

# SSI for Children and Adults with Disabilities

with a particular look at Mitochondrial Disease

Presented by:

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# Federal Financial Benefits:

## Supplemental Security Income (SSI)

- Means tested: Limited income and assets

## Social Security Disability Insurance (SSDI)

- Not means tested but subject to work credits or parents' eligibility

# SSI

- Who is eligible?
  - Blind, Aged or Disabled
- Must have limited assets
  - Deeming
- Must have limited income
  - Dollar for Dollar Reductions
- Be a US citizen or meet alien status criteria

# SSI is Very Limited

- We now have two payments in Massachusetts: SSI and SSP
  - Disabled, Living alone \$835.39
  - Disabled, Sharing expenses \$751.40
  - Disabled, Home of another \$568.25
- Blind, payments go up
- Married, payments go down
- Please see attached chart as an example



# SSI, Continued

## *Disability Defined*

- Mental or physical impairment
- Expected to last at least 12 months or result in death
- Must directly affect a person's ability to work at "substantial gainful activity" (adults)
- Must directly affect the child's ability to reach age-appropriate developmental milestones or to engage in age-appropriate activities of daily living. (children)

# PUBLIC BENEFITS: Healthcare


## MEDICAID (“MASSHEALTH”)

for People with Disabilities Under Age 65

- Medicaid is an automatic benefit in approx. 40 states if you are eligible for SSI payments
- This is so important for people who require community care
- What does it cover?
  - Durable Medical Equipment
  - Dental Treatment
  - Co-pays for medicine and doctor/hospital
  - PCA
  - Nursing
  - HCBS Waivers



# Income Limits

- Income is separated out into two kinds
    - Working Income
    - Non-Working Income
  - Income is counted in the month it is received
  - If it has not been spent, the following month it is a countable resource/asset
- 

# Income – Impact on Benefits

## ➤ Working Income

- Encouraged to work.
- First \$20 of any income disregarded.
- Next \$65 of Working Income disregarded.
- Then every dollar of work reduces the SSI payment by \$.50
- Example: If you have a \$500 SSI payment every month and you earn \$385 from work; you receive an SSI payment of \$350 plus your work income of \$385.
- Net result: if you work, you have income of \$735, if you don't your income is only \$500. It benefits you to work.
- Work does not affect most state supplement payments.



# Income – Impact on Benefits



## Non-Working Income

- First \$20 of any income disregarded.
- All other types of income have different impact on your SSI benefit.
- Long list of payments that are not income:
  - Tax refunds
  - AFDC payments
  - Veterans Benefits
  - State agency payments such as DDS in our state
  - Sheltered workshop payments, and so forth
  - Review the POMS (Program Operations Manual System) for a complete list
  
- Child Support payments – under 18 years old, there is 1/3<sup>rd</sup> disregard, then a dollar for dollar reduction; over 18, no disregard and a 100% dollar for dollar reduction in benefit
  
- Alimony payments – dollar for dollar reduction in benefit
  
- Investment income, pensions, annuities etc. – dollar for dollar reduction in benefit

# Assets Limits

- **\$2,000 individual and \$3,000 married couple**
- Review the POMS (Program Operations Manual System) for a complete list of countable and noncountable assets
- **Virtually all assets are countable; assets usually forgotten:**
  - Retirement assets
  - UTMA and UGMA for your kids
  - Joint accounts
  - College savings accounts (529 plans and the like) are not assets of the child/beneficiary but they are assets of the person who set up the plan
  - Savings Bonds
  - Stock certificates, money in a safe deposit box and furniture and stuff
  - Vehicle – you are allowed to have one and not luxury
  - Home – exempt asset if it's yours



# How do I fix this Asset or Income problem

- Can I give assets away? – Yes, but you will be penalized for it
- Can I refuse income? - No
- How far back does SS look? – 3 years
  - Note that SS can decide that if you owned assets at any time you were receiving benefits they could ask for repayment for every month you were over the asset limit – not a SNAPSHOT
- Can I transfer to Trusts ? – Yes, both assets and income streams can be transferred but the process will depend to some extent on state law



# TRUSTS

- What is a trust?
  - Like creating a company
  - Governed by rules set out by you
  - Holds and disburses assets for a beneficiary
  
- Two Special Needs Trusts
  - Third Party: Other People's Money
  - First Party: Disabled Person's Money

