



HHS Public Access

Author manuscript

Autism Res. Author manuscript; available in PMC 2024 July 01.

Published in final edited form as:

Autism Res. 2023 July ; 16(7): 1437–1449. doi:10.1002/aur.2960.

Health Conditions in Autism: Defining the Trajectory from Adolescence to Early Adulthood

Beth A. Malow¹, Yinge Qian², Jennifer L. Ames², Stacey Alexeeff², Lisa A. Croen²

¹Sleep Disorders Division, Department of Neurology, Vanderbilt University Medical Center, Nashville, TN, USA

²Division of Research, Kaiser Permanente Northern California, Oakland, CA, USA

Abstract

Autistic adults, as compared to non-autistic adults, have increased rates of nearly all medical and psychiatric conditions. Many of these conditions begin in childhood, although few longitudinal studies have been conducted to examine prevalence rates of these conditions from adolescence into early adulthood. In this study, we analyze the longitudinal trajectory of health conditions in autistic youth, compared to age and sex-matched non-autistic youth, transitioning from adolescence into early adulthood in a large integrated health care delivery system. The percent and modeled prevalence of common medical and psychiatric conditions increased from age 14 to 22 years, with autistic youth having a higher prevalence of most conditions than non-autistic youth. The most prevalent conditions in autistic youth at all ages were obesity, neurological disorders, anxiety, and ADHD. The prevalence of obesity and dyslipidemia rose at a faster rate in autistic youth compared to non-autistic youth. By age 22, autistic females showed a higher prevalence of all medical and psychiatric conditions compared to autistic males. Our findings emphasize the importance of screening for medical and psychiatric conditions in autistic youth, coupled with health education targeted at this population, to mitigate the development of adverse health outcomes in autistic adults.

Lay Summary

Health conditions, including weight gain, anxiety, and attention-deficit hyperactivity disorder, are common in autistic adults, with many of these conditions starting in childhood. We found that many health conditions increase from teenage years into early adulthood. Our work emphasizes the importance of screening for these health conditions in autistic teenagers, and providing health education to these youth, to minimize poor health outcomes in autistic adults.

Keywords

Autism; electronic medical records; adolescents; adults; health conditions

Corresponding author: Beth A. Malow, MD, MS. 1161 21st Avenue South, Room A-0116, Nashville, Tennessee 37232-2551. Phone: 615-322-0283; beth.malow@vumc.org.

Conflict of Interest

No authors have conflicts of interest.

Introduction

Autism is a complex and common condition that affects 1 in 44 children (Maenner et al., 2021). It is estimated that in the United States more than 700,000 youth on the autism spectrum will enter adulthood over the next decade (Shattuck et al., 2019).

The transition to adulthood is a particularly vulnerable period for the healthcare of autistic individuals, for several reasons. First, autistic youth tend to have more co-occurring conditions, including psychiatric and neurological conditions such as anxiety and depression (Gotham et al., 2015; Uljarevic et al., 2019, McCauley et al., 2020), than non-autistic peers (Levy et al., 2010; Peacock et al., 2012). These conditions, which emerge throughout childhood and adolescence (Byrne et al., 2022) may be further exacerbated by the social and biological changes of puberty. For example, anxiety and depressive symptoms appear to increase with age, with steeper increases among female compared with male autistic youth (Gotham et al., 2015; Uljarevi et al. 2019). Obesity is also more common in autistic youth, with contributors that include genetic factors, medication use, restricted dietary habits, sedentary behavior, and sleep problems (Matheson et al., 2017; Healy et al., 2019; McCoy et al., 2020). Therefore, autistic youth typically have costly and evolving healthcare needs and healthcare spending throughout childhood and adolescence (Cidav et al., 2013). Second, the transition to adulthood is characterized by the loss of services as autistic individuals leave the school system and age out of pediatric care and developmental services—it has been characterized as a “services cliff” (Roux et al., 2015). Third, relatively few autistic adolescents receive adequate transition planning in healthcare settings (Leeb et al., 2020). Combined with a scarcity of adult providers who are comfortable and competent in the care of autistic adults (Zerbo et al., 2015), autistic youth are vulnerable to unmet healthcare needs and exacerbations of health conditions.

Autistic adults,¹ as compared to non-autistic adults, have increased rates of nearly all medical conditions, including immune, gastrointestinal, sleep disorders, seizures, obesity, dyslipidemia, hypertension, and diabetes; major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive-compulsive disorder, schizophrenia, and suicide attempts are also more prevalent in autistic adults (Croen et al., 2015). Many of these conditions seem to be more prevalent in autistic women compared with autistic men. A 25-year outcome study of autistic adults noted a median number of 11 medical conditions per person (Jones et al., 2016). There is also evidence of worsening mental health over the lifespan, with critical gaps in mental health services for autistic individuals (Maddox et al., 2021). Additional studies have emphasized the negative impact of poor mental health and sleep quality on quality of life in transition-age autistic youth and adults (Lawson et al., 2020), and their poor long-term overall outcomes (Steinhausen et al., 2016).

There are gaps in our understanding of how psychiatric and medical conditions change in prevalence as autistic youth transition to adulthood, with a limited number of studies addressing this issue (Byrne et al., 2022). Esbensen et al. (2009) examined psychotropic

¹To honor the preferences, autonomy, and rights of the autistic community, we have chosen to use identity-first language (e.g., autistic person) in this article when referring to autistic individuals (Bottema-Beutel, 2021).

medication use longitudinally, finding an increased proportion of adolescents and adults taking these medications over time. However, they did not examine specific medical or psychiatric conditions. How health conditions change as autistic individuals transition to adulthood has important clinical relevance, as clinicians can target specific health conditions with the goal of prevention or stabilization. Knowledge about health conditions in autistic individuals transitioning to adulthood is also timely, given the increased attention to the challenges of moving from pediatric to adult healthcare (Cheak-Zamora et al., 2015; Nicolaidis et al., 2015; Zablotsky et al., 2020; Ames et al., 2022).

Davignon and colleagues (2018) published a cross-sectional analysis of the prevalence of health conditions in transition-aged autistic youth, finding that health disparities between autistic and non-autistic youth transitioning to adulthood appear to increase with age and most conditions were also more common in females (Davignon et al., 2018). In this project, our aims were to build upon the work of Davignon et al. to analyze the longitudinal trajectory of health conditions in youth transitioning from adolescence into adulthood and characterize sex differences in these health trajectories during the transition years. Our hypotheses were that health conditions would increase in prevalence with age, and be more prevalent in autistic females than males. We selected psychiatric and medical conditions that affected overall health and quality of life, focusing on a few specific conditions in which sufficient sample sizes were available.

Methods

All study procedures were approved by the Kaiser Permanente Northern California (KPNC) Institutional Review Board.

Study population:

The study population was drawn from the membership of KPNC, a large integrated health care delivery system providing care to over 4.6 million residents in the greater San Francisco and Sacramento areas. The KPNC membership is generally representative of the broader California population, and somewhat more representative of median incomes than the highest and lowest incomes [Krieger et al., 1992; Gordon et al., 2016]. As described previously [Davignon et al., 2018], KPNC maintains comprehensive and longitudinal electronic medical records (EMR) of medical and psychiatric diagnoses, sociodemographic information, inpatient and outpatient visits and procedures, and dispensed medications linked across databases by each member's unique medical record number.

