

Characteristics of children with autism spectrum disorders who received services through community mental health centers



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ABSTRACT Despite the presence of significant psychiatric comorbidity among children with autism spectrum disorders (ASDs), little research exists on those who receive community-based mental health services. This project examined one year (2004) of data from the database maintained by 26 community mental health centers (CMHCs) in the Midwestern US state of Kansas. Children with autism were compared to children with other ASDs – Asperger’s disorder, Rett’s disorder, and PDD-NOS. Children with autism predictably received more special education services than children with other ASDs, while the latter were more likely to have experienced prior psychiatric hospitalization. Children with ASDs other than autism were also significantly more likely to be diagnosed with attention deficit hyperactivity disorder, oppositional defiant disorder, depressive disorders, and bipolar disorder. In 2004, Kansas CMHCs served less than 15 percent of the children estimated to have an ASD. Implications of these findings are discussed.

KEYWORDS
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Introduction

Autism spectrum disorders (ASDs) are a group of disorders characterized by a continuum of impairment in three key areas: verbal and non-verbal communication, social interaction, and repetitive or stereotyped behaviors (NIMH, 2007). In the US, recent epidemiological studies (Bertrand et al.,

2001; Yeargin-Allsopp et al., 2003) have found higher prevalence rates for ASDs than previously reported. Very recently, the Centers for Disease Control (CDC, 2007) estimated that one in 150 children in the US has an autism spectrum disorder.

According to Gillberg and Billstedt, psychiatric and tic disorder 'co-morbidity is to be expected whenever a diagnosis of autism or Asperger syndrome is made' (2000, p. 327). Children with ASDs may require a range of costly, specialized services, many of them behavioral. While not all of these services typically are delivered by mental health providers, many are (Jacobson and Mulick, 2000; Jarbrink and Knapp, 2001; Mandell et al., 2002). Additionally, as private insurance coverage for children with ASDs is very restricted in the US (NIMH ASD Expert Working Group, 2005; Peele et al., 2002), community-based mental health providers may serve children with ASDs from socioeconomic groups not typically seen in community settings.

Although mental health services may produce substantive change in functional ability, scarce attention has been paid in the literature to the amount, type, and duration of these services to children and youth with ASDs. Jacobson and Mulick (2000) have called explicitly for descriptive research on the various service settings – health, mental health, educational, and vocational/rehabilitative – in which children with ASDs receive treatment. Further, they have called for study of the specific populations served in these different settings.

In response to an acknowledged gap in the research base, this study sought to clarify the population and service characteristics of children with autism spectrum disorders who received treatment through the public mental health system in one Midwestern US state. In this time of increased demand for ASD-related services (Ruble et al., 2005) and documented difficulties accessing services in healthcare settings (Kraus et al., 2003), greater knowledge of service and population characteristics may help to optimize community-based service delivery to this high-need population.

Methods

Sample

To analyze service delivery patterns of children with autism spectrum disorders who received community mental health services, we obtained an extraction of data from the Kansas Community Mental Health Centers Automated Information Management System (AIMS). The AIMS database was developed to collect outcome and service data from Kansas CMHCs and their affiliates. AIMS data are updated annually or when a status change

occurs. Data are not claims based, and payment sources vary. They include Medicaid; the Kansas Home and Community Based Services for Youth with Severe Emotional Disturbance (SED) Medicaid Waiver; private insurance; private payment; the Kansas Child Health Insurance Program (CHIP); or a combination of these sources.

Using data from calendar year 2004, unique youth were selected who had an open case at any time during 2004 and a DSM-IV-TR (American Psychiatric Association, 2000) diagnosis of autistic disorder (299.0); childhood disintegrative disorder (299.1); or pervasive developmental disorder not otherwise specified (PDD-NOS), Rett's disorder, or Asperger's disorder (299.8). Given the low prevalence rates of Rett's disorder in the general population (Tidmarsh and Volkmar, 2003), researchers assumed that the DSM diagnostic category 299.8 likely represented a preponderance of children diagnosed with Asperger's disorder and PDD-NOS. Only one child had a diagnosis of childhood disintegrative disorder (299.1). This child was excluded from further statistical analyses due to the low frequency of occurrence.

