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# Research in Autism Spectrum Disorders

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## The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability



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### ABSTRACT

**Background:** People on the autism spectrum may have more physical and mental health conditions in midlife and old age compared to the general population. This study describes the physical and mental health of a unique sample of all middle aged and older Wisconsin Medicaid beneficiaries with an autism spectrum disorder diagnosis and tests differences between those with and without co-occurring intellectual disability.

**Method:** Using de-identified Medicaid claims data for 143 adults with a recorded autism spectrum disorder diagnosis aged 40–88 years with any Wisconsin Medicaid claims in 2012 through 2015, we extracted diagnoses for physical and mental health conditions from fee-for-service claims. Logistic regression analyses—controlling for sex, race, and age—compared the adjusted odds of physical and mental health conditions for those with and without intellectual disability. **Results:** Many physical and mental health conditions, including immune conditions (70.6%), cardiovascular disease (49.0%) and its risk factors (46.2%), sleep disorders (85.3%), gastrointestinal disorders (49.7%), neurologic conditions (55.9%), and psychiatric disorders (72.0%) were highly prevalent in our full sample. Although there were many similarities between those individuals with and without co-occurring intellectual disability, middle aged and older adults on the autism spectrum had higher prevalence of epilepsy and lower prevalence of depression and anxiety compared to those without co-occurring intellectual disability.

**Conclusions:** Findings suggest that people on the autism spectrum have a high prevalence of physical and mental health conditions in midlife and old age, regardless of intellectual disability status.

### 1. Introduction

In comparison to other well-characterized developmental disorders, autism has a relatively brief history as an identifiable and diagnosable condition and as such we are just beginning to witness and study how people on the autism spectrum age in midlife and beyond. Although we know very little about the unique challenges autistic people experience during older age (Piven & Rabins, 2011), a recent and growing body of preliminary evidence suggests that people on the autism spectrum live shorter lives; studies conducted to date have identified a two- to three-decades decreased life expectancy and heightened all-cause and injury mortality in people on the autism spectrum (Guan & Li, 2017; Hirvikoski et al., 2016). Research also suggests that adults on the autism spectrum have more physical and mental health conditions (hereafter called ‘health conditions’) that negatively impact quality of life compared

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to the general population (Bishop-Fitzpatrick et al., 2018; Croen et al., 2015; Davignon, Qian, Massolo, & Croen, 2018; Maddox, Kang-Yi, Brodtkin, & Mandell, 2018; Nylander, Axmon, Björne, Ahlström, & Gillberg, 2018), and recent research indicates that the health gap becomes larger with age (Bishop-Fitzpatrick et al., 2018; Nylander et al., 2018). Differences in health conditions among individuals on the autism spectrum may be evidence of health inequalities (i.e., health differences that are avoidable, unnecessary, and unjust; Whitehead, 1991) that explain some of the decreased life expectancy in autistic people. Since so little is known about the larger population of middle aged and older adults with autism diagnoses, it is imperative to use existing, available population-level data to characterize the health of this population. Characterizing their health allows us to inform individual and systems-level prevention efforts that can help people on the autism spectrum live long, healthy, and self-determined lives in their communities.

Most studies that examine the health conditions of adults on the autism spectrum generally find similar or greater prevalence of most health conditions compared to the general population, although some exceptions do exist. A recent systematic review of the physical health of adults on the autism spectrum found support for higher prevalence of cardiovascular risk factors (i.e., overweight and obesity, diabetes, hyperlipidemia), particularly in those people on the autism spectrum with a co-occurring intellectual disability (ID; Cashin, Buckley, Trollor, & Lennox, 2016). More recent work that characterizes health conditions in older adults on the autism spectrum generally supports the findings of these reviews. Recently, in the first study of health histories of middle aged and older deceased adults on the autism spectrum, we found higher prevalence of most health conditions, including cardiovascular disease, motor problems, hypothyroidism, and neurological disorders (Bishop-Fitzpatrick et al., 2018). These findings related to motor problems echo recent work by Starkstein, Gellar, Parlier, Payne, and Piven (2015) that identified higher incidence of parkinsonism in middle aged and older adults on the autism spectrum. In terms of mental health conditions, findings are mixed: Nylander et al. (2018) identified high prevalence of affective disorders, anxiety, and psychotic disorders in older adults on the autism spectrum without co-occurring ID while Lever and Geurts (2016) found that older adults on the autism spectrum had fewer psychiatric diagnoses than young or middle aged adults on the autism spectrum. However, research in this area is still nascent and we have argued for the necessity and importance of continuing to evaluate these health conditions, incorporating a temporal and life-course perspective (Rubenstein & Bishop-Fitzpatrick, 2018).

