



Published in final edited form as:

Autism. 2017 November ; 21(8): 995–1009. doi:10.1177/1362361316665222.

Comorbidity prevalence, healthcare utilization, and expenditures of Medicaid enrolled adults with autism spectrum disorders

Rini Vohra, Suresh Madhavan, and Usha Sambamoorthi

West Virginia University, USA

Abstract

A retrospective data analysis using 2000–2008 three state Medicaid Analytic eXtract was conducted to examine the prevalence and association of comorbidities (psychiatric and non-psychiatric) with healthcare utilization and expenditures of fee-for-service enrolled adults (22–64 years) with and without autism spectrum disorders (International Classification of Diseases, Ninth Revision–clinical modification code: 299.xx). Autism spectrum disorder cases were 1:3 matched to no autism spectrum disorder controls by age, gender, and race using propensity scores. Study outcomes were all-cause healthcare utilization (outpatient office visits, inpatient hospitalizations, emergency room, and prescription drug use) and associated healthcare expenditures. Bivariate analyses (chi-square tests and t-tests), multinomial logistic regressions (healthcare utilization), and generalized linear models with gamma distribution (expenditures) were used. Adults with autism spectrum disorders ($n = 1772$) had significantly higher rates of psychiatric comorbidity (81%), epilepsy (22%), infections (22%), skin disorders (21%), and hearing impairments (18%). Adults with autism spectrum disorders had higher mean annual outpatient office visits (32_{ASD} vs 8_{noASD}) and prescription drug use claims (51_{ASD} vs 24_{noASD}) as well as higher mean annual outpatient office visits (US\$4375_{ASD} vs US\$824_{noASD}), emergency room (US\$15,929_{ASD} vs US\$2598_{noASD}), prescription drug use (US\$6067_{ASD} vs US\$3144_{noASD}), and total expenditures (US\$13,700_{ASD} vs US\$8560_{noASD}). The presence of a psychiatric and a non-psychiatric comorbidity among adults with autism spectrum disorders increased the annual total expenditures by US\$4952 and US\$5084, respectively.

Keywords

autism spectrum disorders; economic costs; healthcare expenditures; healthcare utilization; Medicaid; medical comorbidity; psychiatric comorbidity

Corresponding author: Rini Vohra, Department of Pharmaceutical Systems and Policy, West Virginia University, 1 Medical Center Drive, Morgantown, WV 26506, 9510, USA. rinievohra@gmail.com.

NOTICE WARNING CONCERNING COPYRIGHT RESTRICTIONS

The copyright law of the United States [Title 17, United States Code] governs the making of photocopies or other reproductions of copyrighted material. Under certain conditions specified in the law, libraries and archives are authorized to furnish a photocopy or other reproduction. One of these specified conditions is that the reproduction is not to be used for any purpose other than private study, scholarship, or research. If a user makes a request for, or later uses, a photocopy or reproduction for purposes in excess of "fair use," that use may be liable for copyright infringement. This institution reserves the right to refuse to accept a copying order if, in its judgement, fulfillment of the order would involve violation of copyright law. No further reproduction and distribution of this copy is permitted by transmission or any other means.

Introduction

Comorbid conditions occurring among individuals with autism spectrum disorders (ASD) are known to adversely affect their core autistic symptoms (Garcia-Villamizar and Rojahn, 2013), activities of daily living, and health-related quality of life (Kamp-Becker et al., 2010). It is well known now, that adults with ASD have a high prevalence of multiple psychiatric comorbidities such as depression, schizophrenia, anxiety, bipolar disorder, and substance dependence disorder (Hofvander et al., 2009; Lugnegard et al., 2011; Lunskey et al., 2009), but the reported rates of such comorbidities vary considerably due to variations in data sources, study period, type of ASD examined, and limited sample sizes, and restricted hospital and/or community settings with a high chance of referral bias. However, a recent study by Croen et al. (2015) used electronic health records of large frequency matched sample of adults with (n = 1507) and without ASD who were enrolled in Kaiser Permanente (KP) Northern California health insurance program from 2008 to 2012 to examine rates of psychiatric and non-psychiatric comorbidities. Some of the psychiatric comorbidities which were highly prevalent among adults with ASD as compared to adults without ASD were depression (26% vs 10%), anxiety (30% vs 10%), bipolar disorder (11% vs 2%), and schizophrenia (7% vs 0.5%). Non-psychiatric comorbidities significantly high in the ASD group were cardiovascular disease (37% vs 23%), gastrointestinal (GI) disorders (35% vs 28%), musculoskeletal disorders (7% vs 2%), and diabetes (8% vs 4%). The study also found a higher prevalence of other health conditions such as epilepsy (12% vs 0.8%), nutritional disorders (38% vs 19%), and thyroid disease (7% vs 3%) among adults with ASD.

In addition to extensive comorbidities, individuals of all ages with ASD also exhibit higher healthcare resource utilization such as outpatient office (OT) visits, inpatient hospitalizations (IP), emergency room (ER) use, prescription drug (Rx) use, longer length of stays and higher healthcare costs as compared to individuals without ASD (Croen et al., 2006; Lokhandwala et al., 2012; Mandell, 2008). For example, Croen et al. (2006) examined KP medical care program 2003–2005 and found that children with ASD aged 2–18 years had a higher annual mean number of total clinic (5.6 vs 2.8), pediatric (2.3 vs 1.6), and psychiatric (2.2 vs 0.3) outpatient visits as compared to children without ASD. In addition, a higher percentage of children with ASD also experienced IP (3% vs 1%) and were nine times more likely to use psychotherapeutic medications. Also, the mean annual member costs for hospitalizations (US\$550 vs US\$208), clinic visits (US\$1373 vs US\$540), and Rx use (US \$724 vs US\$96) were significantly higher for children with ASD as compared to children without ASD.

Previous studies have shown that comorbidities play a significant role in elevating the risk of using additional healthcare resources and high healthcare expenditures among individuals of all ages with ASD (Ahmedani and Hock, 2012; Buescher et al., 2014; Croen et al., 2006; Mandell, 2008; Mandell et al., 2006; Peacock et al., 2012; Wang et al., 2012). Comorbidities along with ASD are specifically associated with higher medication use (Buck et al., 2014; Mandell, 2008; Mandell et al., 2008), greater hospitalization rates, higher expenditures (Peacock et al., 2012), and extremely high lifetime support costs per individual with ASD (ASD = US\$1.4 million and ASD + intellectual disability = US\$2.4 million in the United

States) (Buescher et al., 2014). Therefore, in addition to examining the burden of comorbidities alone, it is also imperative to understand their ramifications on healthcare utilization and expenditures of adults with ASD.

Adults with ASD

Similar to children with ASD, adults with ASD also have very high healthcare needs (Cidav et al., 2013; Howlin et al., 2004; Lunskey et al., 2009; Mukaetova-Ladinska et al., 2012). A paucity of trained mental health professionals and facilities for optimum management of ASD cases (Mauch et al., 2011), consistent physician reports of lack of self-perceived competency and knowledge in treating adults with ASD (Bruder et al., 2012; Golnik et al., 2009; Miller, 2015; Oskoui and Wolfson, 2012), and no clarity on adult ASD treatment guidelines creates complexities in healthcare delivery which could possibly lead to frequent and excessive healthcare services use and high costs among this group.

Even though the current literature indicates a high occurrence of comorbidities (mostly focusing on psychiatric) among adults with ASD (Lugnegard et al., 2011; Lunskey et al., 2009; Unenge Hallerback et al., 2012), there is a gap regarding how different these prevalence rates are from adults without ASD. Despite being a significant addition to the literature, the study by Croen et al. (2015) on prevalence rates of comorbidities among adults with ASD was restricted to KP members in Northern California. In addition, the study also did not examine the impact of comorbidity among adults with ASD on their healthcare utilization and expenditures, which maybe of prime importance to policymakers as ASD related costs are predicted to increase substantially in the next few years (Buescher et al., 2014).

This study aims to (1) examine the prevalence rates of specific types of comorbidities (psychiatric and non-psychiatric) and other health conditions among adults with ASD as compared to adults without ASD, (2) compare healthcare utilization (OT, IP, ER, and Rx) and associated healthcare expenditures among adults with and without ASD, and (3) determine the association of psychiatric and non-psychiatric comorbidity among adults with and without ASD with their respective healthcare utilization and expenditures. The prevalence of psychiatric comorbidities and non-psychiatric comorbidities among adults with ASD were expected to be significantly higher as compared to adults without ASD, based on the findings of the recent study by Croen et al. (2015). There was no a priori hypothesis for prevalence of other health conditions among adults with ASD. We also anticipated that adults with ASD will have a greater use of healthcare services and healthcare expenditures as compared to adults without ASD, a hypothesis supported by findings from previous studies among individuals of all ages with ASD (Ahmedani and Hock, 2012; Buck et al., 2014; Buescher et al., 2014; Croen et al., 2006; Mandell, 2008; Mandell et al., 2006; Peacock et al., 2012; Wang et al., 2012). For the third aim, we hypothesized that presence of comorbidity (psychiatric or non-psychiatric) will be associated with a significant increase in healthcare utilization and expenditures, an association which has been previously observed among children with ASD (Peacock et al., 2012).

