



Health Services Utilization Among Children With and Without Autism Spectrum Disorders

[Janet Cummings](#), *Emory University*
Frances L. Lynch, *Kaiser Permanente*
Kristal C. Rust, *Kaiser Permanente*
Karen J. Coleman, *Kaiser Permanente*
Jeanne M. Madden, *Northeastern University*
Ashli A. Owen-Smith, *Georgia State University*
Vincent M. Yau, *Kaiser Permanente*
Ying Qian, *Kaiser Permanente*
Kathryn A. Pearson, *Kaiser Permanente*
Phillip M. Crawford, *Kaiser Permanente*

Only first 10 authors above; see publication for full author list.

Journal Title: Journal of Autism and Developmental Disorders
Volume: Volume 46, Number 3
Publisher: Springer Verlag (Germany) | 2016-03-01, Pages 910-920
Type of Work: Article | Post-print: After Peer Review
Publisher DOI: 10.1007/s10803-015-2634-z
Permanent URL: <https://pid.emory.edu/ark:/25593/rwxz6>

Final published version: <http://dx.doi.org/10.1007/s10803-015-2634-z>

Copyright information:

© 2015, Springer Science+Business Media New York.

Accessed October 16, 2019 1:14 AM EDT



HHS Public Access

Author manuscript

J Autism Dev Disord. Author manuscript; available in PMC 2017 March 01.

Published in final edited form as:

J Autism Dev Disord. 2016 March ; 46(3): 910–920. doi:10.1007/s10803-015-2634-z.

Health Services Utilization among Children with and without Autism Spectrum Disorders

Janet R. Cummings, PhD¹, Frances L. Lynch, PhD, MSPH², Kristal C. Rust, BS², Karen J. Coleman, PhD³, Jeanne M. Madden, PhD^{4,5}, Ashli A. Owen-Smith, PhD^{6,9}, Vincent M. Yau, PhD^{7,8}, Yinge Qian, MS⁷, Kathryn A. Pearson, BA², Phillip M. Crawford, MS², Maria L. Massolo, PhD⁷, Virginia P. Quinn, PhD³, and Lisa A. Croen, PhD⁷

¹Department of Health Policy and Management, Rollins School of Public Health, Emory University, Atlanta, GA

²The Center for Health Research/Northwest, Kaiser Permanente Northwest (KPNW), Portland OR

³Department of Research & Evaluation, Kaiser Permanente Southern California (KPSC), Pasadena, CA

⁴School of Pharmacy, Northeastern University, Boston, MA

⁵Department of Population Medicine, Harvard Medical School and Harvard Pilgrim Health Care Institute (HPHCI), Boston, MA

⁶Division of Health Management and Policy, School of Public Health, Georgia State University, Atlanta, GA

⁷Division of Research, Kaiser Permanente Northern California (KPNC), Oakland, CA

⁸McKesson Corporation, San Francisco, CA

⁹Center for Clinical Outcomes Research, Kaiser Permanente Georgia (KPGA), Atlanta, GA

Abstract

Using data from multiple health systems (2009–2010) and the largest sample to date, this study compares health services use among youth with and without an autism spectrum disorder (ASD) – including preventive services not previously studied. To examine these differences, we estimated

Corresponding Author: Janet R. Cummings, Ph.D., Dept. of Health Policy and Management, Emory University, 1518 Clifton Road NE, Room 650, Atlanta, GA 30322, jrcummi@emory.edu, (p) 404-727-9198, (f) 404-727-9198. Janet R. Cummings is in the Department of Health Policy and Management at the Emory University Rollins School of Public Health, Atlanta, Georgia. Frances L. Lynch, Kristal C. Rust, Kathryn A. Pearson, and Phillip M. Crawford are at the Center for Health Research/Northwest, Kaiser Permanente Northwest (KPNW), Portland, Oregon. Karen J. Coleman and Virginia P. Quinn are in the Department of Research & Evaluation, Kaiser Permanente Southern California (KPSC), Pasadena, CA. Jeanne M. Madden is in the School of Pharmacy at Northeastern University, Boston, Massachusetts and in the Department of Population Medicine, Harvard Medical School and Harvard Pilgrim Health Care Institute (HPHCI), Boston, Massachusetts. Yinge Qian, Maria L. Massolo, and Lisa A. Croen are in the Division of Research, Kaiser Permanente Northern California (KPNC), Oakland, California. At the time of the study, Ashli A. Owen-Smith was with the Center for Health Research/Southeast, Kaiser Permanente Georgia (KPGA), Atlanta, Georgia, and Vincent M. Yau was in the Division of Research, Kaiser Permanente Northern California (KPNC), Oakland, California. Ashli A. Owen-Smith is currently in the Department of Health Management and Policy at the Georgia State University School of Public Health, Atlanta, Georgia. Vincent M. Yau is currently with McKesson Corporation, San Francisco, California.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

logistic and count data models, controlling for demographic characteristics, comorbid physical health, and mental health conditions. Results indicated that youth with an ASD had greater health care use in many categories, but were less likely to receive important preventive services including flu shots and other vaccinations. An improved understanding of the overall patterns of health care use among this population could enable health systems to facilitate the receipt of appropriate and effective health care.

Keywords

Autism spectrum disorders; health care utilization; preventive services; children; adolescents

Autism spectrum disorders (ASDs) are complex disorders characterized by persistent deficits in communication and social skills, and repetitive patterns of behavior that cause significant functional impairment (American Psychiatric Association 2013). Behavioral interventions and specialty health services that focus on improving communication, social skills, and daily functioning constitute the foundation of treatment for youth with ASDs (Copeland and Buch 2013; Howlin et al. 2009; Myers et al. 2007). Youth with ASDs also have higher rates of comorbid health and mental health conditions compared to youth without an ASD (Joshi et al. 2010; Levy et al. 2010; Simonoff et al. 2008), which can require greater health care utilization to address these issues. Given the increasing prevalence of ASDs and the complex health care needs of youth affected by them (Fombonne 2003; Gurney et al. 2006; Myers et al. 2007), it is important to understand how this population accesses the health care system.

