





# NATIONAL AUTISM INDICATORS REPORT

## Use of Dual Medicaid and Medicare Coverage among Autistic People

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### Authors:

Teal W. Benevides<sup>1</sup>  
Anne M. Roux<sup>2</sup>  
Samuelle Voltaire<sup>2</sup>  
Mary P. Sowers<sup>3</sup>  
Lindsay L. Shea<sup>2</sup>

### Author Affiliations:

<sup>1</sup> Institute of Public and Preventive Health, Augusta University

<sup>2</sup> Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University

<sup>3</sup> National Association of State Directors of Developmental Disabilities Services

### Data Analysis:

Wei-Lin Lee, Jonas Ventimiglia

### Graphic Design:

Chisa Merriweather

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## Executive Summary

This report highlights a critical but overlooked group: autistic adults who are dual eligible for both **Medicaid** and **Medicare**.

About **2.2% of U.S. adults**—around **5.5 million people**—are on the autism spectrum. The number of autistic adults is growing quickly, with rates increasing **nearly 300%** since 2000. Many autistic people also have other physical and mental health conditions, which means they often need specialized health care and community support throughout their lives.

Like other adults with intellectual and developmental disabilities (I/DD), autistic adults often **rely on public health insurance**. Most use **Medicaid** or **Medicare**, and some qualify for both programs. Individuals who qualify for both are called “**dual eligibles**” or “**duals**.”

*Because Medicare is usually thought of as a benefit for people age 65 and older, there is less public awareness that younger adults with I/DD, including autistic adults, can also be dual eligible.*

As autism prevalence rises, public systems like Medicaid and Medicare are struggling to meet the needs of the growing population of autistic adults. Autistic adults frequently use Medicaid to meet their health and service needs, but integrated use of both Medicaid and Medicare among dual eligibles is underdeveloped.

Understanding pathways and reasons for dual eligibility within this population is essential to guide policy and improve care systems. **This report presents new findings about dual eligibility among autistic people.**

## Key Findings

### 1. Autistic dual eligibles were unique compared to the general population of dual-eligible people.

Most dual-eligible adults in the U.S. are 65 years and older and are chronically ill. They typically qualify for Medicare first when they turn 65 and later qualify for Medicaid based on income. **Autistic dual eligibles do not follow this pattern.**

Autistic dual eligibles are generally young (age 45 and under), male, and white. They most often enter Medicaid first by qualifying for disability based on intellectual disability (ID), autism, or psychiatric conditions. They then enter Medicare later also based on disability. **These differences have major policy implications, as dually-eligible autistic adults will likely need lifelong health and developmental services.**

#### Characteristics of autistic dual eligibles versus the general population of dual eligibles

##### Autistic dual eligibles were more likely to:

- Be 45 years or younger
- Be White and non-Hispanic
- Qualify for **Medicaid first** based on disability and Medicare later based on disability

##### The general population of dual eligibles are more likely to:

- Be 46 years or older
- Be Black and/or Hispanic
- Qualify for **Medicare first** based on age and Medicaid later based on financial need

## 2. Autistic dual eligible adults who entered via Medicaid first were characteristically different from autistic adults who entered via Medicare first.

### Characteristics of autistic dual-eligible adults by pathway

Autistic duals who were enrolled in <b>Medicaid first</b> (Medicaid-to-Medicare) were more likely to:	Autistic duals who were enrolled in <b>Medicare first</b> (Medicare-to-Medicaid) were more likely to:
<ul style="list-style-type: none"><li>■ Be 45 years or younger</li><li>■ Qualify for Disability based on autism or psychiatric conditions (which often co-occur with autism)</li></ul>	<ul style="list-style-type: none"><li>■ Be 46 years or older</li><li>■ Have co-occurring intellectual disability and chronic conditions</li><li>■ Qualify for Disability based on intellectual disability (which often co-occurs with autism)</li></ul>

## 3. Autistic dual eligibles were also unique compared to dual eligibles with other disability types, such as those with intellectual disabilities.

### Characteristics of dual eligibles by disability type

Dual eligibles who were autistic were more likely to:	Autistic duals who had <b>intellectual disability</b> were more likely to:
<ul style="list-style-type: none"><li>■ Be 45 years or younger</li><li>■ Live in an urban area</li><li>■ Qualify for Disability based on psychiatric conditions</li><li>■ Qualify for <b>Medicaid first</b> and Medicare later</li></ul>	<ul style="list-style-type: none"><li>■ Be 46 years or older</li><li>■ Live in a rural area</li><li>■ Have co-occurring chronic conditions</li><li>■ Qualify for <b>Medicare first</b> and Medicaid later</li></ul>

The rest of this report explains more about dual eligibility, why dual eligibility is important, findings from our analyses, and implications for shaping disability and health policy to better serve autistic dual eligibles.



## Understanding dual eligibility for both Medicaid and Medicare public health insurance

### *What does dual eligibility mean and how does it work?*

**Dual eligibility** means a person qualifies for both **Medicaid** and **Medicare**. There are different types of dual eligibility. For people who are full dual eligible, Medicare pays for most health care services. After Medicare pays, then Medicaid may pay some of the remaining services and costs that Medicare did not cover. Sometimes Medicaid may also pay for things like Medicare **premiums, copays, or coinsurance**. Sometimes people also purchase supplemental health care plans to cover costs beyond what Medicare pays for. Medicaid may also pay for long-term care.

Benefits are different if someone has partial dual eligibility.

### **Full versus partial dual eligibility**

*There are many types of dual eligibility categories. People who are full dual eligibles receive complete Medicaid benefits along with Medicare coverage for services under Part A (e.g., inpatient, skilled nursing, hospice) and/or Part B (e.g., outpatient care, durable medical equipment). People who are partial duals do not receive Medicaid healthcare benefits but have Medicare coverage. However, Medicaid pays the premiums or cost-sharing of Medicare. Several types of partial dual eligibility exist.*

### **Important facts about people who are dual eligibles**

- Dual eligibles represent one-fifth of public health insurance enrollees, but they account for one-third of Medicaid and Medicare expenditures.
- They tend to be young (under 65 years). Nearly 40% of the \$312.4 billion spent on dual-eligibles in 2013 went to those under 65.
- Dual eligibles overall are more likely to be non-white.
- Dual eligibles often have incomes under \$10,000 annually.

## What is the difference between **Medicaid** and **Medicare**?

Medicaid is a joint federal and state program that helps cover medical costs for people who have low income, are disabled, or are aging. In addition to paying for medical services, Medicaid also pays for some programs that are meant to support independent living in the community called **Home and Community-Based Services (HCBS)**.

Medicaid plays a critical role for individuals with intellectual and developmental disabilities (I/DD), both for **health coverage** and for **long-term services and supports (LTSS)**, especially through HCBS.

