



Characteristics of adults with autism spectrum disorder who use adult developmental disability services: Results from 25 US states

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ABSTRACT

There is a significant increase in the prevalence of autism and autism spectrum disorders (ASD) in children with estimates now reaching 1 in 110 children in the United States. Families report difficulties in finding services for their young and adult children. Many adults with ASD receive services and supports through state intellectual and developmental disabilities (IDD) adult service systems. This study presents descriptive data on a random sample of 12,382 individual users of adult IDD services from 25 states that included 1002 individuals with an autism diagnosis (8.1%). Data are provided on demographic characteristics, diagnoses, communication and relationship status for adults with autism/ASD and a comparison of these findings for IDD service users who have other diagnoses.

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1. Introduction

1.1. Background

The term “autism spectrum disorders” encompasses a range of behaviorally defined conditions that include: autistic disorder (autism), Asperger disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS). Autism spectrum disorder (ASD) is characterized by qualitative impairments in communication and social interaction, as well as restricted, repetitive and stereotyped patterns of behavior (American Psychiatric Association (APA), 2000).

Many individuals with ASD also experience other developmental disabilities, including intellectual disabilities (ID). Recent estimates of the presence of co-occurring ID among children with ASD range from 19.2% (Boulet, Boyle, & Schieve, 2009) to 41% (Centers for Disease Control and Prevention (CDC), 2009). In the past, when ASD was thought of solely in terms of autistic disorder (excluding other ASDs), co-occurring ID was identified in two-thirds or more of children with ASD (Rutter, 2005). In other words, even without eligibility for services arising specifically from their ASD, those individuals with ASD and ID likely were eligible for intellectual and developmental disabilities (IDD) services on the basis of their ID alone. Thus with

Abbreviations: HCBS, Home and Community Based Services; ICF/MR, Intermediate Care Facilities for the Mentally Retarded; NCI, National Core Indicators.

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the rising prevalence of ASD and the introduction of policy initiatives in a number of states intended to provide access to IDD services on the basis of ASD diagnosis alone, there is likely an increasing number of IDD service users with ASD.

Quality of life among adults with ASD is related to receipt of formal supports that are individualized and comprehensive (Renty & Roeyers, 2006). Most individuals with ASD experience poor adult outcomes (Billstedt, Gillberg, & Gillberg, 2005; Howlin, Goode, Hutton, & Rutter, 2004) with ongoing challenges of communication, social relationships, social interactions, employment, and independence (Howlin, Mawhood, & Rutter, 2000; Lawer, Brusilovskiy, Salzer, & Mandell, 2009).

Thus, the research and service context for adults with ASD includes indicators of lowered quality of life and issues of access to adequate service and support systems. State IDD adult service systems represent one major source of services and support, but little is known about the number of adults (age 18 years or older) with ASD who use these services, the types of services they use, and the characteristics of adult IDD service users with ASD as compared to other IDD service users who are not so diagnosed. The current study draws on a 25-state cross-sectional sample of adults from the National Core Indicators (NCI) program to provide descriptive information about these issues.

1.2. Prevalence of ASD and access to adult IDD services

Diagnostic criteria that incorporated a spectrum of autistic symptoms were implemented in the early 1990s. Rates of ASD diagnoses have been increasing steadily since 1990 (Newschaffer, Falb, & Gurney, 2005). For example, a 57% increase in prevalence was observed among eight-year-olds from 2002 to 2006 (CDC, 2009), and one in 110 children in the United States are currently diagnosed with ASD (CDC, 2010). These statistics point to a vast and rapidly increasing demand for effective systems that support individuals with ASD throughout the lifespan. However, with the trend toward early diagnosis of ASD, it is likely that 10–15 years will elapse before these recently documented increases in ASD prevalence will in turn affect service user numbers in the adult IDD system to a similar degree. In recent years policy initiatives within several state IDD service systems have expanded access to persons with ASD diagnoses by amending current service eligibility criteria to include “related conditions” clauses that allow access by persons with ASD diagnoses or by the development of separate autism-specific Home and Community Based Services (HCBS) Section 1915(c) Medicaid waiver programs.

There has been limited and conflicting evidence regarding the prevalence of adults diagnosed with ASD (Hall-Lande, Hewitt, & Moseley, 2011). Such information has been difficult to measure reliably because, (a) lack of access to support services often leaves adults with ASD underrepresented in the literature and underserved in their communities, and (b) many older adults currently served in the IDD system have a primary diagnosis of developmental disabilities (DD) and may not necessarily have an autism diagnosis even though they present with the symptoms. It is also likely that there is also a vast cohort of adults with ASD who are not receiving needed services (Graetz, 2010). In addition, many individuals are deemed ineligible for IDD services because their IQ scores exceed the maximum allowable for ID diagnosis or due to failure to demonstrate functional limitations in three or more life skills (Hall-Lande et al., 2011).

1.3. Demographic characteristics of people with ASD

Boys are nearly four to five times more likely to be diagnosed with ASD than girls (Croen, Grether, & Selvin, 2002; Giarelli et al., 2010; Kogan et al., 2009; Yeargin-Allsopp et al., 2003). Centers for Disease Control and Prevention (2009) reported that, when ASD diagnostic estimates are stratified by gender, approximately one in 70 boys is diagnosed with ASD, while only one in 315 girls is diagnosed with ASD. The Interactive Autism Network (IAN) (2009) proposed that the widely accepted male:female ratio of “four or five to one” applies only to children with ASD and *no* ID. Male:female ratios of children with ASD and ID may be closer to two to one. While fewer females are diagnosed with ASD, the severity with which females experience ASD and co-occurring disorders is substantial. Females with ASD are more likely than males to also be diagnosed with cognitive impairment, seizures, and epilepsy (IAN, 2009).

Inconsistency exists in the results of studies that measure variables of race and the incidence of ASD diagnoses. Yeargin-Allsopp et al. (2003) found comparable ASD prevalence rates by race, whereas Kogan et al. (2009) reported that black and multiracial children may have lower odds of being diagnosed with ASD than non-Hispanic white children. Other studies have reported higher risks of ASD diagnoses among children born to black mothers (Croen et al., 2002; Keen, Reid, & Arone, 2010).

Adults with ASD have been described as having poor social relationships and few close friends (Howlin et al., 2004). From a sample of 42 adults with high-functioning autism or Asperger disorder, it was reported that none were married or had children, and only a few had some kind of partner (Engstrom, Ekstrom, & Emilsson, 2003). Only a small proportion of individuals with ASD develop intimate relationships in adolescence and adulthood (LeBlanc, Riley, & Goldsmith, 2008).

1.4. Communication issues for people with ASD

Language and social skills deficits are core characteristics of ASD. Approximately 40% of children with ASD do not talk (CDC, 2010). Adult outcomes have been positively correlated with speech patterns at six years of age (Billstedt et al., 2005). Symptoms of social impairment among individuals with ASD persist into adulthood and remain a distinct and ongoing challenge (Howlin et al., 2004; Wilkins & Matson, 2009).

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