IssueBrief

MACPAC

June 2025 Advising Congress on Medicaid and CHIP Policy

Access in Brief: Differences in Demographics and Access to Care by Source of Health Coverage for Adults with Intellectual and Developmental Disabilities

Medicaid is the largest payer of long-term services and supports (LTSS), including home- and community-based services (HCBS) for individuals with intellectual and developmental disabilities (I/DD) (GAO 2023). Individuals eligible for Medicaid based on disability accounted for about $205 billion of federal and state program spending in fiscal year (FY) 2021, more than any other enrollment group (Rudowitz et al. 2024). Average Medicaid expenditures for individuals with I/DD are two to five times higher than for all Medicaid beneficiaries with disabilities (GAO 2023). However, research is limited on individuals with I/DD and their access to care. This brief examines differences in the demographic and socioeconomic characteristics of adults with I/DD, as well as access to care for selected services, by their source of health coverage: any Medicaid coverage or private only coverage.[1]

Data on adults with I/DD are limited. For example, no U.S. population-based surveys or self-reported surveys on adult health currently ask questions about intellectual and developmental disability in adulthood (Benevides et al. 2024, Hartman and Turner 2023). Recent research has begun to examine the demographic and service utilization characteristics of Medicaid beneficiaries with I/DD, and has even compared Medicaid beneficiaries with I/DD to those dually eligible for Medicaid and Medicare (MACPAC 2024a, 2020; GAO 2023). However, these analyses do not disagreggate the characteristics and experiences of adults with I/DD by source of health coverage beyond Medicaid and Medicare, or compare them with private insurance.

Health care claims data, including Medicaid claims, have become key resources for examining health care characteristics and outcomes among individuals with I/DD.[2] These datasets offer access to large, diverse populations and include diagnostic codes—such as those from the International Classification of Diseases, Ninth and Tenth Revisions, Clinical Modification (ICD-9-CM and ICD-10-CM)—that researchers can use to identify individuals with I/DD and examine their health care diagnoses and service utilization (ASPE 2025, MACPAC 2024b). However, there are important limitations. Claims data may overlook individuals whose disabilities are not the primary focus of a medical visit or who experience functional impairments without having a formal diagnosis. Additionally, these data only capture those enrolled in health care or insurance programs and offer limited insight into cognitive or functional capacities, which are critical for defining I/DD (ASPE 2025, MACPAC 2024b). There is also no standardized approach or agreement on which codes to include, leading to inconsistencies across studies and data systems (ASPE 2025). Administrative data collected through HCBS assessments and care planning also have the potential to improve demographic data quality for Medicaid beneficiaries with I/DD, but are rarely integrated into the Transformed Medicaid Statistical Information System (MACPAC 2024b).

As an initial step toward addressing the gap in available research on people with I/DD, this issue brief highlights data from the National Survey on Health and Disability (NSHD). We analyzed data from the 2021-2024 NSHD, which surveys adults with disabilities and chronic health conditions including adults with I/DD (University of Kansas Institute for Health and Disability Policy Studies 2024). We compared adults age 18-64 with I/DD across sources of health coverage. We examined differences in their self-reported demographic characteristics including age, race and ethnicity, and socioeconomic characteristics. We also examined their access to selected services, including dental care and HCBS.

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The survey's small sample size (n=599 unweighted) limits our ability to present detailed findings, such as by all racial and ethnic groups. These limitations are described in our methods section. Additionally, these analyses are descriptive and do not adjust for socioeconomic or other factors that may also be associated with the differences, or attempt to establish the reasons for these differences.

Among the study population, our analysis of the NSHD identified several noteworthy differences in how adults with I/DD who are enrolled in Medicaid experience health coverage relative to those with private only coverage.