### How **Medicaid** works:

- The federal government has general rules that all state Medicaid programs must follow, but each state runs its own program. So, eligibility requirements and benefits vary from state to state.
- Medicaid offers benefits that Medicare doesn't normally cover, like nursing home care and personal care services.
- People with Medicaid usually don't pay anything for covered medical expenses but may have a co-payment for some items or services.
- For low-income individuals who can't afford Medicare premiums and coinsurance costs, Medicaid may help by paying Medicare premiums (called "state payment of Medicare premiums").

**Medicare** is a federal (national) health insurance program. Since Medicare is a federal program, it has specific standards for costs and coverage. So, a person's Medicare coverage will be the same no matter what state they live in.

Medicare has four parts, each with different coverage and costs.

- Medicare Part A plus Medicare Part B are often called "Original Medicare."
  - Medicare Part A covers hospital or inpatient care.
  - Medicare Part B covers medical or outpatient care.
- Medicare Advantage Part C allows people to get coverage through private insurance plans that are approved by Medicare.
- Medicare Part D is a separate prescription drug plan available to Medicare enrollees for an additional cost.

People who have Medicare insurance pay part of the costs through monthly payments for medical and drug coverage, called premiums, and deductibles (the amount paid out-of-pocket before insurance starts paying).

## ***What is the history of these public health insurance programs?***

In 1965, the US federal government created **Medicare** as a health insurance program for Americans age 65 or older, and **Medicaid** as a health insurance program for those receiving Aid to Families with Dependent Children (AFDC).

In 1973, **Medicare** started to also cover people under age 65, if they received Social Security Disability Insurance (SSDI) benefits. Medicare now also provides insurance to other groups of people, such as widows and widowers under age 65 with disabilities, and disabled adult children of retired, deceased, or disabled workers.

## ***How do people with disabilities become eligible for Medicaid?***

Most people with disabilities become eligible for Medicaid through two pathways: **eligible for Medicaid through one of two pathways: income-based eligibility or disability-based eligibility**. Income-based eligibility is determined under Medicaid's financial criteria which is often linked to the federal poverty level. Disability-based eligibility typically requires meeting the Social Security Administration's definition of disability and qualifying for Supplemental Security Income (SSI). In most states, SSI recipients are automatically eligible for Medicaid, though some states require a separate application. Additionally, Medicaid expansion under the Affordable Care Act allows adults with low income to qualify regardless of disability status in expansion states. States also offer special programs, such as Medicaid Buy-In, for individuals with disabilities who work and earn above traditional income limits.

Some states allow people who are "medically needy" to qualify for Medicaid. **Medically needy**

means that someone has very high medical care costs but earns too much income (or has too much in assets) to qualify for Medicaid.

## ***How do people with disabilities under the age of 65 become eligible for Medicare?***

People under age 65 may become eligible for Medicare after they have qualified with a Disability Determination by the Social Security Administration and have received SSDI payments for 24 months. However, people are also required to wait 5 months before receiving their SSDI benefits. This means people who qualify for SSDI may wait a total of 29 months before Medicare coverage can begin.

People with a disability can also qualify for Medicare if they are an eligible dependent of a Medicare-qualified person (such as a retired, disabled, or deceased parent). The dependent's disability must have started before age 22.

While uncommon among autistic people, one other way that people under age 65 qualify for Medicare is if they are diagnosed with end-stage renal disease (ESRD) or amyotrophic lateral sclerosis (ALS). These groups automatically qualify for Medicare and do not have to wait for medical coverage.

## ***What are the characteristics of Medicaid beneficiaries?***

Medicaid provides coverage of health care and support services for **one in every three** adults with a disability in the U.S. A majority of people who receive Medicaid are Black, Hispanic, and American Indian or Alaskan Native. Across age groups, a little over **one-third of Medicaid beneficiaries** (36% in 2023) are White. Over **half of Medicaid beneficiaries** are female (55% female; 45% male). The majority of beneficiaries are over 18 years old, with **just over half** (54%) of adult beneficiaries being

between the ages of 19 – 64; those age 65 or older make up 10% of beneficiaries.

## What are the characteristics of Medicare beneficiaries?

Most people who use Medicare are White, and their incomes tend to be lower than average incomes in the U.S. In 2023, approximately **half** of people on Medicare had an annual income below \$36,000 per person, and **one-fourth** had an annual income of \$21,000 per person. In 2023, the total income for people on Medicare was lower for women than it was for men, and **lower for Black and Hispanic people** than it was for White people.

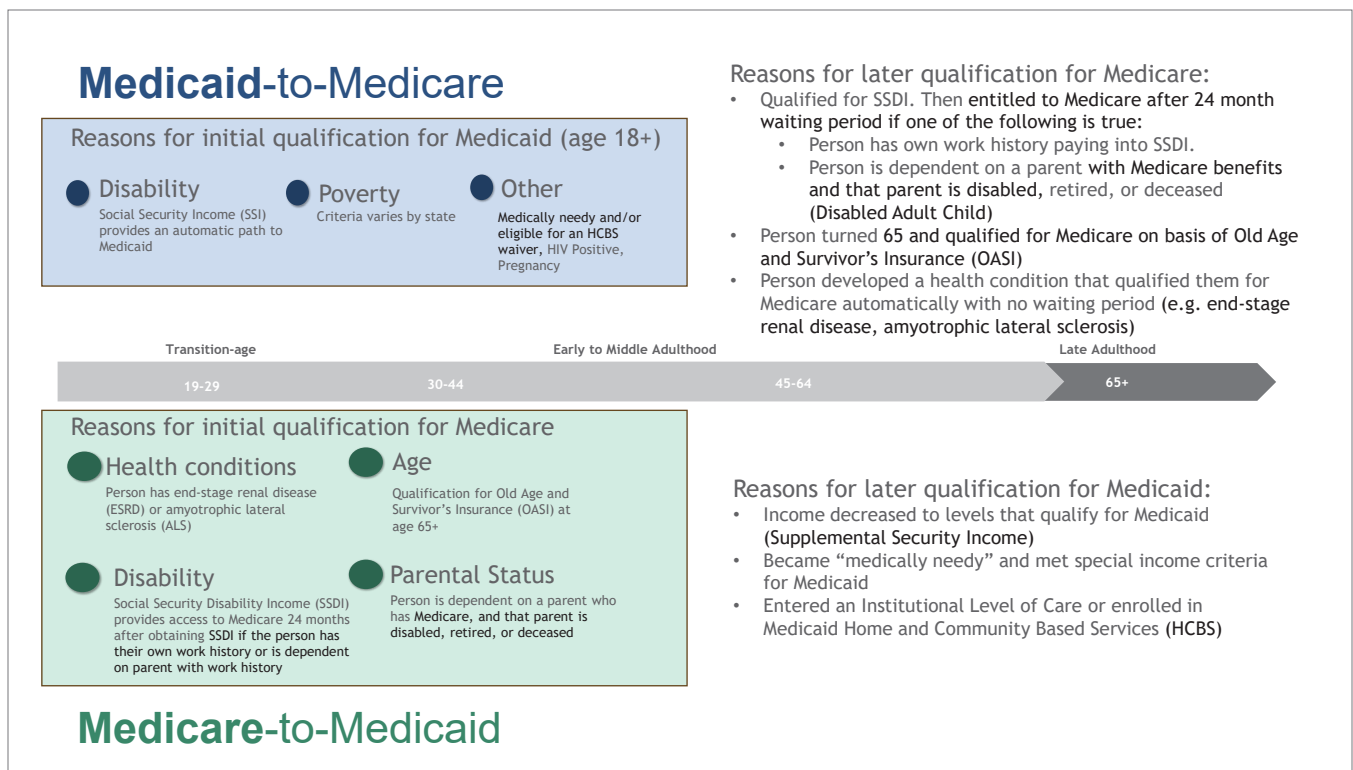
## How do people become dual eligible?

