



Published in final edited form as:

J Ment Health Res Intellect Disabil. 2009 July 1; 2(3): 201–219. doi:10.1080/19315860902741542.

Involvement of Youths with Autism Spectrum Disorders or Intellectual Disabilities in Multiple Public Service Systems

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Abstract

The objectives of this study were to estimate the prevalence of autism spectrum disorders (ASD) and intellectual disability (ID) among youths active in at least one of five public service systems - mental health [MH], educational services for youth with serious emotional disturbance [SED], child welfare [CW], juvenile justice [JJ], and alcohol and drug services [AD]. This study also reports the characteristics and patterns of system involvement among these youths. Results indicate that approximately 12% of a random sample of youths involved in these public service systems had ID or ASD. These disabilities were particularly prevalent in youth in the SED (25%), MH (13%), and CW (13%) systems and were less prevalent in the JJ and AD systems (4% each). Youths with ID or ASD were more likely than other youths to be Caucasian, have a higher socioeconomic status, and be more likely to have externalizing psychiatric and other problems. Of those with ASD or ID, approximately one third were served in more than one service system, with the MH and SED systems most likely to be serving youths with externalizing psychiatric disorders. These findings have important implications for service provision, treatment planning, and workforce development.

Intellectual disability (ID) and autism spectrum disorders (ASD) are two of most common forms of developmental disabilities. Definitions of ID typically include a combination of significantly subaverage intelligence (defined as IQ less than 70), deficits in adaptive functioning, and onset of delays during childhood or adolescence (Individuals With Disabilities Education Act, 2004; Reschly, Myers, & Hartel, 2002), and affect approximately 12 of every 1000 children (Murphy, Yeargin-Allsopp, Decoufle, & Drews, 1995). ASDs are characterized by core impairments in social interaction, verbal and nonverbal communication and the presence of repetitive and restricted interests, with symptoms usually presenting before three

years of age (American Psychiatric Association, 2000). Recent estimates indicate that 6.7 of every 1000 children have an ASD (Centers for Disease Control and Prevention, 2007).

Service provision for youths with ASD or ID is complex, with a variety of service systems providing care (e.g., Krauss, Wells, Gulley, & Anderson, 2001). State-managed Mental Retardation/ Developmental Disability and Special Education systems (especially under the Autism and Mental Retardation categories) clearly play critical roles in providing care for youths with ASD or ID. It is likely, however, that these youths are also served in other public systems of care. In particular, given their high risk for co-occurring mental disorders and behavior problems stemming from impaired coping abilities that are associated with limited cognitive, communicative and adaptive functioning, they may be served in systems that care for youths with mental health needs (Rojahn & Tasse, 1996).

There is growing recognition of the impact of mental health problems in individuals with developmental disabilities, including ASD and ID (U.S. Public Health Service, 2001). For example, the proportion of youths with ID who also have a psychiatric disorder has been estimated at 14–60% compared with 5 to 12% among other youths (Kerker, Owens, Zigler, & Horwitz, 2004). In a study of preschool children, approximately one quarter of 225 young children with ID had clinical levels of behavior problems, compared with less than 10% of typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002). Leyfer and colleagues (2006) reported that 72% of 109 youths with ASD, ages 5–17, met criteria for at least one additional DSM-IV Axis I diagnosis. Similarly, Simonoff et al. (2008) reported that 70% of 112 youths with ASD, ages ten to 14, met criteria for at least one psychiatric disorder. Some of these rates of co-occurring mental health problems may be underestimates due to the methodological challenges of diagnosing psychiatric problems in individuals with developmental disabilities and the difficulty associated with differentiating mental health diagnoses from developmental and communication problems (Kerker et al., 2004).

Epidemiological research suggests that youths with psychiatric disorders, and disruptive behavior disorders in particular, receive care through various public systems including the serious emotional disturbance category of special education, the mental health, child welfare, juvenile justice, and alcohol and drug treatment systems (Garland et al., 2001). Previous research suggests that individuals with IDs and ASDs also receive care in these service systems. For example, in a nationally representative sample of young children involved in the child welfare system, Stahmer et al. (2005) reported that half of these children were at risk for developmental/behavioral problems that would qualify them for early intervention services. In another study of maltreated children in one urban area, 22% had a disability qualifying them for special education services. Of those, approximately 25% were classified with mental retardation, and 0.1% with autism (Sullivan & Knutson, 2000). In a national sample of comprehensive community-based mental health systems, children diagnosed with autism constituted approximately one percent of all those enrolled in these systems of care (Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005a). A national survey of the directors of state juvenile correctional systems found that, on average, over 30% of youths have a disability that qualifies them for special education services. Of these youths, approximately 10% were classified under the Mental Retardation category of special education (Quinn, Rutherford, Leone, Osher, & Poirier, 2005).

