

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

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Objective: The study examined how health care utilization patterns among youths with autism spectrum disorder (ASD) change as they transition into the adult health care system.

Methods: Data came from the Clinformatics Data Mart Database, a nationally diverse, clinically rich, private insurance claims database. The analytic sample consisted of youths ages 16 to 23 who were diagnosed as having ASD (N=16,338). Cross-sectional multivariate linear regressions determined whether service usage in home, office or outpatient, inpatient, and emergency department (ED) settings differed by age.

Results: The proportion of youths with ASD who received services declined with age in each setting except the ED. A similar reduction existed in number of visits to office or outpatient settings and inpatient settings, while home and ED visits remained stable. Service utilization declined faster among youths with co-occurring intellectual disability.

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

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

The autism literature on the transition to adulthood is not well developed. Approximately one in five children with ASD receive transition-planning services, compared with 43% of other children with special health care needs (5). However, little research has explicitly explored the change in service usage among children with ASD as they transition out of the pediatric health care system (6). In addition, the transition from the pediatric health care system often coincides with an exit from the educational system (for example, 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 explored the health care utilization of youths ages 16 to 23 diagnosed with ASD, utilizing a nationally diverse population of privately insured youths. The study sought to determine whether utilization patterns among

youths with ASD change as they transition into the adult health care system.

METHODS

Data came from the Clinformatics Data Mart Database ('Optum'; OptumInsight, Eden Prairie, Minnesota), a nationally diverse, clinically rich administrative data set of deidentified, privately insured beneficiaries spanning 2000–2013 (<http://bit.ly/2dhTl4d>). The data include individuals' full claims history during their entire enrollment period, including place of service and pharmacy prescriptions, covering approximately 55 million individuals in the United States. It was possible to link multiple visits to the same individual.

The analytic sample (16,338 individuals with 48,007 total episodes within a 12-month period) included all youths between the ages of 16 and 23 within the Optum database who had at least one inpatient or two outpatient or office claims with an ICD-9 primary diagnosis of 299.x pervasive developmental disorder (autistic disorder, 299.0; childhood disintegrative disorder, 299.1; specific pervasive developmental disorder [PDD], 299.8; and nonspecific PDD, 299.9). This classification scheme was used in a previous study that examined a population of children with ASD in an administrative database (8). Once a youth was identified in the sample, all claims for that youth were included for the entire time that he or she was observed in the Optum database. A

TABLE 1. Annual change in service utilization (visits) among youths with autism spectrum disorder ages 16 to 23, by setting^a

Setting	Youths with a visit (%)	Average N of visits
Office or outpatient	-.19***	-.38***
Home	-.14*	-.03
Inpatient	-.32**	-.05***
Emergency department	<.01	.01

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

* $p < .05$, ** $p < .01$, *** $p < .001$

binary measure was created for whether the youth was also diagnosed as having an intellectual disability (ID) (ICD-9 codes 317.x–319.x), as indicated by one inpatient claim or two outpatient or office claims within a 12-month period. Year of birth allowed for approximating age at the time of services. The analytic sample for this study can be conceptualized as repeated cross-sections of privately insured youths with ASD.

Health care utilization was assessed across four places of service: office or outpatient setting, home setting, inpatient setting, and emergency department (ED) setting. Both the percentage of youths receiving care at a given age and the average number of visits per year were assessed. The data were modeled as cross-sectional multivariate linear regressions for each outcome in each place of service. Models were adjusted for sex, race-ethnicity (non-Hispanic white, non-Hispanic black, non-Hispanic Asian, and Hispanic), region (Northeast, Midwest, South, and West), household net worth (<\$25,000, \$25,000–\$149,999, \$150,000–\$249,999, \$250,000–\$499,999, and \geq \$500,000), year of visit, the presence of ID, and whether 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' health care. Because youths could have claims across years, all analyses were clustered at the individual level to account for a lack of independence between observations.

Age was modeled continuously, and interactions between age and ID were included for each place of service, drawing from differences in treatment usage seen 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 were not included, given that findings were not consistently significant. Estimates were calculated by using Stata, version 13.0 SE.

RESULTS

Youths included in the sample were primarily non-Hispanic white ($N=12,747$, 78.0%) and male ($N=12,752$, 78.1%), and 15.1% ($N=2,474$) were diagnosed as having an ID. In addition,

over one-quarter of youths lived in households with a net worth between \$150,000 and \$249,999 ($N=4,540$, 27.8%), whereas only 7.4% ($N=1,217$) lived in households with a net worth of less than \$25,000. Most families lived in the Midwest (35.1%) or South (36.9%), with fewer families in the Northeast (14.0%) or West (13.9%) (percentages are approximate because of geographic mobility as the youth aged). [A table reporting demographic characteristics of the sample is available as an online supplement to this report.] In a given year, a majority of children received services in office or outpatient settings (98.6%), which was greater than the proportion who received care in home (9.8%), inpatient (6.6%), or ED (10.7%) settings. Likewise, youths received the most visits in office or outpatient settings (a mean of 11.22 per youth), compared with home (.82), inpatient settings (.89), and the ED (.52).

Multivariate regression results indicated the percentage of youths with ASD receiving care and the total number of visits per year decreased as youths with ASD aged [see online supplement for yearly descriptive means]. The percentage of individuals receiving care in outpatient or office settings decreased by .19% each year ($p < .001$), whereas the number of visits per year in these settings also decreased ($\beta = -.38$, $p < .001$) (Table 1). Youths experienced a similar decline in service utilization within inpatient settings, 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.

