

# Insurance, Waivers and Angelman Syndrome - Community Alternatives

Programs Available to Angelman Syndrome  
Individuals and Families for Community  
Inclusion and Improving Quality of Life  
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# Objectives of the Presentation

- Viewers will have a better understanding of Government benefits specific to individuals and families impacted by Angelman Syndrome
- Viewers will be better equipped to advocate for access to Government benefits and therefore improve the overall quality of life of beneficiaries
- Viewers will have knowledge of key advocacy groups within their own individual states which can help individuals and families navigate the system to access these important Government programs

# Angelman and Developmental Disability

According to the federal government a developmental disability is a severe, chronic disability which:

Is attributable to a mental or physical impairment or combination of mental and physical impairments, and

Is manifested before the person attains age 22, and

Is likely to continue indefinitely, and

Results in substantial functional limitation if three or more of the following areas of major life activity:

Self-care	Receptive and expressive language
Learning	Mobility
Self-direction	Capacity of independent living
Economic self-sufficiency	

# Government Financial Assistance for Individuals with Developmental Disabilities





**SOCIAL SECURITY DISABILITY  
INSURANCE AND SUPPLEMENTAL  
SECURITY INCOME**

**What Are the Differences?**

Both SSI and SSDI are government-based programs designed to benefit the disabled



Both are managed by the  
Social Security Administration

However, the specific eligibility requirements are very different

One significant difference is that SSDI is only available to workers earning enough “work credits” with Social Security



While SSI disability benefits are available to low-income individuals regardless of whether they have earned sufficient work credits

Social Security Disability Insurance (SSDI) provides income replacement for eligible individuals who are unable to work due to a long-term injury or illness that is expected to last at least one year or result in death



## HOW MUCH ARE SSDI BENEFIT PAYMENTS?



United States Treasury

15-51  
000

P 911,126,541

Month	Day	Year
03	03	05

Pay to

46123616

90

PHILADELPHIA

Most SSDI recipients receive  
between \$300 and \$2,200 in  
benefits

*Now the payments range from \$800 - \$2,200*

The average SSDI payment in 2014 is \$1,148 and the maximum disability benefit is currently \$2,642

*Now, the average payment is \$1,277*

After you have received disability benefits for 24 months, you will automatically become eligible for Medicare, regardless of your age

Unlike SSDI, SSI is strictly  
a need-based program

To be eligible, you must have less than \$2,000 in assets if you are single and less than \$3,000 if you are married

In 2014, minimum SSI benefits are \$721 per month for an individual and \$1,082 per month for couples

*The monthly maximum Federal amounts for 2021 are \$794 for an eligible individual, \$1,191 for an eligible individual with an eligible spouse*

Each state has its own requirements  
and guidelines regarding SSI  
eligibility

# For federal Social Security purposes, there are four criteria that must be met to be eligible for SSI:

○ You must be blind, disabled, or age 65 or over

○ You must be either a citizen of the United States, or meet other very narrow requirements >>

○ Your monthly income must be below a certain level

○ The property you own must be worth less than \$2,000 for an individual, or \$3,000 for a couple

# Federal and State Medicaid Programs

- Each state determines how to use federal funds to develop a state Medicaid plan
- The plan combines federal funds with state funds to operate the Medicaid programs
- States must adhere to certain federal guidelines in the operation of Medicaid Programs
- An individual can find more information on the state by state information at <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-State/By-State.html>

# Medicaid and Angelman Syndrome

- Individuals with Angelman Syndrome qualify for Medicaid Waiver Programs
- These programs are offered through Home and Community Based Services Waivers, 1915 (c) waivers
- For more information on home and community based services visit this link:

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Home-and-Community-Based-1915-c-Waivers.html>

# Levels of Waivers, Waiting Lists, and Advocacy

- States provide levels of care for families and individuals with Angelman Syndrome with various levels of support
- Residential Services Waivers typically have long waiting lists
- It is important to get on these lists as soon as possible
- You can obtain another level of waiver supports and service while waiting for more comprehensive waiver services
- Often there is a hierarchy of levels (e.g. level 1, level 2, level 3)
- Waiver names vary state by state and you need to do your research

# Levels of Waivers, Waiting Lists, and Advocacy

- Services provided by most all waivers includes: a.) respite care, b.) personal care support, and c.) attendant care
- Services provided by higher level waivers (e.g., level 2) may include: a.) community living supports, b.) job coaches, c.) case managers, d.) environmental supports (i.e., home modifications)
- Services for the highest level typically includes all the above services and additionally includes residential supports along with funding for 24/7 residential care including staffed residences and group homes

# Levels of Waivers, Waiting Lists, and Advocacy

- The focus of Home and Community Based Services Waivers is to provide support and services within the individuals community
- There are typically two ways to receive supports and services
  - Traditional Provider - An agency who coordinates care along with all supports and services
  - Self Directed Option - allows the individual and representative to coordinate supports through utilizing their own budget to hire, train, and fire individuals from their community (i.e., family, friends, neighbors)
- The purpose of “self directed options” allows an individual with family support to direct services which impact their quality of life
- Regardless of the “how” a plan of care is often developed through the Person Centered Planning process
- Planning for the Future is Key and Medicaid Waivers are Critical!