A limitation of much of the existing research on the mental health, child welfare, and juvenile justice systems is that the disabilities examined were limited to those qualifying for special education services, which may miss other youths with ID or ASD who are not enrolled in those services. Prevalence estimates of ID/ASD disabilities among all youths enrolled in SED or drug and alcohol services are unavailable.

In addition to understanding the prevalence of ID or ASD in various services systems, determining the rates of co-occurring psychiatric or developmental problems is important to help providers understand the probable clinical needs of their clients. Externalizing psychiatric problems are particularly important given that many children with ASD are referred to mental health care for these problems (Mandell et al., 2005a). To our knowledge, there are no data using structured diagnostic instruments to examine the prevalence of co-occurring psychiatric problems in youths with ASD or ID served in public systems. Further, there is no existing research examining which service systems are most likely to serve youths with ID or ASD when they do have different types of co-occurring psychiatric disorders or patterns of multiple system involvement. Although multiple system involvement has been examined for youths with mental health problems (e.g., Farmer, Burns, Phillips, Angold, & Costello, 2003; Garland et al., 2001), no studies to date have examined concurrent enrollment of youths with ASD or ID across multiple systems of care outside of special education (special education eligibility or placement has been used to identify individuals with a variety of developmental disabilities within other service systems). Parents, however, do report that their children are often concurrently receive a number of different therapies and interventions (e.g., Thomas, Morrissey, & McLaurin, 2007), suggesting that multiple system involvement is likely high. The information on enrollment in multiple systems for youths with ID and ASD in this study provides a clearer picture of the location and nature of services these youths are receiving.

Overall, information about the role of public service systems in caring for youths with ASD or ID has important implications for service provision, treatment planning, and workforce development. Individuals with these disabilities may present unique challenges to service providers, especially to those professionals who are not specifically trained to work with this population. Understanding the patterns of public service system involvement can provide information to improve service coordination between specialized Mental Retardation/ Developmental Disability services and other systems of care that may not be aware of the needs of youths with developmental disabilities. Understanding the prevalence of mental health problems, especially externalizing disorders, among these youths can help us plan to effectively meet their mental health needs.

The overall purpose of this study is to examine the involvement of youths with ID or ASD in multiple public service systems using existing data from a large epidemiological study on mental health care across multiple service systems. We examine (1) the prevalence of ID/ASD in a random sample of youths from five service systems (Mental Health, Educational Services for Serious Emotional Disturbance, Child Welfare, Juvenile Justice, and Alcohol/ Drug) in one large urban area; (2) the characteristics of these youths compared to those without ID/ASD enrolled in these systems; and (3) the differences in the rates of externalizing psychiatric disorders and multiple system involvement among youths with ID/ ASD in each of the five service systems. Taken together, the data should assist in resource and treatment planning for ID/ASD youths in various systems of care.

Methods

Participants

The sample for the current study came from the “Patterns of Care (POC)” study of service use within publicly funded agencies in San Diego County (Garland et al., 2001). The POC study included a stratified random sample of 1,715 children and adolescents ages 6–17 who had received services during the previous year in one or more of the following public service systems during the second half of fiscal year 1996–1997: Mental Health (MH), Special Education for Serious Emotional disturbance (SED), Child Welfare (CW), Alcohol and Drug (AD) and Juvenile Justice (JJ). All youths enrolled in AD, MH, and special education for SED services were included in the sampling frame. Only youths under court jurisdiction as wards

in JJ and as dependents in CW were included for those two systems. Youths who had only brief contact with these two services systems (e.g., child abuse report made, but not substantiated) were excluded. Children enrolled in special education services other than SED (e.g., severely handicapped classroom) were not included in this sample. An initial random sample of 3,402 youths was selected from a total eligible population of 12,662. Seven hundred and ninety-three (23%) of those selected for recruitment were not located, 843 (25%) refused to participate, and 54 (2%) did not participate for a variety of other reasons. Of the 2609 youths who were contacted to participate, parent/caregiver interviews were completed with the final sample of 1,715 (66%) between late 1997 and early 1999. Sampling was stratified by race/ethnicity and restrictiveness of care (aggregate versus home residence), and service system affiliation. To ensure adequate sample size for subgroup analysis, specific groups were purposely over-sampled (e.g., Asian/Pacific Islanders and those in Alcohol and Drug treatment). A post-stratification weighting procedure was then used to ensure that the data reflect the proportion of these groups in the total population of service users (Henry, 1990). Participants did not differ significantly from non-participants in their age, gender, system involvement, or racial/ethnic distribution with the exception that slightly fewer Asian-Americans participated relative to the eligible sample (see Aarons, Brown, Hough, Garland, & Wood, 2001 and Garland et al., 2001 for more information on sampling methodology).

