



A US national update of health condition prevalence among privately-insured autistic adults

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Aim: Previous research using state or regional samples has shown that autistic adults have a higher prevalence of health conditions in comparison to the general population. **Methods:** To build upon this important previous research, we conducted a cross-sectional retrospective study of 2019–2020 healthcare claims to determine the prevalence of conditions in a US national sample of privately insured autistic adults ($n = 30,258$) and an age- and sex-matched population comparison ($n = 60,516$) group of adults without autism diagnoses. **Results:** Like previous studies, we found that autistic adults had significantly greater odds of most mental and physical health conditions. However, our prevalence estimates differed from previous studies for several mental and physical health conditions. For example, our sample of autistic adults had higher prevalence of anxiety disorders (55%) and attention deficit hyperactivity disorders (34%), but lower prevalence of asthma (9%) and sleep disorders (3%) than previous studies. **Discussion & conclusion:** Our use of a large US national sample, more recent healthcare claims data, and different methods for identifying health conditions may have contributed to these differences. Our findings alert healthcare providers and policymakers to the health conditions most common among the growing population of autistic adults. We hope these findings lead to improved screening and management of these conditions, inform initiatives to improve access to healthcare, and guide future funding.

Plain language summary

What is this article about? Understanding which physical and mental health conditions are common among autistic adults can help healthcare providers better meet their needs. Previous research examined common mental and physical health conditions using autistic adults from a single US state or region. This is the first study, to our knowledge, to use US national data to examine physical and mental health conditions in autistic and non-autistic adults aged 18–64 years.

What were the results? We found that autistic adults were more likely to have higher odds of nearly all physical and mental health conditions. However, more autistic adults in our study had anxiety disorders (55%) or attention deficit hyperactivity disorders (34%) and fewer had asthma (9%) or sleep disorders (3%) than reported in previous studies. Our results might be different from previous studies because we used a larger national sample, more recent data, and a different way of identifying health conditions.

What do the results of the study mean? These results can help healthcare providers better look for and manage common conditions among autistic adults. In the long-term, this can ultimately help improve well-being among autistic adults in the US.

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An increasing amount of literature shows that autistic adults are more likely to experience many mental and physical health conditions than the general population. For example, autistic individuals have significantly higher rates of depression, anxiety, epilepsy and cardiovascular disease [1–7]. Estimates of the prevalence of mental and physical conditions among autistic adults can help providers and healthcare systems better understand and prepare for

autistic adults' health needs. These prevalence estimates can also inform policy and health promotion initiatives for the growing population of autistic adults [8,9].

Prior studies on the prevalence of health conditions among autistic adults laid important groundwork for the field. However, some studies relied on participant self-report, which is subject to recall bias and may not be accessible for all autistic adults [6,10]. Healthcare claims data are a valuable resource that are not subject to recall bias, include individuals who cannot participate in self-report studies, and allow for analyzing larger samples with fewer resources than prospective studies. Prior studies examining the prevalence of health conditions using healthcare claims data used local or regional data from 2008–2015 [1,2,7], which may or may not be consistent with current US national prevalence estimates. We will build on this important work by providing updated prevalence estimates using US national data from 2019–2020 to provide a current, comprehensive picture of the health of autistic adults to inform healthcare, health promotion, and policy initiatives.

Methods

Data source

IBM MarketScan[®] Commercial Claims and Encounters Databases for the years 2019–2020 were used in this study. These data include privately insured employees, dependents and retirees from across the USA. De-identified individual-level healthcare claims data for inpatient and outpatient services were used in this analysis.

Study population

Autistic adults were included in this study if they: 1) were 18–64 years old; 2) had at least 6 continuous months of insurance coverage during 2019–2020; and 3) had at least one inpatient or two outpatient encounters with an autism diagnosis at any time from 1 January 2019 to 31 December 2020. Autism diagnoses were identified using International Classification of Diseases, 10th edition (ICD-10) codes F84.0, F84.1, F84.5 or F84.9. These ICD-10 codes reflect that autism was a diagnosis that was included in the list of billable diagnoses for the encounter and do not necessarily represent new autism diagnoses received. A matched population comparison (PC) group of adults without autism diagnoses was selected at a 2:1 ratio to autistic adults using group frequency matching for age and sex. The PC group met all the same inclusion criteria, except without a medical encounter containing a diagnosis of autism at any time during the study period.

