

Medicaid is a vital lifeline for adults with Down syndrome, study finds

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Life expectancy has increased substantially for people in the United States with Down syndrome, from a median age of 4 years old [in the 1950s](#) to 57 years old [in 2019](#). This longer life span increases the need

for adequate health care into adulthood for this population, the majority of whom are at high risk of developing Alzheimer's disease or related dementias and other chronic health conditions as they age.

Almost all adults with Down syndrome are enrolled in Medicaid, but there is very little knowledge about how this population with high health care needs actually utilizes health care services. A new study led by a Boston University School of Public Health researcher (BUSPH) is the first to explore this subject among a nationally and racially representative group of more than 120,000 people with Down syndrome.

[Published in the journal *JAMA Health Forum*](#), the study found that individuals with Down syndrome were more consistently enrolled in Medicaid and utilized more health care services than people with no developmental disabilities.

The findings also shed light on racial disparities within this population, showing that White people with Down syndrome have greater access to and utilization of health care services than other racial and ethnic groups. The study underscores Medicaid's critical role in the health and well-being of adults with Down syndrome, while also identifying subgroups of this population that are lacking equitable care.

"The Down syndrome population has not been enumerated like this before," says study lead and corresponding author Eric Rubenstein, assistant professor of epidemiology at BUSPH. Full-time employment—which usually leads to [private health insurance](#)—is rare among people with Down syndrome, so this analysis of Medicaid utilization represents almost all US adults with this genetic condition, he says.

"As more people with Down syndrome survive to older ages, the Medicaid system needs to be ready to serve this population with tailored,

sensitive, and comprehensive care."

For the study, Rubenstein and colleagues from BUSPH and Massachusetts General Hospital (MGH) utilized federal health data to examine Medicaid enrollment, health care usage, and costs among 123,000 adults ages 18 and older with Down syndrome, 1.2 million adults with intellectual disabilities but not Down syndrome, and 6 million adults with no diagnosis of developmental disabilities from 2011 to 2019.

For people with Down syndrome, median enrollment in Medicaid was eight years and median health care costs were nearly four-fold, compared to people with no developmental disabilities. The team did not find substantial differences within these measurements among individuals with Down syndrome and individuals with different intellectual disabilities.

Most adults with Down syndrome are automatically enrolled in Medicaid through Social Security Insurance, so they are much less likely to be ineligible or disenrolled from the safety net insurance program. However, the study showed that Asian, Black, Native American, and Pacific Islander adults with Down syndrome had lower Medicaid claims and costs than their White counterparts, suggesting that barriers to health care are still present among subgroups of this population.

"In our work, we see higher costs and claims among White enrollees, but less in-patient hospitalizations and fewer chronic conditions," Rubenstein says. "We think this points to White enrollees having better access to care, receiving more preventative health services, and having additional Medicaid benefits such as home and community-based service waivers."

He says the team is in the process of examining whether distance to

Down syndrome specialty clinics, which may serve a higher socioeconomic group, are associated with these outcomes.

More information: Eric Rubenstein et al, Medicaid Enrollment and Service Use Among Adults With Down Syndrome, *JAMA Health Forum* (2023). [DOI: 10.1001/jamahealthforum.2023.2320](https://doi.org/10.1001/jamahealthforum.2023.2320)

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