

Insurance, Advocacy, and Resources

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Objectives of the Presentation

Have

- Families will have a better understanding of health insurance benefits specific to individuals and families impacted by Angelman Syndrome

Be

- Families will be better equipped to advocate for access to health insurance benefits and therefore improve the overall quality of life of beneficiaries

Have

- Families 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 health insurance needs



Angelman and Developmental Disability



COMPASSIONATE ALLOWANCE

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



Primary and Secondary Insurance

(Private and Medicaid)

Private Insurance and Autism

- ▶ Individuals with Angelman Syndrome have a high rate of Autism – Steffenburg et al (1996)
- ▶ Large group insurance providers are mandated to provide ABA therapy for individuals with autism – Barner (2009)
- ▶ Check your state regulations at the below websites:
 - ▶ <https://www.appliedbehavioranalysisedu.org/state-by-state-guide-to-autism-insurance-laws/>
 - ▶ <https://www.ncsl.org/health/autism-and-insurance-coverage-state-laws>
 - ▶ <https://www.stepaheadaba.com/blog/does-insurance-cover-aba-therapy-for-autism>



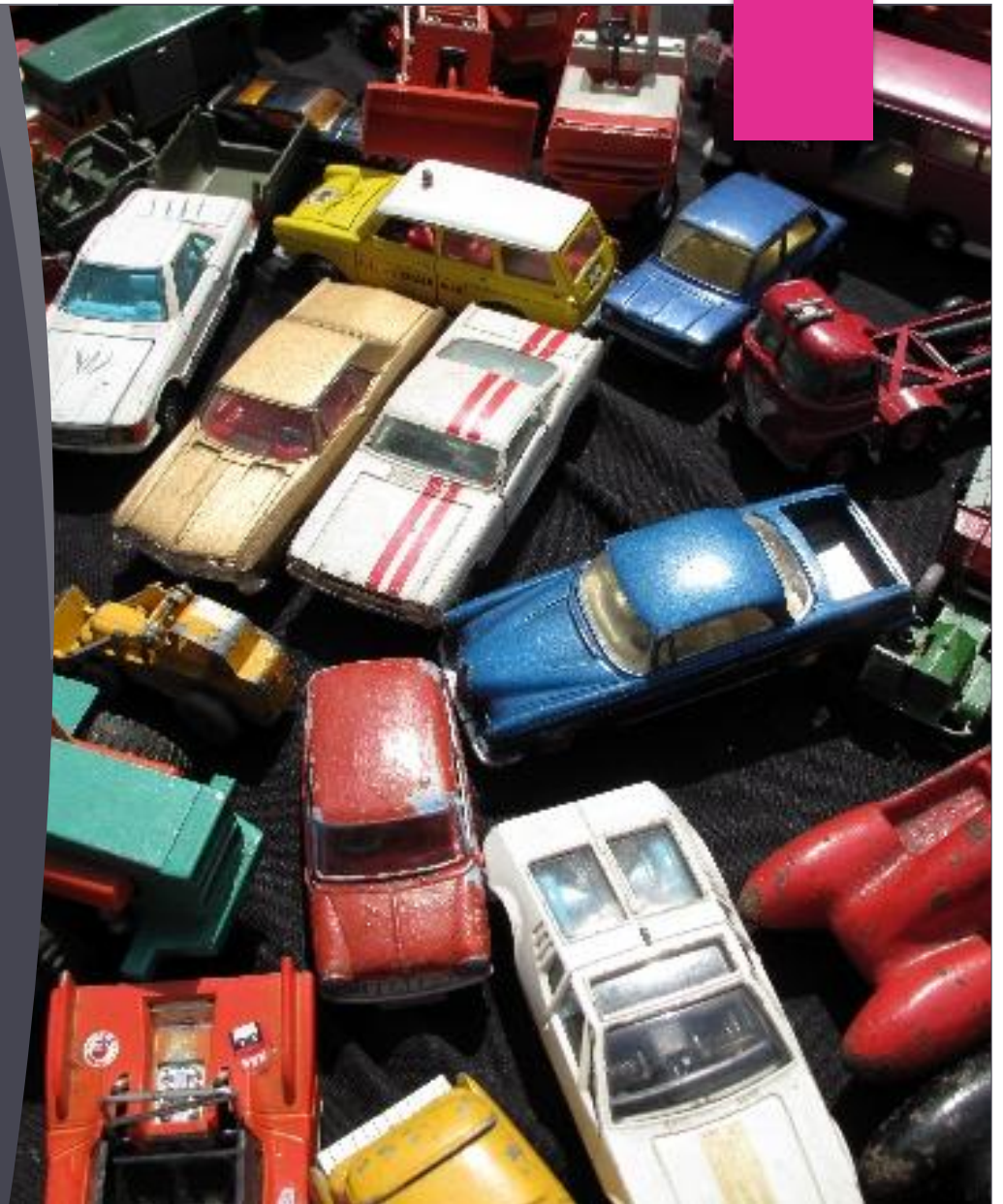
Medicaid and Angelman Syndrome

- ▶ 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:
<https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/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