Variables

We identified mental and physical health conditions from inpatient and outpatient medical claims using the Healthcare Cost and Utilization Project (HCUP) Beta Multilevel Clinical Classification Software (CCS) for ICD-10 [11], which identifies conditions based on the diagnosis codes included in healthcare claims and groups them into a smaller number of clinically relevant categories. [Supplementary Table 1](#) provides a list of all physical and mental health conditions examined and how these were defined in the present study.

Statistical analysis

Demographic characteristics were summarized descriptively. To maintain confidentiality, only conditions where frequency counts were > 10 are shown in the tables. Separate logistic regression models were performed to compare autistic and PC adults on the odds of each condition while controlling for sex, age, rural residence and relationship to insurance policy holder. Rural residence was defined by living in a non-metropolitan statistical area. We used SAS statistical software, version 9.4 for all analyses.

Results

Our sample consisted of 30,258 autistic adults and 60,516 age- and sex-matched PC adults. Demographic information for the sample is provided in [Table 1](#). Most of the sample was male and 18–29 years old was the most common age category. Over 10% of autistic adults had a co-occurring intellectual disability, compared with only 0.5% of PC adults. Approximately 7.9% of the autistic adults and 10.7% of PC adults lived in rural areas. The south was the most common region of residence for both groups, which is consistent with the overall distribution of beneficiaries in the IBM MarketScan[®] Commercial Claims and Encounters Databases.

[Table 2](#) provides information on the prevalence of physical and mental health conditions in autistic and PC adults. The most common physical health conditions in both groups were respiratory infections (29.8% of autistic adults; 31.8% of PC adults), other respiratory conditions (31.8% of autistic adults; 26.5% of PC adults), and

Table 1. Demographic characteristics of beneficiaries with and without autism.

	AS			PC		
	Females (n = 7895)	Males (n = 22,363)	Total (n = 30,258)	Females (n = 15,790)	Males (n = 44,726)	Total (n = 60,516)
Age, n (%)						
18–29	6109 (77.4)	18,626 (83.3)	24,735 (81.7)	12,218 (77.4)	37,252 (83.3)	49,470 (81.7)
30–39	950 (12)	2034 (9.1)	2984 (9.9)	1900 (12.0)	4068 (9.1)	5968 (9.9)
40–49	473 (6.0)	895 (4.0)	1368 (4.5)	946 (6.0)	1790 (4.0)	2736 (4.5)
50–59	285 (3.6)	620 (2.8)	905 (3.0)	570 (3.6)	1240 (2.8)	1810 (3.0)
60–64	78 (1.0)	188 (0.8)	266 (0.9)	156 (1.0)	376 (0.8)	532 (0.9)
Intellectual disability	864 (10.9)	2182 (9.8)	3046 (10.1)	112 (0.7)	176 (0.4)	288 (0.5)
Rural [†] , n (%)	611 (7.7)	1772 (7.9)	2383 (7.9)	1649 (10.4)	4845 (10.8)	6494 (10.7)
US region, n(%)						
South	2984 (37.8)	8091 (36.2)	11,075 (36.6)	7048 (44.6)	19,200 (42.9)	26,248 (43.4)
North Central	1785 (22.6)	4988 (22.3)	6773 (22.4)	3245 (20.6)	9602 (21.5)	12,847 (21.2)
North East	1696 (21.5)	5686 (25.4)	7382 (24.4)	2793 (17.7)	8538 (19.1)	11,331 (18.7)
West	1390 (17.6)	3534 (15.8)	4924 (16.3)	2649 (16.8)	7217 (16.1)	9866 (16.3)
Unknown	40 (0.5)	64 (0.3)	104 (0.3)	55 (0.3)	169 (0.4)	224 (0.4)
Insurance plan, n (%)						
PPO	4037 (51.1)	11,397 (51.0)	15,434 (51.0)	7798 (49.4)	21,721 (48.6)	29,519 (48.8)
HMO	946 (12)	2582 (11.5)	3528 (11.7)	1890 (12)	5295 (11.8)	7185 (11.9)
Consumer-driven health plan	872 (11)	2501 (11.2)	3373 (11.1)	1762 (11.2)	5258 (11.8)	7020 (11.6)
High deductible health plan	926 (11.7)	2596 (11.6)	3522 (11.6)	2055 (13)	6060 (13.5)	8115 (13.4)
POS	727 (9.2)	2135 (9.5)	2862 (9.5)	1502 (9.5)	4261 (9.5)	5763 (9.5)
Comprehensive	142 (1.8)	409 (1.8)	551 (1.8)	220 (1.4)	567 (1.3)	787 (1.3)
EPO	70 (0.9)	150 (0.7)	220 (0.7)	151 (1)	407 (0.9)	558 (0.9)
Capitated POS	44 (0.6)	149 (0.7)	193 (0.6)	117 (0.7)	312 (0.7)	429 (0.7)
Unknown/Other	131 (1.6)	444 (2)	575 (1.9)	295 (1.8)	845 (1.9)	1140 (1.9)
Relationship to policy holder						
Self	1317 (16.7)	3452 (15.4)	4769 (15.8)	4585 (29.1)	13443 (30.1)	18,028 (29.8)
Spouse	553 (7.0)	363 (1.6)	916 (3.0)	1775 (11.3)	1769 (4.0)	3544 (5.9)
Adult child/other	6021 (76.3)	18,541 (82.9)	24,562 (81.2)	9419 (59.7)	29,491 (66.0)	38,910 (64.3)