One specific area that has been understudied to date is differences in health conditions in adults on the autism spectrum with and without co-occurring ID. Currently, approximately 35% of children on the autism spectrum have ID. Notably, the major rise in prevalence of autism is at least partially attributable to the increased identification of people with autism without ID (Baio et al., 2018) through expanded diagnostic criteria and increased awareness. Autistic adults who are currently middle aged and older were diagnosed under older, stricter diagnostic criteria that were less sensitive in identifying autistic adults without ID, suggesting the possibility that the majority of autistic adults who are currently middle aged and older would have co-occurring ID. Although differences in health conditions in midlife and beyond between autistic adults with and without ID have not been specifically tested, previous research suggests autistic adults with ID may have more physical health conditions and die earlier than those autistic adults without ID (Cashin et al., 2016; Hirvikoski et al., 2016). Additionally, ID may serve as a marker for a subgroup at high risk for specific health conditions in midlife and beyond which can both offer clues to specific etiologic origins (Bolton et al., 2011) and help us develop prevention programs and anticipate service use. For instance, we see increased occurrence of epilepsy among children with autism and ID compared to children with autism alone (van Eeghen et al., 2013), which may suggest different neurological mechanisms in this population. However, we do not know if there are health conditions intrinsically tied to autism with ID that develop later in adulthood (Rubenstein & Bishop-Fitzpatrick, 2018). Thus, assessing whether health conditions in the cohort of middle aged and older adults with autism differ between those with and without ID may help us anticipate whether future cohorts will experience similar outcomes despite different prevalence of co-occurring ID (Rubenstein et al., 2018).

Given the urgent need for research in this area, one of the best sources of data are publicly available medical claims. In contrast to a longitudinal cohort study, claims data allow us to efficiently examine health in an entire health system without huge expense or years of follow-up time. For autism, Medicaid is a crucial and large resource of available data. Adults on the autism spectrum in the United States (US) qualify for Medicaid because they meet criteria for disability under Supplemental Security Income or Social Security Disability Insurance (autism or other condition like ID) or because of poverty that results from well-established low rates of employment and underemployment in adults on the autism spectrum (Burgess & Citera, 2014; Taylor, Henninger, & Mailick, 2015). Medicaid claims data have been successfully used in the US to study health and health service utilization in children, adolescents, and young adults with ASD (e.g., Davignon et al., 2018; Mandell et al., 2008; Ruble, Heflinger, Renfrew, & Saunders, 2005; Shea et al., 2018). Because an individual must have a health condition identified by a provider in order to be billed for service, Medicaid claims data may underestimate health conditions that are not treated or identified and be strongly influenced by an individual's access to care. However, Medicaid claims data likely represent the largest US-based population of adults with identified autism spectrum disorder and are a powerful first step that allows for examination of both an individual's health condition profile and a systems level approach to examining service receipt and costs in this population.

We were unable to find any studies that use Medicaid claims data to study health and/or health service utilization in a sample of middle aged and older adults on the autism spectrum. Thus, these data represent a novel use of Medicaid data to study health in midlife and beyond in people on the autism spectrum, and particularly those middle aged and older adults on the autism spectrum with co-occurring ID (Tager-Flusberg & Kasari, 2013) or from socioeconomically disadvantaged groups (Bishop-Fitzpatrick & Kind, 2017) who are generally underrepresented in research on autism spectrum disorder.