We used data from three state Medicaid claims database (IL, NY, and TX) including fee-for-service enrollees from 2000 to 2008. Medicaid is an ideal data source for several reasons. It is the single largest payer for individuals with ASD (Ruble et al., 2005) and utilization of Medicaid provided healthcare services among individuals with ASD is only expected to increase (Semansky et al., 2011). State Medicaid programs provide a wide variety of services to individuals with ASD (Arjun et al., 2011) including primary and secondary health insurance coverage for healthcare services, home and community based waivers, screening and diagnostic services, behavioral support, in home care, respite care, case management, supported employment, self-directed services, and parent training and education (Mauch et al., 2011). Healthcare administrative claims, especially state Medicaid databases have been extensively used for ASD research among children and may help address plethora of questions for adults with ASD as well (Khanna et al., 2013; Mandell, 2008; Maski et al., 2011; Peacock et al., 2012; Spencer et al., 2013).

Methods

Data

Administrative health insurance claims data from three state Medicaid programs (IL, NY, and TX) were extracted from the 2000–2008 Centers for Medicare and Medicaid Services Medicaid Analytic eXtract (MAX) data files. We selected IL, NY, and TX MAX data because of lower managed care penetration rates, greater fee-for-service enrollment during the study period, and large sample of enrollees with ASD in these state MAX files (The Henry J Kaiser Family Foundation, 2013). The MAX offers separate data files which provide varied information on diagnosis codes, service use, demographic characteristics, and state of residence. Separate MAX data files received from Centers for Medicare & Medicaid Services (CMS) can be linked based on beneficiaries' unique identification number.

For this study we used the *personal summary file* (for information on Medicaid eligibility, enrollment type, and demographics), *other therapy file* (for information on two possible diagnoses, utilization of outpatient services such as clinical services, physician office visits, procedures, lab services, psychiatric services, and residential services), *inpatient file* (for information on nine possible diagnoses, hospitalizations, procedures, and length of stays), and the *prescription drug file* (for national drug codes (NDC), prescription fill date, and days of supply). County level variables were obtained from the *area resource file (ARF)* (Quality Resource Systems, 2006) which provides information on type of health facilities, number and type of health professions, resource scarcity measures, health status, economic activities, health training programs, and socioeconomic and environmental characteristics. The Medicaid files were linked with ARFs with a five-digit county identification variable.

Study population and design

A retrospective matched cohort study among adults aged 22–64 years with and without ASD was conducted. Adults with any ASD (at least one inpatient or two outpatient claims on separate service dates with an International Classification of Diseases, Ninth Revision–clinical modification (ICD9-CM) code: 299.xx in any position) who were continuously enrolled in a fee-for-service program from 2000 to 2008 were matched (1:3) to adults

without ASD by age, gender, and race using propensity score matching method with GREEDY (8 to 1) algorithm. An 8 to 1 GREEDY matching technique involves matching the cases and controls with same propensity score (predicted probabilities from a logistic regression on ASD status) till the eighth digit, and if the eighth digit match is unsuccessful, the algorithm attempts to match on seven digits, and so on. The GREEDY matching algorithm employs a sample without replacement and if there are more than one matches then selection of control becomes random. Such an approach for propensity score matching is used to reduce the effects of bias and confounding in observational studies (Austin, 2011). Adults without ASD were identified as those enrollees with at least two medical claims on separate dates of service (either inpatient or outpatient) with no ASD diagnosis throughout the study period (2000–2008). Individuals were excluded from study if they were (1) dual Medicaid/Medicare eligible, (2) managed care enrollees, and (3) dead during the study period. The baseline characteristics such as patient's socio-demographic information, comorbidities, and baseline drug use were extracted from the identification year which was the first medical claim year with any ASD diagnosis and no ASD diagnosis. The outcomes (healthcare utilization and expenditures) were measured in the follow-up year which was a calendar year after the identification year.

Variables

Healthcare utilization and expenditures—Study outcomes included all-cause healthcare utilization and expenditures measured in the follow-up year. We counted the number of OT visits, IP, ER, and any Rx on separate dates of service. We defined the OT visits as any physician/other practitioner's/clinic visits using MAX type of service codes (8, 10, and 12). ER services, which are either rendered in an OT or an IP setting, were identified using any OT or IP claim with revenue codes (450–452, 456, 459, 981), procedure codes (99281–99285), and place of service codes (23). Rx use included claims for prescriptions filled at retail and mail order pharmacies that were billed to the Medicaid's pharmacy benefits. We also estimated average length of stay for hospitalizations as one of the variables in the study. In addition, OT, IP, ER, Rx, and total expenditures (sum of OT, IP, and Rx expenditures) among adults with and without ASD were calculated. Expenditures attributed to ER use were not added separately to total expenditures as they were already a part of OT and IP expenditures. Medical care services part of the annual consumer price index (CPI) was utilized to transform expenditures to 2008 constant dollars. The CPI was obtained from the Bureau of Labor Statistics (Bureau of Labor Statistics, US Department of Labor, 2014).

Socio-demographic and need characteristics—Age (22–40 and 41–64 years), sex (male and female), race (White, African-American, and Other race including Hispanics, American Indian/Alaska Native, Asians, Native Hawaiian/Other Pacific Islanders, and more than one race), state (IL, NY, and TX), identification cohort (before and after 2004), and Medicaid eligibility by cash and medical needs (yes/no) were extracted from the MAX personal summary file. The age group of 22 and above was chosen to exclude children with ASD who could be enrolled in a separate state children health insurance program or individuals under the age of 21 who receive Early and Periodic Screening, Diagnostic and Treatment services (EPSDT) and additional home and community-based service (HCBS) waivers which may or may not be extended to the adult population aged above 21 years

(Department of Health & Human Services, CMS, 2014). In addition, age group of 40 and above has been significantly associated with an increased risk of major life disorders such as heart disease (which is also one of the most common reasons for emergency department use and mortality in the United States). We combined age groups 41–54 and 55–64 due to a very low sample size ($n = 88$) in the latter group. Baseline Rx use (>20 unique Rx claims, 20 unique Rx claims, and no Rx claims) was used as a proxy measure of healthcare needs and was categorized above and equal/below the median of the entire sample (due to non-parametric distribution of baseline Rx use).

County characteristics—We used various county level variables from the ARF as proxy measures of access to services. Such variables were metro status (urban/rural), primary care shortage area (yes/no), mental health specialist shortage area (yes/no), psychiatrist density (high/low), median household income level (quartiles: q1, q2, q3, and q4), and high school education and above density which is a measure of county education status (quartiles: q1, q2, q3, and q4).

Comorbidities—This study focused on two types of comorbidities: psychiatric and non-psychiatric. The psychiatric disorders included in the study were selected based on the prevalence of psychiatric disorders as reported among individuals of all ages with ASD in the literature (Buck et al., 2014; Hofvander et al., 2009; Lugnégard et al., 2011; Lunskey et al., 2009). Comorbidities were identified using either one inpatient or two outpatient claims on separate service dates with a diagnosis in any position for psychiatric or a non-psychiatric disorder. We used the single-level clinical classification software (CCS) provided by Agency for Healthcare Research and Quality (<https://www.hcupus.ahrq.gov/toolsoftware/CCS/AppendixASingleDX.txt>) to categorize diagnosis codes to clinically meaningful categories. A psychiatric comorbidity included adjustment disorders (CCS code: 650), alcohol/substance use disorders (AUD/SUD; CCS codes: 660, 661), anxiety disorders (CCS code: 651), attention deficit disorders (ADD) and conduct behavior disorders (CCS code: 652), developmental disorders (CCS code: 654), mood disorders including depressive disorders and bipolar disorder (CCS codes: 6571, 6572), personality disorders (CCS code: 658), and schizophrenia and other psychotic disorders (CCS code: 659).

This study also included the most common medical conditions which are linked with highest healthcare expenditures and are the leading cause of deaths in the United States, as non-psychiatric comorbidities (<http://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>). A non-psychiatric comorbidity was cancer (CCS codes: 11–37, 39–43, 46, 47), cardiovascular disease (CCS codes: 96–108), diabetes (CCS codes: 49, 50), musculoskeletal disorders (CCS codes: 201–212), GI disease (CCS codes: 138–151, 153–155), and respiratory disease (CCS codes: 125–128, 132–134).