# Third-Party SNT

- Provides supplemental funds for living expenses not covered by other income sources
- May be established by parents, grandparents, guardians or Probate Court
- “Living” SNT lets others contribute
- Trustee has discretion over distributions


# What If The Disabled Person Has Assets?

Establish a First-Party SNT (D4A):

- Provides funds for living expenses not covered by other income sources
- Maintains eligibility for public benefits
- Must be established by parent, grandparent, legal guardian or the court
- Person under 65
- Estate Recovery for all Medicaid expenses



# POOLED TRUSTS

- Can be third party or first party
  - Qualifies for exceptions
  - Pooled assets for management
  - Limited costs
  - Some estate recovery
  - Some states do not allow over 65 first party pooled trusts
- 



# ABLE ACCOUNTS – Will they be helpful

- Yes, but limits to:
  - Amount per year for third party
  - Total amount allowed in the account is \$100,000
  - One account per person
  - Limited uses for distribution
- Federal law allows but not all states have implemented yet
- Still has estate recovery
- Good solution under certain circumstances
  - Prevents necessity of going to court to establish/fund
  - Allows person to create and fund themselves
  - Allows person to control asset if they are able



# Have Questions? Ask!

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# Introduction and Overview



## **Tai Venuti, MPH** **Allsup manager of Strategic Alliances**

- SSDI basics
  - Eligibility (including adult disabled children)
    - Benefits
    - Application and appeals processes
- Challenges for individuals with mitochondrial disease
- Benefits of professional representation and how to evaluate representation options
- Returning to work after obtaining Social Security benefits (the "Ticket to Work" Program)
- Resources

# SSDI Eligibility

- ▶ Social Security Disability Insurance is a payroll tax-funded, federal insurance program. It provides income to people unable to work because of a disability.
- ▶ Workers pay 6.2% in FICA taxes for Social Security, a small portion of which is allocated to SSDI. Employers pay an additional 6.2%.
- ▶ 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 Eligibility for Younger Workers

- Generally you need 40 credits. However, younger workers may qualify with fewer credits.
- Before age 24, you may qualify if you have six credits earned in the three-year period ending when your disability starts.
- Age 24 to 31, you may qualify if you have credit for working half the time between age 21 and the time you become disabled.

**Example:** If you become disabled at age 27, you would need credit for 3 years of work (12 credits) out of the past 6 years (between ages 21 and 27).

# 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 \$1,090 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 begins receiving Social Security retirement or disability benefits.

# 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 2015 is **\$1,165** for an individual and **\$1,976** 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.

# Benefits of SSDI

- **COBRA Extension:** If you receive SSDI, you may be able to extend your COBRA benefit coverage an additional 11 months.
- **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 is not reduced.
- **Return-to-Work Incentives:** Social Security will provide opportunities to return to work while still paying your disability benefits.



# Benefits of SSDI

- **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 benefits:**  
Dependents of someone receiving SSDI, under the age of 18, also can receive a benefit. The dependent(s) typically receives half of the disabled person's monthly benefit.



# SSA Impairment Listings

No impairment listing specifically for mitochondrial disease. However, many diseases are related to defects of mitochondrial function, including:

- Type 2 diabetes-9.00 Endocrine Disorders
- Parkinson's disease-11.00 Neurological
- Stroke-11.00 Neurological
- Atherosclerotic heart disease-4.00  
Cardiovascular System
- Alzheimer's disease-12.00 Mental Disorders
- Cancer-13.00 Cancer

# SSA Impairment listings

Common symptoms of Mitochondrial disease affect ability to work.

- ▶ Visual and/or hearing problems-2.00 Special Senses and Speech
- ▶ Liver disease-5.00 Digestive
- ▶ Kidney disease-6.00-Genitourinary
- ▶ Gastrointestinal disorders, severe constipation-5.00 Digestive System
- ▶ Thyroid and/or adrenal dysfunction-9.00 Endocrine
- ▶ Autonomic dysfunction-12.00 Mental Disorders
- ▶ Confusion, disorientation, and memory loss-11.00 Neurological