[†] Rural residence was defined as living in a non-metropolitan statistical area.

[‡] Reported in thousands of 2017 US Dollars.

AS: Autism spectrum; EPO: Exclusive provider organization; HMO: Health maintenance organization; PC: Population comparison group; POS: Point of sales.

gastrointestinal conditions like gastroenteritis or constipation (18.6% of autistic adults; 10.9% of PC adults). The most common mental health conditions in both groups were anxiety disorders (55% of autistic adults; 17.5% of PC adults), mood disorders (42.6% of autistic adults; 13.2% of PC adults), and attention deficit hyperactivity disorder (ADHD, 34.1% of autistic adults; 7.4% of PC adults).

After adjusting for sex, age and rural residence, autistic adults had significantly greater odds of all physical health conditions except for multiple sclerosis, respiratory infections, arthritis, back conditions and fractures. The largest between-group differences in physical health conditions were noted for epilepsy (odds ratio [OR]: 6.6; 95% confidence interval [95% CI]: 6.2–7.1), cerebrovascular disease (OR: 2.4; 95% CI: 2.1–2.9) and obesity (OR: 2.6; 95% CI: 2.5–2.7). Obesity is included in our study as a physical health condition in this article due to its current classification as a “chronic health condition” by the US National Institutes of Health; however, we recognize that there is ongoing debate in the medical community about the classification of obesity in and of itself as a health condition. Further discussion into this topic is beyond the scope of this paper, but more information is included in Luli *et al.* [12]. Autistic adults also had significantly greater odds of all mental health conditions except for substance use disorders. The largest between-group differences for mental health conditions were for schizophrenia and psychotic disorders (OR: 7.4; 95% CI: 6.7–8.2), attention deficit hyperactivity disorders (OR: 6.5; 95% CI: 6.3–6.8) and personality disorders (OR 6.3; 95% CI: 5.5–7.2).

Table 2. Prevalence of physical and mental health conditions in autistic and PC adults.