Our primary objective was to describe the physical and mental health of a unique sample of all middle and older aged adults with a diagnosis of autism spectrum disorder receiving Medicaid services in the state of Wisconsin between 2012 and 2015. Additionally, we examined whether co-occurring ID was associated with the presence of certain health conditions, as ID is hypothesized to be associated with certain health conditions and disparities (Cashin et al., 2016). We hypothesized that middle aged and older adults

with autism in Wisconsin would have abundant claims for chronic health conditions. We also hypothesized that people on the autism spectrum with co-occurring ID would have more claims for physical and chronic health problems. Conversely, we hypothesized that people on the autism spectrum without ID would have more claims for mental health problems.

## 2. Methods

### 2.1. Data source

We obtained de-identified Medicaid claims data for adults with a recorded autism spectrum disorder diagnosis (see below) aged 40 and older with any Medicaid fee-for-service claims between January 1, 2012 and December 31, 2015 (the years of data provided to our team). Medicaid is a state-administered anti-poverty program that provides free or low-cost health and dental coverage to people with low income and/or disabilities. Data were obtained directly from the Wisconsin Department of Health Services using a limited data use agreement. Data obtained included demographic data (age, race/ethnicity, sex, county of residents, and 5-digit zip code) and full Medicaid-reimbursed pharmacy and non-pharmacy fee-for-service claims data. Claims data included all ICD-9 codes associated with a pharmacy or non-pharmacy fee-for-service claim. Although we did not analyze costs for the purpose of this paper, the Wisconsin Department of Health Services also provided data on reimbursed costs.

### 2.2. Autism spectrum disorder identification

Individuals were included in these data if they had two Medicaid claims for an ICD-9 code on two different days during their entire lifetime period of Medicaid enrollment. Codes that indicated being on the autism spectrum were autism (299.0), Asperger's disorder (299.8) or pervasive developmental disorder not otherwise specified (299.9). Using two claims rather than one ensures that the autism claim is not a rule out diagnosis (i.e., a diagnosis recorded for a suspected health condition but that is not a primary or final diagnosis; Rector et al., 2004) and is consistent with past work examining autism in claims and electronic health records data in adults (Bishop-Fitzpatrick et al., 2018; Croen et al., 2015; Maddox et al., 2018).

### 2.3. Physical and mental health conditions

We examined service claims from all providers (inpatient, outpatient, long-term care, home health, and dental) for health conditions between 2012-2015. We categorized these conditions based on a system used by Croen et al. (2015) for grouping ICD-9 codes (immune conditions, cancer, cardiovascular risk factors, cardiovascular disease, endocrine disorders, neurologic disorders, gastrointestinal disorders, sleep disorders, psychiatric conditions) while also presenting prevalent individual conditions. Similar to how we defined autism, we used a two-diagnosis rule to ensure that the condition documented was not a differential or rule out diagnosis. As this approach may be overly conservative and value specificity over sensitivity, we ran sensitivity analyses without these rule out criteria (results presented in Supplemental Table 1).

### 2.4. Intellectual disability

We determined ID status using the two-diagnosis rule out criteria for claims with five-digit ICD-9 codes starting with 317 ("mild intellectual disabilities"), 318 ("other specified intellectual disabilities," including: "moderate"; "severe"; and "profound" intellectual disabilities), or 319 ("unspecified intellectual disabilities") in the data. Although data were not available on ID claims for the entire lifetime period of Medicaid enrollment like were available for autism claims, based on past literature and billing practice we expect that an individual with ID would receive consistent ID claims across the life course (Shea et al., 2018). We ran sensitivity analyses without restricting ID case status to having two claims (i.e., using only a single claim for ID rather than two claims) to evaluate the effect of our more conservative approach on results (results presented in Supplemental Table 2).

### 2.5. Data analysis

We examined demographic variables provided in the enrollment data and claim type in our total population and by ID status. We then evaluated the presence of physical and mental health conditions (i.e., broader categories for immune conditions, cancer, cardiovascular risk factors, cardiovascular disease, endocrine disorders, neurologic disorders, gastrointestinal disorders, sleep disorders, psychiatric conditions) based on our two-claim rule out approach for the overall sample and by ID group. For the grouped conditions, we calculated unadjusted and adjusted odds ratios (aOR) using logistic regression comparing those with ID to those without. We adjusted for sex, race (white or other), and age (median split of < 50 years or > = 50 years) as all three were associated with ID status in our data and commonly affect health.

