



Exploring Government Benefits, Waivers, and More

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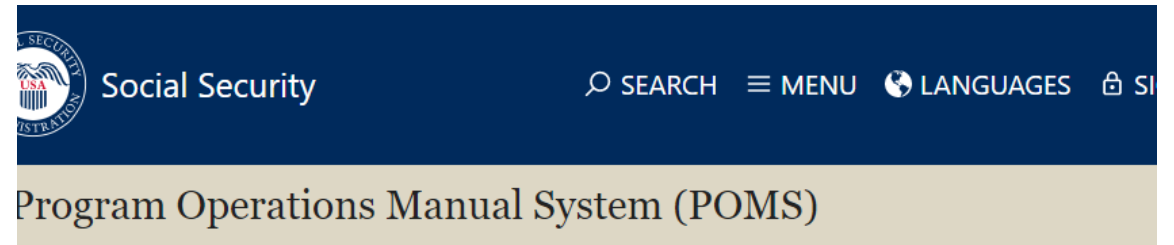
Importance of this Topic and Goals

- Families, friends, and advocates need to understand these benefits
- We need information to advocate for access to Government benefits to improve overall quality of life for families impacted by Angelman Syndrome
- We need state specific resources to help us navigate the system to access these programs



Angelman Syndrome and Federal Programs

- Angelman Syndrome falls into the compassionate allowance (CA) category for the Social Security Administration
- The Angelman Syndrome Foundation and our team advocated for this placement
- CA helps expedite benefits from SSI and SSDI



The screenshot shows the top navigation bar of the Social Security website with the logo and text "Social Security". To the right are links for "SEARCH", "MENU", "LANGUAGES", and a lock icon. Below the navigation bar is a header for "Program Operations Manual System (POMS)".

Effective Dates: 03/28/2018 - Present

Previous
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DI 23022.600 Angelman Syndrome

