



Medicare, Medicaid, and dual enrollment for adults with intellectual and developmental disabilities

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Funding information

National Institute on Aging, Grant/Award Number: R01AG073179

Abstract

Objective: Given high rates of un- and underemployment among disabled people, adults with intellectual and developmental disabilities rely on Medicaid, Medicare, or both to pay for healthcare. Many disabled adults are Medicare eligible before the age of 65 but little is known as to why some receive Medicare services while others do not. We described the duration of Medicare enrollment for adults with intellectual and developmental disabilities in 2019 and then compared demographics by enrollment type (Medicare-only, Medicaid-only, dual-enrolled). Additionally, we examined the percent in each enrollment type by state, and differences in enrollment type for those with Down syndrome.

Data Sources and Study Setting: 2019 Medicare and Medicaid claims data for all adults (≥ 18 years) in the US with claim codes for intellectual disability, Down syndrome, or autism at any time between 2011 and 2019.

Study Design: Administrative claims cohort.

Data Collection and Abstraction Methods: Data were from the Transformed Medicaid Statistical Information System Analytic Files and Medicare Beneficiary Summary files.

Principle Findings: In 2019, Medicare insured 582,868 adults with identified intellectual disability, autism, or Down syndrome. Of 582,868 Medicare beneficiaries, 149,172 were Medicare only and 433,396 were dual-enrolled. Most Medicare enrollees were enrolled as child dependents (61.5%). Medicaid-only enrollees ($N = 819,256$) were less likely to be white non-Hispanic (58.5% white non-Hispanic vs. 72.9% white non-Hispanic in dual-enrolled), more likely to be Hispanic (19.6% Hispanic vs. 9.2% Hispanic in dual-enrolled) and were younger (mean 34.2 years vs. 50.5 years dual-enrolled).

Conclusion: There is heterogeneity in public insurance enrollment which is associated with state and disability type. Action is needed to ensure all are insured in the program that works for their healthcare needs.

KEYWORDS

disability, dual enrollment, intellectual and developmental disability, Medicaid, Medicare

What is known on this topic

- Adults with intellectual and developmental disabilities are often reliant on public insurance systems because of systemic ableism.
- Medicaid is the public health insurer designed to serve people with disabilities, but Medicare plays an important role, even in non-elderly adults.
- State policies and disability types impact Medicaid and Medicare enrollment.

What this study adds

- Fifty-eight percent of adults with intellectual and developmental disabilities were enrolled just in Medicaid in 2019, and 30.9% were dual enrolled in Medicare.
- Medicaid-only enrollees were less likely to be white, non-Hispanic more likely to be Hispanic, and were younger compared to dual- or Medicare only enrollees.
- Given high healthcare need, use, and cost in this population, it is vital that individuals are adequately insured by Medicare, Medicaid, or both.

1 | INTRODUCTION

Intellectual and developmental disabilities are life-long conditions that present early in life and affect an individual's physical, intellectual, and/or emotional development.¹ Most common conditions include idiopathic intellectual disability (significant limitations in intellectual functioning and adaptive behavior), autism spectrum disorder (repetitive and restricted behaviors and interests with differences in social interaction), and Down syndrome (trisomy of chromosome 21, the leading genetic cause of intellectual disability). Because of the nature of these disabilities, structural inequities, and current and historical ableism,² adults with intellectual and developmental disabilities in the United States are at great risk of poverty and poor mental and physical health.^{3,4}

Given extremely high rates of un- and underemployment among people with disabilities,^{5–7} adults with intellectual and developmental disabilities predominantly use public health insurance programs to pay for their health needs.⁸ For children and adults, the Medicaid program is designed to provide coverage as long as the individual meets income limits and/or receives a disability eligibility through social security insurance (SSI).⁹ In 2019, Medicaid insured ~1,000,000 adults ≥18 with intellectual disability, inclusive of ~92,000 adults ≥18 years with Down syndrome, and ~354,000 adults on the autism spectrum (46% with co-occurring intellectual disability).¹⁰ In addition, Medicare, a federal health insurance program for adults ≥65 years and certain younger people with disabilities, also ensures adults with intellectual and developmental disabilities under two pathways: (1) the individual is ≥65 years of age or (2) the individual receives Social Security Disability Insurance (SSDI) for ≥2 years.¹¹ An individual with intellectual and developmental disabilities may receive SSDI through a parent or guardian's SSDI eligibility or work history, or through the individual's work experience (SSDI benefits available after about ~10 years of work earning ~\$6000 per year)¹² SSDI differs from SSI as SSDI is based on disability and work credits and SSI is based on age/disability, income, and resources. An individual can be dually enrolled in