The subsample for the current study includes 1603 (of 1715) youths for whom parent report data on developmental problems were available. This subsample represents 61% of the 2609 who were initially contacted for participation. There were no differences by gender between those included and those excluded from the current study, however, they were slightly younger and were more likely to be Caucasian than the 112 youths not included. Of these 1603 youths, 66% were male and their ages ranged from 6 to 19 years ($M = 14.0$, $SD = 3.2$). The racial/ethnic representation was 40% Caucasian, 19% African-American, 26% Hispanic/Latinos, 7% Asian/Pacific Islander, 5% Biracial, and 3% Other. Average household annual income ranged from \$1,000 to \$200,000 ($M = \$29,736$, $SD = \$27,381$). Parent education level was 25% no degree, 33% high school / GED, 32% associates or vocational tech, and 10% bachelors or advanced degree.

Procedure and Measures

Data for the current study were extracted from the original POC study. Parents were interviewed individually (usually in their home) regarding the youth's mental health and special needs and a variety of factors potentially associated with multiple system service use (e.g., family income, caregiver strain). Parents were compensated \$40 for their time, which averaged three hours per interview. Interviewer training and reliability checks are described in Aarons et al. (2001). A majority of the parent/caregiver informants (hereafter referred to as parents) were biological parents (76%). Other respondents included adoptive (4%), foster (7%), step-parents (1%), other relatives (10%) and non-related caregivers (2%). The measures used in the current study included the following:

The Child Health Questionnaire (CHQ-PF28)—(Landgraf, Abetz, & Ware, 1996) was used to identify youths with ID or ASD (referred to as ID/ ASD) within the full POC sample and to identify associated medical, developmental, and learning problems experienced by these individuals. The CHQ was developed for youths five years of age and older and assesses physical, emotional, and social well-being of the child from the parent perspective. As part of the CHQ, parents were asked whether they had “ever been told by a teacher, school official, doctor, nurse or other health professional that your child has any of the following conditions?” Youths whose parents positively endorsed at least one of two items were classified as having ID/ ASD for the purposes of this study. Specifically, youths whose parent indicated that their children had either autism (the term ASD is used for the purposes of this paper) or mental

retardation/developmental delay were considered to have ID/ ASD. Mental retardation and developmental delay were both classified as ID since these conditions are both considered ID in the Developmental Disability service system in our local community (i.e., California Regional Center). The CHQ also includes items related to other problems including epilepsy, learning problems, and speech, hearing, and vision problems which are used in analyses of clinical characteristics of all youths.

Demographic information was gathered through parent interviews. Parents reported the child's age, sex, race/ethnicity, family income, and parent level of education.

Service System Involvement—Information on system involvement was gathered through administrative records from each of the five service systems. Data for each youth were recorded from each system between June 1, 1996 and June 30, 1997. Youths' names, date of birth, race/ethnicity, and sex were used to search for involvement in each service system separately. Participants were classified as having involvement in a particular service system if there was an administrative record indicating an open case at any point during that year. Because each youth was counted in each system in which they had been active, the proportion of youths across systems can sum to more than 100%.

Child Behavior Problems—The Child Behavior Checklist (CBCL) broadband Externalizing Problem Scale was used to assess youth externalizing symptoms (Achenbach, 1991). The CBCL is a widely-used, standardized parent report measure of youth psychological symptomatology with well-established reliability and validity (Achenbach, 1991).

Psychiatric Diagnosis—The computer-assisted version of the C-DISC-IV (Computerized Diagnostic Interview Schedule for Children, IV (NIMH C-DISC IV), 1997) was administered to all parents and to youths 11 years of age or older by lay interviewers. The DISC-IV is a highly structured diagnostic interview designed to yield *DSM-IV*-based diagnoses through computer algorithm scoring. The DISC-IV has demonstrated reliability and validity comparable with that of other diagnostic measures (Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000).

