

Access in Brief: Adults with Intellectual Disabilities and Developmental Disabilities

Medicaid provides health coverage to millions of Americans, including people with intellectual disabilities and developmental disabilities (ID/DD). This brief examines access to Medicaid coverage for adults with ID/DD using data for fiscal years (FY) 2017 to 2018, the most recent years available. In FY 2018, Medicaid covered more than 86.7 million enrollees nationwide (MACPAC 2019). The number of Medicaid beneficiaries with ID/DD is more than 1.2 million (Larson, et al. 2021). Limited data on the ID/DD population in Medicaid inhibit a more precise estimate of Medicaid beneficiaries with ID/DD and further support the need for this research.¹

Recent analyses of Medicaid beneficiaries with ID/DD often do not disaggregate results about health status, service use, age and dually eligible status, and experience with home- and community-based services (HCBS) by demographic characteristics, including race and ethnicity (MACPAC 2020). Current literature examining access to care among adults with disabilities highlights a need for improved accuracy among disability prevalence data and renewed efforts to include disability status in health care data collection (Hall 2022, NCD 2022). A recent synthesis of disability prevalence studies further emphasizes the correlation between disability status and increased rates of avoidable, disparate health outcomes (Mitra et al. 2022). These studies recommend expanding existing literature by examining the experience of beneficiaries with ID/DD at the intersection of race, sex, and other demographic characteristics to identify potential gaps in receipt of care among the heterogenous disability community (Mitra et al. 2022, Varadaraj et al. 2021).

In this issue brief, we compare the characteristics of adult Medicaid beneficiaries with ID/DD across racial and ethnic groups and by Medicaid-only or dually eligible status. We use survey data from the National Core Indicators In-Person Surveys (NCI-IPS) collected in FY 2017 and FY 2018 to analyze demographics, health status, service use, and experience with Medicaid HCBS. We stratify the results by race and ethnicity, dually eligible status, and age to understand how access, health status, and service use may differ by type of demographic characteristic within the ID/DD community. The NCI-IPS comprises data from 48 states, the District of Columbia, and 22 sub-state entities, each with their own sampling methods. For this reason, although the data are aggregated for national analysis in this brief, there are limitations. 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. We describe additional detail on the approach and limitations in the data and methods section later in this issue brief.

Among adults with ID/DD who are covered by Medicaid, there were several distinctions in reported residency between Medicaid-only beneficiaries and people dually eligible for Medicaid and Medicare (Table 2). For example, a greater share of Medicaid-only beneficiaries resided in an urban setting within their own home, a family house, or an apartment compared with dually eligible beneficiaries. For all Medicaid and dually eligible beneficiaries with ID/DD who received HCBS, about a quarter reported wanting to live in a different residential setting.

Reported health status and service use among all adult Medicaid beneficiaries with ID/DD varied by race and ethnicity (Table 3). Hispanic beneficiaries were more likely to report always needing assistance with mobility compared with white, non-Hispanic beneficiaries. Regarding service use, both Black, non-Hispanic beneficiaries and Hispanic beneficiaries were less likely to have had a dental exam in the past year compared with white, non-Hispanic beneficiaries.



There were fewer variations in HCBS experience across race and ethnicity (Table 6). Compared with white, non-Hispanic beneficiaries, a smaller share of Hispanic beneficiaries was able to contact their case manager or service coordinator when they wanted. However, contrary to existing literature, a greater share of white, non-Hispanic beneficiaries reported poor health outcomes compared with other races and ethnicities (CDC 2022a, Table 3).

Population Demographics

In the analyses below, we compare the demographics of white, non-Hispanic Medicaid beneficiaries with ID/DD to six other racial and ethnic groups (Table 1). We also compare those covered by Medicaid only with those dually eligible for Medicaid and Medicare (Table 2). In our analysis by race and ethnicity, the majority of Medicaid beneficiaries with ID/DD were white, non-Hispanic (68.6 percent). Beneficiaries who identified as Black, non-Hispanic comprised 16.7 percent of all Medicaid beneficiaries with ID/DD; Hispanic beneficiaries comprised 11.0 percent; Asian, non-Hispanic beneficiaries comprised 2.4 percent; American Indian and Alaskan Native (AIAN), non-Hispanic beneficiaries comprised 0.9 percent; Pacific Islander, non-Hispanic beneficiaries comprised 0.2 percent; and all other or multi-racial, non-Hispanic adult Medicaid beneficiaries made up 1.6 percent (Table 2).²

Race and ethnicity comparison

The demographic characteristics of adults with ID/DD differed by race and ethnicity (Table 1). Generally, white, non-Hispanic beneficiaries were more likely to have reported English as their primary language compared with Hispanic beneficiaries; Asian, non-Hispanic beneficiaries; and beneficiaries who identified with other single or multiple races, non-Hispanic. When grouped by age, white, non-Hispanic beneficiaries were older compared with Black, non-Hispanic beneficiaries; Hispanic beneficiaries; Asian, non-Hispanic beneficiaries; and beneficiaries who identified with other single or multiple races, non-Hispanic.