Other health conditions—Some of the other health conditions which were found to be very common among adults with ASD in a recent study by Croen et al. (2015) were also examined in this study. Due to a lack of strong epidemiological evidence on comorbid prevalence of many such conditions among adults with ASD (especially those who are enrolled in Medicaid), our study focused only on establishing their prevalence rates in this population and kept them separate from non-psychiatric comorbidities. Such conditions

included headache/migraine (CCS code: 84), thyroid disease (CCS code: 48), epilepsy (CCS code: 83), other metabolic, nutritional, and endocrine disorders excluding diabetes (CCS codes: 51, 58), nutrition deficiencies (CCS code: 52), lipid metabolism disorders such as hypercholesterolemia (CCS code: 53), fluid and electrolyte dysfunctions (CCS code: 55), jaw and teeth disorders (CCS code: 136), hematological disorders (CCS codes: 59–64), genito-urinary disorders such as tract infections, bladder and urethra disorders, nephritis, renal failure, and others (CCS codes: 156–163), paralysis (CCS code: 82), infections such as tuberculosis, bacterial infections, hepatitis, HIV, and others (CCS codes: 1–9, 135), skin disorders such as skin infections, inflammatory conditions, and others (CCS codes: 197–200), blindness/other vision defects (CCS code: 89), and hearing impairments (CCS codes: 92–94).

Statistical analysis

Chi-square tests of associations for categorical variables and t-tests for continuous variables were conducted to assess the sub-group and mean differences between adults with and without ASD. Mean number of visits/claims and expenditures were calculated for all beneficiaries as well as for those who used a specific service in the follow-up year (OT, IP, ER, and Rx visits). Multivariate logistic regressions adjusting for age, sex, and race were run to compare the odds of each comorbidity and other health conditions among adults with and without ASD. Adjusted odds ratios (AORs) with 95% confidence intervals (CIs) are reported as effect sizes. In addition, Cohen's D estimates were calculated as standardized mean difference (SMD) between ASD and no ASD group for healthcare utilization and expenditures. Cohen's D is an effect size measure accompanying t-tests to indicate standardized difference between two means. Cohen's D is calculated as follows

$$\text{Cohen's } D = \frac{\text{Mean}_{\text{ASD}} - \text{Mean}_{\text{noASD}}}{\text{Pooled Standard Deviation}_{\text{ASD+noASD}}} \quad (1)$$

A positive Cohen's D indicates that the ASD group is superior to the no ASD group on a positive outcome measure (e.g. higher mean office visits). However, a negative Cohen's D represents superiority of the intervention on a negatively oriented outcome measure (e.g. lower mean office visits) (Durlak, 2009). A zero Cohen's D value indicates no effect or sub-group difference of zero strength.

Diagnostic tests for count data (OT, IP, ER, and Rx visits) were run to examine the feasibility of Poisson, negative binomial, and zero inflated regressions. However, the dispersion factor for all regressions did not satisfy the distribution assumptions and count data were categorized into multinomial categories above and below the median of the respective sample distributions for each dependent variable. For comparison between adults with and without ASD, a multinomial logistic regression was conducted to examine the likelihood of ≥ 4 OT visits (vs < 4 OT visits and no OT visit), > 1 IP visit (vs =1 IP visit and no IP visit), > 1 ER visit (vs =1 ER visit and no ER visit), and ≥ 18 Rx claims (vs < 18 Rx claims and no Rx claim) per year.

We used generalized linear modeling with gamma distribution and log-link function to test for differences in Medicaid expenditures (OT, IP, ER, Rx, and total). To account for data with zero expenditures, a two-part model was used (part 1 with logistic regression to examine the association of costs (>0 vs 0) with ASD status and part 2 with generalized linear modeling with log-link function for those who had >0 expenditures). We conducted two-part models to adjust for expenditure differences in adults who did and did not use services. ASD diagnosis was significantly associated with a greater likelihood of positive/non-zero expenditures for OT visits (AOR = 3.67, 95% CI = 2.89–4.66) and Rx claims (AOR = 2.24, 95% CI = 1.75–2.87) and a lower likelihood of positive expenditures for IP visits (AOR = 0.48, 95% CI = 0.41–0.57) and ER visits (AOR = 0.58, 95% CI = 0.51–0.66).

For examining the association of comorbidity type (psychiatric and non-psychiatric) with healthcare utilization and expenditures of adults with and without ASD, we used interaction terms (ASD*psychiatric comorbidity and ASD*non-psychiatric comorbidity) in separate regression analyses. We tested the impact of both types of comorbidity on healthcare utilization and expenditures by (1) estimating the differences in healthcare utilization and expenditures of adults with and without ASD in relation to type of comorbidity (ASD with comorbidity vs no ASD with comorbidity), and (2) estimating the impact of comorbidities on healthcare utilization and expenditures of adults with ASD alone (ASD with comorbidity vs ASD with no comorbidity). AORs (multinomial regressions) along with 95% CIs, and parameter estimates (beta) with standard errors (SEs) for generalized linear models are reported. All analyses were adjusted for selected socio-demographics, county characteristics, baseline Rx use, and comorbidities. Variables which were highly collinear with expenditures such as baseline prescription drug use (e.g. with Rx and total expenditures) were excluded from the model. Findings with cell sizes that were 11 or less are suppressed in accordance with CMS data user agreement. All analyses were conducted using SAS v9.4.

Results

Descriptive analyses

Baseline characteristics—The study sample had 1772 adults with ASD, most of them being male (71%), aged 22–40 years, and under a cash assistance program (82%) (Tables 1 and 2). Psychiatric comorbidity rates were significantly higher among adults with ASD (81%) than those without ASD (41%). Almost 70% of adults with ASD in the sample had developmental disorders, followed by schizophrenia (17%), mood disorders (14%), and anxiety (12%). Rates of non-psychiatric comorbidity were modestly lower among adults with ASD as compared to adults without ASD (40%_{ASD} vs 46%_{noASD}). Adults with ASD had significantly lower prevalence rates of cancer (1.2%_{ASD} vs 2.8%_{noASD}), cardiovascular disorders (14%_{ASD} vs 17%_{noASD}), musculoskeletal disorders (12%_{ASD} vs 16%_{noASD}), and respiratory disorders (15%_{ASD} vs 19%_{noASD}) as compared to adults without ASD. Adults with ASD showed the same odds of having GI disorders as adults without ASD in the logistic regression analyses, even though the prevalence rate in the former group was slightly higher.

Rates of other health conditions that were significantly higher among adults with ASD as compared to adults without ASD were epilepsy (22%_{ASD} vs 5%_{noASD}), thyroid disease

(5%_{ASD} vs 1%_{noASD}), lipid metabolism disorders (5%_{ASD} vs 3%_{noASD}), other endocrine/nutrition disorders (11%_{ASD} vs 4%_{noASD}), hematological disorders (7%_{ASD} vs 5%_{noASD}), genito-urinary disorders (10%_{ASD} vs 8%_{noASD}), infections (22%_{ASD} vs 15%_{noASD}), skin disorders (21%_{ASD} vs 9%_{noASD}), and paralysis (6%_{ASD} vs 3%_{noASD}). Adults with ASD also had a significantly higher prevalence rate of other disabilities such as blindness (5%_{ASD} vs 4%_{noASD}) and hearing impairments (19%_{ASD} vs 4%_{noASD}).

Outcome measures—Most adults with ASD had an OT visit (95%) in the follow-up year (table not shown here). Around 14% of adults with ASD had an IP visit, 33.6% had an ER visit, and 95% had at least one Rx claim in the follow-up year. The IP (20%) and ER visits (40%) were much more common among adults *without* ASD as compared to adults with ASD. The mean annual number of OT visits (32_{ASD} vs 8_{noASD}) and Rx claims (51_{ASD} vs 24_{noASD}) were significantly greater for adults with ASD as compared to adults without ASD. Adults with ASD exhibited higher mean annual OT (US\$4375_{ASD} vs US\$824_{noASD}), ER (US\$15,929_{ASD} vs US\$2598_{noASD}), Rx (US\$6067_{ASD} vs US\$3144_{noASD}), and total expenditures (US\$13,700_{ASD} vs US\$8560_{noASD}) (Tables 3 and 4).

Regression analyses

The odds for ≥ 4 OT visits and ≥ 18 Rx claims were higher for adults with ASD as compared to adults without ASD (Table 5). Interestingly, the likelihood of >1 IP visit or >1 ER visit in a year was 30% and 24% lower among adults with ASD as compared to adults without ASD. Among users, the expenditures for adults with ASD were significantly higher for OT visits, ER visits, and Rx claims as compared to adults without ASD. The average adjusted total Medicaid expenditures (sum of OT, RX, and IP) were US\$1159 higher per year for adults with ASD as compared to adults without ASD, even after controlling for type of comorbidity.

