



POLICY INSIGHT SERIES

NATIONAL AUTISM INDICATORS REPORT:

Introduction to Medicaid and Autism

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DREXEL UNIVERSITY

A.J. Drexel

Autism Institute





Policy Insight Series

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A publication of the Policy and Analytics Center at the A.J. Drexel Autism Institute

Medicaid is the largest source of public health insurance in the U.S. In 2018, Medicaid provided public health insurance for 97 million low-income citizens in the U.S. [including 9 million people with disabilities of all ages](#). In 2020, nearly one in every five people in the U.S. were ensured by Medicaid.

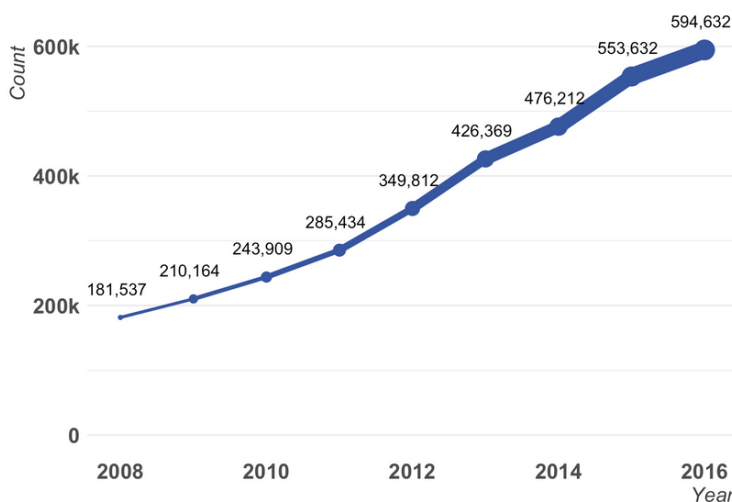
Medicaid is important for autistic people and their family members. Yet, we know that autistic people and their families face difficulties navigating the process to enroll in Medicaid and then accessing the services Medicaid covers. While there are many publications that explain [basic facts about Medicaid](#), and information about [Medicaid for autistic individuals](#), few focus on the how autistic people use this public insurance or on what services Medicaid covers for children, youth, and adults on the autism spectrum. This report explores these topics using data from the Centers for Medicaid and Medicare Services (CMS) from 2008–2016.

Medicaid is a critical public benefit for an increasing number of autistic people.

The number of autistic individuals who are enrolled in Medicaid has steadily increased over time. In 2008, there were about 182,000 people with a diagnosis of autism spectrum disorder in Medicaid claims. This number climbed to nearly 600,000 by 2016. The increase in autistic Medicaid enrollees is no surprise, since the [prevalence of autism in the U.S.](#) has also been increasing since monitoring began in 2000.

Approximately [one in three children on the autism spectrum live in very low-income households](#) and may qualify for public health insurance, as compared to one in four children with special health care needs, and one in five children without special needs. Many autistic adults are unemployed or are employed in low-paying jobs that do not offer health insurance benefits. Therefore, Medicaid is a critical public benefit for this population.

The number of autistic people enrolled in Medicaid **more than tripled** between 2008 and 2016.



Autistic people must meet eligibility criteria in their state to receive Medicaid benefits.

Medicaid is an entitlement program, which means that anyone who meets certain eligibility rules has a right to enroll in and receive Medicaid healthcare coverage. States set qualification criteria that are based on income, disability, and other factors.