Insurance coverage, type of residence, and guardianship also varied by race and ethnicity. White, non-Hispanic beneficiaries were more likely to be covered by Medicaid and Medicare than beneficiaries identifying as Black, non-Hispanic; Hispanic; Asian, non-Hispanic; Pacific Islander, non-Hispanic; and non-Hispanic beneficiaries who identified with other single or multiple races. The majority of all adult beneficiaries with ID/DD resided in HCBS settings, such as their own home or a family home. Notably, beneficiaries with ID/DD who identified as Black, non-Hispanic; Hispanic; Asian, non-Hispanic; and other or multi-racial, non-Hispanic were more likely to reside in their own home, family house, or apartment compared with white, non-Hispanic beneficiaries. Lastly, a larger prevalence of white, non-Hispanic beneficiaries with ID/DD had a legal or court-appointed guardian compared with Black, non-Hispanic; Hispanic; and Asian, non-Hispanic beneficiaries.

TABLE 1. Demographic Characteristics of Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD) by Race and Ethnicity, FYs 2017–2018

Demographic characteristics	Share of all adult Medicaid beneficiaries with ID/DD							
	Total ¹	White, non-Hispanic	Black, non-Hispanic	Hispanic	Asian, non-Hispanic	AIAN, non-Hispanic	Pacific Islander, non-Hispanic	Other or multi-racial, non-Hispanic
Primary language								
English	93.8%	98.8%	98.2%	60.8%*	75.9%*	98.7%	97.2%	87.8%*
Other	6.2	1.2	1.8	39.2*	24.1*	–	–	12.2*
Age								
Under 65	90.5	88.3	94.1*	97.2*	97.8*	88.1	95.4*	94.7*
18–25	17.6	15.6	15.8	29.9*	27.5*	19.1	–	27.4*



Demographic characteristics	Share of all adult Medicaid beneficiaries with ID/DD							
	Total ¹	White, non-Hispanic	Black, non-Hispanic	Hispanic	Asian, non-Hispanic	AIAN, non-Hispanic	Pacific Islander, non-Hispanic	Other or multi-racial, non-Hispanic
26–44	40.8%	37.8%	45.8%*	47.9%*	51.1%*	40.1%	52.9%	51.1%*
45–54	16.3	17.1	17.6	11.1*	10.9*	18.1	–	9.4*
55–64	15.8	17.7	14.9*	8.3*	8.4*	10.9*	–	6.8*
65 and above	9.5	11.7	5.8*	2.8*	2.2*	–	–	5.3*
Insurance coverage²								
Medicaid only	46.5	40.4	60.5*	58.9*	61.6*	42.4	67.4*	56.7*
Medicaid and Medicare	53.5	59.6	39.5*	41.1*	38.4*	57.6	32.6*	43.3*
Type of residence								
Own home, family house, or apartment	57.6	53.4	61.5*	75.1*	68.3*	59.2	52.9	71.2*
Group home or adult family home or foster home or host home	35.9	39.8	31.8*	20.7*	27.0*	35.8	–	24.6*
Assisted living facility or residential care facility	5.6	5.9	5.6	3.7*	4.5	–	–	3.1*
Other ³	0.8*	0.9	0.6	–	–	–	–	–
Guardian								
Person has legal or court-appointed guardian	44.5	49.1	36.4*	30.6*	35.3*	45.3	38.8	43.8
Sex								
Male	58.7	58.0	60.5*	59.0	65.0*	62.4	36.5*	56.7
Female	41.3	42.0	39.5*	41.0	35.0*	37.5	63.5*	43.3
Type of residential area								
Urban	91.3	88.7	96.1*	98.7*	99.2*	83.2	93.1	96.8*
Rural	8.7	11.3	3.9*	1.3*	–	16.8	–	–
Marital status								
Single, never married	95.9	95.6	96.7*	96.7*	97.6*	96.1	100.0*	93.7
Married	1.7	1.8	1.1*	1.7	1.6	–	–	–
Single, married in the past	2.4	2.6	2.2	1.6*	–	–	–	–

Notes: ID/DD is intellectual disabilities and developmental disabilities. FY is fiscal year. AIAN is American Indian or Alaska Native. The values shown here include self-reported information from all individuals 18 years old and older covered by Medicaid or Medicaid and Medicare with a non-missing race and ethnicity from FYs 2017 to 2018.

¹ Total ID/DD beneficiaries with a non-missing race and ethnicity.



² The difference between total Medicaid only and total Medicaid and Medicare is statistically significant at the 95 percent confidence level.

³ “Other” does not include people who are homeless or residing in a temporary shelter. This category was not reported due to the small sample size.

* Indicates the difference from white, non-Hispanic 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, 2023, analysis of FYs 2017–2018 NCI-IPS.

Dually eligible comparison

In 2020, 36 percent of all dually eligible beneficiaries qualified for Medicaid based on their receipt of supplemental security income (SSI) benefits (MACPAC and MedPAC 2023).³ SSI is available to people with limited incomes and assets who are under 65-years-old and disabled or who are 65-years-old or older. Of the adult Medicaid beneficiaries with ID/DD included in our analysis, some individuals had Medicaid-only coverage and some were dually eligible. We found that demographic characteristics differed between these two groups (Table 2).

Dually eligible Medicaid beneficiaries with ID/DD were more likely than Medicaid only beneficiaries with ID/DD to be 45-years-old or older, female, native English speakers, and white, non-Hispanic.³ With regard to residency, dually eligible beneficiaries were more likely to be residents of a group home, adult family home, foster home, or host home; residents of an assisted living facility or residential care facility; or have a legal or court-appointed guardian.

