

Chronic Health Conditions Among Adults With Intellectual and Developmental Disabilities in a State Medicaid System

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Abstract

Despite a growing number of adults with intellectual and developmental disabilities (IDD) and documented risk for adverse outcomes as they age, little is known about the health and healthcare patterns of adults with different IDD throughout adulthood. This study uses Wisconsin Medicaid claims data to characterize health conditions among adults with IDD. Results indicate high prevalence of asthma, diabetes, heart disease, and hypertension. Heart disease rates were particularly high, having been observed among 39% of autistic adults, 64% of autistic adults with intellectual disability (ID), 67% of adults with Down syndrome, and 75% of adults with ID only. Given there are no known biological differences underlying increased morbidities among most people with IDD, developing inclusive prevention measures should be prioritized in future research.

Keywords: autism spectrum disorder, intellectual and developmental disability, physical health, Medicaid, health disparities

Medicaid provides health care coverage to more than 40 million people in the United States (Bruen & Holahan, 2001). Medicaid serves low-income adults, children, pregnant women, elderly adults, and disabled individuals (Centers for Medicare & Medicaid Services, 2019). (The authors of this manuscript chose to use identity-first language [i.e., disabled person, autistic person] to respect the preferences of many of those within the disability community.) According to the Medicaid and CHIP Payment and Access Commission (MACPAC) 2018 report to Congress, over 10 million people qualify for Medicaid on the basis of disability. This population includes disabled adults that present at birth and those who have acquired disabling conditions through illness, injury, or trauma (Centers for Medicare & Medicaid Services, 2019).

Wisconsin's Medicaid Program

Medicaid and the coverage and services provided to its beneficiaries vary from state to state. The way in which a state structures and

implements its Medicaid program is greatly influenced by the program's unique funding structure. Medicaid is funded jointly by states and the federal government (Snyder & Rudowitz, 2015). This state and federal partnership is governed by the federal medical assistance percentage (FMAP), which guarantees federal match funds to states for qualifying Medicaid expenditures (e.g., payments states make for covered Medicaid services provided by qualified providers to eligible Medicaid beneficiaries; Snyder & Rudowitz, 2015). Thus, FMAP, and its corresponding state Medicaid program, varies from one state to the next. Wisconsin's FMAP is set at 66.30% for fiscal year 2023 (Kaiser Family Foundation [KFF], n.d.). This standard FMAP formula applies to the vast majority of Medicaid spending, though there are exceptions that provide higher match rates, many of which were enacted through the Affordable Care Act of 2010 (ACA; Snyder & Rudowitz, 2015). The ACA broadened Medicaid's role, providing healthcare coverage to many adults previously uninsured and increasing the state's FMAP (Snyder & Rudowitz, 2015). That

said, the Supreme Court ruled the ACA's Medicaid expansion optional for states and as of December 2022, 11 states have not adopted it (KFF, 2023). Wisconsin is one of these 11.

Wisconsin has not implemented the ACA's Medicaid expansion, choosing to limit Medicaid eligibility and forgo the enhanced FMAP for their expansion populations (Kaiser Family Foundation [KFF], 2023). States that have adopted the ACA's Medicaid expansion provide coverage to nearly all adults with incomes up to 138% of the Federal Poverty Level (KFF, 2023). In contrast, Wisconsin covers adults up to 100% of the Federal Poverty Level (KFF, 2023). Individuals in Wisconsin must meet these financial requirements set by the state in addition to categorical eligibility requirements in order to be eligible for its Medicaid program. As mentioned previously, many meet the requirements for categorical eligibility on the basis of disability. National estimates from 2008–2016 indicated that 81.7% of autistic adults who were eligible for Medicaid were through disability compared to 8.8% through poverty (Roux et al., 2023).

Nationally, Medicaid beneficiaries enrolled through disability pathways include those with physical disabilities, intellectual and developmental disabilities (IDD), and serious behavior disorders and mental illness (MACPAC, 2018). Among these groups, individuals with IDD are a primary group of beneficiaries. An individual with an IDD, such as autism spectrum disorder (ASD), Down syndrome, and intellectual disability (ID), can qualify for Medicaid in Wisconsin through three pathways: (1) they receive Supplemental Security Income (SSI) benefits; (2) they purchase Medicaid health benefits through the Medicaid Purchase Plan; or (3) they have income at or below 100% of the Federal Poverty Level (KFF, n.d.). In summation, an understanding of the complexity and variability of state Medicaid programs like Wisconsin's and their IDD systems provides essential context for our interpretation of healthcare research. Indeed, the national landscape of Medicaid programs is complex. Although efforts have been made to improve outcomes of disabled individuals on the federal level, it is important to understand how specific states are contributing to or addressing health disparities in adults with IDD. Policies with meaningful improvements for instance may then be implemented in similar

settings. Therefore, an investigation into a state Medicaid program like Wisconsin's may assist in reshaping future healthcare policy, including in potential adoption of the ACA expansion in states that have not done so already.

Medicaid Research With Adults With IDD

Thus far, Medicaid research in relation to individuals with IDD has been limited, and primarily focuses on children and those with ASD (Mandell et al., 2010; Wang & Leslie, 2010). Recent research has examined the changing Medicaid enrollment patterns in autistic adult Medicaid beneficiaries and distinguishes this community as a primary and growing group of Medicaid beneficiaries. Some states have found a consistent influx of new autistic young adults into the state Medicaid system over the past decade, likely corresponding to the increased identification of autistic children (Rubenstein & Bishop, 2019).

Research has also suggested that there may be county-level variation in the prevalence of Medicaid-enrolled autistic children (Mandell et al., 2010). Medicaid-enrolled ASD prevalence varies greatly as a function of several county characteristics. Counties with lower per-student education expenditures, more students, a greater proportion of students in special education, higher per capita number of pediatricians and pediatric specialists, and a greater proportion of Medicaid enrollees and White residents had higher Medicaid prevalence (Mandell et al., 2010). Therefore, it seems that not only do states differ in their implementation of Medicaid policies, but counties within these states may differ as well. It's been hypothesized that these differences in county-level Medicaid implementation may relate to availability of educational resources, counties taking advantage of their state's Medicaid policies, and variation in access in rural and urban areas (Mandell et al., 2010).