Medicaid and Medicare if they are eligible for both programs, and in that situation, Medicare is the first payer with Medicaid covering costs not paid for by Medicare.¹³ A flowchart diagram of pathways for enrollment is presented in Figure 1. The first decision point is an individual's age, which determines older-age-based Medicare coverage. Then, whether the individual receives SSI, and then, if under 65 years of age, if the individual receives SSDI through their own or a parent's (or guardian's) work experience.

For the disabled population, being a dual enrollee offers benefits, with greater healthcare coverage (such as Medicaid coverage of home- and community-based services, adult day care programs, and Medicare's coverage of home healthcare for those who are "home-bound") and lower out-of-pocket costs (such as the combined effect of high Medicare acceptance rates among clinicians and Medicaid's, provision of wrap-around costs for Medicare co-pays).¹³

Reichard et al.¹⁴ described Medicare enrollment for adults with intellectual and developmental disabilities, broadly defined, who were enrolled in 2016. They found ~483,000 enrollees, a majority of whom were eligible based on disability, under 65 years of age, and dual-enrolled in Medicaid. Compared to older enrollees (≥65 years), younger enrollees were less likely to be white and more likely to be dual-enrolled. However, they were not able to compare to Medicaid-only enrollees and did not look at patterns at the state level, where dual enrollment is affected by state Medicaid eligibility requirements and Medicare enrollment may be impacted by state SSDI approval rates.¹⁵ Further, the Down syndrome population is of critical interest because of accelerated aging and early onset dementia¹⁶ that may be best covered by Medicare; the Reichard et al. study did not examine patterns in the Down syndrome population. The average life expectancy for a person with Down syndrome has risen but is still younger than the Medicare age threshold.¹⁷ A specific examination within the Down syndrome population is warranted to help ensure equity in aging care.

Therefore, our objective was to describe the duration of Medicare enrollment for adults ≥18 years with intellectual and developmental disabilities in 2019 and then compare demographics by enrollment