Association of comorbidity with outcomes

Adults with ASD vs adults without ASD—Adults with ASD and a psychiatric/non-psychiatric comorbidity had a significantly greater likelihood of having ≥ 4 OT visits per year and ≥ 18 Rx claims per year as compared to adults without ASD but with a psychiatric/non-psychiatric comorbidity (Table 5). Adults with ASD and a psychiatric comorbidity had higher OT (beta = 1.14, SE = 0.05, $p < 0.001$), ER (beta = 1.42, SE = 0.08, $p < 0.001$), Rx (beta = 0.32, SE = 0.05, $p < 0.001$), and total expenditures (beta = 0.19, SE = 0.05, $p < 0.001$) as compared to adults without ASD but with a psychiatric comorbidity. Adults with ASD and a non-psychiatric comorbidity had higher OT (beta = 1.05, SE = 0.06, $p < 0.001$), ER (beta = 1.58, SE = 0.09, $p < 0.001$), Rx (beta = 0.54, SE = 0.06, $p < 0.001$), and total expenditures (beta = 0.40, SE = 0.06, $p < 0.001$) as compared to adults without ASD but with a non-psychiatric comorbidity. IP expenditures were significantly lower for adults with ASD as compared to adults without ASD regardless of type of comorbidity.

Among adults with ASD—Both psychiatric and non-psychiatric comorbidity among adults with ASD were associated with a greater likelihood of ≥ 4 OT visits per year and ≥ 18 Rx claims per year. A non-psychiatric comorbidity among adults with ASD also significantly increased the odds of >1 ER visit in a year (AOR = 1.96, 95% CI = 1.41–2.72).

Presence of psychiatric comorbidity among adults with ASD significantly increased the OT expenditures by US\$2130, ER expenditures by US\$10,532, and total expenditures by US\$4952. Presence of a non-psychiatric comorbidity among adults with ASD significantly increased the OT expenditures by US\$443, IP expenditures by US\$1990, Rx expenditures by US\$1160, and total expenditures by US\$5084.

Discussion

Our study examined the differences in rates of comorbidities and other health conditions among adults with and without ASD along with their healthcare utilization and expenditures in a 1:3 matched cohort. With an increasing population of adults with ASD (Brugha et al., 2011) and a paucity of literature on their healthcare needs, patterns of healthcare services use, and costs, this study fills a critical gap in the literature.

Although the rates of specific comorbidities among adults with ASD in our study are significantly different from those found in a recent study by Croen et al. (2015), the two studies do share a common finding: prevalence of most psychiatric comorbidities among adults with ASD is significantly higher when compared to adults without ASD. Rates of some psychiatric comorbidities such as depression and anxiety among adults with ASD were much higher (26% and 30%, respectively) in the study by Croen et al. (2015) as compared to our study (15% and 12%, respectively). We also found lower rates of non-psychiatric comorbidities such as GI disorders (35%_{Croen} vs 12.6%) and diabetes (7.6%_{Croen} vs 3.6%) among adults with ASD in our study sample as compared to the study by Croen et al. (2015). There could be many reasons for these differences in prevalence rates of comorbidities between the two studies: (1) Croen et al. (2015) focused only on KP members from Northern California, a population with inherently different demographics from our three state (IL, NY, and TX) Medicaid population; (2) the data in Croen et al. (2015) study was more recent (2008–2012), which represents a period of greater awareness about autism as well as better access to services associated with both mental and physical health needs (Patient Protection and Affordable Care Act, 42 U.S.C. § 18001 (2010)); and (3) we used an algorithm of one inpatient or two outpatient claims to identify a comorbidity which may have excluded patients with a single claim. This criterion, however, helped to create a robust definition of comorbid conditions along with reducing chances of coding errors.

Psychiatric comorbidities

Similar to children with ASD (Maski et al., 2011; Matson and Shoemaker, 2009), adults with ASD also have very high rates of psychiatric comorbidities (81%) (Table 2). Such a rate of psychiatric comorbidity among adults with ASD supports the findings from other small sample studies (Buck et al., 2014; Lugnegard et al., 2011; Lunskey et al., 2009; Tsakanikos et al., 2007). Extremely high rates of psychiatric disorders such as anxiety and ADD not only put the adults with ASD at a greater risk of other disorders such as depression, but are also associated with injurious behaviors and suicide attempts (Kato et al., 2013). In addition, not only have schizophrenia and ASD been linked in previous studies (Hofvander et al., 2009; Mouridsen et al., 2008), but other psychiatric disorders such as ADD/attention deficit hyperactivity disorders (ADHD) and mood disorders have also been shown to share similar

genetic makeup as ASD (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013), therefore showing the increased comorbidity burden in this population.

In the current study, the most common comorbidity among adults with ASD was developmental disorders (70%) which includes intellectual disabilities, communication disorders, learning disabilities, and other developmental conditions. Such a high rate of comorbidity suggests that there is a need for better healthcare coordination and services that focus on addressing adult ASD related healthcare needs, especially since previous studies have shown that presence of intellectual disabilities alone can substantially increase the length of hospital stays and level of needed care (Lunsky et al., 2009) and lifetime costs of individuals of all ages with ASD (Buescher et al., 2014; Knapp et al., 2009). Interestingly, behavioral disorders such as alcohol/substance abuse (2%_{ASD} vs 18%_{noASD}) were significantly less common among adults with ASD as compared to adults without ASD. Literature has shown that typically individuals with ASD are less prone to use of drugs/alcohol; however, higher functioning individuals may frequently engage in alcohol consumption to help alleviate the social difficulties they experience (Santosh and Mijovic, 2006; Sizoo et al., 2009). Since SUD as well as ASD diagnoses among individuals of all ages are associated with greater healthcare resource utilization and worse outcomes (Smith et al., 2015), greater attention and monitoring may be needed to identify SUD among adults with ASD so that timely counseling can be provided.

Non-psychiatric comorbidities

Adults with ASD had significantly lower prevalence rates of non-psychiatric disorders (40%_{ASD} vs 46%_{noASD}) (Table 2). A recent meta-analysis showed that children with ASD have a significantly higher likelihood of having GI disorders as compared to children without ASD (Buie et al., 2010; Gorrindo et al., 2012; McElhanon et al., 2014). Croen et al. (2015) also found a significantly higher prevalence rate of GI disorders among adults with ASD (35%) as compared to adults without ASD (27%). Even though the prevalence rate of GI disorders in our study was slightly higher in ASD group as compared to no ASD group, there was no significant difference between the two groups in a logistic regression analysis. Contrary to the study by Croen et al. (2015), adults with ASD had slightly lower yet closely similar prevalence rates of other non-psychiatric disorders such as diabetes, cardiovascular/cerebrovascular, musculoskeletal, and respiratory disorders as compared to adults without ASD.

Other health conditions

In addition to comorbidities, adults with ASD also had significantly higher prevalence of epilepsy (22%) as compared to adults without ASD (5%), confirming the current evidence on comorbid epilepsy among individuals with ASD (all ages) from other studies (Howlin et al., 2004; Kohane et al., 2012; Maski et al., 2011). Other health conditions which were more common in the ASD group as compared to the no ASD group were thyroid disease, other nutrition/endocrine/metabolic disorders excluding diabetes, lipid disorders, hematological disorders, infections, genito-urinary disorders, and skin disorders. There is some evidence that many of these conditions are also very common among children with ASD (Bakare et al., 2011; Schieve et al., 2012) and a similar finding among adults with ASD was observed

in the Croen et al. (2015) study as well. Pharmacotherapy for individuals with ASD, which usually includes antipsychotics, antidepressants, stimulants, and anticonvulsants has been shown to be associated with increased risk of dyslipidemia, metabolic syndrome, obesity, diabetes, and cardiovascular issues (Ji and Findling, 2015; Rojo et al., 2015). Our study showed a high prevalence of lipid disorders among adults with ASD which could be attributed to high prescription drug use in this population, possibly since early childhood. Considering that a substantial proportion of adults with ASD diagnosed as children continue with these medications for a very long time (Esbensen et al., 2009), their risks of developing such conditions later in life are also high (Croen et al., 2015). Adults with ASD also had a higher prevalence of blindness/vision defects and hearing impairments emphasizing the high disability needs in this population.

