



Promoting Wellness and Recovery

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Social Connectedness in Families of Children & Adolescents with Serious Emotional Disturbance and Autism Spectrum Disorder

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Overview

For six years, the Ohio Department of Mental Health and Addiction Services (OhioMHAS) has administered the Youth Services Survey for Families (YSS-F) to collect information from a statewide random sample of parents and guardians of children with serious emotional disturbances (SED). Among other things, the YSS-F measures caregiver social support with a subscale developed by the Substance Abuse and Mental Health Services Administration (SAMHSA) through its Mental Health Statistical Information Program. This subscale is the operational definition of SAMHSA's National Outcome Measure for social connectedness in families of children and adolescents treated for SED conditions.

The operational definition of SED used by OhioMHAS for SAMHSA Block Grant reports includes the autism spectrum disorder (ASD). However, children with ASD who are seen by OhioMHAS' certified behavioral health (BH) providers are not typically treated for the ASD condition when they present for care. Research indicates that children with ASD are more likely than those with non-ASD intellectual and developmental disorders (DD) to develop comorbid psychiatric symptoms.ⁱ Consistent with research literature, children with ASD in Ohio's public behavioral health system most commonly present with comorbid problems such as attention-deficit hyperactivity, anxiety, and mood disorders.ⁱⁱ

Ohio families of children with ASD can access services through county boards overseen by the Ohio Department of Developmental Disabilities (DODD). Because children with ASD and a comorbid psychiatric disorder can access both the DD and BH systems of care, one might assume that families of children with ASD access a richer array of community supports impacting social connectedness. The present study seeks to answer the following question: Does social connectedness differ between families of children with a diagnosis in the autism spectrum and those whose children with SED do not have this particular diagnosis?

Methodology

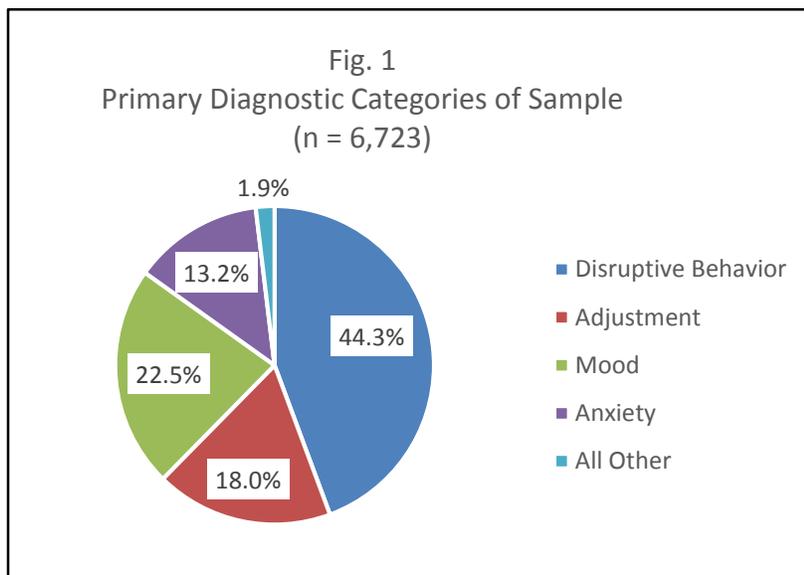
Survey administrators drew a random sample, stratified by race and county/board type, from the MACSIS/MITS billing database each year. The sample size for the youth service population was based on a power analysis for confidence intervals (CI) of +/-3 percent. Racial minorities in the child/adolescent population were over-sampled in an effort to obtain adequate representation. A total of 7,410

completed surveys were collected in the six years between 2011 and 2016. The six-year sample represents an average annual return of 1,235 surveys, at an average annual return rate of 16 percent. Surveys were coded with unique identifiers that allowed researchers to match individual cases with administrative records. Between 90 and 95 percent of each year’s sample received services that were covered by Medicaid, the administrative data source with client information on co-occurring developmental disorders.

Administrative data (claims) containing diagnostic codes was matched to the sample cases. Primary diagnoses were determined by identifying the most frequent diagnostic code appearing in the claims for a case. Codes were collapsed into the following five broad categories: Disruptive Behavior Disorders (attention deficit hyperactivity and oppositional defiant), Anxiety Disorders, Mood Disorders (bipolar and depression), Adjustment Disorders, and All Other. An *ASD condition* was identified by at least one occurrence of any of the following diagnostic codes in the claims data: ICD9 = 299.0-299.91 and ICD10 = F84.0-F84.9. The *ASD condition* was defined further as being present or not present. The variable was coded 1 = present / 0 = not present.