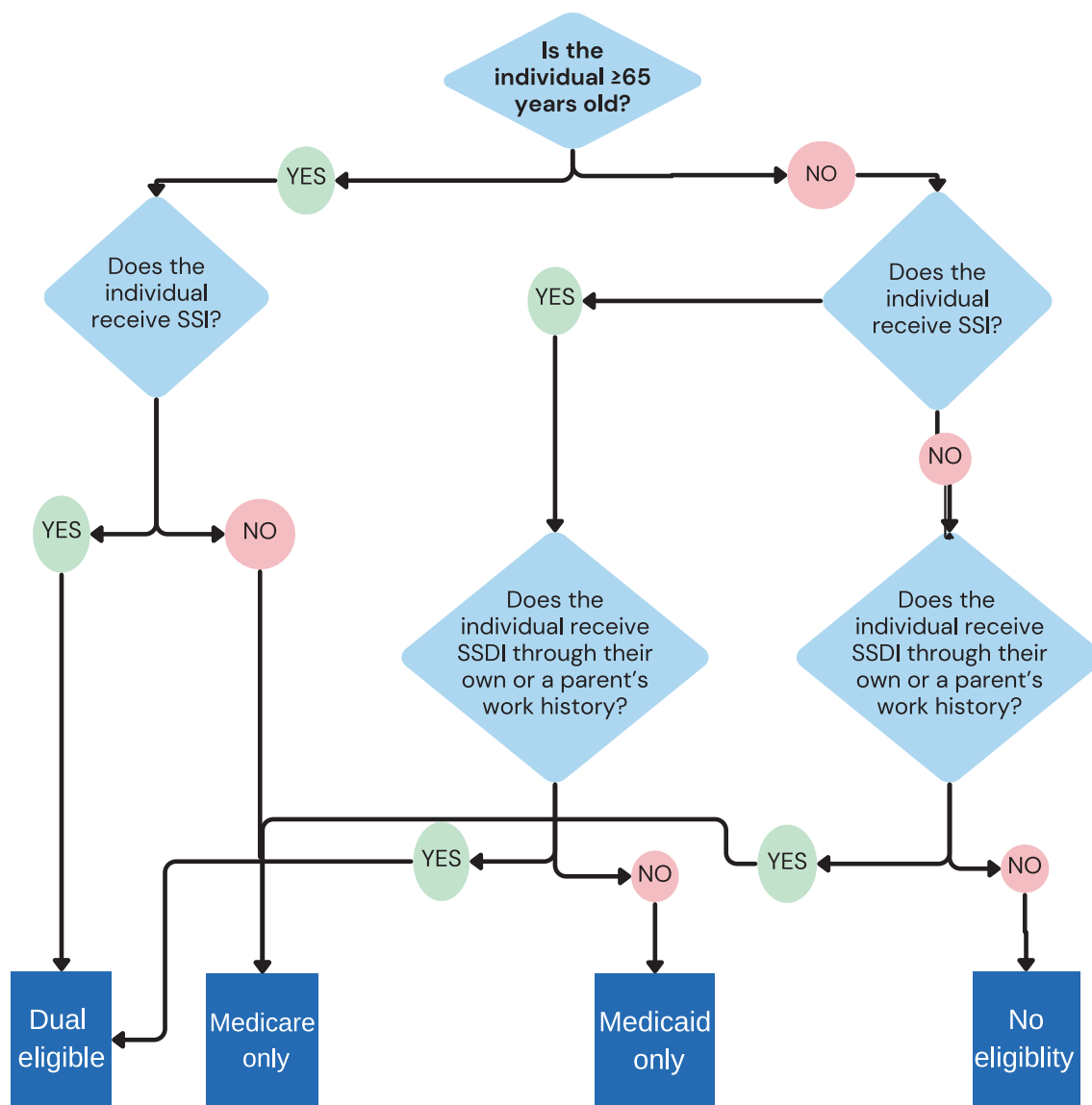


FIGURE 1 Pathways to Medicare, Medicaid, and dual eligibility for adults with intellectual and developmental disability.

type (Medicare-only, Medicaid-only, dual-enrolled). We examined enrollment type by state to examine differences in state Medicaid policy. Further, we evaluated demographic differences in enrollment in the Down syndrome population—for which understanding these patterns is critical for providing appropriate aging care. We hypothesized that any Medicare enrollment would be associated with white race, older age, and Down syndrome.

2 | METHODS

2.1 | Data source

Data were from a cohort of linked Medicaid and Medicare claims data for adult enrollees with intellectual disability, autism, and Down syndrome from 2011 to 2019. International Classification of Disease

9 and 10 codes for these conditions were identified using established algorithms (Supplement 1).^{18,19} We examined these conditions as they are the most common developmental disabilities and represent conditions with known and unknown etiologies. Codes were provided to the Centers for Medicare and Medicaid Services which identified enrollees in Medicaid and Medicare from inpatient, other services, and long-term care claims. This analysis is restricted to the 2019 data.

We linked Medicare to Medicaid data by the unique beneficiary ID. This created three groups: Medicaid only, Medicare only, and dual-enrolled. For Medicare only enrollees' demographic data was taken from the Master Beneficiary Summary File. Demographic data for Medicaid enrollees was from the person summary file and we used multiple imputations to account for missing race and ethnicity (~25% missing). We used the RTI-derived race variable for Medicare data and aligned Medicaid data to that format. See Rubenstein 2023¹⁰ for more information on cohort derivation and imputation.

TABLE 1 Demographic comparison for adults with intellectual and developmental disabilities by public health insurer, 2019.