Chronic Health Conditions in Adults With IDD

Adults with IDD may be at increased risk for chronic health conditions as they age. In its 2010 report on the status of the challenges presented by chronic health conditions, the World Health

Organization (WHO) noted that noncommunicable conditions, such as cardiovascular disease, diabetes, cancers, and chronic respiratory diseases, accounted for nearly two thirds of all deaths worldwide (WHO, 2011). In the United States, chronic health conditions are the main causes of poor health and early mortality, and they account for the highest proportion of health-care expenditures (Bauer et al., 2014). Research suggests that these chronic health conditions are a result of certain risk factors including tobacco use, poor diet, physical activity, excessive alcohol consumption, uncontrolled high blood pressure, and hyperlipidemia (Bauer et al., 2014; Fine et al., 2004). Of these risk factors, adults with IDD are associated with high rates of physical inactivity, obesity, and smoking (Haverkamp & Scott, 2015; Ranjan et al., 2018). Autistic children and adolescents have been found to have higher rates of obesity or being overweight than nonautistic youth, which could increase the risk of conditions such as diabetes, cardiovascular disease, and cancer (Ranjan et al., 2018). Perhaps consequently, a recent study using Medicaid data to compare health outcomes among middle-aged and older autistic adults (48–88 years old) with and without co-occurring ID found high prevalence of most health conditions including immune conditions, cardiovascular disease, sleep disorders, gastrointestinal disorders, neurologic conditions, and psychiatric disorders (Bishop-Fitzpatrick & Rubenstein, 2019). A study of over 1,500 autistic adults, mean age 29, found elevated rates of diabetes, hypertension, and hyperlipidemia, but marginally lower rates of cancer, compared to nonautistic adults in their sample (Croen et al., 2015). It should be noted that decreased risk of certain health conditions, like cancer, have been documented in some studies with autistic adults and other developmental disabilities (Bishop-Fitzpatrick et al., 2018). This could be attributed to disparities in screening and diagnosis, or potential protective factors among this group (Elder et al., 2016). Further research will be needed in this area.

Fortunately, many of the risk factors for chronic disease prevalent among adults with IDD are nongenetic and potentially modifiable or preventable (Fine et al., 2004). It should be noted, however, that adults with Down syndrome do have documented biological differences compared to other disabled

and non-disabled adults (Landes et al., 2020). Those with Down syndrome, or Trisomy 21, have a full or partial extra copy of chromosome 21 (Landes et al., 2020). This additional genetic material can alter the course of development and cause characteristics associated with Down syndrome in adults. For example, many people with Down syndrome experience craniofacial alterations and muscle hypotonia, developmental delays, cognitive impairment, and increased prevalence of some medical conditions including congenital heart disease and early onset Alzheimer's disease (Asim et al., 2015).

Although the underlying genetic cause of Down syndrome is the same, resulting pathologies and their severity vary from person to person (Lana-Elola et al., 2011). Due to advances in diagnosis and treatment of adults with Down syndrome for example, the overall health and mortality disadvantage for this group has improved considerably in the 20th century (Landes et al., 2020). A growing body of research has suggested that contrary to the generally accepted belief, cognitive decline by middle age for adults with Down syndrome, including risk for developing Alzheimer's disease, is not inevitable and can be modified by a number of factors (Zigman et al., 2008). Societal factors including deinstitutionalization and medical factors including improved nutritional and public healthcare practices have resulted in these extensions of life expectancy and improvements in overall health in adults with Down syndrome (Zigman et al., 2008).

As such, differences in physical health conditions among adults with IDD, including those with Down syndrome, may be evidence of health disparities (i.e., health problems that are unjust and avoidable) and perhaps can explain the 2- to 3- decades decreased life expectancy estimated in adults with IDD (Bishop-Fitzpatrick & Rubenstein, 2019; Piven et al., 2011). The preliminary findings from these studies lay groundwork for research into health disparities among adults with IDD.

Ultimately, very little is known about the unique health and healthcare patterns of individuals with IDD throughout their adulthoods and the ways in which different state Medicaid programs address or contribute to these disparities (Anderson et al., 2013; Piven et al., 2011). Most studies to date that examine chronic

health conditions of adults with IDD compare autistic children and young adults to those without disabilities and find greater prevalence of most health conditions (Croen et al., 2015; Weir et al., 2022). It is unclear, however, how health conditions develop across age groups and how they compare across those with different IDD. Therefore, it is critical to use existing systems-level data to characterize the health status of this population. More specifically, assessing the prevalence of chronic health conditions in adults with different IDD can help to inform prevention efforts, anticipate and prepare for service use, lessen healthcare expenditures, and ultimately, reduce health disparities.

Purpose

Given the urgency for research in this area, one of the best tools for efficiently investigating health in an entire health system, without requiring years of follow-up, is the use of Medicaid claims data. Medicaid claims have been successfully used in research related to autistic children, adolescents, and young adults (Mandell et al., 2010; Wang & Leslie, 2010). And more recently, has been used to characterize health outcomes in middle-aged and older autistic adults (Bishop-Fitzpatrick & Rubenstein, 2019; Schott et al., 2022; Vohra et al., 2017). To our knowledge, no studies to date have used Medicaid claims data to characterize and compare health outcomes among young, middle-aged, and older adults with different types of IDD. Thus, this study presents a novel approach to identifying and characterizing health disparities among adults with IDD across the remainder of their lifespans.

For the purposes of this investigation, four of the most common chronic diseases in older adults that could be measured with our existing Medicaid data were chosen: asthma, diabetes, heart disease, and hypertension. Existing research suggests that autistic adults are at significant risk for developing these conditions in mid to later life (Croen et al., 2015; Tyler et al., 2011). How these progress with age, as well as compare to adults with other IDD, needs further investigation.

The overall purpose of this study is to use state-level Medicaid claims data to characterize health outcomes among Medicaid beneficiaries, aged 21+, with IDD. More specifically, we used Wisconsin Medicaid claims from 2008–2018 to

examine the prevalence of chronic health conditions (asthma, diabetes, heart disease, and hypertension) among adults with autism only, autism and ID, Down syndrome only, and ID only, controlling for age, gender, race and ethnicity, and rural or urban county designation. We hypothesized that all groups would have high rates of each physical health condition and that rates would rise as adults aged. Further, we hypothesized that those with ID would have greater prevalence of all conditions.

Methods

Data Source

We obtained de-identified Wisconsin Medicaid claims data from January 1, 2008, to December 31, 2018, through a limited data use agreement with the Wisconsin Department of Health Services. Adults (21+) were included in the data provided if they had two Medicaid claims for IDD on two different days during their entire lifetime period of Medicaid enrollment. Demographic information (age, race/ethnicity, gender, county of residence), medical claims (dental, home health, long-term care, pharmacy and professional, inpatient, outpatient, and crossover claims), and the paid amount for each medical claim were included in the data. Corresponding ICD-9 and ICD-10 codes were provided for each claim, as well as Clinical Classification Software (CCS) codes for all physical and psychiatric health conditions.

