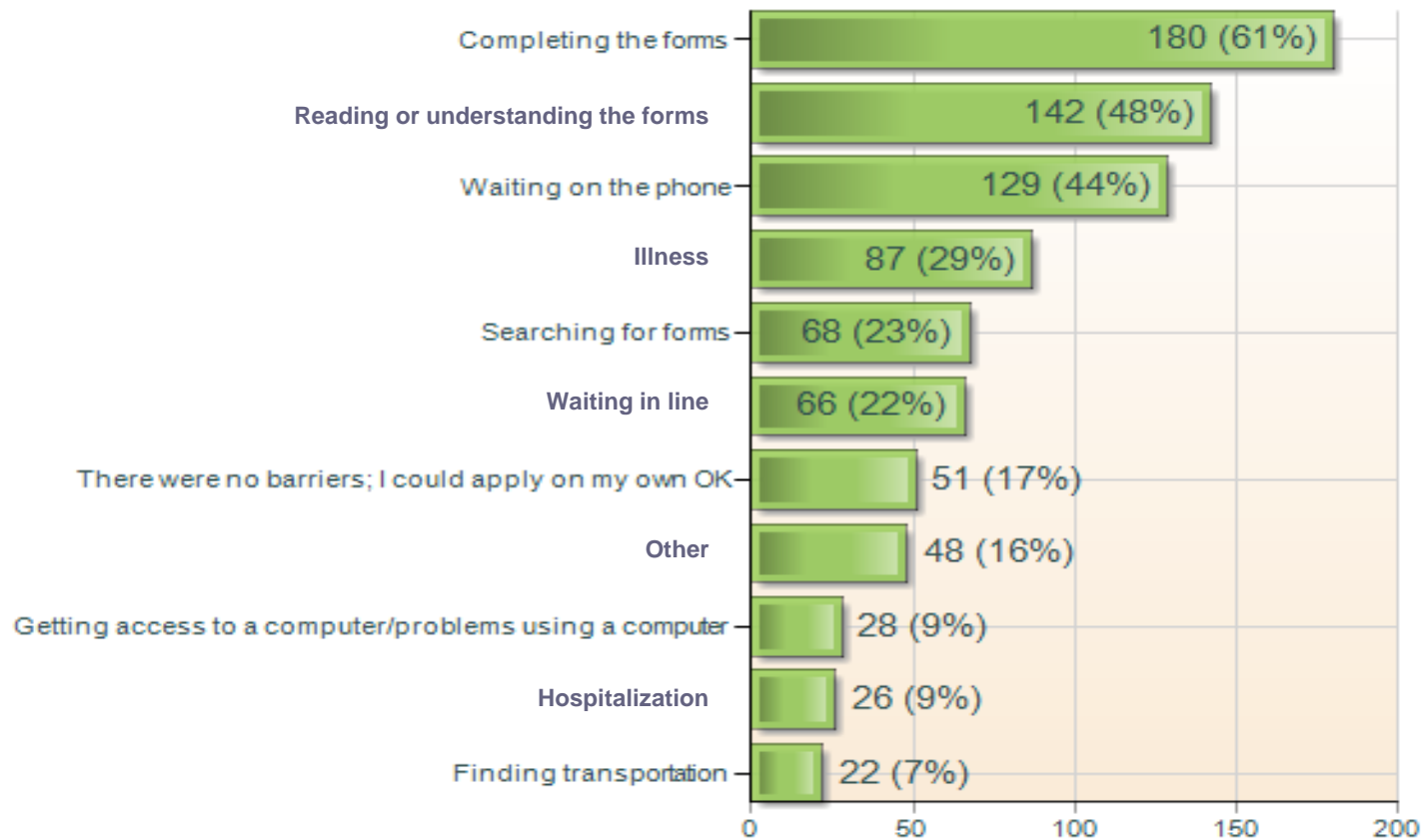
# How Much Does it Cost?



- Fees regulated by the federal government and are contingency based.
- **Flat rate** if awarded at level 1 (determined by SSA) **OR**
- **25%** of retro payment if claim goes through appeal process---capped at \$6,000.
- Clients should ask if representative charges for out-of-pocket expenses, such as medical records, phone calls, travel, etc.

# Difficulties “Going it Alone”

Please provide details on what difficulties you experienced when handling the SSDI process on your own.