A **recent report** looked at how people become dual eligible, meaning how they qualify for both Medicare and Medicaid. Disability plays a big role in this process. Among those who qualified for Medicare first, about 40% did so because of a disability, and later, about 20% also qualified

for Medicaid through disability-related benefits. For people who qualified for Medicaid first, most (55%) did so because of disability, and two-thirds later qualified for Medicare for the same reason.

Overall, more dual-eligible adults (**67%**) **start with Medicare**—usually because they turn 65—and then add Medicaid if they meet state income rules. In contrast, about 27% start with Medicaid, and nearly 70% are under age 65. The infographic below shows the different paths to becoming dual eligible.

**More about disability.** Some people qualify for Medicaid or Medicare because the Social Security Administration (SSA) deemed them to have a disability that made them eligible for Supplemental Security Income (SSI) benefits or Social Security Disability Insurance (SSDI). People qualify for SSI and SSDI by going through a Disability Determination process from the SSA. Qualification for SSI is an important pathway into Medicaid, and qualification for SSDI can be an important pathway into qualifying for Medicare.





## What do previous studies tell us about autistic dual eligibles?

Recent research has examined Medicaid and Medicare use among autistic youth and adults, but only [one study](#) (Benevides and colleagues, 2021) focused on autistic adults who were dual eligible for both programs. In that study, the total number of dual-eligible autistic adults was about the same as the number of autistic adults enrolled in Medicaid only, but there were ten times more dual-eligible autistic adults than the number of autistic people using Medicare only.

**In 2012, spending on dual-eligible autistic adults reached \$6.3 billion**, compared to \$5.2 billion for Medicare-only and over \$5.2 billion for Medicaid-only beneficiaries.

*Understanding who these dual-eligible adults are, their support needs, and how they become dual eligible is an important research priority because of their growing numbers, economic impact, and significant differences from the general population of dual eligibles.*

Unlike the overall population of dual eligible adults, autistic dual eligibles tend to be younger, appear to have disparities in dual eligibility based on race and ethnicity, tend to be full dual eligibles, and can have widely varying costs. Some of the key findings from the 2021 study by Benevides, included:

- **Age.** 61% of autistic dual eligibles were under 35 years of age, reflecting increased autism prevalence since the early 2000s and greater reliance on public benefits.
- **Race and ethnicity.** Black autistic adults were less likely to qualify for dual eligibility and, when eligible, had lower expenditures than their white peers.

Autistic young adults who are dual eligible will likely remain dual-eligible beneficiaries throughout life, requiring resources to manage emerging chronic conditions.

### ***The importance of understanding why and how autistic people become dual eligible***

Understanding different groups (or segments) of the autistic dual-eligible population is essential for policy development. For example:

- **Little is known about how autistic people become dual eligible at such a young age, and how they maintain dual eligibility.** It is difficult to make policy recommendations without first understanding how young people are becoming dual eligible.
- Understanding the experiences of dual-eligible autistic people from different racial and ethnic backgrounds is critical for addressing disparities.
- We do not know the extent to which non-integrated care is a problem and how it impacts autistic people specifically.

Learning more about autistic dual eligibles will help guide equitable state and federal policy for better addressing their needs. Here are further reasons why this is important.

- **Care systems often struggle to provide accessible, coordinated, and integrated services.** People with I/DDs, including autism, face major barriers to getting health insurance for medical needs and home- and community-based services (HCBS) for independent living. The federal process to qualify for SSI or SSDI—and thus Medicaid or Medicare—usually requires multiple applications and financial/legal resources, which is hard for those with limited income.

People with full dual eligibility face the challenge of navigating two complex systems, which can lead to inefficiencies rather than better care. This issue has driven proposals for more integrated care. For autistic duals, integration of care across Medicaid and Medicare is especially important because of their high rates of chronic conditions as they age and early onset health issues that need specialized care and coordination. Understanding their characteristics can guide policy and innovative efforts to integrate care.

- **Studying who becomes dual eligible through different pathways can help improve system integration and guide providers in supporting people with I/DDs.** A recent call to action highlighted the diversity within the dual-eligible population and urged finding better ways to understand different groups of dual-eligible people to inform policy. Policymakers need to understand who these dual beneficiaries are and how their health care costs impact federal and state systems.

## How did we do this study?

We used two data sources for this report.

First, the authors, led by Dr. Teal Benevides, carried out a study using **2012 data from the Medicare-Medicaid Linked Enrollees Analytic Data Source (MMLEADS)**.

MMLEADS is a data set that combines information on demographics, health conditions, and program enrollment for people who have both Medicare and Medicaid. MMLEADS provides an excellent view of dual eligibles, but the most recent MMLEADS data utilized 2012 claims.

We focused on adults who were enrolled in both programs and had either an autism diagnosis (about 82,000 people) or an intellectual disability without autism (about 507,000 people). We looked at these diagnoses separately to examine differences between disability groups.

We grouped individuals who were dual eligible based on whether they first entered Medicare or Medicaid, but we excluded those who started both programs on the same day.

We looked at age, gender, race, rural location, chronic health conditions like diabetes and heart disease, and reasons for eligibility, in addition to other characteristics, to compare across the two pathway groups.

Second, to update our findings about duals, we analyzed more recent **linked Medicaid and Medicare claims data from 2019**.

To learn more about the Methods, please see **Appendix 1: Methods**.

To view details about findings, please see **Appendix 2: Tables**.

## New findings about autistic duals: Our research

### *About this report*

The rest of this report explores new data from our team regarding autistic adults who are dual eligible and their pathways to Medicare and Medicaid. We compared autistic duals to their peers with intellectual disability (ID) to better understand how autistic duals might be unique. We also highlight policy issues to guide future research.

### *What did we learn?*

This study is among the first to measure and describe dual eligibility for Medicaid and Medicare among autistic adults. Most of this study analyzed MMLEADS 2012 data. We focus our reporting on these findings and then provide updated data.

