



April 2023

# MEDICAID

## Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities

## 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](mailto:farbj@gao.gov).

## MEDICAID

### Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities

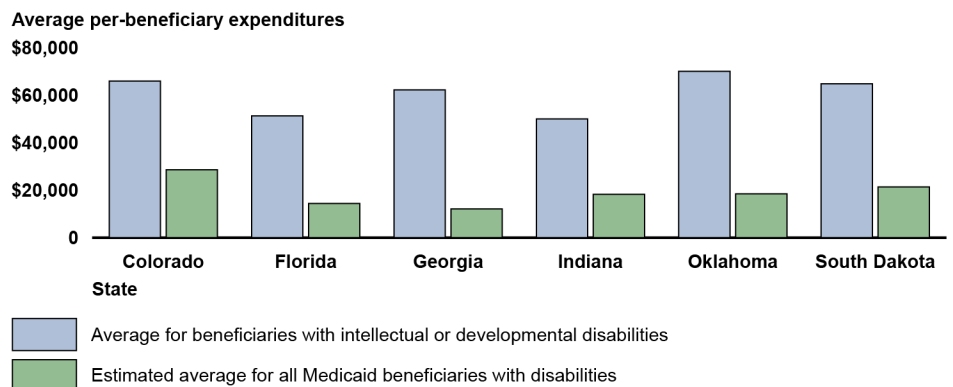
## What GAO Found

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.

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## Abbreviations

CMS	Centers for Medicare & Medicaid Services
HCBS	home- and community-based services
I/DD	intellectual or developmental disabilities
T-MSIS	Transformed Medicaid Statistical Information System

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April 24, 2023

The Honorable Cathy McMorris Rodgers  
Chair  
Committee on Energy and Commerce  
House of Representatives

The Honorable Brett Guthrie  
Chair  
Subcommittee on Health  
Committee on Energy and Commerce  
House of Representatives

Intellectual and developmental disabilities (I/DD) comprise a range of conditions that are present from childhood that can require lifelong care and support. Examples of I/DD include Down syndrome and autism spectrum disorder—conditions that may result in difficulties with learning, problem solving, and the ability to acquire and use everyday life skills.

Medicaid plays an important role in supporting individuals with I/DD to maintain their quality of life. In particular, long-term services and supports provided through Medicaid encompass a broad set of health care, personal care, and supportive services that can help individuals with I/DD perform routine daily activities, such as eating, dressing, and bathing. Medicaid is the nation’s primary payer of long-term services and supports for individuals with I/DD, with estimated nationwide expenditures of about \$23 billion in fiscal year 2018.<sup>1</sup>

Many individuals prefer to receive long-term services and supports in home- and community-based settings, rather than institutional settings, because it can help them maintain their independence and participate in community life to the fullest extent possible. Long-term services and supports delivered outside of institutional settings are known as home- and community-based services (HCBS), and include adult day care, personal care services, and services provided in assisted living. In 2019, states reported there were over 900,000 beneficiaries with I/DD enrolled

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<sup>1</sup>Fiscal year 2018 is the most recent spending estimate available for individuals with I/DD. See Caitlin Murray et al., *Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018* (Mathematica, 2021).

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in Medicaid HCBS programs.<sup>2</sup> Since fiscal year 2001, more than half of Medicaid long-term services and supports spending for individuals with I/DD has been for HCBS, and this proportion has continued to grow over time.

Providing most HCBS is optional, and states have flexibility in designing HCBS programs within broad federal guidelines, including what populations are eligible and what services are covered. States commonly seek approval from the Centers for Medicare & Medicaid Services (CMS), the Department of Health and Human Services agency that oversees Medicaid at the federal level, to provide HCBS under what are referred to as 1915(c) waivers.<sup>3</sup> Under these waiver programs—referred to in this report as HCBS programs—states are permitted to, among other things, target individuals with I/DD and limit the number of beneficiaries served by establishing a predefined enrollment cap.<sup>4</sup> States with enrollment caps may establish a waiting list.<sup>5</sup> A nationwide survey of state Medicaid officials estimated that there were over 650,000 individuals on such waiting lists in 2021. While the survey’s authors caution that waiting lists are imperfect measures of unmet need, the survey found that almost

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<sup>2</sup>Estimate based on nationwide survey of state directors of I/DD programs for state fiscal year 2019. See Residential Information Systems Project, “Medicaid HCBS Spending in FY 2019” (Minneapolis, Minn.: University of Minnesota), accessed January 23, 2023, <https://publications.ici.umn.edu/risp/infographics/medicaid-waiver-recipients-and-expenditures>.

<sup>3</sup>1915(c) waivers, named for the statutory provision authorizing them in the Social Security Act, are the primary means by which states provide HCBS, accounting for over half of HCBS spending in 2019. See Caitlin Murray et al., *Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019* (Mathematica, 2021).

<sup>4</sup>States may also provide certain HCBS through their Medicaid state plan, or through other waivers or demonstrations, but these other authorities are outside the scope of this report. A Medicaid state plan describes the groups of individuals to be covered; the methods for calculating payments to providers, including which types of providers are eligible to receive payments; and the categories of services covered, such as inpatient hospital services.

<sup>5</sup>States must generally serve up to the number of individuals specified in their enrollment caps prior to placing individuals on waiting lists. States also have the option to seek approval from CMS to raise their enrollment caps.



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three quarters of individuals on waiting lists were individuals with I/DD.<sup>6</sup> Wait times for these individuals averaged over 5 years.

Given the unmet demand for HCBS and the need to manage program costs, you asked us to provide information about the characteristics and health care expenditures among Medicaid beneficiaries with I/DD who have long-term care needs. This report describes

1. the health and demographic characteristics of adults with I/DD enrolled in Medicaid HCBS programs in selected states in 2019, and
2. the health care expenditures for adults with I/DD enrolled in Medicaid HCBS programs in selected states in 2019.

To address these objectives, we analyzed Medicaid data for 2019 from six selected states: Colorado, Florida, Georgia, Indiana, Oklahoma, and South Dakota. We selected 2019 because it is the most recent complete and finalized year of data that precedes the COVID-19 pandemic, which affected service utilization and associated expenditures. We selected states that, among other things, (1) had at least one HCBS program covering nonelderly adults (aged 21 through 64 years) with I/DD in 2019; (2) used a fee-for-service delivery model in that year; and (3) had sufficiently reliable data as assessed by CMS for selected variables of interest.<sup>7</sup> Five of our states operated multiple programs for adults with I/DD, and the sixth state, Florida, had one program—all of which were

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<sup>6</sup>According to the Kaiser Family Foundation, waiting lists are an imperfect measure of unmet need for long-term services and supports, in part, because not all states screen individuals on their waiting lists for eligibility. See Alice Burns, Molly O'Malley Watts, and Meghana Ammula, *A Look at Waiting lists for Home and Community-Based Services from 2016 to 2021* (San Francisco, Calif.: Kaiser Family Foundation, 2022). The report also notes that individuals on waiting lists may be able to receive other types of HCBS.

<sup>7</sup>States can choose among delivery systems, such as fee-for-service and managed care, to provide HCBS. Under fee-for-service, states pay providers directly and on a retrospective basis for each covered service they deliver. In contrast, under managed care, states contract with managed care organizations to provide a specific set of covered services to beneficiaries in return for one fixed periodic payment per beneficiary, typically per member per month. We selected fee-for-service programs because provider payment information is included in T-MSIS and available for analysis. States were not required to report payment amounts for services paid for by managed care organizations in T-MSIS until June 2019.

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included in our analyses.<sup>8</sup> (See app. I for more information about these programs.)

To describe characteristics of, and Medicaid expenditures for, adults with I/DD enrolled in Medicaid HCBS programs, we analyzed data from CMS's Transformed Medicaid Statistical Information System (T-MSIS) for selected states, including enrollment, service utilization, and payment data for 2019. Data were extracted from T-MSIS Analytic Files, which are a series of research-ready analytic files CMS created to support analysis, research, and data-driven decisions on key Medicaid topics, as well as program oversight.<sup>9</sup>

We assessed the reliability of T-MSIS data by interviewing knowledgeable federal and state officials; reviewing related documentation, such as studies that assessed the completeness and quality of Medicaid data; comparing the results of our analysis to published figures from CMS, and testing the data for logical errors. We excluded states from certain analyses when their data were missing or otherwise unreliable. Based on data reliability assessment, we determined that the data were sufficiently reliable for the purposes of our reporting objectives. (See app. II for further details on our scope and methodology, including our data reliability assessment.)

We conducted our performance audit from October 2021 through April 2023 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

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## Background

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<sup>8</sup>Colorado, Georgia, Indiana, and South Dakota each had two HCBS programs that served adults with I/DD in 2019. Oklahoma had three programs. However, due to similarities in two of Oklahoma's programs, we treated these two programs as one for the purpose of our analysis. Including Florida's single program, we analyzed a total of 11 programs.

<sup>9</sup>For the purposes of our report, we refer to the data in the T-MSIS Analytic Files as T-MSIS data.

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## Intellectual and Developmental Disabilities

Intellectual and developmental disabilities include a range of conditions, present from childhood, that impair intellectual functioning, adaptive behaviors—learned skills needed for everyday living—or both. Examples of I/DD include autism spectrum disorder, cerebral palsy, and Down syndrome. Although there are no national data on the prevalence of I/DD in the U.S., a research study estimated that there were over 7 million individuals with I/DD in the U.S. as of June 2018.<sup>10</sup>

According to a study commissioned by the Medicaid and CHIP Payment and Access Commission, individuals with I/DD may incur greater health care costs due to the intensity of supports needed, which go beyond those generally needed by older adults and individuals with physical disabilities.<sup>11</sup> While older adults and individuals with physical disabilities commonly need assistance with activities of daily living, such as bathing and dressing, and instrumental activities of daily living, such as managing money, individuals with I/DD have other needs in addition to those. Examples include supervision and cueing to complete tasks, employment-related services, and behavior support services.<sup>12</sup>

Individuals with I/DD may also have other health conditions that require treatment and monitoring. For example, research has indicated that individuals with I/DD may experience a greater prevalence of behavioral health conditions—mental health and substance use disorders—than the general population.<sup>13</sup> As noted in a Medicaid and CHIP Payment and

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<sup>10</sup>The estimated number of individuals with I/DD is based on calculations using I/DD prevalence rates from two federal surveys, Census data, and data on individuals with I/DD living in congregate settings. See Sheryl Larson et al., *Long-term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2018* (Minneapolis, Minn.: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2021).

<sup>11</sup>See Health Management Associates, *Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences, Report to the Medicaid and CHIP Payment and Access Commission* (October 2020).

<sup>12</sup>Behavior support services generally refers to services designed to increase positive behaviors, decrease challenging behaviors, and teach new skills.

<sup>13</sup>While the exact prevalence of mental health conditions among individuals with I/DD is not known, a study based on 2017 and 2018 survey data from 36 states found that 48 percent of individuals with I/DD reported having a mental health condition. See Valerie Bradley et al., “What Do NCI Data Reveal About People Who Are Dual Diagnosed with ID and Mental Illness?,” *National Core Indicators™ Data Brief* (October 2019).

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Access Commission study, a full continuum of services, including behavior support services and behavioral health treatment, is important for individuals dually diagnosed with I/DD and a behavioral health condition, because of the risk of poorer outcomes for those with inadequate treatment. Such outcomes may include traumatic transitions in living situations, inappropriate use of medications to control behavior, and institutionalization.<sup>14</sup>

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## Medicaid Coverage of HCBS

There is no standardized definition of what constitutes HCBS, and states that choose to offer HCBS in their Medicaid programs have flexibility to decide which specific services to cover. In general, HCBS comprise a wide range of services and supports to help individuals remain in or return to their homes or communities. HCBS can include personal care services to provide assistance with activities of daily living or instrumental activities of daily living, adult day care services, and case management to coordinate services and supports. HCBS may also include certain home modifications that allow beneficiaries to remain in their home, non-medical transportation, and respite care for caregivers.<sup>15</sup> A 2014 taxonomy of these services, created by a CMS contractor, grouped the services into a number of categories, such as case management and round-the-clock services.<sup>16</sup> (See fig. 1.)

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By comparison, an estimated 21 percent of adults nationwide experienced a mental health condition, according to 2020 survey data from the Substance Abuse and Mental Health Services Administration. See Substance Abuse and Mental Health Services Administration, Center for Behavioral Health Statistics and Quality, *Key Substance Use and Mental Health Indicators in the United States: Results from the 2020 National Survey on Drug Use and Health*, HHS Publication No. PEP21-07-01-003, NSDUH Series H-56 (Rockville, Md.: 2021).

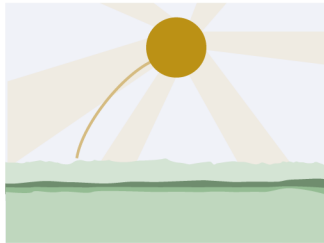
<sup>14</sup>See Health Management Associates, *Medicaid Services for People with Intellectual or Developmental Disabilities*, 32.

<sup>15</sup>Respite care provides a range of services to beneficiaries when unpaid caregivers are absent or need relief.

<sup>16</sup>CMS's contractor used, among other things, expert interviews and analysis of Medicaid claims data, to construct a crosswalk between individual services represented in the claims data to broader categories of HCBS covered by Medicaid programs. The published taxonomy contains 17 service categories. See Victoria Peebles and Alex Bohl, "The HCBS Taxonomy: A New Language for Classifying Home- and Community-Based Services," *Medicare & Medicaid Research Review*, vol. 4, no. 3 (2014).

**Figure 1: Examples of Home- and Community-Based Services Categories**

**HCBS category and examples**



**Day services**

- Day habilitation (regularly scheduled activities to assist in acquiring, retaining, and improving self-help, socialization, and adaptive skills.)



