

Access in Brief: Access to Care, Ability to Work, and Home Life for Adults with Intellectual and Developmental Disabilities with Comparisons by Type of Health Coverage

In this Issue Brief, you'll learn about where adults with intellectual and developmental disabilities (I/DD) live and other facts about their lives.

The facts in this Issue Brief come from a national survey.

You'll learn what the adults with I/DD said. For example, you'll learn:

- if they need help at home;
- if they work;
- if they need help in order to work; and
- if they're able to get dental care.

You can compare the answers from the two groups who took the survey.

The two groups are:

- adults with I/DD with Medicaid; and
- adults with I/DD with private-only health coverage.

You'll also learn about Medicaid spending on adults with I/DD and on all adults with disabilities. You'll be able to compare spending on the two groups.



Understanding Medicaid and Private-Only Coverage

Medicaid and private-only coverage help pay for health care.

Now you know what Medicaid and private-only coverage are. **Do you see other terms you don't understand?**

You'll find terms we use in this Issue Brief on page 14.

Adults with I/DD answered questions for a national survey

Adults with I/DD answered questions for a national survey. Their answers are on the next pages. A total of 599 adults with I/DD took the survey.

599 people took the survey



Respondents who completed the survey

Survey respondents lived in the United States. The survey took place in 2021 and 2023 through 2024.

All respondents were age 18 to 64.

- Two groups of people answered the questions.
 - One group had Medicaid. The other group had private-only coverage.

You can compare the answers of the two groups.



What the questions were about

The survey included questions about many topics. Respondents answered questions like:

- What do you worry about?
- Do you work?
- What do you need so you can work?

Answers to the Survey Questions

In this section, you'll find the topics of the survey questions. You'll also read about how adults with I/DD answered the survey questions.

About needing help at home due to health or disability

Respondents said they needed help at home



Respondents said they needed help at home

6.7 of 10 respondents with
Medicaid needed help at home
due to health or disability



3.8 of 10 of those with private-only
coverage needed help at home
due to health or disability



About living arrangements

Respondents reported who they lived with, if they paid rent, and any worries about housing

All respondents



Respondents reported who they lived with

4 of 10 respondents lived with children, parents, or extended family

Respondents with Medicaid



6 of 10 respondents with Medicaid lived with children, parents, or extended family

Respondents with private-only coverage



Almost 3 of 10 with private-only coverage lived with children, parents, or extended family

Respondents reported if they paid rent



4.2 of 10 respondents didn't pay rent



Respondents reported worrying about their housing even if they had stable housing

Respondents reported whether they worried about losing their housing



9 of 10 had stable housing but worried about losing it within the next six months

About work

Respondents answered questions about their work

All respondents



Respondents answered questions about their work

5 of 10 were not working for pay

Respondents with Medicaid



5.3 of 10 were not working for pay

Respondents with private-only coverage



4.3 of 10 were not working for pay



All respondents



Respondents who worked answered questions about how much they worked

6.3 of 10 of those who were working worked part-time

Respondents with Medicaid



7.9 of 10 of those who were working worked part-time

Respondents with private-only coverage



4.4 of 10 of those who were working worked part-time

Respondents with Medicaid said they needed help to be able to work

Respondents reported whether help at home allowed them to work



4.5 of 10 respondents with Medicaid reported that receiving help at home with personal care or daily activities allowed them to work a paying job



Respondents said that not receiving personal assistance services affected their ability to work

All respondents



6.6 of 10 needed home and community-based services and said that not receiving personal assistance services affected their ability to work or work more at a paying job



Respondents needed personal assistance services but didn't find people to hire

All respondents



Respondents reported on needing and receiving personal assistance services

5.3 of 10 needed personal assistance services



3.5 of 10 needed personal assistance services and didn't get them



4.9 of 10 had problems finding personal assistance services or support workers in the past months

Respondents with Medicaid who received paid home and community-based services



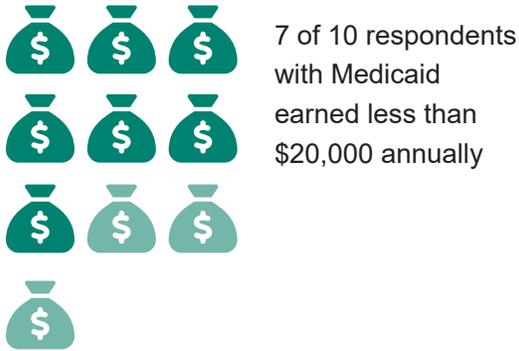
7.2 of 10 self-directed their home and community-based services