## Our Main Findings

### *Autistic dual-eligible adults differed from typical dual-eligible adults in the U.S.*

- Most dual eligible adults in the U.S. are age 64 or older, chronically ill, and enter Medicare first based on age, then Medicaid based on income (**Medicare**-to-**Medicaid** pathway).
- Autistic adults who were dual eligible were generally young (under age 45), male, and white. They most often entered dual status through the Medicaid-to-Medicare pathway.
- Autistic adults most often qualified for disability based on a co-occurring diagnosis of intellectual disability. Although, some qualified based on autism, or on co-occurring psychiatric conditions.
  - Note: A Disability Determination through the Social Security Administration can enable eligibility for SSI, as a pathway into Medicaid, and SSDI, as a pathway into Medicare.
- These differences have major policy implications.
  - Young autistic dual-eligible adults will likely need lifelong health and developmental services.
  - Integrated care for dual eligible people is important for decreasing the barriers

people with disabilities face when having to navigate both Medicaid and Medicare programs as dual eligibles.

### *Autistic dual eligibles had unique characteristics.*

Unlike the overall population of dual eligible adults, autistic dual eligibles tended to be young. **Over 61% were 45 years old or younger**, reflecting increased autism prevalence since the early 2000s and greater reliance on public benefits. These young adults will likely remain beneficiaries throughout life, requiring resources to manage emerging chronic conditions.

More than half (54%) of autistic dual eligibles **entered dual status by qualifying for Medicaid first** (typically based on disability) and then qualified for Medicare later (also typically based on disability.)

In general, public health insurance plan enrollment has dramatically shifted toward the use of managed care plans. Autistic duals, however, were heavily reliant on fee-for-service plans.

- 87% of autistic dual eligibles had **fee-for-service Medicaid** (instead of Medicaid managed care) during all months of 2012. In comparison, only **34% of Medicaid enrollees** used fee-for-service Medicaid plans in 2010-2012.

## Fee-for-service plans versus managed care plans

Medicaid and Medicare both have fee-for-service plans and managed care plans. In **fee-for-service plans**, Medicaid and Medicare pay a provider directly for the service they provide for a patient. Patients can see any provider. In **managed care plans**, also called Medicaid Managed Care Organizations or Medicare Advantage plans, providers are paid a fixed rate for each member per month. The managed care organizations may coordinate care to control costs. Patients are required to use in-network providers except in case of emergency.

- Most autistic dual eligibles used **fee-for-service Medicare** plans in 2012. Only 8% of autistic duals participated in Medicare managed care (Part C, also called Medicare Advantage) during at least one month of the year. However, **27% of Medicare users** overall were in Medicare Advantage plans.

### **Autistic dual eligibles who were enrolled in Medicaid first differed from those who enrolled in Medicare first.**

There were differences in the characteristics of autistic dual eligibles when comparing groups by pathway.

- Autistic dual eligibles in the **Medicaid-to-Medicare** group were more likely to be younger, have Medicaid through SSI, and qualify for SSDI based on autism spectrum disorder.
- Autistic dual eligibles in the **Medicare-to-Medicaid** group were more likely to be older, white, have co-occurring intellectual disability and chronic health conditions, qualify for SSDI based on their intellectual disability, and be eligible for Medicaid under “medically needy” criteria.

Specifically:

- **Age.** Autistic dual eligibles in the **Medicaid-to-Medicare** pathway were younger (87% were under 45 years; 68% were 18–35 years) compared to those in the **Medicare-to-Medicaid** pathway (71% were 46 years or older).
- **Co-occurring conditions.** Autistic adults in the **Medicare-to-Medicaid** pathway were more likely to have co-occurring intellectual disability (84%) compared to 68% in the **Medicaid-to-Medicare** pathway. And those in the **Medicare-to-Medicaid** pathway were more likely to have a chronic condition (68%) compared to those in the **Medicaid-to-Medicare** pathway (53%),



**Insight:** Higher rates of chronic conditions among autistic people who enter Medicare first could be related to their overall older age.

- **Supplemental Security Income (SSI).** 48% of autistic adults in the Medicaid-to-Medicare pathway received SSI compared to 31% in the Medicare-to-Medicaid pathway.
- **Reason for Disability.** Autistic adults in the Medicaid-to-Medicare pathway were more likely to have a Disability Determination based on autism (22%) compared to only 5% of those in the Medicare-to-Medicaid pathway. Those in the Medicare-to-Medicaid pathway were more likely to have a Disability Determination based on intellectual disability (43%) compared to 35% in the Medicaid-to-Medicare pathway.



**Insight:** Since those who qualified for **Medicare first** were generally older, this difference may also reflect lower rates of diagnosing autism among this older cohort.

- **Qualification for Medicaid.** Autistic adults in the **Medicare-to-Medicaid** pathway were more likely to qualify for Medicaid by being “medically needy” (12%) versus 7% of those in the **Medicaid-to-Medicare** pathway.

### **Autistic dual eligibles differed from dual eligibles with ID.**

Autistic duals share similarities with other I/DD duals but differ in key ways. Autistic duals were generally younger, more often male, white, and non-Hispanic compared to duals with ID.

Specifically:

- **Sex.** Autistic duals were more often male (71%) than those with ID (54%).



**Insight:** This difference is consistent with the general pattern of higher rates autism diagnosis in males.

- **Age.** Autistic duals tended to be age 45 or younger (61%), while 62% of those with ID were 46 years or older.



**Insight:** This difference reflects rising autism prevalence

- **Race and Ethnicity.** Autistic dual eligibles were slightly more likely to be white (75%) compared to those with ID (73%). Autistic duals were less likely to be Black (15%) or Hispanic (6%) compared to those with ID who were Black (17%) or Hispanic (7%).



**Insight:** These patterns are consistent with historical inequities in autism screening and diagnosis among Black and Hispanic children.

- **Geography.** While 18% of autistic duals lived in rural areas, 23% of duals with ID lived in rural areas.
- **Co-occurring conditions.** Fewer autistic duals had a chronic health condition (60%) compared to those with ID (69%), which could be related to the general older age of those with ID.
- **SSA Disability:** Approximately 12% of the autistic group qualified for a Disability Determination based on a psychiatric diagnosis, compared to 8% of those with intellectual disability.

While 54% of autistic adults became dual eligible via a **Medicaid-to-Medicare** pathway, only 36% of adults with intellectual disability began in **Medicaid**. This pattern could be reflective of the older age of dual eligibles with ID.

The differences between autistic dual eligibles and those with ID generally held up when looking at characteristics across pathways.

Compared to those with ID, autistic duals in the **Medicaid-to-Medicare** pathway were younger; more often male, white, and non-Hispanic; less likely to live in rural areas or have chronic conditions; and slightly more likely to qualify for Medicare based on disability.

