

MEDICAID HOME CARE

Protect Vital Services for Angelman Families



What is Angelman syndrome?

Angelman syndrome (AS) is a rare disease affecting 1 in 15,000 people. Individuals with AS suffer a nearly universal absence of verbal speech, motor impairment, seizures, and other severely debilitating symptoms. Individuals with AS also suffer from balance and coordination disorders and some are unable to walk. Some individuals with AS exhibit severe anxiety due to their inability to communicate effectively. Many individuals with AS have a hard time falling asleep or staying asleep. Individuals with Angelman syndrome have a typical life expectancy but require lifelong, around-the-clock support for daily needs such as feeding, dressing, and toileting. They are known for their joyful, engaging personalities and are deeply loved by their families and communities.

Why is Medicaid important for people with Angelman syndrome?

Medicaid is essential in supporting the care of individuals with Angelman syndrome, providing critical assistance to families nationwide. For many families, Medicaid helps **cover the services and supports that the individual needs in order to remain at home or in community-based settings**. Medicaid also covers needs that private insurance does not adequately cover, such as complex wheelchairs, prosthetic treatments, home modifications, transportation to medical appointments, and technologies that help people communicate. It is the only insurance that continues to cover intensive services once a child ages out of school-based supports. In a survey of U.S. caregivers, the **annual economic cost associated with caring for a person with AS is close to \$80,000 per year**.¹ Absorbing these costs would be impossible for most AS families without Medicaid.

What are the home and community-based services (HCBS) people with AS need?

Angelman syndrome is a complex condition that requires constant care from loved ones and professionals. Medicaid HCBS makes it possible for individuals to live safely at home and in their communities across their lifespan. Some examples of services include^{2,3}:

- **Assistance with Activities of Daily Living:** With limited vocabulary, and developmental barriers, those with AS require 24/7 care; from sleep management, toileting, difficulty with motor functions such as holding cutlery, assistance from carers is needed. Home care allows for those with AS to be in a safe known environment and get the dedicated attention they require.
- **Medication Management:** There are currently no treatments approved to treat Angelman syndrome, but individuals with AS typically require 3-9 medications per day to treat symptoms such as seizures, sleep issues, and behavioral issues. Medicaid can assist caregivers in managing multiple medications per day.

“... the Katie Beckett waiver has been a lifeline. He would not be where he is now without this critical help. Help with therapies, medication, specialists, testing, literally everything... Even though this funding might not directly help or apply to the majority of people, you never know when your life will be turned upside down and you’ll need this.”

– Mom of child in Georgia

“Medicaid is more than just a healthcare program – it is a lifeline for millions of individuals with disabilities, including my son Chance. At 22 years old, Chance lives with Angelman syndrome, a rare neurogenetic disorder that impacts his ability to walk, communicate, and perform daily tasks independently. Medicaid provides him with the essential support, medical care, and in-home support he needs to thrive.”

– Mom of adult child in Maryland

“Having Medicaid in addition to our private insurance gives us an opportunity to make choices about our son’s health, proactively and in emergency situations, without having to weigh the financial implications of our decisions against the health and well being of our child. This allows caregivers to focus on what’s most important, their child, and not be financially penalized for their decisions.”

– Mom of child in Minnesota.

- **Speech, Language, Occupational and Physical Therapies:** Whether from the condition or a side effect of the symptom treatment, those with Angelman syndrome are doing an average of 3+ therapies per week to ease the burden of the condition. These treatments include speech therapy, physical therapy, and occupational therapy. Physical and occupational therapy helps individuals with AS with mobility and balance issues; speech therapy can help individuals learn sign language, picture communication, or alternate ways to express themselves.
- **Behavioral Health Services:** Individuals with AS often face behavioral health challenges such as aggression, anxiety, impulsivity, hyperactivity and inappropriate hypersocial behavior. Behavioral therapy and mental health services provided by Medicaid can help individuals manage these conditions.
- **Respite Care:** Caregiving for a loved one who requires 24/7 care is a labor of love, but no one can manage it 100% of the time. Respite care provides short-term relief for primary caregivers.⁴

How does Medicaid HCBS work?

Medicaid is a state-federal program with baseline nationwide requirements around eligibility, benefits, and financing. Within the federal rules, states decide which populations, benefits, and services to cover and how to administer their programs. Thus, each of the 56 state, district, and territory Medicaid programs has its own unique features and characteristics.