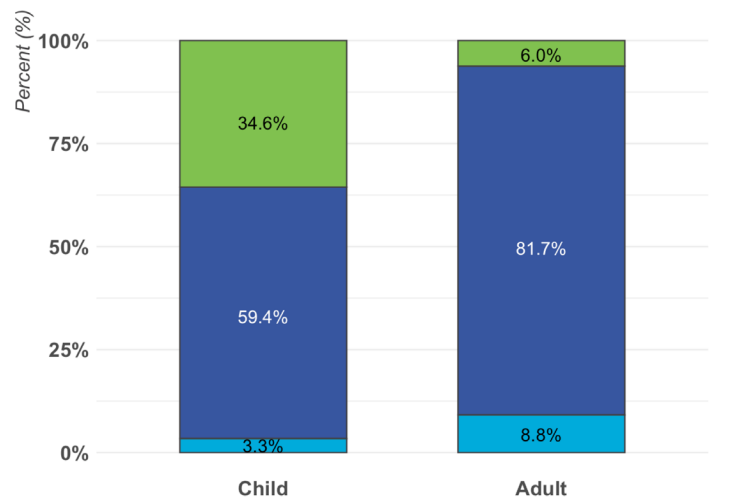
States must cover certain “mandatory” or required populations including:

- Children up until 18 years of age who live in a low-income household
- People who are pregnant and have a low income
- Certain parents or caretakers with very low income; and
- Most seniors and people with disabilities who receive cash assistance through the Supplemental Security Income (SSI) program

Autistic people are not always automatically eligible for Medicaid. They must qualify in the same way as other people with and without disabilities. Most autistic adults qualify for Medicaid based on their disability, and many children also qualify based on disability. Only a small percentage of autistic adults and children qualify for Medicaid based on their own income (for adults) or that of their parents (for children). People can also be eligible for other reasons. Each state can set its own criteria for how adults and children qualify for Medicaid, such as being in foster care or having certain medical conditions. It is sometimes easier for people who have autism and co-occurring intellectual disability to qualify for Medicaid, because [eligibility criteria in some states may require an intellectual disability](#).

One problem with Medicaid is that people’s eligibility can change from month to month, as a person’s income changes. Each state sets a limit for how much

Most autistic people were eligible for Medicaid based on **disability** than **poverty** or **other** reasons.



money (financial assets) a person can have and still keep their Medicaid benefits. If a person makes extra money in a month, they might get “kicked off” of Medicaid for that month. A person may be eligible for Medicaid for most of the year but have a few months in which they lose Medicaid benefits and do not have this public insurance. This is referred to as “churn” in and out of Medicaid eligibility.

Medicaid differs by state. Some states have less restrictive eligibility requirements that make it easier for residents to qualify for Medicaid benefits. States also differ in the types of services they cover through Medicaid. All states receive federal matching funds to help finance what they spend on Medicaid. But each state has a different federal match rate for Medicaid, and some states spend more on Medicaid per beneficiary.

Medicaid covers a wide range of services autistic people need.

Medicaid covers health care and services for autistic children, adults, and their family members, if they meet eligibility criteria. These services support autistic people to live and work in their communities. Medicaid can also cover services provided in more

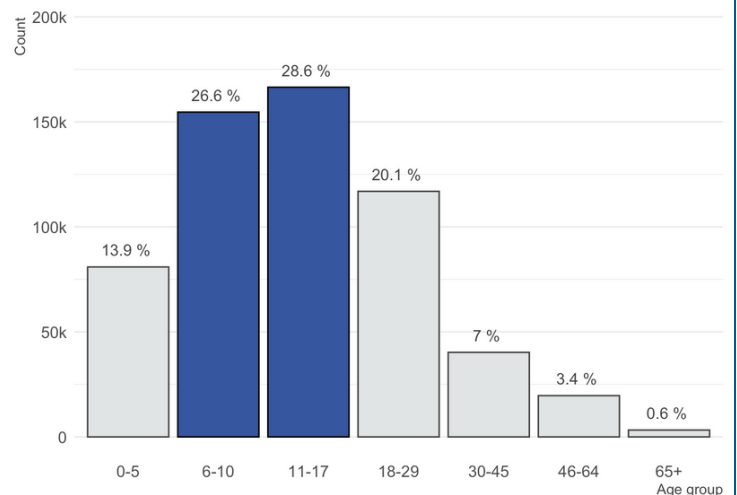
restrictive settings – like hospitals, psychiatric facilities, or institutional care settings. Some states also use Medicaid to pay for mental health (such as psychological care) and behavioral health services (such as treatment for substance use disorders).