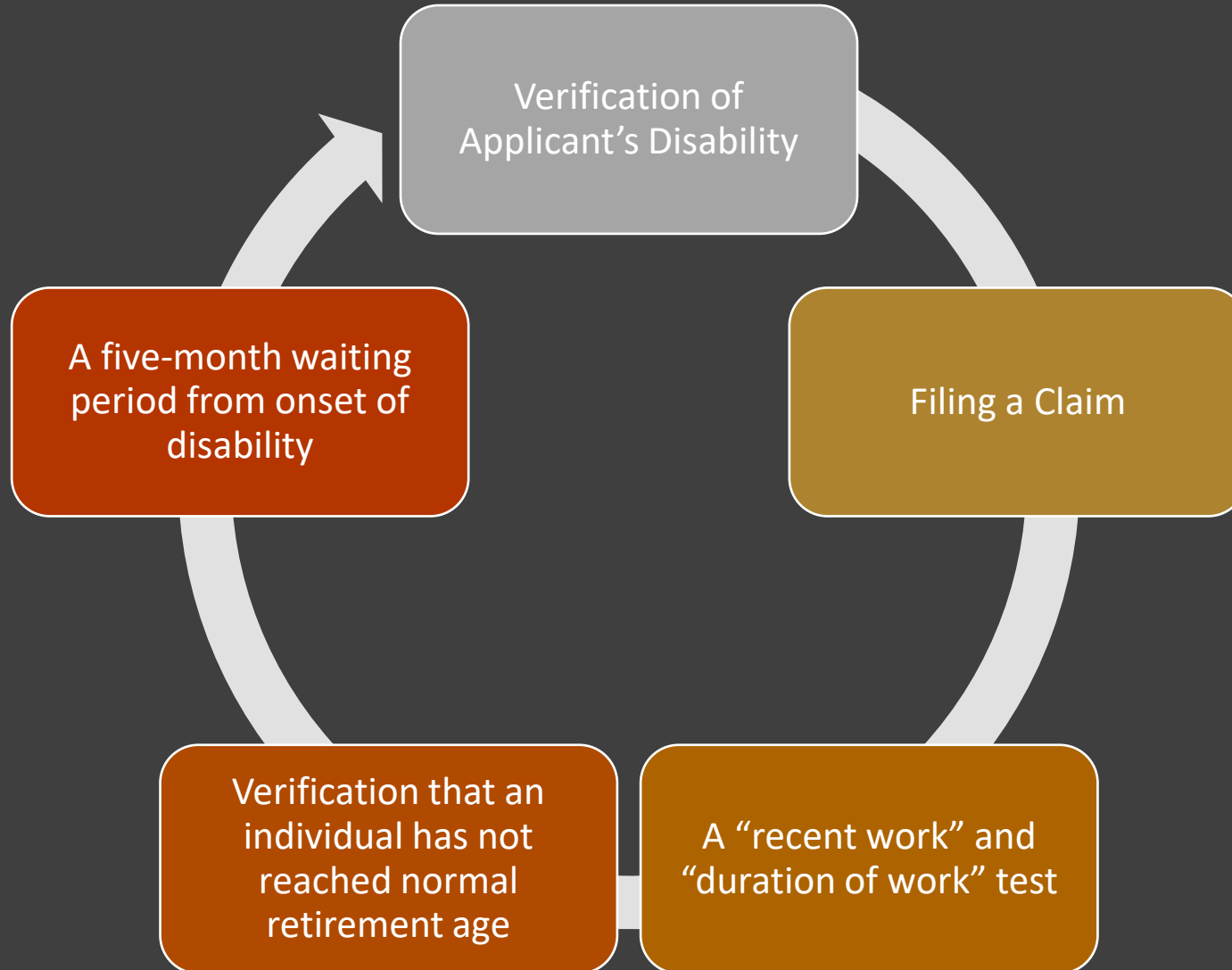
COMPASSIONATE ALLOWANCE INFORMATION

	ANGELMAN SYNDROME
ALTERNATE NAMES	AS
DESCRIPTION	Angelman Syndrome (AS) is a rare genetic neurological disorder that involves deletion of chromosome 15q and mutation of the UBE3A gene. It is characterized by developmental delay, intellectual disability, severe speech impairment with limited vocabulary (usually consisting of less than 10 words), small head size (microcephaly), hypotonia (reduced muscle strength), scoliosis (curved or crooked spine), and ataxia (difficulties with coordination, balance and spasticity). Some children with this disorder experience recurrent seizures varying from major motor to a sudden brief lapse in muscle tone (akinetic). Children with AS are described as generally happy with an excitable demeanor and frequent smiling, laughter, and hand-flapping movements. Hyperactivity and a short

Government Benefits (SSI and SSDI)

- Both SSI and SSDI are governmental 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 SSDI is only available to workers earning enough “work credits” with Social Security.
- While SSI disability benefits are available (based on income levels) regardless of whether they have earned sufficient work credits
- SSDI provides income replacement for eligible individuals who are not able to work for at least one year or longer