| Demographic variable | Medicare only | | Medicaid only | | Dual-enrolled | |
|--|---------------|------------|---------------|------------|---------------|------------|
| | N = 149,172 | | N = 819,256 | | N = 433,696 | |
| | N | % | N | % | N | % |
| Sex | | | | | | |
| Male | 87,678 | 58.8 | 493,102 | 60.2 | 249,983 | 57.6 |
| Female | 61,494 | 41.2 | 325,466 | 39.7 | 183,713 | 42.4 |
| Race ethnicity ^a | | | | | | |
| White | 106,151 | 71.9 | 458,650 | 58.5 | 314,293 | 73.2 |
| Black | 25,729 | 17.4 | 158,168 | 25.4 | 67,972 | 21.0 |
| Other | 1022 | 0.7 | 3264 | 0.5 | 3022 | 1.0 |
| Asian | 1799 | 1.2 | 21,950 | 3.8 | 6277 | 2.1 |
| Hispanic | 11,418 | 7.7 | 123,133 | 19.6 | 34,245 | 9.2 |
| Native American | 1429 | 1.0 | 18,211 | 2.2 | 3720 | 0.9 |
| Missing | 1624 | | 35,880 | | 4167 | |
| Region | | | | | | |
| Northeast | 24,057 | 16.1 | 197,527 | 24.1 | 109,935 | 25.3 |
| Midwest | 38,253 | 25.6 | 188,936 | 23.1 | 125,931 | 29.0 |
| South | 63,444 | 42.5 | 236,077 | 28.8 | 133,328 | 30.7 |
| West | 22,178 | 14.9 | 190,826 | 23.3 | 63,410 | 14.6 |
| US Territories | 1099 | 0.7 | 5887 | 0.7 | 1025 | 0.2 |
| Age at entry in Medicare | | | | | | |
| ≤25 | 50,103 | 33.6 | NA | | 192,896 | 44.5 |
| 26–34 | 36,150 | 24.2 | | | 126,781 | 29.2 |
| 35–44 | 24,310 | 16.3 | | | 81,170 | 18.7 |
| 45–54 | 12,830 | 8.6 | | | 16,188 | 3.7 |
| 55–64 | 7431 | 5.0 | | | 4505 | 1.0 |
| 65–89 | 13,848 | 9.3 | | | 12,157 | 2.8 |
| Mean (SD), median (IQR) | 36.0 (15.2) | 31 (23–45) | | | 29.7 (10.3) | 27 (21–35) |
| Age in 2019 | | | | | | |
| 18–25 | 3299 | 2.2 | 281,636 | 34.4 | 19,825 | 4.6 |
| 26–34 | 15,970 | 10.7 | 232,210 | 28.3 | 62,115 | 14.3 |
| 35–44 | 22,594 | 15.1 | 126,210 | 15.4 | 76,018 | 17.5 |
| 45–54 | 27,306 | 18.3 | 79,314 | 9.7 | 89,107 | 20.5 |
| 55–64 | 33,437 | 22.4 | 68,595 | 8.4 | 100,587 | 23.2 |
| 65–89 | 46,566 | 31.2 | 31,291 | 3.8 | 86,044 | 19.8 |
| Mean (SD), median (IQR) | 55.4 (16.5) | 56 (42–67) | 34.2 (14.1) | 30 (23–42) | 50.5 (15.3) | 51 (38–62) |
| Years person time enrolled in Medicare, all time | | | | | | |
| ≤5 | 15,899 | 10.7 | NA | | 59,345 | 13.7 |
| 6–10 | 28,448 | 19.1 | | | 65,711 | 15.2 |
| 11–15 | 24,014 | 16.1 | | | 53,434 | 12.3 |
| 16–20 | 16,226 | 10.9 | | | 50,404 | 11.6 |
| 21–25 | 19,161 | 12.8 | | | 45,683 | 10.5 |
| 26–30 | 15,012 | 10.1 | | | 44,136 | 10.2 |
| >30 | 30,412 | 20.4 | | | 114,983 | 26.5 |
| Mean (SD), median (IQR) | 19.4 (12.2) | 17 (9–28) | | | 20.8 (13.3) | 19 (9–31) |

TABLE 1 (Continued)

| Demographic variable | Medicare only | | Medicaid only | | Dual-enrolled | |
|--|---------------|------|---------------|---------|---------------|---------|
| | N = 149,172 | | N = 819,256 | | N = 433,696 | |
| | N | % | N | % | N | % |
| Years person time enrolled in Medicaid from 2011 to 2019 | | | | | | |
| 0–<3 | NA | | 82,924 | 10.1 | 2534 | 0.6 |
| 3–<6 | | | 204,530 | 25.0 | 33,649 | 7.8 |
| ≥6 | | | 531,802 | 64.9 | 397,513 | 91.7 |
| Mean (SD), median (IQR) | | | 6.5 (2.6) | 7 (5–9) | 8.3 (1.5) | 9 (9–9) |
| Medicare beneficiary type | | | | | | |
| Child dependent | 62,390 | 41.8 | NA | | 296,093 | 68.8 |
| Primary beneficiary | 82,177 | 55.1 | | | 123,581 | 28.3 |
| Other | 140,222 | 3.2 | | | 4605 | 3.1 |
| Intellectual and developmental disability | | | | | | |
| Down syndrome | 10,904 | 7.3 | 48,955 | 6.0 | 59,049 | 13.6 |
| Autism | 24,363 | 16.3 | 278,127 | 33.9 | 86,998 | 20.1 |
| Intellectual disability | 113,905 | 76.4 | 492,174 | 60.1 | 287,564 | 66.3 |

Abbreviations: IQR, interquartile range; SD, standard deviation.