Sample

Adults (21+) were included in these data if they had two Medicaid claims for IDD on two different days during their entire lifetime period of Medicaid enrollment. Participants with at least two ICD-9 or ICD-10 codes for ASD (299.0, 299.00, 299.01, 299.8, 299.80, 299.81, 299.9, 299.90, 299.91 or F84.0, F84.5, F84.9), ID (317, 318, 318.0, 318.1, 318.2, 319 or F70, F71, F72, F73, F78, F79), and/or Down syndrome (758.0 or Q90, Q90.1, Q90.2, Q90.9) comprised the sample. Prior research has suggested that using two claims rather than one, significantly increases the specificity of conditions studied and helps to ensure that the claim itself is not a rule out for another diagnosis (i.e., the diagnosis is recorded for a suspected condition but is not the primary or final diagnosis; Rector et al., 2004). This method of sampling is also

consistent with past work examining IDD in claims and other electronic health records data in adults (Bishop-Fitzpatrick & Rubenstein, 2019; Vohra et al., 2017).

We classified Medicaid beneficiaries in these data into four separate diagnostic groups: (1) ASD without ID; (2) ASD with ID; (3) Down syndrome; and (4) ID only. Most studies to date either group all adults with IDD together in their analyses or compare autistic adults to non-autistic adults (Anderson et al., 2013). Only recently has research investigated prevalence estimates of certain health conditions stratified by diagnosis (autism, Down syndrome, and ID; Ptomey et al., 2020). Given the heterogeneity of IDDs, it is imperative to assess outcomes by IDD type. This study seeks to add to this literature, recognizing that each type of IDD present differently and that to improve the overall health of adults with IDD, patterns and differences across diagnoses must be better understood.

Our original data included 24,149,448 total medical claims and 49,309 Medicaid beneficiaries with IDD. Of these Medicaid beneficiaries with IDD, 15,257 had medical claims during the study period (January 1, 2008–December 31, 2018). Thus, only those with two claims for IDD and with medical claims during the study period were included in analysis (i.e., complete case analysis). Our final analytic sample includes 2,828 adults with autism only, 1,620 adults with autism and ID, 2040 adults with Down syndrome, and 8,769 adults with ID only.

Chronic Health Conditions

We examined all medical claims for a select group of health condition codes (asthma, diabetes, heart disease, hypertension) between January 1, 2008 to December 31, 2018. Each ICD-9/ICD-10 code corresponds to a CCS diagnosis. The Agency for Healthcare Research and Quality H-CUP Clinical Classification Software (CCS) is a diagnosis and procedure categorization scheme used in projects analyzing data on diagnoses, including those tracking healthcare utilization comorbidity prevalence in autistic adults (Vohra et al., 2017). The CCS collapses ICD codes into a smaller number of clinically meaningful categories that are often more useful for presenting descriptive statistics on a population, rather than individual ICD codes. The CCS allows similar ICD codes to be grouped

into an overarching diagnostic category for analysis. For example, the CCS category of hypertension includes essential hypertension, hypertension complication, and hypertension with complications and secondary hypertension. Thus, a CCS category may contain ICD codes with differing levels of severity. For the purposes of this study, we classified appropriate ICD-9 and ICD-10 codes into single-level CCS codes. Then, we grouped these single-level CCS codes into the multilevel CCS diagnostic categories for asthma, diabetes, heart disease, and hypertension.

Analytic Plan

We first examined demographic variables provided in the enrollment data by IDD status. Race/ethnicity were coded according to the condensed Medicaid categories for race and ethnicity (MAC-PAC, 2022). We summarized categorical variables by using frequencies and percentages and continuous variables through means and standard deviations. Based on the Wisconsin Office of Rural Health rural classifications, we coded all counties into rural or urban categories (Wisconsin Office of Rural Health, 2022). We estimated proportions of physical health conditions by diagnostic group and age category. We then graphed these proportions to highlight the differences in physical health condition claims for each diagnostic group across adulthood (21+). Finally, given the high rates of physical health conditions in adults with ID in our sample, we conducted a post-hoc analysis to examine unadjusted and adjusted odds ratios of each physical health condition comparing those with ID to those without ID.

Results

Demographic comparisons are presented in Table 1. Mean ages as well as age category frequencies are provided. Individuals within the ID only group made up 57.48% of the study population as well as had the highest proportion of older adults (50–64 and 65+). In comparison, 71.75% of individuals within the autism only group fell within the 21–34 age group. Of note, the number of autistic adults with and without ID diminished as age rose. For example, our sample had 2,029 autistic adults aged 21–34 and only 68 aged 65+. Similarly, our sample had 653 autistic adults with ID aged 21–34 and 148 aged 65+. Gender differences were most notable within the autism only group with 72.69% male. All groups had the highest proportion of non-Hispanic

Table 1
Demographic Characteristics of Wisconsin Medicaid Beneficiaries (Aged 21+) With Intellectual and Developmental Disabilities, 2008-2018

Characteristics	Autism Only <i>n</i> = 2828 (18.54%)	Autism + Intellectual Disability <i>n</i> = 1620 (10.62%)	Down syndrome Only <i>n</i> = 2040 (13.37%)	Intellectual Disability Only <i>n</i> = 8769 (57.48%)
Mean Age (<i>SD</i>)	32.63 (11.72)	42.50 (15.12)	46.79 (14.91)	52.21 (17.63)
Age Groups				
21-34	2029 (71.75%)	653 (40.31%)	558 (27.35%)	1763 (20.10%)
35-49	522 (18.46%)	428 (26.42%)	522 (25.59%)	2121 (24.19%)
50-64	209 (7.39%)	391 (24.14%)	713 (34.95%)	2714 (30.95%)
65+	68 (2.40%)	148 (9.14%)	247 (12.11%)	2171 (24.76%)
Gender				
Male	2064 (72.98%)	1122 (69.26%)	1015 (49.75%)	4496 (51.27%)
Female	764 (27.02%)	498 (30.74%)	1025 (50.25%)	4273 (48.73%)
Race/Ethnicity				
White (non-Hispanic)	1685 (59.58%)	1006 (62.10%)	1359 (66.62%)	5491 (62.62%)
Black (non-Hispanic)	139 (4.92%)	122 (7.53%)	63 (3.09%)	778 (8.87%)
Hispanic	68 (2.40%)	28 (1.73%)	44 (2.16%)	211 (2.41%)
Asian or Pacific Islander; Or Native American or Alaskan Native (non-Hispanic)	45 (1.59%)	25 (1.54%)	28 (1.37%)	186 (2.12%)
Other or Unknown (non-Hispanic)	891 (31.51%)	439 (27.10%)	546 (26.76%)	2099 (23.94%)
County Designation				
Urban	2052 (72.56%)	1197 (73.89%)	1399 (68.58%)	6103 (69.60%)
Rural	776 (27.44%)	423 (26.11%)	641 (31.42%)	2666 (30.40%)

Note. Frequencies and percentages are reported for categorical variables. Means and standard deviations are reported for continuous variables. Rural and urban categories are based on the Wisconsin Office of Rural Health rural classifications.