# Additional Medicaid Information

- Waiver eligibility varies state by state. Some states apply the 300% above Federal Poverty Rate (e.g. family of five \$93,120).
- Medical/institutional deeming is another criteria which is often used by state Medicaid plans. States consider a child under 18 as if they are in an ICF/MR facility (i.e., institution) and do not count parents income or assets.
- Most likely, both children and adults qualify for Waivers based on income or if medically/institutionally deemed
- Guardianship becomes important at age 18 -21 and each state has specific procedures for applying for guardianship for an adult with Angelman Syndrome

# Other Medicaid Programs

- State Medicaid Plans include other components which are important to consider
- Some programs are specific for Children
- Some programs can help overall families

# Back to Medicaid - Mandatory Federal Benefits

- Physician services
- Hospital services (inpatient and outpatient)
- Laboratory and x-ray services
- Early and periodic screening, diagnostic, and treatment (EPSDT) services for individuals under 21
- Medical and surgical dental services
- Rural and federally-qualified health center services
- Family planning
- Pediatric and family nurse practitioner services
- Nurse midwife services
- Nursing facility services for individuals 21 and older
- Home health care for persons eligible for nursing facility services

# Medicaid - Optional State Covered Services

- Prescription drugs
- Clinic services
- Dental and vision services and supplies
- Prosthetic devices
- Physical therapy and rehab services
- TB-related services
- Primary care case management
- Nursing facility services for individuals under 21
- Intermediate care facilities for individuals with mental retardation (ICF/MR) services
- Home-and community-based care services
- Respiratory care services for ventilator-dependent individuals
- Personal care services
- Hospice services

# Medicaid and Children 0-21 EPSDT

- E. Early
  - And
- P. eriod
- S. creening
- D. iagnosis
- T. reatment
- PROGRAM

# E.P.S.D.T - From Health Resources and Administration Maternal and Child Health

- "While there is no federal definition of preventive medical necessity, federal amount, duration and scope rules require that coverage limits must be sufficient to ensure that the purpose of a benefit can be reasonably achieved.... Since the purpose of EPSDT is to prevent the onset of worsening of disability and illness and children, the standard of coverage is necessarily broad... the standard of medical necessity used by a state must be one that ensures a sufficient level of coverage to not merely treat an already-existing illness or injury but also, to prevent the development or worsening of conditions, illnesses, and disabilities." Kentucky Example of PT, OT, ST

# Medicaid HIPP Programs

- The Health Insurance Premium Payment Program (HIPP) is a Medicaid program that allows a recipient's family to receive free private health insurance paid for entirely by their state's Medicaid program - Kentucky Example
- A Medicaid recipient must be deemed 'cost effective' by the HIPP program of their state.
- The Omnibus Budget Reconciliation Act of 1990 (OBRA-90) authorized states to implement a HIPP program.

# Advocacy and Resources

- Developmental Disabilities Assistance and Bill of Rights Act (DD Act)
  - Originally authorized in 1963, and last reauthorized in 2000, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), Public Law 106-402, focuses on the needs of the estimated 4.5 million individuals with developmental disabilities. The DD Act ensures that individuals with developmental disabilities participate fully in their communities through full integration and inclusion in the economic, political, social, cultural, religious and educational sectors of our society. The DD Act further ensures that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports and other assistance and opportunities that promote independence, productivity, integration and inclusion in the community

# DD Act and Key State by State Agencies

- State and Territorial Councils on Developmental Disabilities
- University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)
- Protection and Advocacy Systems
- Projects of National Significance

# Developmental Disabilities Councils

- Each state and territory has a Developmental Disabilities Council that functions to increase the independence, productivity, inclusion, and community integration of people with developmental disabilities. DDC activities demonstrate new ideas for enhancing people's lives through training activities, through community education and support, by making information available to policy-makers, and by eliminating barriers.
- A key mission of Councils is to advise Governors and State agencies on the use of available and potential resources to meet the needs of individuals with developmental disabilities. State DD Councils engage in advocacy, build capacity and work to affect change and enhance systems to contribute to a coordinated, consumer-directed and family-centered array of community services, individualized supports and other forms of assistance. Their work allows individuals with developmental disabilities to exercise self-determination and live in their communities.

# University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)

- UCEDD is a grant program providing support to a national network of University Centers to support interdisciplinary training, exemplary services, technical assistance, and information/ dissemination activities. University Centers positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity, and integration into communities.
- University Centers have four broad tasks: conduct interdisciplinary training, promote community service programs, provide technical assistance at all levels (from local service delivery to community and state governments), and conduct research and dissemination activities

# Protection and Advocacy Systems

- Each state has a Protection and Advocacy (P&A) System to empower, protect, and advocate on behalf of persons with developmental disabilities. The P&As are independent of service-providing agencies and offer information and referral services for legal, administrative, and other remedies to resolve problems for individuals and groups of clients.
- P&As enhance the quality of life of people with developmental disabilities by investigating incidents of abuse and neglect and discrimination based on disability. The P&As also provide an annual opportunity for the public to comment on the objectives, priorities, and activities of the system. This gives clients and others in the community an opportunity to voice their concerns and needs to the P&A.

# National and State ARC Chapters

- The Arc of the United States is an organization serving people with intellectual and developmental disabilities. The organization was originally founded in the 1950s by parents of individuals with developmental disabilities.
- Since that time, the organization has established state chapters in 39 states, with 730 local chapters in states across the country. The Arc of the United States is based in Washington D.C.

Thank you!