Autistic people of all ages use Medicaid, but more than half are school-age youth.

Nearly half of autistic children receive coverage through public health insurance like Medicaid. Medicaid offers a benefit called **Early Periodic Screening, Diagnosis and Treatment (EPSDT)** for children and adolescents under age 21. EPSDT services are more generous than the adult Medicaid program, because they are intended to provide early diagnosis and treatment of health and developmental conditions. States are required to inform families of the availability of EPSDT including physical, mental, vision, hearing, and dental services. Despite these benefits, though, Medicaid-enrolled children tend to be receive a later autism diagnosis, after age five, even though diagnosis is possible at the age of two years.

The EPSDT benefit can pay for services beyond what a state typically provides through Medicaid, as long as there is a prescription from a physician showing that the service is medically necessary to prevent worsening of a disability or illness. EPSDT covers the costs of evaluations and services like speech, occupational and physical therapies, and inpatient psychiatric care in hospitals and treatment facilities, if deemed medically necessary by a health care provider. Applied behavior analysis (ABA) is a common behavioral intervention for autism, but states are not specifically required to provide ABA through the EPSDT benefit, as there are many other types of behavioral interventions. Instead, states must consider a range of behavioral interventions

Most autistic Medicaid enrollees in 2016 were between **6 and 17** years of age.



in determining which ones their EPSDT program will cover. If a state does not cover ABA, it still must provide comparable services that target the same outcomes.

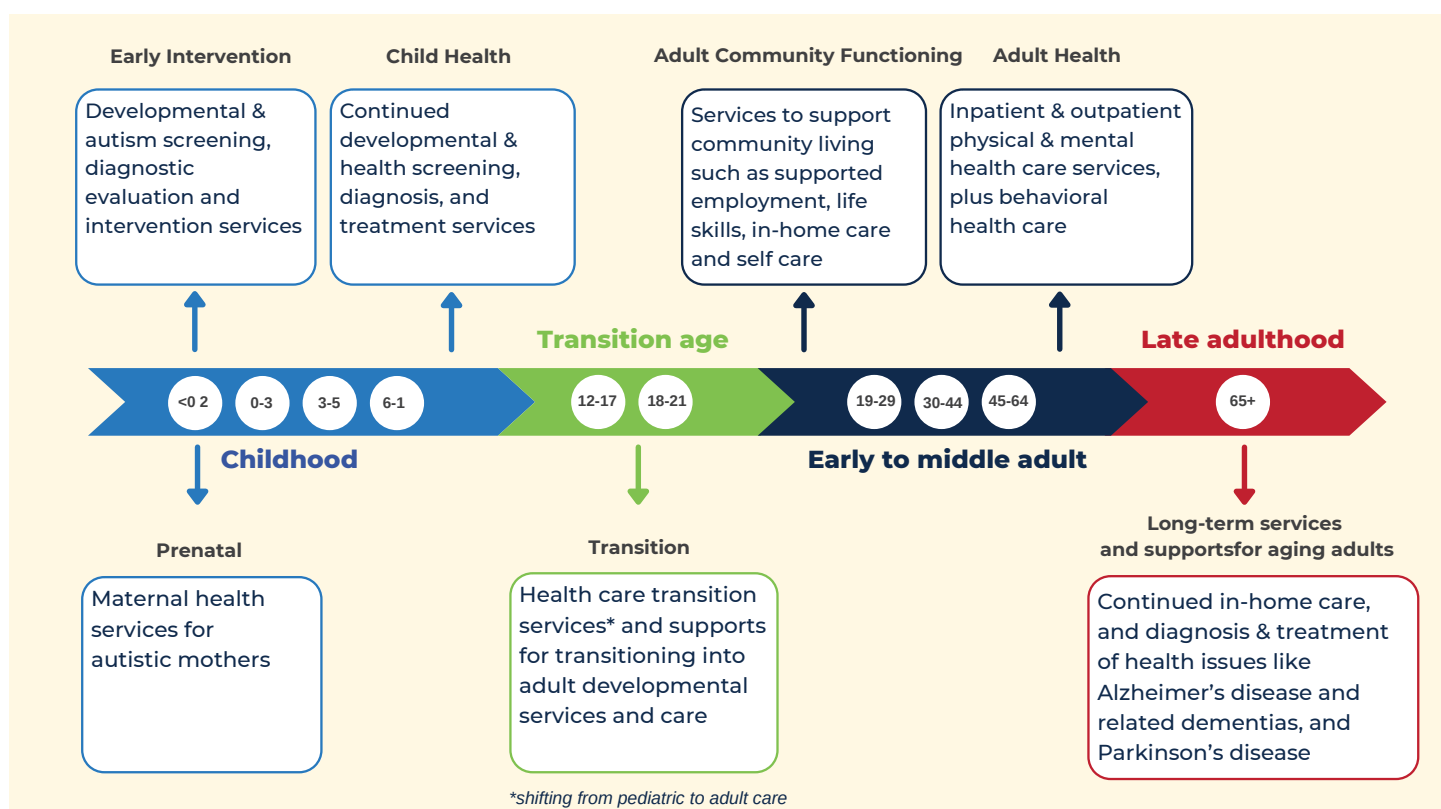
EPSDT is especially important for children with developmental disabilities like autism, because private insurance is often inadequate to meet their needs.

