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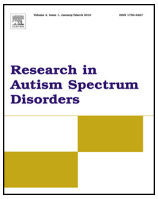

Research Paper

Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States

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A R T I C L E I N F O

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A B S T R A C T

Background: Many children and adults with Autism Spectrum Disorder (ASD) need services and support across their lifespans. Currently many residential and community living supports are delivered through state intellectual and developmental disabilities (IDD) service systems.

Method: A random sample of 11,947 individual users of adult IDD services from 25 states that included 1,459 individuals with an autism diagnosis was analyzed for this study looking at demographic characteristics and living arrangements. Comparisons were made between adults with and without ASD who receive services through the IDD service system.

Results: Overall, individuals with an ASD diagnosis were younger on average, had a higher percentage of males, and had higher percentages of the No Intellectual Disabilities (ID) and Severe ID categories compared to individuals without an ASD diagnosis. There was a significant association between the type of living arrangement and ASD status with a higher percentage of participants with ASD living in a family member's home, but a lower percentage of people with ASD living in agency apartments, in their own home or an "other" living arrangement. However, with age, gender, and level of ID and challenging behavior taken into account, people with ASD had 29% higher odds of living in a family member's home but 42% lower odds of living in their own home when compared to people with other developmental disabilities who received residential services through state IDD service systems.

Conclusions: There are key differences in access and utilization of residential services between people with ASD and people without ASD. While state developmental disabilities systems are serving individuals with ASD there are potential influences of state policies regarding ASD eligibility for various residential services. Implications for future research are discussed.

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1. Introduction

1.1. Background

Autism spectrum disorders (ASD) are among the fastest growing developmental disabilities in the United States. It is estimated that 1 in 68 children in the U.S. is currently diagnosed with ASD (CDC, 2016). The prevalence of adults diagnosed with ASD is less well-documented (Graetz, 2010; Hall-Lande, Hewitt, & Moseley, 2011). Data also reveal that the number of individuals with ASD transitioning from special education to the adult service system is steadily increasing (U.S. Office of Special Education Programs, 2012). As prevalence rates of people with ASD increase, so does the demand for services across the lifespan. These services include an array of long-term services and supports (e.g., residential, employment, community) after a youth transitions out of school and into adulthood. Thus, it is important to better understand the needs and opportunities related to community living and residential supports for individuals with ASD.

Adult prevalence rates of ASD are important to understand in order to determine long-term service and support needs across the lifespan. Yet, total adult ASD prevalence is difficult to estimate as there is not a systematic, reliable way to measure adults with ASD and the landscape of the population of individuals ASD is changing (CDC, 2014; CDC, 2016; Hall-Lande et al., 2011). Prior to the development of an autism spectrum, it was thought that the overwhelming majority of people with autism also had a co-occurring ID (Rutter, 2005). More recent research suggests that as the clinical expertise in identifying ASD evolves, more individuals who receive a diagnosis of ASD may not have an ID (CDC, 2014; CDC, 2016; Edelson, 2006). Thus, a growing number of adults may not currently receive services in the ID service delivery system (Graetz, 2010) since their intelligence quotient (IQ) scores fall above the eligibility cutoff in most states (Hall-Lande et al., 2011). This changing landscape of the population of individuals with ASD will likely have implications for the types of residential services and supports needed in the future.

Research on adults with ASD reveals consistently poor life outcomes across a variety of important life domains including employment, social participation, residential and community living, (Billstedt, Gillberg, & Gillberg, 2005; Eaves & Ho, 2008; Gerhardt & Lainer, 2011; Howlin, Goode, Hutton, & Rutter, 2004). These poor life outcomes across key life domains appear evident even in individuals with ASD with average to above-average intellectual ability (Howlin et al., 2004; Jennes-Coussens, Magill-Evans, & Koning, 2006; Taylor, Henninger, & Mailick, 2015). These challenges are likely related to their lifelong difficulties with communication, relationships, social interactions, employment, and independence (Howlin, Mawhood, & Rutter, 2000; Lawer, Brusilovskiy, Salzer, & Mandell, 2009). Further, the growing and changing needs of the population of individuals with ASD continues to far exceed the available services and supports in community and residential living (Gerhardt & Lainer, 2011).

1.2. Living arrangements

Adequate housing choices and supports for individuals with ASD are essential components of community living and participation. The residential status of individuals with ASD is an important aspect of overall well-being and independence for individuals with ASD. The number of individuals with intellectual and developmental disabilities (IDD), including people with autism, living in family homes continues to increase (Larson et al., 2016). Individuals with ASD also reside in a variety of residential settings, which include congregate group settings (i.e. group homes), intermediate care facilities for IDD, shared living arrangements, and independently in their own homes and apartments (Gerhardt & Lainer, 2011; McConkey, Keogh, Bundting, Iriarte, & Watson, 2016). Many individuals access public supports through Medicaid programs for housing services and supports. New directives outlined in the Center for Medicare and Medicaid Services (CMS) Home and Community Based Services (HCBS) “Final Rule” seeks to increase the opportunities for individuals enrolling in HCBS services to have access to community living and to receive their support services in the most integrated settings.

1.3. Purpose of this study

This secondary data analysis aims to compare and explain variation in residential services utilization and outcomes for people with and without ASD. This study uses data from a national random sample of service users in IDD services systems (HCBS and Intermediate Care Facilities for Individuals with Intellectual Disabilities [ICF/IID]) in 25 states to identify the residential service use and related outcomes experienced by adults with ASD. Comparisons are also made between service users with and without ASD. Research questions include:

1) What type of residential settings do people with ASD live in and how does this compare to service users with other diagnoses?
2) How do people with and without ASD vary across demographic measures and in the types of specific residential services accessed?
3) What are the odds of accessing specific residential settings for people with and without ASD?