# The SSDI Process

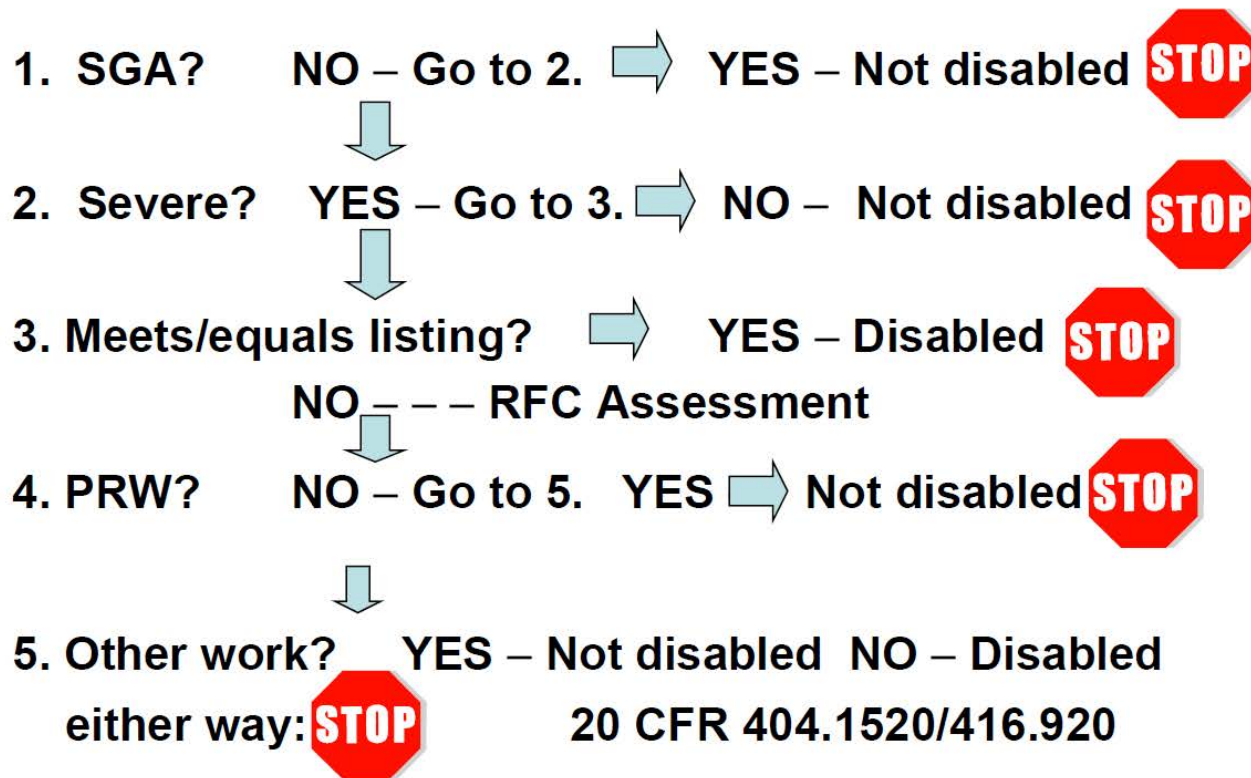
- ▶ Consists of 5 levels in most states.
- ▶ Majority of individuals who file get frustrated with denial percentages and never continue with the process.
- ▶ Appeals process allows individuals to request additional consideration at hearing level.
- ▶ Most hearings involve a representative.

# 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 processing time target at this level = 110 days in 2014.
- **Approximately 68 percent of claims are denied at this level.**

# Sequential Evaluation

## Sequential Evaluation Process—Adults



# 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 application and prior evidence from the initial claim 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 (108 days in 2014).
- **Approximately 89 percent of claims are denied at this level.**

# "Skip"/Redesign States

- ▶ 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 about a year to get a hearing and wait times are growing. Decision typically reached @ 422 days in 2014. Now an estimated 470, according to SSA.
- **Approximately 55 percent of claims are denied at this level in 2014.**

# 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 99% 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



- Nearly 3 million individuals apply for SSDI each year.
- Nationwide backlog.
- Process is complicated and intimidating.
- Nearly 30% denied for technical reasons.
- 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.

# SSDI and Mitochondrial Disease

**The SSDI disability determination process relies on medical evidence.**

- Mitochondrial disease is hard to diagnose and difficult to rule in or out.
- Many symptoms of mitochondrial disease are non-specific (chronic fatigue, confusion, etc.)
- Mitochondrial disease is considered a rare disorder, and adjudicators not familiar with the disease may not fully understand its impact on the ability to work.

**Individuals must prove they are unable to work**

- The severity of mitochondrial disease symptoms may fluctuate.

# Getting Help With SSDI



“If claimants...had representatives earlier in the disability process, some of them may have received an allowance decision at the DDS level, saving them time and SSA money.

