

CARL R. BRASS, LPCC-S, MA
Supervising Professional Clinical Counselor
and Executive Director, Lifeworks Adult Autism
Services, Shaker Heights, OH

DEBRA J. MANDELL, OTR/L, MA
Director, Monarch School of Bellefaire JCB,
Shaker Heights, OH

Where have all the children gone? Intentional communities for adults with autism

AUTISM SPECTRUM DISORDER (ASD) is a neurodevelopmental condition typically diagnosed early in life: the median age at diagnosis is 52 months.¹ Because research demonstrates the benefits of early intervention,² when we think about people with ASD, we generally think about children and adolescents.

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However, autism spans the entirety of one's life. This means that children with ASD will grow to be adults with ASD. The US Centers for Disease Control and Prevention estimated that 1 in 59 children were diagnosed with ASD during the surveillance year 2014,¹ which was nearly double the prevalence from just 8 years earlier,³ and a 15% increase since 2012.⁴ As these children grow up, this translates to an ever-growing number of adults with autism.

■ UNMET NEEDS

Healthcare, housing, and intellectual and developmental disability services for adults with ASD currently fall well short of meeting the needs of this exploding population. If solutions are to be realized, innovative approaches must be employed.

Swetlik et al,⁵ in this issue of the *Journal*, offer valuable insights into the challenges that practitioners and their adult patients with ASD encounter as a result of seismic shifts in diagnostic criteria, increasing prevalence,

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and changes to healthcare financial coverage. They also review behavioral and pharmacologic treatments, reproductive health, and caregiver fatigue and discuss the role of the physician and other healthcare practitioners who are likely to have only limited exposure to adult patients with ASD. These wide-ranging considerations speak to the complexity of the healthcare needs of this population.

Swetlik et al also underscore that transition planning is essential for primary care, psychiatry, behavioral health services, continuing education, skill development, and appropriate prevocational training for adolescents with ASD, and yet it is often underutilized or unavailable. There is a dearth of experienced practitioners across these disciplines to serve adults with ASD. The complexity of navigating bureaucratic processes to secure funding (typically Medicaid) supports the necessity of planning early to achieve desired outcomes for each young adult. Additionally, the number of Medicaid waivers that fund many supportive services are limited.

■ GROWING UP IS HARD; START PLANNING EARLY

Swetlik et al describe the stress these circumstances create for people with ASD and their families. Entering adulthood is a complicated process, fraught with emotional overtones that must include medical care, work considerations, legal and financial arrangements, and, for many, the search for an appropriate residential environment. Planning for these transitions should begin years before adult-

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hood if the process is to work smoothly and effectively.

A transition involving a shift away from a team of familiar pediatric healthcare providers to unfamiliar adult practitioners can be distressing for any adolescent with a chronic condition. For those with ASD, who may have diminished socialization and communication skills, the transition can be especially challenging and must be handled with care.

This transition pales in comparison with the disruptive force of a permanent move out of the family home. Over the next 10 years, 500,000 youths in the United States will age out of school-based ASD services,⁶ and a great many of them will be put on long waiting lists for residential placement.⁷

For young adults with ASD, particularly those with complex needs, establishing an advantageous long-term living arrangement may mean the difference between a healthy, self-directed launch into a new phase of life, or a consequential misstep that exacerbates or worsens symptoms and creates new stressors for the young adult and his or her family. It is especially important that arrangements be made before an aging guardian starts to experience declining health.

Thoughtful and deliberate preplanning helps to reduce stress and prevent emergency placements, and promotes long-term quality of life for people with ASD.

■ OUT OF THE INSTITUTION, INTO THE COMMUNITY

For many years, the prevailing model for the provision of long-term care services for individuals with intellectual and developmental disabilities was institutional care. Large facilities, often located in expansive, self-contained campuses, provided around-the-clock care. Residents slept, ate, worked, and were expected to receive social and emotional fulfillment at the facility.

For some, this was an acceptable model. For many, it was not, but there were few available alternatives. At its best, this model provided a safe environment for its residents, but it did not facilitate achieving an integrated, self-directed life experience. At its worst, neglect and abuse were rampant.