This study focused on a subsample of autistic and non-autistic youth who were included in an earlier study [Davignon et al., 2018]. All individuals ages 14 to 17 years as of January 1, 2014, who were members of KPNC for at least 9 months in each calendar year from 2013 to 2015 were eligible for inclusion. To be considered an autistic case, an individual needed to have a diagnosis of autism recorded in the EMR before 2014. A diagnosis of autism consisted of having at least one International Classification of Diseases, Ninth Revision [ICD-9] code for autism from a KPNC autism evaluation center (in which a comprehensive clinical assessment was administered, including the Autism Diagnostic Observation Schedule), or at least 2 ICD-9 codes for autism from different clinicians (e.g.,

developmental pediatricians, mental health providers) at different times. The total number of individuals meeting these criteria (autistic cases) in the parent study was 1882. Supplemental Table 1 contains the autism codes that were used.

Non-autistic youth were sampled at a 5:1 ratio to autistic cases and matched on sex and age to produce a non-autistic comparison group. In the present study, individuals in both the autistic and non-autistic groups were followed until December 31, 2019, and any individuals with less than 9 months of KPNC membership in each calendar year between 2016 and 2019 were excluded.

Health Outcomes:

Medical and psychiatric conditions were identified from the KPNC EMR using ICD-9 with corresponding ICD-10 codes. These were selected based on common conditions previously reported in autistic adolescents and adults (Davignon et al., 2018) and included psychiatric and medical conditions that affected overall health and quality of life. Our goal was not to provide an exhaustive analysis of each medical and psychiatric condition but to instead focus on a few specific conditions in which sufficient sample sizes were available. The conditions that we selected were obesity, anxiety, attention-deficit/hyperactivity disorder (ADHD), depression, cardiovascular disorders, neurological disorders, and sleep disorders. Cardiovascular diseases were further categorized into dyslipidemia and other cardiovascular disorders. Epilepsy/seizures were included in neurological disorders and were also analyzed separately. Sleep disorders were separated into dyssomnia (which included insomnia and hypersomnia) and organic sleep apnea (which included obstructive sleep apnea). ICD-9 codes with corresponding ICD-10 codes were used to define these specific conditions, guided by phenotype-wide association study methodology (Denny et al., 2010) and previously validated algorithms (Supplemental Table 1). Children with pre-existing ADHD were excluded from the non-autistic group, as they formed a separate control group as part of the larger parent study design (Davignon et al., 2018).

The presence of medical and psychiatric conditions was determined for each year of age between 2014 and 2019, when individuals were between 14 and 22 years of age (i.e., “transition age”). Individuals who were 14 years old at the beginning of the study period were followed through age 19 years, and those who were 17 years old at the beginning of the study period were followed to age 22 years.

Once a patient was given a specific diagnosis, the patient was considered to have this diagnosis in subsequent ages. For example, a patient diagnosed with anxiety at age 14 was considered to retain that diagnosis until the end of the follow-up period, or through age 19. Obesity was defined by the latest BMI recorded at each age; if a BMI was not recorded at a given age, the most recent BMI from an earlier age was used. For adults (age 18 or older), obesity was defined as a BMI of 30 or greater. For children ages 14–17 years, obesity was defined using BMI-for-age cutoffs (Gallagher et al., 2020).

Statistical Analysis

For each condition, we modeled the annual prevalences by age using the modified Poisson regression model with robust error variance, accounting for the correlated longitudinal data

structure (Zou et al., 2013). The modified Poisson regression model was developed for binary outcomes to model prevalences rather than odds (Zou et al., 2004). The approach has been extended to the setting of correlated binary outcomes arising from longitudinal studies in which each subject is followed over time by applying an extension of the sandwich variance estimator to account for correlated data (Zou & Donner, 2013). For each condition, we first fit an age-adjusted longitudinal model which included separate intercepts for the autistic and non-autistic groups and separate slopes for age for the autistic and non-autistic groups and accounted for the correlated longitudinal data structure. We report the estimated prevalence by age and corresponding 95% confidence intervals (CIs) for the autistic and non-autistic groups using this age-adjusted model. We then estimated the prevalence ratio (PR) comparing the prevalence in the autistic group to the prevalence in the non-autistic group at each age. We report the PR and corresponding 95% CI for the age-adjusted longitudinal model and for a fully adjusted longitudinal model that also includes sex (male, female), and race/ethnicity (White-Non Hispanic, Hispanic, Black, Asian, and Other). We also estimated the prevalences stratified by sex.

Results

The demographic characteristics of our study population of 1418 autistic youth and 6029 non-autistic youth are shown in Table 1. Autistic youth and non-autistic youth had similar distributions for age and sex, which were matching factors. Due to matching on sex and the high prevalence of autism among males compared to females, the proportion of males was much higher than females in both the autistic youth and non-autistic youth groups. Autistic youth were more likely than non-autistic youth to be White and non-Hispanic, and more likely to have government insurance.

The percent of most medical and psychiatric conditions was higher in autistic youth at all ages, and the percent of all conditions increased with age in both autistic and non-autistic youth (Table 2). In autistic youth, the most frequent conditions at age 14 were obesity (13.84%), ADHD (8.09%), neurological disorders (7.31%), and anxiety (6.79%). These four conditions remained the most frequent among autistic youth between the ages of 14 to 22, rising to 33.53% for obesity, 24.86% for ADHD, 32.95% for neurological disorders, and 26.3% for anxiety by age 22.

The modeled prevalences from age 14 to 22 are shown in Figures 1 and 2 (corresponding numerical results in Supplemental Table 2). For the medical conditions displayed in Figure 1, we found that obesity, neurological disease, epilepsy/seizures, dyssomnia, and sleep apnea all showed higher prevalence among autistic youth compared to non-autistic youth at all ages, and these differences were statistically significant. In addition, the rate of rise in prevalence for obesity across adolescence was faster in autistic youth than in non-autistic youth; as illustrated in Figure 1a, the peach band for autistic youth and the blue band for non-autistic youth become more divergent at older ages. The modeled prevalence of dyslipidemia was similar at younger ages and significantly higher in the autistic group only at older ages. The prevalence of dyslipidemia across adolescence rose at a faster rate among autistic youth than among non-autistic youth, as shown in Figure 1b. By contrast, the

modeled prevalence of cardiovascular disease was similar for autistic and non-autistic youth at all ages.

The prevalence ratio (PR) of these conditions among autistic relative to non-autistic youth is displayed in Supplemental Figures 1 and 2. The PRs for obesity and dyslipidemia increased between the ages of 14–22 years, conveying that the rate of rise in prevalence of these conditions in autistic youth was faster than in non-autistic youth. For all other conditions, although the prevalences rose in both groups, the PRs demonstrated a downward slope across the ages of 14–22. This indicates that the relative difference in prevalence between the groups was decreasing with age.

Figure 2 displays psychiatric conditions. We found that anxiety, ADHD, and depression all showed significant differences between autistic and non-autistic youth at all ages. Similar to our findings above, the autistic youth had higher rates of these conditions than non-autistic youth at all ages, but the relative difference in prevalence decreased with age (Supplemental Figure 2).

Models stratified by sex.

Figures 3 and 4 show prevalence of conditions over the transition years among autistic and non-autistic youth stratified by sex. Among autistic youth, obesity and ADHD were more prevalent among males than females at age 14, but by age 22, all conditions were more prevalent among females. At all ages, autistic youth exhibited a higher prevalence of obesity, epilepsy/seizures, sleep apnea, dyssomnia, anxiety, and depression, among both males and females, while autistic youth exhibited a higher prevalence of neurological disease only among males. The prevalence of dyslipidemia was similar between autistic and non-autistic youth at all ages among females, but only at younger ages among males, whereas the prevalence of other cardiovascular diseases was similar between autistic and non-autistic youth at all ages for both males and females.

