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Mental Health Service Use Among Adolescents with an Autism Spectrum Disorder

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Abstract

Objective—This study examined prevalence and correlates of mental health service use among adolescents with an autism spectrum disorder (ASD).

Methods—Data from the National Longitudinal Transition Study-2 (NLTS2) was used to examine mental health service use among youth with an ASD (n=920). Nationally representative estimates generalize to students enrolled in the special education autism category. Regression models examined the association of predisposing, enabling, and need factors with service use overall then with receiving these services at school.

Results—Overall, 46% had used a mental health service in the past year. Of those that received a service, 49% had received it at school. Need variables were the strongest correlates of service use. African American youths, and youths from lower income families were more likely to receive school-based services.

Conclusion—The school plays a key role in providing services, especially for vulnerable populations. Focused attention on these youths is needed to ensure continuity of care as they leave high school.

Introduction

Youths with an autism spectrum disorder (ASD – Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder-Not Otherwise Specified) are at high risk for co-morbid mental health problems (1, 2). As many as 70% have at least one co-morbid mental disorder (2) that may warrant mental health treatment. In addition, mental health services are often provided to address behavioral problems and aggression (3), commonly associated features of an ASD diagnosis. Little is known, however, about the rate of mental health service use among these youths. Regional findings suggest that mental health services may be underutilized by youths with an ASD (4) but studies have not reported on national rates.

Schools play a central role in both providing and coordinating mental health services for all adolescents (5–6). A prior study of service use among adolescents across multiple sectors

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found that schools provided 70–80% of the mental health services received and for most youths was the only source of care (6). As growing numbers of youths with an ASD are identified and served through special education (7), it is important to understand the role of the school in providing mental health services to these youths. We examined the prevalence and correlates of mental health service use overall, then the correlates of receiving a mental health service from school among the subgroup that had used a mental health service. We grouped variables into predisposing factors that make an individual more likely to seek care, enabling resources that facilitate access, and need variables, in accordance with Andersen's behavioral model (8). This study fills a gap in our knowledge by providing nationally representative information on mental health service use patterns of a population at high risk for mental health problems.

Methods

We used data from the first wave of the National Longitudinal Transition Study-2 (NLTS2), a nationally representative study of adolescents in special education. A two stage sampling procedure was used and estimates were weighted to generalize to all students age 13–16, in special education in 2000. Further details of the study sample design and weighting have been previously reported (9).

Data were collected in 2001 through telephone interviews with parents or guardians of youths age 13–17 administered in English or Spanish. Parents who were not reached by telephone were mailed a shortened self-administered questionnaire. Parents or guardians of 920 youths in the special education autism enrollment category responded, a response rate of 83.5%. Use of these data is governed by a data use agreement with the U.S. Department of Education and was approved by the University Institutional Review Board. All unweighted sample size numbers were rounded to the nearest ten as required by the data use agreement.

Youths in the sample were selected based on classification into the special education reporting category of autism which does not require a DSM-IV diagnosis of autism, hence we do not have information about the specific type of ASD (i.e. Aspergers, Autistic Disorder or PDD-NOS). Epidemiological surveillance data have found that 99% of children served under the autism educational designation also meet DSM-IV criteria for an ASD (10). However, some youths who meet diagnostic criteria for an ASD may be served under another eligibility category and would not be included in this analysis.

Mental health service use was assessed by asking, "During the past 12 months, has (youth) received any psychological or mental health services or counseling?" Respondents that answered affirmatively were asked a follow-up question to determine whether the services had been through the school. The data did not allow us to determine if youths receiving services in school were also receiving services outside of school. We included gender, race, ethnicity, and parental education as predisposing variables since these often serve as proxies for beliefs about mental health treatments. Language impairment was also considered a predisposing characteristic as lack of speaking ability may limit the perceived appropriateness of mental health services. An indicator for severe language impairment was created for youths who have a lot of trouble speaking clearly or don't speak at all.

Enabling resources included income, health insurance status, case management, having a diagnostic medical evaluation in the past year, and parent and youth involvement in individualized education planning (IEP) meetings. A sequence of questions about insurance status was recoded into private and government/other insurance for analysis. Two dichotomous indicators asked about parent and youth attendance at the most recent IEP meeting.

Measures of need included parent-reported co-morbid Attention Deficit Hyperactivity Disorder (ADHD), social skills, and experiences of bullying. We included ADHD because it is a common co-morbidity among youths with an ASD (2). Unfortunately, the survey did not directly ask parents about other types of comorbidities. Social skills were measured using eleven items drawn from the Social Skills Rating System (SSRS) Parent Form (11), with higher scale scores indicating greater skill. Bullying victimization was measured by collapsing three questions about whether youth had been bullied, teased, or physically attacked at school. Another question asked whether the youth had bullied others.

One logistic regression model examined use of mental health services among all youths with an ASD. A second logistic regression model examined the use of school-based mental health services among the subset of youths that had received any mental health services. Twenty multiply imputed data sets were created using sequential regression in IVEware to handle missing data (12). All estimates are population estimates. Analyses were weighted and variances were adjusted to account for the sampling design and imputation using Stata 11.