Enrollment declines sharply at 18 years of age.

There is a sharp drop-off in Medicaid enrollment once children on the autism spectrum reach the age of 18. At this age, individuals must requalify for Medicaid. This means youth are required to be reassessed for Medicaid eligibility as an individual adult, rather than as a member of a family. To requalify for Medicaid, adults must have a diagnosis such as autism that interferes with their ability to work, and they must earn below a certain level of

income (and have assets below a certain amount set by the state). Eligibility criteria, such as income levels and functional limitations, vary from state to state. For families, navigating the process of re-determining eligibility can be complex and confusing. [One in four autistic youth lose their Medicaid coverage as they enter adulthood, and only half regain it.](#)

The focus of the services Medicaid covers for autistic people changes across the lifespan.



This infographic shows how Medicaid covers services for autistic people across the lifespan, particularly children. Children and young adults under age 21 can receive Early Periodic Screening, Diagnostic and Treatment (EPSDT) services that are considered medically necessary to ensure people are able to function to the best of their abilities, and to support health. In addition, home- and community-based services (HCBS) are available through Medicaid waivers to provide services and supports that assist children and adults with autism to live in the community. These services include screening and assessment, various therapies, life skills, employment services, and other forms of outpatient treatment.

Disparities exist in service access and utilization among Medicaid enrollees.

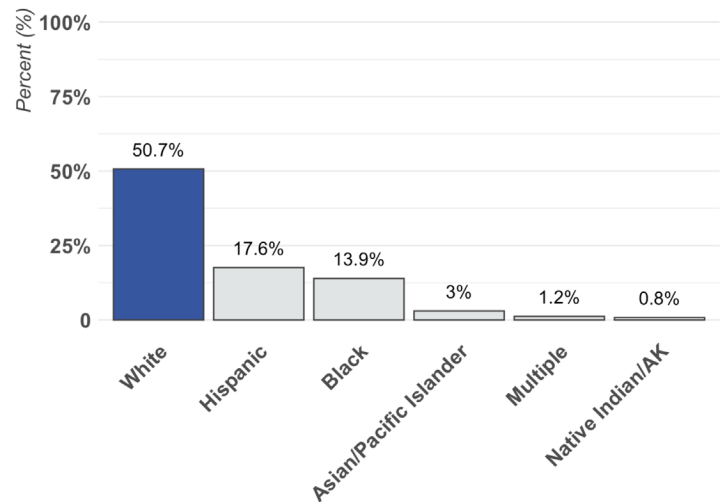
Even though the purpose of public health insurance like Medicaid is to reduce disparities in access to essential health services, not all people may be able to equally access and use these health services. These [differences in health care reflect underlying inequities that stem from racism and discrimination](#). Health and health care disparities exist in the general population but are also evident in health care experiences of autistic people.