Discussion

In this large population of insured, transition-age autistic youth, the prevalence of common medical and psychiatric conditions increased from age 14 to 22 years. The most prevalent conditions at all ages were obesity, neurological disorders, anxiety, and ADHD. Compared to non-autistic youth, autistic youth had a higher prevalence of most conditions at all ages; cardiovascular disease was a notable exception. Dyslipidemia was also similar in the two groups at younger ages but more common in the autistic group than the non-autistic group at older ages. The prevalence of obesity and dyslipidemia rose at a faster rate in autistic youth compared to non-autistic youth. In sex-stratified models, obesity and ADHD were more prevalent among autistic males than autistic females at age 14, but by age 22, all conditions were more prevalent among autistic females than autistic males.

Both autistic males and females exhibited a higher prevalence at every age of obesity, epilepsy/seizures, sleep apnea, dyssomnia, anxiety, and depression, compared to non-autistic males and females, respectively, whereas only autistic males exhibited a higher prevalence of neurological disease than their non-autistic counterparts at all ages.

Our study is unique in that we examined medical and psychiatric conditions longitudinally in the same individuals as they grew older. Previous work has largely been cross-sectional. For example, two cross-sectional studies at Kaiser Permanente found elevated rates of all the medical and psychiatric conditions included in our analysis among both autistic adults (aged 18 years or greater) and transition-aged youth (ages 14–25) compared to age and sex matched non-autistic peers (Croen et al., 2015; Davignon et al., 2018). In both studies, autistic females had a higher prevalence of all conditions compared with autistic males (Croen et al., 2015; Davignon et al., 2018). The prevalence of these conditions appeared to increase across the age groups (e.g., 14–17 years, 18–21 years, and 22–25 years) in the transition-aged sample (Davignon et al., 2018). In a smaller longitudinal sample of 196 autistic youth and 57 additional individuals with other neurodevelopmental conditions (ages 10–30 years), obesity and seizures increased with age (Byrne et al., 2022).

While obesity and dyslipidemia were more prevalent with increasing age in both autistic and non-autistic youth, these conditions increased more rapidly in autistic youth, particularly females. Given that childhood body mass index, cholesterol, and triglycerides are associated with cardiovascular events in adults (Jacobs et al., 2022), our findings identify a critical opportunity for intervention in adolescence to change the trajectory of these health conditions, such as routine screening for these conditions in pediatric primary care and providing health education to autistic youth and their caregivers regarding the management of these conditions. The causes of obesity and dyslipidemia are multifactorial and include several factors that can be modified (Safaei et al., 2021) such as diet (e.g., limiting portion size, increased consumption of fruits and vegetables, avoidance of soft drinks, managing food selectivity) and physical activity (e.g., inclusion in sports, reducing social isolation). Obstructive sleep apnea contributes to obesity and dyslipidemia (Gaines et al., 2018), and insufficient sleep also promotes obesity through changes in hormones that affect satiety, such as leptin and ghrelin (Primack et al., 2021). The American Heart Association's Life's Essential 8 elements for cardiovascular health now include healthy sleep along with diet and physical activity (American Heart Association, 2022). Risk factors for cardiovascular disease related to lifestyle are common among autistic people. For example, a survey of 1183 autistic adults documented less healthy exercise, diet, and sleep patterns compared to non-autistic adults, with autistic women more affected than men (Weir, 2021). Both autistic men and women engaged in significantly less exercise, ate fewer fruits and vegetables and more high sugar beverages, and had difficulty falling asleep, staying asleep, or shorter sleep duration. In a separate report focused on adults with intellectual disabilities, being female, engaging in less moderate physical activity, and drinking greater amounts of soda were associated with higher rates of obesity (Hsieh et al., 2014).

Medications that are prevalent in autistic youth can also contribute to weight gain and dyslipidemia. (Hsieh et al., 2014). In a large cross-sectional study comparing autistic youth at different ages, psychotropic medication use, including antidepressants and antipsychotics (which have been associated with weight gain), increased with age from approximately 42% in 14–17 year-olds to 51% in 22–25 year-olds (Ames et al., 2021). The use of neuropsychiatric medications (e.g., antipsychotic, antidepressant, anticonvulsant, antihypertensive, stimulant, and anxiolytic) increased with age in a longitudinal sample of autistic youth and individuals with other neurodevelopmental conditions (Byrne et al.,

2022). In that sample, antipsychotic medication use was associated with a steeper increase in BMI over time (Byrne et al., 2022).

Unhealthy diet, exercise and sleep patterns, along with the use of psychotropic medications, can be investigated in larger samples, as understanding the contributors to obesity and dyslipidemia are key to promoting health as autistic youth transition to adulthood. Furthermore, as the prevalence of obesity at age 14 in autistic youth was sizable (~14%), there is also a need to understand risk factors operating earlier in childhood in order to guide strategies for preventing the onset of obesity.

Epilepsy/seizures showed a 3 times higher prevalence from age 14 to age 22 among autistic youth. This is in line with a recent meta-analysis which observed that the prevalence of epilepsy in autistic individuals grows from approximately 7% to 19% between childhood and adulthood (Liu et al., 2022).

Psychiatric conditions were more prevalent with age in both autistic and non-autistic groups, and represent an opportunity for intervention, especially given the need for increased mental health support and the negative impact of poor mental health on quality of life in autistic youth and adults (Maddox et al., 2021; Steinhausen et al., 2016). Non-pharmacologic interventions, including cognitive behavioral therapy and mindfulness-based treatments (White, 2018; Reyes, 2019), are particularly promising in that they do not carry the risk of adverse medical effects of psychotropic medications.

Of note, female autistic youth, as compared to male autistic youth, had a higher prevalence of all medical and psychiatric conditions by age 22. Two conditions, obesity and ADHD, were more prevalent among autistic males at age 14 but then became more prevalent in females. These findings emphasize the importance of screening autistic females for medical and psychiatric conditions, especially obesity and ADHD which can be potentially mitigated during the transition to adulthood by attention to diet, exercise and sleep (in the case of obesity) and sleep (in the case of ADHD) (Weiss et al., 2015).

The prevalence of ADHD and anxiety at age 14 in autistic youth (8.09% and 6.79%, respectively) was lower than has been reported in the literature. For example, in autistic adolescents ages 12–17 years, the prevalence of anxiety was 40% and the prevalence of ADHD was 26% based on the parent-reported standardized Child Behavior Checklist (Vasa et al., 2013). In a separate study derived from the parent-reported standardized National Survey of Children's Health, in 12–17 year old autistic youth, the prevalence of anxiety was 54.3% and ADD/ADHD was 59.7% (Kerns et al., 2020). The discrepancies in these prevalences most likely reflect differences in the rigor and methods of assessment between survey data and clinical diagnoses. Healthcare clinicians may report an autism diagnosis and subsume ADHD and anxiety symptoms under that diagnosis. There may also need to be a threshold level of severity present before a clinician assigns an ICD code to a symptom. We encountered a similar discrepancy in clinician (30%) vs. parent-reported (71%) sleep problems in children (Malow et al., 2016). Given this discrepancy, it may be appropriate that clinicians screen autistic youth more thoroughly for these conditions.