Prior research has reported that youth with an ASD have higher utilization of primary care (pediatric visits), specialty care (e.g., psychiatric visits, neurology visits), and acute care (emergency department [ED] encounters, hospitalizations) than youth without an ASD (Croen et al. 2006; Gurney et al. 2006; Liptak et al. 2006). However, none of these studies have controlled for differences in comorbid physical health and/or mental health conditions when examining the association between having an ASD diagnosis and the increased likelihood of health services use. Thus, the extent to which higher rates of health services utilization are explained by higher rates of comorbidities is unknown.

In addition to obtaining an improved understanding of differences in use of primary care, specialty care, and acute care, it is also important to understand patterns of preventive health care utilization – including well-child visits and vaccinations -- among youth with an ASD. Well-child visits provide an opportunity for parents to discuss their child's development, behavior, and well-being with a medical provider (American Academy of Pediatrics 2014). The American Academy of Pediatrics recommends that these visits occur at prescribed intervals, and notes that these visits may include physical measurements, patient history, sensory screenings, behavioral assessments, and planned procedures, such as immunizations (American Academy of Pediatrics 2014). Prior research has reported that these preventive care visits are associated with reduced pediatric hospitalizations (Gadomski et al. 1998). Furthermore, for youth with an ASD that have complex health care needs, well-child visits provide an especially valuable opportunity for screening and ongoing care coordination of

medical, behavioral, and developmental conditions (Hyman and Johnson 2012). However, little is known about how youth with an ASD compare to those without an ASD in their likelihood of receiving a well-child visit.

When considering vaccinations, a number of studies have documented the effectiveness of childhood vaccinations and flu shots to prevent infectious diseases (Andre et al. 2008; Eisenberg et al. 2008; Ferdinands et al. 2014). The United States Centers for Disease Control and Prevention states that flu shots are especially important for children with developmental disorders, as this population is at higher risk for serious influenza-related complications (Centers for Disease Control and Prevention 2014; Keren et al. 2005). Yet, to our knowledge, no study comparing health care utilization between youth with and without ASD has included vaccinations.

A priori, there are reasons to believe preventive service use could be either higher or lower among youth with an ASD. On the one hand, youth with an ASD may be *more* likely to receive specific preventive services than other youth due to more frequent contact with the health care system. Consistent with this hypothesis, prior research has reported that children and adolescents with special health care needs are more likely than other children and adolescents to receive a well-child visit (Selden 2006; Van Cleave and Davis 2008). On the other hand, youth with an ASD may receive *less* preventive care than other children and adolescents due to competing demands for physician time during primary health care encounters (Fontana et al. 1997; Yarnall et al. 2003). Moreover, when considering vaccinations in particular, it is possible that the lingering controversy about the role of childhood vaccinations as a potential cause of ASDs (even though there is no credible research to support this association) may reduce vaccination rates among youth that have been diagnosed with an ASD (Godlee et al. 2011; Taylor et al. 1999). There has been a reported increase in vaccine refusal in the United States (Omer et al. 2009), and it is possible that this trend could be higher among parents who have a child with an ASD. Given the importance of preventive care for youth with complex health care needs, an improved understanding of preventive care utilization among youth with an ASD is warranted.

To address these gaps in the literature, we have conducted the largest study to date that compares patterns of health care utilization among youth with and without an ASD. Our sample was geographically and racially/ethnically diverse and included five large not-for-profit health care systems. We used comprehensive measures of health care utilization, comorbid conditions, and sociodemographic characteristics to achieve our two research objectives. First, we conducted the first known comparison of specific preventive health services (i.e., well-child visits and vaccinations) between youth with and without an ASD. Second, we compared primary, specialty, and acute care utilization among youth with and without an ASD after adjusting for comorbid health conditions and other confounding factors. Because prior research from the public sector indicates that patterns of health care utilization among youth with an ASD are distinct at different stages of development (Cidav et al. 2013), analyses were conducted separately for younger (age 3–9) and older (age 10–17) youth. The findings from this study provide a better understanding of overall patterns of health care use for youth with an ASD.

METHOD

Settings

Data came from an ASD Registry created across five health care systems participating in the National Institute of Mental Health's Mental Health Research Network (MHRN). The MHRN is a consortium of 13 public-domain research centers based in large, not-for-profit health care systems. Together, these systems provide insurance and health care to approximately 12.5 million people living in 15 states (Mental Health Research Network 2015). The following five health care systems participated in the ASD Registry and contributed data to the current study: Kaiser Permanente (KP) Northern California, KP Southern California, KP Northwest, KP Georgia, and Harvard Pilgrim Health Care.

Participants

The study sample was created across two years (2009–2010) from each health care system participating in the ASD Registry. The following inclusion criteria were used to select a sample of youth with an ASD and a matched sample of controls without an ASD: between 3 and 17 years of age during 2010, any enrollment in the health care system during 2009, enrollment for at least 10 months during 2010 (the period during which health care utilization was assessed), and no long-term institutionalization (i.e., > 30 days in an inpatient or institutional setting). Youth with an ASD diagnosis were included if they had at least one claim with an ASD diagnosis (ICD-9 codes 299.0, 299.8, 299.9) during 2009 and at least one additional claim with an ASD diagnosis during 2009 or 2010. Youth without an ASD were included if they had at least one claim in 2009, at least one claim in 2009 or 2010, and never received an ASD diagnosis during the study period. Those younger than 3 years of age were excluded due to concerns about the validity of an ASD diagnosis in this age group (Lord et al. 2006). After applying the inclusion criteria, a 10-to-1 matched sample of youth without an ASD was chosen based on the following matching criteria: age (by year), gender, months of enrollment in 2009 (1–3 months, 4–6 months, 7–9 months, and 10–12 months), having prescription drug coverage (yes/no), and health care system of enrollment. The final sample included 8,325 youth with an ASD and 83,195 comparison youth.