**Home-based services**

- Personal care (assistance with activities of daily living, such as bathing, dressing, and toileting, provided in a person's home and possibly other community settings)
- Homemaker (performance of light housekeeping tasks)



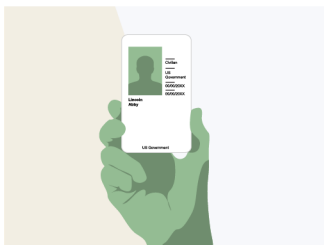
**Mental health and behavior support services**

- Mental health assessment
- Behavior support (services to encourage positive behaviors and to decrease challenging behaviors)
- Counseling



**Round-the-clock services**

- Group home (supervision and assistance with acquiring and retaining skills provided in a home-like environment where multiple people with a disability live)



**Supported employment**

- Assistance to locate and obtain employment
- Assistance to maintain employment
- Career planning

Source: GAO analysis of Centers for Medicare & Medicaid Services information; GAO (illustrations). | GAO-23-105457

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Medicaid allows states to cover a broad range of services for beneficiaries in their HCBS programs, as long as these services are required to prevent institutionalization in a nursing home or other institutional setting. Therefore, to be eligible, individuals must demonstrate the need for an institutional level of care by meeting state eligibility requirements for services in an institutional setting. For individuals with I/DD, institutional care is generally provided in intermediate care facilities for individuals with intellectual disabilities. Further, states' HCBS programs are required by federal law to be cost neutral; that is, states must show that the average Medicaid expenditures for the services provided under the waiver are equal to or less than what average expenditures would be if that same population were to be served in an institutional setting.<sup>17</sup>

States often have multiple HCBS programs within their Medicaid program, for example, to provide specific sets of services to meet the needs of different populations, such as individuals with traumatic brain injury or medically fragile children.<sup>18</sup> Within HCBS programs for individuals with I/DD specifically, states may choose to have more than one HCBS program in order to define sets of services that meet varying levels of need. Many states have established both a program offering a comprehensive array of services and a program with more limited services—referred to in this report as comprehensive and support programs, respectively.<sup>19</sup>

- **Comprehensive programs** target individuals with more complex needs who need residential services, such as services provided in group homes, or who are at greater risk for placement in an intermediate care facility. These HCBS programs cover round-the-clock care for beneficiaries who need it.<sup>20</sup>

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<sup>17</sup>42 U.S.C. § 1396n(c)(2)(D); 42 C.F.R. § 441.302(e) (2021).

<sup>18</sup>Prior to 2014, states were required to have multiple HCBS programs if they chose to target different populations. Beginning in March 2014, CMS permitted states to combine target groups within a single HCBS program, but this option requires the services offered to be the same for all groups.

<sup>19</sup>Although comprehensive and support programs are commonly used terms to describe these program types, CMS officials noted that the Medicaid statute, regulations, and guidance for section 1915(c) programs do not define these program types.

<sup>20</sup>1915(c) waivers do not cover the cost of room and board for the beneficiary.

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- **Support programs** target individuals with I/DD living with family or in their own home, and provide non-residential services and supports. These HCBS programs often impose a cap on spending per beneficiary.

According to the Medicaid and CHIP Payment and Access Commission study, establishing support programs is a way for states to balance the growing need for HCBS program enrollment among individuals with I/DD against budgetary constraints.<sup>21</sup> Support programs provide a more limited set of services and rely on family or other unpaid caregivers to address any remaining needs.

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## Over 45 Percent of Beneficiaries Had Additional Health Conditions; Demographics Were Similar

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### Across Selected States, 47 to 64 Percent of Beneficiaries Had an Additional Behavioral Health or Chronic Physical Health Condition

In five of our six selected states, in 2019, over 45 percent of beneficiaries enrolled in HCBS programs had one or more health conditions in addition to their I/DD diagnosis. The percentages ranged from 47 percent in Indiana to 64 percent in Georgia. Health conditions included behavioral health conditions, such as anxiety disorders, and chronic physical health conditions, such as high blood pressure. The remaining selected state, Florida, was excluded from this analysis due to missing diagnosis codes.<sup>22</sup>

#### Home and Community-Based Services Program Types

Many states have at least two programs that target individuals with intellectual or developmental disabilities.

**Comprehensive programs** target individuals with more complex needs who need residential services and include coverage for round-the-clock care for beneficiaries who need it.

**Support programs** target individuals living with family or in their own homes. They do not include residential services and may have caps on an individual's annual expenditures.

Source: GAO. | GAO-23-105457

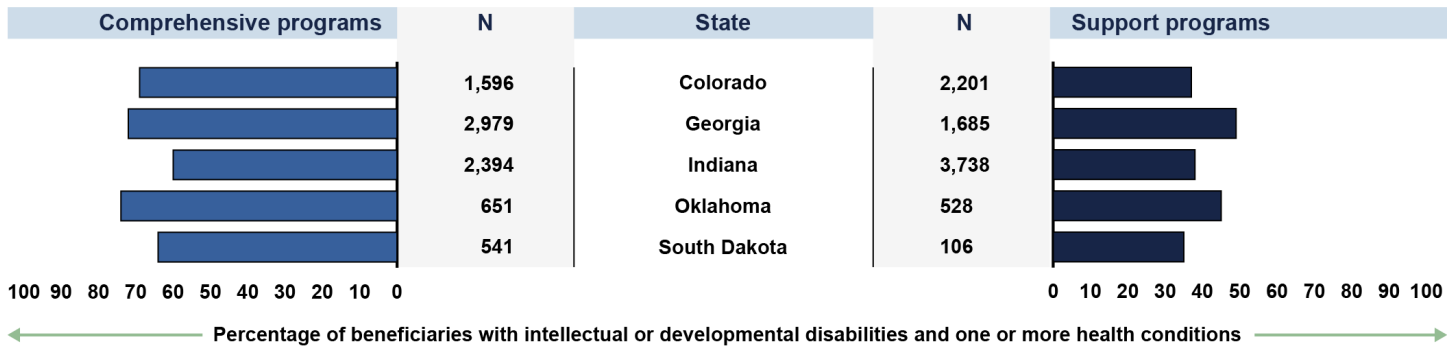
Prevalence of additional health conditions—both behavioral and chronic physical—was substantially higher in comprehensive HCBS programs compared with support programs. (See fig. 2.) This is likely due to the fact that comprehensive programs target beneficiaries with more complex needs.

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<sup>21</sup>See Health Management Associates, *Medicaid Services for People with Intellectual or Developmental Disabilities*, 18.

<sup>22</sup>Florida officials did not identify a reason for the missing diagnosis codes, but said that the issue had been resolved in data for subsequent years.

**Figure 2: Percentage of Beneficiaries with Intellectual or Developmental Disabilities and One or More Additional Health Conditions in Selected States by Program Type, 2019**



*N* refers to the total number of adult beneficiaries with intellectual or developmental disabilities enrolled in each program in 2019

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with intellectual or developmental disabilities in 2019; we excluded beneficiaries who were dually eligible for Medicare. Health conditions included behavioral health and chronic physical health conditions.

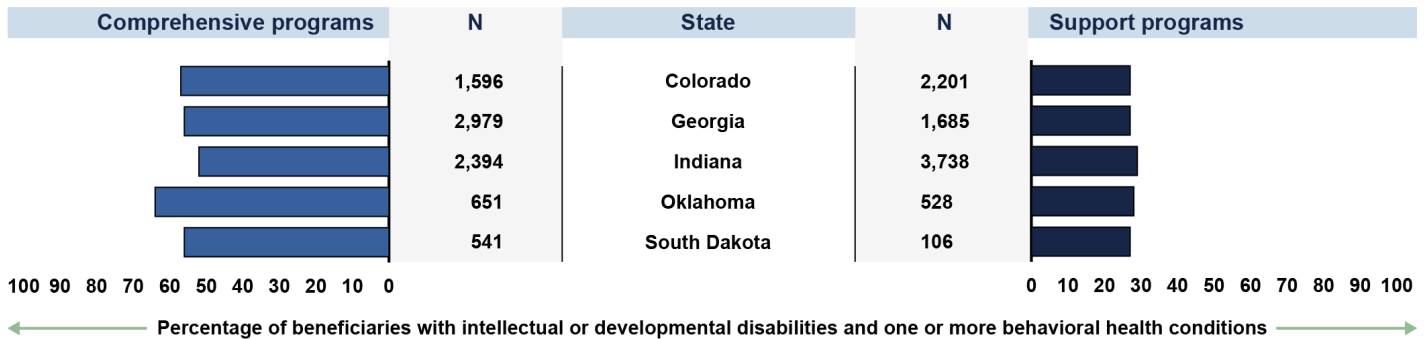
### Behavioral Health Conditions

The prevalence of behavioral health conditions was also higher in comprehensive programs compared with support programs. (See fig. 3.) Prevalence in comprehensive programs, which was over 50 percent in all states, exceeded that of the overall Medicaid population. In 2020, 39 percent of all adult Medicaid beneficiaries were estimated to have at least one behavioral health condition, according to data from the Substance Abuse and Mental Health Services Administration.<sup>23</sup>

<sup>23</sup>Data for the national adult Medicaid population includes Medicaid beneficiaries aged 18 to 64 and is based on self-report survey data from the National Survey of Drug Use and Health, administered annually by the Substance Abuse and Mental Health Services Administration. See Heather Saunders and Robin Rudowitz, "Demographics and Health Insurance Coverage of Nonelderly Adults with Mental Illness and Substance Use Disorders in 2020," Kaiser Family Foundation (San Francisco, Calif.: June 6, 2022), accessed December 16, 2022, <https://www.kff.org/medicaid/issue-brief/demographics-and-health-insurance-coverage-of-nonelderly-adults-with-mental-illness-and-substance-use-disorders-in-2020/>.



**Figure 3: Percentage of Beneficiaries with Intellectual or Developmental Disabilities and One or More Additional Behavioral Health Conditions in Selected States by Program Type, 2019**



*N* refers to the total number of adult beneficiaries with intellectual or developmental disabilities enrolled in each program in 2019

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with intellectual or developmental disabilities in 2019; we excluded beneficiaries who were dually eligible for Medicare. Behavioral health conditions included mental health and substance use disorders.

Of the behavioral health conditions we examined, anxiety disorders, such as panic disorder, were the most common type of behavioral health condition in four of our five selected states with usable diagnosis data: Colorado, Indiana, Oklahoma, and South Dakota. In 2019, from 13 to 21 percent of beneficiaries with I/DD in these states had an anxiety disorder diagnosis. In Georgia, schizophrenia and other psychotic disorders was the most common type of behavioral health condition, affecting 17 percent of beneficiaries with I/DD. (See app. III for additional information on beneficiaries diagnosed with schizophrenia in Georgia.) Attention-deficit/hyperactivity disorder and related conditions, such as conduct disorder, were the second or third-most common behavioral health conditions among beneficiaries with I/DD in all five states.<sup>24</sup>

Across the five selected states, mental health conditions were more common than substance use disorders. While national estimates from the Substance Abuse and Mental Health Services Administration for the adult

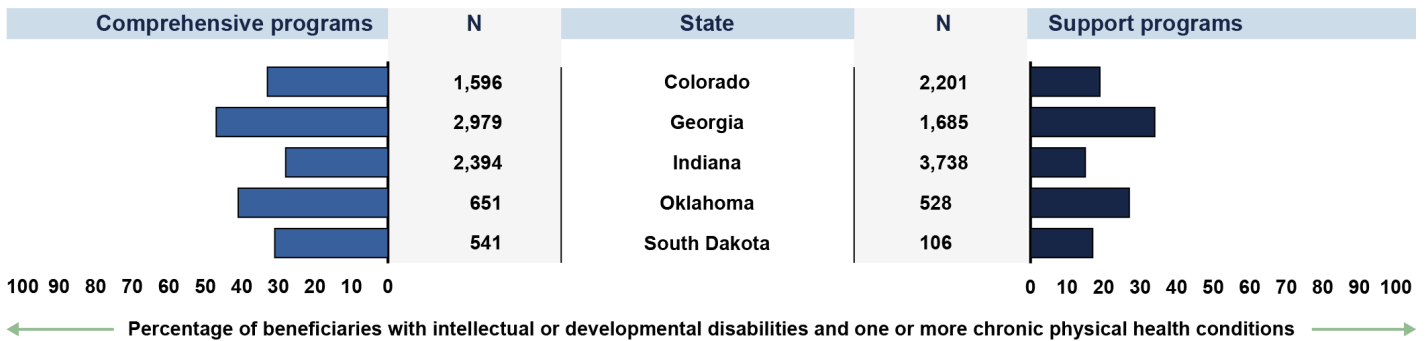
<sup>24</sup>Conduct disorder is a mental health condition characterized by an ongoing pattern of aggressive behavior toward others and violations of rules and social norms.

Medicaid population suggest that about 11 percent had a substance use disorder in 2019, in each of our selected states fewer than 2 percent of beneficiaries with I/DD had an alcohol- or drug-related disorder for that year.<sup>25</sup>

**Chronic Physical Health Conditions**

The prevalence of chronic physical health conditions also varied by program type, with prevalence generally higher in comprehensive programs than in support programs. (See fig. 4.)

**Figure 4: Percentage of Beneficiaries with Intellectual or Developmental Disabilities and One or More Additional Chronic Physical Conditions in Selected States by Program Type, 2019**



*N* refers to the total number of adult beneficiaries with intellectual or developmental disabilities enrolled in each program in 2019

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with intellectual or developmental disabilities in 2019; we excluded beneficiaries who were dually eligible for Medicaid and Medicare. Chronic physical health conditions included diagnoses such as high blood pressure, high cholesterol, and diabetes.