Youth were selected who had any of these diagnoses as the primary diagnosis during treatment, the secondary diagnosis during treatment, the primary diagnosis at discharge, or the secondary diagnosis at discharge. Diagnoses from two different points in the child's service history (during treatment and at discharge for those children who discharged) were gathered in order to ascertain whether diagnoses changed over the course of treatment. For the children who had more than one episode of treatment during this period (e.g. child served at one CMHC, moved and received services at another CMHC), data from the most recent treatment episode were used.

We collected both primary and secondary diagnoses to ensure that we captured all children with any reported diagnosis of ASD. A limitation of the data was posed by the fact that a number of the CMHCs reported a primary diagnosis only in the AIMS database; this diagnosis may or may not have been the ASD diagnosis. Therefore, the estimates discussed in the following tables and graphs underestimate the actual number of children with ASDs served by Kansas community mental health centers.

Measures

This study sought to describe children with autism spectrum disorders served in mental health settings. Researchers chose to use national estimated prevalence rates rather than state-specific Individuals with Disabilities Education Improvement Act (US Department of Education, 2004) data to estimate the total population of children with potential need for mental health services. Mandell and Palmer (2005) found significant interstate

variability in the rates at which children were screened to receive special education services. For this reason, population estimates were used instead.

To compute estimated prevalence of children with autism spectrum disorders in Kansas, researchers used the most recent rate available at the time of the study, i.e. 60 in 10,000 or 6 in 1000 children (Fombonne, 2003). We used the more conservative Centers for Disease Control rate of 5.5 per 1000 to estimate the prevalence of autism only (CDC, 2006).¹

For comparative purposes, and in a manner consistent with current DSM-IV-TR classifications, we divided the ASD cases into two groups. One group was composed of children with a diagnosis of autism. The second group was composed of children with Asperger's disorder, PDD-NOS, or Rett's disorder (and no diagnosis of autism). Children diagnosed with both autism (299.0) and another ASD (299.8) were excluded from the analyses. We chose to compare the two populations because we hypothesized that children with non-autism ASDs might present with profiles of psychiatric comorbidity that differed significantly from the profiles of children with autism.

The two groups were compared with respect to the following general demographic, functional, and diagnostic characteristics: gender, race/ethnicity, age, family income, population density of resident county, last educational placement, last school attendance, last academic performance, serious emotional disturbance (SED) designation, Global Assessment of Functioning (GAF) scores (DSM-IV-TR, 2000), Child Behavior Checklist (CBCL) scores (Achenbach, 1991), and comorbid psychiatric diagnoses.

As in other US states, in Kansas, SED status refers to a diagnosed mental health condition that substantially disrupts a youth's ability to function socially, academically, and emotionally. The GAF score measures functioning in at least three domains; for children, GAF scores of 50 or below indicate serious impairments in social and school functioning or serious psychopathology, such as suicidal ideation, psychotic thought processes, and persistent danger of harm to self or others. Clinicians in CMHCs record GAF scores at intake to the CMHC, at various times throughout treatment, and at discharge. Scores given at admission are overwritten in the database as they are updated. The CBCL is a widely used diagnostic instrument which yields a profile of problematic internalizing or externalizing symptomatology. It is administered upon admission to the CMHC.

Comparisons across the two groups were made with respect to the following service variables: reason for stopping Medicaid waiver services, length of service, child welfare status, reason for discharge, and Social Security Disability Income (SSDI) eligibility. Supplemental Security Income (SSI) and SSDI are federal income supplements designed to help persons with little or no income who are aged, blind, or disabled.

To discern differences in mental health provider responses, acuity ratings were also compared between the two groups. In the AIMS database, acuity is divided into three categories: emergent, urgent, and routine. The three statuses carry a mandated CMHC response time of 3 hours, 72 hours, and 10 working days, respectively. According to the AIMS manual, emergent services must be delivered 'immediately to meet the needs of an individual who is experiencing an acute psychiatric crisis which . . . may meet requirements of hospitalization, or who, in the absence of immediate services, may require hospitalization'. Urgent services are those 'required to prevent a serious complication or deterioration in the individual's health and cannot be delayed without imposing undue risk on the individual's well-being' (Kansas Department of Social and Rehabilitative Services, 2005, p. 13). A routine service response is non-crisis in nature.