Data Sources

Electronic medical and administrative records from each health care system were used to create standard measures of health services use, comorbid health and mental health conditions, and demographic characteristics. Area-level sociodemographic data from the U.S. Census (U.S. Census Bureau 2000, 2006–2010) were merged with these administrative data for each study subject using the finest level of geocoding possible.

Measures of Health Care Utilization

Using information about the type of procedure that was performed (i.e., Current Procedural Terminology [CPT] and International Classification of Disease, Ninth Revision, Clinical Modification [ICD-9-CM] procedure codes (Medicode (Firm) 1996)), the department in which care was received, and the type of specialist that provided care, measures were created to assess utilization of preventive care, primary care, specialty care, and acute care

during 2010. *Preventive care* was assessed with four dichotomous (yes/no) measures of receiving any: (1) vaccination, (2) flu shot, (3) vaccination other than flu shot, and/or (4) well-child visit during 2010. *Primary care* utilization was assessed with a dichotomous and count measure of pediatric visits (which includes well-child visits). The receipt of specialty services commonly used by youth with an ASD was assessed with dichotomous indicators for those who had any one of the following: (1) speech therapy visit, (2) occupational therapy and/or social skills therapy visit, (3) physical therapy visit, (4) psychotherapy visit, and (5) neurology visit. A count measure was also used to assess the total number of specialty visits in these five categories. Outpatient utilization, which included primary care and all specialty care utilization (not just the five specialty categories examined separately), was assessed with a dichotomous indicator and count measure for the total number of outpatient visits. Finally, measures of *acute care* utilization included dichotomous indicators for those who had any ED visit and any inpatient stay.

Control Variables

Measures of individual demographic characteristics included a dichotomous indicator for gender, a continuous measure of age, and a categorical measure of race/ethnicity (White non-Hispanic, Black non-Hispanic, non-Hispanic Asian, Hispanic, other/mixed race, missing information on race/ethnicity). A continuous measure of area-level median household income from the U.S. Census data served as proxy for family socioeconomic status.

Measures of comorbid chronic health conditions included dichotomous indicators for whether the individual had any allergy, autoimmune disorder, cardiovascular disorder, endocrine disorder, genetic disorder, epilepsy, neurological disorder, sleep disorder, or asthma. Measures of comorbid mental health conditions included dichotomous indicators for attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder or conduct disorder (ODD/CD), anxiety disorder, depression, other severe mental illness (i.e., bipolar spectrum disorder, schizophrenia, or other psychosis), and abuse or dependence on alcohol and/or illicit drugs (included for youth age 10 to 17 only). Each comorbid condition was considered present if an individual had at least two claims with the respective ICD-9 code from 2009 to 2010 (See Appendix Table for ICD-9 codes used for each indicator).

Analysis

Analyses were conducted separately for younger (age 3–9; $n = 43,170$) and older (age 10–17; $n=48,350$) youth because prior research using Medicaid claims data indicates that patterns of health care utilization among youth with an ASD are distinct at different stages of development (Cidav et al. 2013). Less than one percent of each sample was missing information on area-level income (age 3–9: $n = 221$; age 10–17: $n = 244$); these individuals were excluded from regression analyses.

Bivariate analyses were conducted with chi-squared tests, Fisher's exact test, and t-tests. Logistic regression models were estimated to examine the association between having an ASD diagnosis and the receipt of any specific type of preventive care, primary care, specialty care, or acute care service after controlling for confounders. Similarly, negative

binomial and zero-inflated negative binomial regressions were estimated when comparing the number of visits between youth with and without an ASD diagnosis (Long 1997). We used likelihood ratio tests of the overdispersion parameter and Vuong tests to identify the most appropriate model for each count outcome (Long 1997).

For each regression, we estimated three models that sequentially controlled for (1) sociodemographic characteristics; (2) comorbid health conditions, and (3) comorbid mental health conditions. All regression models also controlled for variables used in the matching process (i.e., length of enrollment in 2009, drug coverage, and health care system). Due to the number of outcomes examined, we present the results from the fully specified models below, and we discuss key findings from the intermediate models in the text.

The “margins” command in Stata Version 13.1 was used to estimate the model-adjusted percentage point difference (dichotomous outcomes) or the model-adjusted difference in health visits (count outcomes) for youth with an ASD who received a specific health service compared to youth without an ASD (StataCorp LP 2013).

RESULTS

Sample Characteristics

Compared to the age- and gender-matched sample without an ASD, non-Hispanic white individuals were overrepresented among those with an ASD ($p<0.001$) (Table 1). Youth with an ASD were also more likely to live in areas with higher median household incomes than those without an ASD ($p<0.05$).

Although the likelihood of having an asthma diagnosis did not differ between those with and without an ASD, those with an ASD were more likely to be diagnosed with other chronic conditions. For example, youth with an ASD were more than twice as likely to have a diagnosis of a genetic disorder compared to those without an ASD ($p<0.001$). When examining mental health comorbidities, youth with an ASD were more than four to five times as likely than those without an ASD to have a diagnosis for ADHD, oppositional defiant disorder/conduct disorder, anxiety, depression, and/or other serious mental illness ($p<0.001$). Furthermore, the direction and *relative* magnitude of the change in frequency of each comorbid condition across age groups is generally similar for those with and without an ASD -- with a few exceptions (e.g., neurological disorders). For mental health conditions, it is also worth noting that the absolute percentage point increase of the frequency of these conditions across age groups is much greater among those with an ASD than those without an ASD even though the *relative* magnitude of the increase is similar.

Preventive Care Utilization

When examining case-control differences in the likelihood of receiving any well child visit, the findings differed by age group. Among younger youth, those with an ASD were more likely to receive this service than those without an ASD (56.0% versus 54.3%, $p<0.001$); this difference was no longer significant in the adjusted comparison. On the other hand, older youth with an ASD were *less* likely than their peers without an ASD to receive any well-child visit in the unadjusted and adjusted comparison. Specifically, the percentage that

received a well-child visit was 1.8 percentage points lower ($p<0.05$) for older youth with an ASD versus those without an ASD after controlling for covariates.