- Medicaid enrollees with I/DD reported identifying as male more often than their counterparts with private-only coverage (66.6 percent versus 24.8 percent) (Table 2).
- A significantly larger share of respondents with private-only coverage (93.2 percent) reported incomes at or above 138 percent of the federal poverty level (FPL), compared to those with Medicaid coverage (66.3 percent) (Table 2).
- Over 90 percent of all respondents with I/DD (90.5 percent) reported being worried about losing their housing within the next six months, and both Medicaid enrollees and individuals with private-only coverage reported a wide variety of living arrangements (Table 2).
- Adults with I/DD and Medicaid coverage reported higher rates of working part-time (79.7 percent) than individuals with private-only coverage (43.9 percent) (Table 3).
- More than half of all respondents (66.0 percent) reported that not having access to personal assistance services (PAS) impacted their ability to work for pay (Table 3).
- Over two-thirds of respondents with Medicaid coverage (66.7 percent) needed help at home due to health or disability, compared to fewer than half of those with private-only coverage (37.6 percent) (Table 5).
- Among adults with Medicaid who received paid HCBS, the majority (72.2 percent) self-directed their HCBS (Table 5).

Health Coverage

The majority of survey respondents with I/DD who were age 18-64 (54.7 percent) reported having some Medicaid coverage (Table 1). One-third of respondents were enrolled in private only coverage. Adults with I/DD had relatively low rates of uninsurance; just 6.8 percent were uninsured compared to an estimated 11.5 percent of all U.S. adults age 18-64 in the first quarter of 2024 (ASPE 2024a).

TABLE 1. Sources of Health Coverage for Adults Age 18-64 with Intellectual and Developmental Disabilities, 2021—2024

Health coverage grouping	Total	Sources of coverage	Share of beneficiaries
Any Medicaid	**54.7%**	Medicaid and private	22.3%
		Medicaid and Medicare with no private (dually eligible)	16.7
		Medicaid only	15.7
Private only	**33.3**	Private only	33.3
Other coverage or uninsured	**12.0**	Other coverage (e.g., Medicare alone or Medicare with private)	5.2
		Uninsured	6.8

Notes: "Any Medicaid" includes individuals only enrolled in Medicaid, enrolled in Medicaid with private coverage, and people who were dually eligible for both Medicaid and Medicare with no private coverage. "Private only" includes individuals who were exclusively enrolled in health insurance through an employer, family member, or enrolled in exchange coverage.

Source: MACPAC, 2025, analysis of 2021-2024 National Survey on Health and Disability.

Population Demographics

In the analyses below, we examine self-reported demographic characteristics of adults with I/DD enrolled in various types of health coverage (Table 2). We also compare outcomes related to employment, earned annual income, and the impact of accessing PAS on the ability to work (Table 3).

Men comprised nearly half of all survey respondents and made up over two-thirds (66.6 percent) of the respondents who were enrolled in Medicaid (Table 2). This is consistent with research among the general adult population in the United States, which found that men are more likely to be diagnosed with I/DD than women (GAO 2023).

Approximately three-quarters of adults with I/DD (75.4 percent) reported earning at least 138 percent of the federal poverty level, which was $20,783 for an individual in 2024 (ASPE 2024b). Low-income respondents (under 138 percent FPL) made up one third of the population with Medicaid (33.7 percent).

While data on race and ethnicity were limited due to sample size, the majority of respondents identified as white (76.8 percent). There were no statistically significant differences in race and ethnicity by source of coverage.

A large majority of respondents (90.5 percent) had stable housing but worried about losing it in the next six months. The largest share of individuals did not pay rent (42.4 percent) and lived with children, parents, or extended family (44.4 percent). Adults with I/DD with Medicaid were much more likely to live with children, parents, or extended family (61.1 percent) than those with private coverage (26.4 percent).