Numerous legislative acts, court decisions, and advocacy efforts drove the deinstitutionalization movement for individuals with intellectual and developmental disabilities between the early 1960s and today. The 1999 case of *Olmstead v LC*⁸ was among the most significant. In this landmark case, in accordance with the 1990 Americans With Disabilities Act, the US Supreme Court ruled that people with disabilities have the right to receive state-funded services and support in the community rather than in institutions, as long as several criteria are met:

- Community supports are appropriate
- The individual desires to live in the community
- The accommodations to facilitate that arrangement are considered to be reasonable.

In the 20 years since the *Olmstead* decision, residential services for adults have shifted at an accelerated rate away from institutions toward smaller, community-based settings.^{9,10} Community models include but are not limited to:

- Group homes that serve individuals with intellectual and developmental disabilities and provide 24-hour support
- Apartments or homes where individuals live and receive intermittent, less-intensive support
- Adult foster care.

■ DSM-5: AUTISM IS HETEROGENEOUS

In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*,¹¹ ASD is characterized by persistent deficits in social interaction and social communication, which begin in early development and are observed in conjunction with restricted, repetitive behaviors, interests, or activities.

DSM-5 provides more than 20 examples of how these criteria might be met. Further, DSM-5 encourages clinicians to select diagnostic specifiers to address overall symptom severity, cognitive abilities, and associated medical conditions.

■ ONE RESIDENTIAL MODEL DOES NOT FIT ALL

The complex matrix of potential symptom manifestations in people with ASD clearly

Preplanning helps to reduce stress, prevent emergency placements, and promote long-term quality of life

indicates the need for numerous distinctive residential models for adults with ASD.

One person with severe symptoms of ASD may require one-to-one staffing and proactive preparatory support in order to safely leave the house for a desired social experience. The person may be unable to read, to independently access public transportation, to cope with deviations in expected routine, to initiate conversation, or to remain calm if distressed. This person would benefit from a residential model that allows for a high staffing ratio, access to appropriate transportation, sophisticated autism-informed supports, and the availability of social experiences that are easily accessed—in other words, a very controlled environment.

Another person, with less severe symptoms and fewer behavioral challenges, who possesses a driver's license and holds a job, may struggle with isolation and loneliness resulting from social inhibitions and skill deficits. This person's support needs would differ, with emphasis placed on maintaining the appropriate social context rather than on providing a high level of individualized behavioral support.

The shift away from a one-size-fits-all institutional model for long-term care has benefited many individuals with intellectual and developmental disabilities who have experienced opportunities for community integration.

Still, for many adults with ASD, particularly those with complex needs and complex behavior profiles, the widespread conceptual shift to new and different models that assume that all people with intellectual and developmental disabilities will benefit from smaller, scattered-site settings is ill-fitting. It is erroneous to believe that for all adults with ASD, regardless of the complexity of their symptoms, living within a broader community of neurotypically developing neighbors breeds a richer sense of inclusion and connectivity.

■ FINDING CARE CAN BE DAUNTING

Families of adults with severe symptoms of ASD who seek placement in more traditional community residential models often find it difficult to find capable healthcare providers to serve them. Such settings are ill-equipped

to deal with significantly challenging behaviors such as physical aggression, self-injury, property destruction, and elopement (wandering). These supported housing models lack the necessary staffing resources.

Further, publicly available funding options for stand-alone group homes do not typically allow for intensive supervision and management from professionals with expertise in autism. Without specialists who can implement autism-specific best-practice methods for assessment, service planning, staff training, data collection, and the provision of visual and technological supports for residents, it is difficult to achieve desired outcomes. For example, patients can find it challenging to visit physicians' offices for preventive and urgent care. Lacking a caregiver who is familiar with the adult patient with ASD and who can help express his or her concerns to healthcare providers, efficient evaluation of any potentially serious medical issue is a daunting task.

■ INTENTIONAL COMMUNITIES

A residential model that is gaining popularity across the United States among families and individuals affected by ASD is the intentional community.