Healthcare utilization and expenditures

We found that adults with ASD have significantly greater use of OT visits and Rx claims as compared to adults without ASD, regardless of the type of comorbidity associated with either group (Tables 3 to 5). Surprisingly, IP visits were much lower in the ASD group and there were no significant differences in the mean number of ER visits among adults with and without ASD. These results are contrary to findings of previous studies showing a higher inpatient burden among individuals with ASD (all ages) as compared to individuals without ASD (Croen et al., 2006; Lokhandwala et al., 2012; Vohra et al., 2016). However, some studies have also shown that individuals with ASD who participate in HCBS waivers have a significantly lower likelihood of IP or using long term care services (Cidav et al., 2014; Velott et al., 2015). Due to the extreme variations in HCBS waivers and services provided under them across state Medicaid programs (Peebles and Bohl, 2014), identifying types of HCBS waivers and adults using their services was outside the scope of this study. However, we did observe a greater proportion of adults with ASD who used residential services (35%_{ASD} vs 2%_{noASD}), which could be a proxy indicator of HCBS waivers enrollment and use (Peebles and Bohl, 2014).

Adults with ASD also had significantly higher mean expenditures as compared to adults without ASD, similar to children with ASD (Croen et al., 2006; Kogan et al., 2008; Leslie and Martin, 2007; Liptak et al., 2006; Lokhandwala et al., 2012; Mandell et al., 2006; Shimabukuro et al., 2008; Wang and Leslie, 2010). In contrast to lower mean ER visits among adults with ASD, their corresponding ER expenditures were significantly higher than adults without ASD. Adults with ASD had 0.4 times (US\$1159 difference; Table 5) the average annual total expenditures of adults without ASD. Our study also examined the association of comorbidity type with healthcare utilization and expenditures of adults with and without ASD. It was found that there is no significant impact of psychiatric comorbidity on the likelihood of healthcare utilization for adults with ASD as compared to adults without ASD. A non-psychiatric comorbidity did have a modifying effect on the likelihood of IP and ER visits, where adults with and without ASD were no longer significantly different in their IP and ER use. This finding highlights the role of non-psychiatric comorbidities in determining the probability of hospitalizations and ER visits among both adults with and without ASD. In terms of economic burden, adults with ASD had consistently higher OT, ER, Rx, and total expenditures and lower IP expenditures as compared to adults without

ASD, regardless of the type of comorbidity. These findings are in support of a study by Peacock et al. (2012) which established that Medicaid enrolled children with ASD have substantially varying healthcare expenditures depending on the presence of a specific comorbid condition. Children with ASD and ADHD, epilepsy, and intellectual disability respectively had 1.3 times, 1.6 times, and 2.7 times higher annual total expenditures as compared to children with ASD but without the specific comorbidity.

Based on our study findings, it is reasonable to attribute the high healthcare utilization and expenditures to the presence of extensive psychiatric and non-psychiatric comorbidities among adults with ASD. Other reasons for high healthcare use and costs could be the lack of knowledge of ASD among healthcare providers that causes delayed care and frequent revisits to the outpatient settings, ER, and hospitals (Heidgerken et al., 2005; Imran et al., 2011). According to a study by Nicolaidis et al. (2013), adults with ASD (n = 209) are more likely to report lower general and chronic condition self-efficacy, poor satisfaction rates with patient-provider communication, lower receipt of preventive services, and higher unmet needs as compared to adults without ASD (n = 228). This study highlights that there are certain needs of adults with ASD that are not met either due to difficulties in communication or lower access to ASD care. Also, additional social impairments such as blindness and hearing issues among adults with ASD may also not allow them to correctly report symptoms that cause discomfort, leading to possibly a missed/delayed diagnosis and foregone care.

Implications

Addressing the core deficit areas in adult ASD care is the next step where adults can have a better transition from childhood, are able to communicate their issues to a healthcare provider, and receive a well-coordinated and quality care for comorbid psychiatric, non-psychiatric, and other health conditions. Timely management of comorbidities, especially psychiatric conditions which can easily qualify under missed diagnoses due to a similar symptomatology to ASD, can help reduce excessive use of services and healthcare expenditures later in life. From a policy perspective, our study showed that adults with ASD represent a high needs group within the Medicaid population. Medicaid coverage provides substantial number of services for adults with ASD which also transforms into extremely high costs. With the recent efforts to reduce long term healthcare costs and still maintain quality care, understanding the pattern of healthcare utilization and factors influencing the high services use among adults with ASD draws attention to the need for better coordinated care and/or processes to improve communication and treatment experiences of this group.

As noted in many previous studies (Heidgerken et al., 2005; Imran et al., 2011; Liptak et al., 2006; Miller, 2015; Piven et al., 2011), ASD knowledge and training among physicians and other specialty care providers has been reported to be low. In a scenario where there is no gold standard cure and most pharmacotherapies have shown only medium to low level effectiveness (Warren et al., April 2011), greater focus may be needed to provide easy access to early intervention services which have a strong evidence of improving prognosis of ASD (Autism Speaks, 2013; Bailey et al., 2004; Reichow, 2012). In addition, further studies may be needed to address the issue of poor rating of patient-provider communication and greater

unmet healthcare needs that have been reported by adults with ASD in a few small sample studies (Magiati et al., 2014; Nicolaidis et al., 2013).

Strengths

Our study is the first to utilize a large Medicaid database sample of adults for examining comorbidity prevalence and identifying excess healthcare utilization and expenditures among adults with ASD as compared to adults without ASD. Medicaid serves as the largest single payer for individuals with ASD (Ruble et al., 2005), and highlighting the healthcare use patterns and expenditures associated with the ASD group will help promote better education and development of guidelines for healthcare providers on ASD treatment and care. We addressed significant observational differences between adults with and without ASD by matching them on age, gender, and race.

Limitations

To conduct this study, we used a three state Medicaid data-set (IL, NY, and TX) for the period 2000–2008. Even though these states provided variation in demographics and a large sample of adults with ASD, we did not control for any unobservable bias in the study. Identification of ASD and comorbidities in our study has not been validated among adults, and this study may not represent the real world prevalence of adults with ASD. This issue could not be addressed in this study because there are no existing published studies on adults with ASD in the Medicaid population which could be used as a reference point. Our study focused on all-cause healthcare utilization and expenditures, so we did not know what type of diagnoses these outcomes were associated with or what were the reasons of such visits. We required adults with ASD to be continuously enrolled during the study period to capture their true healthcare utilization and expenditures, which could have excluded many individuals with irregular Medicaid enrollment. We did not match the ASD cases and no ASD controls on their enrollment period, which could have created certain baseline differences in the two groups.

Conclusion

Psychiatric comorbidities such as developmental disorders, anxiety, ADD/ADHD, and schizophrenia are very common among adults with ASD. Other health conditions such as epilepsy, thyroid, lipid metabolism disorders, gen-ito-urinary disorders, skin disorders, and infections are also highly prevalent in adults with ASD as compared to adults without ASD. Adults with ASD exhibit excess healthcare utilization in the form of higher number of outpatient visits and Rx claims in a year and annual total Medicaid expenditures as compared to adults without ASD. Even though comorbidities play a significant role in increasing service utilization and expenditures for adults with ASD, they contribute minimally toward the differences in healthcare utilization and expenditures between adults with and without ASD.

Acknowledgments

R.V. would like to thank Dr Mayank Ajmera for his assistance with data analysis, management, and manipulation.

Funding

Autism. Author manuscript; available in PMC 2018 November 01.

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research work was conducted as part of R.V.'s PhD dissertation project.