^aRace categories include only non-Hispanic enrollees of that race.

2.2 | Analytic approach

We first compared demographics within Medicare by enrollment type (Medicare-only, Medicaid-only, dual-enrolled). For those dual-enrolled, we used the demographics from the Medicaid data: there were <1% difference in demographic variable values. We compared differences using chi-square tests for categorical variables and ANOVA or t-tests for continuous variables. Given our sample size, all comparisons were statistically significant even if they were not clinically meaningful, so we elected not to report *p* values or other results from null-hypothesis significance testing. As supplementary analyses, we calculated demographic statistics for the total intellectual and developmental disability sample, and by specific disability (intellectual disability, autism, and Down syndrome). The groups were not exclusive, and an individual could have more than one type of intellectual and developmental disability. We graphed the percent in each enrollment type for US states and territories. Lastly, we evaluated demographic differences among adults with Down syndrome by enrollment type. This analysis was deemed not human subjects research by the Boston University Medical Campus Institutional Review Board.

3 | RESULTS

3.1 | Medicare-only enrollees

In 2019, Medicare was the sole insurer for 149,172 adults with identified intellectual disability, autism, or Down syndrome (Table 1). The Mean age of Medicare-only enrollees in 2019 was 36.0 years (median 31 years) and 20% had been enrolled in Medicare for over 30 years.

Disability was the predominant reason for enrollment. In Supplement 2, we examined demographics by intellectual and developmental disability type for any Medicare enrollment (Medicare-only or dual). Individuals with intellectual disability were enrolled in Medicare for longer and were older entry into Medicare compared to individuals on the autism spectrum and with Down syndrome. Most Medicare enrollees with intellectual and developmental disabilities were enrolled as child dependents (60.7%) with the highest rate in the Down syndrome group (76.5%).

3.2 | Dual-enrolled and Medicaid-only enrollees

Of 582,868 Medicare beneficiaries, 149,172 were enrolled in Medicare only and 433,396 were dual-enrolled in Medicaid (Table 1). There were 819,256 adults with intellectual and developmental disabilities only enrolled in Medicaid. Medicaid-only enrollees were less likely to be white, non-Hispanic (58.5% white non-Hispanic compared to 72.9% white non-Hispanic in dual-enrolled), more likely to be Hispanic (19.6% Hispanic compared to 9.2% Hispanic in dual-enrolled) and were younger (mean 34.2 years Medicaid-only compared to 50.5 years dual-enrolled). Autism was more prevalent in the Medicaid-only group (33.9% compared to 20.1% in the dual-enrolled group). Medicare-only enrollees were 5 years older than dual enrollees and were more likely to be the primary beneficiary (55% compared to 28%). In total 9.3% of Medicare enrollees were first enrolled in Medicare at or after 65 years of age (2.8% in dual-enrolled). The average duration of enrollment was 1.4 years longer for Medicare-only enrollees compared to dual enrollees.

Medicare, Medicaid and Dual Enrolment



FIGURE 2 Percentage of enrollees with intellectual and developmental disabilities in each public health insurance type by state; 2019.

3.3 | State patterns

In Alaska, the Virgin Islands, New Mexico, and Idaho, >45% of adults with intellectual and developmental disabilities were Medicare-only (Figure 2). Three states (IA, SD, ND) had >45% dual-enrolled. AK, PR, VI, and NV had <15% dual-enrolled. Twenty states had >90% enrolled in Medicaid (either Medicaid-only or dual-enrolled) and 6 states had >60% enrolled in Medicare (either Medicare-only or dual-enrolled; AK, ID, ND, NM, VI, NH). State percentages are presented in Supplement 3.

3.4 | Down syndrome

Among those with Down syndrome in 2019 (Table 2), 10,904 were Medicare-only, 48,955 were Medicaid-only, and 59,049 were dual-enrolled. Like the full sample, adults with Down syndrome enrolled in Medicaid-only were less likely to be white non-Hispanic, more likely to be Hispanic, and younger compared to those enrolled in Medicare-only and dual-enrolled. Seventy percent of Medicaid-only enrollees

were ≤34 years of age compared to <20% of the Medicare-only or dual-enrolled adults. Those with Medicare-only enrollment entered Medicare later than those who were dual-enrolled (30.4 years compared to 26.9 years). Dual enrollees were more likely to be child dependents (78%) compared to Medicare-only enrollees (64.4%).