First, the claimants may not have had to go to the hearing level if they had representatives to assist them with completing SSA's forms and providing the necessary evidence at the DDS level.

This could have saved some claimants about 500 days in receiving an allowance decision.”

# How Much Does it Cost?

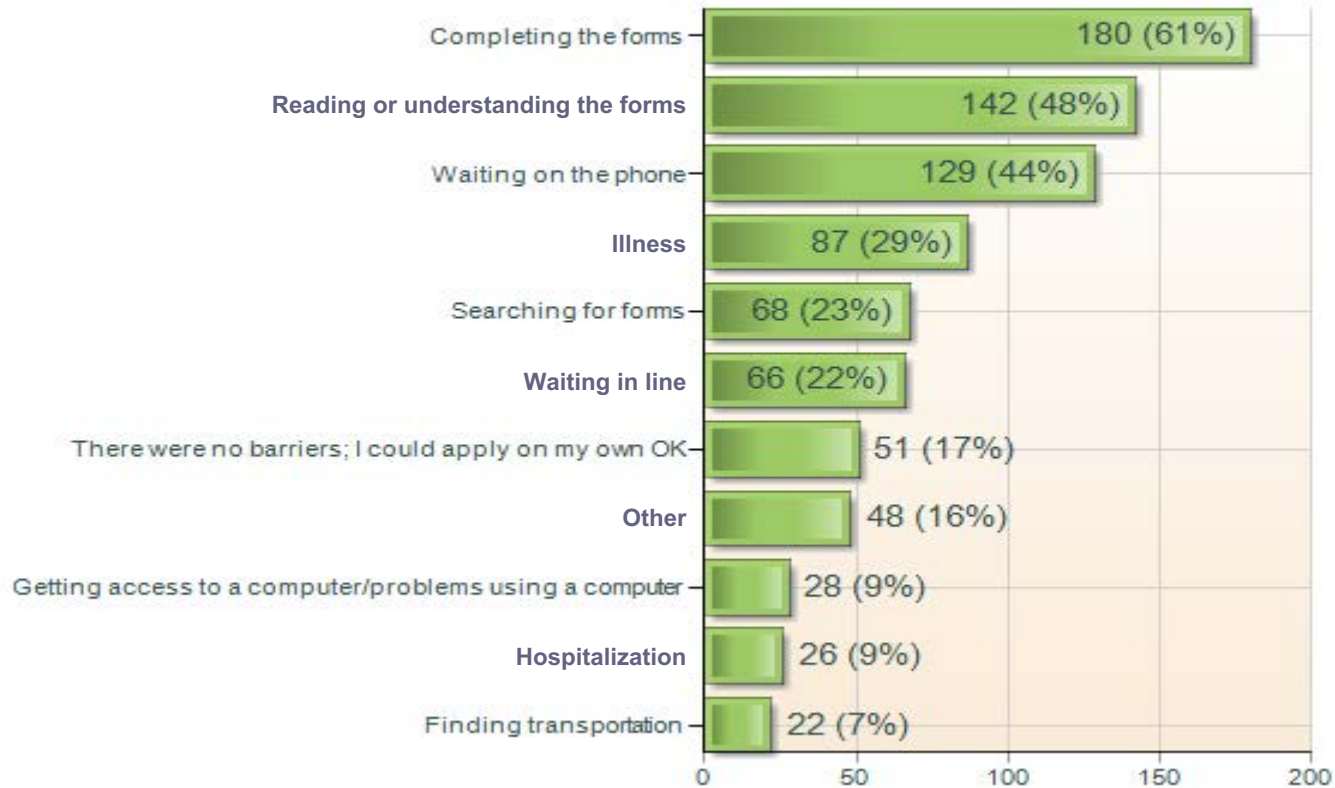


- ▶ Fees regulated by the federal government and contingency based (if Allsup is unsuccessful, individual pays nothing).
- ▶ **Flat rate** if awarded at level 1 (Allsup's high success rate at this level means many clients pay the flat rate) **OR**
- ▶ **25%** of retro payment if claim goes through appeal process---capped at \$6,000.
- ▶ Allsup does not charge for out-of-pocket expenses: copying 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.