Compared to those with ID, autistic duals in the **Medicare-to-Medicaid** pathway were more often male, slightly more likely to be white and non-Hispanic, less likely to live in rural areas or have chronic conditions, and less likely to qualify for Medicare based on age.

### ***What does updated data on autistic dual eligibles signal?***

While our two data sources, MMLEADS 2012 and linked Medicaid-Medicare data in 2019, are not directly comparable, we are able to

#### ***Demographic characteristics of autistic dual-eligibles versus those with ID, by pathway***

<b>Medicaid-to-Medicare</b>		<b>Medicare-to-Medicaid</b>	
<b>AUTISM</b>	<b>ID</b>	<b>AUTISM</b>	<b>ID</b>
87% age 45 years and under	72% age 45 years and under	71% age 46 and older	81% age 46 and over
73% male	53% male	68% male	54% male
72% white	67% white	79% white	76% white
16% Black	19% Black	13% Black	15% Black
7% Hispanic	10% Hispanic	5% Hispanic	6% Hispanic
18% rural	22% rural	17% rural	23% rural
68% had co-occurring ID	n/a	84% had co-occurring ID	n/a
53% had a chronic condition	60% had a chronic condition	68% had a chronic condition	74% had a chronic condition

Source: MMLEADS, 2012

*Demographic characteristics of autistic dual-eligibles versus those with ID, by pathway*

**Medicaid-to-Medicare**

**Medicare-to-Medicaid**

AUTISM		ID	
98% qualified for Medicare based on disability	93% qualified for Medicare based on disability (7% qualified based on old age)	97% qualified for Medicare based on disability	96% qualified for Medicare based on disability
48% qualified for Medicaid based on SSI	48% qualified for Medicaid based through SSI	50% qualified for Medicaid based through SSI	35% qualified for Medicaid based through SSI
12% qualified for Medicaid based on poverty	11% qualified for Medicaid based on poverty	12% qualified for Medicaid based on poverty	12% qualified for Medicaid based on poverty
35% had a Disability Determination* based on intellectual disability	48% had a Disability Determination based on intellectual disability	43% had a Disability Determination based on intellectual disability	46% had a Disability Determination based on intellectual disability
22% had a Disability Determination based on autism	n/a	5% had a Disability Determination based on autism	n/a
14% had a Disability Determination based on psychiatric conditions	10% had a Disability Determination based on psychiatric conditions	10% had a Disability Determination based on psychiatric conditions	6% had a Disability Determination based on psychiatric conditions

Source: MMLEADS, 2012

Note: Information on Disability Determinations were made via the Social Security Administration (SSA). This data should be interpreted with caution given high rates of missing data (21%-33% per group).

draw some general comparisons regarding trends. We note that we were unable to examine pathways into dual eligibility using our linked 2019 data or examine SSA Disability Determinations.

In general, autistic duals continued to be younger and less diverse compared to dual eligibles with ID. More recent data suggested decreasing rates of Medicaid eligibility based on disability but increasing rates of Medicare

eligibility based on disability. These trends should be interpreted with caution and merit continued assessment using more recent data.

In general, lower percentages of autistic duals were using fee-for-service Medicaid or Medicare in 2019 compared to 2012 data. This trend is in line with continued increases in use of managed care among the general population of Medicaid and Medicare enrollees.

**Characteristics of autistic dual eligibles in 2012 versus 2019**

	2012 (MMLEADS) data	2019 (linked Medicaid-Medicare data)
Age	61% were 45 years or younger.	77% were age 45 years or younger.
Race	15% were Black.	11% were Black.
Ethnicity	6% were Hispanic.	8% were Hispanic.
Medicaid Eligibility	40% of Medicaid enrollees likely qualified for disability based on having SSI in 2012.	70% qualified based on disability.
Medicare Eligibility	98% qualified based on disability.	67% qualified based on disability.
Medicaid Plan	87% used fee-for-service Medicaid.	52% used fee-for-service Medicaid.
Medicare Plan	8% used Medicare managed care.	15% used Medicare managed care.

Sources: MMLEADS (2012) and linked Medicaid-Medicare data (2019)



## Recommendations

The findings in this report from 2012 and 2019 will serve as a baseline to help track future trends as the autistic adult population grows and becomes more diverse. The recommendations below address specific concerns that we identified in our analyses.

### 1. *Facilitating access to dual benefits*

Provision of information about Medicaid, Medicare, and dual enrollment is critical for autistic adults.

- **Training for professionals.**

Healthcare providers and Medicaid service coordinators play a key role in educating families and transition-age youth about dual eligibility. Next steps include training care coordinators and benefit coordinators to facilitate provision of accurate information and to ensure providers document challenges that impact work participation for SSA Disability Determinations.

- **Consider the role of employment.**

Qualification for SSDI as a pathway into Medicare is often contingent upon a work history. Autistic adults have poor employment outcomes, limiting their ability to build the work history needed for Medicare. Parents of autistic

children also have reduced workforce participation, which may hinder access to benefits for themselves or their children as “disabled adult children.” Supports that promote employment—such as respite care, benefits counseling, and community programs—may help families meet SSDI criteria and secure Medicare coverage.

- **Address inequities.** The current lack of diversity among autistic duals is concerning given existing racial and ethnic disparities in autism diagnosis and healthcare. Immediate action is needed to help marginalized families access pathways to Medicare and Medicaid.

## 2. Importance of integrated and coordinated care

As more autistic people qualify for both Medicaid and Medicare, states may face higher administrative costs. This makes it important to ensure care is well-coordinated and easier to navigate. Our findings suggest major challenges in coordinating dual benefits. Even with coverage from Medicare and Medicaid, many people with disabilities struggle to access services or find providers who accommodate their needs. Complex and inconsistent requirements across both programs worsen these barriers, underscoring the need for better system integration.

- Recent calls to review age limits for integrated care programs highlight growing awareness of barriers for younger duals with disabilities.

## 3. Need for additional research

The Affordable Care Act created new ways for people to access Medicare and Medicaid, which matters as autistic youth grow into adulthood. To date, some low-income Medicare recipients have gained Medicaid coverage, but more research is needed to understand how these changes affect autistic individuals and to guide policy.

In general, research is needed to understand differences in care and outcomes between autistic people who use only Medicaid versus those who use dual Medicaid and Medicare coverage. This is a critical question given the lack of integrated care options for dual enrollees.

Specific to autistic dual eligibles, our findings suggest that the following research topics are important:

- Medicaid enrollment is the most common pathway to dual eligibility for autistic adults. Research should **examine state policies and practices that help families navigate Medicare enrollment**, as variation across states could reveal effective strategies.
- Future research should **examine barriers autistic adults face during SSA Disability Determinations**. More autistic people may be qualifying for Disability through co-occurring intellectual disability, because it may be easier to prove ID as a work-limiting condition.
- Future research should focus on **outcomes for autistic duals**, identifying coverage gaps and strategies to improve coordinated care that supports health and well-being.
  - Differences in service utilization and outcomes should be examined for autistic duals enrolled in fee-for-service versus managed care plans.
  - More recent value-based care initiatives, such as accountable care organizations within Medicare and Medicaid should be evaluated in their approach to supporting better outcomes with reduced costs.