Of the chronic physical health conditions we examined, the two most common among beneficiaries with I/DD in all five of the selected states with usable diagnosis data were high blood pressure (8 to 26 percent of beneficiaries) and high cholesterol (6 to 20 percent of beneficiaries). Diabetes was the third-most common condition in four of the five states:

<sup>25</sup>The estimate for the national adult Medicaid population includes Medicaid beneficiaries aged 18 and older and is based on self-report survey data. See Substance Abuse and Mental Health Services Administration, Center for Behavioral Health Statistics and Quality, *Results from the 2019 National Survey on Drug Use and Health: Detailed Tables* (Rockville, Md.: August 2020): 947.

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Georgia, Indiana, Oklahoma, and South Dakota. In Colorado, chronic lung conditions, such as asthma, were the third-most common chronic physical health condition among beneficiaries with I/DD. (See app. IV for more detailed information on the prevalence of behavioral health and chronic physical health conditions by category for each selected state.)

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### Sex, Age, and Rurality of Beneficiaries Were Similar across Selected States; Race and Ethnicity Data Were Unreliable in Five States

The distribution of beneficiaries with I/DD by sex, age, and rurality was similar across the six selected states. (See fig. 5.) In most cases, the demographics aligned with trends in the general population or among individuals with I/DD.

- **Sex:** In all six states, the percentage of men with I/DD was higher than the percentage of women. This is consistent with research in the general population indicating that males are more likely than females to be diagnosed with I/DD.<sup>26</sup>
- **Age:** Younger adults (ages 21 to 35) accounted for the largest percentage of beneficiaries with I/DD, followed by adults aged 36 to 50, in five of the six states. This is consistent with research suggesting that generational biases in identification, and reduced life expectancy among those with severe cognitive impairments, may contribute to older adults being underrepresented among the general population with I/DD.<sup>27</sup>
- **Rurality:** Urban residents generally accounted for a larger percentage of beneficiaries with I/DD than rural residents—except in South Dakota where the percentages were nearly equal. In all six states, the distribution of beneficiaries was consistent with overall patterns of urban and rural residence in the state.<sup>28</sup>

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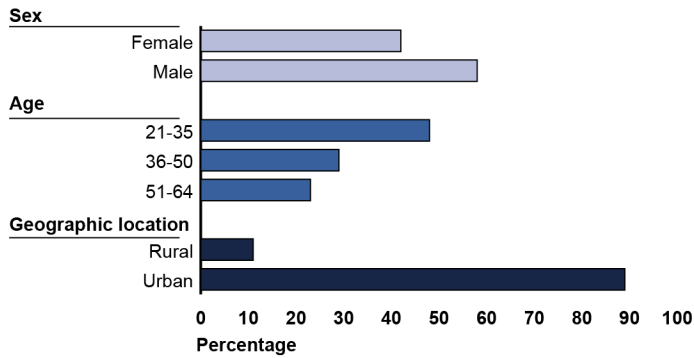
<sup>26</sup>See P. K. Maulik et al., “Prevalence of Intellectual Disability: A Meta-Analysis of Population-Based Studies,” *Research in Developmental Disabilities*, vol. 32 (2011): 423.

<sup>27</sup>See G. T. Fujiura, H. Li, and S. Magaña, “Health Services Use and Costs for Americans with Intellectual and Developmental Disabilities: A National Analysis,” *Intellectual and Developmental Disabilities*, vol. 56, no. 2 (2018): 106.

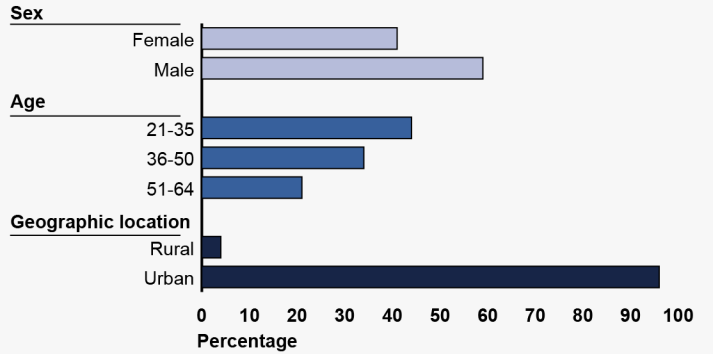
<sup>28</sup>See U.S. Census Bureau, *Percent Urban and Rural in 2010 by State and County* (Washington, D.C.: Mar. 26, 2012), accessed February 16, 2023, <https://www.census.gov/programs-surveys/geography/guidance/geo-areas/urban-rural/2010-urban-rural.html>.

**Figure 5: Demographic Characteristics of Beneficiaries with Intellectual or Developmental Disabilities in Selected States, 2019**

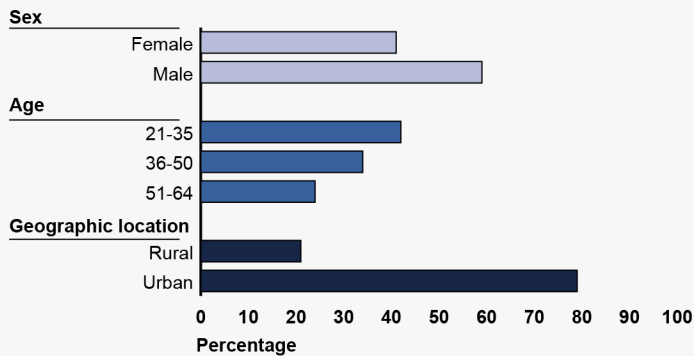
**Colorado (N= 9,138)**



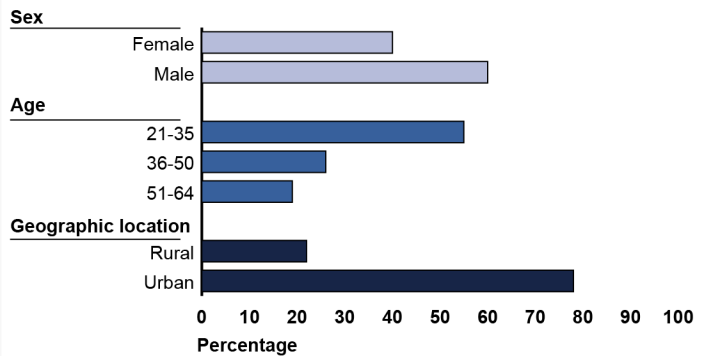
**Florida (N= 26,185)**



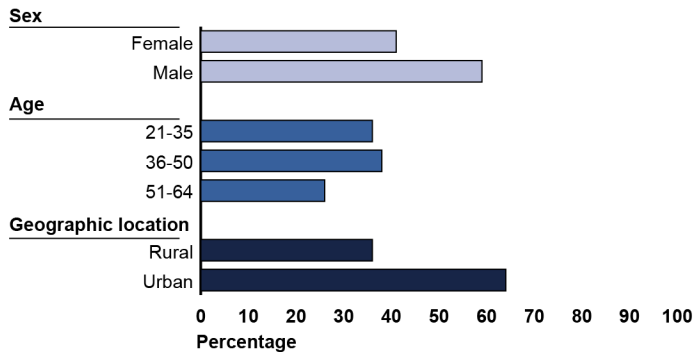
**Georgia (N= 11,349)**



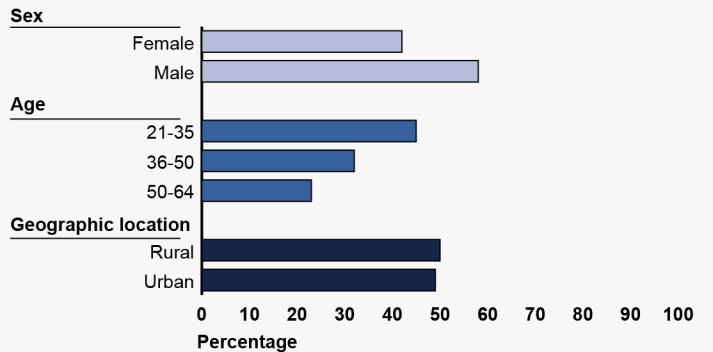
**Indiana (N= 15,839)**



**Oklahoma (N= 4,469)**



**South Dakota (N= 2,518)**



*N refers to the total number of adult beneficiaries enrolled in programs targeting individuals with intellectual or developmental disabilities in each state.*

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

Note: Analysis includes Medicaid beneficiaries aged 21 to 64 years who were enrolled in a home- and community-based services waiver program authorized under section 1915(c) of the Social Security Act that targeted individuals with intellectual or developmental disabilities in 2019. Rural and urban geographic location was determined based on a beneficiary's county of residence.

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Five of our selected states had unreliable data on the race and ethnicity of beneficiaries with I/DD, limiting our ability to analyze the distribution of beneficiaries. The sixth state's data appeared complete.

- **Four states were missing race and ethnicity data for a substantial percentage of beneficiaries.** In Colorado, Florida, Georgia, and Indiana, over 20 percent of beneficiaries with I/DD were missing data on race and ethnicity. Because such a large portion of data is missing, any percentages reported from existing data are unreliable. While many state Medicaid agencies collect self-reported data on race and ethnicity from applicants during the eligibility and enrollment process, officials in two states told us that their processes differed for individuals enrolled in HCBS programs targeting individuals with I/DD. For these programs, officials said that beneficiary enrollment information came from another state or federal agency that determined eligibility, and data on race and ethnicity were already missing for a portion of beneficiaries. Officials from another state explained that the state has more complete race and ethnicity data, but a misalignment between the state's data fields and those available in T-MSIS result in missing ethnicity data for some beneficiaries.<sup>29</sup>
- **One state had unreliable data on race and ethnicity.** In South Dakota, reporting on race and ethnicity for beneficiaries with I/DD appeared to be complete. However, the data showed a higher prevalence of White beneficiaries—and a lower percentage of Hispanic beneficiaries—in HCBS programs compared to the overall Medicaid population in the state. Officials said that their data system defaulted to filling in “White” when information on race was missing in 2019, making the reported data unreliable.<sup>30</sup>
- **One state had data that appeared complete.** In Oklahoma, data on race and ethnicity appeared to be complete. State officials told us that the state's online enrollment application requires a response on the

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<sup>29</sup>This state asks about race and ethnicity using a single question. The Department of Health and Human Services provides guidance, but does not mandate, that states use federal data standards when collecting race and ethnicity data from Medicaid applicants. Current federal standards recommend asking about race and ethnicity in separate questions.

<sup>30</sup>South Dakota officials reported that the state plans to implement a new electronic enrollment system in late 2023 that will address the defaults in the current system. Officials from CMS said that they plan to reach out to South Dakota to discuss these issues.

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question about race before allowing the applicant to progress to the next screen.<sup>31</sup> Analysis of Oklahoma’s data showed a higher prevalence of White beneficiaries, and a substantially lower percentage of Hispanic beneficiaries, in HCBS programs than in the overall Medicaid population for the state.<sup>32</sup>

Issues with missing and unreliable race and ethnicity data for Medicaid beneficiaries is not limited to programs serving individuals with I/DD and has been documented in our prior work and work by others. For example, our 2021 report on data completeness in Medicaid found that 21 of 50 states had acceptable race and ethnicity data for 2016.<sup>33</sup> In other work, we have highlighted the importance of accurate and complete reporting on race and ethnicity by states, jurisdictions, and federal health systems in order to help the federal government better understand existing health disparities and take actions to promote health equity.<sup>34</sup> CMS officials noted that they have recently adopted new data quality measures to assess states’ race and ethnicity data in T-MSIS. Officials told us that these measures may help the agency identify states’ over- or under-reporting in particular categories of race and will be used in ongoing technical assistance work with states beginning this year.

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<sup>31</sup>Although states cannot require applicants to provide race and ethnicity information, they can allow the applicant to select an answer indicating they choose not to answer the question. See State Health Access Data Assistance Center, “Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications: New and Updated Information on Medicaid Data Collection Practices in the States, Territories, and District of Columbia,” *State Health & Value Strategies* (Princeton, N.J.: 2022): 10.

<sup>32</sup>In reviewing the results of this analysis, Oklahoma officials noted that the under-representation of Hispanic beneficiaries in the programs is consistent with patterns officials have observed in the composition of the waiting lists for their HCBS programs. Officials indicated that the results may signal a need for increased outreach to under-represented populations.

<sup>33</sup>See GAO, *Medicaid: Data Completeness and Accuracy Have Improved, Though Not All Standards Have Been Met*, [GAO-21-196](#) (Washington, D.C.: Jan. 14, 2021).

<sup>34</sup>See GAO, *Health Care Capsule: Racial and Ethnic Health Disparities*, [GAO-21-105354](#) (Washington, D.C.: Sept. 23, 2021).