White adults compared to other racial and ethnic identities. Further, 69–75% of all groups had beneficiaries residing in urban counties.

Tables 2A–D present the proportions of adult Medicaid beneficiaries with medical claims for asthma, diabetes, heart disease, and hypertension across diagnostic groups and age categories. In this sample, the prevalence of physical health conditions was high. Within the autism only group, 12.34% had claims for asthma, 18.81% for diabetes, 39.00% for heart disease, and 15.70% for hypertension. Among autistic

adults aged 50–64, 72.25% had claims for heart disease. Further, 82.35% of autistic adults 65+ had a similar claim. Over half of those aged 50–64 had claims for diabetes as well. Notably, prevalence of diabetes (30.31%), heart disease (63.73%), and hypertension (27.78%) were higher for those with autism and ID compared to those with autism only.

Prevalence rates for asthma were similar for those with Down syndrome only (12.70%) and ID only (13.35%). However, overall rates of heart disease and hypertension were statistically

Tables 2A–D

Wisconsin Medicaid Beneficiaries (Aged 21+) With Chronic Health Conditions, 2008–2018

A. Autism Only					
Age Groups	21–34 <i>n</i> = 2029	35–49 <i>n</i> = 522	50–64 <i>n</i> = 209	65+ <i>n</i> = 68	All Ages <i>n</i> = 2828
Asthma	218 (10.74%)	86 (16.48%)	30 (14.35%)	15 (22.06%)	349 (12.34%)
Diabetes	237 (11.68%)	157 (30.08%)	108 (51.67%)	30 (41.12%)	532 (18.81%)
Heart Disease	621 (30.61%)	275 (52.68%)	151 (72.25%)	56 (82.35%)	1103 (39%)
Hypertension	174 (8.58%)	131 (25.09%)	101 (48.33%)	38 (55.88%)	444 (15.70%)
B. Autism + Intellectual Disability					
Age Groups	21–34 <i>n</i> = 653	35–49 <i>n</i> = 428	50–64 <i>n</i> = 391	65+ <i>n</i> = 148	All Ages <i>n</i> = 1620
Asthma	82 (12.56%)	50 (11.68%)	36 (9.21%)	17 (11.49%)	185 (11.42%)
Diabetes	127 (19.45%)	153 (35.75%)	140 (35.81%)	71 (47.97%)	491 (30.31%)
Heart Disease	299 (45.79%)	277 (64.72%)	307 (78.52%)	133 (89.86%)	1016 (62.72%)
Hypertension	85 (13.02%)	124 (28.97%)	162 (41.43%)	79 (53.38%)	450 (27.78%)
C. Down Syndrome Only					
Age Groups	21–34 <i>n</i> = 558	35–49 <i>n</i> = 522	50–64 <i>n</i> = 713	65+ <i>n</i> = 247	All Ages <i>n</i> = 2040
Asthma	63 (11.29%)	77 (14.75%)	84 (11.78%)	35 (14.17%)	259 (12.70%)
Diabetes	87 (15.59%)	160 (30.65%)	224 (31.42%)	79 (31.98%)	550 (26.96%)
Heart Disease	237 (42.47%)	330 (63.22%)	592 (83.03%)	206 (83.40%)	1365 (66.91%)
Hypertension	43 (7.71%)	103 (19.73%)	218 (30.58%)	57 (23.08%)	421 (20.64%)
D. Intellectual Disability Only					
Age Groups	21–34 <i>n</i> = 1763	35–49 <i>n</i> = 2121	50–64 <i>n</i> = 2714	65+ <i>n</i> = 2171	All Ages <i>n</i> = 8769
Asthma	394 (22.35%)	478 (22.54%)	542 (19.98%)	357 (16.44%)	1171 (13.35%)
Diabetes	376 (21.33%)	804 (37.91%)	1261 (46.46%)	1097 (50.53%)	3538 (40.35%)
Heart Disease	967 (54.85%)	1510 (71.19%)	2175 (80.14%)	1950 (89.82%)	6602 (75.29%)
Hypertension	262 (14.86%)	725 (34.18%)	1379 (50.81%)	1188 (54.72%)	3554 (40.53%)

Note. These figures display the proportions of Wisconsin Medicaid beneficiaries (Aged 21+) with claims for asthma, diabetes, heart disease, and hypertension by age and diagnostic group, 2008–2018.

higher among these groups compared to those within the autism only or autism and ID groups. 66.91% of those within the Down syndrome only group and 75.29% of those within the ID only group had claims for heart disease. Across both diagnostic groups, over 80% of those aged 50-64 and 65+ had claims for heart disease. Further, 40.53% of those within the ID only group had claims for hypertension including over 50% of those aged 50-64 and 65+. Plots of the proportions of physical health conditions by age and diagnostic group can also be found in Figures 1A-D. The figures illustrate the overall prevalence of each health condition within each diagnostic group as well as the differences in prevalence across age groups.

In our post-hoc analyses comparing unadjusted and adjusted odds ratios of each of these physical health conditions (Tables 3A-B), we found statistically significant greater odds of heart disease and hypertension among all groups compared to those with autism only. Those within the autism and ID group had significantly ($p < .001$) increased odds of diabetes ($aOR = 1.43$,