When examining differences in the receipt of any vaccinations (Table 2), all of the rates we examined were significantly lower among those with an ASD than those without an ASD. For example, the unadjusted percentage of younger youth with an ASD that received any vaccination in the past year (34.1%) was 4.0 percentage points lower ($p<0.001$) than among their counterparts without an ASD (38.1%). After controlling for covariates, the adjusted percentage was 5.2 percentage points lower for younger youth with an ASD ($p<0.001$) compared to those without an ASD.

To assess whether the negative associations between having an ASD and the receipt of vaccinations were unique to these disorders, we also examined the coefficients and odds ratios associated with other chronic health conditions that were included as control variables in each of these models (not shown). Notably, several other health conditions were significantly associated with the receipt of any vaccination, any flu shot, or any vaccination other than a flu shot in both age groups. Yet, in almost every case in which these associations were significant, there was a positive association between having the condition and the receipt of any vaccination. For example, those with asthma, any allergy, any autoimmune disorder, any genetic disorder, or ADHD ($p<0.05$) were significantly more likely to receive a vaccination in the past year compared to those without each disorder. The only exception to this pattern was for older youth with depression, who were less likely to receive any vaccination than those without depression ($p<0.05$).

Primary Care and Specialty Care Utilization

Although youth with an ASD were less likely to receive most preventive services we examined, they had more contact with their pediatrician compared to youth without an ASD (Table 3). In the unadjusted comparison, younger children with an ASD had nearly two more visits to their pediatrician during the year ($p<0.001$) than those without an ASD. This difference was reduced by more than half in the adjusted comparison ($p<0.001$). Among older youth, the unadjusted (0.8 visit, $p<0.001$) and adjusted (0.1 visit, $p<0.01$) case-control differences in the number of pediatrician visits was also positive and significant, but less pronounced.

With respect to specialty care services, youth with an ASD were more likely than those without an ASD to have each type of visit that was examined in the unadjusted comparisons ($p<0.001$). After controlling for confounding measures, these differences were reduced but remained statistically significant ($p<0.01$). Among younger children, the largest adjusted percentage point differences were observed for receiving any occupational and/or social skills therapy visit (10.4 percentage points, $p<0.001$) and any speech therapy visit (9.9 percentage points, $p<0.001$). Among older youth, the largest adjusted percentage point difference was observed for receiving any psychotherapy visit (4.4 percentage points, $p<0.001$).

When examining the total number of these specialty care visits (psychotherapy, speech therapy, neurology, occupational therapy/social skills therapy, and physical therapy visits

combined) and the total number of outpatient visits, the unadjusted and adjusted case-control differences were larger among younger than among older youth. Among younger youth, those with an ASD had 7.9 and 4.8 more outpatient visits ($p < 0.001$) than those without an ASD in the unadjusted and adjusted comparisons, respectively. Older youth with an ASD had 5.0 and 2.2 more outpatient visits ($p < 0.001$) than their peers without an ASD in the unadjusted and adjusted comparisons, respectively.

Acute Care Utilization

In the unadjusted comparisons, youth with an ASD were at least 2.5 times as likely ($p < 0.001$) to have any inpatient utilization as those without an ASD in both age groups (Table 3). In the adjusted comparisons, these case-control differences were substantially reduced for both age groups and no longer significant among older youth.

Results were mixed when examining case-control differences in ED utilization across age groups. Among younger youth, 20.4% of those with an ASD had any ED visit, compared to 15.3% of those without an ASD ($p < 0.001$). After controlling for demographic and comorbid health conditions, the adjusted case-control difference was no longer significant. Among older youth, however, there was no significant difference in ED use when examining the unadjusted comparison. In the adjusted comparison, however, a negative association emerged that was highly significant for youth with an ASD (adjusted difference = -4.8 percentage points, $p < 0.001$).

Supplemental Analyses

We also estimated intermediate models (not shown) that sequentially adjusted for sociodemographic characteristics, comorbid physical health conditions, and comorbid mental health conditions to assess whether any particular group of variables resulted in the greatest reduction in the difference in health care utilization between those with and without an ASD. In general, the changes in effect size in the adjusted differences were primarily due to the inclusion of comorbid conditions rather than the inclusion of race/ethnicity and SES. For most outcomes, the inclusion of comorbid physical health conditions made the greatest impact on the coefficient of interest. However, the inclusion of comorbid mental health conditions was especially important when examining the likelihood of having any psychiatry visit (both age groups), and for aggregate measures of outpatient care, ED use, and inpatient utilization among older youth.

DISCUSSION

To our knowledge, this is the first study to compare the receipt of specific preventive health services (i.e., vaccinations and well-child visits) between youth with and without an ASD. Our study also provides the first known comparisons of other types of health services – including primary and specialty outpatient care and acute care utilization – after adjusting for differences in comorbid health and mental health conditions. Overall, our study findings indicated that youth with an ASD were less likely to receive specific preventive services (both age groups) and have an ED visit (older youth only), but more likely to receive most other types of health services. Furthermore, case-control differences in the vaccination rates

(both ages groups) and ED use (older youth) became more pronounced in the adjusted comparisons. However, case-control differences in other categories of health services utilization became much less pronounced after adjusting for co-occurring physical and mental health conditions -- although these differences remained significant.

Although we found that youth with an ASD had more contact with their pediatrician than those without an ASD, they were less likely to receive any vaccinations, any flu shot, or any vaccination other than a flu shot. There are at least two possible explanations for this significant negative finding. Even though there is no credible research to support the association between childhood vaccinations as a potential cause of ASDs, the lingering controversy could contribute to lower rates of vaccinations among these youth (Godlee et al. 2011; Taylor et al. 1999). Data from a national survey of primary care physicians reported that family skepticism about vaccinations was more frequently endorsed as a barrier to care for patients with autism (66%) compared to patients with neurodevelopmental conditions (22%) or other complex conditions (12%) (Golnik et al. 2009). A second possible explanation for lower rates of vaccinations among this population compared to those without an ASD could be increased sensory hyper-sensitivity among youth with an ASD (Rogers and Ozonoff 2005). For youth with an ASD who experience discomfort being touched by persons or instruments (Rogers and Ozonoff 2005), their parents may be more reluctant than other parents to have their child receive any type of shot during a primary care visit.