## Appendix: Methods

**Design and Data Source.** We conducted a descriptive, cross-sectional cohort study using the 2012 Medicare-Medicaid Linked Enrollees Analytic Data Source (MMLEADS V2.0). MMLEADS, compiled by CMS, links data on demographics, eligibility, costs, and utilization for dual-eligible individuals. The 2012 file includes over 10 million dual eligibles. Although older, V2 was chosen because it includes Chronic Condition Warehouse (CCW) variables, unlike the 2016 V3 release, and allows examination of historical trends. MMLEADS also provides enrollment, eligibility, and SSA disability diagnosis data not found in other CMS datasets. Institutional review board approval and a CMS Data Use Agreement were obtained before analysis.

**Sample and Dual-Eligible Pathway Groups.** We included individuals who were full, partial, or Qualified Medicare Beneficiary (QMB) duals, aged 18 or older, with valid enrollment dates for both Medicare and Medicaid, and a current or past CCW classification for autism spectrum disorders (n=82,921; ~0.79% of all duals). For comparison, we included duals with intellectual disability (ID) but no autism diagnosis (n=509,003). Using coverage start dates, we classified individuals as “Medicare-to-Medicaid” or “Medicaid-to-Medicare.” Medicaid start dates (from CMS MAX) go back to 1999; Medicare start dates have no limit. We excluded those eligible for both programs on the same date (425 autistic individuals and 2,026 with ID).

**Variables.** We compared demographic, eligibility, and condition variables from MMLEADS Beneficiary and Chronic Condition files. Demographics included age (categorized), gender, race/ethnicity, and rural status (based on 2013 HRSA zip code classification). Condition variables included CCW flags for depression, epilepsy, diabetes (Type I/II), arthritis, heart disease (e.g., myocardial

infarction, hypertension, stroke, heart failure), cancers (breast, colorectal, lung, prostate), Alzheimer’s disease, and obesity.

Eligibility variables included reasons for coverage under both programs. Medicare variables: original and current entitlement reason, and whether the individual had 12 months of FFS coverage or any managed care enrollment. Medicaid variables: monthly maintenance assistance status, annual FFS coverage summary, and most recent state buy-in for Medicare (a poverty marker). Note: CMS retired the maintenance assistance variable in 2014, but our data precede this change.

**SSA Disability Determination variables.** Since Medicare eligibility for people with disabilities often occurs via SSA disability determination (via SSDI), we examined primary SSA diagnosis. Examples include ID, autism, psychotic disorders, organic mental disorders, and mood disorders. SSA diagnosis was missing for 25% of autistic duals and 30% of those with ID.

**Medicare plan.** We report enrollment in Medicare Parts A, B, C, and D, including whether beneficiaries were in FFS or Medicare Advantage (Part C).

**Data Analysis.** We used Stata MP16.1 for all analyses. Beneficiary and Chronic Condition files were merged using unique IDs. Individuals meeting inclusion criteria were classified into pathway groups. For each demographic, condition, and eligibility variable, we report frequencies and proportions by pathway group.

**Limitations.** This study has limitations. It uses one year of data, so newer trends need to be studied. Some people who became eligible before 1999 may not be included. Finally, the higher number of white males in our sample reflects long-standing inequities in autism diagnosis and access to services. These gaps show that many people who need support may still be left out due to systemic barriers.

# Appendix: Tables

**Table 1. Characteristics of dual-eligible autistic adults compared to adults with intellectual disability by dual-eligibility pathways, MMLEADS V2.0**

	Total ASD Dual-Eligible N=82,496		Dual Eligibility Path for ASD Group Medicaid-to-Medicare N=44,751				Total ID Dual-Eligible N=506,977		Dual Eligibility Path for ID Group Medicaid-to-Medicare N=180,252			
	N	Col %	N	Col %	N	Col %	N	Col %	N	Col %	N	Col %
<b>Demographic Variables</b>												
Gender, Male	58,490	<b>70.90</b>	32,685	<b>73.04</b>	25,805	<b>68.37</b>	271,232	<b>53.50</b>	95,941	<b>53.23</b>	175,291	<b>53.65</b>
Age (Years)												
18-25	12,446	<b>15.09</b>	11,969	<b>26.75</b>	477	<b>1.26</b>	23,911	<b>4.72</b>	22,733	<b>12.61</b>	1,178	<b>0.36</b>
26-35	20,722	<b>25.12</b>	18,468	<b>41.27</b>	2,254	<b>5.97</b>	73,098	<b>14.42</b>	64,110	<b>35.57</b>	8,988	<b>2.75</b>
36-45	16,888	<b>20.47</b>	8,531	<b>19.06</b>	8,357	<b>22.14</b>	94,854	<b>18.71</b>	42,950	<b>23.83</b>	51,904	<b>15.89</b>
46-55	17,733	<b>21.50</b>	4,399	<b>9.83</b>	13,334	<b>35.33</b>	132,942	<b>26.22</b>	28,911	<b>16.04</b>	104,031	<b>31.84</b>
56-64	9,137	<b>11.08</b>	658	<b>1.47</b>	8,479	<b>22.46</b>	92,574	<b>18.26</b>	7,399	<b>4.10</b>	85,175	<b>26.07</b>
65+	5,570	<b>6.75</b>	726	<b>1.62</b>	4,844	<b>12.83</b>	89,598	<b>17.67</b>	14,149	<b>7.85</b>	75,449	<b>23.09</b>
Race												
White	62,133	<b>75.32</b>	32,159	<b>71.86</b>	29,974	<b>79.41</b>	369,887	<b>72.96</b>	120,512	<b>66.86</b>	249,375	<b>76.33</b>
Black	12,113	<b>14.68</b>	7,119	<b>15.91</b>	4,994	<b>13.23</b>	83,716	<b>16.51</b>	34,092	<b>18.91</b>	49,624	<b>15.19</b>
Asian/PI	1,532	<b>1.86</b>	1,120	<b>2.50</b>	412	<b>1.09</b>	6,775	<b>1.34</b>	3,852	<b>2.14</b>	2,923	<b>0.89</b>
Hispanic	5,019	<b>6.08</b>	3,188	<b>7.12</b>	1,831	<b>4.85</b>	37,321	<b>7.36</b>	17,509	<b>9.71</b>	19,812	<b>6.06</b>
American Indian/Alaska Native	530	<b>0.64</b>	338	<b>0.76</b>	192	<b>0.51</b>	4,084	<b>0.81</b>	1,785	<b>0.99</b>	2,299	<b>0.70</b>
Other/More than One	741	<b>0.90</b>	476	<b>1.06</b>	265	<b>0.70</b>	3,507	<b>0.69</b>	1,602	<b>0.89</b>	1,905	<b>0.58</b>
Missing	428	<b>0.52</b>	351	<b>0.78</b>	77	<b>0.20</b>	1,687	<b>0.33</b>	900	<b>0.50</b>	787	<b>0.24</b>
Rural	14,540	<b>17.73</b>	8,099	<b>18.20</b>	6,441	<b>17.18</b>	114,370	<b>22.67</b>	39,304	<b>21.90</b>	75,066	<b>23.09</b>
<b>Condition Variables</b>												
Intellectual disability	62,005	<b>75.16</b>	30,285	<b>67.67</b>	31,720	<b>84.04</b>	506,977	<b>100.0</b>	180,252	<b>100.0</b>	326,725	<b>100.0</b>
Chronic condition †	49,382	<b>59.86</b>	23,816	<b>53.22</b>	25,566	<b>67.73</b>	349,720	<b>68.98</b>	108,785	<b>60.35</b>	240,935	<b>73.74</b>
<b>Eligibility variables</b>												
Original Reason for Medicare												
DI	80,696	<b>97.82</b>	44,007	<b>98.34</b>	36,689	<b>97.20</b>	481,878	<b>95.05</b>	166,873	<b>92.58</b>	315,005	<b>96.41</b>
OASI	1,547	<b>1.88</b>	596	<b>1.33</b>	951	<b>2.52</b>	21,654	<b>4.27</b>	11,797	<b>6.54</b>	9,857	<b>3.02</b>
ESRD	107	<b>0.13</b>	79	<b>0.18</b>	28	<b>0.07</b>	1,297	<b>0.26</b>	755	<b>0.42</b>	542	<b>0.17</b>
DI+ESRD	146	<b>0.18</b>	69	<b>0.15</b>	77	<b>0.20</b>	2,148	<b>0.42</b>	827	<b>0.46</b>	1,321	<b>0.40</b>