Analyses

Analyses consisted of first calculating the rate of children with ASDs served in the state and subregions of the state. Comparisons were then drawn across these rates and with estimates of corresponding prevalence rates. Employing cross-tabulations and chi-square statistics for the categorical service variables and t-tests for the continuous variables, the two ASD groups were compared with respect to general demographics, functional and diagnostic information, and service characteristics. To study diagnostic evolution, we also examined discharge information for children whose diagnoses changed over the course of treatment.

Findings

Children with ASDs served by Kansas CMHCs

Figure 1 displays the number of children diagnosed with autism and all ASDs who were served by a Kansas community mental health center in 2004. Figure 1 also displays these same children as a portion of the estimated population of children with autism and ASDs in Kansas. In 2004, Kansas CMHCs recorded service to 107 children with autism and 485 children with Asperger's disorder, PDD-NOS, or Rett's disorder. The total population of children with ASDs served in CMHCs was 586. (Six children were diagnosed with both autism and another ASD and were excluded from the analyses). Compared to best available prevalence estimates of autism and other ASDs (5.5 and 6 children in 1000, respectively), Kansas CMHCs served less than 3 percent of the children expected to have autism and less than 15 percent of the children expected to have an autism spectrum disorder.

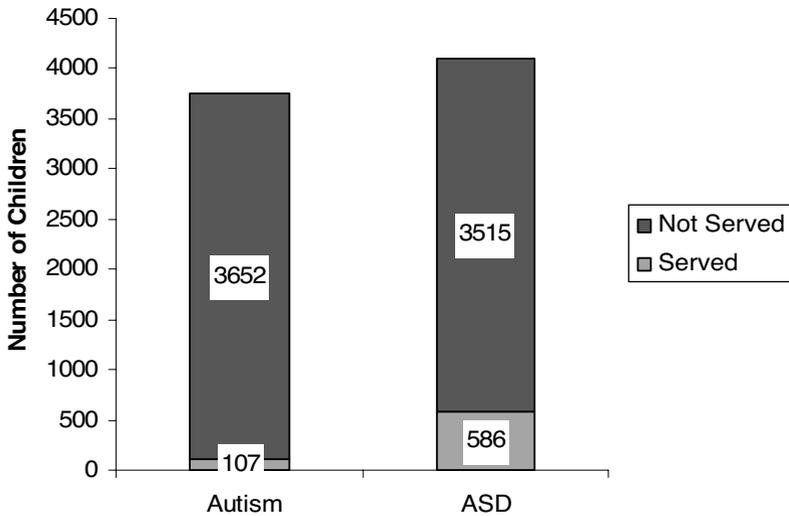


Figure 1 Children in services

Child population description

Table 1 displays demographic, educational, and psychiatric hospitalization data for children with autism versus children with other ASDs. Researchers found few statistically significant differences between groups. The mean age at admission to the CMHC was approximately 9 years for both groups. Both groups were 4:1 boys to girls, and the majorities of both groups were white (82% children with autism; 86% children with other ASDs). Average family income for both groups was \$20,825.

Children differed chiefly in educational services ($p = 0.00$) and prior psychiatric hospitalization ($p = 0.00$). A larger percentage of children with autism received special education programming for more than 60 percent of their school day (46.1% versus 30.3%), whereas a larger percentage of children with other ASDs were integrated into traditional classrooms with no special education services (14.9% versus 8.8%). School attendance in the children's respective school settings was virtually identical; however, the autism group performed slightly better on academic indicators than children with another ASD diagnosis. The two groups of children differed appreciably in their experience of prior psychiatric hospitalizations. Children with non-autism ASDs were hospitalized at more than twice the rate (19.4%) of children with autism (7.5%).