Sample Characteristics

Cases with Medicaid coverage were extracted from the annual survey files, resulting in a six-year aggregate file of 6,723 unduplicated cases with valid Medicaid identifiers. About 70 percent of the sample had received services for longer than a year at the time of survey administration.¹ The sample was 67.3 percent White, 27.4 percent African American, 2.2 percent Other race, and 3.1 percent Unknown/Missing. Hispanic representation was 2.7 percent. About 40 percent were female and 60 percent were male. Geographic county/board representation was 15.2 percent Appalachian, 7.2 percent rural, 17.3 percent small city, 13.2 percent suburban, and 47.1 percent major metropolitan.



Mean age was 11.3 years (SD 3.6 years).

Some 820 cases (12.2%) were identified as having an ASD condition. All but five of these cases had additional behavioral health diagnoses. Among the 815 cases with an ASD condition plus another diagnosis, the modal number of additional diagnostic categories was 3. Among the 5,903 cases without an ASD condition, the modal number of additional diagnostic categories

¹*Longevity* or length of time in services was defined by whether the individual received services for more than 12 months. The variable was coded 1 = greater than 12 months / 0 = 12 months or less.

was 2. Of the cases with ASD, 10.6 percent (n = 87) had as many as five additional diagnostic categories, compared to only 4.4 percent (n = 261) of cases without an ASD condition. Figure 1 shows the distribution of primary diagnostic categories in the sample of 6,723, where 44.3 percent (n = 2,980) are classified with disruptive behavior disorders, 18 percent (n = 1,212) with adjustment disorders, 22.5 percent (1,511) with mood disorders, and 13.2 percent (n = 890) with anxiety disorders. The 1.9 percent (n = 130) with All Other diagnoses is comprised primarily of V codes, but also represents the five cases where ASD is the primary diagnosis.

Figures 2 and 3 show the distribution of diagnostic categories for the 820 cases with ASD and the 5,903 without. Comparing the cases with and without ASD, proportions are roughly equal in the Adjustment, Anxiety, and All Other diagnoses categories. Proportions are different when the Disruptive Behavior and Mood categories in Figures 2 and 3 are compared.

Instrumentation

The YSS-F is made up of subscales that measure the parent/guardian’s perception of care, in addition to the social connectedness as a treatment outcome indicator. Two perception of care subscales are relevant to the present investigation into the effect of an ASD condition on the social connectedness reported by families with children treated for SED. These two perception of care subscales are the six-item appropriateness of care and the two-item access to care. Table 1 lists the items found in the Appropriateness, Access, and Social Connectedness subscales.

Items in the subscales were summed and divided by the total number of items. Cases with subscales where more than one-third of items are missing were dropped from the analysis.

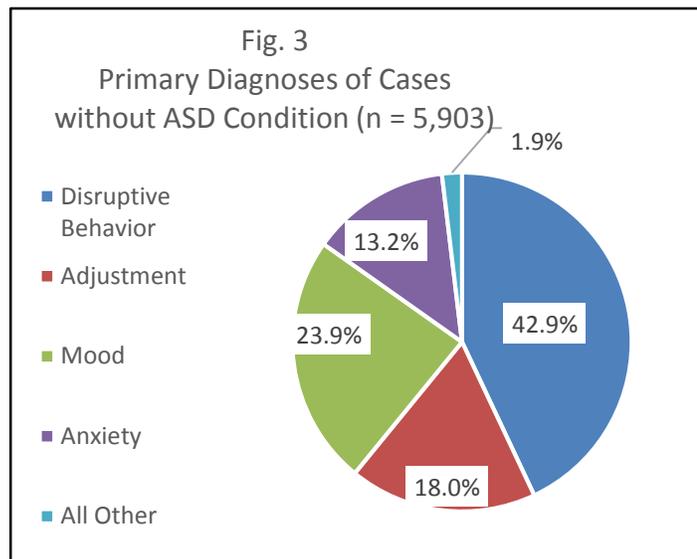
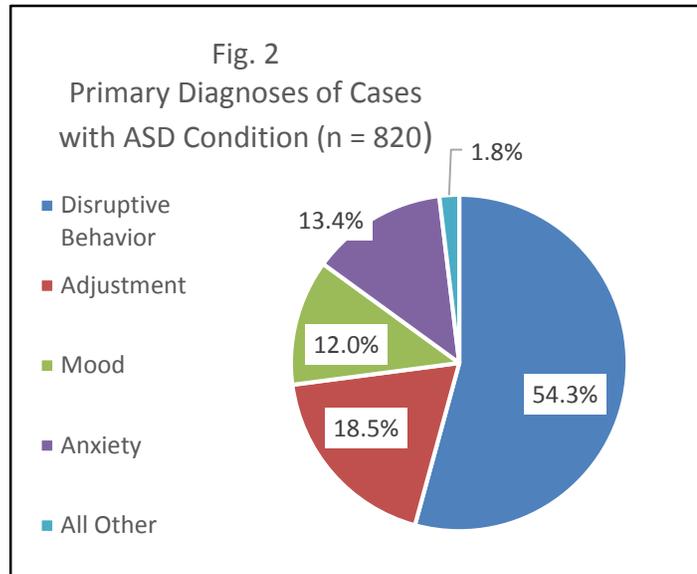