TABLE 2. Demographic Characteristics of Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD) Stratified by Medicaid-only Beneficiaries and People Dually Eligible, FYs 2017–2018

Demographic characteristics	Total ¹	Medicaid only	Medicaid and Medicare
Primary language			
English	93.8%	91.2%	95.8%*
Other	6.2	8.8	4.2*
Age			
Under 65	90.5	98.0	83.5*
18–25	17.6	30.8	6.4*
26–44	40.8	48.6	32.8*
45–54	16.3	11.1	20.9*
55–64	15.8	7.5	23.4*
65 or older	9.5	2.0	16.5*
Type of residence			
Own or family house or apartment	57.6	66.2	48.7*
Group home or adult family home or foster home or host home	35.9	29.1	43.0*
Assisted living facility or residential care facility	5.6	3.9	7.2*
Other ²	0.8	0.4	1.0*
Guardian			
Person has legal or court-appointed guardian	44.6	43.2	46.5*



Demographic characteristics	Total ¹	Medicaid only	Medicaid and Medicare
Sex			
Male	58.6%	60.8%	56.6*%
Female	41.4	39.1	43.4*
Type of residential area			
Urban	91.3	92.6	89.7*
Rural	8.7	7.4	10.3*
Marital status			
Single, never married	95.9	97.4	94.6*
Married	1.7	1.2	2.2*
Single, married in the past	2.4	1.4	3.2*
Race and ethnicity			
White, non-Hispanic	68.6	59.5	76.1*
Black, non-Hispanic	16.7	21.6	12.2*
Hispanic	11.0	14.3	8.7*
Asian, non-Hispanic	2.4	3.3	1.8*
Native Indian and Alaska Native, non-Hispanic	0.9	0.8	1.0*
Pacific Islander, non-Hispanic	0.2	0.3	0.1
Other or multi-racial, non-Hispanic	1.6	1.9	1.3*

Notes: ID/DD is intellectual disabilities and developmental disabilities. FY is fiscal year. The values shown here include self-reported information from all individuals 18 years old and older covered by Medicaid only or Medicaid and Medicare from FYs 2017 to 2018.

¹ Total ID/DD beneficiaries with non-missing dually eligible status and demographic characteristics.

² “Other” does not include people who are homeless or residing in a temporary shelter. This category was not reported due to the small sample size.

* Indicates the difference from Medicaid-only is statistically significant at the 95 percent confidence level.

Source: MACPAC, 2023, analysis of FYs 2017–2018 NCI-IPS.

Health Status

Health status for adult Medicaid beneficiaries with ID/DD varies by race and ethnicity (Table 3). Compared with white, non-Hispanic beneficiaries, Hispanic beneficiaries were more likely to always need assistance with mobility and less likely to be able to navigate their environment with aids or use a wheelchair independently.

The majority of adult beneficiaries with ID/DD had a behavioral or physical health condition (56.5% and 60.0%, respectively). Generally, white, non-Hispanic beneficiaries had more health conditions compared with other races and ethnicities. Black, non-Hispanic; Hispanic; and Asian, non-Hispanic adult Medicaid beneficiaries had a lower prevalence of behavioral health conditions compared with white, non-Hispanic beneficiaries. A higher share of white, non-Hispanic beneficiaries also had one or more physical health condition compared with all other racial and ethnic groups except for Pacific Islander, non-Hispanic beneficiaries.

TABLE 3. Health Status of Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD) by Race and Ethnicity, FYs 2017–2018

Health status measures	Share of all adult beneficiaries with ID/DD							
	Total ¹	White, non-Hispanic	Black, non-Hispanic	Hispanic	Asian, non-Hispanic	AIAN, non-Hispanic	Pacific Islander, non-Hispanic	Other or multi-racial, non-Hispanic
Level of mobility								
Non-ambulatory, always needs assistance	8.9%	8.9%	7.4%*	12.4%*	8.1%	9.0%	–	7.4%
Moves self around environment with aids or uses wheelchair	91.1	91.1	92.6*	87.6*	91.9	91.0	95.4%	92.6
Health conditions								
In poor health	2.7	3.0	1.9*	2.3	–	–	–	–
Behavioral health condition	56.5	59.2	52.5*	47.3*	49.0*	51.3	61.4	61.2
Limited or no vision	9.8	9.9	9.2	9.8	10.0	13.1	–	7.7
Hearing loss, severe or profound	6.1	6.7	4.1*	5.7	4.9*	6.2	–	5.9
No other disabilities other than ID	8.6	7.6	13.1*	8.0	7.7	–	–	–
Has one or more physical health condition	60.0	62.5	59.2*	47.7*	54.1*	53.6*	60.5	54.7*

Notes: ID/DD is intellectual disabilities and developmental disabilities. FY is fiscal year. AIAN is American Indian or Alaska Native. ID is intellectual disability. The values shown here include self-reported information from all individuals 18 years old and older covered by Medicaid or Medicaid and Medicare with a non-missing race and ethnicity in FYs 2017 to 2018.

¹ Total ID/DD beneficiaries with a non-missing race and ethnicity.

* Indicates the difference from white, non-Hispanic 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, 2023, analysis of FYs 2017–2018 NCI-IPS.