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**Per-Beneficiary  
Expenditures  
Averaged Over  
\$50,000, Driven by  
Home- and  
Community-Based  
Services**

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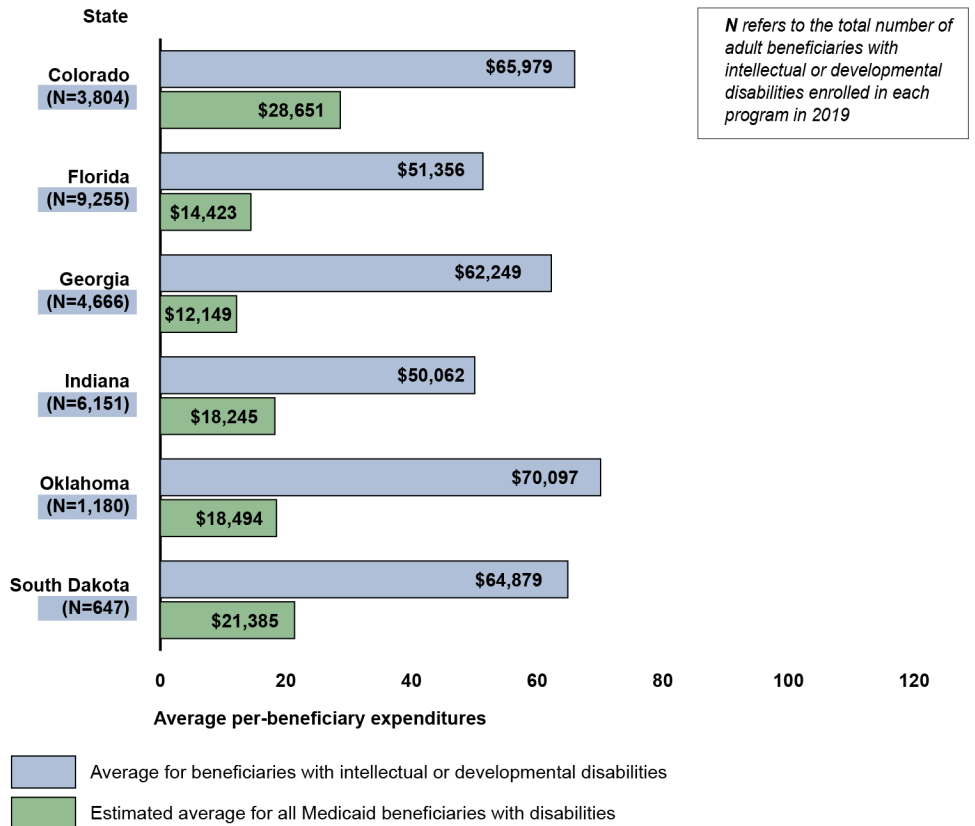
**Per-Beneficiary  
Expenditures Were Higher  
than the Average for  
Beneficiaries with  
Disabilities, but Lower  
than Estimated  
Institutional Costs**

Average per-beneficiary health care expenditures for beneficiaries with I/DD in our six selected states ranged from about \$51,000 to \$70,000, substantially higher than the average for all Medicaid beneficiaries with disabilities. CMS data from 2019 indicated that average per-beneficiary expenditures for all beneficiaries with disabilities in our selected states were two to five times lower, ranging from about \$12,000 to \$29,000.<sup>35</sup> (See fig. 6.)

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<sup>35</sup>CMS's estimates are based on total spending reported by states to the Medicaid Budget and Expenditure System, and the number of enrollees and their expenditures reported by states in T-MSIS. Estimates for beneficiaries with disabilities include children.

**Figure 6: Average Per-Beneficiary Expenditures for Beneficiaries with Intellectual or Developmental Disabilities Compared with All Medicaid Beneficiaries with Disabilities, 2019**



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

Note: Average for beneficiaries with intellectual or developmental disabilities refers to expenditures for beneficiaries aged 21 to 64 years enrolled in home- and community-based services programs authorized under section 1915(c) of the Social Security Act in selected states in 2019. Analysis excludes beneficiaries dually eligible for Medicare.

Average for all Medicaid beneficiaries with disabilities are based on 2019 estimates from the Centers for Medicare & Medicaid Services. These estimates are based on total spending reported by states to the Medicaid Budget and Expenditure System and the number of beneficiaries and their expenditures reported by states in the Transformed Medicaid Statistical Information System. Estimates for disabled individuals include children.

In contrast, average expenditures were generally lower than states' estimated costs for serving beneficiaries with I/DD in institutional settings (i.e., intermediate care facilities for individuals with intellectual



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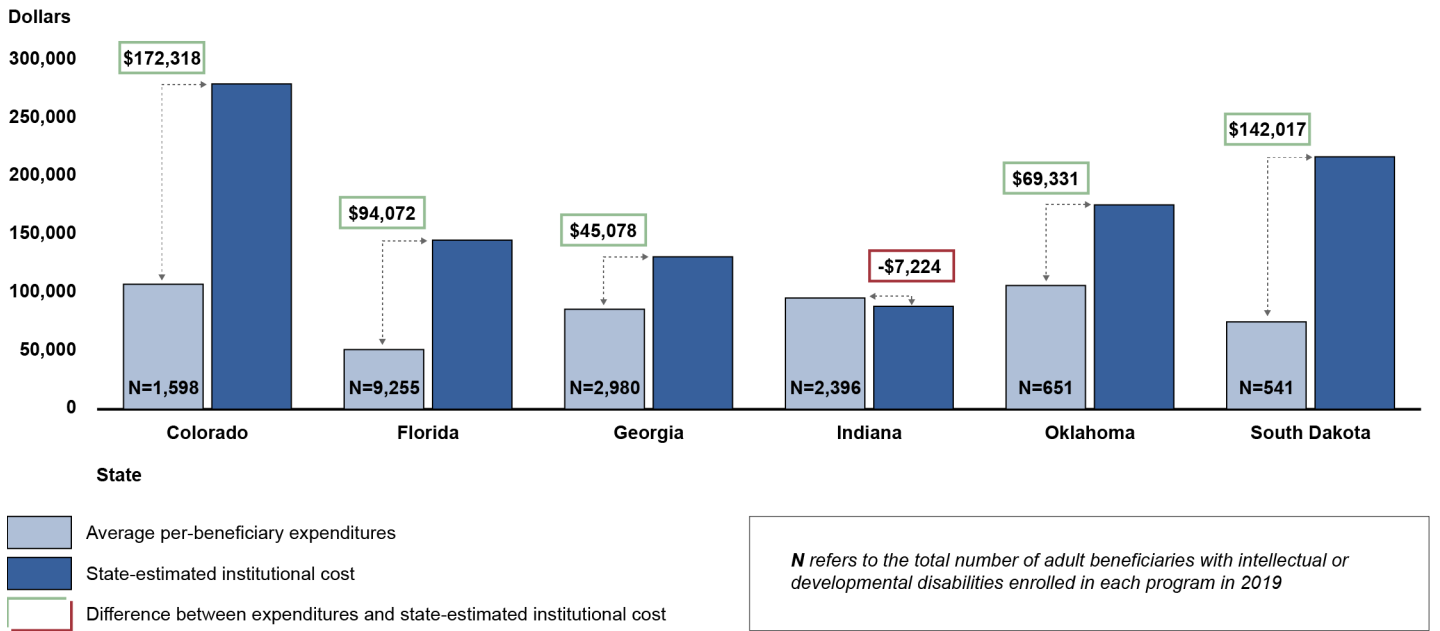
disabilities).<sup>36</sup> For example, for four of the five comprehensive HCBS programs and Florida's combined program, expenditures were about one-third to two-thirds of estimated costs for serving beneficiaries in intermediate care facilities. The exception is Indiana, where expenditures were about 8 percent higher in the HCBS program. Indiana officials said they have updated their methodology for estimating institutional costs to better reflect the intensive care needs of the population.<sup>37</sup> (See fig. 7.)

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<sup>36</sup>Intermediate care facilities for individuals with intellectual disabilities are residential facilities that primarily provide health and rehabilitative services for individuals with intellectual disabilities and related conditions. These facilities provide, among other things, ongoing evaluation, 24-hour supervision, and coordination of services to help individuals function at their greatest ability. In 2019, 81,020 Medicaid beneficiaries received services in an intermediate care facility for individuals with intellectual disabilities. See Min-Young Kim, Edward Weizenegger, and Andrea Wysocki, "Medicaid Beneficiaries Who Use Long-Term Services and Supports: 2019," (Chicago, Ill.: Mathematica, July 22, 2022).

<sup>37</sup>As of 2022, Indiana estimated that it would cost about \$166,000 per beneficiary to serve individuals in an intermediate care facility for individuals with intellectual disabilities, about two-thirds higher than the average of \$95,750 for beneficiaries with I/DD in Indiana's comprehensive HCBS program.

**Figure 7: Average Expenditures for Beneficiaries with Intellectual or Developmental Disabilities in Comprehensive Programs Compared with State-Estimated Institutional Costs, 2019**



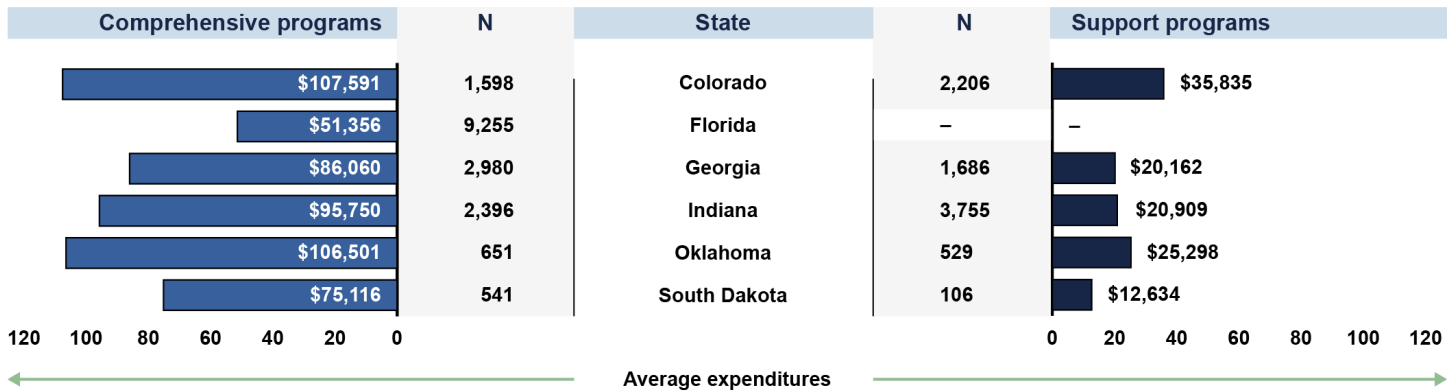
Source: GAO analysis of Centers for Medicare & Medicaid Services data. | GAO-23-105457

Note: Average per-beneficiary expenditures refer to expenditures for Medicaid beneficiaries aged 21 to 64 years enrolled in comprehensive home- and community-based services programs authorized under section 1915(c) of the Social Security Act in selected states in 2019. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services, whereas support programs (not shown) include programs that provide services and supports needed for individuals to remain in the family home or in their own home. Analysis excludes beneficiaries dually eligible for Medicare.

Estimates for institutional costs are as-reported by states in their 1915(c) HCBS waiver applications. Estimates rely on waiver year 2019 where available; otherwise, they are taken from the most recent waiver application.

In our selected states, beneficiaries with I/DD in comprehensive HCBS programs had three to six times the average expenditures of beneficiaries with I/DD in support programs. (See fig. 8.) Higher expenditures for comprehensive programs are likely due to the greater health care needs of the beneficiaries enrolled in them, the greater array of services available, and the lack of spending caps. None of the comprehensive programs in our selected states included an individual cost limit for beneficiaries, whereas three of the five support programs—in Georgia, Indiana, and Oklahoma—had cost limits. Indiana noted in the 1915(c) waiver application for its support program that the state expects beneficiaries in the program to have available services and supports from sources other than the program, such as family caregivers.

**Figure 8: Average Per-Beneficiary Expenditures for Beneficiaries with Intellectual or Developmental Disabilities by Program Type, 2019**



*N* refers to the total number of adult beneficiaries with intellectual or developmental disabilities enrolled in each program in 2019

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services, whereas support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home. Florida has a single HCBS program for individuals with intellectual or developmental disabilities (I/DD), which we categorize as comprehensive based on its coverage of round-the-clock care.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with I/DD in 2019; we excluded beneficiaries who were dually eligible for Medicare.

### Home- and Community-Based Services Were the Primary Driver of Expenditures; the Largest Spending Category was Round-the-Clock Services

Most of our selected states' health care expenditures for beneficiaries with I/DD, including both Medicaid-only and dually eligible beneficiaries, were for HCBS.<sup>38</sup> For Medicaid-only beneficiaries, about 65 to 82 percent of health care expenditures were for HCBS. For dually eligible beneficiaries, the percentage is even higher, accounting for 82 to 95 percent of spending, likely due to other, non-HCBS health care services paid for by Medicare that are not fully captured in Medicaid's T-MSIS data.

Analysis of HCBS expenditures by service category showed that round-the-clock services, such as services provided in group homes, was the largest expenditure category in each state, and it accounted for a large

<sup>38</sup>While we limited reporting of total health care expenditures to Medicaid-only beneficiaries, we included dually eligible beneficiaries—Medicare beneficiaries who are also enrolled in the Medicaid program in their state—in our analyses of HCBS expenditures. Whereas services paid for by Medicare are not fully captured in T-MSIS, most HCBS are paid for by Medicaid, even for beneficiaries with Medicare coverage.

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proportion of HCBS spending. (See fig. 9.) Specifically, round-the-clock services accounted for 40 percent or more of spending, ranging from 43 percent in Oklahoma to 63 percent in Colorado and South Dakota. Average per-beneficiary expenditures for round-the-clock services among users of these services ranged from about \$36,500 to about \$73,000.

**Figure 9: Home- and Community-Based Services Expenditures for Beneficiaries with Intellectual or Developmental Disabilities by Service Category, 2019**



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

Note: Analysis includes expenditures for home- and community-based services (HCBS) for Medicaid beneficiaries aged 21 to 64 years who were enrolled in HCBS waiver programs authorized under section 1915(c) of the Social Security Act that targeted individuals with intellectual or developmental

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disabilities in 2019. Both Medicaid-only beneficiaries and those dually eligible for Medicare are included.

Comprehensive and support programs showed different patterns of spending by category.

- For comprehensive programs, round-the-clock services was the highest expenditure category, followed by either home-based services, such as personal care, or day services, such as adult day care. Combined, round-the-clock, home-based, and day services accounted for over 80 percent of spending among comprehensive programs.
- For support programs, which do not cover round-the-clock services, either home-based services or day services was the largest expenditure category across all states. Case management was second highest in Georgia, Oklahoma, and South Dakota.<sup>39</sup>

(See app. V for additional information regarding HCBS expenditures and utilization in our selected states.)