References

- Ahmedani BK, Hock RM. Health care access and treatment for children with co-morbid autism and psychiatric conditions. *Social Psychiatry and Psychiatric Epidemiology*. 2012; 47(11):1807–1814. [PubMed: 22322982]
- Arjun, L., Hope, C., Guyer, J., et al. Medicaid and its role for children and youth with special health care needs (CYSHCN): A family perspective. Georgetown University, Health Policy Institute: Center for Children and Families. Albuquerque, NM: Family Voices; 2011.
- Austin PC. An introduction to propensity score methods for reducing the effects of confounding in observational studies. *Multivariate Behavioral Research*. 2011; 46:399–424. [PubMed: 21818162]
- Autism Speaks. [accessed 2 March 2016] High-quality early intervention for autism more than pays for itself. 2013. Available at: <http://www.autism-speaks.org/science/science-news/high-quality-early-inter-vention-autism-more-pays-itself>
- Bailey DB Jr, Hebbeler K, Scarborough A, et al. First experiences with early intervention: a national perspective. *Pediatrics*. 2004; 113(4):887–896. [PubMed: 15060241]
- Bakare, MO., Munir, KM., Kinney, DK. Hypothesis. Vol. 9. University of Toronto, Dept. of Medical Biophysics; 2011. Association of hypomelanotic skin disorders with autism: links to possible etiologic role of vitamin-D levels in autism?; p. e2
- Bruder MB, Kerins G, Mazzarella C, et al. Brief report: the medical care of adults with autism spectrum disorders: identifying the needs. *Journal of Autism and Developmental Disorders*. 2012; 42(11):2498–2504. [PubMed: 22427260]
- Brugha TS, McManus S, Bankart J, et al. Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*. 2011; 68(5):459–465. [PubMed: 21536975]
- Buck TR, Viskochil J, Farley M, et al. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2014; 44(12):3063–3071. [PubMed: 24958436]
- Buescher AV, Cidav Z, Knapp M, et al. Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics*. 2014; 168(8):721–728. [PubMed: 24911948]
- Buie T, Campbell DB, Fuchs GJ. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics*. 2010; 125(Suppl. 1):S1–S18. [PubMed: 20048083]
- Bureau of Labor Statistics, US Department of Labor. [accessed 2 March 2016] Archived consumer price index detailed report information. 2014. Available at: http://www.bls.gov/cpi/cpi_dr.htm
- Cidav Z, Lawer L, Marcus SC, et al. Age-related variation in health service use and associated expenditures among children with autism. *Journal of Autism and Developmental Disorders*. 2013; 43(4):924–931. [PubMed: 22941343]
- Cidav Z, Marcus SC, Mandell DS. Home- and community-based waivers for children with autism: effects on service use and costs. *Intellectual and Developmental Disabilities*. 2014; 52(4):239–248. [PubMed: 25061768]
- Croen LA, Najjar DV, Ray GT, et al. A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*. 2006; 118(4):e1203–e1211. [PubMed: 17015508]
- Croen LA, Zerbo O, Qian Y, et al. The health status of adults on the autism spectrum. *Autism: The International Journal of Research and Practice*. 2015; 19:814–823. [PubMed: 25911091]
- Cross-Disorder Group of the Psychiatric Genomics Consortium. Identification of risk loci with shared effects on five major psychiatric disorders: a genome-wide analysis. *The Lancet*. 2013; 381(9875):1371–1379.
- Department of Health & Human Services, Centers for Medicare & Medicaid Services (CMS). Clarification of Medicaid Coverage of Services to Children with Autism. Baltimore, MD: Center for Medicaid and CHIP Services; 2014.

- Durlak JA. How to select, calculate, and interpret effect sizes. *Journal of Pediatric Psychology*. 2009; 34(9):917–928. [PubMed: 19223279]
- Esbensen AJ, Greenberg JS, Seltzer MM, et al. A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2009; 39(9):1339–1349. [PubMed: 19434487]
- Garcia-Villamizar D, Rojahn J. Comorbid psychopathology and stress mediate the relationship between autistic traits and repetitive behaviours in adults with autism. *Journal of Intellectual Disability Research: JIDR*. 2013; 59(2):116–124. [PubMed: 23919538]
- Golnik A, Ireland M, Borowsky IW. Medical homes for children with autism: a physician survey. *Pediatrics*. 2009; 123(3):966–971. [PubMed: 19255027]
- Gorrindo P, Williams KC, Lee EB, et al. Gastrointestinal dysfunction in autism: parental report, clinical evaluation, and associated factors. *Autism Research*. 2012; 5(2):101–108. [PubMed: 22511450]
- Heidgerken AD, Geffken G, Modi A, et al. A survey of autism knowledge in a health care setting. *Journal of Autism and Developmental Disorders*. 2005; 35(3):323–330. [PubMed: 16119473]
- Hofvander B, Delorme R, Chaste P, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*. 2009; 9:35. [PubMed: 19515234]
- Howlin P, Goode S, Hutton J, et al. Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*. 2004; 45(2):212–229.
- Imran N, Chaudry MR, Azeem MW, et al. A survey of autism knowledge and attitudes among the healthcare professionals in Lahore, Pakistan. *BMC Pediatrics*. 2011; 11:107. [PubMed: 22107951]
- Ji N, Findling RL. An update on pharmacotherapy for autism spectrum disorder in children and adolescents. *Current Opinion in Psychiatry*. 2015; 28(2):91–101. [PubMed: 25602248]
- Kamp-Becker I, Schroder J, Remschmidt H, et al. Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *Psycho-Social Medicine*. 2010; 7:Doc03. [PubMed: 20930927]
- Kato K, Mikami K, Akama F, et al. Clinical features of suicide attempts in adults with autism spectrum disorders. *General Hospital Psychiatry*. 2013; 35(1):50–53. [PubMed: 23141028]
- Khanna R, Jariwala K, West-Strum D. Use and cost of psychotropic drugs among recipients with autism in a state Medicaid fee-for-service programme. *Journal of Intellectual Disability Research: JIDR*. 2013; 57(2):161–171. [PubMed: 22471524]
- Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. *Autism: The International Journal of Research and Practice*. 2009; 13(3):317–336. [PubMed: 19369391]
- Kogan MD, Strickland BB, Blumberg SJ, et al. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*. 2008; 122(6):e1149–e1158. [PubMed: 19047216]
- Kohane IS, McMurry A, Weber G, et al. The co-morbidity burden of children and young adults with autism spectrum disorders. *PLoS ONE*. 2012; 7(4):e33224. [PubMed: 22511918]
- Leslie DL, Martin A. Health care expenditures associated with autism spectrum disorders. *Archives of Pediatrics & Adolescent Medicine*. 2007; 161(4):350–355. [PubMed: 17404131]
- Liptak GS, Orlando M, Yingling JT, et al. Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care: Official Publication of National Association of Pediatric Nurse Associates & Practitioners*. 2006; 20(4):245–252.
- Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: data from U.S. national samples. *Journal of Autism and Developmental Disorders*. 2006; 36(7):871–879. [PubMed: 16855879]
- Lokhandwala T, Khanna R, West-Strum D. Hospitalization burden among individuals with autism. *Journal of Autism and Developmental Disorders*. 2012; 42(1):95–104. [PubMed: 21404084]
- Lugnegard T, Hallerback MU, Gillberg C. Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities*. 2011; 32(5):1910–1917. [PubMed: 21515028]
- Lunsky Y, Gracey C, Bradley E. Adults with autism spectrum disorders using psychiatric hospitals in Ontario: clinical profile and service needs. *Research in Autism Spectrum Disorders*. 2009; 3(4):1006–1013.

- McElhanon BO, McCracken C, Karpen S, et al. Gastrointestinal symptoms in autism spectrum disorder: a meta-analysis. *Pediatrics*. 2014; 133(5):872–883. [PubMed: 24777214]
- Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014; 34(1):73–86. [PubMed: 24424351]
- Mandell DS. Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2008; 38(6):1059–1065. [PubMed: 17975720]
- Mandell DS, Cao J, Ittenbach R, et al. Medicaid expenditures for children with autistic spectrum disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders*. 2006; 36(4):475–485. [PubMed: 16586155]
- Mandell DS, Morales KH, Marcus SC, et al. Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. *Pediatrics*. 2008; 121(3):e441–e448. [PubMed: 18310165]
- Maski KP, Jeste SS, Spence SJ. Common neurological co-morbidities in autism spectrum disorders. *Current Opinion in Pediatrics*. 2011; 23(6):609–615. [PubMed: 21970828]
- Matson JL, Shoemaker M. Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*. 2009; 30(6):1107–1114. [PubMed: 19604668]
- Mauch, D., Pfefferle, S., Booker, C., et al. Report on state services to individuals with autism spectrum disorders (ASD). Final report, Subcontract No. S-10 CMS-33 No. 2. Centers for Medicare & Medicaid Services (CMS), ASD Services Project; 2011. Available at: <https://www.cms.gov/apps/files/9-state-report.pdf>
- Miller, SM. Doctoral Projects. Paper 7. San Jose State University; 2015. Nurses caring for adults with autism in an emergency department: a survey of knowledge. Available at: http://scholarworks.sjsu.edu/etd_doctoral/7
- Mouridsen SE, Bronnum-Hansen H, Rich B, et al. Mortality and causes of death in autism spectrum disorders: an update. *Autism: The International Journal of Research and Practice*. 2008; 12(4): 403–414. [PubMed: 18579647]
- Mukaetova-Ladinska EB, Perry E, Baron M, et al. Ageing in people with autistic spectrum disorder. *International Journal of Geriatric Psychiatry*. 2012; 27(2):109–118. [PubMed: 21538534]
- Nicolaidis C, Raymaker D, McDonald K, et al. Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*. 2013; 28(6):761–769. [PubMed: 23179969]
- Oskoui M, Wolfson C. Treatment comfort of adult neurologists in childhood onset conditions. *The Canadian Journal of Neurological Sciences. Le Journal Canadien Des Sciences Neurologiques*. 2012; 39(2):202–205.
- Peacock G, Amendah D, Ouyang L, et al. Autism spectrum disorders and health care expenditures: the effects of co-occurring conditions. *Journal of Developmental and Behavioral Pediatrics: JDBP*. 2012; 33(1):2–8. [PubMed: 22157409]
- Peebles V, Bohl A. The HCBS taxonomy: a new language for classifying home- and community-based services. *Medicare & Medicaid Research Review*. 2014 Epub ahead of print 22 September.
- Piven J, Rabins P. Autism-in-Older Adults Working Group. Autism spectrum disorders in older adults: toward defining a research agenda. *Journal of the American Geriatrics Society*. 2011; 59(11): 2151–2155. [PubMed: 22091837]
- Quality Resource Systems I. Area Health Resource Files: Health Resources and Services Administration (HRSA). Fairfax, VA: US Department of Health and Human Services; 2006.
- Reichow B. Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012; 42(4): 512–520. [PubMed: 21404083]
- Rajo LE, Gaspar PA, Silva H, et al. Metabolic syndrome and obesity among users of second generation antipsychotics: a global challenge for modern psychopharmacology. *Pharmacological Research: The Official Journal of the Italian Pharmacological Society*. 2015; 101:74–85.
- Ruble LA, Heflinger CA, Renfrew JW, et al. Access and service use by children with autism spectrum disorders in Medicaid managed care. *Journal of Autism and Developmental Disorders*. 2005; 35(1):3–13. [PubMed: 15796117]