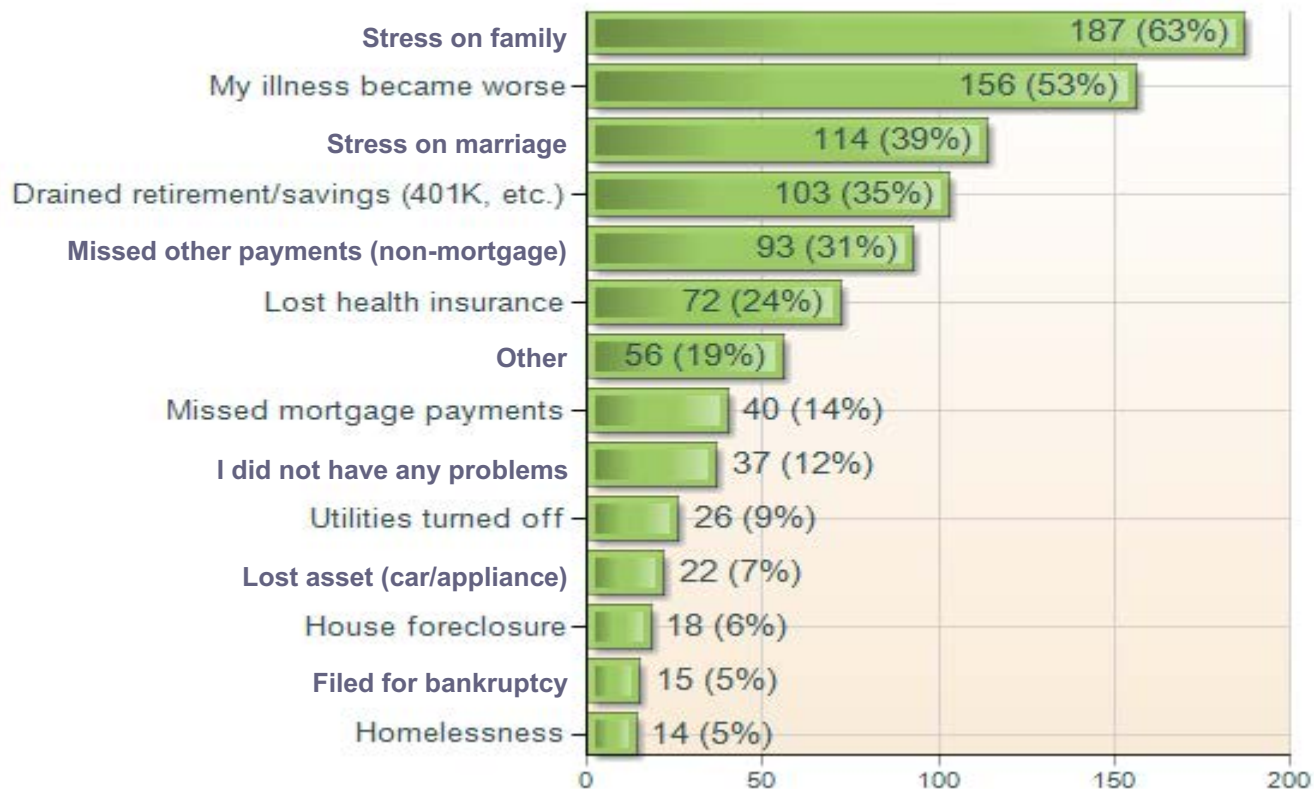


Note: respondents could select more than one



# 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

# Health Insurance Assistance

Allsup assists customers by providing a Certified Application Counselor. A counselor can help you:

- ▶ Determine eligibility for financial subsidies and tax credits-which can reduce your costs for health insurance.
- ▶ Apply for health insurance through the health exchanges serving your state.
- ▶ Determine if you are eligible for Medicaid.
- ▶ Enroll in Medicaid, if eligible.

Allsup has signed an agreement with the Centers for Medicare & Medicaid Services to be a Certified Application Counselor. Allsup abides by the standards and requirements pursuant to 45 CFR 155.225 and applicable Privacy and Security Standards 45 CFR 155.260.

# 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 disability? Especially important for those with rare diseases.
- How will you keep me up to date on what's happening with my claim?

# Meeting the Ticket to Work Challenge

**Challenge: You are eligible for Ticket to Work only after you are awarded SSDI benefits.**

By the time someone asks if you would like to try to work, you have invested months or years providing evidence of your inability to work in order to receive SSDI benefits. The process can take two to three years. By that time, many individuals are likely to have become more isolated, lost critical work capacity and have a diminished desire to work.