Only parent-reported C-DISC-IV data were used for this study. The decision not to use youth self-report C-DISC data was based on the likely cognitive limitations of the subsample of youths with ID/ ASD that may impair accurate reporting on their conditions. Only data on externalizing disorders (ADHD, ODD, CD) were available by parent report because the larger POC study did not gather parent reports on internalizing symptoms and disorders. For this study, a youth was considered to have a specific psychiatric diagnosis for an externalizing disorder if they met complete diagnostic criteria based on the DISC-IV and, when applicable, the parent endorsed at least one moderate level of diagnostic specific functional impairment. The diagnostic specific impairment criterion was judged to best represent the *DSM-IV* criterion for "clinically significant impairment in social, academic, or occupational functioning" and has been applied in other analyses of the POC study data (Garland et al., 2001).

All analyses were conducted using STATA (v. 9) (Stata Statistical Software: Release 9, 2005) with data weighted to represent the system of care population (described above). Prevalence estimates of ID/ ASD were calculated for each of the five systems of care, with youths who were active in more than one system counted in each system. Differences between youths with and without ID/ ASD on socio-demographic and system involvement characteristics were examined using chi-square and t-tests analyses. Differences between these two groups in prevalence of psychiatric and other problems were estimated using logistic regression. Since significant group differences were found between youth age, race/ethnicity, household income, and parent level of education in preliminary analyses, the effects of these variables were

controlled for in subsequent logistic regression analyses. The last set of analyses examined the characteristics only of youths with ID/ ASD in each service system. Specifically, rates of psychiatric problems for youths with ID/ ASD in each service system were also estimated using logistic regression and descriptive analyses were used to examine patterns of overlap in system involvement.

Results

Weighted proportion of youths in public service systems with ID/ ASD

Of 1603 youths enrolled in at least one of the five service systems with available parent report data on developmental problems, 12.3% (220) were identified as having either ID or ASD. Of these, 15% (42) of parents indicated that their child had been diagnosed with an ASD and 85% (178) of parents indicated that their child had been diagnosed with ID. Youth with ID/ASD represented a substantial proportion of youths served in three of the five public service system examined. Specifically, they comprised 13.1% (131) of all youths served in the Mental Health system, 13.0% (62) of those in Child Welfare, and 25.3% (101) of youths in the SED category of special education. Fewer than 5% of those sampled from Alcohol and Drug services or Juvenile Justice had ID/ ASD.

Socio-demographic characteristics for all youths

Table 1 presents sociodemographic characteristics and service system involvement for youths with and without ID/ ASD. T-tests and chi square analyses were used to examine differences on these characteristics between the two groups. Youths with ID/ ASD significantly differed in racial/ ethnic background from other youths (e.g., A higher proportion of youths with ID/ ASD were Caucasian (56.2%) than those without ID/ ASD (35.5%) and were significantly younger). Further, families of youth with ID/ASD had higher average household incomes and a higher proportion of parents with some college educational than the non ID/ASD group.

Clinical characteristics and system involvement for all youths

In an effort to understand the clinical characteristics of the youths with ID/ ASD, their rates of developmental, learning and medical problems, average CBCL externalizing scores, rates of externalizing psychiatric disorders, and rates of services system involvement were compared to those without ID/ ASD, controlling for the effects of youth age, race/ ethnicity, income, and parent level of education.

Developmental, Learning and Medical Problems—Table 2 presents youth clinical characteristics and service system involvement for all youths. Compared to other youths, those with ID/ ASD were significantly more likely to experience learning problems (90% vs. 31%), speech problems (45% vs. 10%), vision problems (35% vs. 19%), seizure disorders (14% vs. 1%), and hearing impairments (11% vs. 5%) according to parent report.

Externalizing Psychiatric Symptoms/ Diagnoses—The CBCL was available for 1545 of the 1603 youths included in the current study (214 with ID/ASD and 1340 without ID/ASD). A multiple regression analysis was conducted to examine the association between ID/ ASD and CBCL externalizing scores after controlling for youth age, race/ ethnicity, income, and level of education (not shown in table 2). These variables (i.e., dummy code of ID/ ASD, CBCL externalizing score and covariates) accounted for a significant amount of variance in CBCL scores, $F(5,1484) = 7.22, p < .01, R^2 = .04$. The mean CBCL externalizing score for youths with ID/ ASD ($M = 63.3, SD = 11.7$) was significantly higher than the mean score for youths without ID/ ASD ($M = 58.5, SD = 12.8$) ($\beta = 4.53, p < .001, CI = 2.5$ to 6.6). On the parent report version of the C-DISC-IV, youths with ID/ ASD were more likely to meet DSM-IV criteria for an externalizing disorder than those without ID/ ASD (73% vs. 46%). Specifically, they

were more likely to meet criteria for each of the externalizing conditions: ADHD (55% vs. 23%), Oppositional Defiant Disorder (53% vs. 33%) and Conduct Disorder (28% vs. 18%).