Our analysis of Medicaid data shows that utilization of other typically high-cost health care services did not appear to be major contributors to our selected states' expenditures in 2019.

- **Institutional long-term care services:** Services in intermediate care facilities for individuals with intellectual disabilities, nursing facilities, and certain mental health facilities were rarely used.<sup>40</sup> Four percent or less of beneficiaries in each state had any institutional long-term care expenditures. In three states, less than one percent of beneficiaries used institutional long-term care services. This is expected because HCBS programs are intended to provide an alternative to institutional care.
- **Inpatient hospital services:** About 6 to 12 percent of Medicaid-only beneficiaries with I/DD in each state had inpatient hospital

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<sup>39</sup>The remaining states, Colorado and Indiana, had home-based services and day services as their second highest expenditure categories, respectively.

<sup>40</sup>In addition to intermediate care facilities for individuals with intellectual disabilities, the T-MSIS long-term care file also includes nursing facilities, mental health facility services, and services provided in independent (free-standing) psychiatric wings of acute care hospitals.

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expenditures. This is lower than the CMS estimate of 14 percent for all adult Medicaid beneficiaries in 2019.<sup>41</sup>

- **Emergency room services:** Use of emergency room services ranged from about 24 to 34 percent of Medicaid-only beneficiaries with I/DD. These figures are similar to rates of emergency room utilization for adult Medicaid beneficiaries we and CMS have reported. For example, our 2017 report examining health care service use among adult Medicaid expansion beneficiaries in four states found 13 to 32 percent of beneficiaries had one or more emergency room visits.<sup>42</sup> Similarly, CMS estimated that 38 percent of all adult Medicaid beneficiaries had at least one emergency room visit in 2019.<sup>43</sup>

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### Average Expenditures Were Higher for Beneficiaries with Additional Behavioral Health or Chronic Physical Health Conditions

For the five selected states with usable diagnosis data—Colorado, Georgia, Indiana, Oklahoma, and South Dakota—average Medicaid expenditures were generally higher for beneficiaries with I/DD who were diagnosed with an additional health condition compared to those who were not. This was true regardless of program type. For example, among comprehensive programs, expenditures were 13 to 40 percent higher for beneficiaries with I/DD and a behavioral health condition than for those without a behavioral health condition. (See fig. 10.)

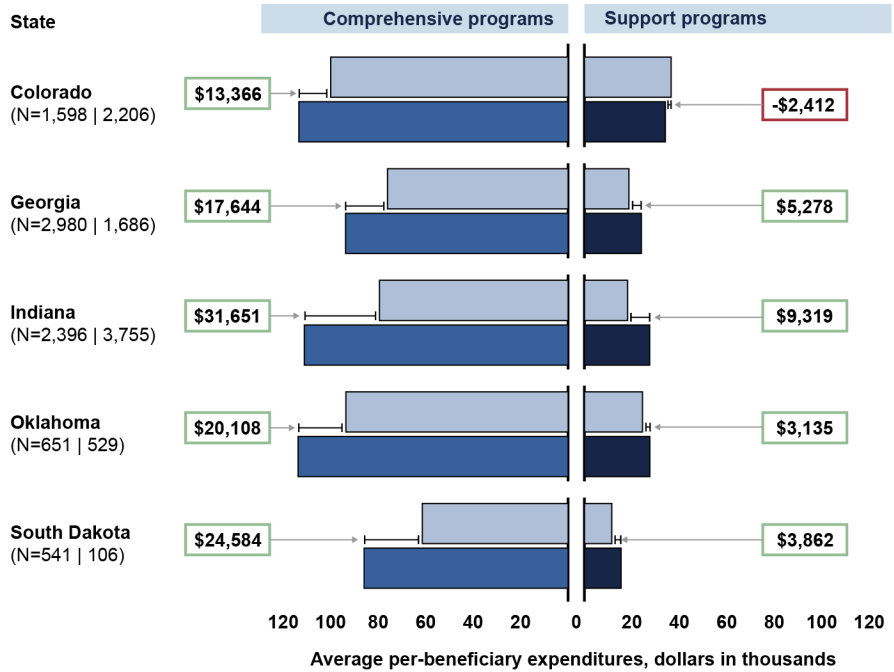
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<sup>41</sup>CMS's estimate is based on self-reported data from the Centers for Disease Control and Prevention's National Health Interview Survey for noninstitutionalized adults aged 18 to 64 years enrolled in Medicaid, the Children's Health Insurance Program, and state-sponsored plans.

<sup>42</sup>Rates for adults with behavioral health conditions were higher—42 to 57 percent. See GAO, *Medicaid Expansion: Behavioral Health Treatment Use in Selected States in 2014*, [GAO-17-529](#) (Washington, D.C.: June 22, 2017).

<sup>43</sup>Estimate based on self-reported data from the Centers for Disease Control and Prevention's National Health Interview Survey for noninstitutionalized adults aged 18 to 64 years enrolled in Medicaid, the Children's Health Insurance Program, and state-sponsored plans.

**Figure 10: Average Differences in Expenditures for Beneficiaries with Intellectual or Developmental Disabilities with and without an Additional Behavioral Health Condition, 2019**



*N* refers to the total number of adult beneficiaries with intellectual or developmental disabilities enrolled in each program in 2019

- Expenditures – no behavioral health diagnosis
- Expenditures – with behavioral health diagnosis
- Difference between expenditures with and without a behavioral health diagnosis

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with intellectual or developmental disabilities in 2019; we excluded beneficiaries who were dually eligible for Medicare. Behavioral health conditions included mental health and substance use disorder diagnoses.

Florida was excluded from our analysis due to missing diagnosis data. However, we found that in that state HCBS expenditures were more than double for beneficiaries with I/DD who used mental health and behavior support services compared with those who did not (about \$62,000 compared to about \$29,000). Florida officials said this difference is



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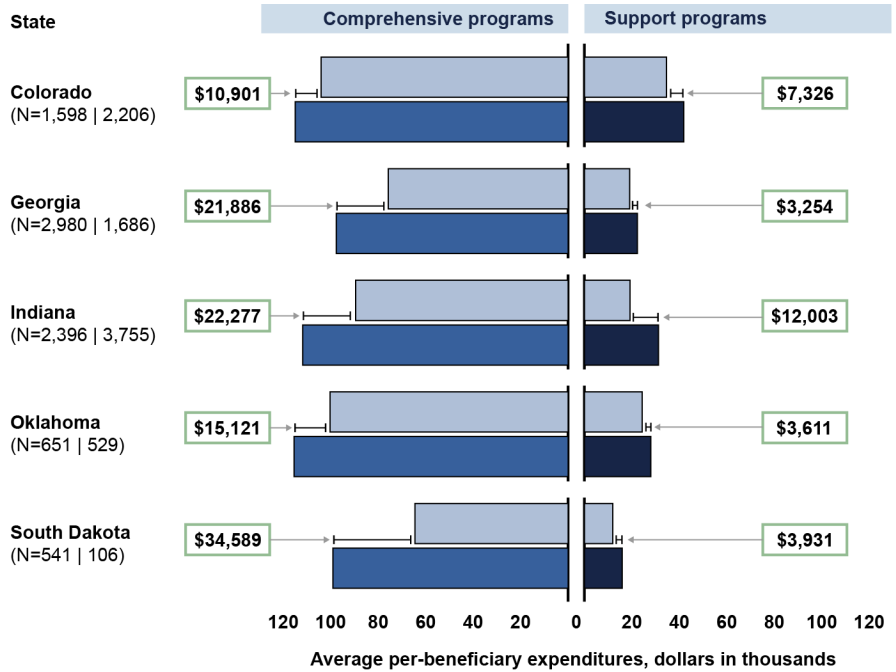
expected, because beneficiaries with I/DD who use these services may need greater supervision to avoid harming themselves or others. In addition to behavior support services that help beneficiaries with I/DD replace challenging behaviors with positive behaviors, the beneficiaries may need companion services and other services that require a lot of staff time to provide needed supervision.<sup>44</sup>

Beneficiaries with I/DD in comprehensive HCBS programs with an additional chronic physical health condition, such as high blood pressure or diabetes, had expenditures that were 10 to 54 percent higher than beneficiaries without such conditions. Differences in support programs ranged from 15 to 62 percent higher. (See fig. 11.)

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<sup>44</sup>Challenging behaviors may include physical or verbal aggression, self-injury, elopement, and disruptive or socially inappropriate behaviors.

**Figure 11: Average Differences in Expenditures for Beneficiaries with Intellectual or Developmental Disabilities with and without an Additional Chronic Physical Health Condition, 2019**



*N* refers to the total number of adult beneficiaries with intellectual or developmental disabilities enrolled in each program in 2019

- Expenditures – no chronic physical health diagnosis
- Expenditures – with chronic physical health diagnosis
- Difference between expenditures with and without a chronic physical health diagnosis

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with intellectual or developmental disabilities in 2019; we excluded beneficiaries who were dually eligible for Medicare. Chronic physical health conditions included diagnoses such as high blood pressure, high cholesterol, and diabetes.

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In prior work, we and others have reported on higher expenditures among Medicaid beneficiaries with chronic conditions.

- Our 2015 report on high-expenditure Medicaid beneficiaries showed that those with chronic physical and behavioral health conditions were overrepresented among the 5 percent of beneficiaries with the highest expenditures. For example, about 3 percent of all beneficiaries had diabetes, while beneficiaries with diabetes consistently constituted nearly 20 percent of the high-expenditure group.<sup>45</sup>
- In a 2018 report, the Medicaid and CHIP Payment and Access Commission documented the effect of behavioral health conditions on HCBS spending. Specifically, they found that high-cost users—those within the top 3 percent of HCBS spending—were more than twice as likely to use mental health and behavioral services than all HCBS users.<sup>46</sup>

In a 2019 report, we reviewed states' and CMS's efforts to identify and manage high expenditure Medicaid beneficiaries.<sup>47</sup> The report highlighted states' use of case management to coordinate care across providers to manage physical and mental health conditions more effectively, and CMS's provision of tools and technical assistance to states to support their efforts.<sup>48</sup>

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## Agency Comments

The Department of Health and Human Services provided technical comments on a draft of this report, which we incorporated as appropriate.

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<sup>45</sup>See GAO, *Medicaid: A Small Share of Enrollees Consistently Accounted for a Large Share of Expenditures*, [GAO-15-460](#) (Washington, D.C.: May 8, 2015).

<sup>46</sup>See Medicaid and CHIP Payment and Access Commission, *Medicaid Home- and Community-Based Services: Characteristics and Spending of High-Cost Users* (Washington, D.C.: June 2018).

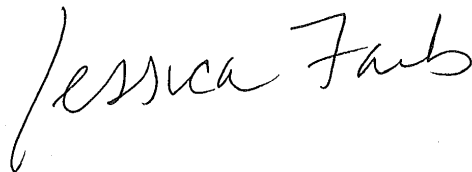
<sup>47</sup>See GAO, *Medicaid: Efforts to Identify, Predict, or Manage High-Expenditure Beneficiaries*, [GAO-19-569](#) (Washington, D.C.: Aug. 13, 2019).

<sup>48</sup>For example, as part of its Innovation Accelerator Program, CMS conducted a nationwide webinar series on Medicaid beneficiaries with complex needs and high costs, including information on identifying and stratifying these beneficiaries.

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We are sending copies of this report to the appropriate congressional committees, the Secretary of Health and Human Services, and other interested parties. In addition, the report will be available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staff have any questions, please contact me at (202) 512-7114 or [farbj@gao.gov](mailto:farbj@gao.gov). Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. Major contributors to this report are listed in appendix VI.

A handwritten signature in black ink that reads "Jessica Farb". The signature is written in a cursive, flowing style.

Jessica Farb  
Managing Director, Health Care

# Appendix I: Home- and Community-Based Services Programs in Selected States

**Table 1: Characteristics of Home- and Community-Based Services Programs Targeting Individuals with Intellectual or Developmental Disabilities in Selected States, 2019**

State	Program title	Program type	Waiting list	Number of program slots <sup>a</sup>
Colorado	Home and Community-Based Services Waiver for Persons with Developmental Disabilities	Comprehensive	Yes	6,957
Colorado	Supported Living Services	Support	No	5,896
Florida	Developmental Disabilities Individual Budgeting Waiver	Combined	Yes	34,742
Georgia	Comprehensive Supports Waiver Program	Comprehensive	Yes	8,350
Georgia	New Options Waiver	Support	Yes	5,058
Indiana	Community Integration and Habilitation Waiver	Comprehensive	No	10,927
Indiana	Family Supports Waiver	Support	Yes	23,087
Oklahoma	Community Waiver	Comprehensive	Yes <sup>b</sup>	3,018
Oklahoma	Homeward Bound Waiver	Comprehensive	No	580
Oklahoma	In-Home Supports Waiver for Adults	Support	Yes <sup>b</sup>	1,551
South Dakota	CHOICES	Comprehensive	No	2,726
South Dakota	South Dakota Family Support 360 Waiver	Support	No	1,170

Source: GAO review of state Medicaid program documents and interviews with state officials. | GAO-23-105457

Note: Programs refer to home- and community-based services waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

<sup>a</sup>Program slots are based upon the 2019 waiver program year, rather than the calendar year. The waiver program year may begin on any day of the year and usually aligns with the effective date of the initial waiver program application, renewal, or modification. Some programs serve individuals outside the 21-64 age range; these individuals were not included in our analyses.

<sup>b</sup>In 2022, in Oklahoma, legislation appropriating \$32.5 million to end the waiting list for Medicaid developmental disability services was enacted.