CMHC service response

Table 2 displays differences in service response for the two ASD groups. Intake and assessment staff judged most children's needs for services to be

Table 1 Child and family characteristics (*n* = 586)^a

	Children with autism % or mean (<i>n</i> = 107)	Children with other ASD % or mean (<i>n</i> = 479)	χ^2 or <i>t</i> -statistic
Child gender (% male)	83.2%	84.8%	n.s.
Child race/ethnicity (% white)	81.9%	85.7%	n.s.
Age at time of treatment (years)	9.18	9.53	n.s.
Family income (\$/year)	\$20,999	\$20,648	n.s.
Population density (resident county):			
Frontier	3.7%	2.1%	n.s.
Rural	9.3%	9.4%	n.s.
Densely settled rural	23.4%	24.9%	n.s.
Semi-urban	32.7%	23.3%	n.s.
Urban	30.8%	40.3%	n.s.
Prior psychiatric hospitalization*	7.5%	19.4%	8.543
Last academic performance:			
Failing or below average	4.5%	13.5%	n.s.
Average	59.1%	57.0%	n.s.
Above average	36.5%	29.5%	n.s.
Last educational placement: special education >60% of the school day*	46.1%	30.3%	9.509
Last school attendance: regular (90–100%)	90.1%	87.1%	n.s.

^a Percentages for variables were calculated without missing cases in the denominator.

* Difference between autism and other ASD group significant at $p < 0.05$.

routine. Non-routine service needs were collapsed for analyses due to their low frequency in the data. Table 2 shows that children with autism were significantly more likely to be judged to require a routine service response than children with other ASDs (97% versus 91%).

Only a minority of children (14%) in either group was receiving SSI or SSDI benefits. Children with autism were slightly more likely to be receiving SSI or SSDI than were those with other ASDs (20% versus 13%), but this difference was not statistically significant at the 0.05 level. Similarly, involvement with child welfare services did not vary significantly between the two groups.

Nearly 70 percent of both groups were still receiving services or had no reported closing date. Discharge reasons did not differ significantly between the groups; however, more than 40 percent of children in each group ended treatment before it was complete. Of those children with a closing date (34 children with autism; 150 with other ASDs), almost all children with autism (88%) received services for less than 12 months, while 63 percent of the children with other ASDs who discharged did so

Table 2 Service response (n = 586)^a

	<i>Children with autism % or mean (n = 107)</i>	<i>Children with other ASD % or mean (n = 479)</i>	χ^2 or t-statistic
Acuity: routine (versus emergent or urgent)*	96.8% (107)	90.6% (477)	3.897
Receiving SSI or SSDI	19.8% (101)	12.7% (448)	n.s.
Child welfare status: out-of-home or under state supervision or custody	11.8% (102)	12.4% (458)	n.s.
Length of service: admission to discharge (service days)*	248.6 (34)	605.1 (150)	-4.316
Discharge reason: treatment not complete	41.2% (34)	42.9% (147)	n.s.

^a Percentages for variables were calculated without missing cases in the denominator.

* Difference between autism and other ASD group significant at $p < 0.05$.

within one year. Average length of service was significantly different between groups. Of those children who discharged, children with autism received less than half the days of service than those with other ASDs. Median days in treatment were 162 for children with autism and 316 for children with other ASDs.

Child functioning

Table 3 provides descriptive information about the functioning of children with ASDs who were seen at the mental health centers and an analysis of group differences between those with autism and those with other ASDs. At the end of the data collection period, 68 percent of the total sample was deemed seriously emotionally disturbed (SED). While the autism group was less likely to be classified as SED, this difference was not statistically significant. Significant missing data reduced the power of statistical analyses with regard to SED status.

Functional levels during the data collection period and at discharge (if the child was discharged in 2004) are based on the DSM-IV-TR Global Assessment of Functioning (GAF) scale. Mean GAF scores for children with autism were significantly lower during treatment than were GAF scores of children with other ASDs. Nearly half the children with autism (49%) and almost one-third of children with other ASDs (32%) had functional levels of 50 and under during treatment. A significantly greater percentage of children with autism had GAF scores under 50 during treatment. There were no significant differences between the GAF scores for the two groups at closing; however, more than a third of each group (38.2% of children with autism and 34.2% of children with another ASD) had GAF scores under 50 at discharge.