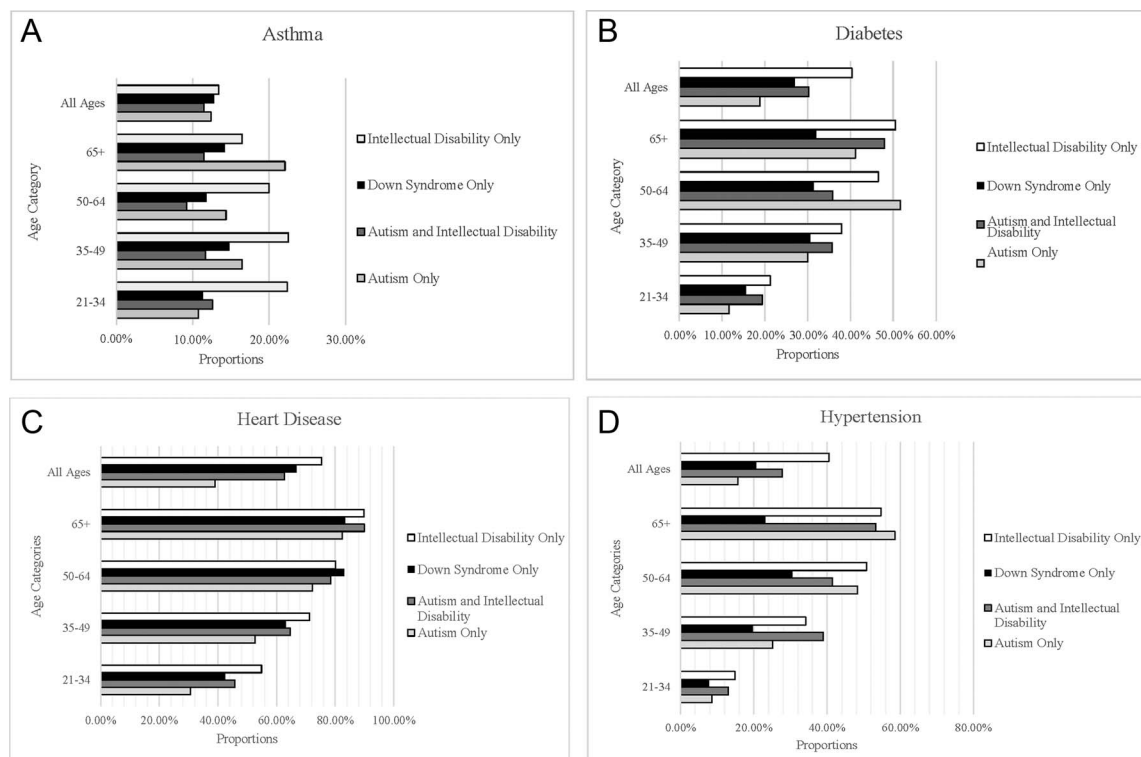
95% CI [1.2, 1.7]), heart disease ($aOR = 1.76$, 95% CI [1.5, 2.0]), and hypertension ($aOR = 1.41$, 95% CI [1.2, 1.6]). Similarly, those with ID only had significantly ($p < .001$) increased odds of diabetes ($aOR = 1.72$, 95% CI [1.5, 1.9]), heart disease ($aOR = 2.12$, 95% CI [1.9, 2.3]), and hypertension ($aOR = 1.83$, 95% CI [1.6, 2.1]) as well. Finally, those with Down syndrome had significantly ($p < .001$) increased odds of heart disease ($aOR = 1.68$, 95% CI [1.5, 1.9]). Across all physical health conditions, those within the ID only group had the greatest odds of having a claim, compared to those with autism only. The adjusted odds ratios are graphed in Figure 2.

Discussion

We used Wisconsin Medicaid claims data from 2008-2018 to examine the prevalence of specified chronic health conditions among adults with IDD aged 21 and over. A small number of previous studies have used Medicaid claims data to identify a higher prevalence

Figures 1A-D

Wisconsin Medicaid Beneficiaries (Aged 21+) With Chronic Health Conditions, 2008-2018



Tables 3A-B
Odds of Chronic Health Conditions for Adult Medicaid Beneficiaries, 2008-2018

Characteristics	Asthma		Diabetes	
	OR [95% CI]	aOR [95% CI]	OR [95% CI]	aOR [95% CI]
Disability Status (ref: autism only)				
Autism + Intellectual Disability	0.92 [.76–1.1]	0.92 [.76–1.1]	1.88 [1.6–2.2]***	1.41 [1.2–1.6]***
Down syndrome	1.03 [.87–1.2]	0.99 [.83–1.2]	1.59 [1.4–1.8]***	1.06 [.92–1.2]
Intellectual Disability Only	1.79 [1.6–2.0]***	1.74 [1.5–1.9]***	2.92 [2.6–3.2]***	1.65 [1.5–1.9]***
Age		0.99 [.99–.998]**		1.03 [1.0–1.1]***
Gender (ref: male)				
Female		1.55 [1.4–1.7]***		1.09 [1.0–1.2]*
Race/Ethnicity (ref: non-Hispanic White)				
Black (non-Hispanic)		1.58 [1.4–1.8]***		1.61 [1.4–1.8]***
Hispanic		0.92 [.69–1.2]		1.54 [1.2–1.9]***
Asian or Pacific Islander; Or Native American or Alaskan Native (non-Hispanic)		0.76 [.54–1.1]		1.44 [1.2–1.9]**
Other or Unknown (non-Hispanic)		0.94 [.85–1.0]		0.99 [.92–1.1]
County Designation (ref: urban)				
Rural		1.00 [.91–1.1]		0.85 [.79–.92]***
	Heart disease		Hypertension	
	OR [95% CI]	aOR [95% CI]	OR [95% CI]	aOR [95% CI]
Disability Status (ref: autism only)				
Autism + Intellectual Disability	2.63 [2.3–2.9]***	1.75 [1.5–1.9]***	2.07 [1.8–2.4]***	1.39 [1.2–1.6]***
Down syndrome	3.16 [2.8–3.6]***	1.69 [1.5–1.9]***	1.39 [1.2–1.6]***	0.81 [.69–.94]**
Intellectual Disability Only	4.76 [2.8–3.6]***	2.09 [1.9–2.3]***	3.66 [3.3–4.1]***	1.75 [1.5–1.9]***
Age		1.05 [1.0–1.1]***		1.04 [1.03–1.04]***
Gender (ref: male)				
Female		1.19 [1.1–1.3]***		0.91 [.84–.98]***
Race/Ethnicity (ref: non-Hispanic White)				
Black (non-Hispanic)		1.18 [1.0–1.4]*		1.66 [1.4–1.9]***

(Tables 3A-B continued)

Tables 3A-B
Continued

	Heart disease		Hypertension	
	OR [95% CI]	aOR [95% CI]	OR [95% CI]	aOR [95% CI]
Hispanic		0.98 [.77–1.2]		1.21 [.94–1.6]
Asian or Pacific Islander; Or Native American or Alaskan Native (non-Hispanic)		0.89 [.69–1.2]		1.19 [.91–1.6]
Other or Unknown (non-Hispanic)		0.93 [.85–1.0]		0.98 [.89–1.1]
County Designation (ref: urban)				
Rural		0.84 [.78–.92]***		0.97 [.79–.94]**

Note. These tables display the unadjusted and adjusted odds ratios of asthma, diabetes, heart disease, and hypertension for Wisconsin Medicaid beneficiaries (21+) with intellectual and developmental disabilities, 2008–2018. *OR* = unadjusted odds ratios; *aOR* = adjusted odds ratios, adjusting for age, race/ethnicity, gender, county of residence.
p* > .05. *p* > .01. ****p* > .001.