- Santosh PJ, Mijovic A. Does pervasive developmental disorder protect children and adolescents against drug and alcohol use? *European Child & Adolescent Psychiatry*. 2006; 15(4):183–188. [PubMed: 16604379]
- Schieve LA, Gonzalez V, Boulet SL, et al. Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, national health interview survey, 2006–2010. *Research in Developmental Disabilities*. 2012; 33(2):467–476. [PubMed: 22119694]
- Semansky RM, Xie M, Mandell DS. Medicaid's increasing role in treating youths with autism spectrum disorders. *Psychiatric Services (Washington, D.C.)*. 2011; 62(6):588.
- Shimabukuro TT, Grosse SD, Rice C. Medical expenditures for children with an autism spectrum disorder in a privately insured population. *Journal of Autism and Developmental Disorders*. 2008; 38(3):546–552. [PubMed: 17690969]
- Sizoo B, van den Brink W, Gorissen van Eenige M, et al. Personality characteristics of adults with autism spectrum disorders or attention deficit hyperactivity disorder with and without substance use disorders. *The Journal of Nervous and Mental Disease*. 2009; 197(6):450–454. [PubMed: 19525746]
- Smith MW, Stocks C, Santora PB. Hospital read-mission rates and emergency department visits for mental health and substance abuse conditions. *Community Mental Health Journal*. 2015; 51(2): 190–197. [PubMed: 25563483]
- Spencer D, Marshall J, Post B, et al. Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics*. 2013; 132(5):833–840. [PubMed: 24144704]
- The Henry J Kaiser Family Foundation. State HMO penetration rate, state health facts. 2013. Available at: <http://kff.org/other/state-indicator/hmo-penetration-rate/>
- Tsakanikos E, Costello H, Holt G, et al. Behaviour management problems as predictors of psychotropic medication and use of psychiatric services in adults with autism. *Journal of Autism and Developmental Disorders*. 2007; 37(6):1080–1085. [PubMed: 17053989]
- Unenge Hallerback M, Lugnegard T, Gillberg C. Is autism spectrum disorder common in schizophrenia? *Psychiatry Research*. 2012; 198(1):12–17. [PubMed: 22421071]
- Velott DL, Agbese E, Mandell D, et al. Medicaid 1915(c) home- and community-based services waivers for children with autism spectrum disorder. *Autism: The International Journal of Research and Practice*. 2015 Epub ahead of print 18 June.
- Vohra R, Madhavan S, Sambamoorthi U. Emergency department use among adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*. 2016; 46(4):1441–1454. [PubMed: 26762115]
- Wang L, Leslie DL. Health care expenditures for children with autism spectrum disorders in Medicaid. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2010; 49(11):1165–1171. [PubMed: 20970704]
- Wang L, Mandell DS, Lawer L, et al. Healthcare service use and costs for autism spectrum disorder: a comparison between Medicaid and private insurance. *Journal of Autism and Developmental Disorders*. 2012; 43(5):1057–1064.
- Warren, Z., Veenstra-Vander Weele, J., Stone, W., et al. Therapies for children with autism spectrum disorders. Comparative effectiveness reviews no. 26, no. 11-EHC029-EF. Rockville, MD: Agency for Healthcare Research and Quality; 2011 Apr. Available at: http://effectivehealthcare.ahrq.gov/ehc/products/106/651/Autism_Disorder_exec-summ.pdf

Description of sample by ASD diagnoses; adults with and without ASD matched on age, race, and gender (n = 7092).

Table 1

	ASD		No ASD		Sig.
	N	Col%	N	Col%	
All	1772	100.0	5320	100.0	
Identification year					
2000	617	34.8	1851	34.8	
2001	250	14.1	750	14.1	
2002	185	10.4	555	10.4	
2003	162	9.1	486	9.1	
2004	163	9.2	489	9.2	
2005	129	7.3	387	7.3	
2006	92	5.2	280	5.3	
2007	174	9.8	522	9.8	
State					
IL	292	16.5	876	16.5	
NY	1216	68.6	3648	68.6	
TX	264	14.9	796	15.0	
Sex					
Female	506	28.6	1518	28.5	
Male	1266	71.4	3802	71.5	
Age (years)					
22-40	1517	85.6	4555	85.6	
41-64	255	14.4	765	14.4	
Race					
White	658	37.1	1974	37.1	
African-American	364	20.5	1094	20.6	
Other	750	42.3	2252	42.3	***
Eligibility					
Cash	1456	82.2	3207	60.3	
No cash	316	17.8	2113	39.7	***

	ASD		No ASD		Sig.
	N	Col%	N	Col%	
Medically needy	77	4.3	912	17.1	
Not medically needy	1695	95.7	4408	82.9	
Rx claims per year ^d					***
>20 Rx claims	1325	74.7	1766	33.2	
20 Rx claims	353	19.9	2857	53.7	
No claim	94	5.3	697	13.1	
<i>County characteristics</i>					
<i>Metro</i>					
Yes	1450	81.8	4570	85.9	***
No	322	18.2	750	14.1	
<i>PCP shortage area</i>					
Yes	1575	88.9	4810	90.4	
No	197	11.1	510	9.6	
<i>Mental health specialist shortage area</i>					
Yes	1434	80.9	4419	83.1	*
No	338	19.1	901	16.9	
<i>Psychiatrist density</i>					
High	1322	74.6	4138	77.8	**
Low	450	25.4	1182	22.2	
<i>Median household income level</i>					
q1	286	16.1	440	8.3	***
q2	69	3.9	438	8.2	
q3	338	19.1	1053	19.8	
q4	1079	60.9	3389	63.7	
<i>HS education and above</i>					
q1	1071	60.4	3164	59.5	***
q2	80	4.5	483	9.1	
q3	244	13.8	737	13.9	
q4	377	21.3	936	17.6	

ASD: autism spectrum disorders; Rx: prescription drug; PCP: primary care provider; Col%: column percentages; HS: higher secondary.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Medicaid Analytic eXtract 2000–2008 (IL, NY, and TX).

Based on chi-square estimates for fee-for-service enrolled individuals aged 22–64 years with no Medicare coverage and alive in IL, NY, and TX Medicaid from 2000 to 2008.

^aEstimates also tested with Wilcoxon–Mann Whitney tests.

Sig.:

*** p < 0.001;

** 0.001 p < 0.01;

* 0.01 p < 0.05.

Table 2

Description of sample baseline characteristics by ASD diagnoses; adults with and without ASD matched on age, race, and gender (n = 7092).