To understand why controlling for comorbid health and mental health conditions results in an exacerbation of the difference in vaccination rates between youth with and without an ASD, it is important to consider the direction of both the *measured* and the *unmeasured* pathways that could explain these differences. Our findings indicated that youth with an ASD were more likely to have each type of comorbid condition examined, and that the association between several comorbid conditions and the receipt of vaccinations was positive and significant. This particular pathway would suggest that youth with an ASD may be more likely to receive vaccinations. Therefore, part of the negative association between having an ASD and receiving a vaccination (due to alternative pathways) was masked by these unmeasured differences in comorbidities in the unadjusted comparison. Consequently, the negative association between having an ASD and receiving any vaccination became more pronounced after comorbid conditions were included in the model.

Turning to well-child visits, our results indicated that there was no difference in the likelihood of receiving this service among younger youth with and without an ASD in the adjusted comparison. Among older youth age 10 to 17, however, those with an ASD were *less* likely to receive a well-child visit than their peers without an ASD. This finding may occur if older youth with an ASD were less likely to receive the services associated a well-child visit due to a greater complexity of the health problems discussed during the primary care visits. Prior research has reported, for example, that parents of children with special health care needs have greater expectations of discussing their child's illness and more illness topics during well-child care visits than other parents (Van Cleave et al. 2007).

At first glance, these findings appear to differ from prior research comparing the number of parent reported preventive care visits between youth with and without autism using data

from the National Survey of Children's Health (Gurney et al. 2006). In this survey, parents were asked how many times in the previous 12 months their child saw a health care provider for preventive medical care such as a *physical exam* or *well-child checkup*. Parents of children with autism (age 3 to 17) were more likely to report that their child had received any preventive care visit (84% versus 75%) and a greater number of preventive care visits (3.9 versus 2.5 visits), than parents of children without autism (Gurney et al. 2006). However, the measure of preventive service use in this prior study likely captured primary health care utilization beyond an annual check-up and well child visit, as demonstrated by the mean number of annual preventive service visits that were reported (2.5 – 3.9 visits). In this context, we interpret the findings from Gurney et. al to be consistent with our findings that youth with an ASD had more pediatrician visits than youth without an ASD.

Our results also build upon prior literature reporting greater specialty care, more outpatient visits, and an increased likelihood of hospitalizations for youth with an ASD compared to youth without an ASD (Croen et al. 2006) by examining these differences after controlling for comorbid health and mental health conditions and stratified by age groups. Overall, there were sizeable reductions in the case-control differences in these outcomes in the adjusted versus the unadjusted comparisons. When considering specialty services such as psychiatry visits, for example, results from the sequence of models we estimated suggest that the higher rate of these visits among youth with an ASD can be explained, in large part, by the higher rates of comorbid mental health disorders among this population. Similarly, the differences in the hospitalization rates among youth with an ASD in the unadjusted comparisons are substantially reduced after controlling for differences in comorbid conditions.

Furthermore, we identified larger case-control differences in the adjusted number of specialty and outpatient visits among children 3 to 9 years old than among those 10 to 17 years old. This pattern of results is consistent with prior research reporting greater outpatient expenditures among younger versus older youth with an ASD in the Medicaid program (Cidav et al. 2013). Among younger children, the most sizeable case-control differences in the adjusted comparisons were observed for speech therapy, occupational/social skills therapy, and physical therapy. These findings may be explained by more intensive efforts by health systems and/or health care providers to address deficits in social skills, communication skills, and daily functioning in specialty health care settings among youth with an ASD at earlier ages versus older ages. These findings may also occur if, as they age, youth with an ASD become more likely to receive services and interventions to improve these deficits through settings outside of the health plan, such as the educational system (Bowen 2014).

Our findings for ED use further highlight the importance of examining health care use patterns separately for different age groups and adjusting for comorbid conditions. Prior studies examining health care use in this population have reported higher rates of ED utilization among youth with an ASD than among those without an ASD when using a pooled sample for all age groups (Gurney et al. 2006) or in unadjusted comparisons (Croen et al. 2006). In the adjusted comparisons, we found that younger children with an ASD did not differ in their likelihood of having an ED visit, whereas older youth were *less* likely to have an ED visit than their peers without an ASD. One possible explanation for the lower

adjusted rate of ED use among older youth with an could be that their increased level of social isolation and decreased level of physical activity (Liptak et al. 2011; Pan and Frey 2006) place them at lower risk for accidents or injuries that lead to ED use among adolescents.

Several study limitations must be noted. First, because the data are cross-sectional, causality cannot be determined in these analyses. Second, although comprehensive measures of health care use were available within each health care system, we were unable to observe service use that occurred outside of the health plan, such as services received in educational settings or from out-of-network health care providers paid for entirely out-of-pocket (Bowen 2014; Thomas et al. 2007). Moreover, some of those with the most severe disabilities may become eligible for state-funded programs delivered outside of these health care systems (Bowen 2014). Finally, the study population included youth receiving health care in five health systems serving members mainly living in 4 US states. Thus, results may not be generalizable to youth receiving services in different health care delivery settings or in geographic regions that were not examined.