Due to the high interest in psychiatric conditions in autism and the common neurologic conditions associated with ID and autism, we ran post-hoc unadjusted and adjusted (adjusting for the same variables as above) logistic regression analyses to evaluate psychiatric and neurologic conditions with > 15% prevalence in our sample. This cutoff was set to ensure adequate sample size per cell. All analyses were conducted with SAS 9.3 and R 3.2.0.

**Table 1**  
Demographic and Claims Characteristics in Adults on the Autism Spectrum Aged 40+ Served by Wisconsin Medicaid, 2012-2015.

	Total N = 143	Intellectual Disability N = 64	No Intellectual Disability N = 79
	N (%)	N (%)	N (%)
<b>Sex</b>			
Male	98 (68.5)	40 (62.5)	58 (73.4)
Female	45 (31.5)	24 (37.5)	21 (26.6)
<b>Race/Ethnicity</b>			
White	113 (79.0)	63 (79.8)	50 (78.2)
Black	6 (4.2)	4 (6.3)	2 (2.5)
Other	21 (14.7)	9 (14.1)	12 (15.2)
Hispanic	3 (2.1)	1 (1.6)	2 (2.5)
<b>Age</b>			
Mean, SD	52.4, 9.6	54.9, 10.1	50.4, 8.6
Median, IQR	50, 13	54.0, 14	49.0, 11
<b>Years Enrolled</b>			
Mean, (SD)	3.56 (0.8)	3.78 (0.5)	3.37 (0.9)
Median, (IQR)	4.0 (1.0)	4.0 (0.0)	4.0 (1.0)
<b>Number of Claims</b>			
Mean, (SD)	176.4 (220.6)	197.4 (205.8)	159.5 (231.9)
Median, (IQR)	110.0 (156.0)	140 (151.0)	98 (168.0)
<b>Claims Type</b>			
Dental	95 (66.4)	50 (78.1)	45 (52.6)
Home health	19 (13.3)	14 (21.9)	5 (6.3)
Inpatient	4 (2.8)	1 (1.6)	3 (3.8)
Inpatient crossover	43 (30.1)	23 (35.9)	25.3 (25.3)
Long-term care	11 (7.7)	7 (10.9)	4 (5.1)
Outpatient	61 (42.7)	30 (46.9)	31 (39.2)
Outpatient crossover	61 (43.9)	43 (43.9)	18 (40.0)
Professional	134 (93.7)	59 (92.2)	75 (94.9)
Professional crossover	125 (87.4)	61 (95.3)	64 (81.0)

Note. N = number; SD = standard deviation; IQR = interquartile range. "Claims Type" represents the number and proportion of participants with each type of claim.

### 3. Results

In our sample of 143 adults  $\geq 40$  (range: 40–88) years old receiving Medicaid services in Wisconsin with at least two autism spectrum disorder claims, 68.5% were male and 79.0% were white (Table 1). Of individuals with co-occurring ID, 62.5% were male and had a mean age at study entry of 54.9 (standard deviation [SD]: 9.6). For those without co-occurring ID, 73.4% were male and mean age at study entry was 50.4 (SD: 8.6). The most common claim type was professional (i.e., claims generated for work performed by non-institutional providers) and professional crossover claims (i.e., claims billed to both Medicaid and either private insurance or Medicare). Based on post-hoc chi-square tests, individuals with ID were more likely to have received dental care ( $X^2 = 7.1$ ,  $P = 0.008$ ) and home health care ( $X^2 = 7.4$ ,  $P = 0.007$ ) compared to individuals without ID. During the four years of study, individuals with ID were enrolled in Medicaid on average 3.78 years and individuals without ID were enrolled for 3.36 years; the distribution between the two groups did not differ in a post-hoc Kolmogorov-Smirnov test ( $K = 0.10$ ,  $P = 0.1$ ).