	ASD		No ASD		Chisq. Sig.	AOR	95% CI	Sig.
	N	Col%	N	Col%				
All	1772	100	5320	100				
Psychiatric comorbidity	1440	81.3	2216	41.7	***	6.37	(5.57, 7.28)	***
Adjustment disorders	58	3.3	138	2.6		1.27	(0.93, 1.74)	
Anxiety	216	12.2	299	5.6	***	2.34	(1.95, 2.81)	***
ADD/ADHD	146	8.2	37	0.7	***	12.89	(8.94, 18.5)	***
Developmental disorders	1231	69.5	270	5.1	***	44.60	(37.9, 52.4)	***
Mood disorders	256	14.4	839	15.8		0.90	(0.77, 1.05)	
Personality disorders	44	2.5	105	2.0		1.26	(0.89, 1.81)	
Schizophrenia	294	16.6	590	11.1	***	1.61	(1.38, 1.88)	***
Alcohol/substance use disorders	36	2.0	948	17.8	***	0.09	(0.07, 0.13)	***
Non-psychiatric comorbidity	708	40.0	2429	45.7	***	0.79	(0.71, 0.88)	***
Cancer	21	1.2	149	2.8	***	0.41	(0.26, 0.66)	***
Gastrointestinal disorders	223	12.6	583	11.0	***	1.17	(0.99, 1.38)	***
Respiratory disorders	267	15.1	1010	19.0	***	0.76	(0.65, 0.88)	***
Cardiovascular/cerebrovascular disorders	242	13.7	897	16.9	**	0.77	(0.66, 0.90)	**
Diabetes	63	3.6	250	4.7	*	0.74	(0.56, 0.99)	*
Musculoskeletal disorders	216	12.2	852	16.0	***	0.72	(0.62, 0.85)	***
Other health conditions								
Epilepsy	403	22.7	257	4.8	***	5.84	(4.94, 6.91)	***
Headache/migraine	18	1.0	176	3.3	***	0.30	(0.18, 0.49)	***
Thyroid	83	4.7	71	1.3	***	3.66	(2.65, 5.05)	***
Other endocrine disorders	192	10.8	214	4.0	***	2.92	(2.38, 3.57)	***
Nutrition deficiencies	15	0.8	42	0.8		1.07	(0.59, 1.94)	
Lipid disorders	84	4.7	131	2.5	***	2.00	(1.51, 2.65)	***
Fluid and electrolyte dysfunctions	84	4.7	168	3.2	***	1.53	(1.17, 2.01)	**
Jaw and teeth disorders	184	10.4	155	2.9	***	3.87	(3.10, 4.82)	***
Hematological disorders	115	6.5	240	4.5	***	1.47	(1.17, 1.86)	***

	ASD		No ASD		Chisq. Sig.	AOR	95% CI	Sig.
	N	Col%	N	Col%				
Genito-urinary disorders	168	9.5	423	8.0	***	1.21	(1.01, 1.46)	*
Paralysis	101	5.7	157	3.0	***	1.99	(1.54, 2.57)	***
Infections	381	21.5	924	17.4	***	1.59	(1.39, 1.83)	***
Skin disorders	376	21.2	786	14.8	***	2.88	(2.48, 3.34)	***
Blindness/vision defects	96	5.4	197	3.7	**	1.49	(1.16, 1.92)	**
Hearing impairments	328	18.5	210	3.9	***	5.54	(4.62, 6.66)	***

ASD: autism spectrum disorders; Col%: column percentages. Fischer's exact tests were run for variables with expected counts of <5. AOR: odds ratio adjusted for age, sex, and race; CI: confidence interval; ADD: attention deficit disorders; ADHD: attention deficit hyperactivity disorders.

Medicaid Analytic eXtract 2000–2008 (IL, NY, and TX).

Based on chi-square and logistic regression estimates for fee-for-service enrolled individuals aged 22–64 years with no Medicare coverage and alive in IL, NY, and TX Medicaid from 2000 to 2008.

Sig.:

*** p < 0.001;

** 0.001 p < 0.01;

* 0.01 p < 0.05.

Table 3

Healthcare utilization and expenditures by ASD diagnoses; mean, medians, and SDs for healthcare utilization and expenditures; adults with and without ASD matched on age, race, and gender (n = 7092).

	ASD		No ASD		Cohen's D		Sig.
	Mean, median	SD	Mean, median	SD	Effect (95% CI)		
Healthcare utilization (number of visits, claims in follow-up year)							
OT	32, 12	49	8, 3	17	0.87 (0.82, 0.92)	***	
IP	0.30, 0	1	0.46, 0	-2	-0.11 (-0.16, -0.07)	***	
Rx	51, 45	38	24, 12	32	0.80 (0.75, 0.85)	***	
ER	1, 0	7	1, 0	3	-0.02 (-0.06, 0.03)		
Healthcare expenditures (2008 constant dollars)							
OT	US\$4375, US\$1092	US\$7836	US\$854, US\$187	US\$2751	0.77 (0.72, 0.82)	***	
IP	US\$3258, US\$0	US\$14,130	US\$4562, US\$0	US\$20,368	-0.07 (-0.12, -0.02)	*	
Rx	US\$6067, US\$4925	US\$5390	US\$3144, US\$625	US\$6798	0.45 (0.40, 0.50)	***	
ER	US\$15,929, US\$0	US\$38,747	US\$2598, US\$0	US\$13,133	0.59 (0.55, 0.64)	***	
Total	US\$13,700, US\$9072	US\$17,095	US\$8560, US\$1760	US\$22,534	0.24 (0.11, 0.29)	***	

ASD: autism spectrum disorders; CI: confidence interval; Rx: prescription drug; OT: outpatient visits; IP: inpatient hospitalizations; ER: emergency room; SD: standard deviations.

Medicaid Analytic eXtract 2000–2008 (IL, NY, and TX).

Based on t-test estimates for fee-for-service enrolled individuals aged 22–64 years with no Medicare coverage and alive in IL, NY, and TX Medicaid from 2000 to 2008. Total expenditures are sum of OT, IP, and Rx expenditures.

Cohen's D: standardized mean difference (Mean_{ASD} - Mean_{noASD}).

Sig.:

*** p < 0.001;

* 0.01 p < 0.05.

Table 4

Healthcare utilization and expenditures by ASD diagnoses among users; mean, medians, and SDs for healthcare utilization and expenditures; adults with and without ASD matched on age, race, and gender (n = 7092).

	ASD		No ASD		Cohen's D		Sig.
	N	Mean, median SD	Mean, median SD	Effect (95% CI)	SD		
Healthcare utilization (number of visits, claims in follow-up year)							
OT	5969	34, 13 49	10, 5 2, 1	0.81 (0.04, 1.57)	18		***
IP	1313	2, 1 37	2, 1 28, 16	-0.08 (-0.23, 0.06)	3		
Rx	6313	54, 48 11	3, 2 8, 4	0.76 (-0.08, 1.60)	33		***
ER	2741	3, 2 17	3, 2 8, 4	0.06 (-0.19, 0.31)	5		*
ALOS	1313	10, 6		0.18 (-0.63, 0.98)	14		
Healthcare expenditures (2008 constant dollars)							
OT	5969	US\$4617, US\$1272 US\$7980	US\$1059, US\$303 US\$22,872, US\$10,199	0.72 (-124.85, 126.28)	US\$3028		***
IP	1313	US\$22,912, US\$11,812 US\$30,928	US\$3613, US\$968 US\$54,578	0.00 (-2112.27, 2112.27)	US\$40,773		
Rx	6313	US\$6388, US\$5298 US\$5342	US\$6441, US\$1937 US\$9007, US\$2058	0.41 (-165.62, 166.44)	US\$7170		***
ER	2741	US\$47,438, US\$15,967 US\$17,128		1.32 (-1159.10, 1161.75)	US\$20,073		***
Total	6809	US\$13,849, US\$9180		0.22 (-504.85, 505.30)	US\$23,028		***

ASD: autism spectrum disorders; CI: confidence interval; Rx: prescription drug; OT: outpatient visits; IP: inpatient hospitalizations; ER: emergency room; ALOS: average length of stay; SD: standard deviation.

Medicaid Analytic eXtract 2000–2008 (IL, NY, and TX).

Based on t-test estimates for fee-for-service enrolled individuals aged 22–64 years with no Medicare coverage and alive in IL, NY, and TX Medicaid from 2000 to 2008. Users represent only those individuals who used respective services.

Cohen's D: standardized mean difference (Mean_{ASD} - Mean_{noASD}).

Sig.:

*** p < 0.001;

* 0.01 p < 0.05.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Based on estimates for fee-for-service enrolled individuals aged 22–64 years with no Medicare coverage and alive in IL, NY, and TX Medicaid from 2000 to 2008.

AORs represent estimates from multinomial logistic regression analyses, respectively, after adjusting for cohort (before/after 2004), state, eligibility, county characteristics (metro status, median household income, above high school education, Primary Care Provider (PCP) shortage area, mental health specialist shortage area, and psychiatrist density), baseline Rx use, psychiatric comorbidity, and non-psychiatric comorbidity.

Parameter estimates represent results from generalized linear models with gamma distribution and log-link function after adjusting for cohort (before/after 2004), state, eligibility, county characteristics (metro status, median household income, above high school education, PCP shortage area, mental health specialist shortage area, and psychiatrist density), baseline Rx use, psychiatric comorbidity, and non-psychiatric comorbidity.

Model for IP expenditures was also adjusted for average length of stay.

Model for Rx and total expenditures was not adjusted for baseline prescription drug use due to high collinearity issues.

Total expenditures represents sum of OT, IP, and Rx expenditures.

Models 1, 2, and 3 represent separate regressions.

Total dollar = exponentiated (beta).

Additional Dollar = exponentiated (intercept)-exponentiated (beta) for each regression.

Sig.:

*** p < 0.001;

** 0.001 p < 0.01;

* 0.01 p < 0.05.