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The Transition to the Adult Health Care System Among Youths with Autism Spectrum Disorder

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Abstract

Objective—The study examines how healthcare utilization patterns change as youths diagnosed with autism spectrum disorder (ASD) transition into the adult healthcare system.

Methods—Data come from the Clinformatics™ Data Mart Database, a nationally diverse, clinically rich, private insurance claims database. The analytic sample consists of youths 16-23 diagnosed with ASD (N=16,338). Cross-sectional multivariate linear regressions determine if service usage differs by age across the home, office/outpatient, inpatient, and emergency department (ED) settings.

Results—The proportion of youths with ASD who receive services declines with age in each setting other than the ED. A similar reduction exists in the total number of visits in the office/outpatient and inpatient settings, while home and ED visits remain stable. Youths with co-occurring intellectual disability experience a faster decline in service utilization.

Conclusions—There is a notable decline in service utilization across multiple settings as youths with ASD transition from pediatric to adult healthcare.

Introduction

The transition from adolescence to adulthood is recognized as a critical crossroad in health care by the American Academy of Pediatrics (AAP), requiring appropriate coordination to ensure high-quality, developmentally appropriate health care services are available without interruption.¹ This transition is a noted challenge for children with special healthcare needs (SHCN).² Children with autism spectrum disorder (ASD), especially those who are diagnosed with a co-occurring medical or psychiatric condition that requires frequent and intensive care,³ may experience additional difficulties.⁴

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The autism literature on the transition to adulthood is not well developed. Approximately one in five children with ASD receive transition-planning services, compared to 43% of other CSHCN.⁵ However, little research has explicitly explored the change in service usage as children with ASD transition out of the pediatric healthcare system.⁶ In addition, the transition from the pediatric healthcare system often coincides with an exit from the educational system (i.e. leaving high school), where many children may receive everyday physical and mental health services.⁷ This distinct transition can further affect service usage.

This study explores the healthcare utilization of youths ages 16-23 diagnosed with ASD, utilizing a nationally diverse population of privately insured youths. The study seeks to determine if there are changing utilization patterns among youths with ASD as they transition into the adult healthcare system.

Methods

Data come from the Clinformatics™ Data Mart Database ('Optum'; OptumInsight, Eden Prairie, MN; for more information visit <http://bit.ly/2dhTl4d>), a nationally diverse, clinically rich administrative dataset of de-identified privately insured beneficiaries spanning 2000-2013. The data include individuals' full claims history during their entire enrollment period, including place of service and pharmacy prescriptions, covering approximately 55 million US individuals. It was possible to link multiple visits to the same individual.

The analytic sample (N=16,338 with 48,007 total episodes within a 12 month period) includes all youths between the ages of 16 and 23 within the Optum database that have at least one inpatient or two outpatient/office claims with an International Classification of Diseases (ICD-9) 299.xx primary diagnosis (Autistic disorder-299.0; Childhood disintegrative disorder-299.1; Specific pervasive developmental disorder (PDD)-299.8; Nonspecific PDD-299.9). This classification scheme has been used in a previous study examining a population of children with ASD in an administrative database.⁸ Once a youth was identified in the sample, all claims were included for that youth for the entire time they were observed in the Optum database. A binary measure was created for whether the youth was also diagnosed with an intellectual disability (ID) (ICD-9 317.xx-319.xx) as indicated by one inpatient claim or two outpatient/office claims within a 12 month period. Year of birth allowed for approximating age at the time of services. The analytic sample for the current study can be conceptualized as repeated cross-sections of privately insured youths with ASD.

Healthcare utilization is assessed across four places of service: office/outpatient, home, inpatient, and emergency department (ED). Both the percentage of youths receiving care at a given age and the average number of visits per year are assessed. The data are modeled as cross-sectional multivariate linear regressions for each outcome in each place of service. Models are adjusted for sex, race/ethnicity (non-Hispanic white, non-Hispanic black, non-Hispanic Asian, Hispanic), region (Northeast, Midwest, South, West), household net worth (<\$25,000, \$25,000-\$149,999, \$150,000-\$249,999, \$250,000-\$499,999, \$500,000), year of visit, the presence of ID, and whether or not the insurance product was administrative services only (ASO). An ASO plan is an arrangement in which an employer hires a third

party to deliver health-related administrative services to the employer, such as claims processing and billing; the employer directly bears the financial costs and risk for its employees' healthcare. As youths could have claims across years, all analyses were clustered at the individual level to account for a lack of independence between observations.

Age is modeled continuously, and interactions between age and ID were included for each place of service, drawing from differences seen in treatment usage in previous research.⁹ Interactions between age and region were included when findings were statistically significant. Other interactions between age and race, net worth, and sex were tested but are not included as findings were not consistently significant. Estimates were calculated using Stata 13.0 SE.

Results

Youths included in the sample were primarily non-Hispanic white (78.0%) and male (78.1%), and 15.1% of youths were diagnosed with an ID. Additionally, over one-quarter of youths lived in households with a net worth between \$150,000-\$249,999 (27.8%), while only 7.4% lived in households with a net worth of less than \$25,000. The majority of families lived in the Midwest (35.1%) or South (36.9%), with fewer families in the Northeast (14.0%) or West (13.9%) (see online supplemental Table A for demographic characteristics). In a given year, the majority of children received services in office/outpatient settings (98.56%), which was greater than the proportion who received care in home (9.80%), inpatient (6.60%) or ED (10.72%) settings. Likewise, youth received the most visits in office/outpatient settings ($\bar{x}=11.22$) compared to home ($\bar{x}=0.82$), inpatient ($\bar{x}=0.89$) and the ED ($\bar{x}=0.52$).