Table 3 Child functioning ($n = 586$)^a

	Children with autism % or mean ($n = 107$)	Children with other ASD % or mean ($n = 479$)	χ^2 or <i>t</i> -statistic
SED status:			
At start of year	78.9% (19)	88.9% (108)	n.s.
At year end	74.7% (79)	81.3% (320)	n.s.
Global Assessment of Functioning (GAF) score:			
Mean score during treatment*	46.77 (102)	50.92 (461)	-3.053
Mean score at closing	49.32 (34)	49.22 (149)	n.s.
% below 50 during treatment*	49.0% (102)	31.9% (461)	10.777
% below 50 at closing	38.2% (34)	34.2% (149)	n.s.
Last CBCL:			
Internalizing	60.02 (55)	66.06 (277)	n.s.
Externalizing	64.51 (55)	67.83 (276)	n.s.
Total problems	70.16 (55)	71.18 (274)	n.s.
Total competencies	28.02 (45)	47.61 (237)	n.s.

^a Percentages for variables were calculated without missing cases in the denominator.

* Difference between autism and other ASD group significant at $p < 0.05$.

Table 3 also displays Child Behavior Checklist (CBCL) scores for the two groups. The externalizing, internalizing, and total problem scales, as well as a measure of child strengths, are tracked in the AIMS database. A T-score of 70 or higher on these scales indicates a clinically significant range of concern. There were no significant differences between the two groups on problem behaviors or competency scores.

Co-occurring psychiatric diagnoses among children with autism and other ASDs are presented in Table 4. Children with ASDs other than autism were significantly more likely to carry a diagnosis of attention deficit/hyperactivity (ADHD) ($p = 0.00$), oppositional defiant disorder (ODD) ($p = 0.00$), depressive disorders ($p = 0.01$), and bipolar disorder ($p = 0.01$). Effect sizes were calculated following Cohen (1988, p. 222). A medium effect size was observed for the difference in populations with regard to ADHD, while other differences had small effect sizes.

At the 0.05 level, no significant difference was observed with regard to disruptive behavioral disorder (DBD), adjustment disorder, anxiety disorders (not including PTSD), or obsessive compulsive disorder (OCD). Although the two groups were significantly different ($p = 0.03$) in their respective diagnoses of post-traumatic stress disorder (PTSD), the effect size was too small to be meaningful. Nine children with a non-autism ASD received a diagnosis of conduct disorder, while none of the children with autism carried this particular diagnosis.

Table 4 Co-occurring psychiatric diagnoses (n = 586)^{a,b}

	<i>Children with autism % or mean (n = 107)</i>	<i>Children with other ASD % or mean (n = 479)</i>	χ^2
Attention deficit hyperactivity disorder*	25.2% (27)	42.8% (205)	11.281
Oppositional defiant disorder*	3.7% (4)	16.3% (78)	11.438
Depressive disorders (major depressive disorder, dysthymic disorder)*	2.8% (3)	11.1% (53)	6.906
Disruptive behavioral disorder NOS	6.5% (7)	10.0% (48)	n.s.
Bipolar disorder*	1.9% (2)	9.6% (46)	6.957
Adjustment disorder	2.8% (3)	7.1% (34)	n.s.
Anxiety disorders (generalized anxiety disorder, panic disorder, social phobia, anxiety disorder NOS)	2.8% (3)	5.4% (26)	n.s.
Post traumatic stress disorder*	0% (0)	4.4% (21)	4.865
Obsessive compulsive disorder	4.7% (5)	3.1% (15)	n.s.
Conduct disorder	0% (0)	1.9% (9)	n.s.

^a Percentages for variables were calculated without missing cases in the denominator.

^b Diagnostic categories are ordered by mean percentage of children with ASDs who have the co-occurring diagnoses listed. Diagnoses are not exhaustive; rather, only the most prevalent diagnoses are listed. Numbers do not sum, as children may have received several co-occurring diagnoses.