Our study has several strengths. First, the use of a longitudinal design in our analysis clearly demonstrates the change in prevalence during the transition ages (14 to 22 years). Second, our study is the largest to date examining transition-age autistic youth longitudinally (more than 1400 autistic youth). Third, 17% received government-based health insurance, which makes our study more generalizable to autistic youth. Fourth, our study sample remained within the Kaiser system throughout the analysis, helping ensure that all health care encounters during the study period should have been captured. Our study also had several limitations. First, all of our sample was insured, and it is likely that health outcomes in autistic youth may be worse in populations without access to healthcare. Disparities based on socioeconomic status along with race and ethnicity have been reported for autistic youth transitioning to adulthood, with low-income and racial/ethnic minority youth receiving fewer health care transition services than autistic Whites or higher-income peers (Eilenberg et al., 2019). Second, we did not ascertain intellectual disability, which was associated with lower BMI in one study, which was attributed to supportive living environments being protective against excess weight (Thom et al., 2022). Diagnosis codes for intellectual disability are not consistently used by healthcare professionals which is why we chose to omit this variable from our work. This limited our ability to examine changes in prevalence of health conditions by cognitive status. Third, our non-autistic sample excluded youth with pre-existing ADHD; therefore, the prevalence of ADHD in that group is an underestimate of the actual ADHD prevalence among non-autistic youth. Fourth, we limited our examination of co-occurring medical and psychiatric conditions to common conditions previously reported in autistic adolescents and adults (Davignon et al., 2018). Finally, we assumed that once an individual received a diagnosis code, that condition continued throughout the rest of follow-up. One of the challenges in analyzing diagnosis codes over time is that individuals may not have healthcare encounters each year, and therefore may not have a specific diagnoses code noted, even though the condition persists. We performed an analysis of the stability of these conditions over time and found that conditions were generally stable. We assessed whether each condition was documented in patient charts during all (100%), most (50%–99%), or some (<50%) of the subsequent years. For study participants with dyslipidemia, we found that 41% had diagnoses in all years, 7% had diagnoses in most years and 52% had diagnoses in some years. For study participants with anxiety, we found that 30% had diagnoses in all years, 35% had diagnoses in most years, and 35% had diagnoses in some years. For study participants with depression, we found that 30% had diagnoses in all years, 32% had diagnoses in most years, and 38% had diagnoses in some years. Of note, our estimates are dependent on individuals having a healthcare encounter each year, and while everyone had membership in the Kaiser system each year, they may not have had healthcare encounters each year. Therefore, these are minimum estimates.

In future work, it will be important to study prevalence trends of less common conditions, and combinations of conditions, to more fully characterize how health status changes over time. It will also be important to examine prevalence trends in later adult years, when conditions such as cardiovascular diseases would be expected to emerge. While we found that cardiovascular diseases showed similar trajectories in autistic and non-autistic youth through age 22, whether these trajectories continue into older adulthood is currently not known, given the increased prevalence of obesity, dyslipidemia, and sleep apnea in autistic

youth. Other future directions for this work include understanding factors that affect weight gain and dyslipidemia in autistic youth, such as antipsychotic medication use and medical conditions such as sleep disorders (Kang et al., 2021), and how these factors may affect the emergence of cardiovascular disease. We will also examine health conditions longitudinally through the lens of health disparities related to socioeconomic status, race, and ethnicity.

In conclusion, a deeper understanding of when medical and psychiatric conditions emerge in autistic youth is an important step toward increased screening for these conditions, and the development of preventive strategies. These include implementation and dissemination strategies targeted at health care professionals interacting with autistic youth, along with direct education of autistic youth and their families regarding the importance of interventions that affect the trajectory of these health conditions (e.g., the effects of diet, exercise, and sleep on obesity, dyslipidemia, and cardiovascular disease), starting at early ages.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

This work was directly supported by a NIH grant to Dr. Malow (K18 MH122755).

Data Availability Statement

Aggregate deidentified data presented in this project will be shared upon request and in accordance with data use agreements.

References

- American Heart Association Adds Sleep to Cardiovascular Heart Checklist. <https://newsroom.heart.org/news/american-heart-association-adds-sleep-to-cardiovascular-health-checklist>. Accessed November 25, 2022.
- Ames JL, Mahajan A, Davignon MN, Massolo ML, Croen LA. (2022). Opportunities for Inclusion and Engagement in the Transition of Autistic Youth from Pediatric to Adult Healthcare: A Qualitative Study. *J Autism Dev Disord*. Mar 9. doi: 10.1007/s10803-022-05476-4. Epub ahead of print.
- Ames JL, Mahajan A, Davignon MN, Massolo ML, Croen LA. (2022). Opportunities for Inclusion and Engagement in the Transition of Autistic Youth from Pediatric to Adult Healthcare: A Qualitative Study. *J Autism Dev Disord*. doi: 10.1007/s10803-022-05476-4
- Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, and Hand BN. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3(1): 18–29. doi.10.1089/aut.2020.0014 [PubMed: 36601265]
- Byrne K, Sterrett K, Elias R, Bal VH, McCauley JB, Lord C. (2022). Trajectories of seizures, medication use, and obesity status into early adulthood in autistic individuals and those with other neurodevelopmental conditions. *Autism in Adulthood*, 4(2). doi.10.1089/aut.2020.0080
- Cheak-Zamora NC, Teti M, First J. (2015). ‘Transitions are scary for our kids, and they’re scary for us’: Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 548–560. [PubMed: 25753589]

- Cidav Z, Lawer L, Marcus SC, Mandell DS. (2013). Age-related variation in health service use and associated expenditures among children with autism. *J Autism Dev Disord.*, 43(4):924–31. doi:10.1007/s10803-012-1637-2 [PubMed: 22941343]
- Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, & Kripke C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814–823. doi:10.1177/1362361315577517 [PubMed: 25911091]
- Davignon MN, Qian Y, Massolo M, Croen LA. (2018). Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD. *Pediatrics*, 141(Suppl 4), S335–S345. doi:10.1542/peds.2016-4300K [PubMed: 29610415]
- Denny JC, Ritchie MD, Basford MA, Pulley JM, Bastarache L, Brown-Gentry K, Wang D, Masys DR, Roden DM, Crawford DC. (2010). PheWAS: demonstrating the feasibility of a phenome-wide scan to discover gene-disease associations. *Bioinformatics*, 26(9):1205–10. doi: 10.1093/bioinformatics/btq126. [PubMed: 20335276]
- Eilenberg JS, Paff M, Harrison AJ, & Long KA. (2019). Disparities Based on Race, Ethnicity, and Socioeconomic Status Over the Transition to Adulthood Among Adolescents and Young Adults on the Autism Spectrum: A Systematic Review. *Current Psychiatry Reports*, 21(5), 32. doi:10.1007/s11920-019-1016-1 [PubMed: 30903399]
- Esbensen AJ, Greenberg JS, Seltzer MM, Aman MG. (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *J Autism Dev Disord*, 39(9):1339–49. doi: 10.1007/s10803-009-0750-3. [PubMed: 19434487]
- Gaines J, Vgontzas AN, Fernandez-Mendoza J, Bixler EO. (2018). Obstructive sleep apnea and the metabolic syndrome: The road to clinically-meaningful phenotyping, improved prognosis, and personalized treatment. *Sleep Med Rev.*, 42:211–219. doi: 10.1016/j.smrv.2018.08.009. [PubMed: 30279095]
- Gallagher D. A Guide to Methods for Assessing Childhood Obesity. Washington (DC): National Collaborative on Childhood Obesity Research. June 2020. <https://www.nccor.org/tools-assessingobesity>
- Gordon N, Lin T. (2016). The Kaiser Permanente Northern California Adult Member Health Survey. *Perm J*. 20(4):15–225. doi:10.7812/TPP/15-225
- Gotham K, Brunwasser SM, Lord C. (2015). Depressive and anxiety symptom trajectories from school-age through young adulthood in samples with autism spectrum disorder and developmental delay. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(5), 369–376.e3. doi: 10.1016/j.jaac.2015.02.005. [PubMed: 25901773]
- Healy S, Aigner CJ, Haegele JA. (2019). Prevalence of overweight and obesity among US youth with autism spectrum disorder. *Autism*. 23(4):1046–1050. doi:10.1177/1362361318791817 [PubMed: 30101597]
- Hsieh K, Rimmer JH, Heller T. (2014). Obesity and associated factors in adults with intellectual disability. *Journal of intellectual disability research. JIDR.*, 58(9):851–863. doi:10.1111/jir.12100 [PubMed: 24256455]
- Jacobs DR Jr, Woo JG, Sinaiko AR, Daniels SR, Ikonen J, Juonala M, Kartiosuo N, Lehtimäki T, Magnussen CG, Viikari JSA, Zhang N, Bazzano LA, Burns TL, Prineas RJ, Steinberger J, Urbina EM, Venn AJ, Raitakari OT, Dwyer T. (2022). Childhood Cardiovascular Risk Factors and Adult Cardiovascular Events. *N Engl J Med.*, 386(20):1877–1888. doi: 10.1056/NEJMoa2109191. [PubMed: 35373933]
- Jones KB, Cottle K, Bakian A, Farley M, Bilder D, Coon H, McMahon WM. (2016). A description of medical conditions in adults with autism spectrum disorder: A follow-up of the 1980s Utah/UCLA Autism Epidemiologic Study. *Autism*, 20(5), 551–561. doi:10.1177/1362361315594798 [PubMed: 26162628]
- Kang EK, Jang MJ, Kim KD, Ahn YM. (2021). The association of obstructive sleep apnea with dyslipidemia in Korean children and adolescents: a single-center, cross-sectional study. *J Clin Sleep Med.*, 17(8):1599–1605. DOI: 10.5664/jcsm.9258 [PubMed: 33739258]
- Kerns CM, Rast JE, Shattuck PT. (2020). Prevalence and correlates of caregiver-reported mental health conditions in youth with autism spectrum disorder in the United States. *Journal Clinical Psychiatry*. 2020;82(1). doi:10.4088/JCP.20m13242

