

Why GAO Did This Study

Medicaid is the nation's primary payer of long-term services and supports, including HCBS programs, for individuals with intellectual or developmental disabilities. Medicaid spending for these services was estimated at \$23 billion in fiscal year 2018, the most recent year of nationwide estimates available. States are permitted to limit enrollment in certain HCBS programs and establish waiting lists. Research has shown people with intellectual or developmental disabilities comprised the majority of individuals on waiting lists for HCBS programs as of 2021, with wait times averaging over 5 years.

GAO was asked to provide information about the characteristics and health care expenditures among Medicaid beneficiaries with intellectual or developmental disabilities with long-term care needs. For selected states, this report describes (1) health and demographic characteristics, and (2) health care expenditures for adults with intellectual or developmental disabilities enrolled in Medicaid HCBS programs in 2019.

GAO analyzed Medicaid data for 2019, the most recent finalized year of data that preceded the COVID-19 pandemic, for six states. States were selected based on, among other things, having at least one HCBS program covering nonelderly adults with intellectual or developmental disabilities in 2019, and having data in the federal Medicaid data system of sufficient detail and quality to conduct analysis.

View [GAO-23-105457](#). For more information, contact Jessica Farb at (202) 512-7114 or farbj@gao.gov.

MEDICAID

Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities

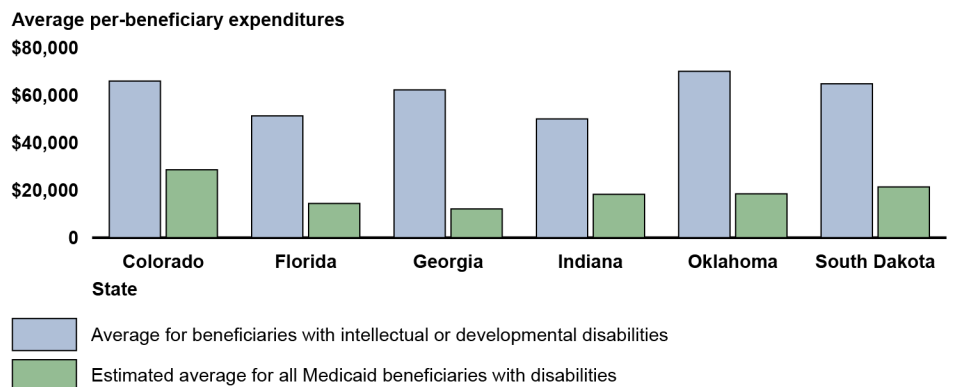
What GAO Found

Intellectual or developmental disabilities, such as Down syndrome, are conditions that are present from childhood that may result in difficulties with learning, problem solving, and using everyday life skills. Medicaid home- and community-based services (HCBS) programs provide a range of services that can help individuals with these disabilities with daily activities, such as eating and bathing.

Reviewing Medicaid data for six selected states, GAO found that over 45 percent of beneficiaries with intellectual or developmental disabilities enrolled in HCBS programs had an additional health condition in 2019. Health conditions included behavioral health conditions, such as anxiety disorders, and chronic physical conditions, such as high blood pressure. Among beneficiaries enrolled in comprehensive HCBS programs, which cover round-the-clock care, the prevalence of behavioral health conditions was higher than in the overall Medicaid population.

GAO's analysis found that average per-beneficiary Medicaid expenditures in 2019 for beneficiaries with intellectual or developmental disabilities in selected states ranged from about \$51,000 to \$70,000. This is two to five times higher than the average expenditure for all Medicaid beneficiaries with disabilities.

Average Per-Beneficiary Medicaid Expenditures, 2019



Source: GAO analysis of Centers for Medicare & Medicaid Services data. | GAO-23-105457

GAO's analysis also found for 2019:

- **HCBS expenditures lower than institutional costs:** Average HCBS program expenditures were generally lower than states' estimated costs for serving beneficiaries with intellectual or developmental disabilities in institutional settings.
- **Expenditures higher for beneficiaries with additional health conditions:** Expenditures were generally higher for beneficiaries with intellectual or developmental disabilities who had additional health conditions. For example, in comprehensive HCBS programs, expenditures were 13 to 40 percent higher for beneficiaries with a behavioral health condition than for those without.