In spite of these limitations, this study provides a comprehensive comparison of health care use between youth with and without an ASD using the largest sample to date. Even though youth with an ASD had higher rates of primary care use, specialty care use, and hospitalizations, they were less likely to receive important preventive services. These findings provide a foundation for future studies to explore the potential reasons that youth with an ASD are less likely to receive specific preventive services in primary care settings. Future studies should also bolster administrative data with survey data to examine the types of services these families seek outside of their health plan and provide comprehensive comparisons of health care utilization between youth with an ASD and youth with other chronic conditions. A better understanding of the overall patterns of health care use (within and outside of the health plan), family beliefs, family preferences, and barriers to care will enable health systems to facilitate the receipt of appropriate and effective health care for youth with an ASD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

We are grateful for the analytic support provided by Matthew Lakoma (HPHCI), Jialuo Liu (KPSC), and Heather Freiman (KPGA) and for the project management support provided by Donna Rusinak (HPHCI), Magdalena E. Pomichowski (KPSC), Marta Lutsky (KPNC), and Heather Freiman (KPGA). This work was supported by the National Institute of Mental Health (grants: U19MH092201, K01MH095823).

References

- American Academy of Pediatrics. [Accessed March 2015] Well-Child Care: A Check-Up for Success. 2014. <http://www.healthychildren.org/English/family-life/health-management/Pages/Well-Child-Care-A-Check-Up-for-Success.aspx>
- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5. American Psychiatric Association; 2013. [dsm.psychiatryonline.org](http://www.dsm.psychiatryonline.org) [Accessed February 1 2015]

- Andre F, et al. Vaccination greatly reduces disease, disability, death and inequity worldwide. *Bulletin of the World Health Organization*. 2008; 86:140–146. [PubMed: 18297169]
- Bowen, SE. *Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD*. Washington D.C: L & M Policy Research, LLC; 2014.
- Centers of Disease Control and Prevention. [Accessed March 2015] People at High Risk of Developing Flu–Related Complications. 2014. http://www.cdc.gov/flu/about/disease/high_risk.htm
- Cidav Z, Lawer L, Marcus SC, Mandell DS. Age-related variation in health service use and associated expenditures among children with autism. *Journal of autism and developmental disorders*. 2013; 43:924–31.10.1007/s10803-012-1637-2 [PubMed: 22941343]
- Copeland L, Buch G. Early Intervention Issues in Autism Spectrum Disorders. *Autism: the international journal of research and practice*. 2013; 3:109.
- Croen LA, Najjar DV, Ray GT, Lotspeich L, Bernal P. 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:e1203–11.10.1542/peds.2006-0127 [PubMed: 17015508]
- Eisenberg KW, et al. Vaccine effectiveness against laboratory-confirmed influenza in children 6 to 59 months of age during the 2003–2004 and 2004–2005 influenza seasons. *Pediatrics*. 2008; 122:911–9.10.1542/peds.2007-3304 [PubMed: 18977968]
- Ferdinands JM, et al. Effectiveness of influenza vaccine against life-threatening RT-PCR-confirmed influenza illness in US children, 2010–2012. *The Journal of infectious diseases*. 2014; 210:674–83.10.1093/infdis/jiu185 [PubMed: 24676207]
- Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *Journal of autism and developmental disorders*. 2003; 33:365–82. [PubMed: 12959416]
- Fontana SA, Baumann LC, Helberg C, Love RR. The delivery of preventive services in primary care practices according to chronic disease status. *American journal of public health*. 1997; 87:1190–6. [PubMed: 9240111]
- Gadomski A, Jenkins P, Nichols M. Impact of a Medicaid primary care provider and preventive care on pediatric hospitalization. *Pediatrics*. 1998; 101:e1–e1. [PubMed: 9481020]
- Godlee F, Smith J, Marcovitch H. Wakefield’s article linking MMR vaccine and autism was fraudulent. *Bmj*. 2011; 342:c7452.10.1136/bmj.c7452 [PubMed: 21209060]
- Golnik A, Ireland M, Borowsky IW. Medical homes for children with autism: a physician survey. *Pediatrics*. 2009; 123:966–71.10.1542/peds.2008-1321 [PubMed: 19255027]
- Gurney JG, McPheeters ML, Davis MM. Parental report of health conditions and health care use among children with and without autism: National Survey of Children’s Health. *Archives of pediatrics & adolescent medicine*. 2006; 160:825–30.10.1001/archpedi.160.8.825 [PubMed: 16894082]
- Howlin P, Magiati I, Charman T. Systematic review of early intensive behavioral interventions for children with autism. *American journal on intellectual and developmental disabilities*. 2009; 114:23–41.10.1352/2009.114:23;nd41 [PubMed: 19143460]
- Hyman S, Johnson J. Autism and Pediatric Practice: Toward a Medical Home. *J Autism Dev Disord*. 2012; 42:1156–1164.10.1007/s10803-012-1474-3 [PubMed: 22411200]
- Joshi G, et al. The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: a large comparative study of a psychiatrically referred population. *Journal of autism and developmental disorders*. 2010; 40:1361–70.10.1007/s10803-010-0996-9 [PubMed: 20309621]
- Keren R, Zaoutis TE, Bridges CB, et al. Neurological and neuromuscular disease as a risk factor for respiratory failure in children hospitalized with influenza infection. *JAMA: the journal of the American Medical Association*. 2005; 294:2188–2194.10.1001/jama.294.17.2188 [PubMed: 16264160]
- Levy SE, et al. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of developmental and behavioral pediatrics: JDBP*. 2010; 31:267–75.10.1097/DBP.0b013e3181d5d03b [PubMed: 20431403]
- Liptak GS, Kennedy JA, Dosa NP. Social participation in a nationally representative sample of older youth and young adults with autism. *Journal of developmental and behavioral pediatrics: JDBP*. 2011; 32:277–83.10.1097/DBP.0b013e31820b49fc [PubMed: 21285894]