SSDI Eligibility Requirements



Payments on Average through SSDI



Lower Level

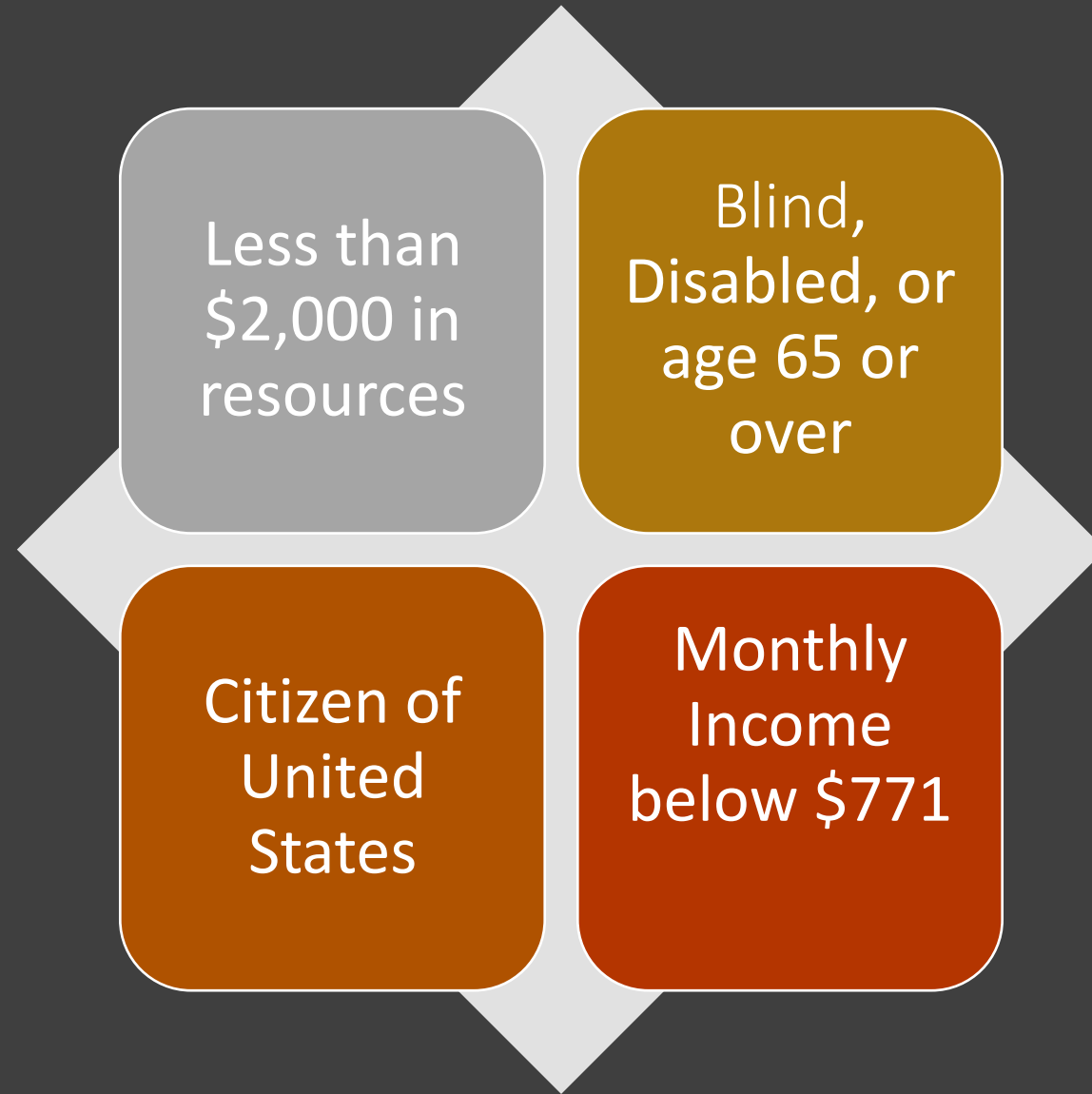
\$300



Upper Level

\$1,800 (max \$2,861)