System Involvement—The proportion of youths enrolled in the mental health and child welfare systems were similar for youths with and without ID/ ASD. These youths were significantly more likely to be enrolled in school SED (32% vs. 13%) and less likely to be enrolled in juvenile justice (14% vs. 32%) than other youths.

Psychiatric disorders in youths with ID/ ASD in each service system

Table 3 lists percentages and odds ratios associated with meeting criteria for a psychiatric disorder in each service system for only those 220 youths identified as having ID/ ASD. The odds ratios reflect the odds of meeting criteria for a specific disorder for youths who were active in a given system versus those who were not active in that system. Over three fourths of youths with ID/ ASD in all systems, except those involved in child welfare, met criteria for at least one externalizing disorder. Youths with ID/ ASD in child welfare were significantly less likely than youths not enrolled in this system to meet criteria for an externalizing diagnosis. Specifically, they were less likely to meet criteria for ODD and CD. Although rates of externalizing disorders were not significantly different between those enrolled in the mental health and SED systems compared to youths who were not enrolled in those systems, youths active in these two systems were more likely to meet criteria for CD. There were no significant differences in rates of psychiatric disorders for those enrolled in the juvenile justice and alcohol/ drug systems from those not enrolled in these systems.

Multiple system involvement for youths with ID/ ASD in each service system

Of the youths with ID/ ASD, 33% were enrolled in more than one of the five public service systems in the year previous to the baseline interview; with 28.5% were involved in two systems of care and 4.5% involved in three service systems. Table 4 lists the proportions of youths with ID/ASD being concurrently enrolled in another system for those enrolled in each service system. A majority of youths in the juvenile justice and mental health systems and a substantial minority of youths in the other systems were served in at least one other service system. Approximately one fourth of youths involved in the mental health system were also enrolled in the school SED and child welfare systems. A substantial proportion of youths in the school SED, child welfare, and juvenile justice systems were also involved in the mental health system (48%, 46%, and 42% respectively). Most of the youths involved in the alcohol/ drug system were also enrolled in the mental health (63%) and juvenile justice systems (71%).

Discussion

This study found that youths with ID or ASD comprise a substantial proportion of those served in public services systems caring for youths with mental health needs, particularly in the Serious Emotional Disturbance (SED) category of special education, as well as the public mental health and the child welfare systems. A second important finding was that youths with ID/ ASD in this sample differed from other youths in a number of ways: (a) They were younger on average, and more likely to be Caucasian, and of higher socioeconomic status. (b) They were more likely to be enrolled in the school SED system and less likely to be involved in the juvenile justice system. (c) They had significantly higher rates of externalizing psychiatric symptoms and diagnoses, and learning, developmental and medical problems. For youths with ID/ ASD, those involved in the child welfare system were less likely to meet criteria for an externalizing psychiatric diagnosis than those with ID/ ASD not enrolled in this system. A majority of youths with ID/ ASD enrolled in the alcohol/ drug and mental health systems were concurrently involved in another system. Across all systems except alcohol/ drug services, youths with ID/ ASD were most likely to also be served by the mental health system.

The finding that approximately one fourth of youths in the school SED system had ID/ASD is consistent with the one other (albeit dated) study in this area, which reported that 22% of children with emotional disturbance referred for special education services had below average intellectual functioning (Mendelsohn & Jennings, 1986). It is not clear why such a high proportion of youths with ID/ ASD are served under the SED special education category instead of autism or mental retardation categories. One possibility is that educational professionals view the youths' behavioral problems as more important or impairing than developmental issues. Alternatively, behavioral problems related to developmental problems may have been misinterpreted as conduct problems, resulting in this placement. A critical examination of placement practices is warranted as an SED educational setting may not be an appropriate environment for youths with ID/ ASD.