Table 1. YSS-F Subscale Items		
	YSS-F Subscale	Items
Perception of Care	<i>Appropriateness</i>	Overall, I am satisfied with the services my child received. The people helping my child stuck with us no matter what. The services my child and/or family received were right for us. My family got the help we wanted for my child. My family got as much help as we needed for my child.
	<i>Access</i>	The location of services was convenient for us. Services were available at times that were convenient for us.
Treatment Outcomes	<i>Family Social Connectedness</i>	I know people who will listen and understand me when I need to talk. I have people I'm comfortable talking with about my child's problems. In a crisis, I would have the support I need from family and friends. I have people with whom I can do enjoyable things.

Analysis

Descriptive and inferential statistics were run on the dependent variable (social connectedness) to better understand distributions among independent variables such as ASD, service longevity, race, gender, age, access, and appropriateness. SPSS automatic linear modeling was then used to determine which variables, if any, predicted the high versus low scores on social connectedness.

Results

A multiple linear regression model was calculated to predict *social connectedness* based on *access*, *appropriateness*, *longevity*, and *ASD condition*. A significant regression equation was found ($F(4,6192)=599.63, p < 0.000$), with an R^2 of 27.9. Although *ASD condition* contributed only 0.003 to the overall R^2 , it was a significant probability of 0.002. Table 2 shows that survey respondents' predicted mean score on *social connectedness* was equal to $2.136 + 0.131$ (access mean) $+ 0.369$ (appropriateness mean) $- 0.072$ (longevity) $- 0.081$ (ASD condition), where access and appropriateness are measured as mean score points, longevity is coded as 1 = more than 12 months, 0 = 12 months or less, and ASD condition is coded 0 = not present, 1 = present.

Table 2. Variables Predicting Social Connectedness			
Model	β	β SE	Sig.
(Constant)	2.136	0.047	0.000
Access Mean	0.131	0.013	0.000
Appropriateness Mean	0.369	0.012	0.000
Longevity	-0.072	0.019	0.000
ASD Condition	-0.081	0.026	0.002

A survey respondent's mean social connectedness score increased 0.131 points for each point increase in mean access and 0.369 points for each point increase in mean appropriateness. A survey respondent's mean social connectedness score decreased 0.072 points for each longevity case coded 1 and decreased 0.081 points for each ASD condition case coded 1.

Limitations

An annual average return rate of 16 percent raises questions about the overall representativeness of the sample. The problem of a low return rate can be somewhat controlled when stratification groups in the sample are representative of the population, but in the case of current study's dataset, racial and geographic groups were not representative. The study sample is further biased by the selection of cases with Medicaid coverage. Between 5 and 10 percent of the child and adolescent service population covered by non-Medicaid sources of funding is not represented in the study. Results may not be generalizable to the population due to potential biases in the sample.

Discussion

Although the present study is exploratory in nature, it can provide useful information for program and policy development concerned with child and adolescent service populations, family assessment of services, and family social connectedness as an outcome of treatment. This study provides an evidence-based estimate that 12.2 percent of the child and adolescent behavioral health service population has a comorbid ASD condition. Second, study results show that the vast majority of child and adolescent service recipients with an ASD condition are treated for a greater number of behavioral health disorders. Those with an ASD condition are more likely to be treated for disruptive behavior disorders, but less likely to be treated for mood disorders than those without the condition. These findings suggest that child and adolescent service recipients with the ASD condition have a complex and distinct clinical profile.

That caregivers of service recipients with an ASD condition report significantly less social connectedness is an indication of just how complex and distinct their clinical profile truly may be. The greatest single predictor of high scores on social connectedness is the caregiver's perception that services were appropriate. This finding prompts the question: *What are appropriate services for families of children with mental illness and ASD?* Programs aimed at increasing the family's network of social supports are clearly indicated. In a service system with limited resources, policies are indicated that prioritize families of children with ASD conditions for social support programs.

ⁱ Bryson, SE & Smith LM. (1998). Epidemiology of autism: prevalence, associated characteristics, and implications for research and service delivery. *Mental Retardation and Developmental Disabilities Research Review*, 4: 97-103.

ⁱⁱ *Autism and Mental Health Issues: A guidebook on mental health issues affecting individuals with Autism Spectrum Disorder*. Center for Autism and Related Disabilities, University of South Florida, Tampa, FL. Available for download at: http://card-usf.fmhi.usf.edu/docs/resources/CARD_ASDMH_Brochure092109.pdf