4 | DISCUSSION

Adults with intellectual and developmental disabilities rely on the public health insurers to provide coverage for healthcare needs. We found that in 2019 Medicare insured >500,000 adults with intellectual and developmental disabilities, of which 75% were dual-enrolled in Medicaid. Despite a major pathway for Medicare eligibility being age, 95% of Medicare beneficiaries with intellectual and developmental disability enrolled prior to age 65. Given the high healthcare need, use, and cost in this population,¹⁰ it is vital that individuals are adequately insured by Medicare, Medicaid, or both.

In the Medicare system, adults with intellectual and developmental disabilities are enrolled primarily due to disability eligibility during

TABLE 2 Demographic characteristics of adults with Down syndrome by public health insurance type, 2019.

| Demographic variable | Medicare only | | Medicaid only | | Dual-enrolled | |
|--------------------------------------|---------------|------------|---------------|------------|---------------|------------|
| | N = 10,904 | | N = 48,955 | | N = 59,049 | |
| | N | % | N | % | N | % |
| Sex | | | | | | |
| Male | 5663 | 51.9 | 24,519 | 50.1 | 31,908 | 54.0 |
| Female | 5241 | 48.1 | 24,381 | 49.8 | 27,141 | 46.0 |
| Race ^a | | | | | | |
| White | 8125 | 75.2 | 25,526 | 54.3 | 43,859 | 74.8 |
| Black | 1212 | 11.2 | 6638 | 14.1 | 5903 | 10.1 |
| Other | 91 | 0.8 | 212 | 0.5 | 469 | 0.8 |
| Asian | 170 | 1.6 | 1735 | 3.7 | 1114 | 1.9 |
| Hispanic | 1087 | 10.1 | 11,733 | 24.9 | 6775 | 11.6 |
| Native American | 114 | 1.1 | 1184 | 2.5 | 114 | 0.2 |
| Missing | 105 | | 1927 | | 430 | |
| Region | | | | | | |
| Northeast | 1142 | 10.5 | 9681 | 19.8 | 13,630 | 23.1 |
| Midwest | 2638 | 24.2 | 8891 | 18.2 | 16,228 | 27.5 |
| South | 5188 | 47.6 | 16,180 | 33.1 | 17,746 | 30.1 |
| West | 1792 | 16.4 | 13,763 | 28.1 | 11,254 | 19.1 |
| US Territories | 118 | 1.1 | 440 | 0.9 | 174 | 0.3 |
| Age at entry in Medicare | | | | | | |
| ≤25 | 5422 | 49.7 | NA | | 31,677 | 53.6 |
| 26–34 | 2838 | 26.0 | | | 17,765 | 30.1 |
| 35–44 | 1300 | 11.9 | | | 8262 | 14.0 |
| 45–54 | 332 | 3.0 | | | 951 | 1.6 |
| 55–64 | 170 | 1.6 | | | 103 | 0.2 |
| 65–89 | 853 | 7.8 | | | 291 | 0.5 |
| Mean (SD), median (IQR) | 30.4 (13.0) | 26 (21–34) | | | 26.9 (7.5) | 25 (20–31) |
| Age in 2019 | | | | | | |
| 18–25 | 278 | 2.5 | 17,866 | 36.5 | 2223 | 3.8 |
| 26–34 | 1416 | 13.0 | 16,281 | 33.3 | 8679 | 14.7 |
| 35–44 | 2529 | 23.2 | 8470 | 17.3 | 13,181 | 22.3 |
| 45–54 | 2993 | 27.4 | 3943 | 8.1 | 16,470 | 27.9 |
| 55–64 | 2134 | 19.6 | 1870 | 3.8 | 14,624 | 24.8 |
| 65–89 | 1554 | 14.3 | 525 | 1.1 | 3872 | 6.6 |
| Mean (SD), median (IQR) | 49.5 (14.6) | 49 (39–58) | 31.4 (11.1) | 28 (23–37) | 47.2 (12.3) | 48 (38–56) |
| Years enrolled in Medicare, all time | | | | | | |
| ≤5 | 1059 | 9.7 | NA | | 7592 | 12.9 |
| 6–10 | 1888 | 17.3 | | | 8484 | 14.4 |
| 11–15 | 1674 | 15.4 | | | 7347 | 12.4 |
| 16–20 | 1677 | 15.4 | | | 7615 | 12.9 |
| 21–25 | 1368 | 12.5 | | | 7008 | 11.9 |
| 26–30 | 1268 | 11.6 | | | 6934 | 11.7 |
| >30 | 1970 | 18.1 | | | 14,069 | 23.8 |
| Mean (SD), median (IQR) | 19.2 (11.1) | 18 (10–27) | | | 20.3 (12.2) | 19 (10–30) |