In this sample, the prevalence of chronic medical conditions was high (Table 2). Of note, 70.2% had at least two claims for immune conditions, 46.2% had cardiovascular disease risk factors while 49.0% had cardiovascular disease. Sleep disorders (85.3%), gastrointestinal disorders (49.7%) and psychiatric disorders (72.0%) were all prevalent, consistent with findings in younger cohorts (Croen et al., 2015; Shea et al., 2018). Because of the similarly in prevalence of cardiovascular disease and cardiovascular disease risk factors, we analyzed concordance. We found that 34.3% of the sample had both cardiovascular disease and cardiovascular disease risk factors, 14.7% had only cardiovascular disease, 11.9% had only cardiovascular disease risk factors, and 39.2% has neither cardiovascular disease nor its risk factors.

Overall, none of the adjusted odds ratios for health conditions comparing ID vs. non-ID were statistically significant. When comparing odds of the categorized conditions between those with and without ID, we saw increased but not statistically significant odds of neurologic disorders (aOR 2.00, 95% confidence interval [CI]: 1.0, 4.1) and gastrointestinal disorders (aOR: 1.57, 95% CI: 0.8, 3.2) in middle aged and older adults on the autism spectrum with co-occurring ID compared to those without. There was decreased but not statistically significant odds for immune conditions (aOR: 0.65, 95% CI: 0.3, 1.4), cardiovascular disease risk (aOR: 0.65, 95% CI: 0.3, 1.3), and psychiatric disorders (aOR: 0.65, 95% CI: 0.3, 1.4) in middle aged and older adults on the autism spectrum with co-occurring ID compared to those without. Similarly, there were no statistically significant differences in adjusted odds ratios comparing adults with and without ID in our sensitivity analyses broadened criteria for diagnoses for health conditions or ID to only one documented claim. Due to the limited detail provided in claims data, we chose to present the more conservative

**Table 2**

Categorical and Individual Health Conditions in Adults on the Autism Spectrum Aged 40+ Served by Wisconsin Medicaid, 2012–2015.