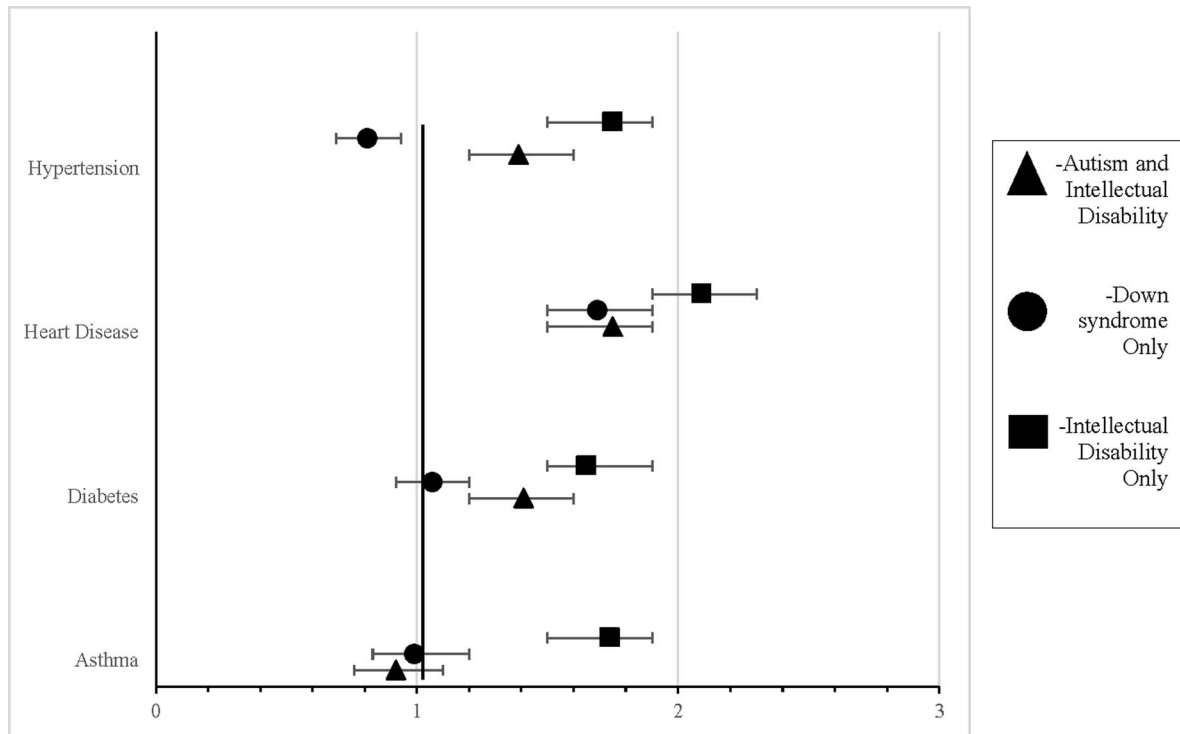
of physical health conditions among autistic adults compared to the general population and have suggested these health disparities will likely increase with age (Bishop-Fitzpatrick et al., 2018; Schott et al., 2022; Vohra et al., 2017). An even smaller number of studies have compared co-morbidity prevalence among middle-age and older autistic adults with and without ID through Medicaid claims and found heightened prevalence of physical health conditions in middle age and beyond, regardless of ID prevalence (Bishop-Fitzpatrick & Rubenstein, 2019). To our knowledge, no previous research has investigated the prevalence of health conditions among adults with IDD in younger, middle, and older adults in a state Medicaid system.

First, our demographic comparisons point to interesting differences among adults with different IDD diagnoses. Medicaid beneficiaries with autism only for instance were younger than other diagnostic groups, with over 70% falling within the 21–34 age group. Autism has a relatively brief history as an identifiable and diagnosable condition compared to other IDD; thus, this finding may represent the influx of new autistic young adults into our state Medicaid systems (Rubenstein & Bishop, 2019). It will be critical to track the changing enrollment patterns of autistic adults over the next few decades as larger cohorts of autistic adults are likely to age within the Medicaid system alongside the continually increasing identification of autistic children. Autistic adults with and without ID in our sample were also predominantly male (69%–73%) whereas adults with Down syndrome only or ID only had a more balanced gender distribution. Interestingly, across all diagnostic groups approximately 70% of beneficiaries resided in urban Wisconsin counties. This may suggest that families with those with disabilities predominantly live in urban areas. However, rural communities may also face significant barriers regarding adequate availability of diagnostic, treatment, and support services for autistic individuals and those with other IDD; thus, these data may be missing misdiagnosed or underdiagnosed adults in rural communities (Antezana et al., 2017).

Building on prior research in this area, our study found a high prevalence of physical health conditions among our adult Medicaid

Figure 2

Adjusted Odds for Selected Health Conditions in Adult Medicaid Beneficiaries Aged 21+ Wisconsin



beneficiaries with IDD. Compared to the other conditions, heart disease rates were particularly high across all groups including approximately 39% of autistic adults, 64% of autistic adults with ID, 67% of adults with Down syndrome, and 75% of adults with ID only. Though overall prevalence of heart disease in autistic adults was 39%, roughly 72% of autistic adults aged 50–64 and 82% 65+ had claims for heart disease during our study period, suggesting that health disparities among adults with IDD are likely to increase with age. Considering these increases in prevalence alongside the drop in number of autistic adults from each rising age category to the next, might point to mechanisms underlying early mortality in this population, though further research will be needed to parse out these causal relationships. Our other findings indicate that over 50% of autistic adults 65+ with and without ID had claims for hypertension. Approximately 27% of adults within the Down syndrome only group and 40% of adults within ID only group had claims for diabetes during the study period. Approximately 11%–13% of

all adults in our study had claims for asthma during the study period.

In a review of the prevalence of chronic diseases among all adult Medicaid beneficiaries, Chapel and colleagues (2017) found that among 29 studies, prevalence estimates for enrollees aged 18–64 years were 8.8%–11.8% for heart disease, 17.2–27.4% for hypertension, 7.8%–19.3% for asthma, and 7.5%–12.7% for diabetes. Though prevalence of chronic diseases among all Medicaid beneficiaries in Wisconsin is unavailable, according to the National Center for Health Statistics, the death rate for heart disease in Wisconsin was 5% lower than the national rate (Centers for Disease Control and Prevention [CDC], 2018). These findings further highlight the heightened prevalence of chronic conditions among adults with different IDD. For instance, heart disease rates in adults with ID are almost seven times greater than the estimates among all adult Medicaid beneficiaries overall.