Service Use

In the analyses below, we compare nine indicators of service use among adult ID/DD beneficiaries by race and ethnicity (Table 4). We also measure service use among dually eligible beneficiaries, disaggregated by age (Table 5). These indicators of service use suggest varying levels of access to primary and preventive care services.



Race and ethnicity comparison

Service use among adult Medicaid beneficiaries with ID/DD varies by race and ethnicity (Table 4). Notably, compared with white, non-Hispanic beneficiaries, we found the share of beneficiaries who had a complete physical exam in the past year was lower among Black, non-Hispanic; Hispanic; and AIAN, non-Hispanic beneficiaries. In contrast, a larger proportion of Pacific Islander, non-Hispanic beneficiaries had a complete physical exam compared with white, non-Hispanic beneficiaries in the past year (95.3 percent compared with 88.0 percent, respectively).

White, non-Hispanic beneficiaries were also more likely to have had a dental exam in the past year than Black, non-Hispanic and Hispanic beneficiaries. Additionally, they were more likely to have had an eye or vision screening in the past year compared with Hispanic beneficiaries; Asian, non-Hispanic beneficiaries; and other single or multi-racial, non-Hispanic beneficiaries. Similarly, a lower share of Asian, non-Hispanic and other single or multi-racial, non-Hispanic beneficiaries reported having had a hearing test in the past five years compared with white, non-Hispanic beneficiaries.

Regarding Pap tests, the share of Black, non-Hispanic beneficiaries who had a test in the past three years was higher than white, non-Hispanic beneficiaries; however, the share of Hispanic and Asian, non-Hispanic beneficiaries who had this test was lower than white, non-Hispanic beneficiaries. Hispanic beneficiaries also had lower rates of mammogram testing in the past two years compared with white, non-Hispanic beneficiaries. Additionally, White, non-Hispanic beneficiaries had a higher prevalence of having had a flu shot in the past year compared with Black, non-Hispanic; Hispanic; AIAN, non-Hispanic; and other single or multi-racial, non-Hispanic beneficiaries.

TABLE 4. Service Use for Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD) by Race and Ethnicity, FYs 2017–2018

Service use	Share of all adult beneficiaries with ID/DD							
	Total ¹	White, non-Hispanic	Black, non-Hispanic	Hispanic	Asian, non-Hispanic	AIAN, non-Hispanic	Pacific Islander, non-Hispanic	Other or multi-racial, non-Hispanic
Had a complete physical exam in the past year	87.1%	88.0%	85.2%*	84.5%*	87.3%	81.1%*	95.3%*	89.6%
Had a dental exam in the past year	81.1	83.0	75.2*	76.9*	81.8	80.8	–	81.6
Had an eye exam or vision screening in the past year ²	58.0	59.4	58.2	53.6*	46.2*	57.3	–	45.7*
Had a hearing test in the past five years ²	56.2	56.9	56.4	55.6	47.8*	50.6	–	45.1*
Had a Pap test in the past three years ²	56.7	57.0	70.0*	42.9*	43.8*	64.6	–	43.4

Service use	Share of all adult beneficiaries with ID/DD							
	Total ¹	White, non-Hispanic	Black, non-Hispanic	Hispanic	Asian, non-Hispanic	AIAN, non-Hispanic	Pacific Islander, non-Hispanic	Other or multi-racial, non-Hispanic
Had a mammogram test in the past two years ²	73.5%	73.7%	77.4%	65.8%*	63.9%	–	–	–
Had a flu shot in the past year	74.1	77.6	68.8*	64.2*	73.9	67.0%*	–	60.3%*
Has a primary care doctor or primary care practitioner	97.5	97.5	97.5	96.5*	98.5	94.7	96.7%	98.5
Has never had colorectal cancer screening or screening was more than 10 years ago	37.2	37.8	37.1	30.9	33.9	26.5	–	24.0*

Notes: ID/DD is intellectual disabilities and developmental disabilities. FY is fiscal year. AIAN is American Indian or Alaska Native. The values shown here include self-reported information from all individuals 18 years old and older covered by Medicaid or Medicaid and Medicare with a non-missing race and ethnicity in FYs 2017–2018.

¹ Total ID/DD beneficiaries with a non-missing race and ethnicity.

² Although statistically significant results were observed across race and ethnicity, variations in screening recommendations by age and risk likely influenced the outcome, as white, non-Hispanic beneficiaries were generally older (Table 1). Vision screening every two years is recommended among adults 18 to 64 years old and annually for people 65 years old and older (AOA 2023). There are not agreed-upon recommendations for routine hearing screening in adults, but variables that influence testing frequency include age, comorbidities, risk factors, and access (ASHA 2023). Pap tests are recommended for those with a cervix 21 to 29 years old every three years or more frequently depending on the risk (CDC 2022b). Most adults with a cervix 30 to 65 years old should be tested every three to five years via either an HPV test, a Pap test, or both, and those older than 65 may not require Pap testing based on risk (CDC 2022b). Only women 50 to 74 years old were recommended to have a mammogram every two years in 2018, but some women 40 to 49 years old may have been recommended to start mammogram testing based on higher risk (USPSTF 2016).

* Indicates the difference from white, non-Hispanic 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, 2023, analysis of FYs 2017–2018 NCI-IPS.

