

MEDICAID MATTERS

Protect Vital Services for Angelman Families



What is Medicaid?

Medicaid provides health insurance coverage for nearly 80 million people in the U.S., including nearly 40 million children. The program helps millions of people with disabilities and chronic conditions get access to long-term services and supports (LTSS).

Medicaid is a federal program with nationwide requirements. Congress sets baseline rules around eligibility and financing that states must follow. Within those rules, states can decide which populations, benefits, and services to cover and how to administer their programs. This means that each of the 56 state, district, and territory Medicaid programs has its own unique features and characteristics.

The federal government and states share responsibility for paying for Medicaid. As a federally protected entitlement, the federal government pays for services for eligible children and adults based on federal and state regulations.

Why is Medicaid important for people with Angelman syndrome?

In a survey conducted by the community, associated medical and daily living costs of Angelman syndrome (AS) are estimated to be around \$80,000 per year.¹ Medicaid helps people with AS throughout their lifetime to get the care they need to protect their health and well-being. Medicaid is essential in supporting the care of most individuals with Angelman syndrome, providing critical assistance to families nationwide by:

- Covering essential health services for children with disabilities or other special health care needs.
- Often covering needs that private insurance does not adequately cover, such as complex wheelchairs, prosthetics, treatments, and technologies that help people communicate and live in the community.
- For many people with Angelman syndrome, Medicaid is their only source of funding for LTSS to enable them to live at home with their families and community.²

Congress Must Protect Medicaid

Proposals that cut or limit Medicaid funding, eligibility, or vital services will put those with Angelman syndrome at risk of losing benefits they depend on every day for their health, safety, development, and independence. We urge Congress to reject proposals that would disrupt Medicaid services in the states.

“... 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.

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 The Katie Beckett waiver provides Medicaid coverage for home-based care for children with serious conditions who would otherwise qualify for institutional care. In 2024, KFF reported 43 states included a Katie Beckett State Plan or comparable option. [Medicaid Eligibility for Katie Beckett Children with Significant Disabilities and Special Income Rule | KFF](#)