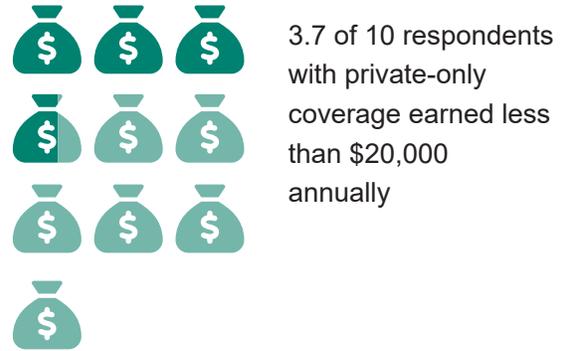
Respondents reported how much they earned, and many earned less than \$20,000 annually

Respondents reported their earnings

Respondents with Medicaid



Respondents with private-only coverage



All respondents



The federal poverty level in 2024 was \$20,783 for an individual.



About dental care

Respondents answered questions about their dental care

More than one-third of respondents weren't able to get the dental care they needed.

Dental care

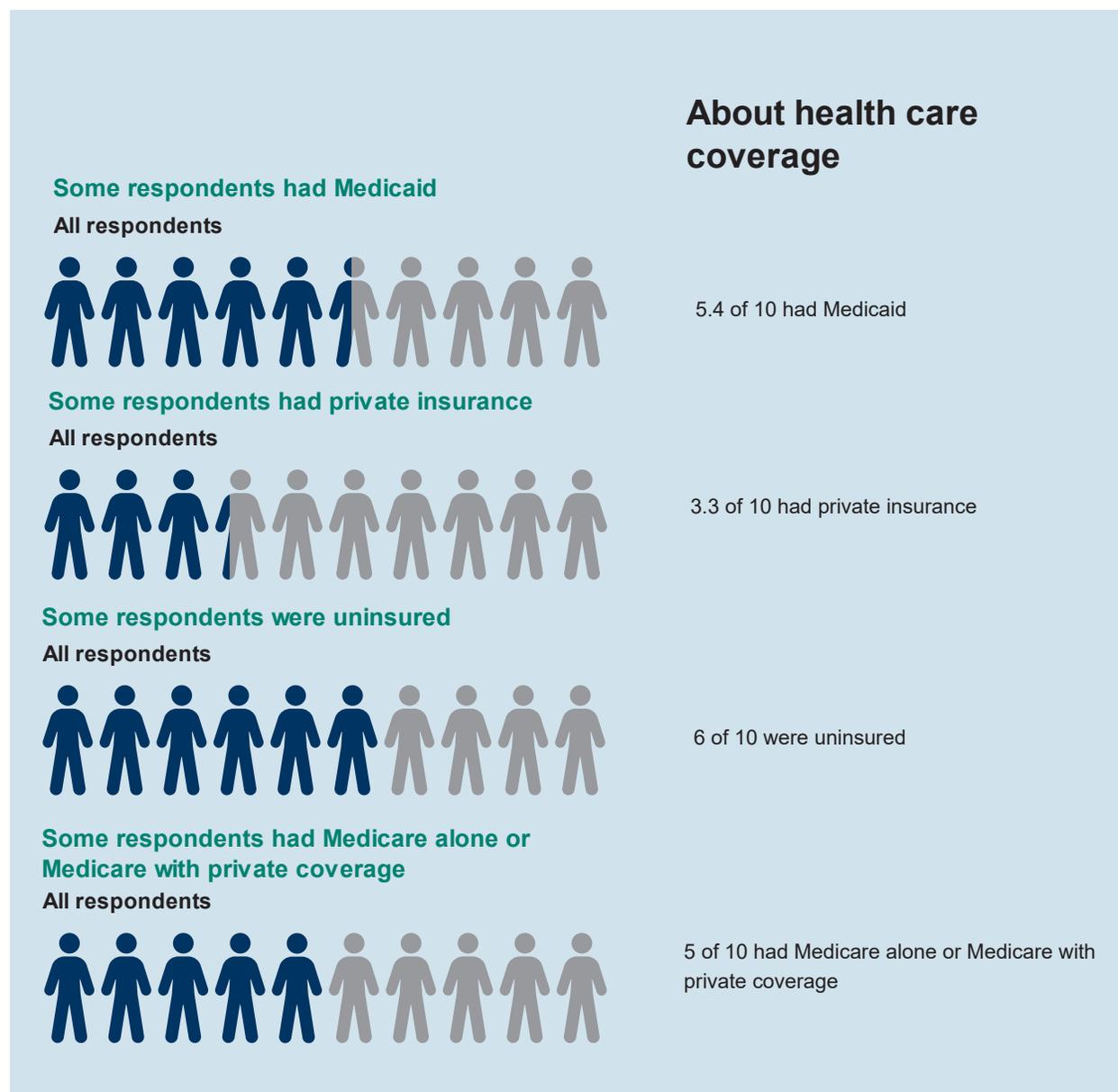
All respondents



6.1 of 10 respondents were able to get necessary dental care in the prior year



About respondents' health care coverage



Now that you learned what respondents said about where they live and about other parts of their lives, read the next section for information about adults with I/DD in the United States.



About People with I/DD in the United States

Information about Medicaid spending and people with I/DD and people with disabilities

In this section, you'll find information on spending on programs for individuals eligible for Medicaid based on disability and on I/DD.

Spending on programs for those eligible for Medicaid based on disability.

About \$205 billion in federal and state program spending in fiscal year 2021 was for those eligible for Medicaid based on disability.

Average expenditures for people with I/DD receiving Medicaid compared with expenditures for all Medicaid beneficiaries with disabilities. Average Medicaid expenditures for all those with I/DD are two to five times higher than the expenditures for all Medicaid beneficiaries with disabilities.



About Our Analysis

Conditions reported and not reported by survey respondents

Survey respondents 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.

Survey respondents may have conditions not listed.

Survey respondents may have a condition that isn't diagnosed. The survey asked for diagnosed conditions.



Terms that we used in this Issue Brief

In this section, you'll find information about some terms we used.

Respondents is the 599 people who answered the survey questions.

Disability is defined as any functional limitation.

Medicaid in the survey discussed includes:

- respondents enrolled only in Medicaid;
- respondents enrolled in Medicaid with private coverage; and
- respondents who were dually eligible for both Medicaid and Medicare with no private coverage.

Private-only coverage in the survey includes:

- respondents who were exclusively enrolled in health insurance through an employer or a family member's employer;
- respondents with health insurance purchased through the exchange; and
- respondents with TRICARE or other military insurance.

Home and community-based services are for Medicaid beneficiaries to receive services in their own homes or communities rather than institutions or other isolated settings.

Long-term services and supports for those with disabling conditions can be institutional care or community-based care.