Results

The majority of youths were male (85%) with a mean age of 15.0±1.2. The sample was 65% white, 22% African-American, and 13% other/mixed race. Eleven percent identified as Hispanic. Overall, 46% of respondents reported their child had received a mental health service in the past 12 months. Of those that had received any service, 49% had received a service through the school or district.

Use of mental health counseling overall did not vary significantly by predisposing characteristics. African-Americans had greater odds of receiving services at school. Several enabling resources were significant. Parent involvement in the IEP process was associated with use of mental health services overall but not with utilization of school-based services. Adolescents who had received a diagnostic medical exam in the past year were more likely to receive services but were less likely to receive those services at school. Youths with household incomes below $50,000 were more likely to receive services at school compared to youths with incomes over $70,000. Need characteristics of having lower social skills, experiencing bullying, and bullying others were associated with receiving services but were not associated with getting the services at school.

Discussion

Our study found that nearly half of youths with an ASD had accessed a mental health service in the previous year. While no other national rates have been reported for youths with an ASD, these rates are higher than the 2001 National Survey of Children with Special Health Care Needs where 25% of participants reported a need for mental health services and 82% of those accessed services (13). Our study is unable to shed light on the exact reason the youths used services and the nature of the mental health services they received. More work is needed to better understand the types of treatments delivered to youths with an ASD in both school and community settings. While applied behavior analysis is an evidence-based practice often recommended for this population, less is known about effective methods for treating co-morbid mental health conditions in youths with an ASD. Adaptation of other evidence-based practices may be needed to address the full range of needs for which these youths seek treatment.

Our examination of the correlates of mental health service use overall found no differences by predisposing characeteristics including race or ethnicity, however, African-American youths were more likely to receive the services at school. Previous studies of adolescent

mental health service use have found racial disparities in rates of outpatient mental health service use but no differences in the use of school-based mental health services (14, 15). The fact that African-American youths who received services in our study were more likely to receive them at school supports these previous findings on the importance of the school in providing services to groups that are less likely to access community-based services.

A similar difference emerged in regard to enabling resources. While there were no differences in overall service use by income, lower income youths were more likely to receive the services at school. Insurance status, however, was not associated with service use in either model. Having a diagnostic medical exam was positively associated with receiving mental health services overall but youths that received services at school were less likely to have had a diagnostic medical exam. Our findings underscore the role of the school in providing mental health service to particular groups. Further research is needed to determine whether the type or quality of the services differs between settings.

Conclusion

Our study is the first to report on mental health service use in a nationally representative sample of youths with an ASD. We found relatively high rates of service use compared to youths with special health care needs overall, highlighting the importance of considering the unique needs of youths with an ASD in the development of mental health interventions. Our findings also point to the important role of the school in providing access to mental health services for underserved groups. Continued mental health support should be considered in transition planning to ensure that these youths do not lose needed services when they exit high school.

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Table 1

Logistic regressions examining correlates of mental health service use overall and correlates of school-based service use among those who had received a service

	Mental Health Services (n=920)		Mental Health Services at School (n=440)	
Variable	**OR**	**95% CI**	**OR**	**95% CI**
Predisposing				
Female	1.22	.76–1.97	.57	.32–1.02
Race				
White	1.00		1.00	
African-American	.83	.54–1.26	3.56***	1.86–6.78
Other	.72	.45–1.16	.99	.41–2.40
Hispanic	1.09	.59–2.03	1.81	.91–3.61
Parent attended				
College	1.29	.84–2.00	1.15	.58–2.31
Nonverbal	.68	.43–1.07	1.00	.54–1.86
Enabling Resources				
Income				
<$25,000	.95	.48–1.90	3.29*	1.09–9.88
$25,000–$50,000	1.22	.69–2.16	2.45*	1.16–5.18
$50,001–$70,000	1.13	.65–1.95	1.61	.74–3.47
>$70,000	1.00		1.00	
Insurance				
Private	1.00		1.00	
Public/other	1.17	.70–1.94	1.32	.63–2.74
Youth has case manager	1.27	.85–1.88	1.13	.65–1.96
Youth had diagnostic medical exam	2.97***	2.08–4.24	.41**	.23–.72
Parent attended IEP	2.33*	1.11–4.88	1.79	.48–6.72
Youth attended IEP	1.42	.99–2.03	.84	.48–1.45
Need Indicators				
ADHD	.91	.63–1.31	1.17	.66–2.09
Social skills scale	.90**	.85–.95	1.07	.99–1.16
Youth was bullied	2.06***	1.43–2.96	.85	.48–1.49
Youth bullied others	1.79*	1.02–3.13	1.83	.95–3.51

* p<.05,

** p<.01,

*** p<.001

Source: National Longitudinal Transition Study 2, Wave 1 Parent Interview/Survey, 2001. Number of multiply imputed data sets = 20. Weighted to population levels. Variances adjusted for sampling method.