



Government Benefits

Programs Available to Angelman Syndrome
Individuals and Families to Support Community Inclusion
and Improve Quality of Life
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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



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

What Are the Differences?

SSI and SSDI

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

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- Both SSDI and SSI are managed by the Social Security Administration



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- However, the specific eligibility requirements are very different
- One significant difference is 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

- Unlike SSDI, SSI is strictly a need-based program



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Supplemental Security Income

- To be eligible, individual must have less than \$2,000 in assets (adult) and \$4,000/\$5,000 (child applicant)
- Even if your child is not eligible for SSI before his or her 18th birthday because you and your spouse had too much income or too many resources, he or she may become eligible for SSI at age 18.
- In 2017, the maximum benefit for eligible individuals was \$735/month and \$8,830.84 per year

SSI and Eligibility

- Each state has their own guidelines
- You must be blind, disabled, or age 65 or older
- You must be a citizen of the United States or meet very narrow requirements
- Your monthly income must be below a certain level
- Assets must be less than \$2,000

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 state 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>

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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

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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 \$83,730).
- 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

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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.

ABLE Act Basics

- Modified the 529 rule to add 529A Achieving a Better Life Experience (ABLE) Act
 - Allows up to \$14,000 per year to be saved into an ABLE account annually.
 - Protects SSI payments with a threshold of up to \$100,000
 - Medicaid benefits are protected regardless of the amounts
 - At the beneficiaries passing state Medicaid programs have the option to recoup Medicaid expenses
 - Special Needs Trust vs. ABLE Act (both have a purpose)

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

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.



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