- 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; 36:871–9.10.1007/s10803-006-0119-9 [PubMed: 16855879]
- Long, JS. *Advanced Quantitative Techniques in the Social Sciences*. Thousand Oaks, CA: Sage Publications; 1997. *Count Outcomes: Regression Models for Counts Regression Models for Categorical and Limited Dependent Variables*; p. 217-250.
- Lord C, Risi S, DiLavore PS, Shulman C, Thurm A, Pickles A. Autism from 2 to 9 years of age. *Archives of general psychiatry*. 2006; 63:694–701.10.1001/archpsyc.63.6.694 [PubMed: 16754843]
- Medicode (Firm). *ICD-9-CM: International classification of diseases, 9th revision, clinical modification*. Salt Lake City, Utah: Medicode; 1996.
- Mental Health Research Network. [Accessed April 21 2015] Mental Health Research Network participating members: 13 sites across the US. 2015. <https://sites.google.com/a/mhresearchnetwork.org/mhrn/home/Members>
- Myers SM, Johnson CP. Council on Children with Disabilities. Management of children with autism spectrum disorders. *Pediatrics*. 2007; 120:1162–82.10.1542/peds.2007-2362 [PubMed: 17967921]
- Omer SB, Salmon DA, Orenstein WA, deHart MP, Halsey N. Vaccine refusal, mandatory immunization, and the risks of vaccine-preventable diseases. *The New England journal of medicine*. 2009; 360:1981–8.10.1056/NEJMs0806477 [PubMed: 19420367]
- Pan CY, Frey GC. Physical activity patterns in youth with autism spectrum disorders. *Journal of autism and developmental disorders*. 2006; 36:597–606.10.1007/s10803-006-0101-6 [PubMed: 16652237]
- Rogers SJ, Ozonoff S. Annotation: what do we know about sensory dysfunction in autism? A critical review of the empirical evidence. *Journal of child psychology and psychiatry, and allied disciplines*. 2005; 46:1255–68.10.1111/j.1469-7610.2005.01431.x
- Selden TM. Compliance with well-child visit recommendations: evidence from the Medical Expenditure Panel Survey, 2000–2002. *Pediatrics*. 2006; 118:e1766–78.10.1542/peds.2006-0286 [PubMed: 17142499]
- Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *J Am Acad Child Adolesc Psychiatry*. 2008; 47:921–9.10.1097/CHI.0b013e318179964f [PubMed: 18645422]
- StataCorp LP. *Stata Statistical Software*. 13.1. College Station, TX: 2013.
- Taylor B, et al. Autism and measles, mumps, and rubella vaccine: no epidemiological evidence for a causal association. *Lancet*. 1999; 353:2026–9. [PubMed: 10376617]
- Thomas KC, Ellis AR, McLaurin C, Daniels J, Morrissey JP. Access to care for autism-related services. *Journal of autism and developmental disorders*. 2007; 37:1902–12.10.1007/s10803-006-0323-7 [PubMed: 17372817]
- U.S. Census Bureau. *United States Census. American Community Survey; 2000, 2006–2010*. <http://www.census.gov/acs/www/>
- Van Cleave J, Davis MM. Preventive care utilization among children with and without special health care needs: associations with unmet need. *Ambulatory pediatrics: the official journal of the Ambulatory Pediatric Association*. 2008; 8:305–11.10.1016/j.ambp.2008.04.003 [PubMed: 18922504]
- Van Cleave J, Heisler M, Devries JM, Joiner TA, Davis MM. Discussion of illness during well-child care visits with parents of children with and without special health care needs. *Archives of pediatrics & adolescent medicine*. 2007; 161:1170–5.10.1001/archpedi.161.12.1170 [PubMed: 18056562]
- Yarnall KS, Pollak KI, Ostbye T, Krause KM, Michener JL. Primary care: is there enough time for prevention? *American journal of public health*. 2003; 93:635–41. [PubMed: 12660210]

Characteristics of youth identified with an autism spectrum disorder (ASD) and a matched sample of controls in five not-for-profit health systems

Table 1

	Age 3-9			Age 10-17		
	With ASD (n=3,926)	Without ASD (n=39,244)	p-value	With ASD (n=4,399)	Without ASD (n=43,951)	p-value
	Mean (S.D.)/%	Mean (S.D.)/%		Mean (S.D.)/%	Mean (S.D.)/%	
<i>Demographics</i>						
Age (years)	6.2 (1.9)	6.2 (1.9)	0.999	13.2 (2.2)	13.2 (2.2)	0.990
Male gender (%)	82.7	82.7	0.980	82.0	82.0	0.991
<i>Race/ethnicity</i>						
White Non-Hispanic (%)	35.8	28.8	p<.0001	44.9	30.9	p<.0001
Black Non-Hispanic (%)	8.1	7.5		6.8	8.3	
Hispanic (%)	29.3	32.4		22.2	30.3	
Asian (%)	11.7	10.2		7.8	7.5	
Other/Mixed Race (%)	1.9	1.6		1.9	1.6	
Unknown/Missing (%)	13.2	19.5		16.5	21.5	
<i>Comorbidities</i>						
<i>Physical Health</i>						
Asthma (%)	13.3	12.9	0.523	10.1	10.3	0.740
Allergy (%)	40.7	36.6	p<.0001	31.8	29.8	0.005
Autoimmune disorder (%)	12.4	7.8	p<.0001	6.6	5.9	0.047
Cardiovascular disorder (%)	2.5	1.9	0.012	3.3	2.1	p<.0000
Endocrine disorder (%)	1.4	0.6	p<.0001	2.3	0.9	p<.0000
Genetic disorder (%)	7.7	3.1	p<.0001	12.7	5.0	p<.0000
Epilepsy (%)	7.5	0.9	p<.0001	8.9	0.7	p<.0001
Neurological disorder (%)	22.6	6.9	p<.0001	19.0	10.1	p<.0000
Sleep disorder (%)	3.8	1.0	p<.0001	6.0	0.8	p<.0000
<i>Mental Health</i>						
ADHD (%)	15.7	3.1	p<.0001	36.5	7.9	p<.0001
ODD/CD (%)	4.2	0.9	p<.0001	7.3	1.5	p<.0001
Anxiety (%)	4.9	1.0	p<.0001	18.5	3.0	p<.0001