* Difference between autism and other ASD group significant at $p < 0.05$.

Table 5 presents data on diagnostic fluctuation over the course of treatment for children with primary DSM-IV-TR diagnoses of autism and other ASDs. Of the 23 children with a primary diagnosis of autism who discharged in 2004, 22 (96%) had autism as the primary diagnosis at discharge. The remaining child had disruptive behavioral disorder as the primary diagnosis at discharge. Of the 66 children with a primary diagnosis of Rett's, Asperger's, or PDD-NOS, 58 (88%) retained their primary ASD diagnosis at discharge. Overwhelmingly, autism spectrum diagnoses remained stable from intake to discharge.

Table 5 Diagnostic change upon discharge (n = 89)

	<i>Children with autism who discharged % or mean (n = 23)</i>	<i>Children with other ASD who discharged % or mean (n = 66)</i>
Retained primary diagnosis	96.0% (22)	87.8% (58)
Changed primary diagnosis	0.04% (1)	0.12% (8)

Discussion

In 2004, community mental health centers in one Midwestern state served less than 3 percent of the population of children 0–18 years of age estimated to have autism and less than 15 percent of the population of children estimated to have any ASD (Rett's disorder, Asperger's disorder, PDD-NOS). This finding suggests that the remaining 85 percent of children with an ASD who were not served by the CMHC system (1) did not have mental health needs and were served by another system such as the developmental disability system; (2) sought and received mental health care through the educational system or the private mental health system; or (3) were underserved by Kansas CMHCs.

The study also found that children with Asperger's disorder and PDD-NOS were significantly more likely than children with autism to experience inpatient psychiatric hospitalization. This subgroup of children was also more likely to be diagnosed with attention deficit hyperactivity disorder, oppositional defiant disorder, depressive disorders, and bipolar disorder. No statistically significant differences were observed between the two populations with regard to disruptive behavioral disorder or obsessive compulsive disorder. In addition, children with autism received more special education services than children with other ASDs.

Limitations

A number of significant study limitations should be considered. First, this study was undertaken to provide an overview of the population of children with autism spectrum disorders and existing challenges to serving them. Using 1 year of cross-sectional data from the community mental health center database restricted our capacity to track, in a meaningful way, changes over time in outcome measures like CBCL scores. We were also limited by the outcome measures available in this administrative database, such as the Global Assessment of Functioning (GAF) score. The GAF was neither designed nor intended to measure functioning in this population. The study was also hampered by significant missing data in the AIMS database. Large amounts of missing data reduced the power of statistical analyses and increased *p*-values. Some data were missing because children were still in treatment at the time of the study and terminal events had not transpired or been recorded.

To estimate ASD prevalence, we chose to rely on population estimates rather than on administrative data from the education system. We did this for two reasons. First, reliable data from the Kansas Department of Education are not available. Second, prior study has indicated that education data are not reliable for tracking autism prevalence (Laidler, 2005). Mandell and

Palmer (2005) found that educational estimates of prevalence vary widely by state and that higher numbers of children served by school systems are positively associated with education-related spending, the number of pediatricians in the state, and the number of school-based centers in the state. While Kansas has a moderate ratio of developmental pediatricians to children, 1:100,000 (Althouse and Stockman, 2006), the state is overwhelmingly rural, ranking 15th in land area among US states. Most developmental pediatricians work in the few urban centers in the state, leaving large portions of the state underserved. Finally, Kansas ranks 25th in the nation for education-related spending (Johnson, 2006). To gauge unmet need, we chose to use population estimates rather than replicate artificially low prevalence rates. However, population estimates are still unreliable, thus limiting the study's generalizability.

Despite putative high overlap between several psychiatric conditions and ASDs (Gillberg and Billstedt, 2000; Sverd, 2003), our ability to estimate the population of children we might expect community mental health centers to serve was limited by three things: (1) as mentioned, the lack of statistical certainty in epidemiological literature about the prevalence of ASDs in the general population; (2) lack of certainty in the psychiatric literature about the prevalence of specific psychiatric disorders within the ASD population; and (3) possible underreporting by CMHCs that enter only primary diagnoses in the AIMS database.