(Continues)

TABLE 2 (Continued)

| Demographic variable | Medicare only | | Medicaid only | | Dual-enrolled | |
|--|---------------|------|---------------|---------|---------------|---------|
| | N = 10,904 | | N = 48,955 | | N = 59,049 | |
| | N | % | N | % | N | % |
| Years enrolled in Medicaid from 2011 to 2019 | | | | | | |
| 0–<3 | NA | | 4666 | 9.4 | 403 | 0.7 |
| 3–<6 | | | 12,028 | 24.1 | 3960 | 6.7 |
| ≥6 | | | 32,261 | 64.7 | 54,686 | 92.6 |
| Mean (SD), median (IQR) | | | 6.6 (2.6) | 7 (5–9) | 8.3 (1.4) | 9 (9–9) |
| Medicare beneficiary type | | | | | | |
| Child dependent | 7024 | 64.4 | NA | | 46,507 | 78.8 |
| Primary beneficiary | 3530 | 32.4 | | | 11,849 | 20.1 |
| Other | 350 | 3.2 | | | 693 | 1.2 |

Abbreviations: IQR, interquartile range; SD, standard deviation.

^aRace categories include only non-Hispanic enrollees of that race.

young adulthood. With systemic ableism that limits opportunity, prevents asset acquisition, and keeps employment rates in the disabled population low,² this population is predominantly eligible via parent SSDI eligibility or through meeting SSDI's intellectual disorder criteria after an evaluation rather than being ≥65 years. Given the majority are enrolled via disability eligibility, there is the potential for disparities in accessing Medicare coverage. First, receiving coverage based on a parent's SSDI eligibility requires parent disability or parent's having adequate work credits. Further, parents who receive Social Security Retirement benefits can have their disabled children as dependents, which would mean relatively early retirement for a parent (e.g., 62 years) which may not be feasible. Average retirement age in people from non-White racial groups and Hispanic ethnicity is later than their white peers.²⁰ Further, receiving SSDI intellectual disorder evaluation takes knowledge of the benefits system, time, and often money.²¹ These reasons may be why we see a smaller percentage of individuals with any Medicare enrollment being non-White compared to Medicaid-only enrollees. Our results could be explained by differential severity between white and non-white races (i.e., white adults with intellectual disability are meeting SSDI intellectual disorder criteria compared to non-white adults) but this goes against consistent literature that finds more severe disability in non-white groups.²²

We found that greater than 400,000 adults with intellectual and developmental disabilities were dual-enrolled in Medicaid and Medicare. The benefits of dual enrollment include the more generous Medicare coverage, Medicaid coverage of long term services and supports, and Home and Community Based Service waivers, and Medicaid covering some of Medicare's out of pocket expenses.^{13,23} Being dual-enrolled is not always ideal; since Medicaid is a state program and Medicare is a federal program, benefits will defer by state Medicaid generosity. Further, there is often bureaucratic red tape and administrative burden when accessing these programs and with the two separate programs needing to communicate to ensure optimal care, coordination of care is a major issue.²³ In our data, 4% of those

receiving Medicaid-only were over 65 years of age (19% of all enrollees ≥65 years with intellectual and developmental disabilities), implying a group that is dual eligible but is not receiving Medicare benefits they are qualified for due to age. In general, dual enrollees have higher healthcare service use and cost compared to Medicare-only and Medicaid-only enrollees,²³ which is likely a result of their more chronic disabling conditions and socio-economic impact of poverty.¹⁴