Condition	Autistic adults n = 30,258 n (%)	PC adults n = 60,516 n (%)	Adjusted OR [†] (95% CI)
Physical Health			
Metabolic Disorders			
Diabetes	2927 (9.7)	3082 (5.1)	2.1 (2.0–2.2)
Obesity [#]	5174 (17.1)	4559 (7.5)	2.6 (2.5–2.7)
Thyroid Disorders	2515 (8.3)	2499 (4.1)	2.1 (2.0–2.1)
Menopausal Disorders	139 (0.5)	215 (0.4)	1.5 (1.2–1.9)
Cancer	3426 (11.3)	5991 (9.9)	1.2 (1.1–1.2)
Nervous System Diseases			
Epilepsy	3674 (12.1)	1010 (1.7)	6.6 (6.2–7.1)
Multiple Sclerosis	49 (0.2)	69 (0.1)	1.6 (1.1–2.4)
Circulatory Conditions			
Hypertension	2756 (9.1)	3904 (6.5)	1.6 (1.5–1.7)
Heart Disease	4734 (15.6)	6527 (10.8)	1.5 (1.5–1.6)
Cerebrovascular Disease	319 (1.1)	255 (0.4)	2.4 (2.1–2.9)
Respiratory Conditions			
Respiratory Infections	9002 (29.8)	19,251 (31.8)	0.9 (0.9–0.9)
COPD	681 (2.3)	995 (1.6)	1.3 (1.2–1.5)
Asthma	2682 (8.9)	3811 (6.3)	1.4 (1.3–1.5)
Other (e.g., Pleurisy, Respiratory Failure)	9631 (31.8)	16,005 (26.5)	1.3 (1.3–1.3)
Gastrointestinal (GI) Conditions			
Upper or Lower GI Disorders	4134 (13.7)	5204 (8.6)	1.7 (1.6–1.8)
Other (e.g., Gastroenteritis, Constipation)	5621 (18.6)	6591 (10.9)	1.9 (1.8–1.9)
Musculoskeletal			
Arthritis	4259 (14.1)	8545 (14.1)	1.0 (1.0–1.0)
Back Conditions [‡]	4156 (13.7)	8854 (14.6)	1.0 (1.0–1.0)
Osteoporosis	119 (0.4)	83 (0.1)	2.2 (1.7–3.0)
Injuries			
Fractures	1035 (3.4)	2066 (3.4)	0.9 (0.9–1.0)
Poisoning	468 (1.5)	428 (0.7)	2.1 (1.8–2.4)
Mental Health			
Mood Disorders	12,895 (42.6)	8003 (13.2)	4.9 (4.8–5.1)
Anxiety Disorders [§]	16,627 (55.0)	10,607 (17.5)	5.9 (5.7–6.1)
Personality Disorders	966 (3.2)	308 (0.5)	6.3 (5.5–7.2)
Suicidality or Intentional Self-Injury	1952 (6.5)	719 (1.2)	5.7 (5.2–6.2)
Substance Use Disorders	2031 (6.7)	4079 (6.7)	1.0 (1.0–1.1)
Schizophrenia and Psychotic Disorders	2066 (6.8)	518 (0.9)	7.4 (6.7–8.2)
Cognitive Disorders [¶]	458 (1.5)	205 (0.3)	3.9 (3.3–4.7)
Sleep Disorders	1010 (3.3)	604 (1.0)	3.5 (3.2–3.9)
Attention Deficit Hyperactivity Disorder	10,304 (34.1)	4505 (7.4)	6.5 (6.3–6.8)

[†]Adjusted for sex, age, rural residence, and relationship to insurance policy holder.

[‡]Includes spondylosis, intervertebral disc disorders, and “other” back problems.

[§]Includes obsessive compulsive disorders, generalized anxiety disorder, phobias, post-traumatic stress disorder, and other anxiety disorders.

[¶]Includes delirium, dementia, amnesia, and “other” cognitive disorders.

[#]Obesity is included on this list due to its current classification as a “chronic health condition” by the National Institutes of Health; however, it should be recognized that there is ongoing debate in the medical community whether obesity is a health condition in and of itself.

AS: Autism spectrum; PC: Population comparison; OR: Odds ratio; COPD: Chronic obstructive pulmonary disease.

Discussion

As the population of autistic adults continues to grow, characterizing the prevalence of health conditions can better equip healthcare providers, healthcare systems, and policymakers to meet this population's needs. The present study provides a unique contribution to the literature in that we use the largest US-based sample to-date to provide a current, comprehensive picture of health conditions among privately insured autistic adults. To our knowledge, this study is also the first to estimate the prevalence of health conditions among autistic adults aged 18–64 years using a US national sample.