**Table 1 (continued)**

	Total ASD Dual-Eligible N=82,496		Dual Eligibility Path for ASD Group			Total ID Dual-Eligible N=506,977		Dual Eligibility Path for ID Group				
	N	Col %	Medicaid-to-Medicare N=44,751	Medicare-to-Medicaid N=37,745	N	Col %	N	Col %	Medicaid-to-Medicare N=180,252	Medicare-to-Medicaid N=326,725	N	Col %
Current Reason for Medicare												
DI	77,541	<b>93.99</b>	43,917	<b>98.14</b>	33,624	<b>89.08</b>	426,383	<b>84.10</b>	165,260	<b>91.68</b>	261,123	<b>79.92</b>
OASI	4,741	<b>5.75</b>	703	<b>1.57</b>	4,038	<b>10.70</b>	77,746	<b>15.34</b>	13,591	<b>7.54</b>	64,155	<b>19.64</b>
ESRD	91	<b>0.11</b>	76	<b>0.17</b>	15	<b>0.04</b>	1,067	<b>0.21</b>	722	<b>0.40</b>	345	<b>0.11</b>
DI+ESRD	123	<b>0.15</b>	55	<b>0.12</b>	68	<b>0.18</b>	1,781	<b>0.35</b>	679	<b>0.38</b>	1,102	<b>0.34</b>
Medicare Part A & Part B State Buy-In (as of Dec 2012)												
No state buy-in of Part A and/or B	3,918	<b>4.75</b>	3,811	<b>8.51</b>	107	<b>0.28</b>	41,831	<b>8.25</b>	13,899	<b>7.71</b>	27,932	<b>8.55</b>
State buy-in of Part A and/or B	77,310	<b>93.71</b>	40,618	<b>90.76</b>	36,692	<b>97.21</b>	449,316	<b>88.63</b>	163,217	<b>90.55</b>	286,099	<b>87.56</b>
Not entitled or enrolled	1,268	<b>1.54</b>	322	<b>0.72</b>	946	<b>2.50</b>	15,830	<b>3.12</b>	3,136	<b>1.74</b>	12,694	<b>3.89</b>
Medicaid Maintenance Assistance												
SSI	32,652	<b>40.16</b>	21,320	<b>47.91</b>	11,332	<b>30.79</b>	198,942	<b>40.47</b>	88,607	<b>49.93</b>	110,335	<b>35.12</b>
Poverty	9,999	<b>12.30</b>	5,434	<b>12.21</b>	4,565	<b>12.41</b>	58,312	<b>11.86</b>	19,777	<b>11.14</b>	38,535	<b>12.27</b>
Other	29,272	<b>36.01</b>	13,628	<b>30.63</b>	15,644	<b>42.51</b>	182,582	<b>37.14</b>	54,108	<b>30.49</b>	128,474	<b>40.90</b>
Medically needy	7,388	<b>9.09</b>	2,939	<b>6.60</b>	4,449	<b>12.09</b>	40,783	<b>8.30</b>	10,588	<b>5.97</b>	30,195	<b>9.61</b>
Section 1115 waiver	202	<b>0.25</b>	121	<b>0.27</b>	81	<b>0.22</b>	1,151	<b>0.23</b>	484	<b>0.27</b>	667	<b>0.21</b>
Unknown	536	<b>0.66</b>	254	<b>0.57</b>	282	<b>0.77</b>	2,937	<b>0.60</b>	911	<b>0.51</b>	2,026	<b>0.64</b>
Not eligible	1,247	<b>1.53</b>	801	<b>1.80</b>	446	<b>1.21</b>	6,886	<b>1.40</b>	2,978	<b>1.68</b>	3,908	<b>1.24</b>
<b>Coverage Type</b>												
Medicare FFS Plan, 12 months coverage (Part A, Part B, or both Part A+B)	71,437	<b>86.59</b>	37,037	<b>82.76</b>	34,400	<b>91.14</b>	441,142	<b>87.01</b>	148,400	<b>82.33</b>	292,742	<b>89.60</b>
FFS 1-11 months of 2012	4,317	<b>5.23</b>	3,991	<b>8.92</b>	326	<b>0.86</b>	17,515	<b>3.45</b>	14,560	<b>8.08</b>	2,955	<b>0.90</b>
Medicare managed care (Part C) at least 1 month of 2012	6,742	<b>8.17</b>	3,723	<b>8.32</b>	3,019	<b>8.00</b>	48,320	<b>9.53</b>	17,292	<b>9.59</b>	31,028	<b>9.50</b>
Medicare Part D plan (as of Dec 2012)	80,213	<b>97.23</b>	43,766	<b>97.80</b>	36,447	<b>96.56</b>	486,502	<b>95.96</b>	174,660	<b>96.90</b>	311,842	<b>95.44</b>
Medicaid FFS Plan, 12 months coverage	53,003	<b>64.68</b>	27,870	<b>62.64</b>	25,133	<b>67.11</b>	338,567	<b>67.20</b>	116,105	<b>64.75</b>	222,462	<b>68.55</b>

Source: Author's analysis of Medicare-Medicaid Linked Enrollees Analytic Data Source (MMLEADS, V2.0), 2012, Center for Medicare & Medicaid Services

Abbreviation: ASD, autism spectrum disorder; DI, Disability Insurance; ESRD, End-stage renal disease; FFS, Fee-for-service; ID, Intellectual disability; OASI, Old-age and survivors insurance

Notes: † Chronic condition was identified as meeting claims or criteria for 2012 Chronic Condition Warehouse diagnoses: depression; epilepsy; diabetes; rheumatoid arthritis; osteoarthritis; acute myocardial infarction, hypertension, stroke, congestive heart failure; cancers including breast, colorectal, lung, and prostate; Alzheimer's disease; and obesity.