There was great heterogeneity in state-specific enrollment patterns. Based on early enrollment in Medicare, age distribution is not likely a major factor in different patterns in state enrollment. Among all enrollees in 2020, states ranged from 4.2% to 19.5% of Medicare enrollees who were dual-enrolled in the Medicaid system.²⁴ In our sample states ranged from 14.5% to 50% dual-enrolled. State patterns may be different because of the arduous path of obtaining SSDI benefits that occur at state-level offices and program administration may be a reason for different state patterns.²⁵ Further, there are socio-economic differences between states (also partially due to policy) that may affect the underlying base population in need of Medicaid, Medicare, or both.¹⁵ In a handful of states, more individuals are only enrolled in Medicare compared to being enrolled in both Medicare and Medicaid—this may be a concern if individuals rely on the wrap-around Medicaid payments or long-term services and support. State-specific policies may be needed to reduce administrative burden on potential enrollees and ensure those eligible receive the services they need.

Medicare is a major insurer for adults with Down syndrome, with most Medicare-enrolled adults being dual-enrolled in Medicaid. An individual with Down syndrome may be more likely to have any Medicare enrollment because of the degree of impairment leading to an intellectual disorder assessment and older parent age (i.e., a parent is more likely to be SSDI eligible). Most adults with Down syndrome are eligible for Medicare as a child dependent, indicating they are eligible through their parent's SSDI eligibility. Two-fifths of Medicare-only and one-fifth of dual enrollees are primary beneficiaries, meaning they

qualified through their work experience or under intellectual disorder SSDI determination. Given the age distribution in the Down syndrome group and low employment rates,²⁶ we can assume most are eligible under the intellectual disorder SSDI determination. With the increased importance of Alzheimer's disease services and treatments in the Medicare population,²⁷ the Medicare system is more generous in coverage surrounding Alzheimer's drugs and care. For instance, the Centers for Medicare and Medicaid Services has announced that Medicare will broadly cover Alzheimer's drugs with appropriate FDA approval²⁸; such coverage in Medicaid would be determined by states and subject to coverage restrictions,²⁷ potentially exacerbating inequities.²⁹

4.1 | Limitations

We examined enrollment in the Medicare and Medicaid systems and were not able to examine insurance use in private insurance plans. Some adults with intellectual and developmental disabilities can qualify for private insurance offered by an insurer or through a parent's private insurance plan. Our analysis is conditional on qualifying for some public health insurance coverage. We were not able to determine whether primary Medicare beneficiaries qualified under intellectual disorder criteria through SSDI work credits. We did not examine differences in "partial" or "full" dual-eligibility, although Reichard et al. report only 5% of the intellectual and developmental disability sample being "partially" dual-eligible.¹⁴ Our data do not present a more refined classification of ethnicity than "Hispanic" or "Non-Hispanic." We did not have historical enrollment data for Medicaid like we did for Medicare. Autism is often under-identified in adults³⁰ and we are likely not including undiagnosed autistic adults. We only examined three relatively common intellectual and developmental disabilities that have been successfully identified in administrative claims data in the past. Future work should investigate conditions that are rarer and harder to identify in claims.

4.2 | Implications

Adults with intellectual and developmental disabilities predominantly use public health insurance coverage. There is large heterogeneity in who is Medicare-only, Medicaid-only, or dual-enrolled, likely attributable to the interplay between federal and state policy. Given the high healthcare needs of this population, it is crucial that individuals with intellectual and developmental disabilities get the coverage they are entitled to and deserve.

ACKNOWLEDGEMENTS

Dr Skotko reported receiving grants from the NIH during the conduct of the study and receiving personal fees from the Gerson Lehrman Group and from serving as an expert legal witness; book royalties from Woodbine House Inc; grants from F. Hoffmann-La Roche Inc, AC Immune, and LuMind IDSC Down Syndrome Foundation; and

nonfinancial support from the Massachusetts Down Syndrome Congress and the National Center for Prenatal and Postnatal Down Syndrome Resources outside the submitted work. No other disclosures were reported. Funding/Support: This project was funded by grant R01AG073179 from the National Institute on Aging. Role of the Funder/Sponsor: The funding source had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication. We would like to acknowledge Kristina Astone, MPH, Boston University, and Ariel Markowitz, MPH, Boston University, for their contribution to project management and manuscript preparation. They received compensation for their work on this project.

FUNDING INFORMATION

This work is funded by the National Institutes on Aging.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Rubenstein E, Tewolde S, Levine AA, et al. Medicare, Medicaid, and dual enrollment for adults with intellectual and developmental disabilities. *Health Serv Res*. 2024;1-10. doi:10.1111/1475-6773.14287