Diagnosis, N (%)	Overall (N = 143)	ID (N = 64)	No ID (N = 79)	OR (CI)	Adjusted OR (CI) <sup>A</sup>
<b>Immune Conditions</b>	101 (70.6)	44 (68.8)	57 (72.2)	0.85 (0.4, 1.7)	0.65 (0.3, 1.4)
Autoimmune Disease	44 (30.8)	18 (28.1)	26 (32.9)		
Allergy	30 (21.0)	15 (23.4)	15 (19.0)		
Asthma	30 (21.0)	14 (21.9)	16 (20.3)		
Infection	80 (55.9)	41 (64.1)	39 (49.4)		
<b>Cancer</b>	8 (5.6)	3 (4.7)	5 (6.3)	0.73 (0.2, 3.2)	0.51 (0.1, 2.3)
<b>Cardiovascular Disease Risk</b>	66 (46.2)	27 (42.2)	39 (49.4)	0.75 (0.4, 1.4)	0.65 (0.3, 1.3)
Dyslipidemia	43 (30.1)	16 (25.0)	27 (34.2)		
Hypertension	39 (27.3)	17 (26.6)	22 (27.8)		
Diabetes	31 (21.7)	8 (12.5)	23 (29.1)		
<b>Cardiovascular Disease</b>	70 (49.0)	35 (54.7)	35 (44.3)	1.51 (0.8, 2.9)	1.29 (0.6, 2.6)
<b>Endocrine Disorders</b>	33 (23.1)	17 (26.6)	16 (20.3)	1.42 (0.7, 3.1)	0.80 (0.4, 1.8)
Thyroid Disease	32 (22.4)	16 (25.0)	16 (20.3)		
<b>Neurologic Disorders</b>	80 (55.9)	43 (67.2)	37 (46.8)	<b>2.32 (1.2, 4.6)</b>	<b>2.00 (1.0, 4.1)</b>
Epilepsy and recurrent seizures	36 (25.2)	23 (35.9)	13 (16.5)		
Headache	11 (7.7)	8 (12.5)	3 (3.8)		
Other Disorders of Central Nervous System	41 (28.7)	23 (35.9)	18 (22.8)		
Hereditary and Degenerative Diseases of Central Nervous System	20 (14.0)	9 (14.1)	11 (13.9)		
<b>Gastrointestinal Disorders</b>	71 (49.7)	37 (57.8)	34 (43.0)	1.81 (0.9, 3.5)	1.57 (0.8, 3.2)
Constipation	23 (16.1)	17 (26.6)	6 (7.6)		
Diarrhea	17 (11.9)	7 (10.9)	10 (12.7)		
Disorders of Stomach and Duodenum	4 (2.8)	2 (3.1)	2 (2.5)		
Functional Disorders	26 (18.2)	13 (20.3)	13 (16.5)		
Gastroesophageal Reflux Disease	19 (13.3)	7 (10.9)	12 (15.2)		
Lower Gastrointestinal	8 (5.6)	8 (12.5)	0 (0.0)		
Other Disease of Esophagus	16 (11.2)	10 (15.6)	6 (7.6)		
Upper Gastrointestinal Mobility	13 (9.1)	7 (10.9)	6 (7.6)		
<b>Sleep Disorders</b>	122 (85.3)	56 (87.5)	66 (83.5)	1.38 (0.5, 3.6)	0.99 (0.4, 2.7)
Dyssomnia	121 (84.6)	65 (25.0)	56 (34.2)		
<b>Nutrition Conditions</b>	41 (28.7)	19 (29.7)	22 (27.8)	1.09 (0.5, 2.3)	0.96 (0.4, 2.0)
Symptom Concerning Nutrition Metabolism Development	30 (21.0)	13 (20.3)	17 (21.5)		
Vitamin Deficiency	8 (5.6)	5 (7.8)	3 (3.8)		
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<b>Other Conditions</b>					
Osteoarthritis	9 (6.3)	5 (7.8)	4 (5.1)		
Osteoporosis	6 (4.2)	5 (7.8)	1 (1.3)		
Hearing Impairment	17 (11.9)	8 (12.5)	9 (11.4)		
Renal Disorders	31 (21.7)	15 (23.4)	16 (20.3)		
Hematology Anemia	16 (11.2)	9 (14.1)	7 (8.9)		
Pulmonary Other	13 (9.1)	8 (12.5)	5 (6.3)		
<b>Psychiatric Conditions</b>	103 (72.0)	43 (67.2)	60 (75.9)	0.65 (0.3, 1.4)	0.65 (0.3, 1.4)
Anxiety Disorder	62 (43.4)	25 (39.1)	37 (46.8)		
Bipolar Disorder	52 (36.4)	28 (43.8)	24 (30.4)		
Attention Deficit Disorders	13 (8.1)	2 (3.1)	11 (13.9)		
Dementia	7 (4.9)	1 (1.6)	6 (7.6)		
Depression	40 (28.0)	11 (17.2)	29 (36.7)		
Obsessive Compulsive Disorder	18 (12.6)	10 (15.6)	8 (10.1)		
Schizophrenia	15 (10.5)	8 (12.5)	7 (8.9)		

Note. N = number; ID = intellectual disability; CI = confidence interval; OR = odds ratio. Significant group differences are delineated with bold text.

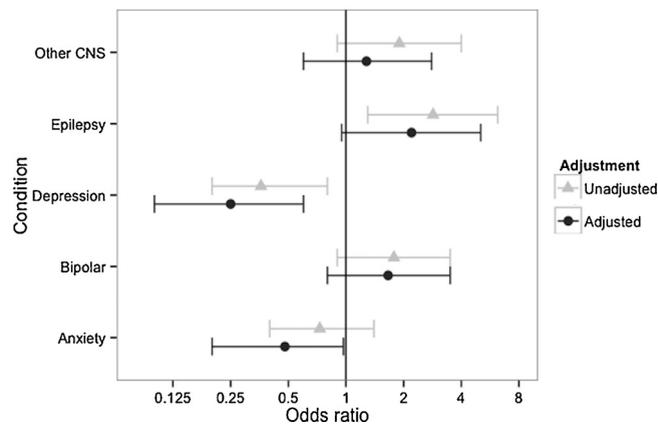
<sup>A</sup> Adjusted for Age ( $\geq 50$  or  $< 50$ ), race (white or other), and sex.

estimates.