Finally, our post-hoc analyses found that in controlling for age, gender, race and ethnicity, and urban or rural county designation, autistic

adults with ID had significantly greater odds of having a claim for diabetes, heart disease, or hypertension compared to autistic adults without ID. Compared to autistic adults without an ID, adults within the ID only group had the greatest odds of having any asthma, diabetes, heart disease, and hypertension claims. All other diagnostic groups had significantly increased odds of having a claim for heart disease compared to autistic adults without ID.

Limitations

These findings should be interpreted in light of several limitations. First, our sample represents Wisconsin Medicaid beneficiaries with a recorded IDD from 2008 to 2018. Given changing diagnostic practices and improved availability of interventions, it is likely that many more adults with IDD have entered this state Medicaid system since the end of the study period. Further, diagnoses of IDD in Medicaid claims are not validated by a standardized clinical examination outside of examinations performed by the clinician at the time of entering the claim, possibly resulting in under and mis-diagnoses. Though measurement validity of adult IDD diagnoses in Medicaid claims has yet to be determined, prior research has found 97%–98% of autistic children with claims for autism did meet research criteria for autism (Fombonne et al., 2004). Further, because of missing data on race, this study could not closely draw comparisons among racial groups. Finally, the variability of state Medicaid programs described previously may impact the generalizability of our findings. The low-income disabled population in Wisconsin may differ from other states or the overall population in the United States in some respects. Wisconsin-specific policies may also impact adult outcomes.

Implications

Despite these limitations, this is among the first United States studies to examine patterns of chronic health conditions among adults with different types of IDD in a state Medicaid program. Our analyses identify high prevalence of asthma, diabetes, heart disease, and hypertension among adults on Medicaid with autism, ID, and Down syndrome. Heart disease, in particular, may be a top area of concern for adults with IDD, especially among those with Down syndrome and other intellectual disabilities. Currently, there are no known biological differences underlying these

increased morbidities prevalent among most people with IDD (Al Dera, 2022; Mandell, 2018). For example, research has suggested that autism and its associated common comorbidities are of multi-origin and caused by a complex interaction of genetic, nutritional, and environmental factors (Al Dera, 2022; Tye et al., 2019). Adults with Down syndrome do have an underlying genetic cause; however, research suggests it does not fully account for their high prevalence of health disparities. With this context and with knowledge of current prevention measures for conditions like asthma, diabetes, heart disease, and hypertension, adverse health outcomes among adults with IDD may be avoidable. It is therefore critical that future research investigate the causal mechanisms underlying these health disparities, and target interventions at both the individual and systems-level. Research should ensure prevention efforts for chronic health conditions are inclusive and evidence-based within IDD communities. Inclusive, systems-level interventions built in partnership with all IDD stakeholders have the potential to reduce healthcare costs and improve the overall health, quality of life, and longevity of adults with IDD.

References

- Al Dera, H. (2022). Cellular and molecular mechanisms underlying autism spectrum disorders and associated comorbidities: A pathophysiological review. *Biomedicine & Pharmacotherapy*, 148, 112688. <https://doi.org/10.1016/j.biopha.2022.112688>
- Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 51(5), 385–398. <https://doi.org/10.1352/1934-9556-51.5.385>
- Antezana, L., Scarpa, A., Valdespino, A., Albright, J., & Richey, J. A. (2017). Rural trends in diagnosis and services for autism spectrum disorder. *Frontiers in Psychology*, 8, 590. <https://doi.org/10.3389/fpsyg.2017.00590>
- Asim, A., Kumar, A., Muthuswamy, S., Jain, S., & Agarwal, S. (2015). Down syndrome: An insight of the disease. *Journal of Biomedical Science*, 22(1), 1–9. <https://doi.org/10.1186/s12929-015-0138-y>

- Bauer, U. E., Briss, P. A., Goodman, R. A., & Bowman, B. A. (2014). Prevention of chronic disease in the 21st century: Elimination of the leading preventable causes of premature death and disability in the USA. *The Lancet*, 384(9937), 45–52. [https://doi.org/10.1016/S0140-6736\(14\)60648-6](https://doi.org/10.1016/S0140-6736(14)60648-6)
- Bishop-Fitzpatrick, L., Movaghar, A., Greenberg, J. S., Page, D., DaWalt, L. S., Brilliant, M. H., & Mailick, M. R. (2018). Using machine learning to identify patterns of lifetime health problems in decedents with autism spectrum disorder. *Autism Research*, 11(8), 1120–1128. <https://doi.org/10.1002/aur.1960>
- Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability. *Research in Autism Spectrum Disorders*, 63, 34–41. <https://doi.org/10.1016/j.rasd.2019.01.001>
- Bruen, B., & Holahan, J. (2001). Medicaid spending growth remained modest in 1998, but likely headed upward. Kaiser Commission on Medicaid and the Uninsured Issue Paper. <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&pageId=13745>
- Centers for Disease Control and Prevention. (2018, April 4). *Stats of the state of Wisconsin*. <https://www.cdc.gov/nchs/pressroom/states/wisconsin/wisconsin.htm>
- Centers for Medicare & Medicaid Services. (2019). *Medicaid state waiver program demonstration projects: Medicaid waivers and demonstrations list*. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html>
- Chapel, J. M., Ritchey, M. D., Zhang, D., & Wang, G. (2017). Prevalence and medical costs of chronic diseases among adult Medicaid beneficiaries. *American Journal of Preventive Medicine*, 53(6), S143–S154. <https://doi.org/10.1016/j.amepre.2017.07.019>
- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814–823. <https://doi.org/10.1177/1362361315577517>
- Elder, J. H., Brasher, S., & Alexander, B. (2016). Identifying the barriers to early diagnosis and treatment in underserved individuals with autism spectrum disorders (ASD) and their families: A qualitative study. *Issues in Mental Health Nursing*, 37(6), 412–420. <https://doi.org/10.3109/01612840.2016.1153174>
- Fine, L. J., Philogene, G. S., Gramling, R., Coups, E. J., & Sinha, S. (2004). Prevalence of multiple chronic disease risk factors: 2001 National Health Interview Survey. *American Journal of Preventive Medicine*, 27(2), 18–24. <https://doi.org/10.1016/j.amepre.2004.04.017>
- Fombonne, E., Heavey, L., Smeeth, L., Rodrigues, L. C., Cook, C., Smith, P. G., Linyan, M., & Hall, A. J. (2004). Validation of the diagnosis of autism in general practitioner records. *BMC Public Health*, 4(1), 1–9. <https://doi.org/10.1186/1471-2458-4-5>
- Havercamp, S. M., & Scott, H. M. (2015). National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal*, 8(2), 165–172. <https://doi.org/10.1016/j.dhjo.2014.11.002>
- Kaiser Family Foundation (KFF). (n.d.). *State health facts: Wisconsin: Medicaid & CHIP*. <https://www.kff.org/state-category/medicaid-chip/?state=WI>
- Kaiser Family Foundation (KFF). (2023, February 27). *Status of state Medicaid Expansion Decisions: Interactive map*. <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>
- Lana-Elola, E., Watson-Scales, S. D., Fisher, E. M., & Tybulewicz, V. L. (2011). Down syndrome: Searching for the genetic culprits. *Disease Models & Mechanisms*, 4(5), 586–595. <https://doi.org/10.1242/dmm.008078>
- Landes, S. D., Stevens, J. D., & Turk, M. A. (2020). Cause of death in adults with Down syndrome in the United States. *Disability and Health Journal*, 13(4), 100947. <https://doi.org/10.1016/j.dhjo.2020.100947>
- Mandell, D. (2018). Dying before their time: Addressing premature mortality among autistic people. *Autism*, 22(3), 234–235. <https://doi.org/10.1177/1362361318764742>
- Mandell, D. S., Morales, K. H., Xie, M., Lawer, L. J., Stahmer, A. C., & Marcus, S. C. (2010). Age of diagnosis among Medicaid-enrolled children with autism, 2001–2004. *Psychiatric Services (Washington, D.C.)*, 61(8), 822–829. <https://doi.org/10.1176/ps.2010.61.8.822>