# Meeting the Ticket to Work Challenge

## Solution:

- If you are thinking about applying or have a claim pending for SSDI benefits, familiarize yourself with the Ticket to Work program before and during the adjudication process.
- Learning about work supports and incentives can help you visualize an eventual return to work. This enhances your mental and emotional capacity to take full advantage of the Ticket to Work program when you are ready.



# Why Work?

- SSDI is an important resource for former workers, but monthly cash benefits are usually much less than previous wages.
- Employment affords the opportunity to build on previous work experience and grow professionally and personally.
- Advances in technology, training and supportive mechanisms have evolved, allowing people with significant disabilities to adapt and ultimately re-enter the economy.
- With the right opportunities and supports, many people can earn a higher standard of living by going to work and leaving the benefit rolls.

# Ticket to Work

- Supports career development for people with disabilities by providing choices, opportunities and supports needed to become and stay employed.
- Ticket to Work holders are SSDI beneficiaries who would like to improve their earning potential and are committed to preparing for long-term success in the workforce.
- The Ticket program and its work incentives allow individuals to keep their SSDI benefits while they explore employment.





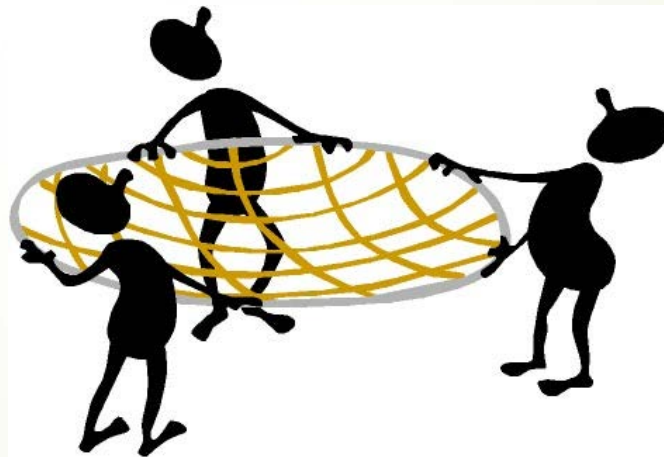
# Incentives for Ticket to Work Participants<sup>48</sup>

1. Trial Work Period (TWP) – Allowed a nine-month trial work period without losing SSDI benefits regardless of work earnings.
2. Extended Period of Eligibility – 36 months after TWP ends. Full benefits continue for months in which earnings are below SGA, as long as you continue to have a disabling impairment.
3. Expedited reinstatement of benefits – Benefits are reinstated without new application for six months while SSA evaluates your eligibility to receive benefits. Can utilize this incentive for up to 5 years after your benefits stop due to work earnings.



# Incentives for Ticket to Work Participants <sup>49</sup>

4. Continuation of Medicare coverage – For up to 93 months after TWP and includes Medicare Part A, Part B (if enrolled), and prescription drug coverage if enrolled.
5. Exclusion from medical continuing disability reviews – As long as you are making timely progress toward your employment goals.





# Provider Resources

- Employment Network (EN)
- State Vocational Rehabilitation Agency (VR)
- Work Incentives Planning and Assistance (WIPA)
- Protection and Advocacy for Beneficiaries of Social Security (PABSS)

# Provider Description

## Employment Network (EN)

- ▶ Contracts with Social Security to provide **free** services to beneficiaries.
- ▶ Helps you develop an Individual Work Plan (IWP).
  - ▶ Defines employment goals.
  - ▶ Describes specialized services the EN will provide.
- ▶ Provides career counseling, job placement, and ongoing support services. Some provide additional services.
- ▶ You can “shop around” for an EN that best suits your needs.

### EN services may include:

- ▶ Career Planning
- ▶ Job Placement
- ▶ Ongoing Employment Support
- ▶ Benefits Counseling



# Summary

1. If you cannot work due to mitochondrial disease and/or other physical or mental conditions, determine your eligibility for SSDI benefits.
2. Get help with your SSDI application at the very beginning of the process.
3. Obtaining SSDI benefits does not mean you will never return to work. The Ticket to Work program provides resources and support to help you re-enter the workforce.

For information and assistance with SSDI, visit [Expert.Allsup.com](http://Expert.Allsup.com) or call (888) 841-2126

For more information on Ticket to Work, visit [www.AllsupES.com](http://www.AllsupES.com) or call (866) 540-5105

# Questions?



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