In addition to possible underreporting in the AIMS database, diagnosis posed two other problems in this study. As mentioned previously, we could not disaggregate the DSM-IV diagnoses used in the administrative database on which the study relied. Accordingly, we were unable to differentiate between the service and population characteristics of children with Asperger's disorder, Rett's disorder, and PDD-NOS. Second, although some studies have found good to excellent diagnostic reliability in this population (Eisenmajer et al., 1996; Hill et al., 2001; Mahoney et al., 1998 in Mandell et al., 2005), we believe that the shortage of qualified personnel in the rural regions of Kansas elevates the risk of misdiagnosis. It is likely that most children who received treatment through the CMHCs received their diagnoses prior to entering this system, and we lacked the ability to evaluate the accuracy of diagnoses. However, to get a sense of the provisional diagnostic process, we analyzed differences from intake to discharge. As with all studies of this population, diagnoses should be regarded with skepticism.

Finally, as the study took place in one Midwestern US state and was non-experimental in design, caution should be used in generalizing these findings to other states or countries.

Implications

Despite these limitations, this study both contributes novel findings to the research literature and corroborates existing studies of services to this population. Overall, the children served by CMHCs mirrored the national population. They were 4–5:1 boys, had co-occurring diagnoses of ADHD (Ghaziuddin et al., 1998; Mandell et al., 2006; Yoshida and Uchiyama, 2004), behavior disorders (Mandell et al., 2006), and mood disorders (Ghaziuddin et al., 2002; Tidmarsh and Volkmar, 2003) and presented with significant impairments in functioning. Over three-quarters of both groups met criteria for serious emotional disturbance (SED), which is not surprising given the potential for significant impairment even in children with high-functioning ASDs. In addition, the designation of SED may have served an important funding function by qualifying these children for additional services through the state's Home and Community Based SED Medicaid Waiver.

Importantly, the great majority of children served by Kansas CMHCs lived at home with their families, remained out of hospitals and in school, and did well academically. It appears that services received at CMHCs helped to stabilize the children served. Children with autism fared somewhat better in this regard than their counterparts with other ASDs. The most significant between-group difference related to inpatient psychiatric hospitalization. Children with other ASDs experienced prior psychiatric hospitalization at more than twice the rate than children with autism.

With regard to co-occurring diagnosis and treatment venue, our study partially supported the findings of Mandell et al. (2006). Mandell and colleagues compared diagnoses and expenditures of children with autism spectrum disorders, children with mental retardation (MR), and other Medicaid-eligible children. In their study, children with autism spectrum disorders had higher expenditures than other children due to greater use of both inpatient hospitalization and outpatient psychiatric services.

Given the co-occurrence of mental retardation in as many as 70 percent of children with autism (Tidmarsh and Volkmar, 2003), we assumed that a sizeable portion of our sample with autism also had comorbid cognitive disability. As in Mandell and colleagues' (2006) study, children in our study with non-autism ASDs (and thus lower rates of MR) had higher rates of inpatient hospitalization than did children with autism (and thus potentially co-occurring MR). It remains unclear if inpatient hospitalization among the children in our sample met least restrictive setting criteria. This finding deserves greater scrutiny.

Moreover, Mandell and colleagues (2006) found that children with MR were less often diagnosed with attention and behavior disorders than children with ASDs. In our study, children with autism were less likely than

children with Asperger's disorder and PDD-NOS to receive attention deficit, behavior, and mood disorder diagnoses. Despite documentation of mood disorders among children with severe intellectual disabilities (Bradley et al., 2004), we anticipated that community-based mental health clinicians would be more likely to recognize and diagnose mood disorders in the children with ASDs other than autism due to inexperience in diagnosing psychiatric disorders in a population with MR. This phenomenon may account for lower numbers of children with autism and co-occurring mood disorders than in previous research. It may also account for shorter stays in care for children with autism: children with autism may have been discharged to other settings like developmental disability organizations.