Although forms and functions may vary, intentional communities are planned residential developments that promote social cohesion and strive to meet the shared needs of its members. Intentional communities for adults with ASD are designed to meet their social, communication, sensory, and behavioral needs. Every detail from the selection of land, to the construction of housing, the selected staffing model, the daily structure, and the considerations for transportation and amenities are all informed by the specific needs of individuals with autism. Safety, integration, self-direction, independence, and social connectivity are common goals.

Successful intentional communities designed for people with intellectual and developmental disabilities often have facilities devoted to recreation, continuing education, socialization, and supportive services. Staff members who work within these communities are highly trained in the unique needs of

Now, 20 years after Olmstead, there has been a shift toward smaller, community-based settings

people with these disorders. Intentional communities aspire to embody the individualized, integrated community-living approach that the Olmstead decision called for, while simultaneously offering the resource-rich, safe, and supportive experience that a campus atmosphere can offer.

Almost all recently developed models allow for residents to live among neurotypical peers and have easy access to the broader community. Communities range in size from several condominiums on a cul-de-sac to expansive developments with more than a hundred homes.

The allure of an ASD-informed intentional community that provides for the social, vocational, health, and safety needs of its residents is similar to that which leads large numbers of aging, neurotypically developing individuals to seek out retirement communities. Nationally recognized models of intentional communities include First Place (Phoenix, AZ), Sweetwater Spectrum (Sonoma, CA), Cape Cod Village (Orleans, MA), and Bittersweet Farms in Ohio.

First Place is a 55-unit apartment complex near downtown Phoenix that identifies as “community-connected” and “transit-oriented.” Although there are some individuals in the complex who do not have ASD, the development was created for those who do. The goal is to enhance the quality of life for residents through the provision of housing, jobs, social opportunities, and a supportive community.

Sweetwater Spectrum is located blocks from the Sonoma downtown plaza, on just under 3 acres of land. It includes several 4-bedroom homes, a community center with a kitchen, exercise studio, media room, and library, an expansive organic garden, and an outdoor pool.

The Autism Housing Network lists more than 75 intentional communities on its resource page. There are many exciting models in development. For example, Monarch Center for Autism in Cleveland, OH, is planning to develop an innovative intentional community. It will include mixed supported living options for adults across the autism spectrum, separate housing options for parents and family members, on-site social and recreational opportunities, green space, and retail stores intended to serve members of the surround-

ing community and provide employment and socialization opportunities for its residents.

Casa Familia in South Florida will soon begin constructing a large intentional community that will include innovative housing options, classrooms, social areas, an auditorium, walkways, bike paths, pools, and social enterprises.

It is critical that these ASD intentional communities continue to emerge to meet the long-term needs of the rapidly growing and aging ASD population.

■ THE TIME TO ACT IS NOW

Swetlik et al synthesize important, contemporary research on adult ASD healthcare considerations, pursuant to informing the many decisions that physicians and other healthcare professionals must make to address the diverse needs of this population. Their article advocates for further research and highlights the crisis surrounding the scarcity of practitioners specializing in adult ASD.

As for current healthcare providers, parents, care coordinators, and other stakeholders who are tasked with transition planning for individuals with ASD, particularly those with severe symptoms, the time to act is now, especially in creating new intentional community models.

Most adult healthcare providers have not been routinely charged with the responsibility, nor do they have the available time and resources to meet the social and communication needs of these patients. But when faced with an ever-expanding group of patients who demonstrate inadequate social and communication skills, the healthcare system must not turn a blind eye.

The symptoms of autism do not magically resolve when a child reaches adulthood. The medical community must partner with society at large to offer transitional solutions, including intentional communities, to the rapidly growing number of adults with ASD. Current demand outweighs supply, but if we work together, we can create innovative and highly effective solutions. After all, children with autism do not disappear. They grow into adults with autism. ■

Intentional communities for people with ASD are gaining popularity across the United States

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ADDRESS: Carl R. Brass, LPCC-S, MA, Executive Director, Lifeworks Adult Autism Services, 22001 Fairmount Blvd., Shaker Heights, OH 44118; brassc@monarchlifeworks.org



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