- Krieger N. Overcoming the absence of socioeconomic data in medical records: validation and application of a census-based methodology. (1992). *Am J Public Health*. 82(5):703–10. doi:10.2105/ajph.82.5.703 [PubMed: 1566949]
- Lawson LP, Richdale AL, Haschek A, Flower RL, Vartuli J, Arnold SR, Trollor JN. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism*, 24(4):954–967. doi: 10.1177/1362361320908107. [PubMed: 32169010]
- Leeb RT, Danielson ML, Bitsko RH, Cree RA, Godfred-Cato S, Hughes MM, Powell P, Firchow B, Hart LC, Lebrun-Harris LA. (2020). Support for Transition from Adolescent to Adult Health Care Among Adolescents With and Without Mental, Behavioral, and Developmental Disorders - United States, 2016–2017. *MMWR Morb Mortal Wkly Rep.*, 69(34):1156–1160. doi: 10.15585/mmwr.mm6934a2. [PubMed: 32853187]
- Levy SE, Giarelli E, Lee LC, Schieve LA, Kirby RS, Cunniff C, Nicholas J, Reaven J, Rice CE. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *J Dev Behav Pediatr.*, 31(4):267–75. doi: 10.1097/DBP.0b013e3181d5d03b. [PubMed: 20431403]
- Liu X, Sun X, Sun C, Zou M, Chen Y, Huang J, Wu L, Chen WX. (2022). Prevalence of epilepsy in autism spectrum disorders: A systematic review and meta-analysis. *Autism*, 26(1), 33–50. doi:10.1177/13623613211045029 [PubMed: 34510916]
- Maddox BB, Dickson KS, Stadnick NA, Mandell DS, Brookman-Frazee L. (2021). Mental Health Services for Autistic Individuals Across the Lifespan: Recent Advances and Current Gaps. *Current Psychiatry Reports*, 23(10), 66. doi:10.1007/s11920-021-01278-0 [PubMed: 34402984]
- Maenner MJ, Shaw KA, Bakian AV, Bilder DA, Durkin MS, Esler A, Furnier SM, Hallas L, Hall-Lande J, Hudson A, Hughes MM, Patrick M, Pierce K, Poynter JN, Salinas A, Shenouda J, Vehorn A, Warren Z, Constantino JN, DiRienzo M, ... Cogswell ME (2021). Prevalence and characteristics of autism spectrum disorder among children aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. *Morbidity and mortality weekly report. Surveillance summaries* 70(11), 1–16. doi:10.15585/mmwr.ss7011a1
- Malow BA, Katz T, Reynolds AM, Shui A, Carno M, Connolly HV, Coury D, Bennett AE. (2017). Sleep difficulties and medications in children with autism spectrum disorders: a registry study. *Pediatrics*. 2016; 137(Supplement_2):S98–104. DOI: 10.1542/peds.2015-2851H
- Matheson BE, Douglas JM. (2017). Overweight and Obesity in Children with Autism Spectrum Disorder (ASD): a Critical Review Investigating the Etiology, Development, and Maintenance of this Relationship. *Review journal of autism and developmental disorders*, 4(2):142–156. doi:10.1007/s40489-017-0103-7
- McCauley J, Elias R, & Lord C. (2020). Trajectories of co-occurring psychopathology symptoms in autism from late childhood to adulthood. *Development and Psychopathology*, 32(4), 1287–1302. doi:10.1017/S0954579420000826 [PubMed: 32677592]
- McCoy SM, Morgan K. (2020). Obesity, physical activity, and sedentary behaviors in adolescents with autism spectrum disorder compared with typically developing peers. *Autism.*, 24(2):387–399. doi:10.1177/1362361319861579 [PubMed: 31364386]
- Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AE, Kapp SK, Weiner M, Boisclair WC. (2015). “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism*, 19(7), 824–831. doi:10.1177/1362361315576221 [PubMed: 25882392]
- Peacock G, Amendah D, Ouyang L, Grosse SD. (2012). Autism spectrum disorders and health care expenditures: the effects of co-occurring conditions. *J Dev Behav Pediatr*. 33(1):2–8. doi: 10.1097/DBP.0b013e31823969de. [PubMed: 22157409]
- Primack C. Obesity and Sleep. (2021). *Nurs Clin North Am.*, 56(4):565–572. doi: 10.1016/j.cnur.2021.07.012. [PubMed: 34749895]
- Reyes NM, Pickard K, Reaven J. (2019). Emotion regulation: A treatment target for autism spectrum disorder. *Bull Menninger Clin*. 83(3):205–234. doi: 10.1521/bumc.2019.83.3.205. [PubMed: 31502870]
- Roux AM, Shattuck PT, Rast JE, Rava JA, Anderson KA. *National Autism Indicators Report: Transition into Young Adulthood*. 2015.