Over 10% of youths in the mental health system had ID/ ASD. In California, as in many states, the mental health and developmental disability systems are administered separately. Unfortunately, although there has been more recent attention devoted to understanding psychiatric conditions in individuals with developmental disabilities such as ID and ASD, their diagnosis and treatment remain problematic (Rush, Bowman, Eidman, Toole, & Mortenson, 2004). Providers may have difficulty recognizing mental disorders in this population (Rush et al., 2004) or under-diagnose mental disorders in individuals with developmental disabilities due to diagnostic overshadowing of emotional disturbances by the presence of significant cognitive deficits (Reiss, 1993; Reiss, Levitan, & Szyszko, 1982). Training mental health clinicians to recognize and treat individuals who have psychiatric and developmental problems is a critical issue for improving services for this population (Moss, Emerson, Bouras, & Holland, 1997).

The finding that more than 10% of youths in our sample who were active in the child welfare system had ID/ ASD is consistent with previous research suggesting that individuals with certain developmental disabilities are at increased risk for child abuse and neglect (Spencer et al., 2005; Sullivan & Knutson, 2000). For example, Mandell and colleagues (Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005b) reported that almost 20% of children with autism had been physically or sexually abused. Developmental issues are not typically considered or identified in the child welfare system (Hibbard et al., 2007), which may be particularly important when determining placement or services. Traditionally, the decision regarding whether to remove children from their homes of origin has focused on careful consideration of issues related to child safety, the impact of removal of the child on the family, parental rights, and permanence of children who have been abused or neglected rather than on developmental issues (Davidson-Arad, Englechin-Segal, & Wozner, 2003). There are some preliminary data suggesting that youths with developmental delays may not fare as well in the foster care system as other youths and that specialized training may be needed to maximize the potential of these youths (Stahmer et al., in press). Child welfare services, such as placement decisions, reunification efforts and parent training, should consider youths' disabilities when helping parents to address their children's needs.

Very few youths with ID/ ASD in this sample were active in the alcohol and drug system. This is consistent with research indicating that substance abuse disorders infrequently occur in people with ID (Glick & Zigler, 1995; Reiss, 1990) and that youths with ASDs are not likely to be referred for alcohol and drug treatment (Mandell et al., 2005a). Likewise, very few youths were involved in the juvenile justice system. This is somewhat inconsistent with research indicating that a substantial proportion of children with a broad array of disabilities are involved in the juvenile justice system (Quinn et al., 2005). It is possible that the low rate involved in juvenile justice relates to the specific disabilities examined or that developmental problems may not have not be identified and reported to parents of youths involved in this system.

The socio-demographic differences between youths with and without ID/ ASD are consistent with documented racial/ ethnic disparities in the timing of diagnosis in autism (Mandell, Listerud, Levy, & Pinto-Martin, 2002) and service involvement, diagnosis, and treatment in youths with mental health problems (Garland et al., 2005; Wood et al., 2005; Yeh, McCabe, Hough, Dupuis, & Hazen, 2003). In this sample, a higher proportion of youths with ID/ASD were Caucasian and had higher income compared to other youths. This is consistent with another recent study in Hong Kong in which parents of young children with ID had higher education and socioeconomic levels than parents of children without ID (Tang, Chen, Lau, & Wu, 2008). It may be that these disabilities go unrecognized in minority communities or that ethnic minority youths identified with these disabilities are more likely to be served in other special education categories not captured in the current study. The higher socioeconomic status of youths with ID/ASD suggests that families with greater resources may be more likely to either recognize or request assessment for developmental problems. A critical examination of these disparities is warranted.

The finding that three fourths of youths with ID/ASD met DSM-IV criteria for an externalizing diagnosis and had more severe behavior problems on the CBCL than other youths without an ID/ ASD is consistent with previous research (Kerker et al., 2004; Leyfer et al., 2006). In the current study, diagnosis on the DISC-IV required a least moderate impairment associated with the symptoms, indicating that these behavior problems may be beyond what would be expected based on having either ID or ASD. These youths also had higher rates of other learning, medical and developmental problems. These results provide additional support for the need for providers within these systems to understand how to serve individuals presenting with complex co-occurring psychiatric and developmental diagnoses.

Although, overall, youths with ID/ ASD had high rates of externalizing disorders across all service systems, youths enrolled in the child welfare system were less likely to be diagnosed with a psychiatric disorders. This finding may be explained by differences in the process of eligibility for services between systems. Specifically, the child welfare system differs from the others examined in that eligibility is based on a youth's risk for maltreatment, not their behavior. Alternatively, there may be differences in characteristics of caregivers that influence their report on the CBCL and DISC-IV (on which externalizing diagnosis and problems were based). Further, youths involved in the mental health or the SED systems were more likely to meet criteria for conduct disorder. This finding may indicate that youths with ID/ ASD enrolled in these systems are likely to exhibit the most severe externalizing problems.