Dually eligible comparison

In addition to racial and ethnic variations in service use, the usage among dually eligible beneficiaries with ID/DD differs by age (Table 5). The share of dually eligible beneficiaries who had an eye exam or screening in the past year, hearing test in the past five years, mammogram test in the past two years, or flu shot in the past year was significantly higher among dually eligible beneficiaries 65 years old and older compared with dually eligible beneficiaries 18 to 64 years old. In contrast, the proportion of dually eligible beneficiaries 65 years old and older



who had a Pap test in the past two years was lower compared with younger dually eligible beneficiaries 18 to 64 years old.⁴

TABLE 5. Service Use for Dually Eligible Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD) by Age, FYs 2017–2018

Service use	Medicaid and Medicare	
	Age 18–64	Age 65 and older
Had a complete physical exam in the past year	88.2%	90.1%
Had a dental exam in the past year	81.8	82.0
Had an eye exam or vision screening in the past year ¹	59.7	70.6*
Had a hearing test in the past five years ¹	55.6	70.2*
Had a Pap test in the past three years ¹	60.9	43.5*
Had a mammogram test in the past two years ¹	76.1	70.1*
Had a flu shot in the past year	78.4	91.5*
Has a primary care doctor or primary care practitioner	97.7	98.1
Has never had colorectal cancer screening or screening was more than 10 years ago	39.3	42.2

Notes: ID/DD is intellectual disabilities and developmental disabilities. FY is fiscal year. The values shown here include self-reported information from all individuals 18 years old and older covered by Medicaid and Medicare with a non-missing age in FYs 2017 to 2018.

¹ Vision screening every two years is recommended for adults 18 to 64 years old and annually for people 65 years old and older (AOA 2023). There are not agreed-upon recommendations for routine hearing screening in adults, but variables that influence testing frequency include age, comorbidities, risk factors, and access (ASHA 2023). Pap tests are recommended for those with a cervix 21 to 29 years old every three years or more frequently depending on the risk (CDC 2022b). Most adults with a cervix 30 to 65 years old should be tested every three to five years via either an HPV test, a Pap test, or both, and those older than 65 may not require Pap testing based on risk (CDC 2022b). Only women 50 to 74 years old were recommended to have a mammogram every two years in 2018, but some women 40 to 49 years old may have been recommended to start mammogram testing based on higher risk (USPSTF 2016).

* Indicates the difference between 18- to 64-year-olds and people 65 years old and older is statistically significant at the 95 percent confidence level.

Source: MACPAC, 2023, analysis of FYs 2017–2018 NCI-IPS.

HCBS Experience

Regarding overall HCBS experience among adult Medicaid beneficiaries with ID/DD, 90.3 percent liked their current living situation (Table 6). In general, beneficiaries with ID/DD were able to contact a case manager or service coordinator when they wanted and nearly all beneficiaries shared they had met their case manager or service coordinator. Furthermore, beneficiaries with ID/DD were generally satisfied with workers' abilities to meet their needs and expressed that services and supports help them to live a good life.

Although the HCBS experience among adult Medicaid beneficiaries with ID/DD was generally consistent across racial and ethnic groups, there were some differences (Table 6). Specifically, compared with white, non-Hispanic beneficiaries, a larger share of other and multi-racial, non-Hispanic Medicaid beneficiaries reported needing additional services. Additionally, a smaller share of Hispanic beneficiaries was able to contact their case manager or service coordinator when they wanted compared with white, non-Hispanic beneficiaries.



TABLE 6. Experience with Home- and Community-Based Services (HCBS) for Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD) by Race and Ethnicity, FYs 2017–2018

Experience with HCBS	Share of all adult beneficiaries with ID/DD						
	Total ¹	White, non-Hispanic	Black, non-Hispanic	Hispanic	Asian, non-Hispanic	AIAN, non-Hispanic	Other or multi-racial, non-Hispanic
Likes home or where lives	90.3%	90.3%	89.9%	90.2%	91.2%	93.3%	91.9%
Able to contact case manager or service coordinator when wants	88.1	88.9	87.1	81.3*	92.4	90.0	81.7
Has met or spoken with case manager or service coordinator	97.2	97.0	98.1	97.0	90.6	98.1	97.5
Staff have right training to meet person's needs	96.9	97.2	96.6	95.8	91.5	97.6	96.7
Services and supports help person live a good life	91.6	92.3	90.7	87.2	87.4	94.7	83.8
Additional services needed	38.2	37.7	38.3	39.2	42.4	40.0	58.9*
Can lock bedroom if wants	53.5	53.5	55.0	50.8	47.6	56.0	54.8
Wants to live in a different residential setting ²	24.6	24.4	27.8*	19.0	28.8	22.0	22.7
Has a way to get places they need to go	99.6	99.6	99.5	98.9	99.8	100.0*	99.7
Others (who do not live in the home) let person know before entering home	90.0	90.0	90.8	87.5	96.6*	85.4	90.6
Others read person's mail or email without asking	12.9	12.6	13.9	13.8	–	8.2	17.5
Can use phone and internet when wants	90.9	91.1	91.1	88.9	89.0	83.2	88.9
Staff treat person with respect	93.1	93.1	93.0	91.2	96.1	93.1	93.8
Case manager or service coordinator asks person what she or he wants	89.1	89.3	90.1	87.6	93.5	82.0	83.4
Staff come and leave when they are supposed to	97.8	97.8	98.4	95.4	99.4*	99.1*	99.5*
Able to choose services	78.8	79.3	79.1	75.0	76.1	71.6	78.1

Notes: HCBS is home- and community-based services. FY is fiscal year. ID/DD is intellectual disabilities and developmental disabilities.