TABLE 2. Selected Demographic and Socioeconomic Characteristics of Adults Age 18-64 with Intellectual and Developmental Disabilities, by Source of Health Coverage, 2021–2024

Demographic characteristics	Total	Any Medicaid	Private only
Age			
18–40	**60.4%**	63.4%	60.1%
41–64	**39.6**	36.6	39.9
Gender			
Male	**49.2**	66.6	24.8*
Female	**20.1**	17.0	25.0
Transgender or non-binary[1]	**30.7**	16.4	50.2*
Income			
Less than 138 percent FPL	**24.6**	33.7	–
138 percent FPL or higher	**75.4**	66.3	93.2*
Race and ethnicity			
White, non-Hispanic	**76.8**	72.9	79.2
Hispanic	**17.3**	20.3	–
Black, non-Hispanic	**10.1**	–	–

Demographic characteristics	Total	Any Medicaid	Private only
Multi-racial, non-Hispanic	**21.8**	19.7	24.2
Housing stability[2]			
Has a place to live today, but is worried about losing it in the next 6 months	**90.5**	93.3	87.7
Does not have a steady place to live	**7.7**	–	–
Home ownership[2]			
Lives long-term with friends or family (not paying rent)	**42.4**	41.3	47.2
Rents	**36.1**	41.0	27.6
Owns	**9.1**	–	19.1
Other	**12.4**	–	–
Living situation			
With children, parents, or extended family	**44.4**	61.1	26.4*
With spouse, partner or significant other	**15.3**	–	23.2
Alone	**14.9**	14.2	–
With some combination of spouse, parents, children, and extended family	**11.6**	4.3	24.0*
With those not related	**11.2**	–	–

Notes: FPL is federal poverty level. The question regarding respondents' race and ethnicity permits multiple, non-mutually exclusive selections. "Other" in the home ownership category is an open-ended question where respondents could submit more information. "Any Medicaid" includes individuals only enrolled in Medicaid, enrolled in Medicaid with private coverage, and people who were dually eligible for both Medicaid and Medicare with no private coverage. "Private only" includes individuals who were exclusively enrolled in health insurance through an employer, family member, or enrolled in exchange coverage. The "any Medicaid" and "private only" categories are mutually exclusive, and significance testing was only conducted between these two subpopulations.

[1] Of survey respondents, 30.7 percent identified as transgender or non-binary, which is higher than the national estimate of 1.6 percent among the adult population in the United States. (Brown 2022). The NSHD data highlight an important self-identification element. This is consistent with existing literature using the Behavioral Risk Factor Surveillance System survey, which found that transgender individuals experience higher rates of disability (defined as any functional limitation) than their cisgender counterparts (Smith-Johnson 2022).

[2] Data not available for 2021.

* Indicates the difference from "any Medicaid" coverage is statistically significant at the 95 percent confidence level.

– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.

Source: MACPAC, 2025, analysis of 2021-2024 National Survey on Health and Disability.

Employment

The findings suggest that adults with I/DD with any Medicaid coverage have higher rates of part-time employment (Table 3). Almost 70 percent of Medicaid enrollees earned less than $20,000 annually, compared with 37.6 percent of adults with private coverage.

The data also highlight the important role PAS play in enabling adults with I/DD to maintain employment. Adults with Medicaid who received HCBS reported that receiving help at home with personal care or daily activities allowed them to work a paying job (44.7 percent). Among respondents who needed HCBS and did not receive

services or did not receive enough services, a majority (66.0 percent) responded that not receiving needed PAS affected their ability to work or work more at a paying job.

TABLE 3. Employment Characteristics of Adults Age 18-64 with Intellectual and Developmental Disabilities, 2021—2024

Employment characteristics	Total	Any Medicaid	Private only
Employed			
No, not working for pay right now[1]	**49.7%**	53.5%	43.2%
Yes, working for pay	**44.8**	41.0	53.5
Type of employment			
Part-time	**63.4**	79.7	43.9*
Full-time	**36.6**	–	56.1
Time in current job			
Less than two years	**44.5**	44.8	45.7
Two years or more	**55.5**	55.2	54.3
Help with personal care or daily activities allows for paid work[2]			
Yes	**44.3**	44.7	–
No	**55.7**	55.3	–
Not receiving needed personal assistance affects ability to work or work more at a paying job[2]			
Yes	**66.0**	–	–
No	–	–	–
Annual employment income[3]			
$0 - $19,999	**53.6**	69.9	37.6*
$20,000 - $49,999	**26.3**	–	25.5
$50,000 or greater	**20.2**	–	36.8

Notes: "Any Medicaid" includes individuals only enrolled in Medicaid, enrolled in Medicaid with private coverage, and people who were dually eligible for both Medicaid and Medicare with no private coverage. "Private only" includes individuals who were exclusively enrolled in health insurance through an employer, family member, or enrolled in exchange coverage. The "any Medicaid" and "private only" categories are mutually exclusive, and significance testing was only conducted between these two subpopulations.