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# Appendix II: Scope and Methodology

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To describe characteristics of, and health care expenditures for, adults with intellectual or developmental disabilities (I/DD) enrolled in Medicaid home- and community-based services (HCBS) programs, we analyzed data from the Transformed Medicaid Statistical Information System (T-MSIS), the Centers for Medicare & Medicaid Services' (CMS) initiative to improve state-reported data available for overseeing Medicaid. Specifically, we reviewed calendar year 2019 enrollment, service utilization, and payment data from the Annual Demographic and Eligibility, Other Services, Inpatient, Pharmacy, and Annual Use and Payment T-MSIS Analytic Files for six selected states.<sup>1</sup> We selected 2019 because it is the most recent complete and finalized year of T-MSIS data that precedes the COVID-19 pandemic, which affected service utilization and associated expenditures.

Our analysis consisted of the following parts: (1) state selection, identifying beneficiaries with I/DD enrolled in HCBS programs, and data reliability; (2) analysis of Medicaid beneficiary characteristics; (3) identification of HCBS claims; and (4) analysis of expenditures.

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## State Selection, Beneficiary Identification, and Data Reliability

We selected six states—Colorado, Florida, Georgia, Indiana, Oklahoma, and South Dakota—based on

- having at least one 1915(c) HCBS waiver program covering adults aged 21 through 64 years with I/DD using a fee-for-service delivery model in 2019;<sup>2</sup>

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<sup>1</sup>T-MSIS Analytic Files are a series of research-ready analytic files CMS created to support analysis, research, and data-driven decisions on key Medicaid topics, as well as program oversight. T-MSIS contains four monthly claims files: Inpatient, Long-term care, Pharmacy, and Other Services. The Other Services file captures all other medical services and payments, such as physician and dental visits, laboratory and X-ray services, and capitation payments. The Annual Use and Payment file contains summarized service use and payment information for each Medicaid beneficiary who used at least one service or had a payment made on their behalf in a given calendar year.

Beneficiaries who did not use a particular type of service in 2019 were not included in the T-MSIS analytic file for that service type. Consequently, the total number of beneficiaries included in analyses for a given state may vary. For example, analyses of Medicaid-only beneficiaries in Colorado's comprehensive program that are based on the Inpatient and Other Services files have a total of 1,596 beneficiaries, whereas there were 1,598 beneficiaries in analyses based on the Annual Use and Payment file.

<sup>2</sup>For the purpose of this report, we refer to HCBS waiver programs authorized under section 1915(c) of the Social Security Act as HCBS programs. States may also provide certain HCBS through their Medicaid state plan, or through other waivers or demonstrations, but these other authorities are outside the scope of this report.

- having acceptable T-MSIS data as assessed by CMS for selected variables of interest; and
- varying geographically, by percentage of long-term services and supports funds spent on HCBS, and waiver enrollment size.<sup>3</sup>

Selected states are not representative of all states and their HCBS programs.

To identify beneficiaries with I/DD enrolled in HCBS programs in our selected states, we collected lists of identification numbers from states for beneficiaries who were enrolled in the programs at any time during 2019. We excluded beneficiaries who were younger than 21 years of age or older than 64 years of age as of January 1, 2019, and individuals who were enrolled in more than one HCBS program in 2019.<sup>4</sup> For selected analyses, we focused on Medicaid-only beneficiaries with I/DD (i.e., those not dually eligible for Medicare). To identify these individuals, we used T-MSIS dual eligibility code data, selecting individuals coded as Medicaid-only for all months the beneficiary was enrolled in 2019, with up to one month of missing data. All other beneficiaries were considered potentially dually eligible. We excluded beneficiaries who had inconsistent or erroneous dual eligibility code data (e.g., had a greater number of months

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Under fee-for-service delivery models, states pay providers directly and on a retrospective basis for each covered service they deliver. Under managed care, states contract with managed care organizations to provide a specific set of covered services to beneficiaries in return for one fixed periodic payment per beneficiary, typically per member per month. We selected fee-for-service programs because provider payment information is included in T-MSIS and available for analysis. States were not required to report payment amounts for services paid for by managed care organizations until June 2019.

<sup>3</sup>In July 2020, CMS introduced a data quality atlas (referred to as the DQ Atlas), which provides interactive, web-based access to information about the T-MSIS Analytic Files data. We refer to states' data that CMS determined as having low data quality concern as acceptable data.

We initially selected Alabama for review based on our criteria, but ultimately did not analyze data for this state. When we examined Alabama's data, we discovered that beneficiaries can be associated with multiple identification numbers, which hampered our ability to identify the relevant beneficiaries in the T-MSIS data and to reliably link them to claims. In addition, it was not possible to determine which beneficiaries were dually eligible for Medicare in Alabama, because of missing dual eligibility code data.

<sup>4</sup>In addition, a small number of beneficiaries identified by the states were excluded because, according to T-MSIS enrollment data, they were not enrolled for at least one month in calendar year 2019. In total, about 28 percent of beneficiaries were excluded from analysis, the majority of which were excluded based on falling outside the 21 to 64 years of age range.

of dual eligibility code data than months they were enrolled in 2019) from analyses by dual status.<sup>5</sup>

We assessed the reliability and usability of T-MSIS data for the six states by interviewing knowledgeable federal and state officials; reviewing related documentation, such as studies that assessed the reliability of Medicaid data; comparing the results of our analysis to published figures from CMS and Mathematica Policy Research; and testing the data for logical errors and missing information.<sup>6</sup> To the extent that we found reliability issues with data for particular analyses, we excluded a state's results from our report.<sup>7</sup> Based on our assessment, we determined the data were sufficiently reliable for the purposes of our reporting objectives.

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## Beneficiary Characteristics

To describe the health and demographic characteristics of beneficiaries with I/DD enrolled in Medicaid HCBS programs in selected states in 2019, we analyzed enrollment and service utilization data in T-MSIS for each state. We considered a beneficiary to have a diagnosed behavioral health or chronic physical health condition if that beneficiary received any outpatient or inpatient services with a recorded diagnosis code for a behavioral health or chronic physical health condition in 2019.<sup>8</sup> Because we measured behavioral health and physical health conditions based on service utilization data, our estimates do not include individuals who did not receive care for their conditions during 2019.

We selected behavioral health conditions based on a list of diagnosis codes CMS developed to identify Medicaid and Children's Health Insurance Program beneficiaries who could benefit from integrated

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<sup>5</sup>This restriction resulted in excluding about 500 beneficiaries across the six selected states.

<sup>6</sup>See Mathematica Policy Research, *Medicaid Policy Brief: Assessing the Usability of Encounter Data for Enrollees in Comprehensive Managed Care Across MAX 2007–2009*, Brief 15 (Washington, D.C.: December 2012).

<sup>7</sup>For example, four of our six selected states had missing data for race and ethnicity of the following percentages: Colorado (32); Florida (23); Georgia (22); and Indiana (25).

<sup>8</sup>For outpatient claims, we considered both primary and secondary diagnoses when determining whether enrollees had a diagnosed physical or behavioral health condition. For inpatient claims, we considered all recorded diagnosis codes.



physical and behavioral health care.<sup>9</sup> We examined the following 10 categories of conditions:

1. anxiety disorders;
2. attention-deficit/hyperactivity disorder and related conditions;
3. bipolar disorder;
4. depressive disorders;
5. personality disorders;
6. post-traumatic stress disorder;
7. schizophrenia and other psychotic disorders;
8. other mental health disorders;
9. alcohol-related disorders; and
10. drug-related disorders.<sup>10</sup>

For one of the HCBS programs in our review, Georgia's comprehensive waiver, we conducted analysis to further examine diagnosis of schizophrenia and other psychotic disorders, and rates of use of antipsychotic medications, a type of medication commonly used to treat such disorders. Diagnosis of schizophrenia and other psychotic disorders was of interest because, in contrast to the other five states, these generally rare conditions were the most commonly diagnosed category of behavioral health conditions in Georgia. Antipsychotic medication use was of interest based on our previous work on the use of antipsychotics

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<sup>9</sup>See Centers for Medicare & Medicaid Services, "Identifying Medicaid and CHIP Beneficiaries Who Could Benefit from Integrated Physical and Behavioral Health Care: Reference Codes," accessed January 3, 2022, [https://www.medicare.gov/medicaid/data-and-systems/downloads/macbis/pbhi\\_reference\\_codes.xlsx](https://www.medicare.gov/medicaid/data-and-systems/downloads/macbis/pbhi_reference_codes.xlsx). In cases where diagnosis codes appeared under more than one category in CMS's list, we chose the more specific category, or followed categorization used by a provider association with expertise in behavioral health.

<sup>10</sup>The drug-related disorders category excludes tobacco use disorder. While we considered tobacco use disorder to be a behavioral health condition, we did not consider it to be a substance use disorder, which is consistent with how the Substance Abuse and Mental Health Services Administration collects and reports data on substance use. For the same reason, we excluded codes related to caffeine use. We also excluded two codes that were specific to fetuses and newborns, because our population of interest is limited to adults.

among Medicaid beneficiaries.<sup>11</sup> Results of our analysis can be found in appendix III.

We selected chronic physical health conditions based on a review of three published studies that examined the prevalence of such conditions.<sup>12</sup> We examined the following five categories:

1. diabetes;
2. heart disease;
3. chronic lung conditions;
4. high cholesterol; and
5. high blood pressure.

To describe demographic characteristics, we used enrollment data to examine age, sex, race/ethnicity, and geographic location. We determined beneficiaries' age, sex, and race/ethnicity as recorded in the relevant T-MSIS data fields.<sup>13</sup> We defined geographic location based on beneficiaries' county of residence, using the T-MSIS data field that provides the American National Standards Institute county numeric code.

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<sup>11</sup>See, for example, GAO, *Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions [Reissued on December 15, 2011]*, [GAO-12-201](#) (Washington, D.C.: Dec. 14, 2011); and GAO, *Children's Mental Health: Concerns Remain about Appropriate Services for Children in Medicaid and Foster Care*, [GAO-13-15](#) (Washington, D.C.: Dec. 10, 2012).

<sup>12</sup>See (1) J. Chapel, M. Ritchey, D. Zhang, and G. Wang, "Prevalence and Medical Costs of Chronic Diseases Among Adult Medicaid Beneficiaries," *American Journal of Preventive Medicine*, vol. 53, no. 6 (2017); (2) Mathematica Policy Research, *HCBS Claims Analysis Chartbook: Final Report* (Chicago, Ill.: Dec. 15, 2017); and (3) E. Mitchell, "Concentration of Healthcare Expenditures and Selected Characteristics of Persons with High Expenses, U.S. Civilian Noninstitutionalized Population, 2019," *Medical Expenditure Panel Survey Statistical Brief #540*, Agency for Healthcare Research and Quality (Rockville, Md.: February 2022).

We defined chronic physical health conditions as conditions other than behavioral health conditions that were included at least two of the three studies, excepting arthritis and other joint disorders, because conditions in this category are most prevalent in individuals over 65 years of age, which is outside the age range of our population of interest.

<sup>13</sup>States use two separate data fields to submit information on a beneficiary's race and ethnicity to T-MSIS, the race code and the ethnicity code. In the T-MSIS Annual Demographics and Eligibility file, these two data fields are combined into a race/ethnicity code with seven categories: White, non-Hispanic; Black, non-Hispanic; Asian, non-Hispanic; American Indian and Alaska Native, non-Hispanic; Hawaiian/Pacific Islander; Multiracial, non-Hispanic; and Hispanic, which include all races.

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To determine whether beneficiaries lived in a rural or urban area of their states, we compared the county each beneficiary lived in, as reported in T-MSIS, to the CMS Core Based Statistical Area state and county code crosswalk, which we used to define rural and urban areas.

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## HCBS Claims Identification

To analyze expenditures among our population, including HCBS expenditures, we took a number of steps to identify HCBS claims in the data. We first selected a set of HCBS procedure codes for each state based on each state's coverage of HCBS in 2019. This involved collecting lists of procedure codes for covered HCBS from each selected state. From the six states' lists, we selected codes that met our definition of HCBS. We defined HCBS as services that are needed for the care of individuals who need assistance with activities of daily living and instrumental activities of daily living on an ongoing basis.<sup>14</sup> Broadly, these services assist individuals to remain in or return to their homes or communities and maintain their quality of life. We excluded general medical services that are routinely used by other populations in Medicaid, including laboratory services; prescription drugs; medical services such as home health, nursing services, and evaluation and management services (i.e., physician services); and dental services. In addition, we excluded some codes on a case-by-case basis if their descriptions suggested they were only covered for children.

Our next step was to categorize states' HCBS procedure codes according to the categories in CMS's HCBS taxonomy.<sup>15</sup> We assigned categories based on the code descriptions themselves, supplemented with more detailed descriptions in states' provider manuals and program websites; the American Medical Association's Current Procedural Terminology guide; and other online materials.

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<sup>14</sup>Activities of daily living refer to routine self-care activities such as bathing, dressing, toileting, and eating. Instrumental activities of daily living include activities such as preparing meals, housekeeping, using the telephone, and managing money.

<sup>15</sup>In 2014, a CMS contractor published an HCBS taxonomy that links individual services with broader categories of HCBS covered by Medicaid programs. The taxonomy comprises 17 categories of services, such as case management and round-the-clock services. See Victoria Peebles and Alex Bohl, "The HCBS Taxonomy: A New Language for Classifying Home- and Community-Based Services," *Medicare & Medicaid Research Review*, vol. 4, no. 3 (2014).

Of the 17 categories in CMS’s taxonomy, we selected 15 for analysis.<sup>16</sup> (See table 2.) For one of the 15 selected categories, other health and therapeutic services, we selected only three of its subcategories: occupational therapy; physical therapy; and speech, hearing, and language therapy. We selected these subcategories, because they provide the foundation for full community participation, including work and volunteer opportunities. Speech, hearing, and language therapy providers also work with individuals on swallowing and feeding, which constitutes an activity of daily living. Other subcategories we did not select—such as physician services, dental services, and prescription drugs—generally represented medical services routinely used by other populations in Medicaid, which we excluded from our definition of HCBS. All of the other categories in the HCBS taxonomy were included in their entirety.