In the 2016 Medicaid data, more autistic Medicaid enrollees were white. About 18% were Hispanic, and 14% were Black. Demographics reflected the [general population in the 2016 U.S. Census](#); although the percentage of Asian/Pacific Islanders was lower among autistic Medicaid enrollees. Disparities do exist in access to and use of health and developmental services among autistic Medicaid enrollees. For example, autistic children and adults of color enrolled in Medicaid are [less likely to receive services like occupational therapy](#) than their white peers.

Autistic Medicaid enrollees may be more likely to have some co-occurring health conditions, similar to those seen in the general population by race and ethnicity. [Autistic Medicaid beneficiaries who are Black, Hispanic or Asian are more likely to have diabetes](#), and Black or Hispanic autistic Medicaid beneficiaries are more likely to be obese and have related conditions like nutrition issues.

In some states, such as [North Carolina](#), children and adults of color with intellectual disability or autism are less likely to receive IDD waiver benefits compared with non-Hispanic whites. In a study of autistic adults on a waiting list for autism waiver access in Pennsylvania, Black autistic people had greater unmet needs for services. (See next section for an explanation of waivers.)

The race and ethnicity of autistic Medicaid enrollees was similar to the demographics of the general population in the 2016 U.S. Census. Over half were **white**.



Note: 12.8% of claims were missing race or ethnicity data.

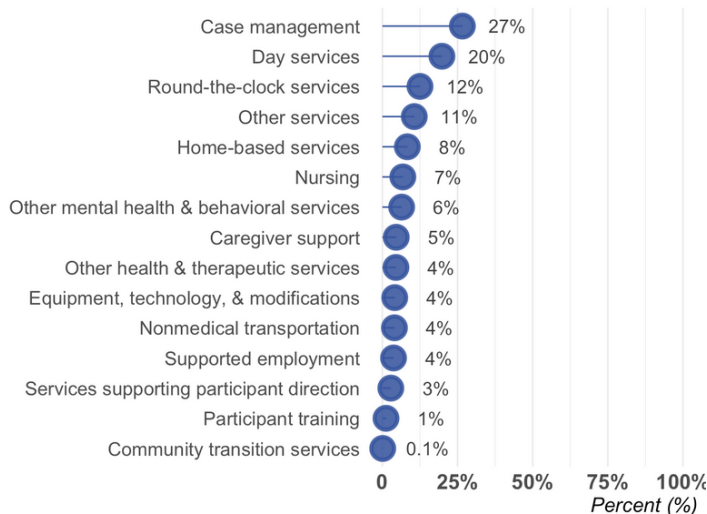
Some autistic people qualify for both Medicaid and Medicare benefits. These added Medicare benefits can help offset the costs of Medicaid by paying for Medicaid premiums. [One of the few studies to investigate dual-eligibility among autistic people](#) found that Black autistic children and adults were less likely to be dual-eligible than their white peers.

Medicaid waivers fund services that assist people with developmental disabilities to live, work and play in their communities.

Medicaid waivers are special arrangements that allow a state to deliver **home and community-based services (HCBS)** to support a disabled person to function in their community. HCBS waivers cover services beyond what is usually covered by Medicaid. Waiver services are meant to help avoid placements in long-term care facilities. States often have several different waivers for people with autism and other developmental disabilities, and each may offer different types of services targeting different needs. For example, HCBS waivers might provide coverage for job coaching, transportation to work and medical appointments, or supports for community living.