In post-hoc analyses of neurological and psychiatric conditions (Fig. 1), we found elevated but not statistically significant increased odds of epilepsy among individuals on the autism spectrum with co-occurring ID compared to those without co-occurring ID (aOR: 2.20, 95% CI: 1.0, 5.1). Individuals on the autism spectrum with co-occurring ID had decreased odds of anxiety (aOR: 0.48, 95% CI: 0.2, 1.0) and depression (aOR: 0.25, 95% CI: 0.1, 0.6) compared to those without co-occurring ID. There were no group differences for bipolar disorder or other central nervous system disorders (non-headache, migraine, epilepsy/seizure disorder, or hereditary central nervous system disease).

#### 4. Discussion

A small number of previous studies have identified higher prevalence of health conditions in adults on the autism spectrum compared to the general population, and this disparity may increase with age (Bishop-Fitzpatrick et al., 2018; Nylander et al., 2018;



**Fig. 1.** Unadjusted and Adjusted Odds Ratios for Selected Health Conditions Comparing Intellectual Disability to No Intellectual Disability in Adults on the Autism Spectrum Aged 40+ Served by Wisconsin Medicaid, 2012–2015.

Starkstein et al., 2015). This study describes the physical and mental health of middle aged and older Wisconsin Medicaid beneficiaries with autism spectrum disorder diagnoses and characterizes differences between those with and without co-occurring ID. To our knowledge, no previous research has assessed the impact of ID on health for middle and older adults on the autism spectrum. Overall, we found high prevalence of most health conditions in our sample, including immune conditions, cardiovascular disease and its risk factors, sleep disorders, gastrointestinal disorders, neurologic conditions, and psychiatric disorders. Prevalence of these conditions in our sample of middle aged and older Wisconsin Medicaid beneficiaries on the autism spectrum was higher than those found in younger adult samples (Croen et al., 2015; Davignon et al., 2018) and similar to results found in smaller, primarily middle aged and older adult samples (Bishop-Fitzpatrick et al., 2018; Nylander et al., 2018). Not only was prevalence of health conditions high in these studies, they found a significantly greater number of health conditions for individuals on the autism spectrum compared to the general population. This suggests that the prevalence of physical and mental health problems is indeed heightened in people on the autism spectrum throughout adulthood but particularly in middle age and beyond.

Given that there are no known biological differences based on the etiology of ASD that cause increased morbidity in people on the autism spectrum as in other developmental disabilities populations (i.e. leukemia and Down Syndrome; Glenner & Wong, 1984; Minami et al., 2004), these health differences suggest that health inequalities could be prevented. However, it is vital to be able to identify specific mechanisms that underlie this disparity. Future research closely comparing this population to the general population as well as individuals with other developmental disabilities would allow us to directly evaluate specific effects of disparities. Further, evaluating temporal order of when conditions are diagnosed may highlight specific patterns and trajectories that should be intervened upon and altered.

Interestingly, although no differences between adults on the autism spectrum with and without co-occurring ID reached statistical significance in broader categories of physical and mental health problems, individuals with co-occurring ID had higher odds of epilepsy compared to those without ID. Conversely, odds of claims for depression and anxiety in middle aged and older adults on the autism spectrum were higher when an individual did not have co-occurring ID. Given the differences of presentation of autism spectrum disorder in autistic people with and without ID (Hoekstra, Happé, Baron-Cohen, & Ronald, 2009; Wiggins et al., 2017) and the previous literature on differences between the health and mortality of adults on the autism spectrum with and without ID (Cashin et al., 2016; Hirvikoski et al., 2016), we expected to find more differences by ID status. Our results reflecting a high degree of similarity in the prevalence of many physical and mental health problems might suggest that having an autism spectrum disorder diagnosis leads to health inequalities regardless of ID status. Given qualification criteria for Medicaid in Wisconsin, our sample of adults with claims for autism spectrum disorder and without co-occurring ID may represent a lower socioeconomic status group that may suffer a “double hit” of health inequalities from both being on the autism spectrum and low socioeconomic status (Bishop-Fitzpatrick & Kind, 2017). Future research should probe these differences between people on the autism spectrum with and without co-occurring ID in larger samples of middle aged and older adults on the autism spectrum from multiple socioeconomic strata that are representative of the full US population.