The last key finding of this study is that approximately one third of the sample was concurrently served in more than one system. The systems under study did not include the California Regional Centers, which coordinate and fund specialty care for individuals with developmental disabilities including ASDs and ID. Likewise, involvement in special education categories not related to emotional disorders (e.g., Autism, Mental Retardation) was not captured in this study. Therefore, it is likely that multiple service system involvement is actually much higher. This is consistent with previous research indicating that children with developmental disabilities are likely to be served by a high number of service providers at the same time (Kohler, 1999; Thomas et al., 2007), and suggests that, perhaps even more than for children without these disabilities, case coordination across systems is critical. Mechanisms for systematically coordinating between MR/DD and these other systems (especially mental health systems) are needed (Beasley & duPree, 2003). Clear guidelines for system navigation are needed for both providers and for caregivers of youths with developmental disabilities. Finally, more information is needed on the types of intervention services youths with ID and ASD are receiving within each service systems, as there may be redundancies and/or gaps in care.

Some study limitations should be noted. First, these data were not collected to examine youths with ID/ ASD, so standardized measures to determine developmental status were not available. Therefore, the identification of ID/ ASD was based on parent report, which may underestimate prevalence as it is based on the parents' knowledge of being identified as having ID or ASD by a professional. A related limitation is that the item used to identify those with ID also included "other developmental delay." Because these groups are both considered to have ID in our local developmental disability system, the ID group in this study is broadly defined. Therefore, our findings can not be generalized to more precisely defined subgroups of children with developmental disabilities. Further, since the CHQ item used to identify children with ASD referred only to "autism," children with other ASD diagnoses may have been missed, which potentially limits the generalizability of the results to the entire autism spectrum.

Another important limitation relates to the assessment of psychiatric disorders in youths with ID/ASD. As with most psychiatric diagnostic instruments, the psychometric properties of the DISC-IV are not available for youths with these disabilities (Leyfer et al., 2006). We also recognize there may be overlap between the behavioral characteristics of developmental disabilities and externalizing psychiatric disorders. However, we feel that identifying psychiatric problems according to DSM-IV criteria is an important first step in understanding psychiatric symptoms with these youths, especially when examining their involvement in public systems of care that serve youths with mental health problems or at risk for mental health problems. There was also no assessment of other mental health conditions as internalizing disorders (e.g. anxiety, depression) or other childhood disorders (e.g., Tourette's, encopresis). Therefore, the overall estimated prevalence of co-occurring psychiatric diagnoses is likely much higher.

Another important limitation of this study is the low participation rate which potentially results in a biased sample. Although the sociodemographic characteristics of the participants were generally similar to the nonparticipants, the clinical characteristics are unknown. Additionally, this study examined youths sampled from public services in one metropolitan area almost a decade ago. Although the findings may not generalize to those served in other publicly funded systems or privately funded systems, the issues related to serving children with ID/ ASD likely remain relevant today as changes to the systems examined in our community have not directly targeted this population. Further, youths were sampled on the basis of their service involvement. For some participants, there may have been a lag between their service involvement and assessment. However, the random order of interviews may reduce any potential impact of time between involvement and assessment.

Despite these limitations, the results highlight the role of multiple public service systems in caring for youths with two of the most common developmental disabilities, ID and ASD. Because the five systems examined were not designed to serve individuals with developmental problems and many professionals in public service systems have limited training needed to work with this population (Matson & Sevin, 1994), the findings support the need to build capacity in these systems to appropriately serve these youths and their families. Guidelines for system navigation for both families and for providers within the public systems are also clearly needed.

Acknowledgments

These data are from the Patterns of Youth Mental Health Care in Public Service Systems Study, which was supported by National Institute of Mental Health grant U01-MH-55282 to Dr. Hough. Preparation of this article was also supported by National Institute of Mental Health grants K23MH077584 (LBF), K01MH069665 (MB), K01MH065325 (AS), and K01MH067628 (DM). The authors would like to thank Mary Joyce Juan and Robin Taylor for their assistance in the preparation of this manuscript.