Pacific Islander, non-Hispanic was not reported due to the small sample size. The values shown here include self-reported information from all individuals 18 years old and older who receive HCBS with a non-missing race and ethnicity in FYs 2017 to 2018.

¹ Total population of ID/DD Medicaid only and dually eligible beneficiaries who received HCBS and with a non-missing race and ethnicity in FYs 2017 to 2018.

² Residential setting indicates residential type: own or family house or apartment (owned or rented); group home, adult family home, foster home, host home (round-the-clock services provided in a single family residence where one or more individuals



receiving services live with a person or family who furnishes services); assisted living facility, residential care facility (housing that may provide some nursing and personal care in addition to housekeeping and other basic help); nursing facility or nursing home; homeless or temporary shelter; other; don't know; and unclear, refused, or no response.

* Indicates the difference from white, non-Hispanic 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, 2023, analysis of FYs 2017–2018 NCI-IPS.

Dually eligible comparison

Beneficiaries who are dually eligible with ID/DD had similar HCBS experiences by age with one exception (Table 7). Those covered by Medicaid and Medicare between 18 to 64 years old were more likely to report that they needed additional services (38percent) compared with beneficiaries 65 years old and older (28.1 percent).

TABLE 7. Experience with Home- and Community-Based Services (HCBS) for Medicaid and Medicare Dually Eligible Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD) by Age, FYs 2017–2018

Experience with HCBS	Medicaid and Medicare	
	Age 18–64	Age 65 and older
Likes home or where lives	89.7%	88.8%
Able to contact case manager or service coordinator when wants	89.2	88.8
Has met or spoken with case manager or service coordinator	97.3	96.2
Staff have right training to meet person's needs	97.7	98.6
Services and supports help person live a good life	92.9	91.4
Additional services needed	38.0	28.1*
Can lock bedroom if wants	54.9	53.8
Wants to live somewhere else	24.4	23.2
Has a way to get places they need to go	99.6	98.6
Others (who do not live in the home) let person know before entering home	89.4	86.9
Others read person's mail or email without asking	13.5	11.0
Can use phone and internet when wants	91.3	91.7
Staff treat person with respect	93.2	92.2
Case manager or service coordinator asks person what he or she wants	89.7	85.7
Staff come and leave when they are supposed to	97.8	96.8
Able to choose services	77.6	78.7



Notes: HCBS is home- and community-based services. FY is fiscal year. ID/DD is intellectual disabilities and developmental disabilities. The values shown here include self-reported information from all individuals 18 years old and older with Medicaid and Medicare who received HCBS in FYs 2017 to 2018 with a non-missing age and dually eligible status.

* Indicates the difference between 18- to 64-year-olds and people 65 years old and older is statistically significant at the 95 percent confidence level.

Source: MACPAC, 2023, analysis of the FYs 2017–2018 NCI-IPS.

Data and Methods

Data for this report are from the FYs 2017 to 2018 NCI-IPS. The data were collected continuously throughout the year for the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute via a direct conversation with the beneficiary receiving services. The survey population includes adults 18 and older with ID/DD and is administered by 48 states, the District of Columbia, and 22 sub-state entities. Each state must attempt to complete a minimum of 400 surveys across a random sample of adults who were receiving at least one publicly funded service besides case management. Most states sample more than 400 individuals to account for refusals and surveys that may be deemed invalid. States can also decide who they are going to exclude from the sample.

All individuals selected into a sample have the opportunity to respond, regardless of their ability to respond and the survey allows for the use of proxy respondents in situations where the individual surveyed could not effectively communicate with the surveyor. States determine their own sampling methodology to identify adults with ID/DD, but many select participants through 1915(c) waiver participation records. Surveys are conducted in-person and states often employ university students, state staff, private contractors, advocacy organizations, and individuals with disabilities and their families to conduct the surveys. Additionally, state records were used to report data on an individual's health status and exam history as well as employment status.

The survey asks respondents about their demographic characteristics and topics related to their health, including personal experiences, involvement in the community, freedom to make their own choices, respect and rights, and access to services.

All differences discussed in this brief were computed using Z-tests and are significant at the 0.05 level.

Limitations

States use NCI-IPS data for their own programmatic purposes. In this brief, we aggregate the NCI-IPS state-level data to report national numbers; however, due to each state's unique population sampling criteria and survey exclusion methodology, the aggregated data may not be generalizable to the entire ID/DD population.

In addition, participating states were missing some Medicare and Medicaid coverage data. For example, the average availability of data on Medicare participation was 90.9 percent among participating states in 2023. There are many potential reasons for missing Medicare coverage information: some states may only have access to quarterly Medicare enrollment data, which may result in those states using outdated data.

Insurance coverage

Coverage source is defined as the health insurance that the respondent had at the time of the survey and comes from state records. An individual may have multiple coverage sources and sources of coverage may change over time, so responses to survey questions may reflect characteristics or experiences associated with a coverage source other than the one assigned in this brief.