The extent to which our findings were consistent with prior studies using healthcare claims data is mixed. Similar to prior studies, we found that overall autistic adults had greater odds of most mental and physical conditions than PC adults [1,2]. However, our prevalence estimates differed from prior studies for several mental and physical health conditions. For example, our sample of autistic adults had higher prevalence of anxiety disorders (55% vs 29–43% in prior studies) and ADHD (34% vs 8–12% in prior studies) [1,2]. Conversely, we found a lower prevalence of asthma (9% vs 13–24% in prior studies) and sleep disorders (3% vs 18–85% in prior studies) [1,2,7].

There are several possible reasons that our prevalence estimates differed from prior studies such as differences in the study samples, temporal factors, and differences in how health conditions were identified. Our sample consisted of privately insured autistic adults aged 18–64 from across the US. In contrast, prior studies focused on autistic adults publicly insured through Medicaid [1]. Individuals insured through Medicaid must meet financial eligibility rules and thus tend to have lower socioeconomic status than privately insured individuals and socioeconomic status is associated with risk of developing some health conditions [13]. Additionally, evidence suggests that individuals with public and private insurance experience differences in access to and utilization of healthcare services [14]. Further, other studies used state specific samples [1,2] or focused on a subset of autistic adults such as those aged 18–24 years [7].

The prevalence estimates may have differed from prior studies as well due to our data being obtained from medical encounters that occurred during 2019–2020, while prior studies analyzed data from 2008–2015. It is possible, therefore, that the prevalence of these health conditions being diagnosed among autistic adults has changed over time. For example ADHD, was not formally recognized as being able to co-occur with autism until 2013 [15], which may have resulted in this condition being underdiagnosed in studies using older claims data. Finally, we used HCUP CCS, which is continually updated to include all current diagnostic codes, to identify physical and mental health conditions in healthcare claims data, while prior studies used different sets of diagnostic codes [1,2,7]. As a result, differences in observed prevalence estimates for these conditions could in part be attributable to how the conditions were identified in the healthcare claims data.

Despite these differences in specific prevalence estimates, the conclusion that autistic adults are more likely than the general population to have mental and physical health conditions has a variety of implications for healthcare delivery and policymakers. First, this information can alert providers to certain conditions that are more common among autistic adults to improve screening and management of these conditions. For example, autistic adults in our sample had nearly six-times greater odds than PC adults to have an encounter for suicidal ideation or intentional self-injury (OR: 5.7, 95% CI: 5.2–6.2), although prevalence was relatively low for both groups (6.5% to 1.2%, respectively). This finding adds to a growing body of literature on the higher prevalence of suicidality and intentional self-inflicted injury among autistic people [16] and underscores the need for better access to mental health services, preventative care, and primary care [17,18]. Second, our findings highlight the need for healthcare system-level and policy-level initiatives to improve autistic adults' access to high-quality comprehensive healthcare [19]. Evidence suggests approximately 30–34% of autistic adults have unmet healthcare needs [20], which may result in some health conditions being left untreated or undertreated. Third, our findings can guide future funding priorities to develop innovative solutions to better manage these conditions. Indeed, research to improve the efficacy and dissemination of services for autistic people is a high-priority area for research [8], yet receives a mere 5% of autism related US federal research funding [21]. Previous work considering the health of individuals with disabilities led the National Institutes of Health to recognize this group as a health disparities population [22]. This recognition calls for research and resources to be dedicated to mitigating these disparities and better serving people with disabilities, including autistic adults. In adding to this literature, we further underscore the need to ensure that agencies prioritize funding research that is valued by autistic people and members of the broader autism community and will have a real-world impact.