- Safaei M, Sundararajan EA, Driss M, Boulila W, Shapi'i A. (2021). A systematic literature review on obesity: Understanding the causes & consequences of obesity and reviewing various machine learning approaches used to predict obesity. *Computers in Biology and Medicine*, 136. doi:10.1016/j.combiomed.2021.104754
- Shattuck P. Drexel University, 2019. Growing numbers of young adults on the autism spectrum. <https://drexel.edu/autismoutcomes/blog/overview/2019/June/Growing-numbers-of-young-adults-on-the-autism-spectrum/>. Accessed November 26, 2022.
- Steinhausen HC, Mohr Jensen C, Lauritsen MB. (2016). A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatrica Scandinavica*, 133(6), 445–452. doi:10.1111/acps.12559 [PubMed: 26763353]
- Thom RP, Palumbo ML, Keary CJ, Hooker JM, McDougale CJ, Ravichandran CT. (2022). Prevalence and factors associated with overweight, obesity, and hypertension in a large clinical sample of adults with autism spectrum disorder. *Sci Rep.*, 12(1):9737. doi:10.1038/s41598-022-13365-0 [PubMed: 35697905]
- Uljarević M, Hedley D, Rose-Foley K, Magiati I, Cai RY, Dissanayake C, Richdale A, Trollor J. Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder. (2020). *J Autism Dev Disord.*, 50(9):3155–3165. doi: 10.1007/s10803-019-04084-z. [PubMed: 31190198]
- Vasa RA, Kalb L, Mazurek M, Kanne S, Freedman B, Keefer A, Clemons T, Murray D. (2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*. 1;7(11):1358–69. 10.1016/j.rasd.2013.07.005
- Weir E, Allison C, Ong KK, Baron-Cohen S. (2021). An investigation of the diet, exercise, sleep, BMI, and health outcomes of autistic adults. *Mol Autism*, 12(1),31. doi: 10.1186/s13229-021-00441-x. [PubMed: 33964967]
- Weiss MD, Craig SG, Davies G. b L, Stein M. (2015). New research on the complex interaction of Sleep and ADHD. *Curr Sleep Medicine Rep* 1, 114–121. 10.1007/s40675-015-0018-8
- White SW, Simmons GL, Gotham KO, Conner CM, Smith IC, Beck KB, Mazefsky CA. (2018). Psychosocial Treatments Targeting Anxiety and Depression in Adolescents and Adults on the Autism Spectrum: Review of the Latest Research and Recommended Future Directions. *Curr Psychiatry Rep.*, 28;20(10):82. doi: 10.1007/s11920-018-0949-0. [PubMed: 30155584]
- Zablotsky B, Rast J, Bramlett MD, Shattuck PT. (2020). Health care transition planning among youth with ASD and other mental, behavioral, and developmental disorders. *Maternal and Child Health Journal*, 24(6), 796–804. [PubMed: 31897930]
- Zerbo O, Massolo ML, Qian Y, Croen LA. (2015). A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System. *J Autism Dev Disord.*, 45(12):4002–14. doi:10.1007/s10803-015-2579-2 [PubMed: 26334872]
- Zou G. (2004). A modified poisson regression approach to prospective studies with binary data. *Am J Epidemiol*, 159(7):702–6. [PubMed: 15033648]
- Zou GY, Donner A. (2013). Extension of the modified Poisson regression model to prospective studies with correlated binary data. *Stat Methods Med Res*, 22(6):661–70. [PubMed: 22072596]

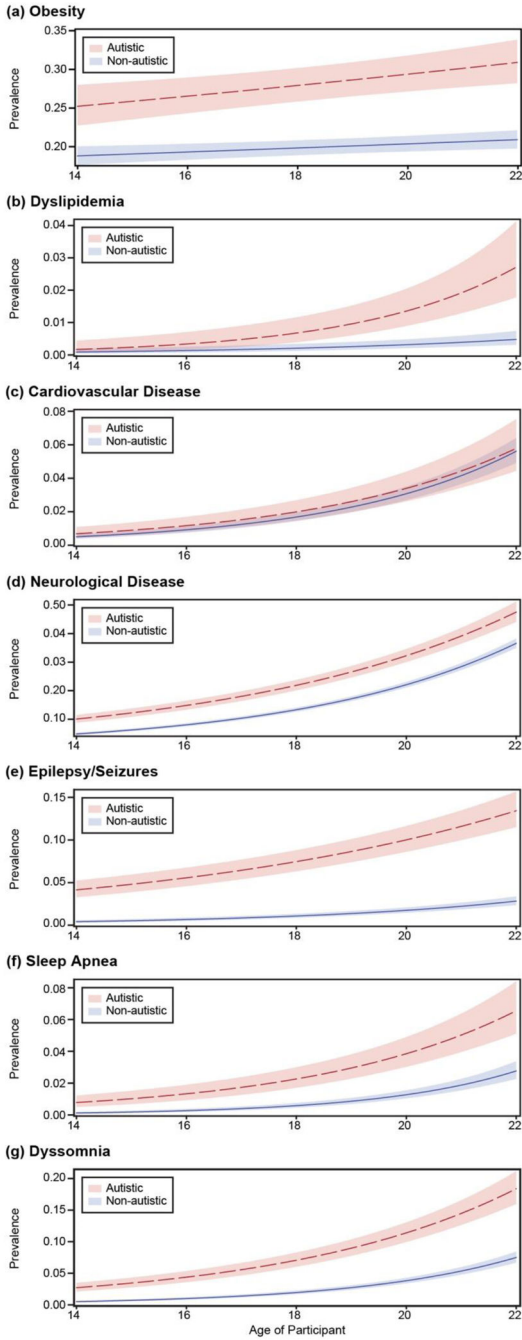
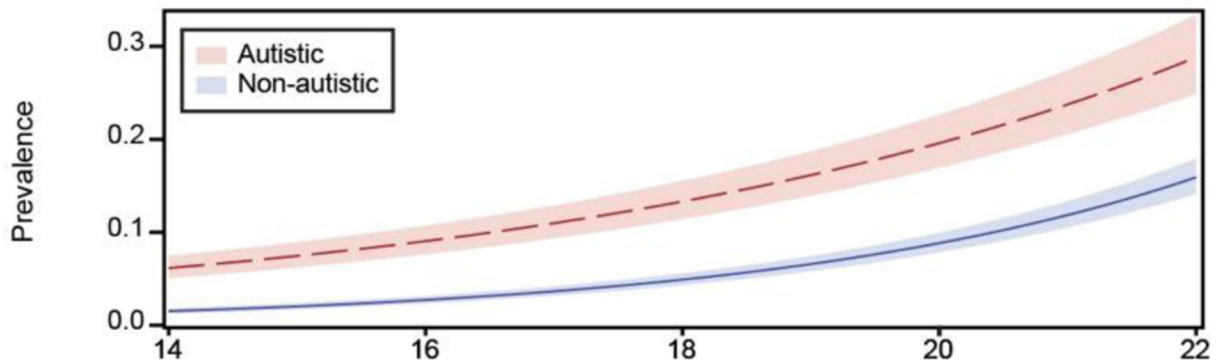
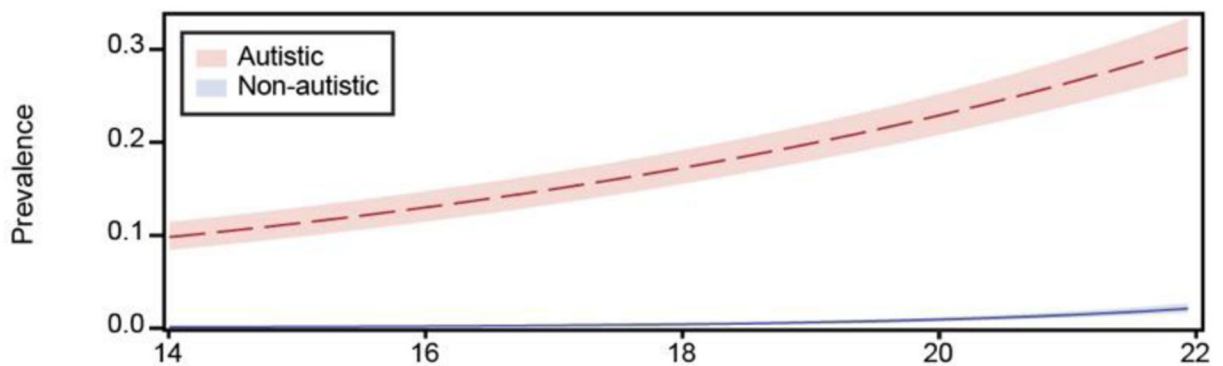
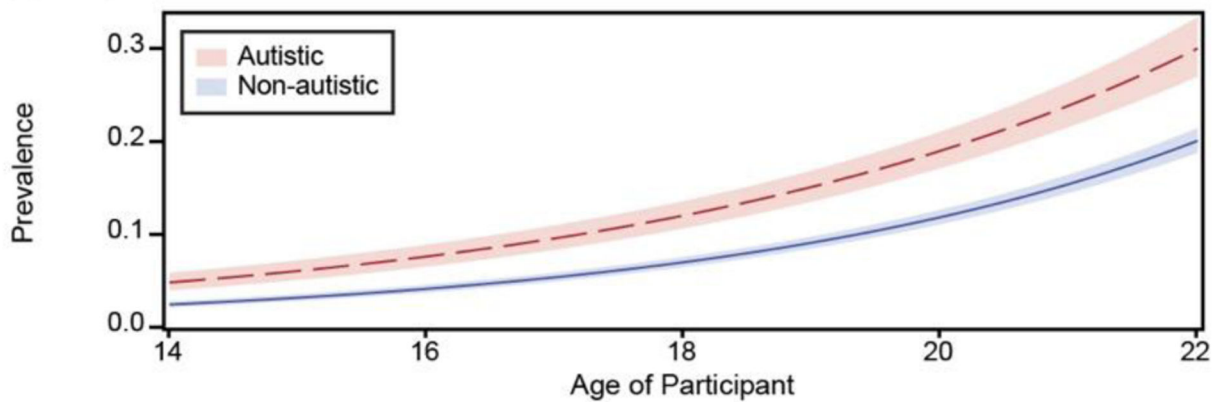