Medicaid HCBS

The following HCBS funding options were represented in this analysis: intermediate care facility for people with intellectual disabilities, Medicaid HCBS waiver-funded services, Medicaid state plan funded services, state funds (no Medicaid long-term services and supports (LTSS) and not receiving Medicaid), Medicaid HCBS waiver-funded services (no Medicaid LTSS but still receiving Medicaid), and Medicare. In the HCBS analysis, only individuals with Medicaid HCBS waiver-funded services were included.

Race and ethnicity

Survey respondents self-identify their race and ethnicity and are able to select all responses that apply. For the analyses presented in this brief, seven race and ethnicity categories were reported. Individuals of Hispanic origin can be any race. Survey respondents self-identify their race and ethnicity separately, but those data are reported as a combination of their responses (e.g., Black, non-Hispanic). Individuals reporting only one race are categorized as follows: AIAN, Asian, Black or African American, Pacific Islander, white, or unknown. Individuals reporting a different race or multiple races are categorized as “other or multi-racial, non-Hispanic.” Given the small sample size and data confidentiality rules, responses from people who identify as Pacific Islander cannot always be identified in publicly available data.

Estimates compared with other data sources

Demographic characteristics of dually eligible beneficiaries with ID/DD described in this brief differ from the overall dually eligible population as described by enrollment data, claims data, payment data, and additional administrative data from the *Data Book: Beneficiaries Dually Eligible for Medicaid and Medicare, 2023*.⁵ For example, in the data book, dually eligible beneficiaries are more likely to be female (MACPAC, MedPAC 2023). In contrast, the results from NCI-IPS for FYs 2017–2018 show that dually eligible beneficiaries with ID/DD were more likely to be male (Table 2). Additionally, the data book reports that just over half of all dually eligible beneficiaries were white, non-Hispanic, but the NCI-IPS survey found that among dually eligible beneficiaries with ID/DD, the share of white, non-Hispanic individuals was 76.1 percent (MACPAC, MedPAC 2023). A similar trend emerged among Medicaid-only beneficiaries: there was a larger proportion of white, non-Hispanic beneficiaries among the Medicaid ID/DD population identified in this brief compared with the overall Medicaid population in the data book.⁶

Endnotes

¹ The number of Medicaid beneficiaries with ID/DD in 2018 includes: beneficiaries who either received Medicaid waiver funded long-term services and supports (LTSS), lived in a Medicaid intermediate care facility for individuals with an intellectual disability, or received support through Medicaid state plan home- and community-based services (HCBS). Beneficiaries can be counted more than once if they fall into multiple service categories.

² The surveyed ID/DD population had a greater share of male dually eligible beneficiaries compared with female dually eligible beneficiaries in 2018 (58.7 percent versus 41.3 percent) (Table 1). Compared with the total dually eligible population (from 2020), the opposite is true: 41 percent were male and 59 percent were female (MACPAC and MedPAC 2023).

³ Most dually eligible individuals are full-benefit dually eligible beneficiaries, meaning, they are eligible for full Medicaid benefits. Partial-benefit dually eligible beneficiaries are Medicare beneficiaries who receive Medicaid assistance with Medicare premiums and, in some cases, Medicare cost sharing, through Medicare Savings Programs (MSPs). (For more information on



MSPs, see Chapter 3 of MACPAC's June 2020 report.) In 2020, 28 percent of all dually eligible beneficiaries were eligible for partial Medicaid benefits (MACPAC and MedPAC 2023).

⁴ The CDC recommends adults 65 years old and older stop Pap testing after several non-cancerous tests within the last 10 years, including at least one in the previous five years (CDC 2022b). Less frequent testing recommendations for this age group impact the results.

⁵ Please refer to the *Data Book: Beneficiaries Dually Eligible for Medicaid and Medicare, 2023* for more detailed analytic methods and sources (MACPAC, MedPAC 2023).

⁶ Due to the new eligibility groups and expanded type-of-service categories in the Transformed Medicaid Statistical Information System (T-MSIS), enrollees as well as some spending may be classified differently than under the Medicaid Statistical Information System (MSIS) depending on how states map eligibility categories and types of service between the two systems. Because of these differences, reliable data on dually eligible beneficiaries are not available for 2017 or 2018, so 2020 data were used in this comparison.

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Appendix A: Total Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities

TABLE A-1. Health Status of Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD), FYs 2017–2018

Health status measures	Total
Level of mobility	
Non-ambulatory, always needs assistance ¹	8.9%
Moves self around environment with aids or uses wheelchair independently	91.1*
Health status	
Poor health ¹	2.7
Fairly good health	28.0*
Very good or excellent health	69.3*
Behavioral health	
Doesn't have a behavioral health condition ¹	43.5
Has only one behavioral health condition	24.6*
Has more than one behavioral health condition	31.9*
Vision	
People without limited or no vision ¹	90.2
Limited or no vision	9.8*
Hearing loss	
People without hearing loss ¹	93.9
Hearing loss, severe or profound	6.1*
Intellectual disability	
No other disabilities other than ID ¹	8.6
Has disabilities other than ID	91.4*
Physical health	
Doesn't have a physical health condition ¹	40.0
Has only one physical health condition	28.9*
Has more than one physical health condition	31.0*

Notes: ID/DD is intellectual disabilities and developmental disabilities. ID is intellectual disability. FY is fiscal year. The values shown here include data from all individuals 18 years and older covered by Medicaid only or Medicaid and Medicare in FYs 2017 to 2018.