**Table 2: Categories of Home- and Community-Based Services (HCBS) from the Centers for Medicare & Medicaid Services’ (CMS) HCBS Taxonomy Selected for Analysis**

HCBS category	Example services
Case management	<ul style="list-style-type: none"> <li>• Development of a written person-centered service plan</li> <li>• Assistance with gaining access to necessary services</li> </ul>
Round-the-clock services	Group home (assistance provided in a home-like environment where multiple people with a disability live)
Supported employment	<ul style="list-style-type: none"> <li>• Assistance to locate and obtain employment</li> <li>• Assistance to maintain employment</li> <li>• Career planning</li> </ul>
Day services	Day habilitation (regularly scheduled activities to assist in acquiring, retaining, and improving skills, such as self-help, socialization, and adaptive skills.)
Home-delivered meals	Prepared meals sent to a person’s home
Rent and food expenses for live-in caregiver	Payment for the additional costs of rent and food that can be attributed to an unrelated direct support worker living with the beneficiary
Home-based services	<ul style="list-style-type: none"> <li>• Personal care (assistance with activities of daily living such as bathing, dressing, and toileting, provided in a person’s home and possibly other community settings)</li> <li>• Homemaker (performance of light housekeeping tasks)</li> </ul>
Caregiver support	Respite (short-term services provided because a support person is absent or needs relief).
Mental health and behavior support services	<ul style="list-style-type: none"> <li>• Mental health assessment</li> <li>• Behavior support (services to encourage positive behaviors and to decrease challenging behaviors)</li> <li>• Counseling</li> </ul>

<sup>16</sup>We excluded the nursing and other services categories. We excluded the nursing category, because we excluded general medical services that are routinely used by other populations in Medicaid from our definition of HCBS. Other services—which includes goods and services, interpreter, and housing consultation—was excluded, because it did not appear to be specific to individuals with long-term care needs.

**Appendix II: Scope and Methodology**

<b>HCBS category</b>	<b>Example services</b>
Health and therapeutic services <sup>a</sup>	<ul style="list-style-type: none"> <li>• Occupational therapy</li> <li>• Physical therapy</li> <li>• Speech, hearing, and language therapy</li> </ul>
Services supporting participant direction	Financial management services (e.g., assistance to manage the disbursement of funds in a beneficiary-directed budget)
Participant training	Training provided to a beneficiary on topics such as treatment regimens and navigation of the service system
Equipment, technology, and modifications	<ul style="list-style-type: none"> <li>• Personal emergency response system</li> <li>• Home or vehicle modifications</li> </ul>
Nonmedical transportation	<ul style="list-style-type: none"> <li>• Transportation to and from waiver services</li> <li>• The purchase of public transit tokens or passes</li> </ul>
Community transition services	One-time set-up expenses for moving from an institutional setting to a residence

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

<sup>a</sup>Unlike the other categories in this table that were included in their entirety, we selected only three of the subcategories from the other health and therapeutic services category: occupational therapy; physical therapy; and speech, hearing, and language therapy. We selected these subcategories because they provide the foundation for full community participation, including work and volunteer opportunities. Speech, hearing, and language therapy providers also work with individuals on swallowing and feeding, which is an activity of daily living. Other subcategories we did not select, such as physician services, dental services, and prescription drugs, generally represented medical services routinely used by other populations in Medicaid, which we excluded from our definition of HCBS.

We used our resulting lists of categorized HCBS procedure codes to identify HCBS in the T-MSIS Other Services file. We examined both procedure codes and associated modifiers, and we considered matching claims to be those that included the procedure codes and all relevant claims modifiers listed by the states, with modifiers in any order.<sup>17</sup> We accounted for the possibility of duplicate claims by restricting our analysis to a single claim for the same service for the same beneficiary on the same day.

**Expenditure Analyses**

To assess total Medicaid health care expenditures, we used data from the T-MSIS Annual Use and Payment file, which contains summarized service use and payment information for each beneficiary who used at least one service or had at least one capitated or supplemental payment

<sup>17</sup>A procedure code modifier is a code added to a procedure code to provide additional information about the service or procedure; for example, the type of provider who rendered the service.

in a given calendar year.<sup>18</sup> Expenditures for each beneficiary are calculated by CMS based on information from the four T-MSIS claims files (Inpatient, Long-Term Care, Other Services, and Pharmacy). We limited our analysis to non-crossover payments, which excludes claims for which Medicare was the primary payer.<sup>19</sup> Total health care costs represent the sum of fee-for-service, capitated, and supplemental payments for each beneficiary.

We report our analysis of total health care expenditures for Medicaid-only beneficiaries with I/DD (i.e., those not dually eligible for Medicare), because services paid for by Medicare are not fully captured in T-MSIS. By contrast, most HCBS are paid for by Medicaid, even for beneficiaries with Medicare coverage. Average per-beneficiary expenditures for Medicaid-only beneficiaries with I/DD were annualized and calculated using the following formula:

$$\left[ \frac{\text{Total expenditures for Medicaid-only beneficiaries in 2019}}{\text{Total months enrollment for Medicaid-only beneficiaries in 2019}} \right] \times 12$$

To assess HCBS expenditures, we used data from the T-MSIS Other Services file to examine payments for services identified for each state as HCBS. Average per-beneficiary HCBS expenditures, overall and by service category, are annualized and calculated as follows:

$$\left[ \frac{\text{Total expenditures for HCBS in the waiver in 2019}}{\text{Total months of enrollment for beneficiaries who used at least one HCBS in 2019}} \right] \times 12$$

$$\left[ \frac{\text{Total expenditures for [HCBS category] in 2019}}{\text{Months of enrollment for beneficiaries who used one or more HCBS in [service category] in 2019}} \right] \times 12$$

In addition to assessing total Medicaid health care expenditures, and HCBS expenditures, we assessed the utilization of institutional long-term

<sup>18</sup>Capitated payments are periodic payments that state Medicaid agencies make to managed care organizations to provide services to enrollees and to cover other allowable costs, such as administrative expenses. Supplemental payments are amounts above the negotiated fee-for-service rate for a specific service provided to a specific beneficiary.

<sup>19</sup>Crossover claims are those for which Medicare is the primary payer. For these claims, Medicaid's responsibility is generally limited to copayment and deductible amounts within the scope of the state's Medicaid plan coverage.

care services, inpatient hospital services and emergency room services. We selected these services because they are generally costly, and may potentially be avoided when beneficiaries with I/DD have access to HCBS and other services to maintain their health and wellbeing. As above, to avoid underestimating utilization, we limited our analysis to Medicaid-only beneficiaries with I/DD.

- For institutional long-term care services, we used counts of beneficiaries from our population of interest who were present in the Annual Use and Payment expenditure summaries for that service type.
- For inpatient hospital services, we used counts of Medicaid-only beneficiaries with at least one claim or encounter for an inpatient service in 2019 as recorded in the Inpatient Services file.<sup>20</sup>
- For emergency room services, we calculated user rates based on the presence of claims or encounters with procedure codes for emergency room professional services in the Other Services file according to the following formula:

$$\left[ \frac{\text{Total months for Medicaid only beneficiaries with at least one emergency room visit in 2019}}{\text{Total months of enrollment for all Medicaid only beneficiaries, 2019}} \right]$$

To better understand how beneficiaries' health characteristics affected their total health care expenditures, we calculated average per-beneficiary expenditures for beneficiaries with and without an additional diagnosed behavioral health or chronic physical health condition. This analysis was limited to Medicaid-only beneficiaries in the five selected states that had usable diagnosis data: Colorado, Georgia, Indiana, Oklahoma, and South Dakota. For Florida, which was excluded due to missing diagnosis data, we conducted an alternative analysis. Specifically, we calculated average HCBS expenditures for beneficiaries who used one or more services from the HCBS category of mental health and behavior support services, compared with those who did not.

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<sup>20</sup>Managed care encounters are claims for services that are paid for managed care organizations as opposed to by state Medicaid programs directly. Colorado and Florida allow beneficiaries in their HCBS programs for I/DD to voluntarily enroll in comprehensive managed care plans for medical services. In 2019, about 9 percent of beneficiaries in Colorado's programs and about 31 percent of beneficiaries in Florida's program were ever enrolled in comprehensive managed care.

Because this analysis did not rely on diagnosis data, it was conducted for both Medicaid-only beneficiaries and those dually eligible for Medicare.

In order to get information necessary for our analyses, and to get perspectives on our results, we conducted interviews with, and received written responses from, state Medicaid officials and officials from state disability agencies that operate Medicaid HCBS programs in the six selected states.<sup>21</sup> For each state, we reviewed documentation for the HCBS programs, such as waiver applications, provider manuals, and information about program enrollment and spending. We also interviewed three national organizations: an organization representing state disability agencies, a provider organization specializing in I/DD services, and an advocacy group for individuals with I/DD.

We conducted our performance audit from October 2021 through April 2023 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

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<sup>21</sup>Each state is required to designate a single state agency to administer or supervise its Medicaid program, and states may designate other state and local agencies to administer and oversee components of their programs, including their HCBS programs. All of our selected states except for Colorado had delegated the day-to-day operation of their HCBS programs for I/DD to state disability agencies.



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# Appendix III: Schizophrenia Diagnoses and Antipsychotic Medication Use in Georgia's Comprehensive Program

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Our analyses found a high rate of diagnoses of schizophrenia and other psychotic disorders among Medicaid beneficiaries with intellectual or developmental disabilities (I/DD) in Georgia's home- and community-based services (HCBS) programs compared to four other states.<sup>1</sup> To better understand this difference, we conducted further analyses on beneficiaries in Georgia's comprehensive program targeting individuals with I/DD.<sup>2</sup> We focused on this program because nearly one in four beneficiaries (23 percent) enrolled in this program had a diagnosis falling within the category of schizophrenia and other psychotic disorders in 2019.<sup>3</sup> Past research on schizophrenia has estimated the prevalence to be less than 1 percent in the general population, and less than 3 percent in Medicaid populations.<sup>4</sup> The prevalence of schizophrenia and other psychotic disorders among beneficiaries with I/DD in the other four states we examined ranged from 6 to 12 percent.

For beneficiaries in Georgia's comprehensive HCBS program, we analyzed information on behavioral health diagnoses and prescription drug use to determine individual diagnoses for beneficiaries with schizophrenia and other psychotic disorders, and the extent to which

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<sup>1</sup>The four other states included in this analysis were Colorado, Indiana, Oklahoma, and South Dakota. Florida was excluded due to missing diagnosis data.

<sup>2</sup>We refer to waiver programs authorized under section 1915(c) of the Social Security Act that provide home- and community-based services as HCBS programs. Georgia, like several other states, has a comprehensive program that covers round-the-clock care and targets individuals with intellectual or developmental disabilities who need residential services, and a support program that provides services and supports needed for individuals to remain in the family home or in their own home.

<sup>3</sup>In Georgia's support program, 7 percent of beneficiaries had a diagnosis falling within the category of schizophrenia and other psychotic disorders.

<sup>4</sup>See J. McGrath et al., "Schizophrenia: A Concise Overview of Incidence, Prevalence, and Mortality," *Epidemiologic Reviews*, vol. 30 (2008): 70; and D. Pilon et al., "Prevalence, Incidence and Economic Burden of Schizophrenia among Medicaid Beneficiaries," *Current Medical Research and Opinion*, vol. 37, issue 10 (2021): 1811.

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**Appendix III: Schizophrenia Diagnoses and Antipsychotic Medication Use in Georgia's Comprehensive Program**

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beneficiaries used antipsychotic medications.<sup>5</sup> Antipsychotic medications are psychotropic medications that are used to treat behavioral health conditions such as schizophrenia and bipolar disorder. While antipsychotics can effectively treat symptoms such as hallucinations, they also carry the risk of side effects including sedation, cardiac arrhythmia, and diabetes.<sup>6</sup>

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**Prevalence of Individual Diagnoses**

Among beneficiaries in Georgia's comprehensive program who had a diagnosis falling within the category of schizophrenia and other psychotic disorders, the three most common individual diagnoses were schizophrenia, unspecified (41 percent of beneficiaries); schizoaffective disorder, bipolar type (28 percent of beneficiaries); and unspecified psychosis not due to a substance or known physiological condition (19 percent of beneficiaries).

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**Antipsychotic Medication Use**

Over 90 percent of beneficiaries with I/DD in Georgia with a diagnosis falling in the category of schizophrenia and other psychotic disorders had used antipsychotic medication in 2019, as did over two-thirds of those with a diagnosis for any other behavioral health condition. Almost a quarter of beneficiaries with I/DD with no behavioral health conditions also had a prescription for an antipsychotic medication. (See table 3.)

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<sup>5</sup>To describe the most common individual diagnoses among beneficiaries diagnosed with schizophrenia and other psychotic disorders, we conducted counts of the number of beneficiaries with each individual diagnosis code on at least one outpatient or inpatient claim in the Transformed Medicaid Statistical Information System (T-MSIS), the information system that collects state-reported Medicaid data. To calculate the percentage of beneficiaries who used an antipsychotic medication, we identified claims in T-MSIS for prescriptions or physician-administered antipsychotic medications. To identify antipsychotic medications, we used a list developed based on research and clinical expertise provided by a contractor for previous GAO work. The list included 126 behavioral health medications divided into 12 categories; for this work, we selected medications categorized as antipsychotics, which included 24 medications.

<sup>6</sup>See J. Muench and A. M. Hamer, "Adverse Effects of Antipsychotic Medications," *American Family Physician*, vol. 81, no. 5 (2010): 617, 619, 620.

