

NEWS

Medicaid waivers curb disenrollment among autistic young adults

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Autistic young adults in the United States are more likely to lose their Medicaid coverage if they live in a state that doesn't provide waivers than if they live in one that does, according to a new [study](#).

Some states use the waivers to extend services to people with a disability who, because of their income, might otherwise be ineligible for Medicaid — a government-funded health insurance program for people with low income in the U.S. Some autistic children and adults qualify for Medicaid regardless of income, but each state has its own criteria.

“A subset of autistic adults rely on income requirements for Medicaid,” says study investigator [Lindsay Shea](#), director of the Policy and Analytics Center at the A.J. Drexel Autism Institute in Philadelphia, Pennsylvania.

One in four autistic adolescents disenrolls from Medicaid coverage when they turn 18, and only half of them regain the coverage later, Shea showed in a 2021 [study](#).

For the new work, Shea and her colleagues examined how the likelihood of disenrollment varies with the availability of a 1915(c) waiver, which covers home- and community-based services for people in a particular target group — in this case, those with intellectual disability or autism.

Among nearly 134,000 autistic people aged 14 to 26 who were enrolled in Medicaid from 2008 to 2016 — across 47 states and Washington, D.C. — about 119,000 remained enrolled by the time they turned 26, whereas nearly 15,000 had disenrolled. (The study excluded three states — Arizona, Rhode Island and Vermont — that use the Social Security Act instead of waivers to provide care.)

The probability that an autistic person disenrolled between ages 14 and 21 was similar across all states. But at age 22, the probability of disenrollment increased by more than 13 percent in states without 1915(c) waivers while remaining stable in states with the waivers.

The findings suggest that the waivers are necessary to retain these youth as they transition into adulthood, says **Joel Cantor**, distinguished professor of public policy at Rutgers University in New Brunswick, New Jersey, who was not involved in the study.

The findings were published in *JAMA Network Open* in March.

About one-third of the 14- to 26-year-olds who disenrolled were actually still eligible for Medicaid services due to their income level, the new study also found.

“A good proportion of them were eligible for Medicaid due to low income in the month before they experienced disenrollment,” says lead investigator **Meghan Carey**, a graduate student at Drexel.

Some people simply might not have the time to complete the paperwork needed to keep themselves enrolled, even when they are eligible, Cantor says. Autistic people should be able to access Medicaid based on their diagnosis, rather than their income level, which often changes, says **Deborah Spitalnik**, professor of pediatrics at Rutgers Robert Wood Johnson Medical School, who was not involved in the study.

“If you are in the disability pathway, you will have more recognition of your service needs” than one does if they’re receiving Medicaid based on income alone, Spitalnik says.

Since the expiration of the pandemic-related Medicaid coverage on 30 March, things stand to become more complicated, Shea says. When the pandemic began, the federal government paused income requirements for Medicaid. But once the emergency period ended, those requirements went back into effect.

“Changes in these rules have introduced confusion nationally,” Shea says. “It is unclear what information is available to autistic adults across state Medicaid programs.”

Shea and her colleagues plan to continue to investigate Medicaid enrollment patterns, focusing on the age at which the transition into adulthood brings elevated risks, Shea says.

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