Although this unique sample represents the largest US study examining the health of middle aged and older adults on the autism spectrum and data are representative of the population of Wisconsin Medicaid beneficiaries, our results should be interpreted as preliminary considering pertinent limitations. First, our sample represents the current generation of middle aged and older adults on the autism spectrum who qualified for Medicaid and who had a recorded autism spectrum disorder diagnosis in their Medicaid claims data. This sample will likely not represent the current generation of adolescents and young adults for whom changes in diagnostic practices and the broader availability of early intervention programs may impact long-term outcomes. Further, given that all adults in our sample qualified for Medicaid and therefore likely met asset requirements for Medicaid our findings may overestimate rates of health conditions compared to the autism population as a whole. Second, diagnoses for autism spectrum disorder, ID, and other physical or mental health diagnoses were not validated by a standardized clinical examination. Like with all claims data, these data may be more accurate at capturing chronic medical conditions (e.g., cardiovascular disease) and less accurate at capturing less

serious medical problems (e.g., constipation). It is also possible that we underascertained chronic medical conditions because data were only from a three-year period. Similarly, because diagnoses for autism spectrum disorder and ID were not clinically validated, it is possible that these represent diagnostic inaccuracies or that some individuals who might qualify for an autism spectrum disorder or ID diagnosis after clinical assessment were not captured by our data. Finally, these data represent only Medicaid fee-for-service claims, and data were not linked to other systems of care, possibly underestimating the health conditions for which these Medicaid beneficiaries were treated.

Despite these limitations, this is the first US study to use claims data to characterize the health conditions of a unique and large sample of middle aged and older adults on the autism spectrum with and without ID. Our analyses identified high prevalence of most health conditions that confirm previous reports of heightened physical and psychiatric morbidity in midlife and old age in people on the autism spectrum (Bishop-Fitzpatrick et al., 2018; Nylander et al., 2018; Starkstein et al., 2015). Interestingly, and counter to our hypotheses, there were many similarities between those middle aged and older adults with and without co-occurring ID. This finding suggests that middle aged and older adults on the autism spectrum may experience greater morbidity in midlife and beyond regardless of ID status. Although our results are preliminary, they highlight the utility of Medicaid claims data in middle aged and older autistic populations and indicate the need for more research on health and mental health in midlife and beyond, particularly for conditions such as cardiovascular disease, neurological problems, and mood problems that may be particularly heightened in people on the autism spectrum compared to the general population.

This dataset will be useful in future research for several additional studies that will expand upon the findings presented in this manuscript. First, we plan to examine profiles of health conditions, and their inter-relationships. Second, we plan to examine service costs and treatment patterns in this sample. Finally, we plan to further explore disparities mechanisms by comparing middle aged and older adults on the autism spectrum to other at-risk populations in Wisconsin. Future research using different data sources should probe biological, behavioral, and environmental factors that could contribute to the emergence of health conditions in people on the autism spectrum with and without co-occurring ID at the end of life.

#### 4.1. Implications

Our findings suggest that people on the autism spectrum have a high prevalence of health conditions in midlife and old age, regardless of intellectual disability status. While more research is needed to confirm these findings and understand mechanisms, our results underscore the importance of prevention at both the individual and systems level. Unlike pediatricians, general practitioners who treat adults with disabilities may not receive specific training in developmental disabilities, including autism (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001; Phillips, Morrison, & Davis, 2004). Physicians treating adults on the autism spectrum in family medicine, internal medicine, or geriatric practice settings should be aware that people on the autism spectrum may have multiple chronic health conditions—including cardiovascular disease, neurological problems, and mood disorders—that should be assessed and treated in addition to behavior problems that commonly co-occur with autism. Autism spectrum disorder may be a particularly expensive condition to treat because of the health inequalities that people on the autism spectrum experience. Work needs to be done at the systems level to identify health disparities and design interventions that can be implemented by practitioners in community settings. Systems-level knowledge and interventions have the potential to reduce the costs and human consequences associated with the health burden of autism spectrum disorder.

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#### Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.rasd.2019.01.001>.

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