Multivariate regression results indicate the percentage of youths with ASD receiving care and the total number of visits per year decreased as youths with ASD aged (see online supplemental Table B for yearly descriptive means). The percentage receiving care in the outpatient/office decreased .19% each year ($p<.001$), whereas the number of visits per year also decreased ($\beta= -.38$, $p<.001$; see Table 1). Youths experienced a similar decline in the inpatient setting with a smaller percentage receiving services ($\beta= -.32\%$, $p<.01$) and fewer visits per year ($\beta= -.05$, $p<.001$). Although a smaller percentage of youths received home services as they aged ($\beta= -.14\%$, $p<.05$), the number of visits per year did not significantly decline. The use of the ED did not appear to be related to the youth's age, with no decline noted in the percentage of youths receiving services or in the number of visits per year.

Youths with both ASD and ID had greater utilization of services in the home ($\beta= 12.16\%$, $p<.001$) and inpatient settings ($\beta= 6.25\%$, $p<.001$) than youths with ASD only. These youths also had a higher number of visits per year in the home ($\beta=2.09$, $p<.001$), outpatient/office ($\beta=1.82$, $p<.001$), and inpatient settings ($\beta=.69$, $p<.001$) than youths with ASD only. Interestingly, youths with ASD and ID had, on average, fewer ED visits per year when compared to youths without ID ($\beta= -.10$, $p<.05$). As they age, however, there is some evidence to suggest that utilization for youths with ASD and ID decreases more rapidly than that of youths with only ASD. The steeper rate of decline equates to an additional decrease of .22 visits per year in the outpatient setting ($p<.05$) and an additional .53% decrease per

year in the likelihood of using inpatient services ($p=.01$). Youths with ID continue to have a higher amount of service utilization in the office/outpatient, home, and inpatient settings than youths without ID as they age.

The results also indicate that utilization and the decline in utilization can vary by region. Youths residing in the Northeast use a greater quantity of office/outpatient services than elsewhere and are more likely to utilize services in this setting than youths living in the South and Midwest ($p's<.001$). Youths in the Northeast are less likely to utilize services in the home and emergency department settings than youths living in the Midwest and West($p's<.001$). Service utilization in the office/outpatient setting declines .38 visits per year faster for youths with ASD residing in the Midwest as compared to the Northeast ($p<.01$). Midwestern youths also experience a faster decline in inpatient utilization ($\beta= -.57\%$, $p<.05$) when compared to youths in the Northeast.

Discussion

As youths with ASD transition out of the pediatric healthcare system, there is a notable decline in both the percentage of youths that receive services and the total number of visits per year across multiple settings. The results also indicate an increased use of services among youths with both ASD and ID compared to youths diagnosed with ASD only, findings which have been replicated in a previous nationally representative sample.⁹ Children with both diagnoses have been found to belong to families with greater financial hardships and poorer insurance coverage than children with ASD only.¹⁰ The faster decline in total yearly office/outpatient visits and in the percentage receiving inpatient services found in the current study may underline the challenges already faced by youths with ASD who also have ID.

The steady use of the ED as youths age may be tied to ongoing need for the services provided at these locations, especially if the ED is used as a substitute source of care as utilization declines elsewhere.¹¹ Significant differences by region could be tied to specific unmet treatment needs¹² but future research is needed to further explore the mechanisms behind the geographical variation associated with service utilization.

The current study presents data from a nationally drawn population of youths diagnosed with ASD. The data provides a unique opportunity to explore the healthcare utilization landscape in the private insurance market. However, there are several limitations of note. The sample does not generalize to individuals covered by other private insurance carriers, nor those receiving public services. Further, the high proportion of non-Hispanic white youths in the sample and their relatively high net worth and lower rate of intellectual disability may be a reflection of the type of individuals enrolled in the private insurance plan. The accuracy of the ASD diagnosis is based solely on claims information – clinicians may have omitted a youth's ASD diagnosis when submitting billing information, resulting in a potential missed case in the current analysis. Finally, the cross-sectional nature of the data does not allow for causal claims.

Conclusions

While an increase in the prevalence of diagnosed ASD among children in the United States has received considerable attention recently, less attention has been paid to the possibility of an eventual corresponding increase in prevalence of adults with diagnosed ASD.¹³ Our results of significant declines in service usage of youths diagnosed with ASD reinforce the AAP's view that the transition from adolescence to adulthood is a critical crossroad in health care. These findings highlight the need for continued research into the transition into the adult healthcare system for youth with ASD, and particularly those with co-occurring ID.

One possible explanation for the decline in service use could be that many practitioners of adult medicine lack specialized training to meet the unique service needs of individuals with ASD.¹⁴ Without such training some practitioners may feel uncomfortable treating these patients. The impact of this capability gap may be magnified by the low level of healthcare transition services received by youths with ASD.¹⁵ Future research could examine the relationship between specialized training among practitioners of adult medicine and transition services for youth with ASD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1
Annual change in service utilization among youths with ASD ages 16-23

Place of Service	Percentage with a Visit	Average Number of Visits
Office/Outpatient	-.19% ***	-.38 ***
Home	-.14% *	-.03
Inpatient	-.32% **	-.05 ***
Emergency Department	<.01%	.01
N	48,007	48,007

*
 $p < .05$

**
 $p < .01$

 $p < .001$

Select results reported from multivariate cross-sectional analyses controlling for sex, race, diagnostic status, region, household net worth, insurance type, and year fixed effects.

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