Individuals with Angelman syndrome typically become eligible for Medicaid due to significant disability.^{5,6} Pathways like the **Katie Beckett waiver** open up Medicaid eligibility for children up to age 19 living at home with significant care needs. Only the child's income and assets are considered for eligibility purposes, which allows some children of higher-income families to qualify.⁷ In 2025, 43 states included a Katie Beckett State Plan or comparable option.⁸

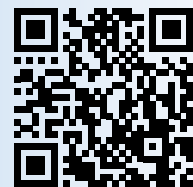
States typically offer Medicaid home care through **waivers, which are optional**. Most commonly, 47 states offer home care for individuals with substantial limitations in activities of daily living through a 1915(c) waiver.⁹

How can we protect access to Medicaid HCBS for people with Angelman syndrome?

Changing federal requirements and funding as well as tightening of state budgets are requiring states to make difficult decisions about Medicaid eligibility and services. Since home care is an optional benefit, states may be compelled to consider cutting or restricting benefits or eligibility. Families caring for an individual with AS may also face administrative challenges to maintain eligibility as eligibility and paperwork requirements change. **We urge policymakers to protect access to Medicaid HCBS services for people with Angelman syndrome:**

- **Protect eligibility:** Continue to support eligibility pathways that allow individuals with AS to qualify for Medicaid, including those specifically designed for children with special health care needs like the Katie Beckett waiver.
- **Protect benefits and services:** Continue to support Medicaid home care benefits provided through HCBS waivers.
- **Ensure benefits are accessible:** Avoid policies that would result in less or delayed access to care, such as provider payment cuts and excessive administrative burden and paperwork for families.

To better understand Angelman syndrome, and the needs of the community, watch this **“Day in the Life”**, showing the lives of three families with AS.



WHO ARE WE?

The **Angelman Syndrome Foundation (ASF)** and the **Foundation for Angelman Syndrome Therapeutics (FAST)** are two organizations united in their commitment to making a significant impact in the Angelman syndrome community. Together, ASF and FAST combine their strengths and expertise, creating a powerful force that drives progress, offers support, and seeks cures for Angelman syndrome. Our collaborative efforts epitomize our shared dedication to making a lasting difference in the lives of those we serve.

- ¹ Jarvis, et al. "The economic impact of caregiving for individuals with Angelman syndrome in the United States: results from a caregiver survey". Orphanet Journal of Rare Diseases. 2025. <https://ojrd.biomedcentral.com/articles/10.1186/s13023-025-03551-4>
- ² Mohamad, M., Burns, A., Watts, M. "What is Medicaid Home Care (HCBS)?". Kaiser Family Foundation. February 18, 2025. <https://www.kff.org/medicaid/what-is-medicaid-home-care-hcbs/>
- ³ Peebles et Al. Medicare & Medicaid Research Review, "The HCBS Taxonomy: A New Language for Classifying Home-and-Community Based Services" (2014). MMRR2014_004_03_b01.pdf
- ⁴ NIH National Institute on Aging (NIA). "What is Respite Care?". October 12, 2023. <https://www.nia.nih.gov/health/caregiving/what-respite-care>
- ⁵ Medicaid and CHIP Payment and Access Commission (MACPAC). "Medicaid 101: Eligibility", 2025. <https://www.macpac.gov/medicaid-101/eligibility/>
- ⁶ Medicaid and CHIP Payment and Access Commission (MACPAC). "Children with disabilities", 2018. <https://www.macpac.gov/subtopic/children-with-disabilities/>
- ⁷ Burns A., Mohamed M., and Watts, M. "Medicaid Eligibility Levels for Older Adults and People with Disabilities (Non-MAGI) in 2025". Kaiser Family Foundation. April 7, 2025. <https://www.kff.org/medicaid/medicaid-eligibility-levels-for-older-adults-and-people-with-disabilities-non-magi-in-2025/>
- ⁸ Kaiser Family Foundation. "Medicaid Eligibility for Katie Beckett Children with Significant Disabilities and Special Income Rule", 2025. <https://www.kff.org/medicaid/state-indicator/medicaid-eligibility-for-long-term-care-through-the-special-income-rule/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
- ⁹ Mohamad M., Burns A., Watts, M. "Medicaid Home Care (HCBS) in 2025". Kaiser Family Foundation. January 5, 2026. <https://www.kff.org/medicaid/medicaid-home-care-hcbs-in-2025/>