\*Include 'Covered under Breast Cancer' and 'Unknown'

**Table 2. Frequencies of types of Social Security Administration Disability Determinations by pathway among dual-eligible autistic adults compared to adults with intellectual disability, MMLEADS V2.0**

Full-dual Eligible Beneficiary SSA Disability Determination, Primary Condition‡	Autism Group			ID Group		
	Total Autism Dual-Eligible N=82,496	Medicaid-to-Medicare N=44,751	Medicare-to-Medicaid N=37,745	Total ID Dual-Eligible N= 506,977	Medicaid-to-Medicare N=180,252	Medicare-to-Medicaid N=326,725
	Col %	Col %	Col %	Col %	Col %	Col %
Intellectual disability #	38.85	35.16	43.20	46.91	47.82	46.40
Autistic disorder and other PDD	13.80	21.54	4.62	0.31	0.69	0.10
Schizophrenic, Psychotic disorders	3.86	3.44	4.36	2.96	2.69	3.12
Mood disorders	3.80	5.02	2.35	1.97	3.18	1.31
Organic mental disorder	2.64	3.45	1.69	1.97	2.98	1.42
Other psychological disorders^	1.92	2.45	1.29	0.60	0.89	0.43
Cerebral palsy	1.19	1.37	0.97	3.15	4.56	2.38
Blindness/Low vision	0.71	0.71	0.72	0.77	0.93	0.68
Other infrequent diagnoses	8.13	5.85	10.84	11.22	10.75	11.47
Missing SSA diagnosis code*	25.1	21.01	29.96	30.14	25.51	32.69

Source: Author's analysis of Medicare-Medicaid Linked Enrollees Analytic Data Source (MMLEADS, V2.0), 2012, Center for Medicare & Medicaid Services

Notes: Abbreviations: ID, Intellectual disability; SSA, Social Security Administration

# Includes 'Intellectual Disability', 'Mild intellectual disability', 'Borderline Intellectual disability', 'Unspecified intellectual disability'

\* Includes '-99' and 'No code available-dx'

^ Includes 'Anxiety', 'Personality disorders' and 'ADD/ADHD'

**Table 3. Characteristics of dual-eligible autistic adults in linked Medicaid-Medicare claims data (2019)**

	ASD Only 68,888		ID Only 552,800		ASD+ID 121,313	
	n	%	n	%	n	%
<b>Sex</b>						
Male	51,124	74.21%	293,384	53.07%	84,415	69.58%
Female	17,764	25.79%	259,416	46.93%	36,898	30.42%
<b>Age Group</b>						
18-25	18,392	26.70%	27,105	4.90%	19,686	16.23%
26-35	24,370	35.38%	86,820	15.71%	33,617	27.71%
36-45	10,586	15.37%	102,596	18.56%	23,586	19.44%
46-55	6,628	9.62%	120,729	21.84%	20,914	17.24%
56-64	4,482	6.51%	109,720	19.85%	14,868	12.26%
65+	4,430	6.43%	105,830	19.14%	8,642	7.12%
<b>Race</b>						
White	51,966	75.44%	379,498	68.65%	85,799	70.73%
Black	7,918	11.49%	102,128	18.47%	21,215	17.49%
Asian/PI	1,770	2.57%	11,180	2.02%	3,035	2.50%
American Indian/Alaska Native	587	0.85%	5,493	0.99%	785	0.65%
Hispanic/Latino	5,489	7.97%	52,546	9.51%	9,753	8.04%
Other	17	0.02%	57	0.01%	12	0.01%
Missing	1,141	1.66%	1,898	0.34%	714	0.59%
<b>Urbanicity</b>						
Urban	56,224	81.62%	424,516	76.79%	100,502	82.85%
Micropolitan (Large rural)	6,993	10.15%	72,953	13.20%	12,172	10.03%
Small Rural Town	3,523	5.11%	36,806	6.66%	5,706	4.70%
Isolated Small Rural Town	*	*	18,421	3.33%	2,908	2.40%
Unknown	*	*	104	0.02%	25	0.02%
<b>Medicaid Eligibility</b>						
Children	230	0.33%	284	0.05%	240	0.20%
Adults	605	0.88%	3,144	0.57%	745	0.61%
Disability	47,665	69.19%	372,363	67.36%	105,251	86.76%
Aged	2,732	3.97%	87,922	15.90%	8,605	7.09%
Expansion	1,012	1.47%	1,848	0.33%	569	0.47%
Missing	16,644	24.16%	87,239	15.78%	5,903	4.87%
<b>Medicare Eligibility</b>						
ESRD Disabled	170	0.25%	1,927	0.35%	227	0.19%
ESRD Aged	31	0.05%	488	0.09%	28	0.02%
ESRD	62	0.09%	371	0.07%	54	0.04%
Disabled Only	45,958	66.71%	317,540	57.44%	98,629	81.30%
Age Only	3,121	4.53%	89,448	16.18%	8,753	7.22%
Not enrolled	19,546	28.37%	143,026	25.87%	13,622	11.23%
<b>Coverage Type (see codebook)</b>						
Medicare FFS Plan (All months enrolled)	7,904	11.47%	71,479	12.93%	5,233	4.31%
Medicare Any FFS (Any months enrolled)	1,061	1.54%	4,836	0.87%	356	0.29%
Medicare Part C plan (at least 1 month)	10,579	15.36%	66,696	12.07%	8,026	6.62%
Medicare Part D plan (December 2019)	8,798	12.77%	75,770	13.71%	5,455	4.50%
Medicaid Managed Care Plan (All months enrolled)	33,274	48.30%	274,331	49.63%	69,246	57.08%
<b>Chronic Condition (see codebook)</b>						
Any Chronic Condition	39,843	57.84%	426,001	77.06%	84,527	69.68%

NOTES: At least 1 month indicated as dual in Medicare, enrolled in Medicaid and/or Medicare for 10+ months  
Source: Linked 2019 Medicaid-Medicare data.