Figure 1. Prevalence of Medical Conditions by Age. The prevalence by age of participant is displayed for the autistic (peach band) and the non-autistic (blue band) participants. The dotted line shows the estimated prevalence for each age group with the band reflecting the 95% confidence interval. Note that for obesity and dyslipidemia, the autistic and non-autistic curves become more divergent with increasing age.

(a) Anxiety**(b) ADHD****(c) Depression****Figure 2a-c.**

Prevalence of Psychiatric Conditions by Age. The prevalence by age of participant is displayed for the autistic (peach band) and the non-autistic (blue band) participants. The dotted line shows the smoothed prevalence for each age group with the band reflecting the 95% confidence interval.

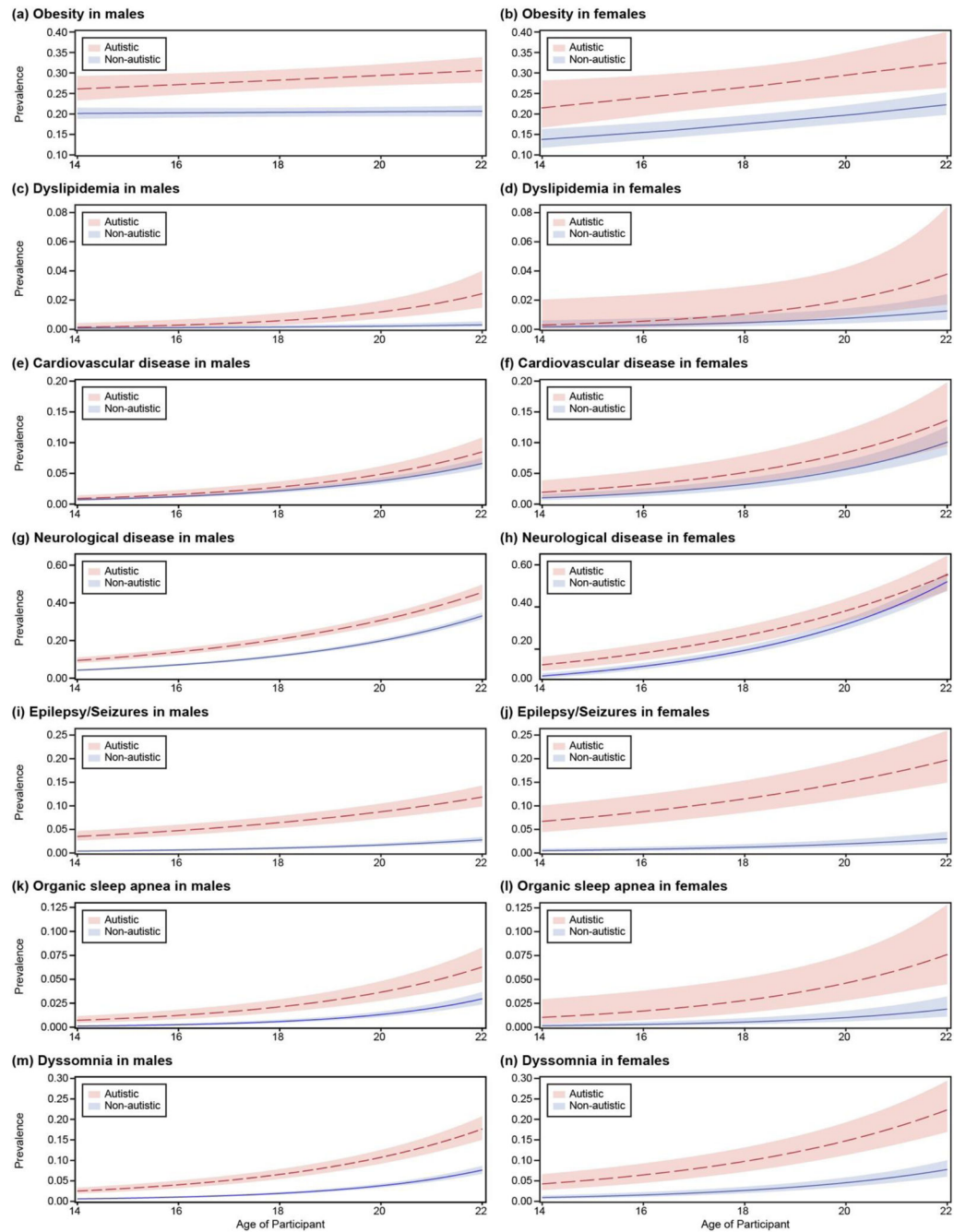


Figure 3a-n.

Prevalence of Medical Conditions by Age, stratified by sex. The prevalence by age of participant is displayed for the autistic (peach band) and the non-autistic (blue band) participants, stratified by sex (male and female). The dotted line shows the smoothed prevalence for each age group with the band reflecting the 95% confidence interval.