SSI Eligibility Requirements



How much does SSI Pay Monthly in 2020

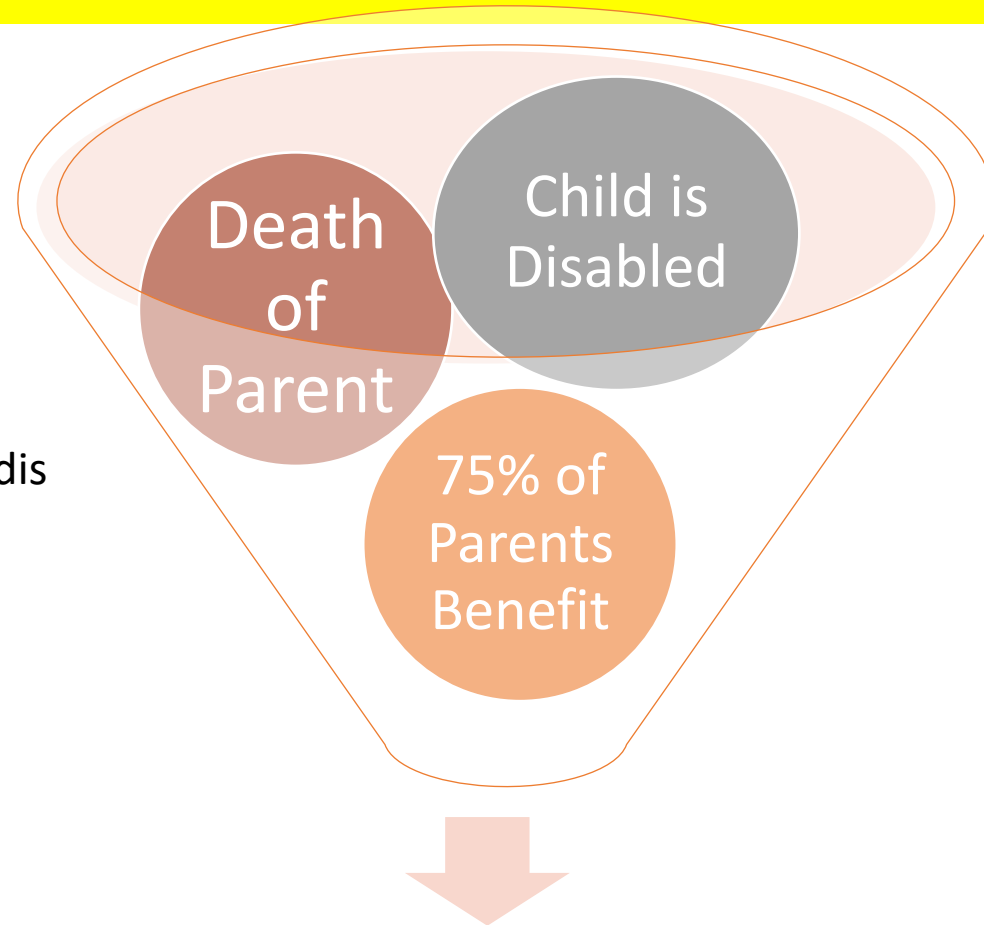
2020
\$783



**C.O.L.A.
Annually**

**Increased
Benefit
Annually**

Other Considerations for Social Security – Example of Parent with Maximum Benefit



Source 2020 SSA
<https://www.ssa.gov/planners/disability/family.html>


Example
\$783 SSI
+75% of ***max*** SSB
(2,842.5)
=\$3,625.50
monthly
payments to child

Total being no more than 150-180 percent total family benefit

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 at <https://www.medicaid.gov/state-overviews/index.html>



Medicaid Waivers 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:

<https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.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
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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 payments for residential supports along with funding for 24/7 residential care including staffed residences
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Levels of Waivers, Waiting Lists, and Advocacy


The focus of Home and Community Based Services Waivers is to provide support and services within the individual's community

- There are typically two ways to receive supports and services
- Traditional Provider – An agency who coordinates care along with all supports and services
- Person Directed – 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 “person directed” allows an individual with 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 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; \$92,040).

- 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
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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

Mandatory Federal Benefits to Consumers

- 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



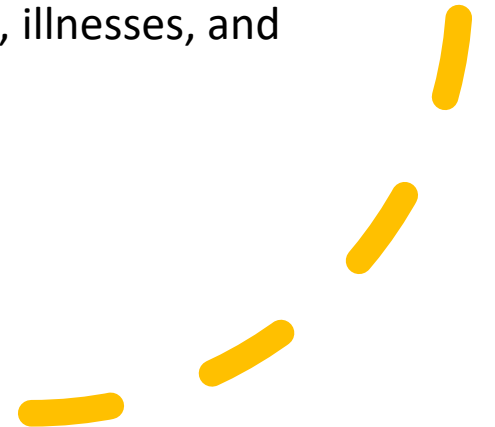
Medicaid and Children 0-21 EPSDT

- E.arly
 - and
- P.eriodic
- S.creeening
- D.iagnosis
- T.reatment
- PROGRAM



E.P.S.D.T. – Described

“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)



Advocacy and Agencies

- ARC of the US with State Chapters
- Councils on Developmental Disabilities
- Protection and Advocacy Councils
- University Centers of Excellence in Developmental Disabilities Education, Research and Service (UCEDD)

The Future of Medicaid

- Three things in life are constant
 - Change – Change is coming but we are not sure just how it will impact individuals with Angelman Syndrome
 - Choice – We have a choice to advocate. Advocacy is standing up for those who may not be able to speak for themselves. “Nothing About Us Without Us!”
 - Principle – What is your story?

July
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Questions

Time to Share