**Appendix III: Schizophrenia Diagnoses and Antipsychotic Medication Use in Georgia's Comprehensive Program**

**Table 3: Antipsychotic Medication Use by Diagnosis Group among Beneficiaries with Intellectual or Developmental Disabilities in Georgia's Comprehensive Program, 2019**

<b>Diagnosis group</b>	<b>Number of beneficiaries</b>	<b>Number who used antipsychotic medication</b>	<b>Percent who used antipsychotic medication</b>
Schizophrenia and other psychotic disorders	686	649	95
Any other behavioral health condition	983	710	72
No behavioral health condition	1,310	296	23

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

Note: Analysis includes Medicaid beneficiaries aged 21 to 64 years enrolled in Georgia's comprehensive home- and community-based services program authorized under section 1915(c) of the Social Security Act in 2019. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs (not shown) include programs that provide services and supports needed for individuals to remain in the family home or in their own home. Analysis excludes beneficiaries dually eligible for Medicare.

While antipsychotic medications can constitute appropriate medical care for beneficiaries diagnosed with schizophrenia and some other mental health and developmental disorders, these results raise questions regarding the use of these medications.<sup>7</sup> Joint guidance for providers from the Substance Abuse and Mental Health Services Administration, the Centers for Medicare & Medicaid Services, the Health Resources and Services Administration, and the Administration for Community Living acknowledges that individuals with I/DD are often prescribed sedating medications such as antipsychotics as a way to manage disruptive behavior. The guidance emphasizes that such use is inappropriate due to a lack of evidence of efficacy and because the drugs can cause serious side effects.<sup>8</sup> After reviewing this analysis, CMS officials told us that the agency plans to reach out to Georgia in order to request further information and to discuss strategies to address possible excessive or unnecessary medication use.

<sup>7</sup>In addition to schizophrenia, some antipsychotic medications are approved by the Food and Drug Administration for other conditions including major depressive disorder, bipolar disorders, and autism spectrum disorder.

<sup>8</sup>See Substance Abuse and Mental Health Services Administration, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, and Administration on Community Living, "Guidance on Inappropriate Use of Antipsychotics: Older Adults and People with Intellectual and Developmental Disabilities in Community Settings" (Rockville, Md.: 2019), accessed December 14, 2022, <https://store.samhsa.gov/product/Guidance-on-Inappropriate-Use-of-Antipsychotics-Older-Adults-and-People-with-Intellectual-and-Developmental-Disabilities-in-Community-Settings/PEP19-INAPPUSE-BR>.

# Appendix IV: Prevalence of Behavioral Health and Chronic Physical Health Conditions

Tables 4 and 5 provide information about the percentage of Medicaid-only beneficiaries enrolled in home- and community-based services programs targeting intellectual or developmental disabilities (I/DD) who had a health condition in addition to their I/DD diagnosis in 2019 in five selected states. Table 4 shows the percentage of beneficiaries with mental health conditions and Table 5 shows the percentage of beneficiaries with chronic physical health conditions. Prevalence of substance use disorders was low, with fewer than 3 percent of beneficiaries in each program having an alcohol- or drug-related disorder. Conditions are not exclusive; a beneficiary may have more than one condition and be counted in more than one column or table.

**Table 4: Percentage of Beneficiaries with Intellectual or Developmental Disabilities and Mental Health Conditions by Program, 2019**

State and program type	Category of disorder							
	Anxiety	ADHD and related	Bipolar	Depressive	Personality	Post-traumatic stress	Schizophrenia and other psychotic	Other mental health
<b>Colorado</b>								
Comprehensive (N = 1,596)	20	16	20	13	4	8	15	6
Support (N = 2,201)	12	6	4	8	1	2	4	3
<b>Georgia</b>								
Comprehensive (N = 2,979)	16	18	16	14	2	2	23	5
Support (N = 1,685)	9	9	5	5	1	0	7	2
<b>Indiana</b>								
Comprehensive (N = 2,394)	17	16	18	15	4	4	11	4
Support (N = 3,738)	11	8	6	9	1	1	4	3
<b>Oklahoma</b>								
Comprehensive (N = 651)	26	26	28	19	2	3	18	6
Support (N = 528)	13	7	5	8	0	1	5	4
<b>South Dakota</b>								
Comprehensive (N = 541)	23	19	12	18	2	2	7	11
Support (N = 106)	14	8	4	10	1	0	3	5

Legend:

ADHD = attention-deficit/hyperactivity disorder

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

**Appendix IV: Prevalence of Behavioral Health  
and Chronic Physical Health Conditions**

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with intellectual or developmental disabilities in 2019; we excluded beneficiaries who were dually eligible for Medicare.

**Table 5: Percentage of Beneficiaries with Intellectual or Developmental Disabilities and Chronic Physical Health Conditions by Program, 2019**

State and program type	Chronic lung conditions <sup>a</sup>	Diabetes	Heart disease	High blood pressure	High cholesterol
<b>Colorado</b>					
Comprehensive (N = 1,596)	8	9	2	13	15
Support (N = 2,201)	6	5	1	6	5
<b>Georgia</b>					
Comprehensive (N = 2,979)	8	14	2	29	22
Support (N = 1,685)	5	8	1	21	15
<b>Indiana</b>					
Comprehensive (N = 2,394)	7	10	2	13	9
Support (N = 3,738)	4	5	1	6	4
<b>Oklahoma</b>					
Comprehensive (N = 651)	8	14	4	22	17
Support (N = 528)	7	8	1	12	10
<b>South Dakota</b>					
Comprehensive (N = 541)	4	11	2	12	15
Support (N = 106)	7	8	2	3	3

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home.

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with intellectual or developmental disabilities in 2019; we excluded beneficiaries who were dually eligible for Medicare.

<sup>a</sup>Chronic lung conditions include chronic obstructive pulmonary disease and asthma.

# Appendix V: Home- and Community-Based Services Expenditures and Utilization, Calendar Year 2019

Tables 6 and 7 provide information about Medicaid beneficiaries' home- and community-based services (HCBS) expenditures by state and program. These analyses include both Medicaid-only beneficiaries with intellectual and development disabilities (I/DD) and those dually eligible for Medicare. Across our six selected states, comprehensive waivers constituted the majority of HCBS spending and had substantially higher per-beneficiary expenditures.

**Table 6: Total Home- and Community-Based Services Expenditures by State and Program, 2019**

State	Support program	Comprehensive program	Total
Colorado	\$54,553,404	\$388,997,880	<b>\$443,551,284</b>
Florida	—	—	<b>\$916,862,908</b>
Georgia	\$60,685,998	\$511,293,147	<b>\$571,979,145</b>
Indiana	\$71,245,990	\$545,456,224	<b>\$616,702,214</b>
Oklahoma	\$23,509,419	\$256,331,963	<b>\$279,841,382</b>
South Dakota	\$1,775,915	\$110,061,397	<b>\$111,837,313</b>

Legend: — = not applicable

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home. Florida has a single HCBS program for individuals with intellectual or developmental disabilities (I/DD).

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with I/DD in 2019. Analysis includes both Medicaid-only beneficiaries with I/DD and those dually eligible for Medicare.

**Appendix V: Home- and Community-Based  
Services Expenditures and Utilization,  
Calendar Year 2019**

**Table 7: Average Per-Beneficiary Home- and Community-Based Services Expenditures by State and Waiver, 2019**

State	Support program	Comprehensive program	Overall average
Colorado	\$13,511	\$78,236	\$49,325
Florida	—	—	\$35,237
Georgia <sup>a</sup>	\$14,775	\$71,486	\$50,859
Indiana <sup>a</sup>	\$9,460	\$72,856	\$41,265
Oklahoma <sup>a</sup>	\$17,007	\$85,025	\$63,733
South Dakota	\$6,249	\$51,051	\$45,924

Legend: — = not applicable

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

Note: Programs refer to home- and community-based services (HCBS) waiver programs authorized under section 1915(c) of the Social Security Act. Comprehensive programs include state programs that cover round-the-clock care and target individuals who need residential services. Support programs include programs that provide services and supports needed for individuals to remain in the family home or in their own home. Florida has a single HCBS program for individuals with intellectual or developmental disabilities (I/DD).

Analysis includes Medicaid beneficiaries ages 21 to 64 who were enrolled in an HCBS program targeting individuals with I/DD in 2019. Analysis includes both Medicaid-only beneficiaries with I/DD and those dually eligible for Medicare.

<sup>a</sup>Support waivers in these states impose individual cost limits for beneficiaries.

Tables 8 and 9 show average per-beneficiary spending for, and utilization of, HCBS by category in calendar year 2019 by state.<sup>1</sup> While we analyzed 15 categories of HCBS, three of those categories are not presented in the tables due to low utilization: community transition services, home-delivered meals, and rent and living expenses for live-in caregiver. One other category, participant training, is not presented because none of our selected states covered services in that category.

<sup>1</sup>To determine HCBS utilization, we calculated user rates, which are defined as the percent of beneficiaries who used at least one service in that category in a year, weighted by beneficiaries' length of enrollment in the program.

**Appendix V: Home- and Community-Based  
Services Expenditures and Utilization,  
Calendar Year 2019**

**Table 8: Average Per-Beneficiary Home- and Community-Based Services (HCBS) Expenditures by Category among Users of Services in That Category, 2019**

<b>HCBS category</b>	<b>Colorado (N = 9,096)</b>	<b>Florida (N = 26,182)</b>	<b>Georgia (N = 11,341)</b>	<b>Indiana (N = 15,633)</b>	<b>Oklahoma (N = 4,434)</b>	<b>South Dakota (N = 2,508)</b>
Caregiver support	\$5,089	—	\$2,858	\$7,479	\$6,307	\$1,103
Case management	\$2,106	\$1,681	\$2,235	\$1,582	\$4,730	\$6,211
Day services	\$10,899	\$6,653	\$13,518	\$5,500	\$6,071	\$13,346
Equipment, technology, and modifications	\$865	\$1,173	\$1,992	\$949	\$1,677	\$666
Home-based services	\$6,696	\$19,444	\$28,929	\$31,450	\$30,211	\$5,328
Nonmedical transportation	\$2,567	\$3,322	\$1,727	\$1,711	\$2,186	—
Health and therapeutic services	—	\$5,473	\$445	\$1,766	\$1,818	\$352
Mental health and behavior support services	\$2,027	\$4,431	\$2,431	—	\$2,463	\$1,710
Round-the-clock services	\$56,382	\$47,211	\$72,801	\$69,592	\$49,000	\$36,538
Services supporting participant direction	\$714	\$839	\$794	—	—	—
Supported employment	\$9,936	\$2,972	\$3,335	\$1,716	\$10,575	\$2,086

Legend: — = not applicable

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

Note: Analysis includes Medicaid beneficiaries with intellectual or developmental disabilities (I/DD) aged 21 to 64 years enrolled in home- and community-based services programs authorized under section 1915(c) of the Social Security Act in selected states in 2019. Analysis includes both Medicaid-only beneficiaries and those dually eligible for Medicare. The “—” indicates that there was no utilization of services in that category in 2019 and therefore no per-beneficiary average could be calculated. Community transition services, home-delivered meals, and rent and living expenses for live-in caregiver categories are not shown due to low utilization. The participant training category is not shown because none of our selected states covered services in that category. Average per-beneficiary expenditures are among users of one or more services in that category.



**Appendix V: Home- and Community-Based  
Services Expenditures and Utilization,  
Calendar Year 2019**

**Table 9: Percentage of Beneficiaries with Intellectual or Developmental Disabilities Using Home- and Community-Based Services (HCBS) by Category, 2019**

<b>HCBS category</b>	<b>Colorado (N = 9,096)</b>	<b>Florida (N = 26,182)</b>	<b>Georgia (N = 11,341)</b>	<b>Indiana (N = 15,633)</b>	<b>Oklahoma (N = 4,434)</b>	<b>South Dakota (N = 2,508)</b>
Caregiver support	10.8	0.0 <sup>a</sup>	8.3	13.4	3.8	1.9
Case management	99.7	99.7	99.3	98.8	99.2	99.8
Day services	80.1	49.8	85.6	44.5	48.2	67.3
Equipment, technology, and modifications	14.5	23.5	26.1	1.9	29.2	51.2
Home-based services	18.4	61.9	33.5	50.0	71.1	8.6
Nonmedical transportation	85.4	38.0	0.5	50.2	72.9	0.0
Health and therapeutic services	0.0	6.0	2.5	0.3	28.2	0.1
Mental health and behavior support services	25.1	18.3	9.8	0.0 <sup>b</sup>	18.5	28.4
Round-the-clock services	55.1	32.6	35.5	27.4	55.0	79.2
Services supporting participant direction	0.8	1.1	16.3	0.0	0.0	0.0
Supported employment	28.1	6.3	9.0	8.3	37.4	26.4

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

Note: Analysis includes Medicaid beneficiaries with intellectual or developmental disabilities (I/DD) aged 21 to 64 years enrolled in home- and community-based services programs authorized under section 1915(c) of the Social Security Act in selected states in 2019. Analysis includes both Medicaid-only beneficiaries with I/DD and those dually eligible for Medicare. Community transition services, home-delivered meals, and rent and living expenses for live-in caregiver categories are not shown due to low utilization. The participant training category is not shown because none of our selected states covered services in that category.

<sup>a</sup>According to Florida Medicaid officials, respite care for adults is provided as one of a range of services included under personal care services, and it is not possible to distinguish respite from personal care services based on the procedure code. Personal care is categorized as a home-based service.

<sup>b</sup>We were unable to analyze use of mental health and behavior support services in Indiana, because procedure codes for these services were not available at the time of analysis. Indiana officials we spoke with said that although these mental health and behavioral support are not waiver services, they are covered for beneficiaries with I/DD through Indiana's Medicaid state plan.

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# Appendix VI: GAO Contact and Staff Acknowledgments

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## GAO Contact

Jessica Farb at (202) 512-7114 or [farbj@gao.gov](mailto:farbj@gao.gov)

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## Staff Acknowledgments

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