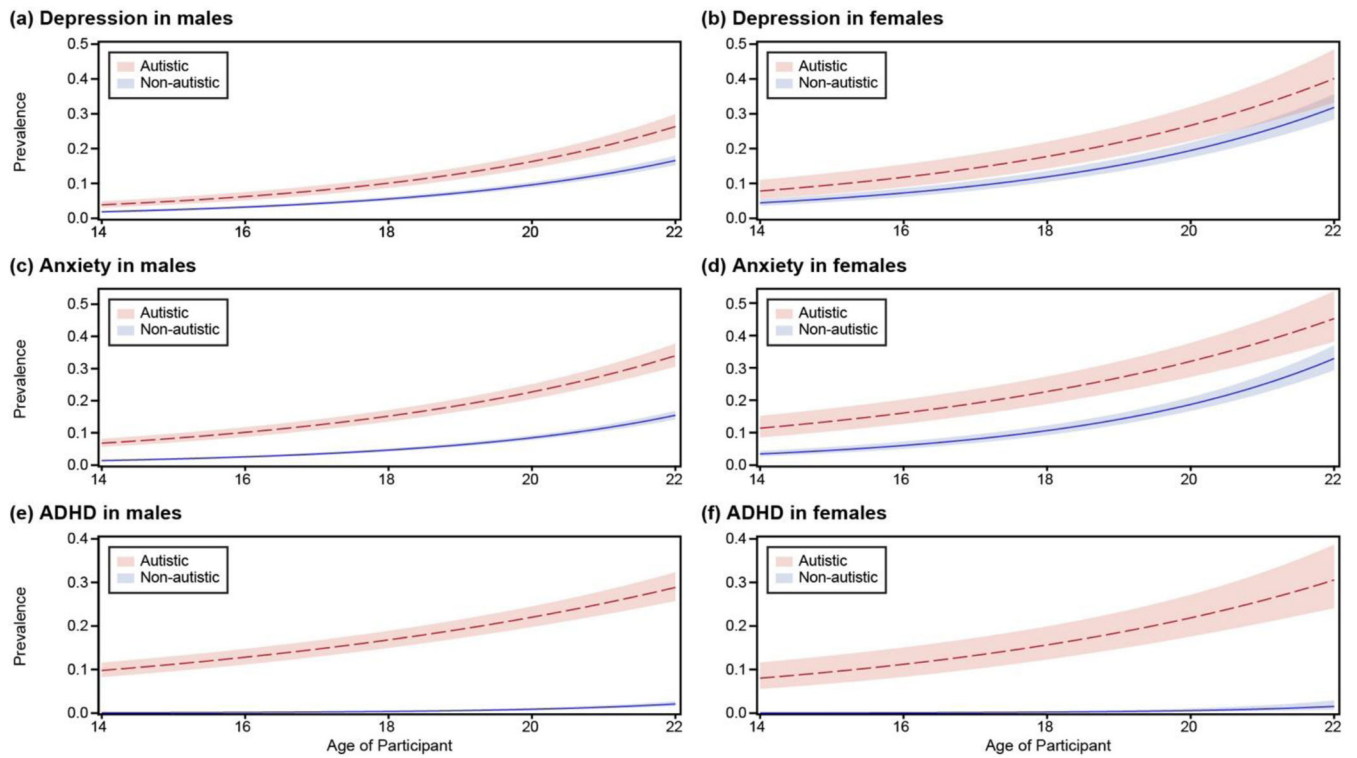


Figure 4a-f. Prevalence of Psychiatric Conditions by Age, stratified by sex. The prevalence by age of participant is displayed for the autistic (peach band) and the non-autistic (blue band) participants, stratified by sex (male and female). The dotted line shows the smoothed prevalence for each age group with the band reflecting the 95% confidence interval.

Table 1.

Demographic Characteristics of Transition-Aged Individuals

Characteristics	Autistic (N = 1418)	Non-autistic (N = 6029)	p-value
Age on January 1, 2014			0.0618
14 years	383 (27.01)	1491 (24.73)	
15 years	378 (26.66)	1516 (25.15)	
16 years	311 (21.93)	1482 (24.58)	
17 years	346 (24.40)	1540 (25.54)	
Sex			0.3842
Female	281 (19.82)	1134 (18.81)	
Male	1137 (80.18)	4895 (81.19)	
Race			<0.0001
White, non-Hispanic	678 (47.81)	2065 (34.25)	
White, Hispanic	119 (8.39)	410 (6.80)	
Black	123 (8.67)	547 (9.07)	
Asian	264 (18.62)	1326 (21.99)	
Other	234 (16.50)	1681 (27.88)	
Insurance as of January 1, 2014			<0.0001
Commercial and Self-Pay	1172 (82.65)	5550 (92.05)	
Government (Medicaid)	246 (17.35)	479 (7.94)	

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2.

Count and percent of medical and psychiatric conditions by age.

	Age (in years)													
	14		15		16		17		18		19		20 ^c	
	autistic	non-autistic	autistic	non-autistic	autistic	non-autistic	autistic	non-autistic	autistic	non-autistic	autistic	non-autistic	autistic	non-autistic
	N=383	N=1491	N=761	N=3007	N=1072	N=4489	N=1418	N=6029	N=1418	N=6029	N=1418	N=6029	N=1035	N=4029
Medical Conditions														
Obesity	53 (13.84)	124 (8.32)	123 (16.16)	364 (12.11)	221 (20.62)	647 (14.41)	315 (22.21)	923 (15.31)	382 (26.94)	1018 (16.89)	373 (26.30)	1040 (17.25)	297 (28.70)	807 (17.25)
Dyslipidemia	1 (0.26)	3 (0.20)	1 (0.13)	4 (0.14)	3 (0.28)	5 (0.11)	6 (0.42)	11 (0.18)	11 (0.78)	15 (0.25)	14 (0.99)	19 (0.32)	15 (1.45)	11 (0.26)
Cardiovascular diseases ^a	1 (0.26)	11 (0.74)	10 (1.31)	29 (0.96)	19 (1.77)	55 (1.23)	39 (2.75)	107 (1.77)	47 (3.31)	154 (2.55)	56 (3.95)	212 (3.52)	47 (4.54)	187 (4.15)
Neurological disorders ^b	28 (7.31)	54 (3.62)	102 (13.40)	199 (6.62)	195 (18.19)	425 (9.47)	303 (21.37)	743 (12.32)	382 (26.94)	989 (16.40)	437 (30.82)	1219 (20.22)	325 (31.40)	1000 (22.25)
Epilepsy/Seizures	14 (3.66)	6 (0.40)	38 (4.99)	21 (0.70)	73 (6.81)	35 (0.78)	110 (7.76)	51 (0.85)	127 (8.96)	70 (1.16)	140 (9.87)	93 (1.54)	106 (10.24)	77 (1.72)
Dyssomnia	7 (1.83)	4 (0.27)	28 (3.68)	17 (0.57)	55 (5.13)	46 (1.02)	93 (6.56)	89 (1.48)	122 (8.60)	140 (2.32)	156 (11.00)	192 (3.18)	128 (12.37)	181 (3.95)
Organic sleep apnea	1 (0.26)	1 (0.07)	9 (1.18)	4 (0.13)	18 (1.68)	7 (0.16)	31 (2.19)	24 (0.40)	38 (2.68)	43 (0.71)	50 (3.53)	63 (1.04)	36 (3.48)	63 (1.35)
Psychiatric Conditions														
Anxiety	26 (6.79)	12 (0.80)	71 (9.33)	64 (2.13)	145 (13.53)	172 (3.83)	230 (16.22)	274 (4.54)	294 (20.73)	407 (6.75)	350 (24.68)	550 (9.12)	268 (25.89)	496 (10.82)
ADHD	31 (8.09)	0 (0.00)	92 (12.09)	0 (0.00)	159 (14.83)	5 (0.11)	231 (16.29)	12 (0.20)	277 (19.53)	20 (0.33)	303 (21.37)	37 (0.61)	239 (23.09)	36 (0.77)
Depression	14 (3.66)	14 (0.94)	38 (4.99)	75 (2.49)	89 (8.30)	224 (4.99)	153 (10.79)	389 (6.45)	195 (13.75)	495 (8.21)	237 (16.71)	615 (10.20)	206 (19.90)	517 (11.35)

for each condition, the number of cases is listed with the percentage of cases in parenthesis

^aCardiovascular diseases other than dyslipidemia

^bNeurological disorders included epilepsy/seizures

^cThese total Ns decrease because youth ages 14–16 are only followed for 5 years, and are not counted in the older ages