	Age 3–9				Age 10–17			
	With ASD (n=3,926)	Without ASD (n=39,244)	p-value	Mean (S.D.)/%	With ASD (n=4,399)	Without ASD (n=43,951)	p-value	Mean (S.D.)/%
Depression (%)	0.4	0.1	p<.0001	8.3	2.4	p<.0001	8.3	2.4
Other Serious Mental Illness (%)	0.6	0.03	p<.0001	4.9	0.4	p<.0001	4.9	0.4
Substance Use Disorder (%)	-	-	-	0.3	0.9	p<.0001	0.3	0.9
<i>Median Household Income[†]</i>	\$63,226 (\$25,987)	\$62,373 (\$25,787)	0.049	\$ 66,666 (\$27,680)	\$62,919 (\$26,284)	p<.0001	\$ 66,666 (\$27,680)	\$62,919 (\$26,284)

Notes: Age and gender were two of the variables used to identify the sample of matched controls of those without an ASD. Fisher's exact test (other serious mental illness, age 3–9) and chi-squared tests (all other outcomes) were performed to compare gender, race/ethnicity, and comorbid health and mental health conditions across samples. Two-sample t-tests were performed to compare age and median household income across samples

[†] 221 youth age 3–9 and 244 youth age 10–17 have missing information about area-level income

Table 2
Preventive care utilization among children with and without ASD in five health systems (2010)

	Age 3–9				Age 10–17			
	With ASD		Without ASD		With ASD		Without ASD	
	%	%	Unadjusted [§]	Adjusted [±]	%	%	Unadjusted [§]	Adjusted [±]
<i>Ary Vaccination (%)</i>	34.1	38.1	-4.0***	-5.2***	33.7	35.4	-1.7*	-3.5***
<i>Any Flu Shot (%)</i>	17.1	20.0	-3.0***	-4.2***	15.2	15.5	-0.3	-2.1***
<i>Any Other Vaccination (%)</i>	23.2	25.3	-2.1**	-2.4***	24.3	26.5	-2.2**	-3.1***
<i>Ary Well Child Visit (%)</i>	56.0	54.3	1.8*	0.9	41.9	44.1	-2.2**	-1.8*

Notes

* p<0.05,

** p<0.01,

*** p<0.001

[§] Age 3 – 9; N=43,170; Age 10 – 17; N=48,350. Unadjusted differences were calculated by subtracting the value of the outcome for controls from the value for cases (There may be slight differences in these numbers presented in the table due to rounding).

[±] Age 3 – 9; N=42,949; Age 10 – 17; N=48,106 (Individuals missing on income were excluded). Adjusted differences come from logistic regression models controlling for sociodemographic characteristics, physical and mental health comorbidities, length of enrollment in 2009, drug coverage enrollment, and health care system of enrollment.

Table 3
 Primary, specialty, and acute care utilization among children with and without ASD in five health systems (2010)

	Age 3-9				Age 10-17			
	With ASD	Without ASD	Difference (Percentage Point/#)	Without ASD	With ASD	Difference (Percentage Point/#)	Without ASD	With ASD
	%/Mean (S.D.)	%/Mean (S.D.)	Unadjusted [§]	%/Mean (S.D.)	%/Mean (S.D.)	Unadjusted [§]	%/Mean (S.D.)	%/Mean (S.D.)
Primary Care								
<i>Any Pediatric Visit (%)</i>	92.5	87.3	5.2***	81.9	79.5	2.4***	81.9	79.5
<i>Total Pediatric Visits (#)</i>	4.9 (7.2)	3.0 (3.3)	1.9***	3.1 (4.0)	2.3 (2.6)	0.8***	3.1 (4.0)	2.3 (2.6)
Specialty Care								
<i>Any Specialty Care Visit^a (%)</i>	40.0	5.9	34.2***	36.6	10.8	25.9***	36.6	10.8
<i>Any Speech Therapy (%)</i>	14.2	1.3	12.9***	2.6	0.3	2.4***	2.6	0.3
<i>Any Occupational Therapy and/or Social Skills Therapy Visit (%)</i>	16.1	1.0	15.1***	4.9	2.8	2.1***	4.9	2.8
<i>Any Physical Therapy Visit (%)</i>	11.1	0.7	10.4***	3.6	2.2	1.4***	3.6	2.2
<i>Any Psychotherapy Visit (%)</i>	13.6	2.7	10.9***	23.4	6.4	17.0***	23.4	6.4
<i>Any Neurology Visit (%)</i>	14.5	1.4	13.1***	12.9	1.8	11.1***	12.9	1.8
<i>Total Specialty Care Visits^a (#)</i>	5.6 (24.1)	0.3 (2.6)	5.4***	2.2 (7.1)	0.5 (3.1)	1.7***	2.2 (7.1)	0.5 (3.1)
All Outpatient Care								
<i>Any Outpatient Visit (%)</i>	97.4	92.0	5.4***	95.7	90.0	5.8***	95.7	90.0
<i>Total Outpatient Visits (#)</i>	11.9 (21.5)	4.0 (5.1)	7.9***	4.8***	4.0 (5.6)	5.0***	4.8***	4.0 (5.6)
Acute Care								
<i>Any Emergency Dept. Visit (%)</i>	20.4	15.3	5.1***	14.1	14.6	-0.5	14.1	14.6
<i>Any Inpatient Stay (%)</i>	3.7	1.3	2.4***	4.0*	1.6	2.5***	4.0*	1.6

Notes:
 * p<0.05,

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**

p<0.001

§ Age 3 – 9; N=43,170; Age 10 – 17; N=48,350. Unadjusted differences were calculated by subtracting the value of the outcome for controls from the value for cases. (There may be slight differences in these numbers presented in the table due to rounding).

± Age 3 – 9; N=42,949; Age 10 – 17; N=48,106 (Individuals missing on income were excluded.) Adjusted differences come from logistic and count data regression models controlling for sociodemographic characteristics, physical and mental health comorbidities, length of enrollment in 2009, drug coverage enrollment, and health care system of enrollment.

^a Includes only the five types of specialty care examined (psychotherapy, speech therapy, neurology, occupational & social skills therapy, and physical therapy).