Some states use Medicaid waivers to provide both individual and **family supports** to assist families who are supporting an individual with a disability in the family home or in other settings. Families might receive assistance to apply for state and/or federal benefits, as well as support to plan for transitions their youth will make in the future (such as transitioning from pediatric to adult health care, and transitioning from school into employment and adulthood). [Indiana's Family Supports Waiver](#) allows *family & caregiver training* services, as well as a limited amount of yearly respite services, which permit family members to take a short break from their caregiving responsibilities. [Maryland's Family Supports Waiver](#) includes respite care in addition to providing *family and peer mentoring supports* from other parents/caregivers with shared experiences, and family and caregiver training and empowerment services to educate and support the family caregiver to increase their ability to provide care. Other waivers may also provide family supports. For example, [Maryland's Waivers for Children with Autism Spectrum Disorder](#) provide family consultation services. [Pennsylvania's Person/Family Directed](#)

Among autistic adults enrolled in a Medicaid waiver in 2016, the most common home and community-based services were case management and day services. Overall, few autistic waiver enrollees received these types of services.

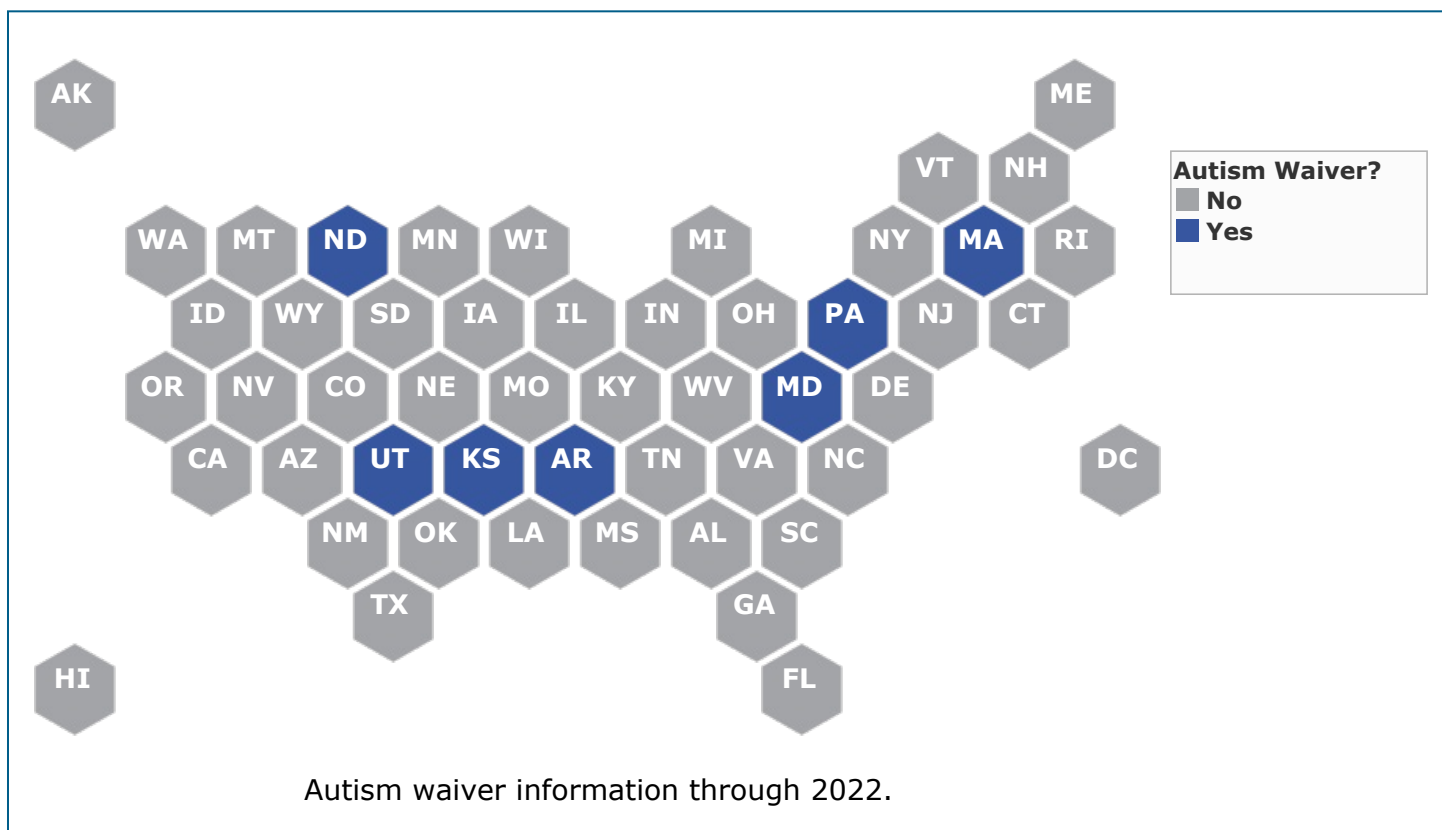


[Support Waiver](#) also provides *family medical support assistance* – a person who can support the family with coordinating and scheduling medical appointments, nursing services and other in-home supports, as well as interfacing with insurance providers, and training support people about the individual's service plan.