- Medicaid and CHIP Payment and Access Commission (MACPAC). (2018). *People with disabilities*. <https://www.macpac.gov/subtopic/people-with-disabilities/>
- Medicaid and CHIP Payment and Access Commission (MACPAC). (2022). *Availability of race and ethnicity data for Medicaid beneficiaries*. https://www.macpac.gov/wpcontent/uploads/2022/03/MACPAC-brief_Race-and-Ethnicity-Data-Availability.pdf
- Piven, J., Rabins, P., & Autism-in-Older Adults Working Group. (2011). Autism spectrum disorders in older adults: Toward defining a research agenda. *Journal of the American Geriatrics Society*, 59(11), 2151–2155. <https://doi.org/10.1111/j.1532-5415.2011.03632.x>
- Ptomey, L. T., Walpitage, D. L., Mohseni, M., Dreyer Gillette, M. L., Davis, A. M., Forseth, B., Dean, E.E., & Waitman, L. R. (2020). Weight status and associated comorbidities in children and adults with Down syndrome, autism spectrum disorder and intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 64(9), 725–737. <https://doi.org/10.1111/jir.12767>
- Ranjan, S., Nasser, J. A., & Fisher, K. (2018). Prevalence and potential factors associated with overweight and obesity status in adults with intellectual developmental disorders. *Journal of Applied Research in Intellectual Disabilities*, 31, 29–38. <https://doi.org/10.1111/jar.12370>
- Rector, T. S., Wickstrom, S. L., Shah, M., Thomas Greenlee, N., Rheault, P., Rogowski, J., Freedman, V., Adams, J., & Escarce, J. J. (2004). Specificity and sensitivity of claims-based algorithms for identifying members of Medicare+Choice health plans that have chronic medical conditions. *Health Services Research*, 39(6p1), 1839–1858. <https://doi.org/10.1111/j.1475-6773.2004.00321.x>
- Roux, A. M., Chvasta, K., Koffer, M., Kaitlin H., Cooper, D., Tao, S., Assing-Murray, E., Shattuck, P., & Shea, L. (2023, March). *National Autism Indicators Report: Introduction to Medicaid and Autism*. Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University.
- Rubenstein, E., & Bishop, L. (2019). Is the autism boom headed for Medicaid? Patterns in the enrollment of autistic adults in Wisconsin Medicaid, 2008–2018. *Autism Research*, 12(10), 1541–1550. <https://doi.org/10.1002/aur.2173>
- Schott, W., Tao, S., & Shea, L. (2022). Co-occurring conditions and racial-ethnic disparities: Medicaid enrolled adults on the autism spectrum. *Autism Research*, 15(1), 70–85. <https://doi.org/10.1002/aur.2644>
- Snyder, L., & Rudowitz, R. (2015). *Medicaid financing: How does it work and what are the implications*. Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/medicaid-financing-how-does-it-work-and-what-are-the-implications/>
- Tye, C., Runcles, A. K., Whitehouse, A. J., & Alvares, G. A. (2019). Characterizing the interplay between autism spectrum disorder and comorbid medical conditions: An integrative review. *Frontiers in Psychiatry*, 9, 751. <https://doi.org/10.3389/fpsy.2018.00751>
- Tyler, C. V., Schramm, S. C., Karafa, M., Tang, A. S., & Jain, A. K. (2011). Chronic disease risks in young adults with autism spectrum disorder: Forewarned is forearmed. *American Journal on Intellectual and Developmental Disabilities*, 116(5), 371–380. <https://doi.org/10.1352/1944-7558-116.5.371>
- Vohra, R., Madhavan, S., & Sambamoorthi, U. (2017). Comorbidity prevalence, healthcare utilization, and expenditures of Medicaid enrolled adults with autism spectrum disorders. *Autism*, 21(8), 995–1009. <https://doi.org/10.1177/1362361316665222>
- Wang, L., & Leslie, D. L. (2010). Health care expenditures for children with autism spectrum disorders in Medicaid. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49(11), 1165–1171. <https://doi.org/10.1016/j.jaac.2010.08.003>
- Weir, E., Allison, C., & Baron-Cohen, S. (2022). Autistic adults have poorer quality healthcare and worse health based on self-report data. *Molecular Autism*, 13(1), 23. <https://doi.org/10.1186/s13229-022-00501-w>
- Wisconsin Office of Rural Health. (2022, October 25). *WISH: Urban and rural counties*. Wisconsin Department of Health Services. <https://dhs.wisconsin.gov/wish/urban-rural.htm>
- World Health Organization. (2011). *Global status report on noncommunicable diseases 2010*.
- Zigman, W. B., Devenny, D. A., Krinsky-McHale, S. J., Jenkins, E. C., Urv, T. K., Wegiel, J., Schupf, N., & Silverman, W. (2008). Alzheimer's disease in adults with Down syndrome. *International Review of Research in*

Mental Retardation, 36, 103–145. [https://doi.org/10.1016/S0074-7750\(08\)00004-9](https://doi.org/10.1016/S0074-7750(08)00004-9)

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