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TABLE 1

Sociodemographic Characteristics of Youths Ages 6 to 17 Enrolled in Five Public Service Systems

Characteristics	ID/ ASD (n=220) M (SD)/ % ^a	Non ID/ ASD (n=1383) M(SD)/ %
Youth Average Age (years) **	12.8 (3.3)	13.9 (3.3)
Youth Gender (male)	67.8	65.3
Race/ Ethnicity: **		
Caucasian	56.2	35.5
Hispanic/Latinos	13.9	30.3
African American	19.6	22.1
Other	14.7	7.9
Average Household Income ** (\$ per year)	\$36,323 (30,918)	\$27, 645 (25,989)
Parent Education level:		
Some college or college degree **	59.6	38.4

Note: n=1603

^a% = weighted percentages

**
p<.01

TABLE 2

Clinical Characteristics and Service System Involvement for All Youths

Characteristics	ASD/ID (n=220) % ^a	Non ASD/ ID (n=1383) %	Odds ratio	Total (N=1603) %
Learning, Developmental, and Medical Problems				
Learning Problem	89.8	30.6	18.5**	37.9
Speech Problem	44.6	10.1	5.3**	14.4
Vision Problem	34.6	18.7	2.4**	20.7
Epilepsy	14.4	1.3	13.3**	2.9
Hearing Impairment	11.1	4.6	2.1*	4.4
Psychiatric Diagnoses ^b				
Any Externalizing Disorder	72.5	45.6	3.1**	49.4
ADHD	55.0	22.3	3.5**	27.4
ODD	53.0	33.0	2.3**	35.5
CD	28.0	17.7	1.8**	19.3
Service System Involvement ^c				
Mental Health	57.5	53.6	1.2	54.6
School SED	32.3	13.3	2.6**	15.4
Child Welfare	35.0	33.0	0.8	33.3
Juvenile Justice	11.4	31.3	0.4**	29.7
Alcohol/ Drug	1.3	3.8	0.5	3.5

Note: n=220 for all analyses except psychiatric diagnoses, for which n=196. SED = serious emotional disturbance; ADHD = attention-deficit/hyperactivity disorder; ODD = Oppositional defiant disorder; CD = Conduct disorder; OR = odds ratio. Odds ratios represent the odds of having the characteristic for youths with ID/ ASD versus those without ID/ ASD; All analyses controlled for the effects of youth age and ethnicity and SES.

^a% = weighted percentages

^bBased on parent report of past year diagnosis with moderate impairment on the C-DISC-IV.

^cYouths may have been active in more than one system.

* p<.05

** p<.01

TABLE 3
 Psychiatric Diagnoses Within Each Service System for Only Those Youths with ID/ASD

	System											
	Mental Health (n=117)		School SED (n=92)		Child Welfare (n=56)		Juvenile Justice (n=24)		Alcohol-Drug (n=8)		%	OR
Psychiatric Diagnoses ^c	%	OR	%	OR	%	OR	%	OR	%	OR	%	OR
Any	78.3	2.0	78.8	1.6	55.0	0.3**	81.3	1.8	92.2	4.6		
Externalizing												
ADHD	61.7	1.9	64.5	1.8	46.5	0.6	33.9	0.4	80.9	3.5		
ODD	59.8	1.9	61.0	1.6	33.3	0.3**	57.8	1.2	80.9	3.8		
CD	34.0	2.1*	37.9	2.0*	14.3	0.3**	24.6	0.8	30.6	1.1		

Note: n=196 due to missing data. SED = serious emotional disturbance; ADHD = attention-deficit/hyperactivity disorder; ODD = Oppositional defiant disorder; CD = Conduct disorder; OR = odds ratio. Odds ratios represent the odds of having the psychiatric diagnosis for those who were active in a given system versus those who were not active in that system.

^a Columns do not total to 100%. Youths may have been active in more than one system.

^b % = weighted percentages.

^c Based on parent report of past year diagnosis with moderate impairment on the C-DISC-IV.

* p < 0.05

** p < .01

TABLE 4
Multiple System Involvement Within Each Service System for Only Those Youths with ID/ ASD

	Service System								
	Mental Health (n=131)	School SED (n=101)	Child Welfare (n=62)	Juvenile Justice (n=26)	Alcohol-Drug (n=8)	% ^a	%	%	%
Any Multiple System Involvement	56.7	48.8	46.0	44.9	70.9				
System Overlap ^b									
Mental Health		47.9	46.0	41.6	63.1				
School SED	26.9	--	8.2	9.4	0				
Child Welfare	28.0	8.9	--	0	0				
Juvenile Justice	8.2	3.3	0	--	70.9				
Alcohol/ Drug	1.5	0	0	8.3	--				

Note: n=220. SED = serious emotional disturbance

^a% = weighted percentages.

^bYouths may have been active in more than one system.