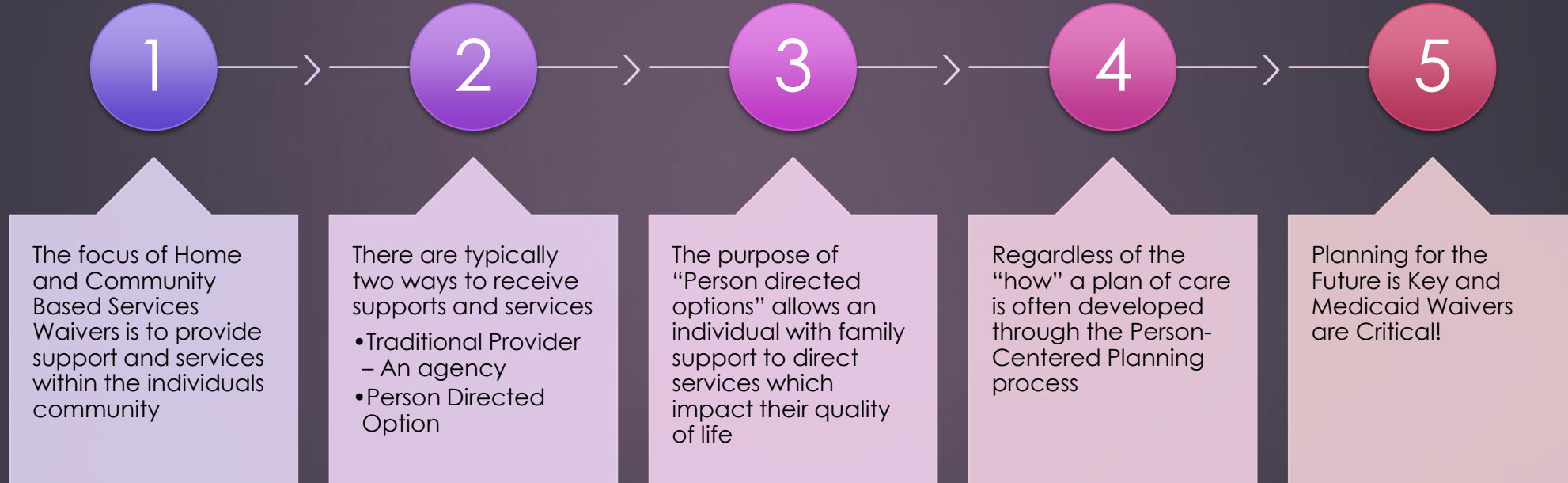


Levels of Waivers, Waiting Lists, and Advocacy

- ▶ 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



Additional Medicaid Information

Waiver eligibility varies state by state. Some states apply the 300% above Federal Poverty Rate (e.g., family of five \$104,790).

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

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

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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 Programs

HIPP

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.

Question
What if I get a
denial from
insurance?
Answers
Include:
A.ppeal
S.eek Help
S.olve Problem

- ▶ A.S.S. Acronym – You don't have to be an ASS but let them know you will be a pain in theirs until you get what your child/loved one needs.
- ▶ A. Appeal using resources at your fingertips (i.e., write letters, use Artificial Intelligence, get Medical Necessity Letters from Providers)
- ▶ S. Seek Help – Ask another parent, guardian, or advocacy group in your community. Talk with your insurance provider and ask about process and coverage. Reach out to your state legislators for help. Find community resources in your area which help with medical needs (i.e., United Way, Shriners)
- ▶ S.earch to Solve Problem – Be present in the moment and take care of yourself to help you take care of your loved ones. Show perseverance and resilience by searching and searching.

A.ppeal

Example of AI generated Appeal letter.

Anthem Blue Cross and Blue Shield
[Insurance Company Address]
[City, State, ZIP Code]

Subject: Appeal for Coverage of Safety Sleeper for [Your Daughter's Name]

Dear [Insurance Company Representative],

I am writing to formally appeal the denial of coverage for a Safety Sleeper for my daughter, [Your Daughter's Name], who has been diagnosed with Angelman Syndrome. This specialized bed is not merely a convenience but a medical necessity for her safety and well-being.

Angelman Syndrome is a rare neuro-genetic disorder characterized by severe developmental delays, lack of speech, seizures, and walking and balance disorders. Due to these challenges, [Your Daughter's Name] is at significant risk of injury during sleep. She has a history of nocturnal seizures and frequent nighttime wandering, which pose serious safety concerns.

The Safety Sleeper provides a secure and enclosed environment that prevents falls and wandering, ensuring [Your Daughter's Name]'s safety throughout the night. This equipment is essential in preventing injuries and providing peace of mind for our family. Without it, we face constant anxiety and the potential for serious harm to our daughter.

We have consulted with [Your Daughter's Name]'s healthcare providers, including her neurologist and occupational therapist, who have all recommended the Safety Sleeper as a critical component of her care plan. Enclosed are letters of medical necessity from her healthcare team, detailing the importance of this equipment for her safety and health.

I respectfully request that you reconsider your decision and approve coverage for the Safety Sleeper. This equipment is vital for [Your Daughter's Name]'s safety and quality of life. We appreciate your understanding and prompt attention to this urgent matter.

Thank you for your time and consideration.

Sincerely,

S. Seek Help DD Councils and 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

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.

Search to Solve Problem

*Search AI

*Search Google

*Search on Social Media Groups

*Search AS Websites

*Search...Search...
Search

Here are some resources that might help you secure coverage for a Safety Sleeper for your child with Angelman Syndrome:

1. ****Angelman Syndrome Foundation****: They provide detailed guidance on how to secure insurance coverage for a Safety Sleeper. This includes tips on preparing your support system, obtaining a letter of medical necessity, and navigating the appeals process[1] (<https://www.angelman.org/articles/insurance-coverage-for-safety-bed/>).
2. ****Abram's Nation****: The manufacturer of The Safety Sleeper offers customer support to help families with insurance claims. You can contact their Customer Care team at 724-96-SLEEP or email customercare@abramsnation.com for assistance[1] (<https://www.angelman.org/articles/insurance-coverage-for-safety-bed/>).
3. ****Safe Sleep Systems****: This resource offers information on various safe sleep products, including enclosed beds and other specialized equipment that might be suitable for children with Angelman Syndrome[2] (<https://www.angelman.org/resources/safe-sleep-systems/>).

Thank you!