Pennsylvania is the only state that provides an autism-specific Medicaid waiver for adults.

Pennsylvania's Adult Autism Waiver is offered to adults who are at least 21 years old and have autism. Recipients of the Adult Autism Waiver must be assessed and determined eligible for Medicaid, as well as meet certain income requirements, which are determined separately by each county. Services covered by the waiver include assistive technology, career planning, community transition services, day habilitation, family support, home modifications, nutritional consultation, residential habilitation, respite, and employment.

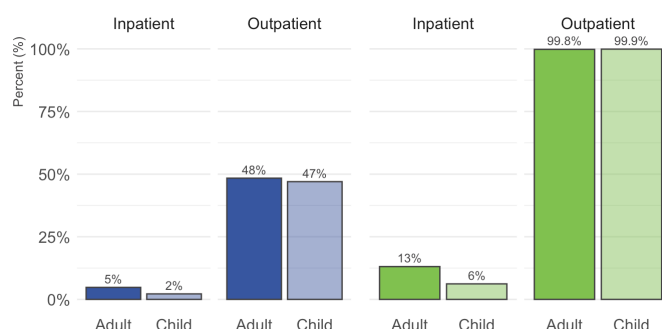
Autistic people are usually served under Medicaid waivers that are designed for people with intellectual and developmental disabilities. But some states have designated “autism waivers” that only serve autistic people. Most of these waivers are designed to serve children, and Pennsylvania is the only state with an adult autism waiver.



What types of Medicaid-funded health services do autistic people use?

Medicaid covers costs of both inpatient and outpatient services for physical and mental health. **Most Medicaid-funded services for autistic children and adults were outpatient services for physical health.** Across settings, for both physical and mental health, expenditures for adult care were higher than expenditures for children.

Most child and adult Medicaid-funded services were for **physical health** in an outpatient setting, and far fewer received **mental health** services.