While our study largely supported one of the few existing studies of children who received services through comprehensive community mental health settings (Mandell et al., 2005), one notable difference is worth mention. As in the study by Mandell and colleagues, a significant number of children in our study had disruptive behavior diagnoses (attention deficit/hyperactivity disorders, oppositional defiant disorder, and disruptive behavior disorder). The current consensus on this issue (Clark et al., 1999; Jensen et al., 1997) emphasizes careful differential diagnosis, as these diagnoses may be more appropriately characterized as sequelae of the ASD diagnosis itself rather than true comorbid conditions.

In their study of community mental health settings, Mandell and colleagues (2005) also found that children with Asperger's were more likely than children with autism to have a history of family violence and parental substance abuse. In this study, we did not find significant differences in child welfare involvement (a proxy for documented abuse and neglect history) between children with autism and those with other ASDs. However, compared to the general population of children in Kansas in 2005, 4.4 per 1000 children, the rate of child welfare involvement is quite high (Moore et al., 2006). This finding is disturbing and consistent with a study of maltreatment by Sullivan and Knutson (2000), who found that children with a disability were 3.4 times more likely to be maltreated than their non-disabled peers.

Our study contributes novel findings with regard to diagnostic changes over the course of treatment. Generally, we found that ASD diagnoses were stable over time. This was truer for autism than for other ASDs. In the small number of cases in which diagnoses did change, there were no identifiable trends.

Also of interest are CBCL scores for the two groups. For both groups, the last available CBCL total problem scores were in the clinically significant range. Despite the severity of presenting symptoms, over 90 percent of children with ASDs (97% autism and 91% other ASDs) were classified

as in need of only a routine response when the family contacted the CMHC. While this may represent an appreciation among mental health providers of the chronic nature of these disorders, it may also signify the opposite: a lack of training with regard to the management of significant disability. Based on anecdotal evidence from parent focus groups conducted in conjunction with the study reported here, this may be particularly true of the autism population. Children with autism can present with problematic behaviors (e.g. self-injurious behaviors) that may be regarded not as mental health symptoms but rather as MR/DD symptoms.

Finally, days in treatment for children with ASDs were relatively low; over 40 percent of those who left treatment during the year left before treatment was complete. Those who did leave treatment showed little functional gain. Of children who discharged, more than a third of children in both groups ended treatment with GAF scores below 50, indicating the persistence of severe symptoms or serious impairments in social and school functioning. These data suggest the need to examine the efficacy of current interventions with the ASD population.

Conclusion

Little information about mental health services to children with ASDs exists in the literature at present. The goal of the study was to describe current demographic, diagnostic, and service delivery patterns among children in this high-risk population. Findings from this study reveal that children with autism spectrum disorders who received services through the Kansas public mental health care system presented with significant psychiatric comorbidity and functional limitation.

While this degree of comorbidity and chronicity may be due to selection bias, it may also suggest underlying need. There is little evidence to suggest that children with ASDs would not respond well to accepted treatments for comorbid conditions such as ADHD, tic, mood, and behavior disorders (Gillberg and Billstedt, 2000). Thus, a considerable subpopulation of children with ASDs likely would benefit from mental health treatment. At present, it appears that a small percentage of the estimated population of children with ASDs is receiving treatment in community mental health settings. Furthermore, our study indicates that on the whole, CMHC services stabilized children; however, these services also left a significant portion of children highly symptomatic at discharge. The short-term, crisis orientation of community mental health may require modification to serve populations with long-term needs.

Although the results of this study should be applied with caution, the findings do suggest the need to more closely examine the adequacy and

appropriateness of treatment for children with ASDs and mental health needs in the US community mental health system and potentially elsewhere. The public mental health care system, in partnership with the developmental disability and educational systems, would benefit from the creation of treatment guidelines and disorder-specific training to address the inter-system and lifelong needs of children with complex social, communication, and behavioral problems.

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Note

1 Analyses were completed prior to release of the most recent CDC data, which estimated that 6.7 per 1000, or 1 in 150, children has an autism spectrum disorder (CDC, 2007). As the new estimates are very close to those used in this study, they do not substantially alter our findings.

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