Personal care assistance refers to assistance needed at home due to health or disability.

Self-directed Medicaid services are services that participants, or their representatives if applicable, may access by recruiting, hiring, training and supervising those who provide the services.



Data, our methods, and notes about our analysis

In this section, you'll find information about how we did our analysis.

Behavioral Risk Factor Surveillance System is the system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. It was established in 1984.

Why we used National Survey on Health and Disability data instead of Medicaid data. Most adults with I/DD get their healthcare coverage through Medicaid. Medicaid is the largest payer of personal assistance and long-term care (long-term services and supports and home and community-based services).

We found that data from the National Survey on Health and Disability offer insights not available from Medicaid data, so we used the 2021–2023/2024 National Survey on Health and Disability.

How to learn more about the National Survey on Health and Disability. Information about recruitment of survey respondents and data collection is at <https://ihdps.ku.edu/nshd-background-and-overview>.

How we divided up the groups in our analysis. “Any Medicaid” and “private-only coverage” are mutually exclusive, and significance testing was only conducted between these two subpopulations. We didn't analyze facts about people with I/DD who were uninsured or people with other coverage types.

What researchers should know about our study. Our sample size (599) was small. Also, although the variable estimates were weighted, the weights we used weren't designed specifically for the I/DD population.

We analyzed the sex of the respondents. Of all respondents with Medicaid, 66.6% were male. Of those with private-only coverage, 24.8% were male.



Note: Looking at the entire adult population in the United States, researchers found that men are more likely to be diagnosed with I/DD than women.

We analyzed the race and ethnicity of the respondents. Of all respondents, 76.8% identified as white.

We found no statistically significant differences in race and ethnicity when comparing those with Medicaid and those with private-only coverage.

This Issue Brief presented information on adults with I/DD who have Medicaid on topics such as housing, concerns about housing, and access to dental care.

It enabled you to compare what adults with I/DD with Medicaid said with what adults with I/DD with private-only coverage said about some topics.

It also provided you with information on how much adults with I/DD in the United States earn and how much is spent on Medicaid beneficiaries with disabilities and on Medicaid beneficiaries with I/DD.



References

To learn more about the sources of information for this Issue Brief, visit MACPAC's [publications page](#).

Disclaimer

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