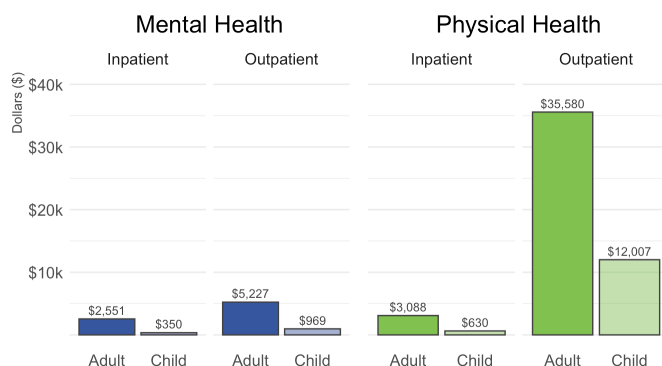
Medicaid funds services delivered in both community-based and institutional care (facility-based) settings. [Community-based services could include](#) medical visits at doctor's offices, life skills lessons at a service agency or at home, employment supports delivered at a job site, and other forms of outpatient treatment are funded using HCBS waivers.

Institutional services could include hospitals or psychiatric facilities, group homes or larger institutions where people live and work, nursing homes, or work facilities that primarily employ people with disabilities. **Hospitals were the most common setting for autistic adults who received institutional care funded by Medicaid.**

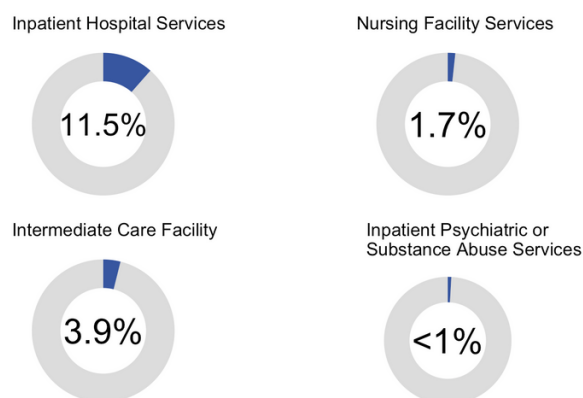
Case management and day services (to support daytime activities usually in facility-based care) were the most common HCBS services among autistic adults.

Medicaid also covers **long-term services and supports (LTSS)** including medical care, care coordination, and assistance with activities of daily living (ADLs). ADLs are everyday tasks such as eating,

Adult costs were at least three times that of child costs.



Among autistic Medicaid enrollees who received services in institutional settings, the majority received care in inpatient hospital settings.



meal preparation, bathing, dressing, medication management, and transportation. Services are available to help in each of these areas and are provided in the least restrictive setting possible. Services can be provided in an individual’s home, at a nursing or daycare facility, via transportation services, or as part of employment support. LTSS are

sometimes provided in institutional care but are also paid for with HCBS waivers.

It is common for adults over age 65 to use LTSS, but **no published research has explored how older autistic adults use LTSS.**

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How can we better support the critical role of Medicaid for autistic people and their family members?

Improving the care experiences and health outcomes of autistic individuals who use Medicaid-funded services involves a complex and critically important set of policy issues. Our **Policy Brief on Supporting the Critical Role of Medicaid for Autistic People**

and their Family Members highlights 10 key issues, policy recommendations, and questions that state policymakers and others can ask to learn more about Medicaid for people on the autism spectrum in their state.

10 Key Policy Issues

- 1 Navigating Medicaid eligibility is complex and confusing.
- 2 Access to services is affected by a lack of providers who accept Medicaid.
- 3 Medicaid waivers provide coverage for essential services, but few states have autism-specific waivers.
- 4 People with multiple service needs report remaining on waitlists for Medicaid waiver services for many years.
- 5 We lack Medicaid providers who are competent in serving autistic people.
- 6 Disparities in access to Medicaid and service utilization
- 7 Developmental disability services, largely funded by Medicaid waivers, tend to fund facility-based services more than community-based services.
- 8 Little is known about how autistic adults use long-term services and supports, especially as they age.
- 9 There is a lack of supports for unpaid family caregivers.
- 10 State policies that tie Medicaid eligibility to work requirements are problematic for autistic adults.

About this Report

The *National Autism Indicators Report: Introduction to Medicaid and Autism* is a publication of the Policy and Analytics Center at the A.J. Drexel Autism Institute, Drexel University.

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