The percentage of youths with a visit in a home or inpatient setting was higher among youths with both ASD and ID compared with youths with ASD only ($\beta = 12.16\%$ and 6.25%, respectively, $p < .001$ for both comparisons). Youths with both ASD and ID also had a higher number of visits per year in the home ($\beta = 2.09$), outpatient or office ($\beta = 1.82$), and inpatient settings ($\beta = .69$), compared with youths with ASD only ($p < .001$ for all comparisons). Notably, youths with ASD and ID had, on average, fewer ED visits per year compared with youths with ASD only ($\beta = -.10$, $p < .05$). However, there is some evidence to suggest that utilization of services decreases more rapidly among youths with ASD and ID as they age compared with youths with only ASD. The steeper rate of decline equated 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 continued to have a higher amount of service utilization in the office or outpatient, home, and inpatient settings as they aged compared with youths without ID.

The results also indicate that utilization of services and the decline in utilization can vary by region. Youths residing in the Northeast used a greater quantity of office or

outpatient services compared with youths living elsewhere and were more likely than youths living in the South and Midwest to utilize services in this setting ($p < .001$ for all comparisons). Youths in the Northeast were less likely to utilize services in the home and ED compared with youths living in the Midwest and West ($p < .001$ for all comparisons). Service utilization in office or outpatient settings declined faster, by an additional .38 visits per year, for youths with ASD residing in the Midwest compared with the Northeast ($p < .01$). Midwestern youths also experienced a faster decline in inpatient utilization compared with youths in the Northeast ($\beta = -.57\%$, $p < .05$).

DISCUSSION

As youths with ASD transition out of the pediatric health care system, there is a notable decline in both the percentage of youths who 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 with youths diagnosed as having ASD only, findings that have been replicated previously in a 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 visits in office or outpatient settings and in the percentage of individuals receiving inpatient services among children with both diagnoses compared with children with ASD only may underline the challenges already faced by youths with ASD and ID.

The steady use of the ED by youths as they 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 needs (12), but future research is needed to further explore the mechanisms behind the geographical variation associated with service utilization.

This study presented data from a nationally drawn population of youths diagnosed as having ASD. The data provide a unique opportunity to explore the health care utilization landscape in the private insurance market. However, there were several limitations of note. The sample does not generalize to individuals covered by other private insurance carriers, nor to 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 ID may be a reflection of the type of individuals enrolled in the private insurance plan. The accuracy of the ASD diagnosis was 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 this analysis. Finally, the cross-sectional nature of the data does not allow for causal claims.

CONCLUSIONS

Although 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 findings of significant declines in service usage among youths diagnosed as having ASD reinforce the AAP's view that the transition from adolescence to adulthood is a critical crossroads in health care. These findings highlight the need for continued research into the transition into the adult health care system for youths with ASD, 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 health care 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 youths with ASD.

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REFERENCES

1. Cooley WC, Sagerman PJ: Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 128: 182–200, 2011
2. Stewart D: Transition to adult services for young people with disabilities: current evidence to guide future research. *Developmental Medicine and Child Neurology* 51(suppl 4):169–173, 2009
3. Levy SE, Giarelli E, Lee LC, 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* 31:267–275, 2010
4. Liptak GS, Stuart T, Auinger P: Health care utilization and expenditures for children with autism: data from US national samples. *Journal of Autism and Developmental Disorders* 36:871–879, 2006
5. Cheak-Zamora NC, Yang X, Farmer JE, et al: Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics* 131:447–454, 2013

6. Roux AM, Shattuck PT, Rast JE, et al: National Autism Indicators Report: Transition Into Young Adulthood. Philadelphia, Drexel University, Drexel Autism Institute, Life Course Outcomes Research Program, 2015
7. Kang-Yi CD, Locke J, Marcus SC, et al: School-based behavioral health service use and expenditures for children with autism and children with other disorders. *Psychiatric Services* 67:101–106, 2016
8. 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* 43:924–931, 2013
9. Zablotsky B, Pringle BA, Colpe LJ, et al: Service and treatment use among children diagnosed with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics* 36:98–105, 2015
10. Zablotsky B, Kalb LG, Freedman B, et al: Health care experiences and perceived financial impact among families of children with an autism spectrum disorder. *Psychiatric Services* 65:395–398, 2014
11. Mandell DS, Xie M, Morales KH, et al: The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine* 166:68–73, 2012
12. Chiri G, Warfield ME: Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Journal of Maternal and Child Health* 16:1081–1091, 2012
13. Leigh JP, Du J: Brief report: forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of Autism and Developmental Disorders* 45:4135–4139, 2015
14. 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* 42:2498–2504, 2012
15. Cheak-Zamora NC, Farmer JE, Mayfield WA, et al: Health care transition services for youth with autism spectrum disorders. *Rehabilitative Psychology* 59:340–348, 2014

Submissions Invited for Culture & Mental Health Services Column

A new column in *Psychiatric Services*, Culture & Mental Health Services, edited by Roberto Lewis-Fernández, M.D., aims to clarify the ways that culture shapes the utilization, delivery, and organization of mental health services. Submissions may examine the influence of culture at the level of the individual seeking care (e.g., the impact of a person's cultural views of illness on treatment choice and level of engagement), the provider (e.g., the role of implicit racial-ethnic biases on service recommendations), the program (e.g., how local socioeconomic and organizational factors influence the package of services offered at a clinic), or the mental health system (e.g., how political forces affect reimbursement structures that determine availability of services). Dr. Lewis-Fernández welcomes papers that focus on aspects of culture related to interpretation (meaning making), social group identity (e.g., race-ethnicity, language, and sexual orientation), and social structures and systems. The goal of the column is to make visible the social-contextual frameworks that shape care. Papers, limited to 2,400 words, may be submitted online as columns via ScholarOne Manuscripts at mc.manuscriptcentral.com/appi-ps. The cover letter should specify that the submission is for the Culture & Mental Health Services column.