¹ Indicates comparison group for determining statistical significance at the 95 percent confidence level.

* Indicates the difference from the comparison group is statistically significant at the 95 percent confidence level.

Source: MACPAC, 2023, analysis of the FYs 2017–2018 NCI-IPS.

TABLE A-2. Service Use for Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD), FYs 2017–2018

Service use	Total
Physical exam	
Had a complete physical exam in the past year ¹	87.1%
Did not have a complete physical exam in the past year	12.9*
Dental exam	
Had a dental exam in the past year ¹	81.1
Didn't have a dental exam in the past year	18.9*
Eye exam	
Had an eye exam or vision screening in the past year ¹	58.0
Didn't have an eye exam or vision screening in the past year	42.0*
Hearing test	
Had a hearing test in the past five years ¹	56.2
Didn't have a hearing test in the past five years	43.8*
Pap test	
Had a Pap test in the past three years ¹	56.8
Hasn't had a Pap test in the past three years	43.2*
Mammogram	
Had a mammogram test in the past two years ¹	73.4
Hasn't had a mammogram test in the past two years	26.6*
Flu shot	
Had a flu shot in the past year ¹	74.1
Didn't have a flu shot in the past year	25.9*
Primary care	
Has a primary care doctor or primary care practitioner ¹	97.5
Does not have a primary care doctor or primary care practitioner	2.5*
Colorectal	
Had a colorectal cancer screening in the past 10 years ¹	37.0
Hasn't had a colorectal cancer screening in the past 10 years	63.0*

Notes: ID/DD is intellectual disabilities and developmental disabilities. FY is fiscal year. The values shown here include data from all individuals 18 years and older covered by Medicaid only or Medicaid and Medicare in FYs 2017 to 2018.

¹ Indicates comparison group for determining statistical significance at the 95 percent confidence level.

* Indicates the difference is statistically significant at the 95 percent confidence level.

Source: MACPAC, 2023, analysis of the FYs 2017–2018 NCI-IPS.



TABLE A-3. Experience with Home- and Community-Based Services (HCBS) for Medicaid Beneficiaries with Intellectual Disabilities and Developmental Disabilities (ID/DD), FYs 2017–2018

Experience with HCBS	Total
Lock bedroom	
Can lock bedroom if wants ¹	53.4%
Cannot lock bedroom if wants	46.6*
Wants to live in a different residential setting²	
Wants to live somewhere else ¹	24.5
In between	9.8*
Does not want to live somewhere else	65.7*
Likes home	
Likes home or where they live ¹	90.3
In between	5.7*
Does not like home or where they live	4.0*
Additional services	
Additional services needed ¹	38.4
No additional services needed	61.6*
Contact case manager	
Able to contact case manager or service coordinator when they want ¹	88.1
Sometimes	5.5*
Not able to contact case manager or service coordinator when they want	6.3*
Transportation	
Has a way to get places they need to go ¹	99.6
Does not have a way to get places they need to go	0.4*
Staff training	
Staff have right training to meet person's needs ¹	96.9
Staff does not have the right training to meet person's needs	3.1*
Privacy	
Others (who do not live in the home) let person know before entering home ¹	90.0
Sometimes	6.3*
Others (who do not live in the home) do not let person know before entering home	3.7*
Mail privacy	
Others do not read person's mail or email without asking ¹	87.1
Others read person's mail or email without asking	12.9*
Phone and internet use	
Can use phone and internet when wants ¹	90.8
Cannot use phone and internet when wants	9.2*
Respect	
Staff always treat person with respect ¹	93.1
Staff do not always treat person with respect	6.9*
Relationship with case manager	
Has met or spoken with case manager or service coordinator ¹	97.2
Has not met or spoken with case manager or service coordinator	2.8*
They can ask for what they want	
Case manager or service coordinator asks person what they want ¹	89.2
Sometimes	6.4*
Case manager or service coordinator does not ask person what they want	4.3*



Experience with HCBS	Total
Staff come and leave on time	
Staff come and leave when they are supposed to ¹	97.9%
Staff do not come and leave when they are supposed to	2.1*
Able to choose services	
Yes ¹	78.9
Had some input	17.2*
No	4.0*
Services and supports	
Services and supports help person live a good life ¹	91.6
In between	6.7*
Services and supports do not help person live a good life	1.6*

Notes: HCBS is home- and community-based services. FY is fiscal year. ID/DD is intellectual disabilities and developmental disabilities. The values shown here include self-reported information from all individuals 18 years and older who received HCBS.

¹ Indicates comparison group for determining statistical significance at the 95 percent confidence level.

² Residential setting indicates residential type: own or family house or apartment (owned or rented); group home, adult family home, foster home, host home (round-the-clock services provided in a single family residence where one or more individuals receiving services live with a person or family who furnishes services); assisted living facility, residential care facility (housing that may provide some nursing and personal care in addition to housekeeping and other basic help); nursing facility or nursing home; homeless or temporary shelter; other; don't know; and unclear, refused, or no response.

* Indicates the difference is statistically significant at the 95 percent confidence level.

Source: MACPAC, 2023, analysis of the FYs 2017–2018 NCI-IPS.