[1] Includes individuals who are not employed but are currently looking for work.

[2] Not available in 2023-2024.

[3] Data not available for 2021.

* Indicates the difference from "any Medicaid" coverage is statistically significant at the 95 percent confidence level.

– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.

Source: MACPAC, 2025, analysis of 2021-2024 National Survey on Health and Disability.

Access to Care

In this section, we compare the experiences of adults with I/DD in accessing dental care and HCBS across sources of health coverage (Tables 4 and 5). The data suggest that adults with I/DD face unmet need regardless of health coverage.

Dental care

There were no statistically significant differences in access to dental care by source of coverage (Table 4). The majority of respondents (61.7 percent) reported being able to get necessary dental care in the prior year. Individuals with any Medicaid or private only coverage had similar rates of access to dental care.

TABLE 4. Access to Dental Care for Adults Age 18-64 with Intellectual and Developmental Disabilities, 2022–2024

Access to dental care	Total	Any Medicaid	Private only
Received all dental services in the past 12 months			
Yes	**61.7%**	63.6%	66.4%
No	**34.0**	33.0	30.7

Notes: "Any Medicaid" includes individuals only enrolled in Medicaid, enrolled in Medicaid with private coverage, and people who were dually eligible for both Medicaid and Medicare with no private coverage. "Private only" includes individuals who were exclusively enrolled in health insurance through an employer, family member, or enrolled in exchange coverage. The "any Medicaid" and "private only" categories are mutually exclusive, and significance testing was only conducted between these two subpopulations.

Source: MACPAC, 2025, analysis of 2021-2024 National Survey on Health and Disability.

Home- and community-based services

Individuals with any Medicaid coverage were more likely than those with private coverage only to need personal care at home (66.7 percent and 37.6 percent, respectively) (Table 5). However, those with private coverage were significantly more likely to report that they needed personal care but did not get it (62.4 percent compared to 23.0 percent). When asked whether "you have been able to get all the personal assistance services you need in the past twelve months," those with private coverage who needed HCBS were more likely than Medicaid enrollees to report that they were not able to get all the care they needed (86.9 percent compared to 54.8 percent). It is important to note that sample sizes were limited for the number of respondents with private coverage who received HCBS or paid HCBS, which limits direct comparisons by coverage type among HCBS beneficiaries. Among respondents with Medicaid who needed HCBS, about half (54.8 percent) reported unmet need. The majority of respondents with Medicaid who received paid HCBS self-directed those services (72.2 percent). For individuals with Medicaid who needed HCBS, over half had trouble finding workers (51.3 percent).

TABLE 5. Access to Personal Assistance Services for Adults Age 18-64 with Intellectual and Developmental Disabilities, 2021–2024

Access to PAS	Total	Any Medicaid	Private only
Receives personal care at home due to health or disability[1]			
No, I do not need this type of help in my home	**46.9%**	33.3%	62.4%*
Yes, needed this type of help:	**53.1**	66.7	37.6*
I need this type of help but do not get it	**35.3**	23.0	62.4*
I get all the help I need	**43.5**	53.6	–
I do not get enough help	**21.2**	23.3	–
Support staff is paid[1]			
Yes	**37.0**	29.3	–
No	**63.0**	70.7	–
Self-directs services			
Yes	**74.0**	72.2	–
No	–	–	–
Able to get all PAS in the past 12 months (if needed)[2]			
Yes	**33.4**	45.2	–
No	**66.4**	54.8	86.9*
Had problems finding PAS or support workers in the past 12 months[2]			
Yes	**49.4**	51.3	–
No	**50.6**	48.7	51.6

Notes: PAS is personal assistance services. "Any Medicaid" includes individuals only enrolled in Medicaid, enrolled in Medicaid with private coverage, and people who were dually eligible for both Medicaid and Medicare with no private coverage. "Private only" includes individuals who were exclusively enrolled in health insurance through an employer, family member, or enrolled in exchange coverage. "Any Medicaid" and "private only" are mutually exclusive and significance testing was only conducted between these two subpopulations.