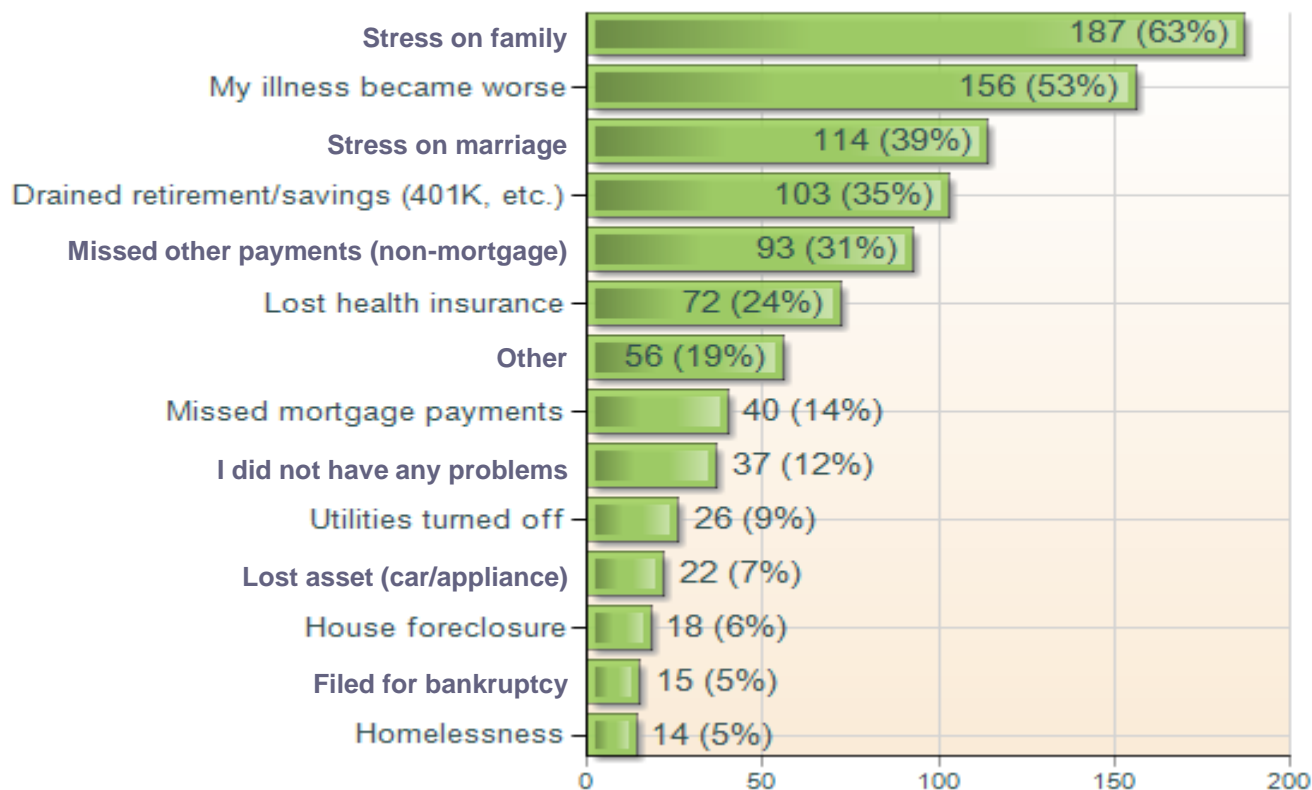


Note: respondents could select more than one

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# Experiences While Waiting

**Did you face repercussions during the time period before you received your SSDI award, and if so, what were they? (Please select all that apply.)**



Note: respondents could select more than one

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# Harness the Power of Disability Literacy

Increasing disability literacy can **empower** individuals and their caregivers to connect with resources, obtain needed benefits, and minimize the negative impacts of unemployment due to disability.

## To increase disability literacy

- Become disability literate yourself
- Incorporate disability literacy in educational outreach
  - Finances
  - Healthcare
  - **Available resources**
- Develop and/or refer to print and web-based resources
- Research and disseminate available disability resources



# Harness the Power of Disability Literacy

SSI and SSDI provide monthly income and access to Medicare/Medicaid, contributing to stability and access to care for people with chronic diseases and disabilities.

## **To increase access to SSDI benefits, including Medicare**

- Research and disseminate SSDI assistance resources, including non-attorney representation.
- Take advantage of free services, such as SSDI eligibility screenings.
- Encourage individuals to get help at the very beginning of the process, and inform them they can seek assistance at every level.
- Encourage individuals to assemble all the documentation and patience they can.
- **Encourage individuals to continue and document treatment, explaining it is necessary to obtain and maintain benefits.**

# Harness the Power of Disability Literacy

## Questions to ask potential SSDI representatives

- Do you specialize in SSDI?
- Do you help with initial applications?
- What is your success rate?
- What is your success rate at the initial level? Those approved quickly at the application level and receive no retroactive award typically pay much less.
- What specific activities will you handle? Obtain medical records, follow up with physicians, contact SSA for status updates?
- Do you have experience representing someone with my mental illness?
- How will you keep me up to date on what's happening with my claim?

# Additional Disability Literacy Resources

- [Free SSDI Eligibility Screening](#)
- [Personal Story Videos](#)
- [Allsup's Online Guide to Personal Finance](#)
- [Financial Planning for Family Caregivers](#)
- [Financial Planning Calculators](#)
- [Veterans Disability Overview](#)
- [Disability and Earned Income Tax Credit](#)
- [Individual Development Accounts](#)
- [Family Self-Sufficiency Program](#)
- [Plan to Achieve Self-Support \(PASS\)](#)
- [Medicare Extra Help](#)

# Connect with Allsup

- [Expert.Allsup.com](http://Expert.Allsup.com)
- Disability Evaluation Center –  
Free SSDI evaluation at (888) 841-2126

## If your group would like to host a speaker, presentation or webinar:

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