Methodologic considerations

There are a few limitations that we would like to acknowledge. There were variables we could not control for, including race, ethnicity, socioeconomic status and social support, as IBM MarketScan® Commercial Claims and Encounters Databases does not include this information. It is also important to acknowledge that these data only include individuals who are privately insured, so the results of this study may not generalize to individuals who are publicly insured or uninsured. We also relied solely on diagnostic codes found in healthcare claims data, which may have impacted the accuracy of our prevalence estimates and underrepresented some conditions for which individuals do not seek or receive medical care. Nevertheless, the prevalence estimates reported here reflect the health conditions for which our national sample of privately insured autistic adults in the US received medical care. Additionally, we only included autistic adults with a medical encounter with a formal diagnosis code for autism, which excluded individuals who are self-diagnosed and may exclude those with a formal diagnosis who did not have a medical encounter with an autism diagnosis code during 2019–2020. We also do not know the age at which the included autistic individuals were diagnosed with autism, including whether their diagnosis was initially received in childhood or adulthood. Autistic adults with racial and ethnic minoritized identities may have been underrepresented in the sample as well, as they may be more likely to be underdiagnosed with autism [23]. There are also several directions that were beyond the scope of the present study but are important considerations for future work. For example, it will be important to determine the extent to which prevalence of health conditions differs between autistic young adults and middle-aged adults, examining change over time in the prevalence of health conditions, and the extent to which the SARS-CoV-2 pandemic may have differentially impacted health conditions experienced by autistic and PC adults.

Conclusion

There is a growing body of literature on the prevalence of health conditions among autistic adults. Our study builds upon the established literature in this area by providing updated prevalence estimates of physical and mental health conditions among privately insured autistic adults. This study is the first, to our knowledge, to examine this prevalence at a US national level among autistic adults aged 18–64 years. Consistent with prior studies, we found that autistic adults had significantly greater odds of most physical and mental health conditions. These findings alert healthcare providers and policymakers to the health conditions most common among the growing population of autistic adults to improve screening and management of these conditions, inform initiatives to improve access to healthcare, and guide future funding priorities. Ultimately, this work supports the prioritization of innovative and comprehensive person-centered healthcare approaches to evaluate and address the specific mental and physical healthcare needs of autistic adults.

Summary points

- An increasing amount of literature shows that autistic adults are more likely to experience mental and physical health conditions than the general population.
- Prior studies on the prevalence of health conditions among autistic adults laid important groundwork for the field; however, these studies often relied upon participant self-report as well as regional data.
- We built on this important work by providing updated prevalence estimates using US national data from 2019–2020 to provide a current, comprehensive picture of the health of autistic adults to inform healthcare, health promotion and policy initiatives.
- Our sample consisted of 30,258 autistic adults and 60,516 age- and sex-matched PC adults.
- The largest between-group differences in physical health conditions were noted for epilepsy (odds ratio [OR]: 6.6; 95% confidence interval [95% CI]: 6.2–7.1), cerebrovascular disease (OR: 2.4; 95% CI: 2.1–2.9) and obesity (OR: 2.6; 95% CI: 2.5–2.7).
- The largest between-group differences for mental health conditions were for schizophrenia and psychotic disorders (OR: 7.4; 95% CI: 6.7–8.2), attention deficit hyperactivity disorders (OR: 6.5; 95% CI: 6.3–6.8) and personality disorders (OR 6.3; 95% CI: 5.5–7.2).
- There are several possible reasons that our prevalence estimates differed from prior studies such as differences in the study samples, temporal factors and differences in how health conditions were identified.
- These findings alert healthcare providers and policymakers to health conditions common among the growing population of autistic adults to improve screening and management of these conditions, inform initiatives to improve access to healthcare, and guide future funding priorities.
- This work supports the prioritization of innovative and comprehensive person-centered healthcare approaches to evaluate and address the specific mental and physical healthcare needs of autistic adults.

Supplementary data

To view the supplementary data that accompany this paper please visit the journal website at: <https://bpl-prod.literatumonline.com/doi/10.57264/cer-2023-0051>

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The authors have no financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

Competing interests disclosure

Brittany N Hand reports receiving grant funding from the National Institutes of Health and Department of Defense related to health and healthcare for autistic adults. She is also a member of a stakeholder advisory board on a Patient-Centered Outcomes Research Institute-funded project examining medical management of ADHD symptoms for autistic people. The authors have no other competing interests or relevant affiliations with any organization or entity with the subject matter or materials discussed in the manuscript apart from those disclosed.

Writing disclosure

No writing assistance was utilized in the production of this manuscript.

Ethical conduct of research

The Institutional Review Board of Ohio State University reviewed this study and determined it to be IRB-exempt due to the use of limited datasets.

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