[1] Harmonized across years 2021, 2022, and 2023-2024 due to sample size limitations.

[2] Data not available for 2021.

* Indicates the difference from any Medicaid coverage is statistically significant at the 95 percent confidence level.

– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.

Source: MACPAC, 2025, analysis of 2021-2024 National Survey on Health and Disability.

Data and Methods

The data in this brief are from the 2021–2023/2024 waves of the NSHD. Data were collected annually via a private and confidential online survey that was completed by adults with I/DD, who may also use a proxy respondent such as a family member or PAS provider. Recruitment of participants includes partnerships with disability organizations across the United States Outreach for the 2022 wave of the survey, which yielded the largest number of responses yet, included partnerships with over 80 disability and condition-specific organizations, as well as emails to individuals who participated in previous years and gave permission to be contacted again.

Differences between private only and any Medicaid coverage discussed in this brief were computed using Z-tests and are significant at the 0.05 level.

The NSHD is administered by the University of Kansas Institute for Health & Disability Policy Studies (KU-IHDPS, https://ihdps.ku.edu/nshd) and funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR project #90IFRE0050). The contents of this publication do not necessarily represent the policy of NIDILRR, the Administration for Community Living (ACL), or the U.S. Department of Health and Human Services (HHS) and readers should not assume endorsement by the federal government.

I/DD self-identification

Beginning in 2019, the NSHD asked respondents to self-identify their disability or health condition via an open-ended question. Individuals who selected having an intellectual and developmental disability reported the following conditions: Autism Spectrum Disorder, Bachmann Bupp Syndrome, chromosome 12q duplication, Down Syndrome, Fragile X syndrome, I/DD, Noonan syndrome, Rett syndrome, Rubinstein-Taybi syndrome, schizencephaly, and White/Sutton syndrome.

Health coverage groupings

To maximize comparability by source of health coverage, multiple response options from the survey were combined into two categories presented in this brief: any Medicaid and private only (Table 1). “Any Medicaid” includes individuals only enrolled in Medicaid, enrolled in Medicaid with private coverage, and people who were dually eligible for both Medicaid and Medicare with no private coverage. “Private only” includes inividuals who were exclusively enrolled in health insurance through an employer or a family member’s employer, health insurance purchased through the exchange, TRICARE, or other military insurance. “Any Medicaid” and “private only” are mutually exclusive and significance testing was only conducted between these two subpopulations. This analysis did not include people who were uninsured or people with other coverage types such as Medicare only or Medicare with private coverage.

Limitations

One important limitation to note is the small sample size of responses. Each wave of the NSHD was weighted to be representative of adults age 18 to 64 with one or more disabilities with internet access using the American Community Survey and the September Health Reform Monitoring Survey for each respective year. Weights accounted for gender, race and ethnicity, educational attainment, income, metropolitan status, mental health status, and disability type. Although the variable estimates were weighted, the weights used in this analysis were not designed specifically for the I/DD population.

Endnotes

[1] "Any Medicaid" includes individuals only enrolled in Medicaid, enrolled in Medicaid with private coverage, and people who were dually eligible for both Medicaid and Medicare with no private coverage. "Private only" includes individuals who were exclusively enrolled in health insurance through an employer, family member, or enrolled in exchange coverage.

[2] Health care claims are requests for payment providers submit to insurers for services delivered to patients, and claims data are the detailed information captured from these requests, including diagnoses, procedures, costs, and service use.

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